Abstracts of the 9th Congress of the European Association for Palliative Care (EAPC)
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs

Aachen, Germany, 8–10 April 2005
Aix la Chapelle, Allemagne, 8–10 avril 2005

ABSTRACTS
RÉSUMÉS

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Couverture: View of the Hague par Pieter Gerard Vertin (1819–1893)/ Bridgeman Art Library
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8 APRIL 2005
Invited lectures and oral presentations
Abstract number: 1
Presentation type: Invited
Poster number:

Curriculum for Palliative Nurse Education
Phil Larkin, Dept. Palliative Medicine, Galway, IRELAND, Françoise Porchet, Centre Hospitalier Universitaire Vaudois CHUV, Lausanne, SWITZERLAND

As part of the EAPC TASKFORCE Strategy on Education, a taskforce was identified to prepare guidelines that would provide a framework for palliative nurse education in Europe. This document, recently published by the EAPC, offers a plan of action for centres who wish to pursue the development of palliative nurse education and highlights key considerations, skills and competencies and identifies the supportive and inhibitory factors to sound education for nurses.

In this workshop, a brief overview of the key recommendations will be given, followed by the opportunity for audience participants to share their experiences of organizing, facilitating and evaluating education initiatives, and in doing so changing the reality of education for nurses within the European context.

Abstract number: 2
Presentation type: Invited
Poster number:

Palliative care – an international perspective: the work of the International Observatory on End of Life Care
David Clark, International Observatory on End of Life Care, Lancaster, GREAT BRITAIN

Founded at Lancaster University in 2003, the International Observatory on End of Life Care is the first ever research and development project to centre on the comparative analysis of hospice and palliative care provision around the world. The Observatory is unique in being focussed solely on end of life care and in its emphasis on a social science perspective. The aims of the Observatory are: 1. To provide clear and accessible research-based information on hospice and palliative care provision in the international context, incorporating ethnographic, historical and ethical perspectives as well as health care systems analysis. 2. To disseminate this information through the Observatory website and through published articles, monographs, reports, CDs and other media, in ways that facilitate cross-national comparative analysis and stimulate practical development. 3. To undertake primary research studies and reviews to generate such information. 4. To support academic work relating to the aims of the Observatory in resource poor regions. 5. To work in partnership with key organizations and individuals, nationally and internationally as a ‘community of effort’ for the global improvement of end of life care. This session will provide an opportunity to learn more about the developing programmes of the Observatory. Prior to attending, please visit the Observatory website: http://www.eolc-observatory.net

Abstract number: 3
Presentation type: Invited
Poster number:

"Palliative care – an international perspective – the observatory".
Carlos Centeno, Hospital Los Montalvos, Salamanca, Spain

In this session we are going to explain the four lines of work of the EAPC Task Force on development of Palliative Care in Europe:

a) Literature review and summary of any published work on the development of palliative care in each of the countries. This job is mainly carried out by Javier Rocafor with the help of Anthony Greenwood.

b) International survey to boards of the National Associations of Palliative Care, seeking opinions about the general situation, strengths and opportunities for palliative care in their country.

c) International survey to an expert within each country, to gather concrete data about the state of palliative care service delivery and organizations in the country.

d) Research on the national Directories of Services, whether published, printed or online.

Also, the present state of the study and our upcoming plans will be explained.

Abstract number: 4
Presentation type: Invited
Poster number:

Opioids pharmacogenetics – does it matter clinically?
Pål Klepstad, Dept. Intensive Care Medicine, Trondheim, NORWAY

Variability of opioid efficacy caused by genetic variations has been recognized for several years. The most established clinical significant genetic variability is related to the CYP2D6 enzyme metabolizing codeine to morphine. Slow metabolizers of codeine produce less morphine and have a less pronounced analgesic effect from codeine. Genetic variability has also been shown to influence on the efficacy of opioids for moderate to severe cancer pain such as morphine. This genetic variability may be complex. This complexity of genetic variability is illustrated by the interplay of genes coding morphine metabolism, genes coding the mu-opioid receptor, genes coding morphine transport through the BBB and genes coding modifying non-opioid systems. All these candidate genes are shown to influence on the clinically needed morphine dose. However, also in the presence of such evidence it is still relevant to ask if this matter clinically. If the needed dose is not possible the clinical consequence is simply that we will have to perform an appropriate titration of the opioid. While this is true I will still argue that it is important for clinicians to be aware of the pharmacogenetic variability in respect to opioid efficacy. This knowledge will give a theoretical foundation for recognizing that patients are different in respect to the dose needed for pain relief. As a consequence opioids must be titrated with respect to effect, not to some limit in terms of an absolute amount of drug. Furthermore genetic studies may in the future explain the basis for the interindividual variable effect from different opioids. Such knowledge can give the clinicians the rationale explaining improved pain relief or worsened effects following a change in the opioid substance.

Abstract number: 5
Presentation type: Invited
Poster number:

Opioid Pharmacogenetics – does it matter clinically?
Luks Radbruch, Department of Palliative Medicine, University of Aachen, Germany

The recommendations of the expert working group of the European Association for Palliative Care (EAPC) has evaluated the level of evidence of the available opioids. Summarizing this evaluation, the efficacy of opioids is well proven. Morphine and other opioids of the WHO-steps 2 and 3 are effective for the treatment of cancer pain.

With the increasing number of available opioids and application forms individual differences in the efficacy of these opioids have led to the opinion that the indication for opioids and specific application routes should be decided for the individual patient in the specific setting. The rationale for this differentiated approach is found in individual differences in the efficacy of different opioids, differences in the side effect profile, efficacy with different pain syndromes such as neuropathic pain or breakthrough pain, and differences with organ dysfunction or failure such as renal or hepatic insufficiency.

With the introduction of new slow release application forms in the last years differences in the side effect profile have been postulated. Less constipation with transdermal fentanyl, lower incidence of neurotoxic side effects with oxycodone and lower risk of respiratory depression with buprenorphine have been postulated. Buprenorphine might be advantageous in renal impairment, as part of the drug is excreted through bile and gut. Fentanyl or methadone could offer advantages for patients with hepatic impairment.

The opioid activities of some opioids, especially the reuptake inhibition of monoaminergic transmitters and the NDMA-antagonism, have been considered as advantages of tramadol and methadone for neuropathic pain.

Using evidence-based criteria, these theses must remain under discussion. It remains unclear, whether data from animal pain models or healthy volunteers can be transferred to cancer patients. An individually adapted opioid therapy, taking pain syndrome, receptor status and patient metabolism into account, remains a vision for the future. Until then, differential use of opioids will be more trial and error than evidence-based, and opioid rotation will remain a valuable tool if the opioid chosen by the physician fails.

Abstract number: 6
Presentation type: Invited
Poster number:

Outcomes in palliative care research in the clinic
Stein Kaasa, Department of Cancer Research and Molecular Medicine, NTNU, Trondheim, Norway, Christoph Oestgathe, Klinikum der Universität zu Köln, Köln, Germany

Over the past decades palliative care has developed dynamically in Europe and care for patients with far advanced diseases has improved – without reaching a status of sufficient provision in most countries. In spite of many challenges of methodological, ethical, economical, size of samples, etc. the amount of palliative care research has increased of the past decade.

Within medicine in general there is a call for more scientific evidence to build clinical decisions upon. This challenge also applies for...
palliative care. In the process of designing both clinical research as well as quality assurance – audit programs, outcomes must be defined. The focus in palliation is symptom control, improvement of quality of life, family satisfaction, place of palliative delivery, etc. In this session the experts will give a short overview of existing literature and our experience in choosing outcomes in the clinic. There will be time for discussion on which outcomes to be considered as most appropriate and other related areas.

Abstract number: 9A
Presentation type: Invited
Poster number:

Can we find a common language when we discuss terminal or palliative sedation?

H. Christof Müller Busch, Dept. of Anesthesia, Pain Therapy and Palliative Care, Berlin, GERMANY

All definitions have three parts: term being defined, classification and identifying characteristics. The terminological problems with sedation near death reflect different viewpoints and attitudes among clinicians and palliative care experts: “sedation for intolerable distress in the immediately dying”, “end-of-life sedation”, “slow-euthanasia”, “palliative sedation”, “total sedation”, “sedation in the final phase”, “palliative sedation therapy” a.s.o. The ambiguous term “terminal sedation (TS)” is used most often. Helpful for a starting point is a technical description: “Sedation in the terminal or final stages of life can be defined as the use of medications (usually benzodiazepines with or without complementary opioids given by the intravenous or by the subcutaneous route) to reduce the level of consciousness sufficiently deep to provide comfort for the patient until death occurs.” The implementation of guidelines will be facilitated, when different forms, technical details, procedural intentions and circumstances of TS (in those irresolutely dying) are identified and characterised. There is broad consensus that the indication for sedation in patients near death is the control of intolerable and by other means refractory physical and/or psychological symptoms. But controversies exist on the aims and intentions of TS with relation to the quality of dying. Different forms of sedation in end-of-life care can and should be identified by a generally accepted terminology. Sedation in palliative care should be distinguished clearly from euthanasia.

Abstract number: 9B
Presentation type: Invited
Poster number:

Sedation in palliative care – an update

H. Christof Müller Busch, Dept. of Anesthesia, Pain Therapy and Palliative Care, Berlin, GERMANY

The use of sedation in terminally ill patients has been investigated by a number of studies in recent years. The problems associated with sedation in end-of-life care as well as different viewpoints and attitudes among clinicians and palliative care experts are reflected in inconsistency. There is much debate about where to draw the borderline between sedation for refractory symptoms that are of a mainly physical/somatic nature and for those psychological symptoms that are mainly due to existential suffering. In the last years an international consensus group has investigated and discussed sedation in end-of-life care with the intention to facilitate recommendations.

‘Terminal’ or ‘palliative’ sedation in palliative care must be distinguished from euthanasia. This has been pointed out in the EAPC Task Force position paper. The main differences to euthanasia were clarified. Relating to the principles and recommendations of the EAPC Task Force position paper can help to locate the appropriate place of sedation in end-of-life care and diminish misuse or moral prejudices. With respect for personal needs the terminology, intentions, definitions and indications for sedation in palliative care will be discussed in this session with regard to medical and non-medical indications, decision-making, further research and ethical implications. The following topics will be reflected: 1. Can we find a common language when we discuss terminal or palliative sedation? (Christof Müller-Busch) 2. Sedation in palliative care and euthanasia – different settings, different approaches, different intentions (Bert Broeckaert) 3. Sedation in terminal stages of intolerable suffering – moral obligation or slippery slope. What are the limitations? (Philippe Poulain) 4. Indications, guidelines, documentation, further research (Nathan Cherny)

Abstract number: 10
Presentation type: Invited
Poster number:

Palliative sedation and euthanasia – different settings, different approaches, different intentions

Bert Broeckaert, Belgium

In a considerable number of terminal patients palliative sedation still remains necessary to control a number of refractory symptoms (dyspnoea, delirium, etc.). For many working in palliative care, palliative sedation has nothing to do with euthanasia. Indeed, as most intense and ultimate form of pain and symptom control, it is, according to this position, radically different from euthanasia. Moreover, as it is capable of adequately addressing refractory symptoms (physical, psychological, existential) and thus efficiently easing unbearable suffering, it makes euthanasia superfluous. Others, however, see sedation very differently. For them sedation is nothing but ‘slow euthanasia’: a disguised, hypocritical and barely humane form of euthanasia or ending of life. In this paper a number of important discussions on sedation and euthanasia are critically reviewed: the early debates in Journal of Medical Ethics (1994–1995) and in Journal of Palliative Care (1996), the Vacco v. Quill U.S. supreme court case (1997), the role of sedation in the Belgian euthanasia debate (1999–2002) and the recent Dutch controversy in which the practice of sedation is accused of being a way of circumventing the strict euthanasia regulations. Conceptual clarifications and empirical data, i.e. the result of a large-scale multi-centered Belgian study on sedation in palliative care units (2002–2005), are used to discuss the relationship between euthanasia and sedation. Clear and fundamental differences between palliative sedation and euthanasia are shown to exist, though it is recognised (and regretted) that in clinical practice the border between the two is sometimes knowing but secretly crossed (hence the confusion) and though the recognition of these fundamental differences does not make sedation ethically totally unproblematic nor necessarily an acceptable option for those advocating or demanding euthanasia.

Abstract number: 13A
Presentation type: Invited
Poster number:

1. The position of volunteers in the field of palliative care

Hans A.J. Bart, Director of the National Centre, Bunnik, NETHERLANDS

In 2003 the National Centre gave the commission to the research institute JVA to do research under clients about the satisfaction with the volunteers in palliative care. On a 10 point scale the clients gave a 8,7 for the work of the volunteers. They stated that that in this combination only can be given by volunteers – personal contact, emotional involvement and support, time and attention, practical support. Our 1,800 volunteers are activated in giving care to terminal ill patients and their relatives from the perspective of “Being There”. They are all trained on local and national level (yearly 75-80 programs for 1100 trainees) in subjects
like communication, loss and bereavement, dilemmas as a volunteer, spirituality and beliefs, etc. As a volunteer they are professional but they don’t really earn money for their work of the professional caregivers. They work in home situations as well as in almost-like-home houses and hospices. VITZ was one of the initiators on a statement of the need of volunteers in care. A statement that was signed by 13 national organisations for volunteers in care like the Dutch National Red Cross, Salvation Army, etc. with a total of 150,000 volunteers.

A recent report from our national Social-Cultural Institute (SCP) shows that 80% of the Dutch population thinks that in the future hand in hand with people with serious illnesses will have to depend more on family, friends and other informal caregivers. In that perspective it’s very important to be aware of the position of the volunteers and give them the opportunity to be a volunteer and not an underpaid professional. What can you expect and what may you expect from the support of volunteers?

Abstract number: 13B
Presentation type: Invited
Poster number:

2. Cooperation between volunteers and professionals in palliative care

Hans A.J. Bart, Director of the National Centre, Bunnik, NETHERLANDS, Nynke Wilbrink, National Centre Volunteers in Palliative Care, Bunnik, NETHERLANDS

There is a clearly defined distinction between the professional and the volunteer when you talk about the activities that are restricted to the professionals. This distinction is not so clear when you talk about the daily care from person to person. The volunteers can do the same activities as the closely related friends and family but they are not always entitled to that. On the other hand they are, like the family and friends, the most time near the patient and know sometimes more about the mental and spiritual condition of the patient. How can they cooperate to make the last phase of life a good time for the patient and his/her relatives? You have to overcome discussions about authority and competence. This issue has to be dealt with in the home situation as well as in hospice care. I send a letter to Mr. Kaasa and Mr. Radbruch (27-9-2004) with the request to be chair for the subject.

Abstract number: 17
Presentation type: Invited
Poster number:

The Clinical Challenges of Pain Management in the old palliative care patient

Declan Walsh, The Cleveland Clinic Foundation, Cleveland, Ohio, USA

Sixty-five per cent of cancer occurs in people over the age of 65 years. In addition a variety of painful conditions are common in elderly people, e.g., post herpetic neuralgia or occur as co-morbidities in elderly cancer patients. Pain is a common complaint with increasing age and provides multiple challenges to the prescribing physician. The challenges may be considered to exist in the following areas: 1) pain assessment 2) drug compliance 3) co-medications 4) poly-pharmacy 5) pharmacokinetics 6) drug side-effects 7) pharmacodynamics Pain assessment in the elderly is complicated by practical, cognitive, cultural and educational issues. Drug compliance is a challenge because of the influence of family members, failing memory, and physical infirmity. Co-medications which affect brain, heart, lung, kidney, and liver function are frequent in the elderly. In addition the aging process is associated with extensive physiological changes which significantly influence pharmacokinetics of many commonly prescribed drugs, e.g., changes in body fat and water, cardiac reserve. The number of medications (prescribed and self administered) increases rapidly in individuals over 55 years. This raises practical problems of poly pharmacy and significant issues of drug interactions and drug side-effects. The elderly are at increased risk of drug side-effects particularly from cardiovascular and neuropsychological drugs. Despite the complexities much can be done to improve the quality of pain management in the elderly and combat the numerous challenges. Key approaches include the use of simple age appropriate measurement scales, providing written instructions concerning drug use (dose, route, frequency, use in relation to food, common side-effects). Careful recording of changes in medication profile and pharmacokinetic compliance. Nursing education is vital.

Abstract number: 18
Presentation type: Invited
Poster number:

Pharmacological treatment of pain in old and frail palliative care patients: is there a base for evidenced based medicine?

Sebastian Mercadante, Pain Relief and Palliative Care Unit, La Maddalena Cancer Center, Palermo, Italy

Pain is more common with higher age, the prevalence ranging 40–79% among patients aged 85 years and above. Pain has been found to be associated with functional limitations, fatigue, sleeping problems, depressed mood and quality of life. Despite this body of evidence, outcomes studies are lacking and attention to principles of care as they apply to this particular population is advised.

According to recent guidelines, pharmacotherapy continues to be the mainstay of treatment to control pain in older patients. Patients’ experience and response to drug therapy is unique and individualize assessment that incorporates an analysis of the patient’s physiological status (co-morbidity and concurrent drug prescriptions), determination of realistic goals, and monitoring of outcomes on a regular basis could provide the best balance between risks and benefits of analgesic pharmacotherapy. It is a reasonable expectation that most serious pain can be significantly mitigated. Elderly patients may experience a similar level of pain intensity but require a lower amount of analgesics than younger adults. A key to success in the application of pharmacotherapy in geriatric pain management is slow, careful titration of drugs with specific subjective and objective end-points, while anticipating, preventing, and treating adverse effects. Patients who are experiencing severely disabling pain require more rapid titration and necessary hospital admission for close monitoring of safety and efficacy of therapy.
Atopic reactions are the most common adverse effect of NSAIDs. Epidemiological studies indicate that the risk for this complication is 10 times higher in patients >80 than those <49 years. That is less known is that the risk for renal and cardiac failure is doubled for those above 65 years, and for those with a history of cardiac disease the risk for heart failure is 26 times higher.

The second of a new class of NSAIDs has entered the market. These are the COX-2 inhibitors, expected not to block the formation of prostaglandins related to homeostasis, only those related to inflammation. However, if there is no adverse effect profile was expected. Data indicates that atopic complications may be lower in younger people, however, this has not been shown in older persons. Moreover, since COX-2 enzymes are found in the kidney, one cannot expect that renal and cardiac complications are reduced for these drugs. Withdrawal of rofecoxib indicates that these drugs also have safety problems.

NSAIDs should be used with great care in elderly, paracetamol is the recommended alternative.

Abstract number: 20
Presentation type: Invited
Poster number:

The immunological effects of opioids drugs: could they be particularly relevant in the frail patient?

Paola Sacerdoti, Pharmacology, Milano, ITALY

Acute and long-term administration of opioids is known to have an inhibitory effect on several immune functions, including antibody and cellular immune responses, NK cell activity, cytokine expression and phagocytic activity. Consistently opioid administration has been associated with increased susceptibility of animals to bacterial and viral infections and with decreased survival in tumour bearing animals. In order to assess the clinical relevance of opioid-induced immunosuppression, it is important to distinguish between transient immune alterations and actual initiation or facilitation of disease A normal healthy host can in fact tolerate some immune perturbations, and deleterious consequences are not usually dependent on disturbances in one function. However there are clearly some moments of the life span and some situations where the risks derived from opioid-induced immunosuppression may become relevant. A greater vulnerability of the immune system is present in the young and in the aged individuals, when the immune system undergoes developmental changes: maturing in the infant and in decline in ageing. The opioid-induced immunosuppression can obviously result particularly dangerous in the already immunocompromised patients, such as the HIV+ patients. Another situation at risk is the perioperative period, since it is well known that anaesthesia and surgery affect the immune response. As a consequence, for example, the treatment of peri-operative pain in the elderly patients constitutes a critical point. Interestingly it is emerging, mostly from experimental studies in the animal, that not all opioids share the same immunosuppressive properties, and that some decades are more protective of the immune system. Although only a few comparative studies of the immunomodulating effects of different opioids in human have been made, the present scarce data of immunosuppressive effects deserves further attention.

Abstract number: 21
Presentation type: Invited
Poster number:

Life threatening illness, what happens in the family?

Pam Firth, Isabel Hospice, Hertfordshire, UK

Frances Sheldon was a major international figure in social work and Palliative Care. Her early death in 2004 was a great loss but her legacy of writing and teaching lives on for us to use and develop. We will hear from four colleagues about her work and influence. This brief paper will look at the value and need to provide psychosocial care for the patient and his/her family. Frances promoted the role of social workers, within a multiprofessional, team offering palliative care and in her book and many articles and book chapters she clearly articulated the need to assess the patient within the various systems within which he/she operated. The author a practising social worker with training in family and groupwork will draw on the work of systemic therapists to show the need for comprehensive services which can assess and help the whole family. Frances believed that what happened to one family member had a profound effect on all the family especially children and this will be illustrated from the author’s own practises.

Abstract number: 22
Presentation type: Invited
Poster number:

The development of EAPC

Franco De Conno, National Cancer Institute of Milan, Italy, Heidi Blumhuber, National Cancer Institute of Milan, Italy

The European Association for Palliative Care (EAPC) was established on 12 December 1988, with 42 founding members and following important initiatives by Professor Vittorio Ventafredda and the Floriani Foundation. The aim of the EAPC is to promote palliative care in Europe and to act as a focus for all those who work, or have an interest, in the field of palliative care at the scientific, clinical and social level. The rapid development of the palliative care movement and the growth of national associations in the European countries made a change in the EAPC’s structure necessary to enable these associations to join the EAPC collectively. This decision was a big step forward in the development of the membership. In 1992, the EAPC accepted 3 associations as its first collective members increasing the number of persons represented to 1028 persons. In 2004 the number of associations has increased to 31 representing a total of approximately 50,000 members, and there are still 200 individual members. The members come from 24 European countries and 9 Countries from outside Europe. Even though the EAPC is a European association, it has members from many non-European countries. Since 1990 the Head Office of EAPC has been based at the Division of Rehabilitation and Palliative Care within the National Cancer Institute in Milan. In 1998 the EAPC was awarded the status of NGO – Non Governmental Organisation of the Council of Europe. We can list the following initiatives of the EAPC:

- ITS CONGRESSES: Since 1990 the EAPC has organised 8 European Congresses: in Paris, France (October 1990), Bruxelles, Belgium (October 1992), Bergen, Norway (June 1994), Barcelona, Spain (December 1995), London, United Kingdom (September 1997), Geneva, Switzerland (September 1999), Palermo, Italy (April 2001), Den Haag, the Netherlands (April 2003). The 9th EAPC Congress is held in Aachen, Germany, April 2005. The 10th EAPC Congress will be held in Budapest 2007.

- THE EAPC FORUM ON RESEARCH IN PALLIATIVE CARE: The First Research Forum of the EAPC in December 2000 was such a success that the EAPC Board of Directors decided to continue to organise such meetings every second year in between the EAPC Congresses. The second Forum was held in Lyon, France, May 2002. The third one in Stresa, June 2004. The 4th Forum will be held in Venice, Italy, 25 to 28 May 2006.

- THE WEB - WWW.EAPCNET.ORG


- THE “RESEARCH NETWORK”

- PALLIATIVE CARE IN EASTERN EUROPE: AN EAPC PROJECT

- THE “TASK FORCES” (Projects)

- The EAPC Ethics Task Force on Palliative Care and Euthanasia

- EAPC Taskforce on Palliative Care Development in Europe

- Taskforce on Palliative Care for – Taskforce on Nursing Education – Survey on Medical Education – Taskforce on Medical Education.

Abstract number: 25
Presentation type: Invited
Poster number:

Interdisciplinary Education

David Oliviere, St. Christopher’s Hospice, London, UK

This tribute to Frances Sheldon will emphasise her work with all disciplines through education in particular. Multi-professional working, education and networking were Frances’ strengths and she released the synergy of various professional disciplines in her teaching. She worked in the contexts of practice, academia and Europe and, more recently, in user involvement. Her practice and writings are clearly patient-centred. The presentation will be divided into attitude, inter-disciplinary education and challenges for modern palliative care. This will include the ability to deliver education directly (using diverse and contrasting of teaching methods) and indirectly, setting up training programmes (e.g. the first MSc in Psychosocial Palliative Care in Europe).

As a founder of modern palliative care in Europe, the paper explores Frances’ principles in inclusion, inter-disciplinarity and integrity. A true European, the influence of her education will continue ‘beyond the border’.

Abstract number: 26
Presentation type: Invited
Poster number:

Life and Death Decisions: researching the way forward

Sheila Payne, Psycho-social and Spiritual Care, London, UK

This paper aims to highlight the contributions of Frances Sheldon to the palliative care research agenda. I will reflect upon her role within research and how her values were influential in guiding the production of policy and management of research projects. While Frances was not primarily a researcher, she was an active collaborator on many projects and a teacher. She promoted critical scholarship
within her own discipline of social work and supported the research of many students and colleagues. This paper will argue that her approach was derived from social science and prioritised the perspectives of patients and carers. She valued attention being given to the practical, personal and social problems facing dying people and their families and practitioners. Her legacy will live on in the many students and colleagues she supported in gaining their first understanding of research and its application to practice.

Abstract number: 27
Presentation type: Invited
Poster number:

Working to improve access to palliative care around the globe: the role of the International Association for Hospice and Palliative Care (IAHPC)

Lilliana De Lima, IAHPC, Houston, US

Evidence shows that in many parts of the world there are few or no palliative care services and an almost total absence of palliative care education and training in universities and colleges. Millions are dying with unnecessary suffering and their doctors and nurses often unaware of what can be done to help them. The International Association for Hospice and Palliative Care (IAHPC) was created to provide experience, expertise and education to programs, institutions and individuals and fulfill some of the unmet needs of the patients, families and health care workers who do not have access to palliative care.

The organization has developed programs to support and promote the development of palliative care around the World which have proven to be effective in disseminating information, increasing awareness, changing public policy and educating health care workers and social workers to improve the care of patients with far advanced conditions. This session will describe the main programs of the organization, including the Traveling Fellowship Program, Traveling Scholarship Program, Learning House Program and the Faculty Development Program, as well as its future projects to develop a global network of support among existing individuals, programs and institutions.

Abstract number: 29
Presentation type: Invited
Poster number:

Palliative Care in India: the way forward

Robert Twycross, Oxford University, Oxford, UK

Past (1990s): some 60 doctors and nurses came to UK for 8-week training course. A few became activists. The Pain and Palliative Care Clinic in Calicut, Kerala, led by Dr MR Rajagopal, became the jewel in the crown. Received much foreign financial aid. Schlumberger and now has 40 Link Clinics. Indian Association of Palliative Care founded 1994; begat the Indian Journal of Palliative Care. Ongoing struggle to simplify regulations governing morphine availability. Present (2000s): PIPCS now Institute of Palliative Medicine led by Dr Suresh Kumar. With Christian Medical Association of India, runs a 2-year distance-learning programme for Fellowship in Palliative Medicine. A Neighbourhood Network in Palliative Care functions in several Districts in northern Kerala; has thousands of supporters and volunteers. Dr Rajagopal, now at Amrita Institute of Medical Sciences, Kochi, has established a 2-year residential fellowship programme. Both Calicut and Kochi have ‘Basic Certificate Course in Palliative Medicine. Reena George is now Professor of Palliative Care at CMC Vellore. Oncology fellows rotate through her department; so too at the Postgraduate Institute for Medical Education and Research, Chandigarh. Several other activist centres emerging, notably in Bangalore, and Guwahati, Assam. Pharmacy courses will still depend on dedicated and determined pioneers. Palliative care needs to be introduced into the curricula of Medical Colleges and Nursing Colleges. Also need for an accreditation system for palliative training. The barriers to the developing palliative care services throughout India are similar to those seen elsewhere; include general medical indifference, opposition in most Regional Cancer Centres, bureaucratic obstacles in relation to the availability of oral morphine, State and Union Health Ministry inertia, and lack of support from the Medical Council of India.

Abstract number: 29B
Presentation type: Invited
Poster number:

Breaking down regulatory barriers to opioid availability in Europe: Is there progress?

David Joranson, University of Wisconsin CCC, Madison, USA, Daniela Mosouli, Study Centre for Palliative Care, Brasov, ROMANIA

Adequate relief of pain due to cancer and HIV/AIDS is often blocked by regulatory barriers to the availability and prescription of opioid pain medications that are recommended by the World Health Organization. This session will present progress to identify and remove regulatory barriers in European countries, review the mandate and resources available to address this problem, and describe related activities of the World Health Organization. The focus will be on Eastern Europe, in particular a national project to identify and remove regulatory barriers to pain relief in Romania. The session will conclude with audience discussion about progress and issues in their countries and next steps.

Abstract number: 30
Presentation type: Oral
Poster number:

A ten year review of an Australian palliative care quality assurance program

Fiona Lindsay, Palliative Medicine, OXFORD, GREAT BRITAIN, Rebecca Strutt, Prince of Wales Hospital, Sydney, AUSTRALIA

Aim: To evaluate the adverse outcomes recorded over a decade by the South Eastern Sydney Palliative Care Service (SESPCS) quality assurance program. Method: A retrospective review of the SESPCS quality assurance data was undertaken. Since 1993, at the weekly multidisciplinary team meeting adverse events that occurred during the previous week were reported. The services involved in the evaluation included a hospital support team, a community service and an inpatient hospice. Outcomes were systematically considered within the categories of death without dignity, uncontrolled symptoms for greater than 24 hours, out of hours admittance of unqualified clients and colleagues, missed faecal impactions, and development of pressure sores. All data collected between July 1993 and June 2003 was evaluated and collated in six month intervals. Results: The total number of adverse outcomes recorded was 1749. With an increasing trend, the greatest numbers of events reported were in the categories of uncontrolled symptoms for greater than 24 hours (maximum 52/six month period), and dissatisfied clients and colleagues (maximum 31/six month period). There was a downward trend in the reported number of outcomes in death without dignity and missed faecal impactions. Qualitative data identified where care could be enhanced by improved communication with colleagues and focussed education in symptom management.

Conclusions: The SESPCS weekly quality assurance process has led to identifiable identification of problems involved in the delivery of good quality palliative care. This model of quality assurance goes ‘beyond the border’. It has been transferable across different clinical settings and embraced a diversity of physical, psychological and social outcomes. Through the quality assurance cycle, it is advocated future evaluation of adverse outcomes are measured against standards.

Abstract number: 31
Presentation type: Oral
Poster number:

A survey of clinical audit tools and risk assessment tools in inpatient palliative care units in the UK and Ireland.

Liam O’Sorain, Palliative Care, Dublin, IRELAND

Background: Clinical Governance promises a more accountable health service with an emphasis on creating an environment where excellence in clinical care will flourish. Measuring excellence has been achieved by many challenges. One of these is establishing the evidence for which tools are most useful measuring outcome in palliative care. Bereavement risk assessment has been identified as in determining best use of resources and its presence is a further marker of quality in a service. Aims and objectives: To determine the use of validated clinical audit tools in inpatient palliative care units in the UK and Ireland. To identify which tools are in use and what the geographic clustering implies. To identify whether risk assessment in bereavement is part of standard practice and to identify which tools are being used. Methodology: A postal questionnaire was sent to all inpatient units in the UK and Ireland. A response rate of 75% was achieved after a second postal reminder. Results: Just over 50% of units carry out clinical audit using a variety of validated tools. There is clear geographical clustering with certain tools popular in different geographical areas. There is no clear favourite tool although POS developed by Prof Irene Higginson is the most widely used tool. Risk assessment is carried out more often than use of a clinical audit tool although most respondents are using inhouse tools or modified versions of the assessment tool developed by Murray-Parker.

Abstract number: 32
Presentation type: Oral
Poster number:

Professional caregivers’ requests for consultation to palliative care consultation teams (PCCM)

Marike Groot, Centre for Quality of Care Research (229), NIJMegen, NETHERLANDS, Myrna Vernooij-Dassen, Radboud University Nijmegen Medical Center, NIJMegen, NETHERLANDS, Anemie Courtoens, University Hospital Maastricht, MAASTRICHT,

Invited lectures and oral presentations

FRIDAY & APRIL
Abstract number: 35
Presentation type: Oral
Poster number:

Personal coping with difficult situations in palliative care. A Delphi Study
Carlos Centeno, Programa de Medicina Palliativa, Pamplona (Navarra), SPAIN, Helena Franco, Hospital Campo de Araúñez, Navalmoar de la Mata (Caceres), SPAIN, Belén López, Unidad de Cuidados Palliativos, Hospital Los Montalvos, Salamanca, SPAIN, Ana Carvajal, Programa de Medicina Palliativa, Clinica Universitaria de Navarra, Pamplona (Navarra), SPAIN, Francisco Vara, Unidad de Cuidados Palliativos, Hospital Los Montalvos, Salamanca, SPAIN

With the aim of studying the management of feelings and personal sources of help in difficult situations, at the Palliative Care Unit of the H. Los Montalvos (Salamanca), we have completed a Delphi Process, considering the whole team as a group of experts. All 32 professionals in the group were invited to participate and 93% were included: 4 doctors, 18 nursing staff, 6 porters, 2 aides (most of whom experience was 4 years, age 38 years, 9 males, 31 females). Three rounds were completed by 29 persons (96%). The initial open question provided 132 different proposals which were then grouped and submitted for the group's evaluation in two further rounds. The greatest consensus (high median) was found in gratefulness, teamwork, fullness of personal life, interiorisation.

Expression of feelings and experience had intermediate median, meaning that these is a help for an important part, but not the majority. The thematic groups, religiousness, rationalization, avoidance and distancing were strategies for a specific group. The greatest consensus was obtained for the following proposals: 1. I accept and acknowledge that the 'Great Team' that works at the Unit and its working methods are a great help to patients and their families and that comes from me and helps me to see life (and death) in a different way. The Delphi system is the result of an researching procedure able to examine a complex question: the personal coping with the problems. In this group, the gratitude personal and personal life and the support of the team were the most useful tools when working in Palliative Care.

Abstract number: 36
Presentation type: Oral
Poster number:

Burnout Syndrome in Palliative Care Professionals in Spain
Marina Martínez, Programa de Medicina Palliativa, Pamplona (Navarra), SPAIN, Carlos Centeno, Clínica Universitaria de Navarra, Pamplona (Navarra), SPAIN, Álvaro Sanz Rúbiales, Hospital Universitario de Valladolid, Valladolid, SPAIN, Ana de Santiago, Clínica Universitaria de Navarra, Pamplona (Navarra), SPAIN, Elena Abarca, Hospital de Vitoria, Vitoria-Gasteiz, SPAIN, Carmen Martínez, Clínica Universitaria de Navarra, Pamplona (Navarra), SPAIN, Luis de Nicolás, Facultad de Psicología, Universidad de Deusto, Bilbao, SPAIN

Research on Palliative Care professionals has usually reported levels of Burnout Syndrome lower than the levels stated for other health professionals, despite the fact that daily work on
Palliative Care has traditionally been considered hard and potentially stressful due to the daily contact with suffering and death. Our objective was to provide decision makers with appropriate tools to facilitate improvements in the quality of care provided to dying Canadians, their families and caregivers. We systematically reviewed over 7,000 references obtained from academic journals, government reports and the internet. A total of 50 performance measures were identified as pragmatic and oriented toward service delivery. An inventory was constructed which contains eleven descriptors for each measure. Eighty-six percent of measures rely on prospective questionnaires, 12% on chart review and 2% use administrative data. The vast majority of these measures were not validated. We conclude that performance measures for palliative and end-of-life care are in the early stages of development and therefore require substantial investment by all levels of government.

Abstract number: 37
Presentation type: Oral
Poster number:

An Inventory of Evidence-Based Performance Measures in Palliative and End of Life Care Service Delivery

Konrad Fassbender, Palliative Care Research Initiative, Edmonton, Alberta, CANADA; Carleen Brenneis, Capital Health, Edmonton, CANADA; Donna Wilson, University of Alberta, Edmonton, CANADA; Pam Brown, Calgary Regional Health Authority, Calgary, CANADA; Linda Slater, University of Alberta, Edmonton, CANADA

Our objective was to provide decision makers with appropriate tools to facilitate improvements in the quality of care provided to dying Canadians, their families and caregivers. We systematically reviewed over 7,000 references obtained from academic journals, government reports and the internet. A total of 50 performance measures were identified as pragmatic and oriented toward service delivery. An inventory was constructed which contains eleven descriptors for each measure. Eighty-six percent of measures rely on prospective questionnaires, 12% on chart review and 2% use administrative data. The vast majority of these measures were not validated. We conclude that performance measures for palliative and end-of-life care are in the early stages of development and therefore require substantial investment by all levels of government.

Abstract number: 38
Presentation type: Oral
Poster number:

Beyond the Border – Developing a national network for Children’s Bereavement Services in the UK

Barbara Monroe, Chief Executive, Sydenham, London, GREAT BRITAIN

This paper will consider the impact of palliative care on the development of children’s bereavement services. It will examine the activity of the Childhood Bereavement Network (CBN) since its inception in 1998 as a multi-agency collaborative project aiming ‘to improve the quality and range of bereavement support for children, young people and their families in the UK’. It now has over 260 members; two thirds organisational, one-third individual. In a recent UK survey (Rolls and Payne, Palliative Medicine 2003; 17) hospices/palliative care services made up 44% of host organisations for children’s bereavement services. A shortfall remains in services open to all and offering support to those bereaved through expected as well as unexpected death. The presentation will report on a mapping exercise undertaken by the CBN for the UK Government; 700 questionnaires identified 47 open access services on a national basis. Thirty-three of these services returned a self-assessment evaluation of their services against the consensus developed CBN Guidelines for Best Practice. Results will be reviewed. The mapping exercise revealed gaps in service provision. The CBN now has funding for a consultancy service to encourage service developments in under resourced geographic areas. The CBN website (www.ncb.org.uk/cbn) and on-line national service directory were also established. Other CBN outputs include: policy development and advocacy at Government level; development of ‘Guidelines for Participation’ for children and young people; regional meetings and national conferences; resource development e.g. videos; regular newsletters and e-mail updates; collaboration in a St Christopher’s and Help the Hospices innovation – the UK’s first university validated courses in Childhood Bereavement. Next steps include a service self-assessment quality assurance scheme and an international network.

Abstract number: 39
Presentation type: Oral
Poster number:

Developing a bereavement counselling manual for people with intellectual disabilities: Journeys without maps

Susan Read, Nursing and Midwifery, Stoke on Trent, GREAT BRITAIN

Aim: There is limited empirical research that has investigated bereavement counselling as an intervention for people with intellectual disabilities (ID). A seven-year participatory action research study conducted within a voluntary bereavement counselling organisation in Staffordshire, England, enabled the organisation to develop a specialising counselling service to accommodate bereaved people with intellectual disabilities. This was a unique, specialist service in that it was embedded and developed upon a generic counselling model that was adapted to accommodate the needs of a different client population. The emergent aim of this collaborative research study was to develop a bereavement counselling manual for people with intellectual disabilities. Method: The researcher explored the process and outcome of the bereavement counselling experience with a small group of bereaved clients (N=28) and associated counsellors. This paper will offer an overview of the four phases of the action research study; describe methodological approaches used and present the findings of the study in relation to current theory and practice. Results: The strength of action research is its application and implications to practice, and the resultant manual is presented as a unique and welcomed resource within this sensitive and neglected area of psychological support for a marginalized population.

Abstract number: 40
Presentation type: Oral
Poster number:

The use and experience of volunteers in UK childhood bereavement services

Elizabeth Rolls, School of Health and Social Sciences, Cheltenham, GREAT BRITAIN; Sheila Payne, Palliative and End-of-Life Care Research Group, University of Sheffield, Sheffield, GREAT BRITAIN

Childhood bereavement services are a recent UK phenomena (Rolls and Payne 2003) and the use of volunteer unpaid staff within them remains largely unexplored. One aim of a wider qualitative study on UK childhood bereavement services was to explore the role and work experiences of unpaid volunteer staff. Method: In the first phase, a survey was conducted to identify and describe childhood bereavement services in the UK, including staffing arrangements (N=108). The second phase adopted an organisational case study design to examine 8 childhood bereavement services in depth. Data were collected from 23 paid staff and 37 unpaid volunteer staff, using semi-structured interviews, and analysed using a grounded theory approach. In addition, a postal survey of unpaid volunteer staff (N=73) was undertaken, and analysed using SPSS. Discussion: Within childhood bereavement services, the staffing and deployment of unpaid volunteer staff varies and is less well differentiated and formalised than in hospices and specialist palliative care services. Within the study, three types of staffing arrangements were identified, with 11% of services being wholly run by paid staff (n=10), 14% wholly run by unpaid volunteers (n=13) and 73% (n=66) a mixture of paid and unpaid staff (n=66). Greater difficulties with role boundaries were experienced where there was a mixture of paid and unpaid staff, and in these there were more limits on the range and type of activities that unpaid volunteers were able to undertake. However, unpaid volunteer staff were well-qualified, with 68% (n=50) holding 1 or more qualifications. Paid staff valued their contribution and recognised that service interventions would be very difficult to provide without them. Despite the difficulties that arise in trying to locate ‘volunteering’ within this type of service provision, unpaid volunteer staff are a well-qualified group who make an important contribution to childhood bereavement services.

Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005

Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005

FRIDAY 8 APRIL
Abstract number: 41
Presentation type: Oral
Poster number:

A bereavement support programme for spouses during one year after the patients' death

Ingrid Nilsson, Sjukvårdsstemet, Uppsala, SWEDEN, Maria Carlsson, Dept. Public health and caring sciences Uppsala University, Uppsala, SWEDEN

One cornerstone in palliative care is to offer the patient's family support during the illness and after the patient's death. In this study four times during a year. The meetings cover many issues, for example: A memorial service which includes discussions on the experience of bereavement, a presentation on the significance of physical exercise for general well-being in bereavement, changes in insurance and financial matters and a church service during the Advent season. The team is furthermore planning to start a telephone-helpline, open one week for, the families in bereavement. Finally, the team has a future vision for the unit to become a center of bereavement counselling in Iceland mainly by informing and supervising other professionals. Also, there is an emphasis on research to evaluate the importance and the accomplishment of the bereavement program.

Abstract number: 44
Presentation type: Oral
Poster number:

Bereavement Support following Home and Hospice Deaths

Alison McNulty, School of Nursing, Midwifery and Health Visiting, Chedidle, GREAT BRITAIN

Following cancer deaths in the hospice or home, hospice and home care services provide much valued bereavement support to the family. The objectives were to explore experiences of bereavement and compare the support provided in both settings. The needs of the bereaved, what they value and what they perceive as barriers to support were explored. The implications being to explicate the needs of the bereaved, and where services could focus their provision and remove barriers. In-depth interviews were conducted with the bereaved. Hospice and home services completed a survey upon each occurring death over a three-month period, stating the support offered. Finally focus groups using participatory evaluation methods were conducted with the bereaved to explore needs, valued interventions and barriers to support. Interviews (n12) showed similar experiences, closely echoing literature as to typical expressions of grief. The provision of support differed greatly in both settings (22 services). Of 50 bereaved, 50 were offered support. The hospice sample was more likely to be offered support but it was more likely to be offered earlier in the home. Hospices favoured letters, telephone calls and sympathy cards whereas home services strongly favoured visits and telephone calls as methods of support. Focus groups (n5) revealed the value of support groups and personal visits at the funeral attendance. Needs included practical/financial help, more information, and the need for early interventions. Barriers included transport to events and the event itself. Hospices identified as a poor source of support. Hospice and home care services are structured differently, reflecting their provision of support. However the experience and needs of the bereaved are similar. The findings show the needs for support, what is valued, and perceived barriers. By breaking the borders of the service structure person-centred support can be offered.

Abstract number: 46
Presentation type: Oral
Poster number:

Cross-cultural investigation on spirituality, religiosity, and mental health of patients with amyotrophic lateral sclerosis (ALS) approaching death

Maria Wasner, Klinikum Grosshadern, Munich, GERMANY, Vivian Drory, Tel Aviv University, Tel Aviv, ISRAEL, Grazia Grassi, Interdisciplinary Center for Palliative Medicine, Munich, GERMANY, Steve Albert, Columbia University, New York, U.S.T.34

Background: Little research is available on variation in end-of-life care in ALS across countries. It is also unclear how cultural variation may affect patients’ and family members’ experiences at the end of life. For example, does the risk of depression at the end of life vary according to the cultural setting? How do religiousness and spirituality of patients with...
ALS and their caregivers change with the nearing of death? We investigated these issues using a standardized protocol in three countries: USA (New York), Israel (Tel Aviv), and Germany (Munich). Objective: To assess depression, perceived meaning in life, quality of life, religiosity, and spirituality in ALS patients and caregivers. Methods: Patients with a definite or probable ALS and a forced vital capacity of 60% and their caregivers were interviewed every 2–3 months using standardized measures (visual analogue scales, SEIQOL-DW, Beck Depression Inventory, ALSFRS, FACT-Sp, Idler Index of Religiosity, and SEL). Results: To date, 19 patients from New York, 12 patients from Tel Aviv, and 17 from Munich have been enrolled and were available for analysis. Sociodemographic characteristics were similar at all sites. At baseline, Israeli patients were significantly more depressed than German and American patients. Even with adjustment for differences in disability status, Israeli patients reported significantly less religiosity and less spirituality than American and German patients, depressive symptoms were significantly higher among them. German and Israeli patients reported less wish to live than American patients. The three groups did not differ in the perceived meaning of disease.

Discussion: These first results suggest an association between religious and spiritual beliefs and apprehension to the nearing of death. Data analysis is still ongoing, prospective data will allow further insights on these issues.

Abstract number: 47
Presentation type: Oral
Poster number: 

**Amongst the peasants, food is placed as the sky** (Chinese proverb): older Chinese people's views on food and end-of-life care

Sheila Payne, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN, Alice Chapman, University of Sheffield, Sheffield, GREAT BRITAIN, Jane Seymour, University of Sheffield, Sheffield, GREAT BRITAIN, Margaret Lloyd, University of Sheffield, Sheffield, GREAT BRITAIN.

Background: Chinese cuisine has an international reputation and has spread globally with the migration of Chinese people. Chinese foods, herbs and other products feature strongly for their therapeutic uses in Chinese traditional medicine. This paper explores the perceived contribution of these products to end of life care. People of Chinese origin make up approximately 5% of all minority groups in the UK. They make little use of palliative care services but it is not known why. Aims: As part of a large study exploring the views of older Chinese people about cancer and palliative care, we elicited their understandings of the role of food in cancer causation, cancer treatment and end of life care. Method: A qualitative research study was designed, involving 7 focussed group discussions with Chinese community groups (n=46), and semi-structured interviews with older Chinese people (n=25, age range 50–80). Data were collected in Cantonese or Mandarin, transcribed and translated into English for analysis using the software NVIVO. Results: The following themes were resulted from the data: *Majority of the older Chinese people in the studied groups did not know anything about Palliative care treatment* and it is evident that this group of people viewed ‘having care choices’ as the right of an individual or an important part of health care. *Barriers to participating in making health choices* included: language, culture and beliefs, lack of information, education, unsuitable food and environment. Implications: When promoting ‘patients choice’ it is important to consider the individual’s needs and background and ethnicity. An important question to ask is ‘Whose and what choices?’ as the right of an individual or an important part of health care. *Barriers to participating in making health choices* included: language, culture and beliefs, lack of information, education, unsuitable food and environment. Implications: When promoting ‘patients choice’ it is important to consider the individual’s needs and background and ethnicity. An important question to ask is ‘Whose and what choices?’ as the right of an individual or an important part of health care.

Abstract number: 49
Presentation type: Oral
Poster number: 

**Implementation of Palliative Care into the existent health system in Croatia**

Ivanka Kolišnik, Vice President of the Association, Zagreb, CROATIA-HRVATSKA, Anica Jusci, Croatian Society for Hospice/Palliative Care, Zagreb, CROATIA-HRVATSKA, Egidio Cepublic, Croatian Association of Hospice Friends, Zagreb, CROATIA-HRVATSKA.

The Croatian Hospice Movement started in 1994 on the background of very cruel war, with organisation of First Symposium Hospice and Palliative Care and foundation of Croatian Society for Hospice/Palliative Care, as the part of Croatian Medical Association. The great number of conferences, courses, lectures with invited speakers from abroad were held, all the time involving different professions and covering different problems. Psychosocial issues, volunteers, children’s palliative care, neurological palliative care, primary care physicians, stopping the senseless treatment, homes for elderly and sick caregiver, and others. Six books were translated and edited, great number of journals articles and chapters in textbooks were published. In October 2002 Regional hospice in Zagreb was opened, owned by Croatian Association of Hospice Friends and supported by Ministry of Health. Since 2000 the interdisciplinary/multi professional hospice home visits started, almost all members of the team being volunteers. In March 2002 the 1st session of the Committee for Palliative Care of Ministry of Health was held. In summer 2003 the new croatian law on health protection was issued with many articles involving palliative care. The very actual problem of redesigning the homes for elderly and sick into care nursing home (we have not got any) with correspondent staff was approached by the ministerial Committee also. The education in palliative care is slowly getting academic status. The postgraduate pain course was held already four times. The postgraduate course in palliative care for primary care physicians is held this year for the first time. Two guest professors for undergraduate studies of Medical faculty, Zagreb, were officially elected – Kathleen Foley and David Oliver. At the High health school, Zagreb, there is the third year subject palliative care, finding its audience.

Abstract number: 50
Presentation type: Oral
Poster number: 

From Latin to local: How words for covering, curing and caring have moved beyond European borders of language, location and lifetime in two millennia

Peter Whan, Chemsreide West, AUSTRALIA

Background: The phrase ‘Palliative Care’ seems to have first appeared in print in 1956. However, words for palliation, curing and caring have been used in European languages for a very long time. Aim: This presentation illustrates the history of such words as they have passed from language to language in Europe in the past two thousand years, and track the ways the ideas expressed by these words have been applied in dealing with sick and dying people. Methods: Ancient and later documents in European languages which contained references to palliation, care, or medical somnolence, especially groups of documents linked in a chain of translation. Surgical texts written in Latin in France, Italy and Spain, and translated into Middle English and Early Modern English were particularly useful. The documents were examined to find the earliest identifiable uses of words cognate with ‘palliative’, ‘cure’ and ‘care’, in English and other European languages, and also to determine the way ancient, medieval and early modern authors viewed the concepts behind such words. Results: The history of New Testament translation reveals that words for curing, healing and caring have been used in Greek, Gothic, Latin, Anglo-Saxon, Middle English, German, French and Early Modern English. The Middle English word ‘cure’ was used to describe what would now be called palliative treatment. Guy de Chauliac nominated three situations where ‘palliative care’ was an acceptable approach. Conclusion:
Abstract number: 51
Presentation type: Oral
Poster number: 
What is suffering for you?

Vicente José de Luis Molero, Centro de Especialidades Coronel de Palma, Móstoles/Madrid, SPAIN, Rosa Quibén Pereira, IMASLUD, Hospital de Móstoles, Móstoles/Madrid, SPAIN, Mª Paz Carrizo, Equipo de Cuidados Paliativos Domiciliario AECC, Móstoles/Madrid, SPAIN, Mª Ángeles Villa Vigo-Escalera, Equipo de Cuidados Paliativos Domiciliario AECC, Móstoles/Madrid, SPAIN

Objectives: To know what suffering is for each one of the members of Programme of Palliative Care of the 8 Health Area of Madrid: patients, caregivers and health professionals. To compare the grade of suffering in terminal cancer patients as a result of suffering experienced by their caregivers and professionals. To search a possible relationship between suffering and pain. Method: Descriptive qualitative study through two questionnaires drawn up by themselves; one for patients (16 questions) and another for caregivers and professionals (18 questions). Enrollment criteria: *Patients enrolled in the Programme in two equal periods of 2003 and 2004 (from 1st March to 15th October) * These patients’ primary caregivers. *Health Professionals involved in their care: General Practitioners in charge of the Care Unit, Home Palliative Care Unit and General Practitioners in charge of the Programme. Exclusion criteria: *Patients with cognitive impairment, Karnofsky index < 30 or low standard education. *Caregivers with low standard education. *Caregivers with low cognitive impairment, Karnofsky index < 30 or low standard education. Results: 1) Have you experienced any type of suffering these days? Affirmative answers: 58.4% of patients (n=80). (38.4% ± 1.45) and professionals (4.42 ± 2.98) 2) Numeral evaluation (0–10) of suffering these days? Affirmative answers: Patients 53.31%, caregivers 51.4%, professionals 38.4% 2) Numeral evaluation (0–10) of suffering (m ± ds): Patients 5.25 ± 1.33; caregivers 6.83 ± 1.43; professionals 4.42 ± 2.98 3) Do you think physical pain is related to suffering these days? Affirmative answers: Patients 58.4%, caregivers 6.83 ± 1.43; professionals 4.42 ± 2.98 4) You think physical pain is related to suffering in any way? Affirmative answers: Patients 53.31%, caregivers 51.4%, professionals 69.2%. Conclusions: *A high level of suffering (m ± ds): Patients 5.25 ± 1.33; caregivers 6.83 ± 1.45; professionals 4.42 ± 2.98 in all those who attend terminal cancer. *An early death that hindered the interview. *Caregivers with low standard education. *Caregivers with low cognitive impairment, Karnofsky index < 30 or low standard education. *Caregivers with low cognitive impairment, Karnofsky index < 30 or low standard education. *Involvement of nurses in the care process for patients requesting euthanasia: a qualitative study in Flanders (Belgium)

Nele De Bal, Centre for Biomedical Ethics and Law, Leuven, BELGIUM, Christ Gastmans, Centre for Biomedical Ethics and Law, Leuven, BELGIUM, Tina De Beer, Centre for Health Services and Nursing Research, Leuven, BELGIUM, Bernadette van der Casteren, Centre for Health Services and Nursing Research, Leuven, BELGIUM

Although nurses worldwide are confronted with euthanasia requests, the experiences of nurses on their involvement in the care process surrounding euthanasia remain unclear. To explore nurses’ experiences on their involvement in this care process, a qualitative Grounded Theory strategy was used. In anticipation of new Belgian legislation on euthanasia, we conducted one-on-one semi-structured interviews with 15 nurses who were working in one of three general hospitals in Flanders (Belgium), were confronted with a euthanasia request and were willing to volunteer for an interview. Although euthanasia was still illegal, nurses unanimously stated that they were personally and intensely involved in the care for patients requesting euthanasia. Factors contributing to the difficult confrontation, characterized by powerlessness, could be classified into three categories: the euthanasia request, the nursing care context. Differences between the experiences of palliative care and non-palliative care nurses were most obvious in the group of contextual factors. Participants unanimously stated that they had an important role in total care for patients requesting euthanasia. Their involvement really began at the moment their patient formulated a euthanasia request (implicitly or explicitly) and ended after the patient’s death. Throughout the care process nurses paid special attention to the physical and psychological care of themselves and their relatives, primarily by informing and encouraging them. Nurses underscored the importance of caring for themselves and their nursing colleagues as intrinsic to the personal conditions. Our findings indicate that each stage of the euthanasia process requires that nurses involved possess specific caring and supporting competencies. Nurses’ willingness to personally care for these patients, in addition to their specific care expertise, allow them to be skilled companions of their patients requesting euthanasia. 

Abstract number: 54
Presentation type: Oral
Poster number: 
German physicians’ view on euthanasia

Birgitt van Oorschot, Abteilung für Strahlentherapie, Jena, GERMANY, Andrea Tietze, Juristische Fakultät, Universität Göttingen, GERMANY, Nicole Nickel, Juristische Fakultät, Göttingen, GERMANY, Volker Lipp, Juristische Fakultät, Göttingen, GERMANY, Alfred Simon, Akademie für Ethik in der Medizin e.V., Göttingen, GERMANY

The Germans distinguish several forms of euthanasia. Direct active euthanasia is prohibited, but indirect euthanasia (relieving of pain or other symptoms with possible life-shortening effect) and passive euthanasia (letting someone die) is possible and sometimes recommended. From the point of view of jurisdiction, both withholding and withdrawing treatment are seen as passive euthanasia. We know less about physicians’ perception. Methods: Between October 2003 and May 2004 a standardized questionnaire was sent to a representative number of physicians in Thüringen, Bayern and Westfalen Lippe (n=1557, 419 specialists for anesthesia/intensive medicine (Al), 916 specialists for internal medicine (IMs) and 641 general practitioners (GPs)). The professionals should assign several treatment/non-treatment options (all not active euthanasia in the view of German judgement) to different forms of euthanasia. A final situation and patients characteristics were used as preconditions. Results: 710 questionnaires were sent back (response 45.6%, 277 GPs, 199 Albs, 234 IMs). 3.2% of GPs, 1.0% of Albs and 0.9 % of IMs said that alleviation of pain with possible life-shortening effect is active euthanasia. Non-treatment of pneumonia was considered to be active euthanasia for 4.5% of Albs, 4.7% of IMs and 7.9 % of GPs. While withholding of artificial ventilation (AV) was seen as active euthanasia for 9.0% of Albs, 9.4% of IMs and 12.6 % of GPs, 37.2 % of GPs, 37.6 % of IMs and 47.2 % of Albs said that withdrawal of AV is active euthanasia. Withholding artificial fluid via vene (AF) was considered active euthanasia for 8.3% of GPs, 12.4% of IMs and 16.6% of Albs. 18.4 % of GPs, 26.9% of IMs and 35.2 % of Albs said that withdrawal of AF is active euthanasia. Conclusion: A remarkable part of physicians does not adopt the legal view on passive euthanasia. There is a notable space in the perception of withholding and withdrawing treatment. Open communication is necessary.
Abstract number: 55  
Presentation type: Oral  
Poster number:  

Public attitudes towards euthanasia in 33 European countries. Socio-demographic and cultural factors associated with the justification of euthanasia  

Joachim Cohen, End-of-Life Care Research Group, Brussels, BELGIUM, Isabelle Marcoux, VU University Medical Center, Amsterdam, NETHERLANDS, Johan Bilsen, Vrije Universiteit Brussel, Brussels, BELGIUM, Gerrit van der Wal, VU University Medical Center, Amsterdam, NETHERLANDS, Luc Deliens, Vrije Universiteit Brussel, Brussels, BELGIUM  

Objectives: To describe and compare the public attitudes towards euthanasia in 33 European countries, and to examine the socio-demographic, socio-economic, and cultural factors associated with the justification or rejection of euthanasia. Methods: We used the European Values Survey data of 1999–2000 with a total of 41,125 respondents (63% response rate) in 33 European countries. The main outcomes of our study concerned the moral justification of euthanasia (rated on a scale from 1 to 10). A multivariate ordinal regression was performed to examine the determinants of attitudes towards euthanasia. A weight factor corrected for socio-demographic characteristics within countries and for the population size of countries. Results: The justification of euthanasia by the general public expressed in mean scores; 95% CI tended to be high in countries as the Netherlands (6.69; 6.52–6.85), Denmark (6.61; 6.41–6.81), France (6.16; 6.02–6.30) and Sweden (6.07; 5.90–6.25). A markedly high opposition to euthanasia was found in Malta (2.23; 2.09–2.37) and in Turkey (2.78; 2.61–2.95). The mean score in all 33 European countries together was 4.71 (4.67–4.74). Of all respondents 13.0% felt that euthanasia was always justified, 31.2% never. Factors associated with the justification of euthanasia were age, marital state, socio-economic status; religious and moral value orientations; and country-specific differences. Conclusions: A liberal stand towards euthanasia often seemed to be associated with socio-economic and religious and moral value orientations; and country-specific differences.  

Abstract number: 56  
Presentation type: Oral  
Poster number:  

Reasons for dose changes after starting terminal sedation  

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Introduction: In 2001 the Liverpool care pathway for the dying phase (LCP) was introduced into the Palliative Care and Symptom Control Unit, to structure the care of the dying and the communication with them and their relatives. The professionals should record variances in outcomes on the pathway. The LCP was used to evaluate the problems and their relations to PS was given in 83 cases (64% of 129). No differences in primary disease, hospital survival and disease progression were seen between the group with indication to PS and the group without indication to PS. PS was successful in 69 patients. Midazolam was the most frequently used drug (46%) followed by haloperidol (40%) and chlorpromazine (35%). In 14 cases failure of PS was associated with a lack of communication or of clinical expertise of the palliative care hospital staff. All the 18 patients referred to the ICU died there, survival was comparable with the other patients and most of them were also sedated. Admission to the ICU was discussed with the PCCU staff. Conclusions: PS is frequently needed in the management of refractory symptoms due to advanced cancer at the end of life. PCCU management of the tertiary cancer center in collaboration with oncology hospital staff was feasible in most cases, but better integration and organization of services can improve outcome.

Abstract number: 57  
Presentation type: Oral  
Poster number:  

Main problems of relatives after starting terminal sedation  

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Abstract number: 59
Presentation type: Oral
Poster number:

A comparison of the practice of terminal sedation and euthanasia in the Netherlands

Judith Rietjens, Department of Public Health, Rotterdam, NETHERLANDS, Johannes van Delden, Julius Center, University Medical Center Utrecht, NETHERLANDS, Agnes van der Heide, Department of Public Health, University Medical Center Rotterdam, Rotterdam, NETHERLANDS, Gerrit van der Wal, Department of Occupational Health and Institute for Research in Extramural Medicine, VU University Medical Center, Amsterdam, NETHERLANDS

Background: It is unclear to what extent terminal sedation (defined as the administration of drugs to keep the patient continuously in deep sedation or coma until death without giving artificial nutrition or hydration) is or can be used as an alternative to euthanasia (defined as administering a lethal drug at the explicit request of a patient with the explicit intention to hasten death). We studied clinical differences and similarities between terminal sedation and euthanasia in the Netherlands, where both practices are legal. Methods: Personal interviews were held with a nationwide stratified sample of 410 physicians (response: 85%) about the most recent case in which they used terminal sedation (n=211) or performed euthanasia (n=123). We compared characteristics of the patients, the decision making and medical care between both practices. Results: Terminal sedation and euthanasia mostly concerned patients with cancer. Patients receiving terminal sedation were more often anxious (37%) and confused (24%) than patients receiving euthanasia (15% and 2%, respectively). Euthanasia requests were mostly the result of the patients' sense of loss of dignity and independency, suffering without chance of improving, and inability, whereas requesting terminal sedation was more often related to severe pain. Physicians applying terminal sedation estimated that the patient's life had been shortened by more than one week in 27%, as compared to 73% in euthanasia cases. Conclusions: Terminal sedation and euthanasia are seen as two mutually exclusive practices: both are often applied to address severe suffering in terminally ill cancer patients and both can have a life-shortening effect. However, terminal sedation is typically used to treat severe physical and psychological suffering in dying patients, whereas loss of dignity during the last phase of life is a major problem for patients who request euthanasia.

Abstract number: 61
Presentation type: Invited
Poster number:
Palliative care in chronic conditions: extending our borders

Julia M Addington-Hall, School of Nursing and Midwifery, Southampton, GREAT BRITAIN

There is growing evidence that people who die from, for example, heart failure, respiratory disease, HIV, renal disease and neurological conditions have unmet palliative care needs at the end of life. Hospice and palliative care services are often wary about caring for these patients because they fear they lack the skills they need, because they fear being overwhelmed (partly because of prognostic uncertainty beyond cancer), and because of funding concerns. Health professionals caring for these patients may fear 'empire building' by palliative care, and their patients may not want to be referred to services associated with terminal cancer. Educating ourselves in the principles and practice of palliative care is therefore important, as is partnership working with, for example, family doctors, geriatricians and cardiologists. Many (but not all) non-cancer patients are older, and improving palliative care in nursing homes is therefore important. There is little evidence to date that hospice and palliative care benefit non-cancer patients. Demonstration projects are therefore needed, with careful evaluation so we can learn what works best, and how best to how ensure that all can die well, regardless of disease or setting.

Abstract number: 62
Presentation type: Invited
Poster number:
Opioids, pain and the immune function

Paola Sacerdote, Pharmacology, Milano, ITALY

In the bidirectional network existing between the nervous and the immune system a pivotal role is played by the strict links existing between opioid receptors and ligands with cytokines and immune cells. These interactions take place at multiple levels. In the brain, the presence of a functional cytokine system is important in order to have the development of functional opioidergic pathways regulating antinociception. For example a series of studies have shown that in the IL-6KO animals and in the IL-1KO animals an impaired development of the endogenous opioidergic system is present. Moreover in these animals the responses to morphine and the development of tolerance to morphine antinociception are altered. Central IL-6 and IL-1 are therefore involved in the development of neuronal mechanisms involved in the response to both endogenous and exogenous opiates. In the periphery, cells of the immune system produce and release opioid peptides that can participate in peripheral antinociception. On the other hand, it is well known that opioids significantly affect the functionality of many immune cell types, binding both opioid receptors in the brain and those on immune cells. Endogenous opioids are formed by many immune responses by skewing the Thelper (Th1/Th2 balance towards Th2. On the contrary, the administration of morphine at pharmacological doses leads to an impairment of Th1 and an increase of Th2. On the contrary, the administration of morphine at pharmacological doses leads to an impairment of Th1 and an increase of Th2. During chronic treatment it has to be taken into consideration that tolerance to the immune effects of morphine develops at different moment for the function considered. The final impact on the immune system can vary depending on the duration of treatment. In conclusion, it is clear that the elucidation of the many interactions between opioids and immunity can have a great relevance for the better comprehension of the physiological basis of antinociception as well as for a better pharmacological approach to pain.

Abstract number: 63
Presentation type: Invited
Poster number:
Clinical implications of morphine services being too much

Per Sjøgren, Pain Center, Copenhagen, DENMARK

Animal studies have demonstrated that, the analgesic potencies of M6G is several times higher than morphine after intrathecal (i.t.) injection indicating that the brain penetration of M6G is significantly attenuated relative to that of morphine. High concentrations of M6G in the brain may account for the durable analgesic effect of M6G to opioids. Furthermore, a 3-fold slower rate of elimination of M6G compared to morphine has been demonstrated (1). M6G has analgesic effects in patients with cancer, but its potency compared to morphine has not been established. A critical clinical issue is the contribution of M6G to the analgesic action seen after long-term morphine administration. Animal studies have found that M3G administered by the i.t. route produces symptoms of sensory and motor excitation (2). Clinically, hyperalgesia, allodynia and migraine have been described in cancer patients treated with high doses of morphine administered by several different routes (3). In reports describing these symptoms very high plasma levels of morphine and M3G as well as accumulation of M3G relative to morphine or M6G has been demonstrated (3).


Abstract number: 64
Presentation type: Invited
Poster number:
CYP2D6 Genetic Variability and Efficacy of Analgesics

Urirke Stamer, Klinik und Poliklinik für Anästhesiologie, Bonn, GERMANY, Eberhard Klischik, Malteser Krankenhaus Bonn, Bonn, GERMANY, Frank Stüber, Rheinische Friedrich-Wilhelms-Universität Bonn, Bonn, GERMANY

The human genome project has revealed data on genomic variation which may influence the pharmacological responses. In pain therapy, the genetic background may influence the efficacy of opioid therapy is of special interest. Screening for variations in expression of drug metabolizing enzymes has been suggested as a potential tool for improving analgesia and reducing side effects. CYP2D6 genetic variability is supposed to be a major factor of adverse drug reaction, possibly influencing hospital stay and total costs. Polymorphisms within the cytochrome P450 2D6 have been associated with a poor metabolizer phenotype and display a frequency of about 10% in the Caucasian population. Several commonly used drugs like beta-blockers, anti-arrhythmic drugs, SHT3-antagonists, tricyclic antidepressants, opioids and others are metabolized by this enzyme. Furthermore, inhibitors of CYP2D6 like amiodarone and cimetidine might block metabolism of CYP2D6 dependent drugs. Poor metabolizers for CYP2D6 show a lower response rate to codeine, and tramadol analgesia than individuals with at least one wild type allele (1, 2). Therefore, CYP2D6 genotype has an impact on pharmacological response to drugs metabolized by this enzyme. Further candidate genes involved in pain perception, pain processing and pharmacogenetics like opioid receptors, transporters and other targets of pharmacotherapy are under investigation. Aspects of genetic differences influencing efficacy, side-effects and adverse outcome of pharmacotherapy will be of importance for future pain management. References: 1. Stamer
Abstract number: 65  
Presentation type: Invited  
Poster number:  

**Genetic variability of the mu-opioid receptor**  

Pal Klepstad, Dept. Intensive Care Medicine, Trondheim, NORWAY  

Clinical studies have shown no or low associations between serum concentrations of morphine and M6G and clinical outcomes. These results suggest that the interindividual variability in morphine efficacy is related to variations in the way morphine and M6G interacts with the mu-opioid receptor. Several polymorphisms have been demonstrated within the mu-opioid receptor gene. One of these variants (position 268 amino acid change: serine to proline) near abolish receptor signaling after stimulation with opioids. However, because of its low frequency the contribution from this SNP to the population variability is limited. A more common SNP is a position 118 nucleotide A to G substitution. Volunteers with this polymorphism are shown to have decreased pupillary constriction after M6G administration. Furthermore, cancer patients homozygous for this variant will need about twice the morphine doses as wild type patients, and this effect is related to decreased amphetamine induced release of the endogenous opioid peptides. Animal studies have identified that differences in the mu-opioid receptor gene can be caused by mechanisms other than polymorphisms. Animal studies have identified that differences in the expression of exons during translation to mRNA give multiple mu-opioid receptor variants (splice variants) that may be responsible for varying analgesic response and adverse effects from morphine and M6G. Moreover, experimental studies in animals have shown that antisense targeting of specific exons in the mu-opioid receptor gene has a different influence on antinociceptive effects of various opioids, including morphine and M6G. Mu-opioid receptor splice variants have also been demonstrated in the human brain. It will be of interest to see if such splice variants can explain the variable effects from different opioid substances.

Abstract number: 66  
Presentation type: Invited  
Poster number:  

**The place for nursing homes in palliative care**  

Carl Johan Fürst, Stockholm, SWEDEN  

In most societies there is an increasing prevalence of patients with cancer and an increasing cancer incidence compared with a reduction of oncology and other hospital beds. There is an increasing number of cancer patients and of deaths in nursing homes. Palliative care in nursing homes will be discussed in the perspective of the WHO 1990 and 2002 definitions. The need for team-based palliative care is sometimes evident in this patient group but for many patients the palliative care needs are more intermittent and treatment related. In this presentation some aspects of the Swedish experiences from this borderland between community and health care sectors will be discussed. Nursing home referrals is not always based on a rigorous needs assessment and total problems of this organizational model in terms of competence, organization and payment will be discussed.

Abstract number: 67  
Presentation type: Invited  
Poster number:  

**The work of clinical nurse specialists in palliative care with nursing homes in the Republic of Ireland**  

Julie Ling, IRELAND  

The Republic of Ireland has a relatively young population with only 11.5% of the population aged 65 or over and of these approximately 5% are in long-term residential care. As a result of changing demographics this figure is set to rise. As populations age and more people end their lives in residential care settings, this area of care has increasing relevance. A recent study in the United Kingdom has assessed the input of community clinical nurse specialists in palliative care to nursing homes. The study presented is a replication of this work.

The aim of this work was to assess the current level of input of community-based clinical nurse specialists in palliative care to nursing homes in the Irish Republic. Questionnaires were distributed to all community-based palliative care clinical nurse specialists via the National Council for the Professional Development of Nursing and Midwifery database. The total population of 114 community-based clinical nurse specialists in palliative care were approached and 63 completed questionnaires were returned achieving an overall response rate of 55%. This session will focus on the findings of this study and will compare the findings from the UK with those from the Republic of Ireland.

Abstract number: 68  
Presentation type: Invited  
Poster number:  

**Using an ‘integrated care pathway for the last days of life’ as a way of developing quality end of life care in nursing homes**  

Jo Hockley, Education, Edinburgh, GREAT BRITAIN  

Nursing homes are now becoming a place of care where older people die. One in five older people will die in a nursing home in the UK. Education has been one way of developing nurses/care assistants palliative care knowledge in these settings. However, nurses have found it difficult to bring about the necessary change in practice. In the final phase of a larger action research study, an integrated care pathway [ICP] for the last days of life based on the LCP (Liverpol Care Pathway) was implemented and fully evaluated as part of a multi-faceted project to develop quality end of life care in eight independent nursing homes. The LCP for the last days of life is a framework based around the available evidence of quality end of life care. This session will look at what ‘hindered’ and what ‘facilitated’ implementation of the ICP documentation across the nursing homes. It will pay special attention to the important part played by the ‘context’, and ‘facilitation’ of any project when trying to implement evidence into practice. It will also discuss the five themes (greater openness around death and dying; taking responsibility for recognising and marking the dying process; improved teamwork; critically utilizing palliative care knowledge to improve practice; and, deeper and more meaningful communication) that emerged from the data as a result of the project. Staff in the nursing homes were given greater confidence to acknowledge death and dying as an important part of nursing home care and helped to bring a greater holistic view of care to the residents and their families.

Abstract number: 69  
Presentation type: Invited  
Poster number:  

**Prognostication in Advanced Cancer: Ethical Perspectives**  

Bert Broeckaert, BELGIUM  

When discussing the ethical issues concerning prognostication, it is important to realise that prognostication entails three rather different aspects: a prognosis is established, used and communicated. All three aspects entail their own ethical dilemmas. Several arguments can and will be given, however, that clearly demonstrate that, though physicians often feel uncomfortable when formulating prognoses, in many cases establishing a prognosis is both necessary and inevitable, that poor prognostication or a refusal to prognosticate can have dire consequences and thus be very unethical. Once established, a prognosis should of course be used in an appropriate way. We will argue that treatment decisions are and should be based on a number of variables, including prognosis, and that everything that can be done should be done.

The fact that prognostic information is per definition probabilistic and that even the very best prognostication will be dramatically inaccurate in a significant number of cases, provides in our view an additional reason for rejecting prognostication, state-of-the-art though it may be, that is not deeply embedded in an open, flexible, patient-centered and dialogical approach. When not put in this broader perspective, guidelines on prognostication in advanced cancer patients can have an adverse impact. As far as prognosis communication is concerned, we will argue that, though the patient has a right to be informed about his prognosis, and that all these variables should receive and continue to receive due attention. Marking the dying process; improved confidence to acknowledge death and dying as an important part of nursing home care will help to bring a greater holistic view of care to the residents and their families.
Abstracts number: 71
Presentation type: Invited
Poster number:

Prognostic factors in palliative care

Paul Glare, Department of Palliative Care, Royal Prince Alfred Hospital, Sydney, AUSTRALIA

Accurate survival predictions are an important part of care for patients with life-limiting illnesses. Many studies have shown that clinicians’ subjective assessments of survival are inaccurate (1). As with other types of clinical assessment, actuarial (statistical) judgement of prognostication, based on empirically established relations between prognostic factors and survival, should be superior to processing such information in one’s head. There are an enormous number of possible prognostic factors that are candidates for actuarial judgment of survival. They can be grouped into disease-, patient- and environment-related ones. In patients with advanced cancer, disease-related ones such as tumour size and histology seem less important than the other ones. In patients with other life-limiting illnesses such as heart failure or dementia, disease-related ones may still be important. In advanced cancer patients, poor performance status, various symptoms (particularly symptoms of cancer cachexia, breathlessness and cognitive impairment) and certain simple laboratory tests (lymphocytopenia, C-reactive protein) reached level B. Prognostication of life expectancy is a significant clinical commitment for clinicians involved in oncology and palliative care; more accurate prognostication is feasible and can be achieved by combining clinical experience and the evidence from the literature. Using and communicating prognostic information should be part of a multidisciplinary palliative care approach.

Abstract number: 73
Presentation type: Invited
Poster number:

Families – a resource for home care

Sheila Payne, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN

This paper will briefly introduce the literature and current theoretical perspectives on the contribution of families to enabling patients to receive care and to die at home. It starts with a discussion of the terms ‘families’ and ‘carers’ and explores the assumptions which underpin the use of these terms, and the extent to which the word ‘carer’ is used by others compared to being self-attributed. A synthesis of the palliative care literature demonstrates that while families’ voices are present, they have predominantly been consulted as proxies for patients rather than in their own right. What research there has is tended to portray caring as a ‘burden’ and carers as victims of circumstance. The extent to which current palliative care policies in the UK recognise the separate needs of families as opposed to the preferences and needs of patients in planning and managing end-of-life care will be discussed.

Abstract number: 74
Presentation type: Invited
Poster number:

Patient-family centred care: from definition to practice

Daniela Mosoiu, Study Centre for Palliative Care, Brasov, ROMANIA

The definition of palliative care implies that care is delivered in such a modality that the best quality of life is achieved for patients and their families. In our attempt to make the patient and family our unit of care there are several challenges during therapy. Some are related to the family, others to society and some come from barriers in communication. The fact that families act in some culture as interface in between the healthcare system and the patients adds new responsibilities like treatment decision-making to their roles. To acknowledge the twofold position of the family members both as caregivers and also as service users and to act appropriately is not an easy task to accomplish especially when we work in resource limited settings, in countries where palliative care is in a pioneering stage.
Abstract number: 77
Presentation type: Invited
Poster number:

Palliative care networks: challenges and pitfalls
André Rhebergen, Director, Bunnik, NETHERLANDS

Networks can be described as organisations and/or persons working together to realise one or more specific aims. This raises questions on participants (who, goal (why), tasks (what) and functions (how). The organisational theory of networks can help clarifying some of the general and more specific problems palliative care networks might face. On the organisational level a palliative care network will improve understanding and coordination between the organisations, thus creating a palliative health care chain from hospital, specialized palliative care organisations like units or hospices to home care. The network will manage the patient flow. On the professional level a palliative care network will improve understanding and coordination between the professionals working in the different settings, thus creating optimal palliative care on an individual patient level. Palliative networks have two important tasks: 1. Provide care and skills to the patient, to make it possible that the patient receives optimal care at home, 2. If this is no longer possible, provide specialized palliative care beds where the patient can die. Ideally a palliative network realises cooperation on both the professional and the organisational level, and performs both tasks. There are different network solutions possible, depending on regional and cultural circumstances, financial arrangements and policy. However, since networks in most cases are more a loose construct than a formal organisation, the question of coordination and control is the major challenge for all palliative care networks. The session on palliative care networks will offer help in finding answers in describing experiences with palliative care networks in different countries. 1. Participating partners 2. Tasks of the network 3. Activities 4. Evaluation studies of the network 5. The use of networks 6. Development of networks: state of networks in different countries. 1. Participating partners 2. Tasks of the network 3. Activities 4. Evaluation studies of the network 5. The use of networks 6. Development of networks: state of networks in different countries.

Abstract number: 78
Presentation type: Invited
Poster number:

Palliative care networks: challenges and pitfalls
Tine De Vlieger, UA/campus Drie Eiken/gebouw 5:1, drielinie, BUNNIK, NETHERLANDS

Introduction: A network for palliative care is a platform for caregivers. The main task is to stimulate and to build out good palliative care for the region the network is responsible for. In Belgium the government started to install 28 networks since 1992. Palliative Hulpverlening Antwerpen v.z.w. is one of the 15 Flemish networks. This network has a particular way of offering help. Basic is the practise of the emancipatory caremodel. The government give a slight financial support. Therefore, they expect registration of the activities every year and bring visits for a regular evaluation. Tasks of the network: Its task is multiple: sensibilisation and training of caregivers and professionals, to give support to every caregiver (professional and non-professional) wherever they work, to improve skills and to stimulate palliative care teamwork, to install and manage a platform of volunteers, to do or help scientific research. Activities: It is a challenge for the team of the network to create a teamspirit that leads to high quality interdisciplinary teamwork that enforces care possibilities. An important goal to stimulate and to help implement the palliative care philosophy in their region. The organisation of a network is multidisciplinary. Team members are nurses, GPs, a social worker, a psychologist and administrates. They all have the expertise to recognize and offer needs in palliative care of patients and their family. They give support to the caregivers working in hospitals, elderly homes, at home when they ask for it. Every year the network realises an evaluation of the basic and advanced level in palliative care and this for different disciplines. It is a continual task to recruit and support volunteers. Evaluation possibilities of a network: study of colleague Trudie Van Iersel, Brugge Belgium concerning the Flemish networks. Development of the networks: A network of palliative care is a particular organisational structure to stimulate and improve knowledge about palliative care in the society. For the government it is clear that it is a right of every citizen in Belgium to receive good palliative care when needed. Networks have the task to support patients, their families and all caregivers involved in palliative care. Since 1992 there is an evolving and changing network. For Palliative Hulpverlening Antwerpen v.z.w. it’s still a challenge to practise the emancipatory caremodel to offer support in care.

Abstract number: 79
Presentation type: Invited
Poster number:

Netzwerk Palliativmedizin Essen: network project for the implementation of palliative care at different levels in accordance to the patients needs
Marianne Kloke, Kliniken Essen-Mitte, Essen, GERMANY

Background: 2001, heads of oncology departments initiated a working group for PC. First, a consensus about the concept of PC was elaborated: Basic PC should be ubiquitous available and integrated into routine work. Qualified PC can be delivered by nurses and physicians who underwent additional curricular and continuing training. A prerequisite for the ‘specialized’ level is the licensed transfusion authorisation. In addition a specialized institution for PC. Second, curricular education in PC was started. Member of all professions contributing to PC developed the concept of a regional network. This project ‘Netzwerk Palliativmedizin in Essen’ was granted by the Alfred Krupp von Bohlen und Halbach-Stiftung and started in November 2003. Structure and strategy: Hospital support teams (HST) consisting of a ‘qualified’ nurse and a physician have been installed at each hospital in order to offer qualified PC and to implement basis PC in their institution. A data bank with important in formations for daily work has been processed with access to all HST. The local HST are supported to develop a tailored training to meet their institution by the leading group (LG). The LG consists of 6 elected and 3 delegated persons representing the different professions as needed in PC. In order to provide a ‘qualified’ PC a 24 hours hotline for local physicians and nursing services has been installed with round the clock backup by specialists in PC. Transprofessional palliative conferences are held 2-4 times per month in a regular basis (5 a year). The minutes of these conferences are the basis of ongoing quality assurance. The policy is to stick to international recognized recommendations in palliative care and to transcribe them successively into an proper ‘recommendation book’. All these activities are coordinated by an office with two employees with specific education in PC.

Abstract number: 80
Presentation type: Oral
Poster number:

The assessment and response to needs among informal carers: findings from a closed file audit
Celia Leam, Social Work, London, GREAT BRITAIN, Richard Harding, Dept of Palliative Care & Policy, King’s College London, London, GREAT BRITAIN

Aims: Although palliative care aims to improve outcomes for informal carers, their needs remain high and largely unmet. This study aimed to audit carers’ self-identified needs, in order to inform an audit cycle and ensure that interventions reflect carers’ priorities, taking account of existing coping strategies. Methods: Data was extracted from 145 random closed files of patients receiving hospice care at home over a 6-month period in London, UK. Assessment notes were thematically coded and ranked according to domains developed from an initial pilot extraction of 10 files and subsequently refined. Results: 70% of patients (n=100) had an identified informal carer. Primary changes reported by carers were: loss of independence and reduced social activities; anxiety and depression; significant changes in domestic roles and employment; relationship difficulties with the patient. Existing coping strategies reported by carers were: family and friends; stress reactions (e.g. anger, crying, smoking); employment as an alternative; frank order of unmet needs and issues presented by carers were: financial difficulties (n=64); general support needs (n=36); anxiety and depression (n=31); respite (n=27); practical help (n=23); fatigue (n=13); children and young people (n=12); physical care (n=12); personal relationship tensions (n=12). Conclusions: That 70% of patients had an identified informal carer suggests a need for significant resource allocation to this high need population. Multiprofessional support is required to meet the full range of self-identified needs. These were responded to by hospice staff, but further research is required to establish the specific methods of intervention and their relative effectiveness in resolving carers’ needs. Carers and their needs can be identified, but good practice requires the continuing development of assessment tools and protocols for systematic, accurate assessment and recording of need and timely appropriate staff responses.

Abstract number: 81
Presentation type: Oral
Poster number:

A pilot study to assess the effectiveness of a palliative care clinic in improving the quality of life in patients with severe heart failure
Paul Paes, Palliative Medicine, Oxford, GREAT BRITAIN

Aim: To assess the effectiveness of a palliative care clinic in improving the quality of life in patients with severe heart failure. Method: Patients with NYHA III or IV heart failure were randomised to 2 groups. The intervention group attended a palliative care clinic for 6 months as well as their normal cardiology follow-up. The control group continued with their normal cardiology follow-up. Both groups completed 3 questionnaires (EORTC QLQ-C30, Kansas City Cardiomyopathy and HAIDS scales) at the start and end of the study. They were compared using a linear mixed-effects model. Results: 16 patients agreed to take part, 9 in each group. Differences between the 2 groups were not statistically significant. Conclusions: There are no statistically significant differences between the 2 groups. The intervention group also faked out feedback forms. Results: 16 patients agreed to take part, 9 completed the study. There were no statistically significant differences between the 2 groups.
significant results. However, patients in the intervention group did better than the control group with regard to anxiety, depression, fatigue, nausea, pain, information needs and to quality of life scores. The control group did better in one symptom score, dyspnea. Conclusions: This pilot study suggests that patients attending the palliative unit might be less depressed, more satisfied with the improved quality of life compared to the control group. However this would have to be carried out as a full-scale study to achieve statistically significant results.

Abstract number: 83
Presentation type: Oral
Poster number:

Daycare in palliative medicine: patients wishes
Hanna Ludwig, Abteilung für Schmerztherapie und Palliativmedizin, Remscheid, GERMANY, Charles Daniels, St. Luke’s Hospice Harrow, London, GREAT BRITAIN, Uwe Junker, Sana-Klinikum, Remscheid, GERMANY

In England, many hospices are running a daycare-unit. Patients are invited to stay once or twice a week for the whole day in a special area of the hospice. They receive medical treatment (eg, transfusions, pain therapy, wounddressings), but also simply loving care and entertainment. Professionals wanted to know whether the patients come to daycare because they want easy access to the health professionals, meet other people with the same problems or prefer different offers of the hospice (eg, massage, art-therapy, beauty-treatment).

48 patients returned our short questionnaire, mean age 73 years, 45 diagnosed with cancer. Their answers show that it is as important to have medical treatment as meeting other people. One explanation for this might be the old age. The appointment in daycare is very often the only opportunity for our patients to leave the house. From the physician’s view daycare for palliative patients is a very good way to build up a close relationship and to realize and treat imminent problems.

Abstract number: 84
Presentation type: Oral
Poster number:

Judging the quality of care at the end of life by proxies, general practitioners in a specialist palliative care unit, a home care setting and regular hospital care
Dietmar Beck, Palliative Care Unit, Göttingen, GERMANY

Background: Prospective studies on ascertaining the quality of life of dying patients prior to death are fundamentally biased as they only represent the proportion of patients who are relatively well and therefore able to participate. To overcome this difficulty, informations were gathered from proxies in an ‘after death approach’ study. The query focussed on aspects of medical care, nursing care and the efficacy of symptom control in three different places and settings of terminal care. A questionnaire was sent to 439 proxies of deceased patients. Results: 59 proxies were included in the palliative unit group (68% of addressable), 40 proxies (55%) of patients that died in a home care setting, and 125 (44%) proxies of patients who died in hospital. The quality of care was judged in the categories ‘very good’, ‘good’, ‘sufficient’ and ‘very poor’. 88% of proxies judged the quality of care as ‘very good’ in the palliative unit group (pu), 72% in the home care group (hc) and 58% in the hospital ward group (hw). Positive evaluations of nursing care were delivered in 85% (pu), in 78% (hc) and in 53% (hw) respectively. Pain control was estimated ‘very good’ in 85% (pu), 64% (hc) and 58% (hw), 86% of proxies reported that their relatives died without severe pain (pu), compared with 79% (hc) and 76% (hw). Conclusion: Proxies are a vital source of information for dying cancer patients. In a retrospective observational study they described distinctions in the quality of care depending on different places of death. In view to medical care, nursing care and symptom control, a specialist palliative care unit was superior to a home care setting, followed by regular hospital care.

Abstract number: 85
Presentation type: Oral
Poster number:

ALL PATIENT REFINED-DIAGNOSTIC RELATED GROUP (APR-DRG) AND CASE MIX INDEX (CMI) IN AN ACUTE PALLIATIVE MEDICINE UNIT
Declan Walsh, Hematology/Oncology, Cleveland, OH, U. STATES, Ruth Lagman, The Cleveland Clinic Foundation, Cleveland, U. STATES, Mellar Davis, The Cleveland Clinic Foundation, Cleveland, U. STATES, Susan LeGrand, The Cleveland Clinic Foundation, Cleveland, U. STATES

Background: The All Patient Refined-Diagnostic Related Group (APR-DRG) is a modification of the traditional DRG and includes four classes of severity of illness and four classes of risk of mortality. This presents a more accurate assessment of the complexity of cancer care needs. When individuals with advanced illness are admitted to an acute inpatient palliative medicine unit there may be a perception that they get less intense acute care. Our experience is that most patients are multisymptomatic, have several comorbidities and are older.

Methods: We prospectively compared DRGs and APR-DRGs from January 1 to June 30, 2003 and February 1 to July 31, 2004. A template/guide was followed by staff physicians to document clinical information that included sites of malignancy, site of metastases, complications, symptoms and comorbidities. In addition to the primary site of malignancy, sites of metastases included bone, brain, lung, and lymph nodes etc. Examples of complications of advanced disease are hypercalcemia, pathologic fracture and spinal cord compression. Pain, dyspnea, nausea, vomiting and constipation are examples of symptoms. Comorbidities included hypertension, diabetes mellitus (types I and II), anemia (iron deficiency or chronic disease etiology). Results: The number of cases seen were 305 in 2003 and 302 in 2004. The overall average severity of illness increased 19%. Mean length of stay decreased from 9.11 to 8.88 days. Mean direct cost per case increased $573.

Conclusion: Better documentation of clinical information that included symptoms. Comorbidities included hypertension, diabetes mellitus (types I and II), anemia (iron deficiency or chronic disease etiology) was significant results. However, patients in the intervention group did better than the control group with regard to anxiety, depression, fatigue, nausea, pain, information needs and to quality of life scores. The control group did better in one symptom score, dyspnea. Conclusions: This pilot study suggests that patients attending the palliative unit might be less depressed, more satisfied with the improved quality of life compared to the control group. However this would have to be carried out as a full-scale study to achieve statistically significant results. 

Abstract number: 83
Presentation type: Oral
Poster number:

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Hanna Ludwig, Abteilung für Schmerztherapie und Palliativmedizin, Remscheid, GERMANY, Charles Daniels, St. Luke’s Hospice Harrow, London, GREAT BRITAIN, Uwe Junker, Sana-Klinikum, Remscheid, GERMANY

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B. J. Luczak, Palliative Medicine Chair and Department of Karol Marcinkowski University of Medical Sciences in Palliative Medicine Chair and Department of Karol Marcinkowski University of Medical Sciences in Poznan POLAND, M. Klužak, Hospice Pallium, Poznan, POLAND

Abstract number: 87B Presentation type: Oral Poster number: Masked and unmasked End of Life Care

Object of the study was to evaluate the differences between masked (M) and unmasked (UM) end of life care (EoLC) using the opinion of hospice caregivers. Methods. An open questions questionnaire addressed to hospice caregivers, including age, sex, occupation, time of working in hospice, religious denomination and questions dealing with their description of M and UM EoLC, caregivers’ experiences in caring for the dying, descriptions of differences, their preparation for providing care for the dying, their proposals to improve the EoLC. Results. 80 from 98 hospice caregivers participants of palliative care cases answered the questionnaires: 9 men (21–74), 71 women (18–75), mean age 42, 3; occupation: 6 doctors (in hospice >1 year 6), 30 nurses (>1 > 14, <1y 6, candidates 10), 44 non-medical volunteers (35 >1y, 6-1 year 3, candidates including 1 priest), all Roman Catholics. Understanding the difference UM v M EoLC. UNMASKED EoLC: if both patient and families are prepared to dying of the pts: truly informed about illness and prognosis – 73 % (83% of doctors, 93% of nurses, 60% volunteers), sharing feelings with beloved – 65% and carers 75%, closing unfinished business 60%, supported spiritually %, receiving spiritual support from religious practices/prayer – 45%. MASKED EoLC: patients and families are not prepared for dying/death of pts: 75%: diagnostic/ informations kept very serious diagnosis/pts condition/prognosis not told, no awareness of death (83% of doctors, 93% of nurses, 60% volunteers), isolation 40%, unconscious 35%: including non-religious and sedation. Most of the responders who give examples of M and UM EoLC also shared their experiences of EoLC of beloved person or patients who died in hospitals – usually not receiving good EoLC. The responders stressed the needs of their better preparation to EoLC and the role of hospice care for improving EoLC, especially home care as a better place than hospital for dying (70%). Conclusion. 1. Lack of awareness of impending dying, lack of preparation for dying is perceived as the main factor of masked EoLC. 2. Communication skills, practical experiences gained from team work in hospice are important factors to improve EoLC. It is a need for continuous training/education. 3. Hospice/PC should be available in all settings where the pts are dying.

Abstract number: 88 Presentation type: Oral Poster number: End of life care for all – Palliative Care in the Intensive Care Unit

John Ellershaw, Department of Palliative Medicine, Liverpool, GREAT BRITAIN, Laura Chapman, Royal Liverpool University Hospital, Liverpool, GREAT BRITAIN, Maureen Gambles, Royal Liverpool University Hospital, Liverpool, GREAT BRITAIN, Eoin O’Connor, St. James’ University Hospital, Liverpool, GREAT BRITAIN

One of the challenges facing palliative care is to transfer best practice of care for the dying from a hospice setting to other care settings, and to non-cancer patients. One tool for achieving this is the Liverpool Integrated Care Pathway for the Dying Patient (ILCP). This is a multi-professional document that incorporates evidence-based practice and appropriate guidelines related to care of the dying. The ILCP has been developed for the care of the non-cancer patient, but with modifications can be used in non-cancer patient populations. Aim Patients on the Intensive Care Unit (ICU) have a high mortality rate and many patients with advanced illnesses spend some time ICU during their final hospital admission. We carried out an action research project with the aim of producing a revised LCP, designed specifically for use on ICU. Method and Results: Two focus group interviews were carried out in order to gain an insight of how staff from a busy, adult ICU felt dying patients were cared for. In particular, the relevance of the ILCP in its current format and suggestions for modification. A thematic analysis of findings was undertaken. Key findings included the opinion that care of the dying could be improved, particularly around diagnosing dying. There was strong support for LCP in an ICU. A working group, made up of members of the ICU, palliative care teams, used these findings to amend the ILCP. After further consultation, the new LCP was launched on ICU with an accompanying teaching programme run by the palliative care team. Completed LCPs were analysed after the project and compared with a base review of documentation carried out previously. Conclusion: This demonstrates how palliative care can cross the borders into intensive care, and provides a model for successful integration into other clinical areas.

Abstract number: 89 Presentation type: Oral Poster number: Medical end-of-life decisions in oncology and non-oncology patients in Flanders, Belgium

Lieve Van de Block, End-of-Life Care Research Group, Brussels, BELGIUM; Jann Bilsen, Vrije Universiteit Brussel, Brussel, BELGIUM; Jan L. Bernheim, Vrije Universiteit Brussel, Brussels, BELGIUM; Deliens Luc, Vrije Universiteit Brussel – VU University Medical Centre The Netherlands, Brussel, BELGIUM

Objective: Robust incidence studies worldwide have reported high frequencies of end-of-life decisions with a possible or certain life-ending effect (ELDs) among cancer patients, but no in-depth comparative analysis between oncology and non-oncology patients has been made. In this study the frequencies of ELDs among oncology and non-oncology patients are compared. Method: We selected a random representative sample of all death certificates of 2001 (n=2950) in Flanders, Belgium. Anonymous questionnaires concerning ELDs were mailed to the physicians who signed the death certificates. In this study we analyze all non-sudden deaths involved. Logistic regression analysis was used to calculate corrected odds ratio (95% CI). Results: Ninety-five percent of the cancer patients died suddenly versus 70% of the non-cancer patients. For these non-sudden cancer and non-cancer deaths respectively, an ELD was made in 74% and 50% (OR 2.9; CI 2.3–3.5), euthanasia and physician-assisted suicide in 1.2% and 0% (OR not possible), life-ending acts without patient’s explicit request in 3.4% and 1.8% (OR ns). All interventions based on a hypothetical patient with a potentially life-shortening effect (APS) in 53% and 23% (OR 3.8; CI 3.1–4.6), and non-treatment decisions (NTD) in 16% and 25% of the cases (OR 0.5; CI 0.3–0.8). Considering the higher frequency of APS, dying among oncology patients is more often related to (potentially lethal) drug administration than among non-oncology patients. Conclusion: We present evidence of a difference in probability of drug administration with explicit intention of hastening death. NTD is practised more often among non-cancer patients. These findings show that the frequency and kind of ELD is strongly related to the nature of the disease and argue for in-depth research on ELDs differentiating between diseases and illness-trajectories.

Abstract number: 90 Presentation type: Oral Poster number: Did you say aggressive or palliative end-of-life care?


Introduction: This study aimed to assess markers of aggressive care in the last month of life among adults dying from chronic diseases requiring palliative care in Quebec, Canada. Methods: Data for all adults who died in 1997–2001 were obtained from the Quebec mortality database. Using the ICD classifications, chronic diseases requiring palliative care were determined by consensus of experts. Data for all hospitalizations in acute care hospitals and all medical interventions provided during the 2 years before death were obtained from the provincial databases maintained by the comprehensive public health insurance system. Markers of aggressive care in the last month of life included some interventions (intravenous chemotherapy, mechanical ventilation, reanimation, surgery, admission in intensive care units) and acute care hospital use (>2 admissions and >14 days of hospitalisation). Results: Among the 264,389 deaths, 68.2% (180,436) were classified as requiring palliative care. Cancers accounted for 45.8% of these deaths but the majority (54.2%) were attributable to other chronic diseases. Aggressiveness of care in the last month of life decreased with age and varied with cause of death. Percent with one or more marker of aggressive interventions was 26.0% overall and ranged from 5.8% for mental diseases to 45.6% for chromosomal/congenital malformations. Percent spending >14 days in acute care hospitals was 28.2% overall and ranged from 10.7% of patients with mental diseases to 40.0% of those with blood diseases. Conclusion: Age and cause of death greatly influence end-of-life care. Better predictive models for the time of death and increased access to palliative care may decrease aggressiveness of end-of-life care while responding to the needs of the dying and their families.
Abstract number: 91
Presentation type: Oral
Poster number:

Which patients die at home in Flanders, Belgium? Analysis of the determinants of dying at home, in hospital or in a nursing home.

Joachim Cohen, End-of-Life Care Research Group, Brussels, BELGIUM, Johan Bilsen, Vrije Universiteit Brussel, Brussels, BELGIUM, Peter De Hoof, Ministry of Flanders, Brussels, BELGIUM, Gerrit van der Wal, VU University Medical Center, Amsterdam, NETHERLANDS, Luc Delfens, Vrije Universiteit Brussel, Brussels, BELGIUM

Objective: The knowledge of determinants for place of death is important for policy aimed at quality end of life care. We investigated the influence of clinical, socio-demographic, contextual and healthcare-system factors on the place of death. Method: We included all 55,759 deaths of 2001 in Flanders, Belgium. We gathered our data via the officially registered death certificates and anonymously linked them with healthcare statistics. A multivariate multinomial logistic regression was used to examine the associated factors (home, hospital and nursing home as dependent categories). Results: Of all deaths in Flanders, 53.7% took place in a hospital, 24.3% at home and 19.8% in a nursing home. The place of death was found to be significantly associated with the patient's sex, age, living environment, cause of death, and residence. The probability of home deaths strongly varied per region. Dying at home (compared to dying in a hospital) was less likely among people suffering from non-malignant chronic diseases (ORs from 0.86 to 0.27), lower educated people (OR: 0.72, 95% CI: 0.63–0.80), people living single (OR: 0.77, 95% CI: 0.73–0.81) and older patients living in institutes (OR: 0.16, 95% CI: 0.14–0.18). Conclusions: Important clinical, socio-demographic and contextual determinants for place of death were found; healthcare system factors were less important. Although dying at home is wished by many, most people in Flanders, Belgium in 2001 died in a hospital, which places responsibility on hospitals and nursing homes to ensure a quality end-of-life care for many. Characteristics of patients who chose to die at home could be identified, which is important for policy interventions to support home death.

Abstract number: 92
Presentation type: Oral
Poster number:

The perceived meaning of crying among cancer patients at the end of life

Karen Rydé, Faculty of Health Sciences, Linköpings University, Norrköping, SWEDEN, Maria Friederichsen, Department of Welfare and Care, Norrköping, SWEDEN, Peter Strang, Karolinska Institutet, Stockholm, SWEDEN

Introduction: Crying is a typical human expression for emotions and has physiological as well as behavioural functions. Still, there is sparse literature about adult crying among patients in a palliative care context. The aim of this study was to explore the perceived meaning of crying among patients. Method: A purposeful sampling aiming at 15–20 informants was undertaken. Tape-recorded semistructured interviews were performed and analysed using a hermeneutic approach. Up until this date, the sample consisted of ten cancer patients at two palliative-hospital based home care units in the county of Östergötland in Sweden. Preliminary results: Different types of crying experiences were described by the patients: 1) Strong and hysterical/uncontrolled crying that was impossible to stop and started e.g. after receiving bad news. The situation was overwhelming and the only was to express their feelings right then was by crying 2) Quiet sad and melancholic crying, with tears streaming slowly down the cheeks. This type of crying was common when crying together with a relative. They showed their feelings without hiding them from their relatives and in these situations they experienced a feeling of sharing a difficult situation. The intensity was different in these two types of crying. Crying was related to close relationships and the future. It broke through when patients felt disappointed, powerless and without the possibility to influence the progression of the disease. Crying also had some positive effects, for example relationships became stronger, during the process of crying coping strategies were born and crying created relaxation. By crying, dark thoughts were brought to an end and allowed for new energy. However, for some informants, crying was the worst way of coping and they described crying as unnecessary and as a loss of energy.

Abstract number: 93
Presentation type: Oral
Poster number:

Advance Directives – What do Health Care Workers in Oncology feel about them?

Caroline Usborne, Wirral, GREAT BRITAIN

Background: In Great Britain there is increasing interest around the issues of Advance Directives (A.D.s) and Living Wills, as a possible way of ascertaining the wishes of patients regarding medical treatment, should they be rendered mentally incompetent. Currently they are used infrequently in Great Britain compared to the USA. Aim: To look at the attitudes towards, and knowledge of A.D.s held by health care workers (H.C.W.s) at a Regional Cancer Centre. Method: A 13-item, semi-structured questionnaire addressing attitudes, experience, and understanding of A.D.s (as defined by the British Medical Association) was distributed to the H.C.W.s at a Regional Cancer Centre. Results: Completed questionnaires were received from 97% of H.C.W.s. The responses were then divided into four groups; doctors, qualified nurses, auxiliary nurses and other professions allied to medicine (P.A.M.s). Although the majority of doctors (69%), qualified nurses (77%) and P.A.M.s (55%) had heard of the term, correct understanding of the term was very poor. Only 19% of qualified nurses had had any discussion with patients about A.D.s and only 10% had cared for a patient with one. No other H.C.W. group had had any experience of A.D.s. Information leaflets, both for patients and H.C.W.s, were felt would be of benefit by the majority, although some felt that this would not be helpful, particularly for patients. Conclusion: Although a significant proportion, 64% (62,) of H.C.W.s had heard the term A.D., it was confused with a Living Will rather than a true A.D. Qualified nurses appeared to be the only group that had encountered A.D.s in clinical practice. Beliefs surrounding the legal position of A.D.s were varied. However, the fact that they can be legally binding (by case law) in Britain appears to be poorly understood. However, the majority were enthusiastic about further education for staff and patients.

Abstract number: 94
Presentation type: Oral
Poster number:

Effects of an Advanced Illness Coordinated Care Program on Patients and Surrogates


This randomized study examined the effectiveness of a structured intervention, the Advanced Illness Care Coordination Program (AICCP) designed to improve coping with advanced illness and end-of-life care planning, including patient involvement in shared decision-making and communication between patients, families, and health care professionals. 233 patients with advanced illness and their surrogates were randomly assigned to the AICCP condition or to a comparison group receiving usual care (UC). Patients and their surrogates were assessed at study enrollment and at three months post-enrollment on measures of patient and surrogate satisfaction with health care and provider communication. Results showed that AICCP significantly increased patient satisfaction with end-of-life care and provider communication, while surrogates of patients in the AICCP reported fewer problems with emotional and spiritual support from providers. AICCP participants were significantly more likely than UC to have filed at least one advance directive (AD) and displayed more continuous advance planning as reflected by significantly greater numbers of discussed AD and DNR/DNI orders. AICCP represents a means to help physicians comprehensively meet the extensive needs of seriously ill patients and their surrogates in medical, psychological, spiritual and practical domains of care.

Abstract number: 95
Presentation type: Oral
Poster number:

Palliative care in patients with head and neck cancer (SCCHN)

Claudia Bausewein, Klinikum der Universität München – Großhadern, München Annette Walz, HNO-Klinik Universitätsklinikum Schleswig Holstein, Lübeck, GERMANY, Thure Kupella Köln, GERMANY, Barbara Wollenberg, HNO-Klinik Universitätsklinikum Schleswig Holstein GERMANY

Objective: Despite radical primary therapy the survival rate of patients with advanced stages of SCCHN has remained unchanged over the past 50 years. Tumour recurrence in the upper aerodigestive tract causes serious symptoms and psychosocial problems during the last months of their life. Method: Retrospective chart review of patients who have been seen by the hospital support team and on the palliative care unit in the University Hospital Munich from 1st October 2002 to 30th September 2003. 41 patients (8 women, average age 62 years) with different locations of head and neck cancers (7 oropharynx, 6 floor of the mouth/tongue, 9 hypopharynx, 5 larynx, 6 sinus, 8 other). Local recurrence occurred in 26 patients (63%). Results: Best possible treatment plans were developed for each patient between patients from ENT and palliative medicine. General symptoms were pain (66%), dyspnoea (27%), dry mouth (24%), anxiety (19%), nausea
Abstract number: 96
Presentation type: Oral
Poster number:

**Continuity in supportive and palliative care: a study across 3 London Cancer Networks**

Louise Jones, Mental Health Science, London, GREAT BRITAIN, Michael King, Royal Free and University College Medical School, London, GREAT BRITAIN, Irwin Nazareth, Royal Free and University College Medical School, London, GREAT BRITAIN, Alison Richardson, Kings College, London, GREAT BRITAIN, Adrian Tockman, Royal Free Hospital NHS Trust, London, GREAT BRITAIN

Background: Delivering continuous supportive care in cancer crosses primary and secondary care and is encouraged by NICE Guidance for Palliative and Supportive Care (March 2004). Research evidence is needed on how this might be achieved. Aims: A study funded by the NHS Service Delivery Organisation of continuity of cancer care, from diagnosis to palliation. Method: A cross-sectional qualitative study recruiting, from primary care, 30 patients with breast, lung or colo-rectal cancer at 5 transitions in care: diagnosis, end first treatment, remission, relapse, palliation. Nominated close persons and primary and secondary health care professionals also interviewed. Results led to development of instruments for a quantitative longitudinal cohort study recruiting 250 patients from secondary care in 3 London cancer networks, followed for 1 year at home. Results: Qualitative analysis (NuDisT and case study methods) and preliminary analysis of quantitative data revealed 5 key factors affecting continuity: 1) individual patient factors: reactions to diagnosis, acceptance of diagnosis and treatment, relationships with close persons; 2) family factors: relationships between family members and information sharing; 3) communication and coordination between patients and services, and primary and secondary care; first contact can set the scene for relationship to follow 4) decision-making: how much patients and their close contacts desire and are included in, decision-making with professionals 5) interest and motivation of staff: services differ in structure and staff personalities, both impact on patients and their families’ engagement with services. Findings: Twenty-six carers were interviewed. Two-thirds were aged 65 and under. Sixteen were spouse carers (2 men), 8 daughters. The two main patient diagnoses were cancer and neurological conditions. Length of caring ranged from 1–20 years; median 7. Half of the carers found looking after their relative was having a moderate impact on their life; for 9 the impact was substantial. Twenty-three carers felt that they had benefited from their relative’s respite service. All carers found the respite service valuable; the good quality of nursing care was a particular issue. A particular model of respite care was in place, ‘to give the carer a break’, which may not be best suited for those patients in the last few months of life. Conclusion: This study highlighted the impact on carers looking after a relative with a life-threatening illness. It suggests that hospice units may need to reconsider their approach to respite care. For carers the quality of specialist palliative care is an issue when utilizing respite services.

Abstract number: 97
Presentation type: Oral
Poster number:

**Respite care in the hospice setting: what do the carers think?**

Julie Skillbeck, Caret, School of Nursing and Midwifery, GREAT BRITAIN, Sheila Payne, University of Sheffield, Sheffield, GREAT BRITAIN, Mike Nolan, University of Sheffield, Sheffield, GREAT BRITAIN, Christine Ingleson, University of Sheffield, Sheffield, GREAT BRITAIN, Andrea Hanson, St Luke’s Hospice, Sheffield, GREAT BRITAIN

Background: A common reason for unplanned admissions near the end of life is carers’ inability to provide continuing care. One strategy to overcome these challenges has been to offer inpatient respite admissions. Little is known about respite services, particularly how respite is experienced by caregivers or to what extent inpatient respite services address the carers’ needs. Aim: This study examined carers’ experiences of looking after a relative with a life-limiting illness and their expectations of a hospice inpatient respite service, UK. Methods: A prospective observational study, using qualitative and quantitative methods. Interviews were conducted with carers before and after respite admission. The Relative Stress Scale inventory was also administered. Interview data were audio-taped, transcribed, and analysed using constant comparison. Categorical data were described using descriptive and comparative statistics undertaken. Findings: Twenty-six carers were interviewed. Two-thirds were aged 65 and under. Sixteen were spouse carers (2 men), 8 daughters. The two main patient diagnoses were cancer and neurological conditions. Length of caring ranged from 1–20 years; median 7. Half of the carers found looking after their relative was having a moderate impact on their life; for 9 the impact was substantial. Twenty-three carers felt that they had benefited from their relative’s respite service. All carers found the respite service valuable; the good quality of nursing care was a particular issue. A particular model of respite care was in place, ‘to give the carer a break’, which may not be best suited for those patients in the last few months of life. Conclusion: This study highlighted the impact on carers looking after a relative with a life-threatening illness. It suggests that hospice units may need to reconsider their approach to respite care. For carers the quality of specialist palliative care is an issue when utilizing respite services.

Abstract number: 98
Presentation type: Oral
Poster number:

**Palliative care at home: a systematic literature review**

VITO CURIALE, Gerontologia e scienze motorie, GENOVA, ITALY, FABRIZIO FAGGIANO, UNIVERSITA’ DI TORINO, TORINO, ITALY

Palliative care is available at the patient’s home in developing countries but the effectiveness of such services is not supported by clear evidence. This study is a systematic review on the effectiveness of palliative care at home. We searched the following databases: Medline, EMBASE, Cochrane Central Register of Controlled Trials, Cochrane Library, Database of Abstracts of Reviews of Effects. The key words used were: palliative care, cancer, oncology, hospice, primary care, home. The selection criteria were: 1) systematic reviews (SRs) or randomized controlled trials (RCTs) 2) subjects: adult cancer patients in palliative treatment 3) comparison: home care versus other models of care 4) localization in western countries. 6 RCTs and 8 SRs were selected. We decided to overview the 9 good quality studies evaluating 67 studies and 18,700 subjects all together. The studies showed methodological quality ranging from RCTs to case reports. The outcomes evaluated in five single categories composed 4 areas: 1) patient’s 2) patient’s & caregiver’s 3) caregiver’s 4) health care professional’s. We summarized the results as a narrative synthesis. Palliative care at home is effective and costs low showed: improved or similar quality of life (Qol), pain and symptom control, improved satisfaction with care and quality of life, less time spent in hospital. Palliative care at home can support caregivers, is cost effective, costs less then other models of end of life care. The effective care is characterized by multidisciplinary team visiting patients at home. We indicate satisfaction with care, patient’s preference and opinion, and time spent in hospital as the best outcome measures for a palliative care service at home. Qol, and symptom control must be monitored but not considered as markers of effectiveness.

Abstract number: 99
Presentation type: Oral
Poster number:

**Factors affecting the place where cancer patients die: a systematic review**

Barbara Gomes, Palliative Care and Policy, London, GREAT BRITAIN, Irene J Higginson, The Cicely Saunders Foundation/King’s College London, London, GREAT BRITAIN

Introduction: Place of death has been regarded internationally as an outcome measure of the quality and performance of palliative care. This comes from evidence that most patients with advanced illness wish to die at home but most die in acute hospitals. Aims: (1) To identify the factors which influence place of death for cancer patients, and (2) to develop an explanatory model of the variations of place of death. Method: Systematic literature review – search on MEDLINE (1966–2004), psyCINFO (1972–2004), CINAHL (1982–2004) and ASSIA (1987–2004) and handsearching relevant journals. Studies were included if they tested the association of variables (proxy) with the place of death among patients where more than 50% had cancer. The quality of studies was assessed using a standardized scale. Data was qualitatively analysed. Research identified 240 papers of which 61 were included. Various comparisons were made – home vs. hospital, institutional vs. home, nursing home vs. home, making it difficult to combine studies. Twenty-seven studies were multivariate. Elements of evidence were contradictory with multivariate and univariate studies sometimes showing opposite effects. Three groups of factors were identified. (1) Healdness-related factors – non-solid cancer and a short dying trajectory were associated with hospital death; (2) Demographic and personal factors – people with low socio-economic resources and from an ethnic minority were less likely to die at home. Patients’ home preference was one of the factors with greater weight on determining a home death (e.g., ORs ranged from 2.19 to 8.36); (3) Environmental factors – intensity of home care and social support were associated with home death. Conclusions: Our findings suggest that a complicated network of factors is affecting place of death. These should be considered in policy, clinical practice and research.
Invited lectures and oral presentations

Abstract number: 100
Presentation type: Oral
Poster number:

Type and quality of care received by terminal cancer patients: an Italian mortality follow-back survey

Massimo Costantini, Unit of Clinical Epidemiology, Genova, ITALY, Beccaro Monica, National Cancer Institute, Genova, ITALY, Merlo Franco, National Cancer Institute, Genova, ITALY

Study objective: to describe type and quality of care received by Italian cancer patients during their last three months of life. Methods: this is a mortality follow-back survey of 2,000 cancer deaths, identified with a 2-stage probability sample, representative of all Italian adult cancer deaths. In the 1st stage, 30 (15.2%) Local Health Districts (LHD) were randomly selected. In the 2nd stage a fixed proportion of death certificates were drawn from each LHD. The main non-professional caregiver was identified using all available sources of information. After consent, a trained health professional interviewed the caregiver using a structured interview. It covered most of the multidimensional problems of the patient and of the family, and type and quality of care received was assessed. All the LHDs participated to the study. The main caregiver, identified for 1,900 patients (95.0%), was the child (41.7%), the spouse (36.4%), another relative (17.4%), or a friend (1.5%). For 57 patients (3.0%) without caregiver a health professional was identified. 70% of the caregivers were female. Interviews failed because the caregiver could not be located (8.1%), was refused (20.1%), was deceased or too ill (2.4%), or for other (2.1%). We obtained 1,271 valid interviews (63.5%). The median time between the patient’s death and the interview was 234 days (range 103–374), and most interviews were performed 4–8 months (58.9%) after patient’s death. The compliance was homogeneous among the four geographical areas (65.4%–68.7%; p-value=0.733). A significant trend (p-value<0.01) was observed between time of contact with the caregiver and compliance. The compliance decreases from 74.6% for contacts 4–6 months after patient death to 56.6% for contacts 10–12 months after patient death. Conclusion: The results confirm that palliative care can be provided in several areas of Italy with similar results. However, there is a need for improvement in the quality of care provided during the last months of life. Particularly, a better communication between caregivers and healthcare providers is needed to ensure adequate palliative care.

Abstract number: 101
Presentation type: Oral
Poster number:

Do people with MS (Multiple Sclerosis) have palliative care needs?

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Background and aims: Neuromuscular conditions such as Multiple Sclerosis (MS) have unmet needs, which palliative care might be able to address. However, there is little detailed information in this area. Our project therefore sought patients’ views. MS-specific issues were perceived as important by people with more advanced MS, their informal carers and health care professionals (HCPs), and to compare their perceptions. Method: Over 6 months we conducted semi-structured interviews with 23 people with MS and 17 Carers in Southeast London, and 12 focus groups and 4 individual interviews with health care professionals in hospitals, rehabilitation, or palliative care across Southeast England. These interactions were taped and transcribed and a content analysis performed. Results: The main preoccupations of people with MS were their experiences of loss and change, relating to mobility, independence, and personal relationships. A few people with MS had specific concerns regarding pain, medication, non-specialist care, and end-of-life issues. Informal carers were particularly troubled by the quality of care, services and information received. We identified issues affected by MS. HCPs also identified issues relating to continuity of care and service provision. In addition, HCPs highlighted the unpredictability of the disease process, specific physical and psychological problems, and end-of-life issues, specifically terminal care and decision-making. Conclusion: People with progressive MS have symptom control problems and needs relating to provision of care and obtaining services and information. HCPs identify some of these issues, and also highlight needs in other areas, particularly towards the end of patients’ lives with MS. Any service for people with progressive MS should address this range of issues. Specialist palliative care can offer particular expertise in doing so, in collaboration with neurology and neurorehabilitation.

Abstract number: 102
Presentation type: Oral
Poster number:

Norwegian Standard for Palliative Care

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Palliative care is performed throughout the health care system. At the same time, palliative medicine is developing into a specific area of medicine, with a defined range of services. The Norwegian Association for Palliative Medicine was asked by the Norwegian Medical Association to develop a Standard for Palliative Care. The aims were to ensure an adequate organisation of the services and to define minimum requirements for the medical contents and competence. The work was completed in November 2003. The document has been reviewed within the Medical Association and by external parties, and the revised version will hopefully be approved by the Medical Association in the autumn of 2004. The Standard for Palliative Care is based on the recommendations of the Norwegian Cancer Plan (1997) and a national report on palliative care (1999). The document defines basic palliative care, to be provided to all seriously ill and dying patients according to need. The organisation of palliative care services is described on all levels: 1. Regional palliative care centres in university hospitals 2. Multidisciplinary palliative care units in central hospitals 3. Palliative care units in nursing homes 4. Palliative care in ordinary hospital wards, nursing homes, and home care. Detailed requirements for professional and clinical contents, organisation, staffing, and facilities are given for each organisational element. Cooperation and networking are thoroughly described. One important element is the network of work of nurses in hospitals and primary care. The document includes separate chapters on education/training, competence, and research. Quality indicators are proposed to monitor the effects of the recommendations. Developing a standard for palliative care is pioneer work which we consider to be of major importance for the development of palliative care in Norway.

Abstract number: 103
Presentation type: Oral
Poster number:

Patterns and Predictors of Palliative Care Service Utilization in Alberta

Konrad Fassbender, Palliative Care Research Initiative, Edmonton, Alberta, CANADA, Robin Fainsinger, University of Alberta, Edmonton, CANADA, Carleen Brenneis, Capital Health, Edmonton, CANADA, Norah Keating, University of Alberta, Edmonton, CANADA, Janet Fast, University of Alberta, Edmonton, CANADA

In the mid 1990s, comprehensive and integrated community-based models of palliative care services were introduced in Edmonton and Calgary (Alberta, Canada) and resulted in an increase in access to cancer patients from 45% in 1993 to 81% in 2000. This means that roughly 500 out of the 2,600 patients that die from cancer each year do not receive palliative care services. We therefore explore potential determinants of access to palliative care services. A review of the literature revealed the following potential barriers to accessing palliative care services: geographic, financial, social, minorities, diagnoses, caregiver support and temporal barriers. A statistical analysis of comprehensive administrative data revealed no significant predictors of access. We conclude that better data and prospective studies are required to identify the potential existence of marginalized populations.

Abstract number: 104
Presentation type: Oral
Poster number:

The effectiveness of a nursing science investigation in daily nursing practice: the Pain Education Program

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Introduction: In the Netherlands, a Pain Education Program (PEP) was developed, a tailored education program in which verbal instruction, a pain brochure and the use of a pain diary were combined to inform and instruct cancer patients about pain and pain management. The PEP was provided either in the hospital or at home; this was done by specially trained hospital or district nurses. Main purpose of implementing the PEP was to improve the quality of pain management. The study aimed to assess the overall effectiveness of the PEP in terms of patients’ knowledge of pain management and pain intensity. In addition, the effectiveness of the PEP as administered by nurses and the nurse specialist was compared. Methods: The PEP was implemented in daily nursing practice of three hospitals. Nurses on the hospital wards were provided 1 day of training, then they were trained as pain counsellors to educate and instruct patients. Nurses educated patients individually about pain topics only when patients’ pain was ascribed as insufficient. The percentage of patients who received training was 100%. Results: A total of 154 patients are presented. Overall results showed that patients’ pain knowledge increased and pain intensity decreased significantly. The percentage of patients with a pain intensity of 4
or more decreased significantly. Although some nurses had difficulties implementing the PEP into practice, no difference in effectiveness was found between nurses and the nurse specialists providing the PEP. Conclusion: The use of the PEP has been effective for cancer patients in chronic pain in daily nursing practice.

Abstract number: 105
Presentation type: Oral
Poster number: 

Rural Palliative Care (PC) Education: Results of a Hybrid Course with Face-to-Face and Online Learning

Jose Luis Pereira, Division of Palliative Medicine, Calgary, Alberta, CANADA, Robert Wedel, Chinook Health Region, Lethbridge, CANADA, Maria Palacios Mackay, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA, Jaci Lyndon, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA, Alison Murray, University of Calgary, Calgary, CANADA

Background: Providing palliative care distance education using web-based technologies can be challenging. We delivered a compulsory palliative care course to a rural family medicine program using a combination of instructional strategies that included face-to-face instruction, online instruction, and objective structured clinical examinations (OSCEs). Methods: Pre-and post-course knowledge quizzes, surveys, OSCEs and focus groups were used to assess course effectiveness. Results: There was a significant improvement in knowledge overall when comparing pre- and post-knowledge tests (t = 4.44, p<0.001). Jaco's alpha = 0.50. Residents felt more comfortable overall in caring for PC patients (mean = 4.5 on a 5-point Likert scale) after the course. Overall the course was well received. Students generally preferred the face-to-face instruction, followed by online case discussions and OSCEs. Conclusions: A course using multiple instructional strategies and technologies met the PC learning needs of rural residents. Lessons learned are applicable to other PC programs and Web-based distance learning programs.

Abstract number: 106
Presentation type: Oral
Poster number: 

Palliative Care Psychospiritual Learning Online: What do the learners think?

Murray Murray, Division of Palliative Medicine, Calgary, Alberta, CANADA, Lyndon Jaci, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA, Maria Palacios Mackay, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA, Jose Pereira, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA

Background: The ability of e-learning to support education related to the psycho-social-spiritual domains of care is often doubted. Recognizing the importance of these domains we included them as part of an online component of a compulsory palliative care (PC) course for rural family medicine residents registrars. Using asynchronous, reflective small-group discussion, four 2-week long modules were offered on ‘Dignity & Narrative’, ‘Suffering & Self-awareness’, ‘Spirituality’ and ‘Hope’. Methods: Pre and post focus groups, open-ended surveys and content analyses of the online discussions. Results: Gender differences were observed on questions regarding psycho-spiritual aspects. Male residents rated exploring spirituality concerns lower than females (3.3 vs. 5, on a 5-point Likert scale). Female residents felt spirituality concerns were relevant and appreciated the opportunity to discuss them. When asked about their undergraduate medical training, residents stated that psycho-social and spiritual domains had not been explicitly covered in the curriculum. Several learners pointed out that the medium (i.e. web-based instruction) had prompted them to reflect much deeper and share their thoughts in a more comprehensive manner then would have happened in a traditional face-to-face setting. Conclusions: Asynchronous online small-group discussions provide an effective medium to introduce the psycho-social and spiritual domains of care. In some ways it may prompt more reflection than traditional face-to-face classroom-based courses. Effective facilitation is paramount.

Abstract number: 107
Presentation type: Oral
Poster number: 

Objectives Structured Clinical Encounters (OSCEs) for Palliative Care education of medical students and residents: Practicalities and Psychometrics.

Terry Collin, Centre for Distance Learning in Palliative Care, Calgary, CANADA, Jose Pereira, University of Calgary, Calgary, CANADA, Robert Wedel, University of Calgary, Calgary, CANADA, Alison Murray, University of Calgary, Calgary, CANADA, Lyle Galloway, University of Calgary, Calgary, CANADA

The traditional clinical examination has shown to have serious limitation in terms of its validity and reliability. The objective structured clinical examination (OSCE) provides improved psychometrics and is becoming more popular to assist in the evaluation of clinical performance. Moreover, OSCEs are also useful as educational tools. In this course, OSCEs were implemented as teaching tools and assessment methods in two of our Palliative Care (PC) education programs. In one of them, the rural family medicine program, OSCEs consist of 4 standardized clinical scenarios with trained actors. The cases elicit communication, clinical and ethical decision-making and advanced planning skills related to palliative care. Using case examples and data from our own PC program, including video-material of OSCEs, this presentation will a) Define OSCEs; b) Explore the psychometric properties of OSCEs; c) Provide a step-by-step approach to implementing OSCEs in the PC setting including the pros and cons; d) Discuss methods of grading OSCEs; e) Provide the OSCEs providing examples of score sheets; and e) Summarize the response of learners to this method of instruction and evaluation.

Abstract number: 108
Presentation type: Oral
Poster number: 

Becoming an ‘Online Guide’: Results of an International Course for Palliative Care (PC) Educators

Jose Luis Pereira, Division of Palliative Medicine, Calgary, Alberta, CANADA, Jaci Lyndon, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA, Maria Palacios Mackay, Centre for Distance Learning in Palliative Care, Tom Baker Cancer Centre, Calgary, CANADA

Background: There is growing interest in providing online health-related education. However, e-learning programs present challenges for instructors and learners alike. This 7-week long international course, delivered entirely online, aims to equip palliative care educators with the skills required to facilitate online group-based learning. Readings, asynchronous online discussions and simulated scenarios are used. Online facilitating skills are practiced through mentorship. The feasibility of the first international iteration of this course is reviewed. Methods: Pre and post course surveys. Results: 15 PC educators from Canada, Wales, Argentina, South Africa and Portugal registered. 11 participants were active throughout the course. Learners found the course empowering and the workload acceptable. The course gave them first-hand experience of the transitioning journey from face-to-face to online learning environments. Content analysis (using Transcript Analysis Tool) revealed the discussions to be reflective and enlightening and demonstrated that learners achieved good facilitation skills through the mini-courses. Conclusions: PC educators considering teaching online should acquire the skills required for effective online facilitation. A Web-based course such as this provides educators with the necessary basic skills and increases access to training without having to travel.

Abstract number: 109
Presentation type: Oral
Poster number: 

Palliative Care Research and Education in the Developing World: Is it Possible?

Liliana De Lima, Director, Houston, U. STATES, Richard Harding, Kings College, London, GREAT BRITAIN, Jose Pereira, Centre for Distance Learning, Calgary, CANADA, Deborah Norval, Centre for Palliative Learning, Johannesburg, S. AFRICA

Learning Objectives: At the end of this session, participants will be able to learn: 1. Main challenges that health care physicians face in developing countries in the provision of palliative care; 2. Current resources available for palliative care education and research in developing countries; 3. Strategies that have been applied in developing countries which have been effective addressing problems related to education and research; 4. The role that organizations may play in providing technical expertise and resources for education and research to programs in developing countries. Session Description: In this session presenters will give an overview of current health care resources available for treatment, research and education. Programs and individuals in poor countries are under the pressing need to develop research and educational strategies which will enable them to access funding and technical support. Samples of strategies and programs which have proven to be successful in overcoming barriers will be presented. Emphasis will be given to solutions that have worked in the past and their applicability to programs that face similar problems. Barriers such as low socioeconomic conditions which affect the efficiency and effectiveness of the programs and their ability to conduct the needed education and research, curricular issues which may hinder educational and research programs will be discussed.

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FRIDAY 8 APRIL
A Palliative Medicine Curriculum for Medical Students in Japan

Tsuneo Kato, Working Party for a Palliative Medicine Curriculum, Okayama, JAPAN

Tsuneo KATO, ‘Working Party for a Palliative Medicine Curriculum’ (Introduction) In Japan, there have been few systematic education programs for medical students in palliative medicine. We organized a working party and developed an appropriate curriculum for undergraduate medical education. Method: The working party comprised a GP, an oncologist, a chaplain, a palliative care specialist, a geriatrician, and 2 specialists in medical education, all of whom were committed to palliative care. From 2001 to 2003, we conducted a series of four 2-day workshops. Result: Our aim was that this curriculum would allow students to: 1) consider not only palliative medicine but also human life as the basis of clinical medicine, 2) focus mainly on pain management in the area of symptom control, 3) learn team approaches, 4) respect each patient, family, and care team as individual persons or groups, 5) learn inter-professional, inter-medical disciplinary, inter-facility, and inter-community cooperation, 6) learn care continuity, 7) be acquainted with service provision systems, 8) become familiar with particular domiciliary care, 9) learn about group dynamism within a family and a care team, and 10) understand the importance of alternative and complementary medicine for most patients. We identified 13 educational categories, which include: 1) the concept of palliative medicine, 2) psycho-social issues, 3) ethical issues, 4) communication, 5) cooperation with other disciplines, 6) caring for families, 7) spirituality, 8) home care, and 9) caring for support-team members. Discussion: Although this is still a list of learning objectives, we are in the process of developing a total curriculum to include strategies, resources, and assessments according to the user’s locality. (Note) Other members of the Working Party are: Takeshi SAITO, Shinya SAITO, Hidetoshi SATO, Kazuko MATOBA, Nobutaro BAN, Motohumi YOSHIDA

Invited lectures and oral presentations
Abstract number: 111
Presentation type: Poster
Poster number: P1

The Palliative Care Consultation: a quantitative study
David J. Feuer, Palliative Care Team, London, GREAT BRITAIN, Patricia Sealy, Barts and The London, London, GREAT BRITAIN

Objectives: To review the palliative care consultation and quantify the types of recommendations given and their uptake, and to try to identify some of the possible reasons for the non-uptake of that advice. Setting: A hospital palliative care team in a large teaching hospital and cancer centre. Design: A prospective study of the consultations performed by a Specialist Registrar and a Clinical Nurse Specialist over a 3 month period. Results: A total of 72 new patient episodes were studied, 33 doctor assessments and 39 nurse assessments. During these, 323 recommendations were given at an average of 4.5 per patient episode, the most common being an adjustment in the patients drug therapy. Out of these recommendations, 46 (14.2%) were not taken up ~ 32 (18.6%) of nurse given recommendations and 14 (9.3%) of doctor given recommendations. The most common reason for non-uptake of advice was the rationale for that advice appeared not to be understood. Discussion: In general, the advice given by the hospital palliative care team appears to be effected by the referring team. There were demonstrated differences between the types of advice and uptake of advice given by clinical nurse specialist and doctor and this may reflect the ongoing development of both roles within the health service.

Abstract number: 112
Presentation type: Poster
Poster number: P2

The approach to systematic symptom assessment in palliative care – PAT-C
Marianne Hjermstad, Institute for Behavioural Sciences in Medicine, Oslo, NORWAY, Jon Håvard Loge, University of Oslo, Oslo, NORWAY, Stein Kaasa, Norwegian University of Technology and Science, Trondheim, NORWAY

Background. Palliative care patients have high levels of various subjective symptoms, but there is low consistency on how to assess these systematically. Subjective symptoms are the main targets for clinical interventions and palliative care research, thus a valid, main targets for clinical interventions and research. The objective of the PAT-C project will encompass palliative and general medical patients, to ensure a higher prevalence of cognitive dysfunction and sufficient sensitivity for the tool. Electronic gathered data will facilitate tailored symptom assessment to the benefit of patients, clinicians and researchers.

Abstract number: 113
Presentation type: Poster
Poster number: P3

Changes in chief of complaint of patients by concerning in palliative care team ‘Assessment of a consultation type palliative care team in a university hospital’
Toshikiiko Nakatani, Palliative Care Centre, Izumo, JAPAN, Misuzu Nitta, Shimane University Hospital, Izumo, JAPAN, Ruiko Hatoo, Shimane University Hospital, Izumo, JAPAN, Nohue Uchida, Shimane University Hospital, Izumo, JAPAN, Yoji Saito, Shimane University Hospital, Izumo, JAPAN

Introduction: Palliative care centre has been established in our university hospital on Oct. 2003. This centre has a consultation type palliative care team which is consisted of several specialists. As about a year have passed since establishment, it should be required to assess the activity of palliative care team, focusing on the treatments for the chief complaint in which was most frequently requested to our palliative care team. Methods: The objects were patients who were consulted to our palliative care centre during 10 months from Oct. 2003. The number of patients was 63. As the most complaint which was need to treat was pain (60 patients), we checked changes of pain score measured by Wong-Baker's Face scale and scores in degree of pain relief at the point of consultation and post our care. We investigated about the medical treatments to cancer patients by palliative care team. Results: Pain score was significantly improved by concerning of palliative care team after consulting, Wong-Baker's Face scale decreased from 3 to 2.7 after treatments. Treatments which our team have mainly cared for patients were induction of opioids, opioids rotation, increasing dose of opioids, induction of radiotherapy. Implications: The effectiveness in pain control was determined. It is important for us to educate the usage of opioids for physicians in charge. We should improve the ability to take care of patients beyond the border which exists among the specialists especially between a physician in charge and palliative care team.

Abstract number: 114
Presentation type: Poster
Poster number: P4

The Role of Prognosis in the Process of Admission Decision Making
Kevan Ritchie, Palliative Medicine, London, GREAT BRITAIN, Teresa Garcia-Baquero Merino, St. Joseph’s Hospice, London, GREAT BRITAIN

Background: There is often pressure for specialist palliative care beds. Our admission decisions come in the form of an EBS referral, possibly with additional clinical information or investigation results. Decisions are then made at a multi-professional admission meeting, taking into consideration the information provided and in particular the prognostic estimate in those patients referred for continuing care. The accuracy of the prognostic estimate is critical to making the correct decision and prevents the potentially traumatic discharge of patients and unnecessary prolonged bed occupancy. Aims: We wanted to evaluate the accuracy and validity of the patients’ prognosis as given by the referrers and to consider the value of supporting information (i.e. investigation results, clinical information etc) supplied. We wanted to assess the difficulty in computing sufficient information to make decisions and whether factors such as diagnosis affect the accuracy of the prognosis. Method: A two-month pilot survey was undertaken followed by a four-month survey. Data was collected from EBS referral forms and letters onto a recording sheet. This data was collected from the multi-disciplinary admission meeting by one observer (for continuity, a second observer was involved when the first had to be absent). The date of death was then recorded for the in-patients and the progress of those not accepted was traced. Results: Conclusions: Early results show a disparity in the estimated prognosis and the date of death; in most cases the estimate was too long. Insufficient information also led to difficulties in reaching decisions. It could therefore be proposed that standards be set in terms of the information required at referral (i.e. specialist reports, investigation results or validated prognostic indicators).

Abstract number: 115
Presentation type: Poster
Poster number: P5

The problems experienced by patients with cancer, and their needs for palliative care
Bart H.P. Osse, Center of quality of care research, WOK, Nijmegen, NETHERLANDS, Myrna, J.F.J. Vernooij-Dassen, Center of quality of care research, WOK, Nijmegen, NETHERLANDS, Egbert Schade, Dept. of General Practice, Academical Medical Centre University of Amsterdam, Amsterdam, NETHERLANDS, Richard P.T.M. Geel, Center of quality of care research, WOK, Nijmegen, NETHERLANDS

Goal of work: To investigate the problems that patients experience, and their met and unmet needs for professional help. This information is necessary to tailor palliative care to the needs of patients. Patients and Methods: Patients (N=94) with disseminated cancer completed a validated checklist with 90 potential problems and needs for care (FPNC questionnaire). Main results: On average, patients experienced 17 problems (range 0–68), and required more professional attention for 8 problems (range 0–71). The 5 most prevalent problems were: fatigue, heavy household work, coping with the situation of the future, fear for metastases, and frustrations because I can do less than before. The 5 issues most in need for extra attention were: informational needs, coping with the unpredictability of the future, fear for metastases, fear for physical suffering, and difficulties remembering what was told (during consultations). Younger patients experienced more social, psychological and financial problems. Some patients (10%) expressed a multitude of problems and needs. Conclusions: When patients with metastases have experienced a wide variety of problems, they asked for more support for only a few specific problems. Evidently ‘problems’ are not synonymous with unmet needs. Therefore not
only problems, but also needs for care should be assessed. A structural need for support to cope with fears for suffering and loss of autonomy was found. 10% of the patients expressed a multitude of problems and needs, and might benefit either from psychological counseling, or a better palliative care.

Abstract number: 116
Presentation type: Poster
Poster number: P6

OUR EXPERIENCE FROM JAN.01.2004. TO JULY 01.2004

Adnan Delibegovic, Tuzla, BOSNIA & HERZEGOVIN

Our overall vision of palliative care is: Complete care of the patient when the nature of the illness is incurable and terminal and the prognosis is predictably short. Our focus in palliative care is to provide the best quality of life and care possible for us. In providing palliative care we aim to: Affirm life and regard dying as a normal process Provide relief from pain and other symptoms Integrate the psychological and spiritual aspects of patient care Offer a support system to help patients live as actively as possible until death. In providing rehabilitation we aim to: Help patients gain opportunity, control, independence and dignity Respond quickly to help people to adapt to their illness. Taking a systematic approach to defined goals Take the pace from the individual. The aim of this presentation is to show ~ The numbers of those treated in our department from 01.01 to 01.07.2004. The numbers of deaths and those admitted for rehabilitation who were discharged, *According to sex *According to age ~According to location of primary tumor. The total number of patients treated was 122. The number of deaths and those admitted for rehabilitation who were discharged. The majority were men aged between 60-70 years, with lung cancer being the most frequent cause of death in men, and breast cancer in women.

Abstract number: 117
Presentation type: Poster
Poster number: P7

Lessons from implementing a dedicated psycho-oncology team into a palliative care service

Peter Martin, Caritas Christi Hospice, Melbourne, AUSTRALIA, Diane Clifton, St. Vincent’s Health, Melbourne, AUSTRALIA, Maxine Braithwaite, St. Vincent’s Health, Melbourne, AUSTRALIA, Brian Lowe, St. Vincent’s Health, Melbourne, AUSTRALIA

Despite increased need for psychological care in palliative care (PC) services few have the resource to fund the development of the service. This study has investigated the impact of the establishment of a dedicated psycho- oncology team in a busy adult hospice. The team consists of a clinical psychologist and a clinical oncologist and has been working with patients with advanced cancer since 2003. The team has been involved in the care of patients with advanced cancer. In most cases patients referred to the team are seen by the psychologist and oncologist jointly. The team was established in response to the high demand from patients and carers for a dedicated psychological palliative care service. They are based in a clinical setting in the day hospital and have access to the full range of hospice services. The team, who are part of the hospice governance board, has a wide range of patient and carer needs. They also have expertise in videoconferencing, and may provide psychological counseling, or a better palliative care service. The team, patient and carers. We want our colleagues to learn from this experience. In particular we will outline various referral pathways, assess mechanisms interventions that have been offered. Key issues include the re-defining of role function for the psychosocial / spiritual team. Innovations include the setting up of a psychosocial / spiritual forum to determine how this team works best supports a team. This is a descriptive study. Strategy documents address the issue of psychosocial and psychological care, but there is little in the PC literature describing the introduction of new disciplines such as PO into the multi- disciplinary team. We know that distressing psychological symptoms require specialist assessment and treatment modalities. In summary we feel that a dedicated psycho- oncology team adds a vital component to care of PC services. Discussion regarding the benefits and risks of this service model will assist future service planning.

Abstract number: 118
Presentation type: Poster
Poster number: P8

Symptom Prevalence and Severity in 59 patients with advanced urological malignancies referred to a Hospital Palliative Care Team

Elizabeth Ferguson, Palliative Care, Ayr, GREAT BRITAIN, Kathleen Sherry, The Ayrshire Hosp, Ayr, GREAT BRITAIN, Gwen McAuley, The Ayrshire Hospice, Ayr, GREAT BRITAIN

Introduction: Prostatic Carcinoma is the second most common cancer in men in the UK. Hospital Palliative Care Teams (HPCT’S) provide an integrated advisory specialist palliative care service in the acute setting Validated Tools eg The Patient Outcome Score (POS) are used to comprehensively and systematically assess symptoms and are effective in this setting. This study reviews referral patterns, HPCT activity, patient characteristics and symptom prevalence and severity using POS in 59 uro-oncology patients referred to the team over a 12 month period. Method: Retrospective review of HPCT documentation over 12 months. Data collected: Demographic, socioeconomic,reason for referral, HPCT activity, ECOG, length of referral episode, POS analysis, HPCT referrals, 59 patients, Age range: 37~90 years, Mean age 71. 54% Prostatic Ca, 10% Renal, 8.5% Bladder, 8.5% Other urological cancer, 7% uro-gynaecological. 95% reviewed within 24 hours, 84% referred for symptom control, ECOG1/2: 42%, 3/4 46%. 24 symptoms documented. HPCT mean contact time 9 days, Desired place of Death discussed in 40%: 66% desired Home, 23% Hospital, 13% Hospice. POS Analysis: 30% completed 1, 24% 2 or more. Initial POS symptom severity (moderate or severe): pain 66%, Nausea / Vomiting 53%, Fatigue 66%, Anorexia 44%, Constipation 39% Anxiety 44% Mouth problems 11% Dyspnoea 33% Second POS comparison; Scores for pain, nausea / vomiting, anxiety, dyspnoea improved; Fatigue scores increased, anorexia score static. 9 / 28 had ECOG 3 or 4 when completing. Mean POS scores: 1. 166, 2. 137. Outcomes: 23% died, 44% discharged, 44% with specialist palliative care review, 9% Hospice transfer Conclusion Detailed analysis of these patients confirms the range of symptoms and severity they experience. This group of patients which is often underestimated . This data will help us to specifically target a tailored education programme for the urology multidisciplinary team.

Abstract number: 119
Presentation type: Poster
Poster number: P9

Validity and reliability of the Modified Edmonton Symptom Assessment Scale (M-ESAS) in the Flemish palliative care population

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Background: Quality of life in palliative care is negatively affected by the amount of symptoms patients are confronted with and the accompanying symptom distress they undergo. Adequate symptom control necessitates a systematic and standardized assessment of this symptom experience. Aim: This study investigates the key aspects of the validity and reliability of the M-ESAS. Methodology: Our modification of the ESAS (Bruera et al., 1991) was based on a theoretical model concerning symptom experience (Armstrong, 2003) and entailed adding 10 Visual Analogue Scales to assess symptom distress. Moreover, palliative care experts (content validity) recommended the addition of 3 symptoms (dry mouth, constipation and disturbed sleep) and reprising of 3 other symptoms. In a second phase we tested this M-ESAS on validity and reliability. A prospective, descriptive, comparative, longitudinal design was used based on a convenience sample of 56 cancer patients from 3 palliative care units and 39 nurses. On 3 occasions nurses and patients independently assessed symptom occurrence and distress. Functional status and depression were scored on day 1 of the assessment. Results: Supported the content, face, construct and concurrent validity. Inter-rater agreement revealed there was a highly significant, but moderate agreement between patients’ and nurses’ scores (r = 0.3 – r = 0.6). Internal consistency analysis showed that a symptom distress score based on a total score of symptom occurrence and distress. Functional status and depression were scored on day 1 of the assessment. Conclusion: M-ESAS is a promising instrument for assessing symptom experience, though large-scale research (which is being pursued) and psychological distress. Partial results available by March 2005 is needed to confirm these preliminary results.

Abstract number: 120
Presentation type: Poster
Poster number: P10

Assessing Patients’ Supportive Care Needs: Do High Scores Require Interventions?


It is often assumed that QL measures alone identify patients’ distress and need for supportive care. In practice, staff have difficulty recognising distress and identifying spiritual/social needs and do not appropriately refer patients to other services. This study developed for assessing the needs of patients in research studies may be of value in clinical practice. 80 patients with advanced breast cancer were followed through chemotherapy until death. Their needs were assessed using the EORTC QLQ-C30 and a symptoms & problems checklist. Scores on these measures were followed up by nurse researchers, who used a...
This study used its assessment of bowel function in patients with advanced cancer, and is a task that can be performed consistently by nursing staff (Sykes, 1990). The aim of this study was to evaluate nurses’ use of a standardized scale employed in Millford Hospice, Ireland, in the assessment of constipation. Auditing of practice ensures high standards of nursing care are consistently maintained. A retrospective review of patient notes was undertaken. Nursing constipation assessment charts, with a standardized stool form scale (Davies et al 1986) displayed, were reviewed. Descriptive statistics of stool consistency and amount (large, small) were documented. Documentation consisted of ‘bowels open’ / ‘bowels not open’. Descriptors of stool consistency (hard, soft, normal) and/or problems, but they do not adequately identify their desire for supportive care. Patients’ desire for more accurately identified patients’ significant symptoms and/or problems, but the results did not indicate that any referral was helpful. 3) Patients perceived themselves as ‘bed-bound’. Only 64 of the high scoring symptoms/problems patients volunteered that acknowledgment of their distress during their assessment was in itself sufficiently supportive. Quality of life measures may identify patients’ significant symptoms and/or problems, but they do not adequately identify their desire for supportive care. Patients’ desire is more accurately identified with an patient-completed questionnaire combined with a staff-administered response/intervention sheet. A further study is planned in the near future.

Abstract number: 122
Presentation type: Poster
Poster number: P12
Development of an Integrated Care Pathway for the Holistic Assessment of Palliative Care Patients on Admission to Hospice
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The aim was to develop a holistic patient needs assessment of patients referred to hospice. A patient-centred approach was adopted, structured in the form of an integrated care pathway (ICP), a tool which can facilitate the delivery of quality care. The need for an improved assessment process was identified from clinical staff, who felt that existing assessment was not truly ‘holistic’, dependant on the skills of the assessors and lacking appropriate actions/goals. The recently published NICE guidance on Improving Supportive & Palliative Care for Adults with Cancer, also highlighted key areas for the improvement of patient assessment in specialist palliative care. 2 A multi-disciplinary group comprising doctors, nurse managers, nurses, social workers, occupational therapists, psychologists and social care practitioners, identified issues which nurses support and researcher was established. Relevant issues to be addressed within an initial assessment (on admission) were mapped, from the perspective of each of the professionals. Issues were drawn from scrutinised against current research evidence. Issues were then grouped and ordered chronologically. Issues to be assessed within the first 24 hours of admission, included generic demographic details, orientation to hospice, functional and physiological assessments. Days 2–3 focussed on the assessment of emotional, social and spiritual domains, ending with a summary of the patient’s current needs, goals and proposed actions. All issues within the ICP are recorded, with unmet items documented through variance recording. The ICP was pilot tested for 12 months, with adaptations made in response to user feedback. Implementation of the ICP has resulted in a systematic and timely holistic assessment process for patients. The ICP effectively addresses the NICE recommendations for the assessment of specialist palliative care patients. 1 De Luc K. (2001). Developing Care Pathways. Radcliffe Medical Press, Ltd. 2. National Institute for Clinical Excellence (2004). www.nice.org.uk.

Abstract number: 123
Presentation type: Poster
Poster number: P13
Place of death – an outcome of Home Care
Jens Papke, Praxis for Oncology, Neustadt/Sachsen, GERMANY

Qualified palliative care is a chance for terminal cancer patients to spend the end of life at home. Aim of the study was to investigate the proportions of the places of cancer death in our region and to look for changes in patients cared by a specialised home care service. In the german rural district Saechsische Schweiz from 1997 to 2003, 2793 cancer patients died to death. 49% died at home, 7% died in nursing homes. From 1997 to 2003 249 terminal cancer patients were cared by a home care service in the same region. From these patients 10% survived the end of life at home. Specialised home care is a human way for caring of cancer patients and to allow them spending the end of life with their loved ones at home.

References

Prediction of patient survival by 5 professional groups in a hospice setting
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Aim To assess the ability of 5 cognate professional groups in a hospice-based multidisciplinary palliative care team to accurately predict the survival of patients admitted to an inpatient hospice over an 8-month period. Method A prospective study of 221 patients with advanced malignant and non-malignant disease, drawn from a mixed urban/rural population of 580,000. Within 48h of admission, a member of each group (Ward Sisters, Registered Nurses, Care Assistants, Consultant Palliative Care Physician and Non-Consultant Physicians) predicted one survival category (3 months) for each patient. Predictions were based on an assessment of overall status with due regard to all relevant information available. No group made a prediction for every patient. Results Patients were 52% female, mean age 67.2 years. 94.1% had a malignancy and of these 87% had metastatic disease. 66.5% were independently mobile and 50.7% had a significant medical comorbidity on admission. Ward Sisters were the most accurate group, with 45% of predictions correct. When in error, they were more often pessimistic than optimistic regarding survival (33% vs. 23%), as was the consultant physician (36% vs. 28%). When incorrect the non-consultant physicians tended to be more optimistic (33%). 46.5% of errors in prediction were inaccurate by one category and when of greater magnitude (13.2%) occurred in patients who survived longer. Conclusion The study confirms that although estimated patient survival correlates well with actual survival, it remains in itself an inaccurate predictive tool. We found that nursing staff were correct marginally more often than medical staff, while senior medical and nursing staff when inaccurate, were more likely to under-estimate survival.

Abstract number: 124
Presentation type: Poster
Poster number: P14
The Suffering of Refractory Symptoms – a difficult challenge
Kim Devery, Department of Palliative and Supportive Services, Dow Park, AUSTRALIA, David Currey, Flinders University Supportive Services, Daw Park, AUSTRALIA, Katrina Breaden, Flinders University Australia, Adelaide, AUSTRALIA, Meg Hegarty, Flinders University Australia, Adelaide, AUSTRALIA

To be able to relieve suffering is, probably, one of the reasons many of us chose to work in health care. Relief of suffering is the very heart of humane health care, and consequently when things don’t go according to plan, patient care can become extremely fraught for the patient, family and staff involved. Clinicians can find themselves in some very difficult and psychologically draining situations where feelings of inadequacy around patient care combined with high levels of emotional reactions of the family and interdisciplinary team. This talk will

• Define ‘refractory/intractable’ symptoms
• Discuss and clarify the limits to palliative and supportive care
• Suggest a genuine way to optimise clinical decision making process for defining a symptom as refractory
• Present and discuss the approach to the management of refractory symptoms
• Discuss the effects of refractory

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symptoms on patients, carers and health care workers. The Flinders ‘What the . . .‘ framework is designed to give guidance to clinicians in the situation where patient’s symptoms are not reversible and not responding to palliative treatments and considered attention.

Abstract number: 126
Presentation type: Poster
Poster number: P16

Development of a measure for physical functioning in palliative care

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The project ‘Palliative Assessment Tool – Computerized‘ (PAT-C) aims at developing a computer-based tool for assessment of symptoms and functioning in palliative care patients by using Item Response Theory. Physical functioning (PF) is one of the domains included. The PF-study has 4 phases: 1) Systematic literature study to identify existing questionnaires for PF assessment 2) Decide for a conceptual framework to classify aspects of PF 3) Evaluate the conceptual framework and chosen aspects by an expert panel. 4) Extract PF items from identified questionnaires in accordance with phase 2 and 3 to develop a final item pool for the PAT-C PF. The present study reports results of the first two phases. A systematic search, which was updated up to June-04 was conducted for the term physical functioning(ing) AND terms related to population (e.g. old, frail, cancer, HIV) AND related to assessment or outcome. 2334 papers met the selection criteria. Adding ‘quality of life’ (QoL) to the searching terms, gave 24 836 hits, thus QoL was excluded. All abstracts were screened to detect named instruments. Of 253 identified, those assessing only symptoms, single domains other than PF, or patients with non-relevant diseases (e.g. sinusitis) were excluded (N=53). Additional instruments were screened to detect named instruments. Of 251 met the selection criteria. Adding ‘quality of life’ (QoL) AND terms related to population (e.g. old, frail, cancer, HIV) AND related to assessment or outcome. 2334 papers were evaluated. Results The returned questionnaires (N=228) from 24 countries were coded and translated. 247 were complete for analysis. The majority of the returned questionnaires were in English (N=183). 50% of the patients were from clinical care, 27% from home care and 23% from rehabilitation. The majority of respondents was from the USA (N=112). To develop the PAT-C PF the multidimensional framework for life quality assessment was used. The framework was combined with the Dutch SF-36. The items were extracted from the SF-36 and the instruments developed. The questionnaire consisted of 13 items, each item had 5 answer categories from 1 (not at all) to 5 (very much). The item pool was tested on 40 patients in an oncology setting. The test-retest reliability was 0.68. The internal consistency was 0.85. The margin of error was estimated at ±0.75. Conclusion: The PAT-C PF is designed to give guidance to clinicians in the situation where patient’s symptoms are not reversible and not responding to palliative treatments and considered attention.

Abstract number: 128
Presentation type: Poster
Poster number: P18

Multidisciplinary decision trees in symptom management

Henk Vreken, Haematology, Utrecht, NETHERLANDS, Ginette Hesselman, University Medical Center Utrecht, Utrecht, NETHERLANDS, Birgit Frohleke, Comprehensive Cancer Centre Midden Nederland, Utrecht, Utrecht, NETHERLANDS, Wynn Ross, University Medical Center Utrecht, Utrecht, NETHERLANDS, Saskia Teunissen, University Medical Center Utrecht, Utrecht, NETHERLANDS

Introduction During the period 1999–2001 the Centre of Development of Palliative Care Utrecht developed and implemented guidelines concerning 23 symptoms and problems in palliative care. Between 1994 and 2000, oncological nursing guidelines were developed for 19 symptoms and problems by the Dutch Association of Comprehensive Cancer Centres. These guidelines have not yet been structurally implemented in daily practice.

Evaluation showed limited use due to the volume of guidelines. The main reasons were the unspecific nature of the guidelines. The students wanted a compact, multidisciplinary, decision tool. The Delphi method was used in order to reach consensus on this point. The decision tool has allowed efficient and effective combining of expertise from a group of regional dispersed experts. The advisory team (n=23) consisted of nurses, medical doctors and paramedical experts, including the regional consultants of the palliative care team. Content, practical use and application were analyzed and evaluated. Results The returned questionnaires have been analyzed and 2 compact decision trees based on the multidisciplinary and multidimensional guidelines have been developed. Conclusion The decision trees support the professional caregivers in the treatment and decision-making process of patients with advanced cancer concerning pain and fatigue. The framework of the decision trees is linked to the model palliative reasoning of Utrecht (Teunissen 2004). We are currently developing a method to evaluate the decision trees as a useful strategy for implementing the guidelines into daily practice.

Abstract number: 129
Presentation type: Poster
Poster number: P19

CLASSIFICATION OF PATIENTS IN PALLIATIVE CARE BY THE ESTIMATION OF REMAINING LIFE TIME?


Aim of investigation: The classification of patients in palliative care with relation to remaining life expectancy is a difficult task, though aims and intentions of care, communication strategies with patients and proxies and the consideration on perhaps burdensome diagnostic and therapeutic procedures depend on a time related prognosis of expected outcome. The intention of this study was to relate a prognostic classification system on decision making and consequences of care palliative care. Methods: Between 2001 and 2004 750 patients on admission to the Palliative Care Unit (PCU) of Havelhöhe where consecutively grouped into the staging system of Jongen-Thielenmann, which differentiates rehabilitative, preterminal, terminal and final phases. Outcome parameters were analysed with relation to clinical diagnosis, main symptoms and kind of care. Results: The predominant classification into the preterminal stage of most of our patients on admission signified the prognostic uncertainty and ethical dilemmas on decision making, communication and consequences of care in patients in ‘earlier’ end-of-life situations, while classification into terminal, final and rehabilitative stages enabled a more patient centered care. Conclusions: The agreement of patients in palliative care using a time related prognostic score could improve patient-centred approaches in different end-of-life situations. Criteria for the preterminal phase should be further investigated.

Abstract number: 130
Presentation type: Poster
Poster number: P20

Who should assess the patient’s spiritual care needs? A randomized study.

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Background: Assessment of the patients’ spiritual care needs is an integral part of palliative care. We developed a semi-structured interview with the acronym SPIR, based on the PICA interview by C. Puchalski. The aim of the
The first purpose of this study was to determine the prevalence of the need for psychosocial care in patients with cancer and their relatives in the outpatient clinic of our hospital. The second purpose was to assess the nature of the expressed needs. Methods. A simple questionnaire to assess psychosocial needs was developed by the investigator and approved by a board of oncologists, nurses, psychologist, social worker and minister. A total of 217 patients and relatives attending the outpatient clinic of the medical oncology department were given this Psychosocial Care Needs Questionnaire to complete. 184 (85%) completed questionnaires were returned. The population consisted of 119 patients (65%), 52 spouses (28%) and 13 family members (7%). Results. 63% of the responders perceive a need for psychosocial care or expect to need psychosocial care in the near future. Of this group the psychosocial symptom need was assessed. 70% express a need for emotional counselling, 26% have a need for information about nutrition, 25% have a need for information on chemotherapy and 22% want counselling to cope with pain. Conclusions. Considering two thirds of the responders perceive a need for psychosocial care it seems warranted to offer all patients and their relatives the possibility of receiving psychosocial counselling as part of their treatment in the medical oncology department. On assessing the perceived need for psychosocial care the diverse nature of the need warrants a multidisciplinary approach. Thus offering comprehensive supportive care instead of psychosocial care alone.

Abstract number: 134
Presentation type: Poster
Poster number: P24

Physical compatibility of oxycodone injection with supportive drugs in palliative care

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Although oxycodone injection has been available in the UK since May 2003. its use in continuous subcutaneous infusions has not been widespread. One of the main reasons for this is the lack of comprehensive compatibility data, such as those available for diamorphine and alfentanil. The aim of this study was to assess the compatibility of oxycodone with mixtures containing codeine or other supportive drugs commonly encountered in the palliative care setting. Investigations were carried out over a 24 hour period. Twenty nine syringes containing one mixture of oxycodone with supportive drugs were prepared extemporaneously. They were made to a 20ml volume with saline 0.9%. A repeat experiment was performed using 0.9% Water for Injections as the diluent. The syringes were stored at room temperature under artificial light. Visual checks for precipitation, crystallisation and discoloration were made using polarised light were performed at 0, 8 and 24 hours. The pH of the solutions was also checked at 0 and 24 hours. All test syringes demonstrated no precipitation, crystallisation...
Abstract number: 135  
Presentation type: Poster  
Poster number: P25

Measuring Satisfaction with Terminal Care: Development and Testing of Two Tools
Ireen M. Poot, Institute For Bioethics, Maastricht, NETHERLANDS, Veron Schrijnemakers, Centre for Development of Palliative Care, Maastricht, NETHERLANDS, Liesbeth van Hoef, Centre for Development of Palliative Care, Maastricht, NETHERLANDS, Annemie Courtens, Centre for Development of Palliative Care, Maastricht, NETHERLANDS, Huda Hujer Abu-Saad, American University of Beirut, Beirut, LEBANON

Aim: In this study two instruments have been developed for measuring satisfaction with end-of-life care from the perspectives of terminally ill persons and their caregivers. Emphasis was placed on development of person-perceived questionnaires which are short and easy to complete. Method: A review of qualitative research into the experiences of terminally ill persons and informal caregivers was used to develop domains and item pool. This result has been reviewed by selected experts from the palliative care field, including experienced palliative care professionals (patient and informal caregiver). The tools were tested between February 2003 and January 2004 in home care, hospital, nursing home and hospice (patients n=45; informal caregivers n=99). Results: The tools include the following domains (differing domains for caregiver satisfaction between parentheses): continuity and organization of care, autonomy and control (keeping control), physical aspects, instrumental support, information (and instruction), emotional support, existential and spiritual aspects, family, approach by professionals, competence/reliability of professionals. The format is that only in case of not enough satisfaction at a given item, questions about the importance of the item, caregivers involved and possible improvements have to be filled in. The clinical utility, feasibility, content validity, and internal consistency (Cronbach’s alpha patient tool 0.87; caregiver tool 0.84) appeared to be good. Discussion: This study has shown that the tools identify relevant information about patient and caregivers satisfaction concerning the care given (clinical relevance), and might also be useful as outcome measures in studies into palliative care (scientific relevance). Further research is needed into the validity and reliability of the tools.

Abstract number: 136  
Presentation type: Poster  
Poster number: P26

The use of Support Team Assessment Schedule (STAS) in 1000 sequential patient deaths in a specialist palliative care unit.
Liam O’sinion, Palliative Care, Dublin, IRELAND

Background: STAS is one of the few validated tools used as a clinical outcome measure in palliative care. It has been used for over 14 years in a variety of different settings and has accumulated a significant number of published papers. Newer tools are being developed with an emphasis on patient rating calling into question its usefulness. STAS has been used in this specialist palliative care unit as a clinical audit tool. This sample of 1000 patients is the largest ever presented. Aims and Objectives: 1. To describe the patient population is age, sex, religion, diagnosis, symptom profile on admission. 2. To provide detail on the STAS scores of patients dying with diagnosis and other variables. Results: This sample of 1000 sequential deaths in a specialist palliative care unit will provide useful information on both symptoms and psychosocial issues. The use of STAS as an audit tool will be discussed identifying its strengths and weaknesses.

Abstract number: 137  
Presentation type: Poster  
Poster number: P27

Assessment of caregivers satisfaction: results of the use of a questionnaire in Biella’s Palliative Care Network
Carlo Peruselli, Palliative Care Unit / Oncology Dept., Biella, ITALY, Maileto Michele, Palliative Care Unit, Biella, ITALY, Basinico Tiziana, Fruolo, Biella, ITALY, Zublena Nicoletta, Hospice, Biella, ITALY, Bider Chiara, Hospice, Biella, ITALY

Since January 2002, families of patients assisted by the Palliative Care Network (PCN) in Biella have received a questionnaire in order to evaluate how satisfied they are with the care given. The questionnaire is given to all the patients’ families assisted both at home and in the inpatient hospice. The percentage of replies received was 62% in 2002 and 71% in 2003. The questionnaires are anonymous and they are sent to the home address together with a pre-stamped envelope to facilitate the reply: they are sent out 1–2 months after the patients death. In the questionnaires of this year we have tried to evaluate not only the overall satisfaction for the care, but also to analyse specific aspects referred to the symptom control, psychological and social support and the speed at which problems were addressed. Results: –The caregiver’s satisfaction on the care given by the PCN is very high. –The symptom control, both referred to the whole period of assistance and the last hours of life, appears to be better in the Hospice in respect to the care at home. It was to be expected, considering that care in the Hospice was more continuous than at home. –Very positive the judgement reported on psychological support to the family on the part of the P.C. team. –Caregivers reported that the patient’s wishes were respected. It’s an important ethical issue, which is not always analysed in similar questionnaires in Italy. –As regards the place of death, the data referring to the home (the preferred place, both by patients and relatives) appear significantly different in respect to the Hospice. These data confirm what is well known: in Italy, home, if possible, remains the patient’s preferred place to live the end of the life, even if the Hospice represents a fundamental opportunity in a palliative care network for those patients who cannot be assisted at home.

Abstract number: 138  
Presentation type: Poster  
Poster number: P28

Hand Washing Audit on a Hospice In-Patient Unit
Maura Cochrane, Patient Services, Quality, London, GREAT BRITAIN, Michael Coughlan, St Joseph’s Hospice and City University, London, GREAT BRITAIN

Hand washing is widely acknowledged to be the single most important activity for reducing the spread of disease, yet evidence suggests that this simple procedure is often not performed by health care professionals (Pittet et al, 2000; RNC 2000). While great emphasis has been placed on hand washing and infection control in the acute hospital setting, little has been documented regarding these issues in a hospice setting, and yet the philosophy of Palliative Care is to improve the patient’s quality of life through prevention and relief of suffering by means of early identification and impeccable assessment and treatment (WHO 2003). In a small audit carried out on an in-patient unit of an inner city hospice, we found that: 42.5% of Nursing Staff, 18.5% of Paramedical Staff and 0% of Medical staff washed their hands in accordance with established guidelines (NICE, 2004). Although the audit did not look at the effectiveness of hand washing techniques it has supported the claim that, hand washing, while an essential element of care, is not currently an integral part of the culture of all health services (CDC, 2002).

Abstract number: 139  
Presentation type: Poster  
Poster number: P29

Transfusions in Palliative Care
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Transfusions are expensive and, especially in home care, time consuming. It is therefore important to have clear indications set up for each pt. We used the palliative care research network in Sweden (PANIS) to outline the frequency of transfusions during one month in spring 2004. 22 palliative care units participated. The information was collected by questionnaires at the end of the study period and registered through a web based survey generator. The median age of the population (1047 pts) was 68 yrs (55% females). 146 pts (14%) were treated in in-p units and 901 pts (86%) in their homes by advanced home care teams. 907 pts (87%) had cancer. 175 pts (17%) had transfusions during this month. Haematological malignancy: 39% had transfusions, prostate cancer: 31%, colorectal/tum/breast cancer: 10–14%, non-malignant pts: 11%. 49% of the transfusions were given in private homes. 53% of the pts had a central venous catheter or a subcutaneous venous access. 171 pts had erythrocyte transfusions with a median of 2.9 units given to each pt at 1,6 occasions. For 103 pts a haemoglobin level below which a transfusion was supposed to be given was specified in advance (median 90 g/l). It was considered that at least 117 pts (68%) benefited from their erythrocyte transfusions. For 44 pts the advantage was uncertain and for ten pts the transfusions were of no use. 23% of those 70 yrs or younger (n=100), but only 62% of the older pts (n=71), benefited from the treatment. The mean transfusion time was 80 min/unit. Only 14 pts had thrombocyte transfusions. We conclude that treatment with erythrocyte transfusions in palliative care is quite common, and that most patients, especially the younger ones, benefit from the treatment.
Abstraction number: 140  
Presentation type: Poster  
Poster number: F30  

Review of opioid rotation to methadone in a specialist palliative care unit  
Cathryn Bogan, Palliative Medicine, Cork, IRELAND, Tony O’Brien, Marymount Hospice, Cork, IRELAND

Introduction: Over 18 months a number of patients have been opioid rotated to methadone despite the absence of a standard conversion regime. We review prescribing patterns with a view to developing a protocol. Aims and Methods: The aim was to review prescribing practices when opioid rotating patients to methadone. Patients opioid rotated to methadone for pain control were included; those prescribed methadone for its antitussive properties were excluded. We performed a retrospective chart review and recorded data including the total daily pre rotation opioid (PRO) dose and route of administration, the starting and final doses of methadone, number of days for conversion and morphine equivalent methadone conversion ratio. Results: 17 patients were opioid rotated to methadone. Neurogenic pain was the predominant feature for all patients. 16/17 were commenced on methadone at a fixed daily schedule (usually 5mg bd). In 14/17 the patients the PRO dose was reduced by 33.7% on day 1 and the mean time to cessation of PRO was 4.9 days. Average time stabilisation was 6.94 days. Discussion: Our results indicate that despite the lack of protocol for opioid rotation to methadone, certain trends have developed. Methadone is introduced as a regular twice daily dose (5mg bd if the equivalent daily dose of oral morphine is <100mg and 2.5mg bd if it is <100mg) with a fixed dose (5mg or 2.5mg) used to treat breakthrough pain. When rotating to methadone the PRO is reduced by a third on day 1 and is stopped within five days. Our review has limitations, namely insufficient documentation of pain scores and adverse effects, thereby prohibiting comparison of efficacy of this routine with previously described schedules. We are currently drafting a protocol based on these results.

Abstract number: 141  
Presentation type: Poster  
Poster number: F31  

Symptom control and prediction of follow-up of far-advanced cancer patients in a palliative care outpatient clinic  
Josep Porta-Sales, Palliative Care Service, L’Hospitalet-BCN, SPAIN, Gala Serrano-Bermudez, Institut Català d’Oncologia, L’Hospitalet-BCN, SPAIN

Aim: To describe patients attending our outpatient clinic and know how much symptoms can be controlled and to identify predictive factors in order to improve the ambulatory follow-up. Method: We enrolled consecutively patients attending outpatient clinic from October 02 to September 03. A standardized interview data was always done, including Numerical Verbal Rating (0–10) for pain, anorexia, constipation, insomnia, weakness, anxiety and depression. Only patients able to attend appointments without visits were considered assessable. Wilcoxon test was used in comparing symptom scores, and logistic regression to identify predictive variables of ambulatory follow-up and withdrawal. Results: During the study period 534 patients were enrolled. Only 203 (38%) were assessable, mainly cause of removal was Palliative Care Unit admission (75%). Of the evaluate patients, 73.9% were men, mean age 65.3 ± 6.7. CAGE ≥ 2.5%: Past history of psychopathology 20.2%, ESS ≥ 11: 43.3%, MME ≥ 24, 12.8% at 1st visit. The median time between 1st and 2nd visit was 21 days, and between 2nd and 3rd visit was 27.5 days. Between 1st and 2nd visit, pain (p = 0.27) and depression (p=0.47) improved, and between 1st and 3rd visit a significant improvement in pain (p=0.001), anorexia (p=0.027), insomnia (p=0.042) and depression (p=0.009). Looking at the predictive model Karnofsky index (or =1.06, C.I.95%[1.05–1.08]) and anxiety (or=9.92, C.I.95%[0.86–0.98]) are able to clearly classify 71.7% patients whom will or not arrive to a third consecutive visit. Conclusion: We are able to attend 3 consecutive visits in our clinic obtains an overall good control of symptoms, but weakness and anxiety. b) Patients with low Karnofsky index and high anxiety are at risk of need an early admission, so careful follow-up and extra alert on the emotional situation of the patient and family should be mandatory. c) It is needed to review our current policy on weakness and anxiety management.

Abstract number: 142  
Presentation type: Poster  
Poster number: F32  

Take ‘as directed’: Audit of the transcription of prescription instructions  
Karen Groves, Welsh & SFF Palliative Care Services, Southport, GREAT BRITAIN, Justine Purnell, Queenscourt Hospice, Southport, GREAT BRITAIN

In palliative care the importance of correct timing of medication in order to achieve good symptom control cannot be over emphasised. It was discovered that, despite accurate instructions being written on the prescription, and compliance sheets with detailed instructions being given to patients and carers, the instructions subsequently written on the drug label by the pharmacist often bore little resemblance to the prescriber’s instructions. An audit was carried out to compare the instructions requested by the prescriber (Consultant in Palliative Medicine) on the FP10 prescription, with the instructions written by the pharmacist (several community pharmacists). This audit showed that 29 of 30 patients had incorrect transcription. The pharmacist had inserted statements (such as ‘as directed’) which improved quality of care. The pharmacist was requested to insert ‘as directed’. This suggestion was taken up by Community Pharmacists.

Abstract number: 143  
Presentation type: Poster  
Poster number: F33  

USER EVALUATION OF THE IMPLEMENTATION OF THE CARE PATHWAY FOR THE DYING IN HOSPITAL, HOSPICE AND COMMUNITY  
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Aim: To evaluate the implementation of the Liverpool Care Pathway for the Dying (LCP) in a hospital, hospice and community settings by professional user views on the use, usefulness of the pathway in the delivery of multi-disciplinary terminal care and the quality of education and training. Methods: The LCP was piloted across 2 health districts (popn 445,000) in hospice, hospital and community, with training provided by the specialist palliative care services. User questionnaires were completed by medical and nursing staff, to assess: frequency of usefulness, multi-disciplinary working, quality of care, facilitation of good end of life care, involvement and standard of education and training. Results: 63% response rate (83/132); Length of use of pathway: range 6–24 months, median 15. 59% of respondents found the LCP was useful with clear goals of care. 66 (80%) judged the Pathway as multi-disciplinary, but 10% assessed the sections for each discipline as unclear. Greatest effect was changing practice in the community (74%) and hospital (69%) with improved symptom management, holistic care, communication and co-ordination of care. 82% stated that the LCP improved quality of care by improved documentation, facilitation of patient and carer involvement 48% and 65% respectively. 16% in hospital and community perceived the LCP as too time-consuming. 53% assessed training as effective, however18% were dissatisfied of whom; the majority were community staff. A common theme was improved support in the decision-making process of commencing the pathway and symptom management. Conclusion: Majority of users reported the LCP as an effective tool, which improved quality of care by changing practice for care of the dying, in particular in hospital and community settings. User evaluation resulted in extension of length of staff training and going twice daily with appointment of pathway facilitators.

Abstract number: 144  
Presentation type: Poster  
Poster number: F34  

DEMAND OF PALLIATIVE CARE: NURSING CARE MANAGEMENT PREVIOUSLY TO FIRST INTERVENTION OF A PALLIATIVE CARE TEAM  
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Introduction: Nurse of palliative support team of hospital manages all demands received to look after terminal ill patients. The aim is the selection of the best palliative resource (hospital, socio health centre and home teams) according needs of every specific situation. The information process is obtained by means a structured questionnaire recorded by phone contact. The needs assessed are: disable level, priority of care related with symptoms severity, ability hospital transfer, real and potential palliative care home teams. The result of case management depends of a consensus between patient, family and the health team who will finally look after the patient. The complexity of this management model generated the need to audit this process in order to improve the steps and assess its effectiveness. Aims: Describe the work method of nurse who establishes case management. Implement and assess the effectiveness of an audit system. Methods: Complete Structured questionnaire recorded in the first phone contact to all demands. Follow up form that make possible obtain data about the patient’s characteristics, circumstances of best palliative resource, visit prioritisation and final result of this management. The recruitment period has been 36 months (November 2001 and November 2004). Results: A total of 1,800 demands and 5,400 phone calls of follow-up. In preliminary analysis we have tried a sample of first 104 patients. The results were: a) 77% were finally visited in outpatient setting.

Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005  
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005
Clinic of acute hospital with an attending compliance of 90.5%; b) 13% palliative home team; c) 3% died previously in acute hospital in no palliative services; c) 1% admission to no palliative service of acute hospital; c) 2% no possibility of patient contact. Conclusion: We clearly identify the role of nurse in case management, in make decision process and the correct use of resources. A standard process improves effectiveness in relation to a systematic process.

Abstract number: 145
Presentation type: Poster
Poster number: P35

An audit of out-of-hours calls in a domiciliary home care team setting.

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Background: Home care teams are a well established part of a specialist palliative care service. In Ireland they usually function as a support to the community services including general practitioners and public health nurses. The provision of an out of hours service (from 6pm to 8am) varies in practice. In Our Lady’s Hospice, out of hours is covered by phone advice from nursing staff on the inpatient unit.

Objective: To review the existing out-of-hours service offered and establish whether it is adequate to meet the needs of patients and families. Methodology: A prospective study was carried out over 12 weeks. Home care team members completed a questionnaire following every out-of-hours call. Results: 114 questionnaires were completed. 95% of callers phoned the Palliative Care Unit (rather than hospital switchboard) about symptom control/medication. A small number of patients were seen at accident and emergency departments. Conclusion: Most problems were resolved by phone. The few admissions to hospitals during the audit were appropriate ie chest infections.

Abstract number: 146
Presentation type: Poster
Poster number: P36

A Prospective Study of Palliative Medicine Service Utilization in an Academic Center

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Background care of patients with incurable illnesses requires comprehensive palliative medicine. The Cleveland Clinic Palliative Medicine is a comprehensive service. Services include 1) in-patient unit 2) in-patient consultation service 3) outpatient clinics and consultation 4) managing self and in-patient service 5) 24-hour on call and on call telephone services. Palliative services provide 1) continuity of care 2) rapid access throughout the illness. We performed a prospective study of service utilization to help palliative medicine program development. Method Consecutive patients were followed for service utilization after initial consultation. Patient demographics, consult location, and referring service were recorded. New service utilization was defined as: 1) in-patient admission, 2) hospice admission, 3) in-patient hospice admission, 4) outpatient clinic visit, 5) telephone contact. Results 238 consecutive patients were evaluated 10/13/03-12/31/03. 100 (42%) were not followed. The median age of the patients was 70 years (19-102 years), 56% were female; 73% Caucasian and 25% African American. Cancer diagnosis accounted for 77% of all palliative service contact was: 1) in-patient consultation 47%, 2) outpatient consultation 38% 3) direct admission 18%, 4) referrals were from medical oncology (49%), internal medicine (6%), hospital medicine (15%) services. 74% were followed collaboratively.

Abstract number: 147
Presentation type: Poster
Poster number: P37

Palliative Care needs and Palliative Care input in a major UK Cancer Centre

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OBJECTIVE: Assessment of current PC (Palliative Care) needs and of input by the PC liaison team for Onc [Oncology] and Haem [Haematology] patients in one of the largest UK Cancer Treatment Centres. The aim was to aid planning of PC services after future relocation to a private initiative NHS hospital with an ambulatory care model. METHODS: For this survey a staff questionnaire was designed and ethics approval sought. One questionnaire per patient was filled out by the nurses on the Onc and Haem wards on the 16th December 2003. The data was analysed with Excel. MAIN RESULTS: 74 of 75 questionnaires were returned and analysed [39 Onc, 35 Haem]. 30% of patients had experienced severe or overwhelming pain during their admission; 23% experienced severe or overwhelming symptoms other than pain; 32% were anxious, worried or depressed for most of the time. Of those 68%, 65% and 72% were seen by the PC team respectively, 19% of patient’s family or friends expressed anxiety or concerns repeatedly. In 50% of these cases the patient had been seen by the PC team. Symptom control was the reason for admission in 11% of patients. The PC team saw 22 patients in total. 3 had been referred to PC and had not been seen. 8 had neither been seen nor referred but had PC needs. CONCLUSIONS: More than 40% of patients had symptoms indicative of PC needs. 33% were referred to the PC team, leaving approximately 10% who would potentially benefit from PC input. Less than half of distressed relatives were known to the PC team. A single assessment tool which includes a screen for relatives’ distress might increase the pick up rate of patients as well as families that require support. Further studies could employ patient questionnaires to increase reliability and validity. They could also investigate if the 11% of patients admitted for symptom control would be more appropriately managed by PC services otherwise PC team, e.g. in an ambulatory care or on a PC inpatient unit.

Abstract number: 148
Presentation type: Poster
Poster number: P38

AUDIT OF DOCUMENTATION OF PRESCRIBING IN A HOSPICE

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Aim: Drug administration is the final step in a multidisciplinary process. Clear documentation on drug charts and medicine policies help reduce the risk of drug administration errors. We aim to assess quality of documentation of our prescription charts. Method & Results: We reviewed inpatient charts in our hospice over a one week period. This included the pre-printed PRN section, which has common PRN drugs that need dose and frequency deciding then signing. 98% of charts had accurate patient details recorded and were legible. 70% of amended prescriptions were rewritten separately as per policy. Of the pre-printed presciptions only 31% were prescribed generically and 53% for opioids. For PRN prescriptions only 16% had possible frequency of administration documented. Conclusions: We feel the good level of documentation and legibility reflects a wish to reduce risk of errors, minimise requests to rewrite prescriptions for improved legibility and an individual sense of accountability. Given the number of dose alterations (i.e. opioid titration), a level of 70% of prescriptions being rewritten is moderate. The pre-printed section reduces number of available sections for further drugs and hence a reluctance to completely rewrite prescriptions. We still use non-generic prescriptions and feel this was due to an attempt to minimise confusion (e.g. Buscopan). There are 2 pre printed opioids on the chart. The morphine prescription was often amended to clarify an immediate release preparation. Conclusions: It also does not account for the wide range of now commonly used opioids. The frequency for PRN drugs use was poorly documented because the pre-printed section has a 24-hour dose section but none for frequency of administration. We plan to: Reconsider which medications are included PRN. Incorporate a specific frequency section. Create a local policy for opioid generic prescribing.

Abstract number: 149
Presentation type: Poster
Poster number: P39

Internet use by cancer, palliative and supportive care professionals: Data from the PIES website evaluation

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BACKGROUND: Professionals in cancer, palliative and supportive care need access to good quality information. Much is already available via the internet, but users need a simple reliable filter. PIES (www.piesforcancer.info) stands for Personalised Information, Education and Support for cancer patients and carers. Improved knowledge of user requirements helps develop good quality information resources based on the needs of the community. Part of the PIES evaluation, we sought internet usage data from an expert user group of professionals. METHODS: Data gathered Sep 2002–Sep 2004 using self-completed questionnaires and semi-structured interviews. RESULTS: 93 forms received. 82% female users. Nurses form key user group (45% of sample). 25% ‘very little’ internet experience. 75% had used internet for cancer information search 3 or more times. Top 5 information topics sought: 1 Treatment Choices (cited by 76% of all respondents) 2 Effects 76% 3 Causes of Illness 72% 4 Illness Types 65% 5 Voluntary/self-help groups 62%. 64% said ‘yes’ they would encourage patients/carers to use PIES, 2% said ‘no’. 82% rated PIES overall good or very good. 75% good
or very good navigation. 80% good or very good for finding relevant, reliable information. 57% said PIES would be quite or very useful in future for finding cancer information. Users were split on whether a discussion forum shared between professionals and consumers would be a good idea (43% yes; 38% not sure; 6% no). CONCLUSIONS: Majority of these professionals use the internet for information on a range of basic care issues. They will recommend some websites to patients and carers. Nurses form a key user group. Since 23% of web-using professionals had ‘very little’ internet experience, the figure among all professionals may be even higher, and this may affect how well the web facilitates access to the evidence base.

Abstract number: 150
Presentation type: Poster
Poster number: P40
A review of the practice of opioid rotation in cancer patients in a palliative care inpatient unit
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Background and Objectives: There is now a broad range of strong opioids to choose from each exhibiting differing pharmacodynamic and pharmacokinetic properties. The identification of problems such as tolerance and toxicity have led to experimentation with different opioids from which the practice of opioid rotation was developed. There are no formal guidelines in place in Our Lady’s hospice, Harolds Cross, Dublin for opioid rotation and therefore this review aims to assess the practice of opioid rotation in the in-patient unit and to evaluate the reasons and outcomes of the rotation.

Methods: Retrospective study examining the medical notes of all patients admitted to the inpatient unit in a 6-month period. A pilot study was completed following which data was collected using a data collection form by one investigator. Data was collected on the initiating opioid, reasons for changing, adverse effects and outcomes of the switch. Results were analysed using descriptive statistics.

Results: 67 out of 81 patients notes were eligible for analysis, 97 rotations took place of which 64 (66%) were drug rotations and 57 (59%) were route rotations. The main reasons given for rotation were patient deterioration (36%), toxicity (17%), adverse effects (19%) and poor pain control (14%). The main treatment of toxicity is opioid rotation (21%) followed by dose reduction (5%) and rehydration (1%). The outcomes of toxicity treatment showed less toxicity in 56% and no improvement in 38%, 6% were not recorded.

The most common drug before rotation was morphine.

Conclusions: Indications for opioid rotation given in this study are similar to other opioid rotation studies. The treatment strategy of toxicity in the unit does not follow recommended guidelines and in order to achieve the best possible symptom control in these patients this may only be rotated when the other clinical strategies (dose reduction and rehydration) have been attempted.

Abstract number: 151
Presentation type: Poster
Poster number: P41
Evaluation of two hospital support teams regarding different settings
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The goal of the current study is to find out the focus of activities and the expenditure of time regarding two different settings of hospital support teams. One team is located at the regular hospital for acute cases in Rottenmann and the other at a private hospital in Graz. In Graz the hospital support team cooperates with the in-house palliative care unit, so patients can be transferred if necessary, whereas in Rottenmann an in-house palliative care unit is not available and the patients are treated by the team in course of their whole stay in the hospital. While the patients are being taken care of, data are collected by members of the hospital support teams. Physical and mental health status of the patients are recorded as well as the activities of the hospital support teams. At present only interim results are available based on a sample of 50 cases. According to our current findings we assume that the activities of the hospital support teams are focused on the psychosocial domain. On average 100.8 minutes (SD=61.6) per patient and visitation are taken for those activities. However, in Rottenmann visitations of the hospital support team are more often associated with the patient’s physical complaints than in Graz, due to the lack of a palliative care unit (Graz: 31.0% vs. Rottenmann: 66.7%), whereas the team in Graz is more frequently consulted solely for its psychosocial activities. In Graz patients are also more often visited by the hospital support team only once because of the in-house palliative care unit (Graz: 40.0% vs. Rottenmann: 28.0%). Further statistical analyses based on a sample of more than 100 cases are planned for the final report, which will be available at the end of 2004.

Abstract number: 152
Presentation type: Poster
Poster number: P43
A peer education service for advance care planning: a development study with older adults
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This project aims to develop, implement and evaluate a means of raising awareness of issues in advance end of life planning among older adults living in the community. Objectives 1. To develop a model of peer education to enable older adults to: 1) access information about care and treatment options in the last days of life, and 2) to exchange expertise about approaches to discussing these issues with their families and health professionals. 2. To assess the feasibility and acceptability of the model as a means of public education in end of life care for older adults. Method This is a pilot study in progress in one locality in the UK. Using an action research approach, we are working collaboratively with a range of community advisors drawn from voluntary groups representing older people. There are 5 stages to the project: 1. Literature review and development of information resources and their collaborative evaluation with community advisors 3. Development of education guides; development and implementation of a model of peer education for community advisors who will act as peer educators. 4. Testing of education guides by peer educators within their community groups, and assessment of their acceptability. Ongoing evaluation by an independent evaluator. Proposed outcomes 1. A useful database of resources and materials for public education in end of life care. 6. An assessment of the potential transferability of the model to other contexts.

Abstract number: 153
Presentation type: Poster
Poster number: P44
The last days of life in progressive disease cancer patients: Different perceptions of relatives and doctors
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Introduction: An important goal of palliative medicine within the last weeks of life is symptom control. However, the perceptions of the last days and of the patients symptoms may be differing between professionals and non-professionals. Within the project ‘Patients as partners’ we did initial interviews with progressive disease cancer patients (n=272) and their relatives (n=64); after the patients had died interviews were made with the same relatives (n=25) and the family doctors (n=91). Results: On initial interview, hospital doctors (n=256) judged the patients actual health status clearly better (average 6.29 on an 11 step likert scale) than patients themselves (average 5.86) or their relatives (average 4.9). Retrospectively, 56% of the relatives judged the patients general status within the last days of life as maximum poor. Reasons for this were pain (68%), nausea (21%), shortness of breath (53%) and confusion (37%). Only 31% of the family doctors judged the status of the patient as maximum poor within the last days of life. Most doctors described a complex picture of somatic and psychological problems; ‘pain’ (19%) was most commonly stated, as were confusion (7%) and shortness of breath (18%). Not the doctors but the patients did not know about. Conclusions: It is known that patients, relatives and doctors judge symptoms and health status differently. With regard to relatives, these differing perceptions are also imminent in the last days of life. Besides professional symptom control it is important to early communicate about death and symptoms to avoid misunderstandings, frustration and the call for termination of life.
Should the DoH ‘Copying letters to Patients’ Initiative be extended to Voluntary Palliative Care Settings?

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The aim of the study was to assess the potential value of copying ‘letters between doctors’ to their patients, in a voluntary hospice palliative care setting. In 2000 the UK’s Department of Health (DoH) published The NHS Plan which stated that ‘Patients have the right to see their medical records, though in practice communication between professionals is not available to the patient concerned. Patients often do not know why they are being referred, or what is being said about them. In future letters between clinicians about an individual patient’s care will be copied to the patient as of right’.

In 2001 the DoH pilot initiative for copying patient letters was commenced. Perceived benefits include an improvement in patient’s understanding of their condition, allowing for more informed decision making and improved doctor-patient communication.

A questionnaire survey was conducted by an independent researcher, in a 66 bedded adult hospice to ascertain the opinions of both palliative care patients and doctors to the value of adopting the DoH ‘copying patient letters’ initiative. Upon recruitment to the study, patient participants were shown a ‘sample’ letter to raise their awareness of the issue, prior to completion of the questionnaire. Results demonstrated that 94% of palliative care patients (n=63) would want to receive copies of letters, from which 78%–88% would not wish any adaptation of language or content from the original. Hospice doctors (n=11) also viewed the initiative positively. Almost all patients surveyed attending hospice would wish to receive copies of letters. We recommend that the DoH ‘copying letters initiative’ should be extended to hospice/palliative care settings and will discuss both the findings of the study and implications for the introduction of the initiative in the hospice setting.

References

Do patients with incurable cancer feel sufficiently informed about disease-related topics?

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Most cancer patients appreciate to be fully informed about their disease. We studied to what extent cancer patients report to have been informed about disease-related subjects in the last phase of life. Hundred-and-twenty-eight patients suffering from breast, lung, colorectal, prostate, or ovary cancer were included within two months of being informed that their cancer was in principle incurable. They filled out a questionnaire and were interviewed personally. The majority of the patients were informed about treatment options and side effects, physical symptoms, where to get help, helpful devices, and diet, while less than half of the patients were informed about psychosocial care, euthanasia, and complementary care. Of all patients, 39% would have appreciated additional information. Topics mentioned included physical symptoms, diet, euthanasia, and alternative or complementary care. Nineteen percent would have appreciated extra written information. Most patients (78%–88%) were satisfied with the information giving by the clinical specialist, oncology nurses, and non-specialised nurses, but only 63% evaluated the information giving by general practitioners as good. Most patients feel sufficiently informed about several items, but about some specific issues and are satisfied with the information giving by their health care professionals. Nevertheless, a considerable number of patients would like to receive additional information about a varying list of topics. Open communication between health care professionals and patients is important to address this need.

Disclosure of Cancer Diagnosis and Prognosis Among the Italian Cancer Patients: Results from an Italian Mortality Follow-back Survey

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STUDY OBJECTIVE: This study was aimed at estimating the proportion of Italian patients deceased for cancer who had received information about diagnosis and prognosis and their determinants. METHODS: this is mortality follow-back survey of 2,000 adults cancer deaths identified with a 2-stage probability sample representative of the whole country. Information on patients’ expertise was gathered from the non-professional caregiver with an interview conducted by trained professionals. A schedule covered questions on the disclosure of diagnosis and prognosis to the patients.
patients. RESULTS. Valid interviews were obtained for 63.5% (n=1,271) of the theoretical sample. Only 38.8% (95% CI=35.9–41.6) of patients already had extensive end of life care. Cancer had received information on the nature of their illness before death. Among the informed subgroup, patients had received information on diagnosis by a physician (79.2%), another health professional (10.6%), or a relative (14.7%). A small by significant group (5.0%) sought information by themselves. The caregivers reported that 52% of the non-informed patients were aware of the nature of their illness. Disclosure of cancer diagnosis was significantly associated with a younger age and a high education level of the patient (P<0.001). Cancer patients tolerated (head and neck, skin and breast), and for diseases with a longer interval between diagnosis and death. Only 13.4% of the patients (95% CI=7.5–19.2%) received information about the bad prognosis of disease. The caregivers reported that 63% of the patients had no information on prognosis were aware of bad prognosis the illness. CONCLUSIONS: Although different patterns in attitudes of physicians in the process of disclosure of cancer diagnosis and prognosis are reported in different countries, this high proportion of non-informed cancer patients in Italy is unexpected. This situation should be considered as a public health emergency and coherently faced up by health administrators.

Abstract number: 159
Presentation type: Poster
Poster number: F50

The family doctor in charge of dying cancer patients - How succeeds communication, participation and consideration of individual preferences?

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Introduction: The general practitioner (GP) plays an important role in the medical and psychological care of the palliative situation. An essential tool for a successful caretaking is a clear perception and best possible realisation of patients preferences and moral concept. Within the project Patients' we were interested in how GP's could realise patients wishes of participation and individual preferences at the end of life. Method: We interviewed patients (n=272) with cancer and metastases or cancer and metastases. Nearly 90% of the GP’s described their relation to the patient as a partnership. Consultation, care and tolerance were regarded as the main features of partnership. One in two doctors refrained from medical procedures in the last days of life. An advanced directive from the patient was available in 6/91 cases and had practical consequences in 3 cases. One GP was asked for assisted suicide. 58% of all patients died, not always according to their wish, at the hospital and 32% died at home. Discussion: For the GP, the extension of life care is a great challenge. To allow a patient-centred and preference-oriented dying in dignity a trouble-free co-operation between specialists, professional carers and patients family is necessary. There is a need for an improved establishment of palliative care teams to help the GP's deal with complex medical problems, co-ordination, and psychosocial issues.

Abstract number: 160
Presentation type: Poster
Poster number: F51

COMMUNICATION OF AN ONCOLOGICAL DIAGNOSIS: A PATIENTS' NEED BUT A DOCTORS' PROBLEM

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Introduction: the communication of bad news is difficult in an oncologic setting. Today it has been observed a trend to communicate the truth to the oncologic patient. Several studies have analyzed the communication, how the degree of awareness regarding the disease. Patients and Methods: we given out a questionnaire which is composed of two parts, one for the doctor and the other for the patient. We evaluated the doctor’s ability to communicate about the diagnosis and prognosis through the analysis of patients’ understanding about diagnosis and prognosis. So we analyzed how this ability change according to pts’ prognosis. We evaluated 137 pts (53 males and 84 females) aged from 30 to 60 years and an mean high school education from March ’00 to October ’00. The most frequent tumors were: breast, colon-rectus, lung and kidney cancer; good prognosis 70% and poor 30%. Results: the doctor communicates completely the diagnosis (95%) and the prognosis (85%) when the prognosis is expected to be good, these percentages decreased to 76% and 12% respectively when the prognosis is poor. Independently of real prognosis doctors communicate: recovery (92%), disease improvement (12%), disease stabilisation (8%), symptoms control (0%), so pts (93%) have disease recovery. 128 pts (94%) believe they understand the diagnosis, only 88 (64%) are able to define their disease (54% bad prognosis, 30% good prognosis). 128 pts (94%) want to be informed about the disease, 108 (79%) about the prognosis, and 104 (77%) even if it is expected to be poor. Conclusion: Communication regarding diagnosis and prognosis depend on disease stage and prognosis. Doctors have difficulties to communicate the exact evolution of the disease. The most of patients would like to be informed independently from prognosis.

Abstract number: 161
Presentation type: Poster
Poster number: F52

On-line survey of Occupational Therapist’s core skills with people who have life threatening illnesses in the UK

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Core skills published by the College of Occupational Therapy (COT, 2003) may not necessarily be the core skills of Occupational Therapists working with people who have life-threatening illnesses (PWLTI). Likewise, skills taught in the academic field does not hugely reflect the existing realities of clinical practice. The best manner to explore the skills core of OT practice among PWLTI is to gather professional consensus from experts themselves. In this study, OTs who work with PWLTI was employed all accessed through COT’s clinical interest group, HOPF. This group has received the core of OT practice. Furthermore, it identifies whether these skills vary across level of experience and work environment. Permission to carry out the study was obtained from 40 out of 195 respondents completed the on-line survey. SPSS version 11.5 was used to analyse quantitative data and Atlas/ti software was utilised to analyse qualitative feedback. The results have come up to the consensus of the skills core to their practice with PWLTI in areas/use of models of practice, assessment, treatment, supervision and continuing professional development. This study highlights to link educational establishment/s and clinical practice setting/s in preparing OT’s of ‘beyond’ within the field of palliative care with skills needed to be an effective OT practitioner/s. Future research should consider respondents’ Internet knowledge involving on-line surveys and increase number of sample size to make the consensus more representative of the OT population among PWLTI in the United Kingdom.

Abstract number: 162
Presentation type: Poster
Poster number: F53

Evidence-based integration of relatives

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Current situation: In spite of different efforts and undoubted successful projects and researches, the relative-integration still needs an improvement. Particularly there is a lack in the application of instruments which produce an valid, evidence based and practicable set of information to monitor and manage this process. Targets To develop a valid and improved Standard Operation Procedure by using a new relative assessment based on the standard of the evidence-based-method. Method: The new developed ‘Relative Assessment’ includes 40 questions along 6 Dimensions: Experience and Confidence, Knowledge, Necessary Skills, Participation and Expert, Resources and Fitness. Utilising this brain-screening, the user gets a sufficient overview about that relevant health topics and their individual tendency. This knowledge is necessary to realise the intended short term impacts as well, to manage and monitor the long term ones. The dimension ‘Necessary Skills’ will be customized to the specific tasks and targets of the users needs. The translation of evidence-based working in the integration of relative means: to identify the valid requirement, research the valid studies, qualify the best practice and evaluate the own documents. Therefore it is easy to define the targets / programs of independent best-practice health organisations. Results: The first clinical researches (n = 200) had been realised in hospital- and care-settings. The results of a factor analysis confirm the chosen construction. The description of the spot-check group combined with the principles of cbm-recommendations produces on-line targets to build up strategies, performances and services. After the methodological development the Relative-Assessment is a short and cost-saving instrument to integrate the relatives more effectively empower of the patients, manage the providing process by less cost, raise the quality of life of the patient and relatives and discharge the professional team.
Abstract number: 163
Presentation type: Poster
Poster number: P54

Supporting people with intellectual disabilities through terminal illness: A distance learning workbook for paid carers
Irene Tuffrey-Wijne, Mental Health (Learning Disability), London, GREAT BRITAIN

Aim: To describe an effective distance learning course about palliative care for paid carers in intellectual disability services. As more people with intellectual disabilities are now dying of age-related illnesses such as cancer, the provision of high quality end-of-life care gains increasing importance. However, there is a lack of educational materials for carers in intellectual disability services about palliative care. UK national guidelines stipulate that such materials should be available and accredited.

Method: An experienced palliative care nurse and intellectual disability nurse produced an extensive and unique interactive workbook, aimed at inexperienced paid carers. The contents, including the activities, were trialled with groups of carers. The book was published and the course delivered by the British Institute for Learning Disabilities. A poster will present examples from the workbook, together with comments from users. Results: The workbook is of benefit both to students seeking accreditation, and to intellectual disability services looking for relevant, focused learning opportunities. Conclusion: Focused, accessible materials relating to palliative care are important for inexperience carers, and professionals.

Abstract number: 164
Presentation type: Poster
Poster number: P55

CARER ADVISORS IN PALLIATIVE CARE: DESCRIPTION OF AN INTERVENTION
Louise JONES, Mental Health Science, London, GREAT BRITAIN, Christina MASON, St Josephs Hospice Hackney, London, GREAT BRITAIN, Kri Walsh, Royal Free And University College Medical School, London, GREAT BRITAIN, Adrian Askman, Royal Free Hospital NHS Trust, London, GREAT BRITAIN, Michael King, Royal Free And University College Medical School, London, GREAT BRITAIN

Background: We conducted a randomized controlled trial of a brief intervention to reduce distress in carers of patients receiving specialist palliative care in north London (funded by Cancer Research UK, 2000–2003). Results showed the intervention produced a significant reduction in distress which was not sustained when the intervention was withdrawn. In this presentation we describe the format of the intervention. Aims: To describe the training of advisors and implementation of a carer focused intervention. Methods: Two advisors were recruited to implement the intervention which consisted of 6 weekly visits to carers by advisors. Advisors received training from physicians, nurses and psychosocial team members as outlined in the Skills Awareness Handbook. The principal domains covered were: Carer fatigue (Health needs of carer, Practical needs, Respite care, Social networks, Dynamics of carer, Support), Emotional support for carer (Social networks, Dynamics of family relationships, Sexuality in carer and patient, Management of children where relevant), Care of the patient (Symptom management, Handling/management/Sliding & gliding, Feeding and diet, Complementary therapies, Sleeping and bedrest, Crises management), Finance, Benefits and Housing, Legal issues, Child provision.

Carer advisors used checklists to record details of domains covered at each visit. Weekly clinical supervision with research team was held to discuss issues arising. Results: Our trial suggests that increased support for carers alleviates distress and that such input could be maintained through a standard rather than delivered as a brief intervention. Conclusions: Increased awareness amongst palliative care team members might be facilitated by use of the Carer Advisor Skills Awareness Handbook as a basis for in-service education sessions. Key elements of this intervention could be incorporated into routine care.

Abstract number: 165
Presentation type: Poster
Poster number: P56

Undergraduate palliative care medical education – how effective is it?
Paul Paes, Palliative Medicine, Oxford, GREAT BRITAIN, Amanda Taylor, Kettering General Hospital, Kettering, GREAT BRITAIN

Background: There is increasing emphasis on palliative care training within the medical school curriculum. There has been little research on the effectiveness of this teaching. This study seeks to explore how effective the teaching is in one area of palliative care, pain control. Method: Pre-registration house officers (PRHOs) completed a questionnaire at the start of their jobs. The questionnaire contained 4 questions exploring concepts of pain management and 2 questions testing practical knowledge of pain management. Results: 15 PRHOs participated. The majority had a good understanding of pain management, 10 of the WHO analgesic ladder, 10 side-effects of opioids, treatment of neuropathic pain, and non-drug treatments of pain. Very few were able to answer the questions testing their practical knowledge. Discussion: PRHOs had a good understanding of concepts of pain management from their undergraduate training. They were less good at practical prescribing of analgesia. To overcome this, palliative care teams need to develop educational programmes to help junior doctors put their theoretical knowledge into practice.

Abstract number: 166
Presentation type: Poster
Poster number: P57

Education beyond the borders of palliative care.
Marianne Klee, Vaerlose, DENMARK

One of the biggest challenges facing palliative care in the coming years is how to ‘spread the word’. All doctors and nurses who work with somatic patients should have a basic knowledge about how to manage symptoms and address psychosocial issues. There are a number of issues that have to be considered: 1. Most health care professionals have no formal training in palliative care. 2. Many health care professionals ‘do not know what they do not know’ so they have no information. When a palliative care facility does exist it tends to take over the patient instead of transferring knowledge by teaching. 4. Health care professionals are busy and may not be able to find time to attend lectures and other traditional teaching. 5. Any teaching should be based on the concept of adult learning. 6. Most specialists in palliative care spend the majority of their time on clinical work and little on postgraduate teaching. One of the solutions is the development of a website teaching the basic clinical skills of palliative medicine. This website should be based on the concepts of adult learning needs and it should be designed in a way that the learner can use the information in his or her clinical work without further input.

Abstract number: 167
Presentation type: Poster
Poster number: P58

Education beyond the borders, a website teaching about symptom management.
Marianne Klee, Vaerlose, DENMARK

The website www.symptomscontrol.com is a clinical website that teaches all doctors and nurses working with seriously ill and dying patients, how to diagnose and treat the patients’ symptoms. The aim is to teach the basic skills of how to manage physical and psychological symptoms. It is designed to meet the needs of postgraduate learners. It can be used as a manual, as a set of guidelines and as a textbook. It is constructed as ‘a clinical teacher on the net’ with the emphasis on ‘how to’ written in English and is designed to be internationally. The graphics has been created for the site and it will later be possible to download these for teaching purposes. Later on more comprehensive e-learning will be developed allowing health care professionals to get a more systematic training and documentation for this.

Abstract number: 168
Presentation type: Poster
Poster number: P59

Beyond the borders of traditional teaching, using a website to spread the information
Marianne Klee, Vaerlose, DENMARK

Palliative care is faced with a big challenge: Most health care professionals that are currently practicing have not had any training in basic palliative care. This means that they do not have any structured knowledge about the management of symptoms nor how to address the patients’ psychosocial needs. The internet is becoming an important tool in the postgraduate teaching and in the area of palliative care a number of websites have been developed. An overview of the best websites (written in English) informing and teaching about palliative care will be given, including their addresses and content.

Abstract number: 169
Presentation type: Poster
Poster number: P60

The obstacles in group dynamics in healthcare service. The importance of having an external psychological supervisor in P.C. teams
Gustavo F. Rodio, Psychosocial Area, Capital Federal – Buenos Aires, ARGENTINA, Marcelo Medelywosky, Hospice San Camilo, Olivos, ARGENTINA, Dora Gonzalez, Hospital Gamullo, Lomas de Zamora, ARGENTINA, Gabriela Boso, Hospital Churruca – Visca, Buenos Aires, ARGENTINA, Ana Ottone, Hospital Marie Currie, Buenos Aires, ARGENTINA

Taking care of professionals that make up a treating team asks for specific and accurate intervention within the context of P.C. Clinical supervision may play an important part in preventing dysfunctions in group dynamics and habitual syndromes related to this kind of task (such as burn out). This oral presentation seeks...
to: – Reflect on the importance of self-care. – Enrich intervention and promote proactive communication, as opposed to reactive communication. – Understand invisible patterns and also transference – counter-transference connections in professional – patient/family and professional – professional relationships. – Teach how to tolerate tension in conflicts, so as not to fall into judgments of the ‘this is good / or this is bad’ type. – Reveal attitudes and reactions that facilitate the professional/patient/family relationship – Share experiences and testimonies.

**Abstract number:** 171  
**Presentation type:** Poster  
**Poster number:** P62

**Family physicians’ knowledge about pain control in Poland**

Krzysztof Buczkowski, Family Medicine, Bydgoszcz, POLAND, Malgorzata Kajniś, Medical Academy, Bydgoszcz, POLAND, Jacek Budzyński, Medical Academy, Bydgoszcz, POLAND.

The well-organized palliative care should involve participation of family physicians in the management of end-of-life symptoms. Their knowledge about symptom control is essential for providing competent service. The basic is a proper diagnosis and treating of pain. The aim of this study was to assess family physicians knowledge about pain control. Method: A postal questionnaire surveyed a sample of 384 Polish family physicians. The response rate was 51%. The questionnaire consisted of clinical cases connected with pain control. Results: All cases were divided into three groups according to percentage of correct answers. The first group, with the highest percentage of correct answers – areas of strength (more than 50%), the second between 33% and 50%, and the third with percentage of correct answers lower than 33% – areas of weakness. Strengths in physicians’ knowledge include neuropathic pain characteristic, usage of standard-release morphine in the management of breakthrough pain and conversion of oral to subcutaneous opioids. The second group included drugs used in the management of neuropathic pain, dealing with constipation and nausea caused by opioids. The areas of weakness were formed by management of bone metastases pain and the reason for not increasing the dosage of opioids in a patient with cancer pain. No participant was afraid of drug addiction during opioid therapy. Conclusion: The knowledge of family physicians in Poland about pain control is insufficient and worse than in other countries. This situation demands improvement.

**References**


**Abstract number:** 172  
**Presentation type:** Poster  
**Poster number:** P63

**Palliative Care Education and Support Programme for Community and District Nurses**

Tracy Cunningham, Community Palliative Care Team, London, GREAT BRITAIN

Many people express a wish to die at home but this does not always happen. In 2001 the Department of Health provided training money to build on and develop the existing palliative care knowledge and skills of Community Nurses in order for them to support carers and patients with palliative care needs dying at home and prevent hospital admissions. The North East London Cancer Network (NELCN) met with education providers and district nurse operational leaders in order to plan and develop the project. The programme aims to provide education to three hundred nurses over three years. The course lasts for four and a half days and has been running twice a year. The course incorporated the following components:

**Philosophy and principles of palliative care; Counselling skills and therapeutic communication; Symptom control and management of care; Understanding feelings – bereavement and loss.** The education was provided and took place at various sites throughout the Network including St Josephs Hospice in Hackney. At St. Joseph’s, the education sessions used various teaching strategies provided by the multi-professional Community Palliative Care, the Pastoral Team, education specialists and external speakers. Overall, the targets were met and across the Network over 348 nurses undertook the training. Detailed evaluations indicated that the course was well received and enjoyed. A sense of achievement amongst the teaching group in providing education to community staff and relating theory to practice was fundamental to the course. The project has finished. The course, expanded to include health professionals, continues to run. Details of its content and evaluation will be included in the presentation.

**Abstract number:** 173  
**Presentation type:** Poster  
**Poster number:** P64

**An evaluation of a bespoke training programme for f grades in specialist palliative care**

Elaine Lennan, Cancer Care Directorate, Southampton, GREAT BRITAIN

A bespoke training programme was developed for f grades in specialist palliative care in response to an inability to fill clinical nurse specialist positions. There were many reasons for these vacancies going unfilled but a clear problem was a lack of confidence to take the leap of faith into the specialist role and / or the lack of core skills to take on the role. With this in mind we developed a rotational programme for 3 f grade nurse to have the opportunity to work in the hospital palliative care team, the home care team and the in patient unit in a supernummary capacity. Alongside this clinical experience we offered support for academic work with a protected study day each week. No job descriptions were available as we felt it important to meet individual needs whilst on this development programme. The target was an individual personal development plan was created with the help of a mentor. This was done using the RCN Clinical Competencies for nurses working in specialist palliative care (2002). In addition to clinical and academic exposure we felt it important to ensure the individuals were part of a group and not isolated. This was achieved in 2 ways Firstly a second monthly needs led workshops addressing issues the participants had raised and secondly a monthly formal clinical supervision. To date 2 evaluations are complete with the third and final one due in January 2005. Results are encouraging though not all positive. Full analysis will be described in the poster.
Abstract number: 174  
Presentation type: Poster  
Poster number: P65

Role models and moral attitude in palliative care  

Gert Olthuis, 232 Ethics, Philosophy And History Of Medicine, Nijmegen, NETHERLANDS, Wim Dekkers, UMC St Radboud, Nijmegen, NETHERLANDS

- Object of study: Our previous research into the moral attitude of palliative care professionals established that the motivation and interaction between role models and their profession in palliative care depends on two features: characteristics of professionals and the attractiveness of providing palliative care. The study suggested several clues for developing moral attitude. One of them is using role models. Recently however, the usefulness of role models has been criticized.
- Aim of the present study: to investigate if and how role models should play a part in the education of moral attitude in palliative care.
- Methods: 1) 19 Semi-structured interviews with palliative care professionals. 2) Reviewing relevant literature on role models, moral education and virtue ethics.
- Results: Moral attitude lies at the heart of professional practice: the manner in which practitioners perform the roles and tasks of their profession in conjunction with their patients. Four terms which make up the pivot of professional practice – doing, knowing, being, becoming – served as a guide for the analysis of moral attitude in palliative care. Since the aim was to study education of moral attitude, attention was focused on ‘becoming’. In the literature some claim that role models may be an unreliable tool of education of moral attitude on the basis of role models. The study suggested several clues for developing moral attitude. One of them is using role models. Recently however, the usefulness of role models has been criticized.

Abstract number: 176  
Presentation type: Poster  
Poster number: P67

Why Do Junior Doctors Need an Educational Supervisor?  

Maria Teresa Garcia-Baquero Merino, Palliative Medicine, London, GREAT BRITAIN, Richard Hillier, St. Joseph’s Hospice, London, GREAT BRITAIN

All junior doctors at St Joseph’s Hospice receive regular clinical supervision and also attend a support group enabling them to process their clinical practice positively. In addition, during the year the doctors have received educational supervision by somebody who did not work clinically with them. We wanted to introduce the doctors to the idea of reflective practice and to provide support, not only professionally but also personally. A survey was undertaken to assess the perceived value of this one-to-one educational supervision. The survey was intended to assess the level of confidence as a result of the sessions and to evaluate this in relation to the doctors’ work in the multi-professional team. We also wanted to explore the impact of these sessions on the individual’s career planning. An 8-item questionnaire was distributed and completed by the 7 junior doctors. An appropriate timescale was given for the return of the completed questionnaires and all 7 replied. From the returned questionnaires it was found that there was a clear preference to have these educational sessions at a higher frequency. All junior doctors either completely agreed or agreed that the objective of these sessions had been achieved. Most doctors felt the need to elaborate further – with very positive comments – in the “Additional Comments” section. We conclude that educational supervision, when undertaken by a senior doctor not involved in clinical practice, is a valuable experience. Educational supervision doesn’t clash with day-to-day supervision of clinical practice. It complements and adds to it. Nor would it appear from the responses does educational supervision interfere with the effectiveness of the support group where the junior doctors felt their individual needs were dealt with.

Abstract number: 178  
Presentation type: Poster  
Poster number: P69

Beyond the Border. Taking Palliative Care training to the wider community  

Frances Kraus, Candle Project, London, GREAT BRITAIN, David Oliviere, St Christopher’s Hospice, London, GREAT BRITAIN

This project has involved St Christopher’s Hospice Candle project in a major training initiative with the London Metropolitan Police since 2000. When a sudden death such as a homicide, suicide or road traffic accident occurs and the police are involved, the Family Liaison Officer is assigned to work with the family until the case is resolved or closed. These officers did not receive any specialist training until a Public Inquiry by Lord Macpherson in 1999 following a high profile unsolved murder case reported that their care for bereaved families was inadequate and needed attention. The Candle Project has, for the last 3 years, received support from the Home Office to develop training for Family Liaison Officers. The project has provided training in 10 sessions over 1 year were timetabled. The programme for the first session was posted to all of the targeted GPs. Attendees had to confirm their attendance by fax and the first teaching session was held on 2nd September 2004 in the new Hospice building. A register of attendees was taken on the day and certificates of attendance were presented following the session. The GPs were asked to complete an evaluation form before they left. The uptake of the first teaching session was disappointment although feedback from the GPs was encouraging with future teaching sessions adjusted to accommodate the comments received. In addition to the teaching programme, the GPs had an opportunity to view the new Hospice building. The post-session evaluations showed that our programme is on target to address the GPs declared educational needs and the programme of sessions for the future is also appropriate. The doctors seemed particularly keen to have more practice outlook of palliative care. GP workload constraints are an obstacle to attendance. Continuous monitoring of evaluations by attendees should within a number of cycles optimise the programme.

Abstract number: 177  
Presentation type: Poster  
Poster number: P68

International Education at St. Christopher’s Hospice – Spanish Day  

Maria Teresa Garcia-Baquero Merino, Palliative Medicine, London, GREAT BRITAIN, St. Christopher’s Hospice in South East London is an important centre for education in palliative care and people come from all over the world to attend teaching sessions there. For a number of years education sessions specifically for French speakers have been held at St. Christopher’s. Two years ago it was decided to hold an annual conference for Spanish speakers. The first 2 of these were in September 2002 and February 2004. The objectives of this educational event were as follows: Ø To offer an overview of Hospice care for Spanish speakers in their own language. Ø To discover how the Hospice movement has developed from St. Christopher’s Ø To enable participants to glimpse Specialist Palliative Care in a modern Hospice. Information about the conference was sent to addresses in the Spanish Directory of Palliative Care and also distributed at stands in other conferences. The programme was designed to address specific learning issues using Spanish speakers working in the United Kingdom. Participants were given a complete form of evaluation at the end of the 2 days and this helped with the next year’s programme planning. The uptake of the invitation to attend was good. The initial plan had been to ask for a single day conference. At the request of the participants it has grown to a 2-day event. The conferences were very well evaluated. Participants wanted even more than the 2 days’ time and the opportunity for more in-depth topic teaching. Another aspect that was appreciated was the variety of teaching input and content. The programme of sessions for the past 3 years has indicated an on-going need for further “Spanish days” and these will continue to be arranged and evaluated. The next is planned for 25th-26th February 2005. Overseas Spanish speaking professionals appreciate the opportunity to have these days in a Hospice in addition to teaching on topics relating to palliative care.
Abstract number: 179
Presentation type: Poster
Poster number: P70

Combining palliative care theory with practice – an innovative approach
Chris Ward, Specialist Palliative Care Team, Northallerton, GREAT BRITAIN; Aston Tessa, Hambleton and Richmondshire Primary Care Trust, Northallerton, GREAT BRITAIN

Introduction The aim of the poster is to describe a model of education delivery which combines the theory and practice of palliative care. Participants undergo an extensive training programme consisting of an academic module and a 2-week secondment working in specialist palliative care. The programme culminates in the participant undertaking a work-based project which focuses on changing practice. Method The poster will evaluate the programme as outlined below: Factors leading to the development of the training – Target audience for success – Specific details of the programme – Discussion of linking the theory to practice of palliative care – Outline of the methods employed to evaluate the programme – Successful outcomes including tangible changes in practice and recognition of the programme – Transferability into other training areas Conclusion The poster will report on the success of the programme in bridging the theory and practice of palliative care. The model has been well received by the health workers and could be adapted for use in other specialist training programmes.

Abstract number: 181
Presentation type: Poster
Poster number: P72

TOGETHER AGAINST PAIN
Claudia Pesenti, Servizio Cure Palliative, Viganello, SVIZZERLAND; Pietro Sanna, Istituto Oncologico della Svizzera Italiana Iosi, Lugano; Viganello, SVIZZERLAND; Hans Neuenschwander, Istituto Oncologico della Svizzera Italiana Iosi, Lugano; Viganello, SVIZZERLAND

For several years the SCL has been promoting an audit program aiming to improve the quality of pain management in cancer patients. This well structured program is a framework with a number of issues audited by well defined indicators. The program will be shortly evaluated by an independent organisation such as SCL. The evaluation of the program will be a framework with a number of issues audited by well defined indicators. The program will be shortly evaluated by an independent organisation such as SCL.

Abstract number: 183
Presentation type: Poster
Poster number: P74

Training of volunteers in the Palliative Medicine Clinic and Home Hospice in Wroclaw
Jolanta Zietek, Palliative Medicine Clinic, Home Hospice, Wroclaw, POLAND, Krystyna Sambor, Palliative Medicine Clinic, Home Hospice / Oncology Centre of Lower Silesia, Wroclaw, POLAND, Ewa Woyton, Palliative Medicine Clinic, Home Hospice / Oncology Centre of Lower Silesia, Wroclaw, POLAND, Renata Opalinska, Palliative Medicine Clinic, Home Hospice – Oncology Centre of Lower Silesia, Wroclaw, POLAND, Malgorzata Rosolowska, Palliative Medicine Clinic, Home Hospice / Oncology Centre of Lower Silesia, Wroclaw, POLAND

Training of volunteers in the Palliative Medicine Clinic and Home Hospice in Wroclaw. Since 1997 seven courses for the volunteers have been organized. About 350 persons have completed these courses, 133 helped the patients of our team. The course included 61 hours of lectures and 147 hours of practical classes, the latter in

the best part of the course. The presentation will illustrate how these evaluations have been used to modify and improve the programme. The outcomes of this process are as follows: 1. The care model has been adopted for police forces throughout the UK and has been piloted in Holland. 2. The Candle Project was appointed as bereavement consultant to the British Government for the memorial services arranged for the families of the 9/11 World Trade Centre and Bali bomb terrorist attacks. The expertise of palliative care professionals was recognised at ministerial level, and impacted directly on the care the bereaved relatives received. The presentation will conclude with a summary of the lessons to be learnt for the palliative care field. Reference. Macpherson, William [1999] The Stephen Lawrence Inquiry.London; Her Majesty’s Stationery Office.
small groups containing 5–7 persons. The lectures and exercises are provided by experienced professionals of the Team: doctors, nurses, psychologist, physiotherapist, social worker and chaplain. The main topics are: the idea of palliative care, management of pain and other symptoms, psychological and spiritual issues and end-of-life care. Indications are medically ill people. The practical exercises involve basic nursing, rehabilitation, as well as psychological workshops. The course lasts 2 months. It is very important to involve the volunteers of the Hospice as soon as possible after they completed the course. After the last course, 65% of volunteers work directly with the patients, 20% with families, 7% help with administrative work. The volunteers continue their education by attending monthly meetings, conferences and lectures about palliative care.

Abstract number: 184
Presentation type: Poster
Poster number: P75

...and what about us?: Developing and evaluating a formal service, Training programme for hospice staff

Cath Baldry, Terence Burgess Education Centre, Southport, GREAT BRITAIN, Shirley Balmer, Queenscourt Hospice, Southport, Merseyside, GREAT BRITAIN, Rob Case, Queenscourt Hospice, Southport, Merseyside, GREAT BRITAIN

With the development of a purpose built education centre at the hospice, the opportunity arose to provide regular educational workshops for all members of hospice staff. Apart from planned mandatory training sessions, provision in the past had been rather ad hoc and improvised. It was felt a more structured approach was needed. We set the scene, several study days were organised for staff. The emphasis of these days was on team building and covered mandatory and organisational training issues, and local and national palliative care developments. Following this several lunchtime sessions were arranged for staff. Topics included assessment and management of common symptoms, issues surrounding spirituality and social and practical aspects of holistic care. The sessions were repeated at insistence to allow as many staff members as possible to attend. Initial evaluation of the programme was very positive. Following the first year of the structured programme an anonymous survey was completed. A short questionnaire was carried out to assess the impact of regular education workshops. This poster describes the development of the programme, the results of the survey and plans for the future.

Abstract number: 185
Presentation type: Poster
Poster number: P76

From little acorns: Hospital Health Care Assistants Palliative Care Link Group

Cath Baldry, Terence Burgess Education Centre, Southport, GREAT BRITAIN, Lesley Dunlevy, West Lancs, Southport & Formby Palliative Care Services, Merseyside, GREAT BRITAIN, Shirley Balmer, Queenscourt Hospice, Southport, GREAT BRITAIN, Christine Corder, Queenscourt Hospice, Southport, GREAT BRITAIN, Karen Groves, Queenscourt Hospice, Southport, GREAT BRITAIN

Much of the end of life care in hospitals in the U.K. is delivered by health care assistants. There is little data to underpin the value of their contribution, as part of the ward team in this situation, and to increase their knowledge and skills. In this area we already have two separate ‘link’ groups for qualified nurses, one for hospital and one for community nurses. These groups meet regularly throughout the year to refresh knowledge • reflect upon practice in care of the dying • disseminate information within their own work setting. With the permission and support of hospital managers, it was agreed to run a pilot scheme for health care assistants. One nominated person from each ward attended four days over twelve months for palliative care education appropriate to their particular needs • to act as a link health care assistant for their ward • reflect upon their care of dying patients. This poster describes the development of the pilot scheme and the evaluations of the first year along with the plans for further continuation of the scheme.

Abstract number: 186
Presentation type: Poster
Poster number: P77

Spiritual Care: A program for staff training in spiritual care.

Marijte Drijftbout, WL, SKF Palliative Care Services, Southport, GREAT BRITAIN, Cath Baldry, Queenscourt Hospice, Southport, GREAT BRITAIN, Ruth Killin, Queenscourt Hospice, Southport, GREAT BRITAIN, Justine Purnell, Queenscourt Hospice, Southport, GREAT BRITAIN, Sandra Leyland, Queenscourt Hospice, Southport, GREAT BRITAIN

Providing spiritual care is one of the aspects of the holistic philosophy of care that guides those who work in Queenscourt Hospice, Southport, UK. A recent audit told us that we are not very good at recording our Spiritual care. Less than 20% of records had an entry under the heading ‘Spiritual’. New UK wide guidelines on ‘Supportive and Palliative Care for Adults with Cancer’ (NICE 2004) state that the spiritual aspect of palliative care needs to be explicit, formalised and accountable. Prompted by the above, we designed a training course for Hospice Staff, aimed at making the existing spiritual assessment and care more explicit, and encouraging better communication and recording. We began with a session for all staff, aimed at ‘setting the scene’. This was followed by sixteen small group sessions, around four different themes: - definition of spirituality; - communication; - documentation; - mission. We used a mix of small group teaching techniques: facilitated discussion, group role play, paper-patient scenarios. The feedback so far has been very positive. We are planning to repeat the audit early next year, and the poster shows the change in the quality and quantity of our documentation of spiritual care.

Abstract number: 187
Presentation type: Poster
Poster number: P78

Stepping out with confidence: Primary Care Palliative Medicine Education for GP Registrars

Paula Powell, Terence Burgess Education Centre, Southport, GREAT BRITAIN, Cath Baldry, Queenscourt Hospice, Southport, GREAT BRITAIN, Christine Corder, Queenscourt Hospice, Southport, GREAT BRITAIN, Karen Groves, Queenscourt Hospice, Southport, GREAT BRITAIN

A survey, in 2002, of GP Registrars in the Mersey Deanery, resulted in an overwhelming majority requesting education in Palliative Medicine for primary Care. As a result of this a 3 day course in palliative medicine for GP Registrars, specifically aimed at primary care issues, was devised and delivered by doctors trained in both primary care and palliative medicine and supported by Mersey Deanery. Following this an attempt was made to evaluate the success of the intervention measured against the needs originally identified by GP Registrars. To date four courses have been held accommodating 45 doctors from the Mersey Deanery. The final course evaluations were very positive and have been documented previously. It was important however to know whether the theory had been translated into practice and was seen by the Registrars to have filled the gaps in their knowledge. This poster describes the results of a follow up questionnaire and compares them with the results of the volunteers from which the course originated, and goes on to describe further developments resulting from this.

Abstract number: 188
Presentation type: Poster
Poster number: P79

Reflections: District Nurse Case Studies following Palliative Care Education Course

Cath Baldry, Terence Burgess Education Centre, Southport, GREAT BRITAIN

One of the recommendations of NHS Cancer Plan 2000 U.K. was to increase the numbers of home cancer deaths. To achieve this district nursing teams were to be given the opportunity to undertake further palliative care education. The District Nurse Education programme in West Lancs, Southport & Formby undertook to give every district nurse the opportunity to update palliative care skills and knowledge, and thereby increase their confidence. All district nurses attended a 6 day course and completed a pre and post course questionnaire which measured the changes in their knowledge and attitudes. Some of the results of these are described and have been documented previously. Following the course nurses were also asked to write a short case study to reflect on the effect of the course on their daily practice by describing a situation or situations which either had been, or could have been, improved due to their increased knowledge and skills. These proved enlightening, and enriched the unanswerable daily documentation. This poster describes the case studies returned and the nurses’ descriptions of the impact of the education.

Abstract number: 189
Presentation type: Poster
Poster number: P80

INTEGRATED MULTIPROFESSIONAL TRAINING TO DEVELOP THE PALLIATIVE THERAPY NETWORK OF THE LOCAL HEALTH AUTHORITY IN REGGIO EMILIA

Rosanna Carbognani, Primary Care, Reggio Emilia, ITALY, Daniela Bicco, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Daniele Govi, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Pierantonio Magnani, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Cristina Pedroni, Reggio Emilia Health Authority, Reggio Emilia, ITALY

Background: Properly planned training is a determining factor in the development of a network of palliative care, due to its intrinsic potential to encourage sharing of objectives, with a view to developing functional teams, creating a common language and discussing the problems faced by professionals. In our context, palliative therapies are promoted as an area of expertise which is desirable for all professionals.
who deal with advanced stages of illness, not only oncology. Goals: a) Greater awareness of palliative treatments among professionals in different local contexts and hospital contexts. b) Development of a shared set of standard skills: Communication skills which allow professionals to establish a relationship of effective professional support to care for patients and families – Organizational skills based on team cooperation, through the acquisition of a conceptual/organizational model of reference, and the definition of a methodology that can also be used to analyze ethical questions – Technical skills, i.e. Hospice and home care. Methods: Awareness is encouraged, it is a continuous training. In addition to – an introductory course in palliative treatment, organized in four modules aimed at dealing with the themes of ethics, law and codes of conduct, clinical medicine and organization of services – various supplementary courses on special subjects throughout the year. The development of a common set of standard skills in services like Hospice and home care is pursued by planning various in-service training projects. The methods used are in keeping with adult learning processes. Evaluation: This structured training has encouraged or shall encourage the Local Health Authority (AUSL) and the other points in the network (public and private non-profits), and a cultural and professional development work visible in work methods and the re-orientation of service goals.

Abstract number: 190
Presentation type: Poster
Poster number: P81

Dutch experiences with the development of multidisciplinary palliative care education

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In the last decade palliative care has been recognised as an integral and multidisciplinary part of healthcare, not exclusively belonging to a specific medical field. This facilitated the further development of education in palliative care. Advanced courses for general practitioners, nursing home physicians and medical specialists were initiated. Essential aspects addressed in the courses are: symptom control, ethical dilemmas, communication and management of care. Experiences with these modules stimulated thinking about the possibilities for organising multidisciplinary courses. Questions regarding the design of such courses relate to the incorporation of concepts from different disciplines into a course that enhances competences for the individual and promotes a multidisciplinary approach in palliative care. Another question is whether the same learning methods can be used for different medical disciplines. During a workshop we want to address these questions and report our positive experiences towards the development of a multidisciplinary course. By sharing experiences and/or ideas with other experts we want to formulate recommendations for multidisciplinary advanced courses in palliative care.

Abstract number: 191
Presentation type: Poster
Poster number: P82

St. Christopher's Hospice (SCH) & King's College Hospital Epidural Service

Julie O'Neill, Nuffield Ward, London, GREAT BRITAIN, Ailish Carr, as above Sally Carr, as above Vicky Robinson, as above Sue Peat, King's College Hospital, London, GREAT BRITAIN

Introduction Hospices face increasingly sophisticated methods of pain control. An audit in 2003 showed that 6% (n=42) of SCH patients had invasive procedures for pain management. Nurses have to be competent and confident to care for patients with indwelling epidural catheters. To meet this small, significant demand, revised nurse training began in 2003. Aim The SCH Epidural Coordination Group (ECC) was formed in Jan 2004. Comprising of senior hospice nurses, an anaesthetist and a hospice physician it aims to oversee and coordinate the weekly anaesthetic round and to ensure nurse and medical training and support is maintained. Method Theory A mixture of workshop and hands-on supervision is available to clinical staff. The workshop covers anatomy and physiology, indications for intervention, drugs and equipment used, followed by practical demonstration. An ECC nurse works with the anaesthetist every Wednesday afternoon. Staff who have undertaken the theoretical training are then supervised in the care of patients having both continuous epidural infusions and those having one-off nerve blocks. Those yet to undertake training observe the procedure and are helped to care for the patient before and after. Results During the first 9 months of 2004 a total 64 (n=36) referrals made to the anaesthetist. 17 nurses are now competent in the care of epidurals. A further 11 have completed the workshop and are awaiting practical assessment. Discussion The ECC ensures a systematic, flexible approach to achieving and maintaining clinical competence. It is less in our caring for this small but significant patient group. The training pack and ECC ensures clinical competence for clinicians, thus minimising risk to patients requiring invasive analgesic techniques

Abstract number: 192
Presentation type: Poster
Poster number: P83

Palliative Medicine Training : Potential Tools for Assessment and Appraisal

Dwipat Jatta London, GREAT BRITAIN

Palliative Medicine training for specialist registrars in the UK is broader in its scope and emphasis than ever before. The trainee is expected to demonstrate his or her competency in a more formal manner than has traditionally been the case. This is in line with changes being made to training in all specialties. The use of formal appraisal tools for performance is well established in industry but less so for training in the medical profession. The ability of these tools to monitor and highlight areas suitable for training needs to be viewed cautiously and not as the only method for assessing, and education of trainers and trainees is vital before implementation.

Abstract number: 193
Presentation type: Poster
Poster number: P84

Forum of Oncology Nurses and Social Workers in the Community

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Rationale In Israel, in the last few years, the trend is towards health economy and the patients’ desire to stay at home. There has been a change in attitude towards the terminal of a result, more treatment is given within the community instead of hospitalization. In light of this change, new community services have been developed, including oncology patient services. Macabi Health fund gives palliative care to oncology patients throughout all stages of the disease, including physician-nursing treatment and psychology-social-family treatment and support by a multi-disciplinary team. Throughout the process, oncology patients need support by multi-disciplinary team. Their role is to ease the patient’s burden by support care and allowing the patient the right to an inevitable death hopefully. This team, also need support and accompaniment. The team must work together which is able to reach symptoms control, support-giving and possible solutions to the needs of the patients and their families and mutual support between the team and patients. As a continuation to the training of the nursing and social worker staff in oncology community health care, a decision was made to have a cooperative oncology forum. Goals: Staff support and accommodation. Opportunity to discuss issues, difficulties, dilemmas, obstacles in treatment of difficult situations and patients. Giving of information, tools and skills in dealing with extremely ill patients. Giving patients and families the opportunity for a holistic prospective towards the illness. Skill development for multi-disciplinary team work. Method : Two hour meetings, once every three months Contents of General Meetings Presentation and discussion of case studies and ethical dilemmas. Discussion of issues, difficulties and dilemmas dealing with treatment options and multi-disciplinary team involvement. Discussion of difficulties and dilemmas of the caregivers at the personal level.

Abstract number: 194
Presentation type: Poster
Poster number: P85

What 6th year medical students know about cancer pain treatment

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Introduction: In the curriculum at the Medical University in Wroclaw, palliative care is at 6thyear, at the end of the study. Material and Methods: All 6th year medical students were asked to fill, prior to the palliative care, anonymous questionnaires with 9 questions concerning cancer pain. Results: Only 54% of respondents knew the effects of morphine, 50% knew the WHO ladder. Only 29% stated that most often used route for morphine(mph) administration is oral, most patients’ care. As a result, morphine always cause addiction. 71% indicated constipation as main adverse effect of mph, but 21% is afraid of respiratory depression. Only 44% could named at least one weak opioid, 72%
know morphine and fentanyl as strong opioids, but as many as 48% estimated pethidine as a useful drug in chronic cancer pain. The students believe they had this information from the pharmacology, and met in the clinical practice during the study. Conclusion: The basic knowledge of the methods of cancer pain treatment among first-year medical students is very poor. It is necessary to improve and unify the process of teaching and introduces the problem of pain treatment as very important part of the curriculum.

Abstract number: 195
Presentation type: Poster
Poster number: P86

Clinical Ethics Committees in Germany – ethical, legal and practical reasons for the empirical failure of a concept of clinical ethics consultation

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A supreme Court decision in Germany ruled out processes in health care or concerning the end of life. Instead, such conflicts are – if necessary – to be referred to and resolved within the regular legal system [1]. As these issues, which are of specific importance to palliative care, have so far often been regarded as their ‘Clasical domains’, clinical ethics committees in Germany now happen to be deprived of a legal basis. This failure of a concept of clinical ethics consultation for legal reasons coincided with other serious concerns [2]: Ethical concerns focus on their lack of formal legitimation, the questionable independence of the committee and its’ members and an ideological unilateralism towards the confessions and notions of the health care providers, by whom these committees are implemented. Matters of practical concern are e.g. the necessary qualifications of the members of these committees, the quality of their teaching and counselling and the accessibility and compatibility of their activity [3]. Consequently, clinical ethics committees in Germany were empirically never ever accepted among any group of the involved professionals (e.g. physicians, nurses, jurists). Latest research revealed that even among those few hospitals, which so far claimed to have implemented such a committee, these were usually only “established” to gain a certificate – without in reality working at all [2]. Alternative concepts of clinical ethics consultation, e.g. clinical ethics consultation services (CES) run by interdisciplinarily trained physicians, especially with preferable expertise also on the field of palliative care, or the likewise interdisciplinarily development of guidelines on ethical and legal issues in medicine will play an increasingly important role in the future [2]. References: 1. Bundesgesetzblatt (BGH) (2003); Beschluss vom 17. März 2003: XII ZB 2/03 Supreme Court Decision on the “Luebeck Case” 2. M. Sträfing, B. Sedemund-Adib, P. Schmucker (2004); Klinische Ethik-Komitees in Deutschland – Von Ende einer wohlmeinenden Illusion (Clinical Ethics Committees in Germany – the end of a well-meaning illusion); BiPRAK 2004: 176 (Heft 5 / 2004).

Abstract number: 196
Presentation type: Poster
Poster number: P87

Finding palliative patients

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In the southeast of Sweden is an area called “Kalmar län”. There lives 250 000 people. The area is 240 km from north to south and 60 km from east to west. There are 3 hospitals run by “landstinget”. Landstinget also offers medical homecare performed by GPs and homecare nurses. The responsibility for social welfare lies within 12 different communities. There are also some private caregivers – mainly GPs. Many years ago a pioneer doctor started a palliative home care service around the major city in the south, Kalmar. A pioneer nurse developed the idea of palliative advisory team for the rest of the southern parts. Even though half of the population lives in the northern half of Kalmar län it was for a long time decided that it wouldn’t be cost-effective to have a palliative service. 3 years ago a palliative advisory team was set up after all in the northern part. Today it consists of 3 nurses full time and 1 doctor full time. This team is to work towards all kind of caregivers, landstinget, community and private. To educate the staff and also working as consultants are the two major missions. Now, 5 years later, we can see an increasing number of patients with an official diagnosis of palliative care. The service is asked for on a regular base and 40 nurses have got a special training in palliative care. The barrier between the hospitals and GPs is lowered but not completely taken away. In some parts there is also regular meetings with people from the church to learn and help each other. This team has been evaluated twice by the highschool in Kalmar and found being useful among patients, relatives and staff. This work will survive the coming bad economy which is supposed to reduce the costs in landstinget with at least 20 milj Euro. The team sees nowadays 250 new families per year. The rate of deaths at home is increasing mostly because the caregivers at home feel secure with the support they can get from such a team.

Abstract number: 197
Presentation type: Poster
Poster number: P88

Spirituality and Palliative Care for Clinical Pastoral Carers

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Spirituality in Palliative Care is a multi-professional domain with a rather wide body of applications. The authors taught an initial course of 120 hours with 22 clinical pastoral carers from both the Protestant and the Catholic faith traditions. The course was organized in a cooperation between the Academy for Palliative Medicine and Palliative Care in Munich and the Institute for Pastoral Continuous Education in Freising, both in Germany. To our knowledge, a curriculum for teaching Palliative Care and Spirituality to Clinical Pastoral Care workers does not exist so far. The course consists of theoretical teaching, current practice and provided available evidence, especially from the Anglo-American body of literature. Pastoral carers were invited to share what was experienced as difficult in their practice, when working with those who are at the last trajectory of their lives. Exercises were designed, to train appropriate bedside behavior, with the colleagues being the criterion for results and success of such training. Connecting to an ongoing study at the University in Munich on spirituality (Waster et al.) a pre-and post test, as well as a 6 month follow up study were performed. During the congress, results are expected to be made available, both as to results of the statistics, as well as to action research, performed by the participants at the end of the course. Teaching the course raised many questions as well as exciting results. We are especially seeking a discussion with the next generation of spiritualists as well as the general population about spirituality for (clinical) pastoral care workers and the topics considered as useful.

Abstract number: 198
Presentation type: Poster
Poster number: P89

Training in Palliative Care – Priority of Medical College – Plovdiv, Bulgaria

Petroniya Karamitrevra, Director of the college, Plovdiv, BULGARIA, Penka Kolchakova, College of Medicine, Plovdiv, BULGARIA, Nedalka Khristeva, College of Medicine, Plovdiv, BULGARIA

In today’s area of healthcare education in Bulgaria there is still lack of adequate training in palliative care in the sphere of accredited college education. The aim of the present study is to fulfill one essential lack in Bulgarian nurses’ knowledge and training in palliative care through introducing a new separate study subject “Palliative Care” at the College pre-graduate education of nurses. Methods: multi-factor analysis; historical and documental methods, statistical methods Results: The need of training of nurses in PC is proved through multi-factor analysis of the existing situation in the following directions: healthcare education in PC in Bulgaria; oncological, general health and demographic situation; healthcare equipment, economic and political situation; health and social care. We found out that there were only about 15 hours for training in PC distributed among other study disciplines in our study plans and programs for education of nurses in the last 30 years. We conducted an experimental sociological research among 238 of all 260 nurses on the course in our College during the period 2000–2001 and we found that according to their self-esteem they need to improve their knowledge about palliative care. In 2004 we conducted an experimental post-graduate education in palliative care for nurses, which were provided by the OSI in 2004 and we continue to work in the field of nurses education in PC. Conclusions: Having in mind the lack and the big necessity of qualified specialists for developing the palliative care in Bulgaria and on the base of the acquired experience we introduce a new study subject “Palliative Care” in the pre-graduate education of nurses at Medical College – Plovdiv since 2005.
his sufferings, his fears and their families troubles too. Tutors, in such delicate context, have the hard task to make aware the students, introducing them, gradually and not violently, in a personalised relationship with the patients. Helping an oncological invalid means understanding his embarrassment, his shames so that he could forget the disease. Clinical approach involves his fears and his feelings. We introduced the ‘Clinic Tutoring Project in Palliative Care’, to five didactic university co-ordinators of nursing sciences to the University of Central England, to meet this need. The Project is characterised by an introductory seminar, about the organizational general aspects of the Palliative Care Unit, and of his most important goal is giving the capability to the students to operate at peak possibilities in the Palliative Care domain. We have tried to facilitate their training with a handbook, an useful theoretical tool and with a ‘log book’ to fill in, during the training period and thanks to the tutor help. We have followed 88 students right now and we have got many important suggestions: 1. Achievement of the specific Palliative Care targets 2. Difficult and interesting moments 3. Tutor importance in Palliative Care. The student could be one of the patient’s point of reference and could play an important role during his sickness but he might have the right valours and motivation, an experience that only a tutor can help do.

Abstract number: 200 Presentation type: Poster Poster number: P91

Improving Information Giving Services in Cancer and Palliative Care

Increasing access to local and reliable cancer information and support is central to cancer policy in the UK (Secretary of Health, 2000). In order to deliver this a workforce is needed with skills in communication and information management (National Institute for Clinical Excellence, 2004). Interviews were conducted with current managers of information and support services. Their training needs were assessed and the need was identified for greater education and training in the management of information and communication skills required to support the users of services who demonstrated a range of information and support needs. Macmillan Cancer Relief, a UK-wide cancer charity has developed a partnership with the Information Studies Department at the University of Central England, to meet this educational need. Flexible access postgraduate education in Health Information Services Management has been developed, incorporating: Selection, management and development of information resources; Communication skills, to help people cope with the consequences of information received, using a multiple intellligence framework; Responding to the needs of diverse communities; Critical appraisal tools for health information. The result is an innovative programme drawing together knowledge from health and information studies to educate current and future workers in this field. References
Abstract number: 204  
Presentation type: Poster  
Poster number: P95  

**Education model of palliative care in Hungary**  
Katalin Hegedus, Dept of Bioethics, Budapest, HUNGARY, Zsuzsa Biro, Semmelweis University of Medicine, Budapest, HUNGARY

Introduction: In Eastern Europe 60% of the newly diagnosed cancer patients still die, however education on palliation is still at the periphery. Medical education has basically a somatic attitude, is paternalistic and has a treatment-oriented approach. Introduction of palliative care to undergraduate and post-graduate training might be helpful in changing attitude. Results: In undergraduate training the 30 hours course on palliative therapy organized for medical students and the 20 hours module in health care higher education (nurses, physiotherapists, social workers) is quite a novelty. However the post-graduate 40 hours basic and 40 hours advanced hospice trainings for health care workers are being successful for more than 10 years. Currently over 3000 people have attended on those courses. The model which is exemplary even in Eastern Europe is completed with one-year hospice specialist nurse education and co-ordinator trainings. The poster presents the teaching programs and their connection points. Conclusions: In the future, palliative inpatient centres to be established at universities require medical education model.

**Abstract number:** 205  
**Presentation type:** Poster  
**Poster number:** P97  

**Desire for death near the end of life: The role of depression, anxiety and pain**  
Kyriaki Mystakidou, Pain Relief and Palliative Care Unit, Athens, GREECE, Barry Rosenfeld, Dept. of Psychology, Fordham University, Bronx, U. STATES, Efi Parpa, Pain Relief and Palliative Care Unit, Athens, GREECE, Emmanuela Katsouda, Pain Relief and Palliative Care Unit, Athens, GREECE, Eleni Tsilika, Pain Relief and Palliative Care Unit, Athens, GREECE

Objective: This study evaluated the desire for hastened death in advanced cancer patients to determine the relationship to psychological distress. Patients and Methods: 120 terminally ill cancer patients were surveyed from June 2003 to November 2003 at a Palliative Care Unit, in University of Athens, Greece. The Greek Schedule of Attitudes toward Hastened Death (G-SADH), the Greek Hospital Anxiety and Depression Scale (HADS) and the Greek Brief Pain Inventory (G-BPI) were administered. Results: Significant correlations were seen between desire for hasten death with G-BPI (r=0.279, p<0.002) as well as with G-HADS (r=−0.326, p<0.0005). The strongest correlations were observed in HADS-anxiety (r=0.605, p<0.0005), and HADS-depression (r=0.636, p<0.0005). Results of multiple regression analyses showed that current pain (B=−0.583, p=0.0005) and anxiety (B=0.583, p=0.0005) were significant predictors of G-SADH. In a further multiple regression analysis, HAD-depression (p<0.0005) and age (p=0.034) provided independent and unique contributions to the prediction of desire of hastened death.

Conclusions: Depression and anxiety (HAD-Scales) appeared to have a statistically significant relationship with desire for hastened death. Depression and current pain were the strongest predictors of desire for hastened death in terminally ill cancer patients. Effective management of psychological and physical symptoms seemed to be an important aspect of adequate palliative care in order to reduce the desire for hastened death.

**Abstract number:** 206  
**Presentation type:** Poster  
**Poster number:** P98  

**Palliative care in cancer and other chronic diseases: predicting supportive care needs and life expectancy – patients know best**  
Louise JONES, Mental Health Science, London, GREAT BRITAIN, Shamsul Shaml, Royal Free Hospital NHS Trust, London, GREAT BRITAIN, Martin Blanchard, Royal Free And University College Medical School, London, GREAT BRITAIN, Adrian Tookman, Royal Free Hospital NHS Trust, London, GREAT BRITAIN, Michael King, Royal Free And University College Medical School, London, GREAT BRITAIN

Background: There is a recognised need for supportive care for patients with non-cancer illnesses. Difficulties in predicting prognosis are barriers to early referral to palliative care services. Referrals depend on health professionals and patients recognising when it is appropriate. Aim(s): To compare in patients with end-stage cancer and non-cancer illnesses: 1) the accuracy of patients’ and physicians’ estimations of prognosis 2) patients’ and physicians’ perceptions of the seriousness of the illness and needs for supportive care. Method(s): Twenty patients with advanced non-malignant disease (heart failure, chronic obstructive pulmonary disease and renal failure), 20 patients with advanced cancer, and 36 physicians were involved in a prospective cohort study. Patients’ and physicians’ estimates of health status, palliative care needs, prognosis and patient survival at six months was recorded. Results: Non-cancer patients perceived that they had similar needs for supportive care as cancer patients although the latter were much less likely to survive. All patients were willing and able to estimate their own life expectancy. Cancer patients correctly estimated a poorer prognosis than patients without cancer. In contrast, although physicians made little distinction in palliative care needs between patients with and without cancer, they were imprecise in their estimations of prognosis and were overly pessimistic in non-cancer patients. Conclusions: It is important that physicians with advanced non-cancer illnesses important end-of-life questions, which may be helpful in planning their future care. Patients are accurate judges of their health status and life expectancy. Non-cancer patients have similar needs for supportive care as cancer patients.

**Abstract number:** 207  
**Presentation type:** Poster  
**Poster number:** P99  

**COMFORT AND CONSCIOUSNESS: BENZODIAZEPINE PRESCRIBING IN THE LAST WEEK OF LIFE IN A SPECIALIST PALLIATIVE CARE UNIT**  
Rachel Thorp, PALLIATIVE MEDICINE, GLASGOW, GREAT BRITAIN, KATHLEEN SHERBY, THE AYRSHIRE HOSPICE, AYR, GREAT BRITAIN, MIRIAM TADJALI, THE AYRSHIRE HOSPICE, AYR, GREAT BRITAIN, ROBERT RUSSELL, UNIVERSITY OF PAISLEY, PAISLEY, GREAT BRITAIN

The purpose of this study was to review prescribing of benzodiazepines in the last week of life of patients in a 20 bedded specialist palliative care unit; to compare prescribing between patients who remained conscious throughout and those who became unconscious (defined by the use of the Comfort Assessment Tool for the unconscious patient) at some point and to determine levels of consciousness and comfort in the latter. A retrospective case note review found that 10% of the 100 consecutive deaths was carried out. Admissions of less than 7 days excluded. Data was collected on daily opioid dose; benzodiazepine prescribing (daily dose, indicated indications). The number of patients unconscious; length of time from starting Midazolam infusion, becoming unconscious and death; daily discomfort (presence of 7 possible signs and unconsciousness scores (modified GCS) of unconscious patients. Of 100 patients: 39 males (mean age 70). Unconscious patients: 64: 28 males (mean age 68). Conscious patients: 36: 11 males (mean age 78). 92 patients were prescribed Midazolam, (81% of conscious, 93% of unconscious) often as an infusion. The most frequent indications were agitation, dyspnoea and anxiety. Mean length of time from starting a Midazolam infusion to becoming unconscious: 2 days (range 0-19days, mean 2.4) patients unconscious to death: 29hrs (median 52hrs). Median daily dose of Midazolam: unconscious: 15mg; conscious: 10mg. GCS scores: range 3-14. Max: GCS score: 1. From this study it can be seen that most patients remain conscious until the day before death. Most patients are prescribed Midazolam at some point in their life. Unconscious patients were more likely to be prescribed Midazolam and at higher doses. The wide range of doses reflect prescribing which is tailored to the individual although median doses in unconscious patients remained stable. Unconsciousness levels fluctuated greatly. Comfort among unconscious patients was high.
Guiding informal carers of terminal cancer patients by specialized district nurses

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Introduction: Informal carers are pivotal in the health care system. Studies indicate that informal carers need information and support, particularly with regard to the patient’s situation and their role as a caregiver. However, these needs are often not met. Within the scope of the present study, district nurses will be trained to guide and support informal carers of terminal cancer patients, since taking care of this patient category is burdensome for informal carers. During four home visits over a period of six weeks, information and guidance are provided regarding the patient’s situation (e.g., medical condition, symptom management) and the position of the informal caregiver (e.g., health, time management). This will be done partly by a standard programme, partly with reference to specific needs of the individual caregiver. In the present study, the effects of this guiding programme will be examined. Method: A randomized clinical trial (RCT) will be conducted among 90 informal carers of terminal cancer patients who stay at home and have a life expectancy of less than four months. Informal carers who are part of the control group receive standard care. Informal carers in the experimental group will be guided by specialized district nurses, in addition to standard care. All informal carers participating in the study will be asked to fill in a questionnaire twice: at entry of the study, after which random assignment will take place, and eight weeks afterwards. The questionnaire concerns aspects of the care and support being offered to them and to the patient they take care of. Other outcome measures are the burden informal carers perceive and their quality of life. Results: Data collection will start in December 2004. Some preliminary results will be available in April 2005.

Abstract number: 210
Presentation type: Poster
Poster number: P102

CEF: Promotion of End of Life Culture


The Committee for Ethics at the End of Life – Floriani Foundation (CEF) was founded in Milan in 1991. CEF is entirely devoted to the examination of issues concerning the end of life, stimulating people as well as institution to consider such issues. Immediately at the beginning, CEF was asked to fill a sort of manifesto entitled Ethical Principles in Palliative Care, which had a good impact, becoming a reference point in the Italian discussion on the matter. In 1997 CEF presented the Charter of Rights of the Dying, giving a strong impulse to the new attitude which brought to the legislation on palliation enacted in Italy in 2001. After the charter, an analytic comment was published in order to clear possible doubts concerning controversial issues. Such a commentary is directed to professionals as well as to general public and it promoted a good discussion. CEF is regularly considering real cases arising at the end of life, which are presented by professionals attending the Italian School of Palliative Medicine. A selection of the best cases was published in a book: Comitato Etico Fondazione Floriani, Alla fine della vita. Casi e questioni etiche, Guerini e Associati, Milano 2001, pp. 160. New programs are going to be presented and the CEF will be delighted to present some of these prospects directly at the Congress. Committee for Ethics at the End of Life Floriani Foundation President: Patrizia Borsellino, PhD (philosopher of law) Deputy-President: Sergio Fucci, PhD (Magistrate) Members: Giorgio Di Mola, MD (Medical anthropologist) Michele Gallucci, MD (Palliative care) Simonetta Lagorio, PhD (Non-profit organization executive) Maurizio Mori, PhD (Bioethics) Dario Focar, PhD (Jurist) Franca Porciani, MD (Scientific Journalist) Franco Toscani, MD (Palliative care)

Abstract number: 211
Presentation type: Poster
Poster number: P103

The Social Representation of ‘Good’ and ‘Bad’ Deaths in an English Hospice: findings from an embedded multiple-case study

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It has long been acknowledged that the bereaved can be affected in positive or negative ways by the quality of a loved one’s death, but little is known about how this applies to health care professionals use when evaluating the quality of death as opposed to life, or discussing this with a patient’s family. These are likely to have lasting impact because they give rise in response to this socially and culturally constructed event which may have importance beyond their immediate social and psychological loss, but few have analysed the role of health care in defining this event for the bereaved. This study examined the social representations made by health care workers when defining a death as ‘good’ or ‘bad’ using an embedded multiple-case study design in an English hospice which incorporated multiple data collection methods including focus groups, informal and formal interviews, participant observation and documentary analysis over a six month period. Whilst one cannot generalise from this case-study, the data did suggest that hospice workers defined what was a ‘good’ death, and to a large extent, predictable criteria when evaluating the quality of a death such as the absence of pain or physical symptoms; but there was marked disagreement among the professionals about criteria such as spiritual preparedness or acceptance of death. Control and autonomy featured highly in their descriptions of ‘good’ deaths, but these were regarded as being complex when exercised to ‘excess’ by clients and their families which suggest that hospice workers may occasionally be subject to cognitive, as well as philosophical dissonance when caring for dying patients. The study also found that there was little construct permanence between hypothetical and literal cases of ‘good’ and ‘bad’ deaths, and a tentative hypothesis for this variance is offered.

Abstract number: 212
Presentation type: Poster
Poster number: P104

Ethnographic review and analysis of literature written by people facing death from cancer and other types of disease, covering the period since 1950

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Aims: To analyse a sample of narratives written since 1950 by people knowing they were facing death as a result of cancer and other illnesses in order to compare experiences and show how these relate to wider changes in practice in end of life care. Methods: A bibliography search of libraries, archives, journal and internet sources located English-spoken literature including books, poems, newspapers, journal articles, diaries, internet postings of writings by different authors since 1950 was reviewed. Discussion: Over the last 54 years there have been changes in both the volume of available literature and patterns of writing about end of life. With few writings in the 1950s and 60s, from the 1980s there was an increase in books and journal articles. The 1990s and 2000s saw a sharp rise in all types of literature but unprecedented internet communications. Only a tiny proportion actively reports end of life experiences. Therapeutic benefits in writing are reported combined with the purpose of sharing the story. There is a clear sense of social needs when dying, along with issues of communication with medical staff, spiritual needs and religious spiritual aspects of dying. Differences were found in the nature and style of writing between cancer and other illnesses.

Abstract number: 213
Presentation type: Poster
Poster number: P105

Culture and Religion at the End of Life: First Generation Moroccan Elderly in Antwerp, Belgium


Background: In palliative care and end of life (EOL) ethics, cultural and religious issues often receive insufficient attention. It is especially true for the religious and cultural values and issues of ethnic minorities, which leads to unmet palliative care needs and ethical problems that are often not managed properly. Although Islam has become the second largest religion in most European countries including Belgium, and this religion has a powerful impact on the lives and attitudes of its...
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Posters

Description of patients’ and carers’ perceptions in relation to engaging in discussions about advance care planning.

Abstract number: 215
Presentation type: Poster
Poster number: P107

Benchmarking care of the dying with the Liverpool Care Pathway (LCP)
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The LCP is a multi-professional document that promotes the delivery of appropriate care in the dying phase. It can facilitate the clinical governance agenda by providing demonstrable standards and outcomes of care and is currently incorporated in the cancer collaborative project including a cancer network in the north west of England. A benchmarking exercise was recently undertaken using the LCP to facilitate the evaluation of care delivered to dying patients and their carers across the network with the specific aim of: (1) identifying the current LCP use and to provide a meaningful comparison between organisations within the hospice, hospital and community sectors. 24 organisations were invited to contribute 20 consecutive pathway results suggest that good practice exists in all sectors, particularly for goals concerned with anticipatory prescribing and discontinuation of inappropriate interventions. However, data from hospital samples generally has a higher proportion of missing data for the majority of pathway goals. We can conclude that the pathway is a useful tool providing meaningful comparative data in different areas of care. Participation organisations will now come together to share good practice to facilitate further improvement.

Abstract number: 216
Presentation type: Poster
Poster number: P108

A qualitative evaluation of hospice staff views of the Liverpool Care Pathway (LCP)
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Background: The Liverpool Care Pathway (LCP) is a multi-professional document that provides an evidence-based framework for the delivery of care during the dying phase. Originally developed to facilitate holistic care practice from Specialist Palliative Care into the acute sector, the document was then introduced into the Marie Curie Hospice, Liverpool in 1997. A focus group study of nursing staff recently undertaken in the acute sector identified the usefulness of the LCP in the delivery of care in the dying phase. However, no work has yet been undertaken around the perspectives of hospice staff. Aims: To explore doctors’ and nurses’ perceptions of using the LCP within the hospice setting. Method(s): A purposive sample of 10 nurses and 5 doctors working within the hospice for at least 6 months was selected. This was designed to represent staff working at various grades within the organisation. Individual interviews (audio or video recorded and transcribed) lasting between 30 mins and one hour were undertaken. A semi-structured topic guide was used to enable the identification of salient themes Results: A total of 12 interviews were undertaken (9 nurses, 3 doctors). The LCP was generally regarded by both groups as a useful and important document for the delivery of competent and appropriate care to dying patients and their carers. Its usefulness as a teaching tool for new/inexperienced staff was also highlighted. Perceptions of hospice staff and staff from the acute sector differed in subtle ways. Conclusions: The pathway was generally regarded favourably by both doctors and nurses in this sample.

Abstract number: 217
Presentation type: Poster
Poster number: P109

Meeting existential needs at the end of life: a systematic review of interventions
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Introduction: Patients’ existential needs in palliative care are being increasingly recognized such as the importance of ‘talking about the meaning of death’ and ‘knowing that life has meaning, purpose and has been productive’. Less is known on effective ways of addressing this palliative care goal. Aims: To explore the available evidence on the effectiveness of existential interventions with terminally ill patients. Method: Systematic review – articles were searched from MEDLINE (1966–2004), EMBASE (1980–2004), CCTR, psychINFO (1972–2004), SCI (1956–2004), CINAHL (1982–2004), and AMED (1985–2004).
Inclusion criteria: adult patients facing a terminal or advance life-threatening illness. Exclusion of a non-pharmacological intervention explicitly addressing existential issues; outcomes of anxiety or depression. The quality of the studies was assessed using a modified version of the Hopkins List criteria and the quality rating system of the Cochrane Collaboration Depression, Anxiety and Neurosis Review Group. Results: Of a total 231 returns, 4 studies met the inclusion criteria. There were methodological limitations that might compromise the generalisability of findings (e.g., all studies were group interventions and three were conducted with women with breast cancer). The evidence available suggests a general positive impact of existential interventions on patients’ psychological distress, although effects of factors may affect the effectiveness of the intervention (e.g., closeness to death). The most distressed patients appear to derive maximum benefit from these interventions. Conclusions: Our findings show that although research on existential therapies is still in an embryonic stage, these appear to have the potential to improve outcomes in palliative care. Further research requires improved methods and development of relevant and validated measures for domains such as existential well-being.
Abstract number: 218
Presentation type: Poster
Poster number: P110

Hospice End of Life Pathway (H.E.L.P.) – Development of a modified ICP for Hospice/Special Palliative Care

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Introduction The application of Integrated Care Pathways (ICP) has become widespread in medicine. In hospital settings and particularly in palliative care, the Liverpool Care Pathway (LCP) for the dying patient (Ellershaw et al) has been commonly adopted. Aim To monitor the implementation of the LCP in a hospice setting, and then introduce and review a revised LCP called the Hospice End of Life Pathway (HELP) specifically designed for use in a Specialist Palliative Care Unit / Hospice, catering for the potentially more complex patient problems and accounting for specialist skills of the staff. Method Retrospective review of 30 consecutive patients’ LCP documentation scrutinising accuracy of form completion, initiation assessment goals and pain/comfort measures. LCP documentation was then entirely redesigned both in terms of content, guidelines and layout (gate leg folder design allowing clear sight of all relevant records). HELP formed a stand alone document comprising all necessary paperwork for all disciplines. The audit cycle was completed with 30 patients using HELP. Results Patient demographics were similar between the two groups. However a greater accuracy of data recording was shown in HELP. Patients were commenced on HELP earlier and had an improved ‘satisfactory outcome’ as defined by < 2 variances per 24 hours after a diagnosis of presleeping (2.54 more medications, CI 2.20–2.88; p<0.001). There was a decrease in MCMC (1.05 decrease, CI 0.82–1.26; p<0.001). There was a more marked increase in SSN in patients admitted to hospital close to death. Patients with better performance trended towards using more SSN. The greater number of medications taken by elderly patients with a diagnosis of MCMC. Shorter duration of survival was seen in patients with lower performance status and those taking larger numbers of MCMC. Conclusions: Although MCMC are reduced, more work is needed to assist practitioners in the appropriate rationalisation of medications to focus on helpful treatments while minimising harm from polypharmacy.

Abstract number: 220
Presentation type: Poster
Poster number: P112

Death in the Emergency Department: practices and ethics

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Death in the Emergency Department is a reality. In French hospitals, it generally occurs in the short term hospitalisation unit linked to the Emergency Department. The primary aim of these units is to welcome emergency patients waiting for being allocated a bed in an hospital ward or needing just monitoring watching for a short period. In France, the number of deaths in these units is quite high (the third higher after intensive care unit and oncology or internal medicine ward in our study). However these units are neither meant, nor seem to be organized, to provide palliative care. There is a gap between the goal to provide rapid and temporary acute care and the reality of end of life. The aim of this study is to explore care and support practices to dying patients and their relatives and to analyze the caregivers’ feelings about their work. Various methodologies have been combined to study death in two French Emergency Departments (one in the west France and one in the suburbs of Paris); an epidemiological retrospective patients’ records analysis, sociological observation and focus groups sessions carried out with a psychodynamic work approach. We will present two different types of end of life trajectories and explore the major issues concerning care management: First : how to identify occurrences of end of life period and, more generally, to detect the possible cases of withholding treatment Second : decision making process to withhold or withdraw futile care Third : how to find an hospital bed for patients and their relatives TIME FOURTH : how to develop early team work with the palliative care team to provide continuity and quality of care This study underlines the necessity of defining a specific multidisciplinary reflection on the place of death not only in the emergency departments faced with this serious and frequent event but also for the acute hospital ward under drastic economic constraints.

Abstract number: 222
Presentation type: Poster
Poster number: P114

Posters

Interviews on death

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Abstract Objective: This study is done to examine the ideas of elderly individuals on life, death and treatment at the end-of-life in order to understand what the basis for those wishes and desires are. A qualitative study. Participants and setting: Eight Icelandic individuals 70 years old or more interviewed at their homes. Results: All participants had a history of a good life despite experiences of death and enjoyment of life, an accepting attitude towards death was evident. Everyone agreed on the necessity to limit life prolongation if there was no hope of recovery, more mental and physical ability compromised, no possibility of living a good life and being a burden to others. The participants based their attitudes toward end-of-life treatment on the...
likely outcome, their age and health, views on life and death, relationship with others and experience. Discussion: A model of end-of-life decision making between a physician and a patient is presented: The discussion takes place within an ethical and cultural framework, which is sometimes discussed. Physicians give information on diagnosis, prognosis and treatment options. Patients evaluate the information in view of their health and age, views on life and death, relationship with others and experience. Conclusion: Elderly patients evaluate treatment options in view of their own age and health, views on life and death, relationship with others and experience.

Abstract number: 223
Presentation type: Poster
Poster number: P115

Treatment Aspects of Spiritual Approaches that Enhance Patient–Clinician Communication
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The spiritual beliefs and practices of both professionals and their patients are pivotal and important resources in coping with chronic and terminal illness. Spiritual approaches, e.g. prayer and meditation, are an understudied aspect of patient–clinician communication. The purpose of this study is to understand how spiritual approaches and other factors influence the interaction with palliative care patients. Two samples (total N=327) of American social workers were surveyed regarding their use of spiritual approaches in practice. Linear discriminate analyses were performed where a categorical variable defined the set of dependent variables. The five dependent variables included working with clients who had: cancer, HIV/AIDS, struggles with death and dying, physical illness and disability/handicap. A total of 21 independent variables were screened as possible predictors that included variables such as theoretical orientation, religious preference, the respondents' personal issues or struggles with health, mental health and other variables. All predictors below were found to be significant at p<.001. Predictors in working with Cancer patients were: guided imagery/visualization, the therapists' self-reported mental and physical illness (56% – classified); HIV/AIDS: use of yoga, free-writing, etc., any physical illness (58%); Struggles with death/dying: reading and/or recommending spiritual or religious materials and the use of yoga, free-writing, etc. (58%); Physical illness: use of guided imagery/visualization, exploring religious and spiritual elements in dreams, use of yoga, free-writing, etc. (61%); and Disability/handicap: self-reported physical illness and situational stress, and use of yoga, free-writing, etc. (58%).

Study results support the use of spiritual approaches that may foster patient-clinician communication.

Abstract number: 224
Presentation type: Poster
Poster number: P116

‘Being Heard’: Engaging patients and families in designing, developing and evaluating palliative care in the UK
Anita Sargeant, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN, David Olivieri, St. Christopher's Hospice, London, GREAT BRITAIN

Background: UK government policies advocate that patients and their families should be involved in the design and evaluation of health care services. Aim: –To identify how palliative care service providers across the views of patients and families; –To explore how patients and families experience this process.Method: A purposive sample of 20 patients and 8 caregivers who had used or were currently using cancer or palliative care services were recruited. In addition 17 health professionals and 5 academic experts were contacted. Semi-structured interviews exploring the various methods used by service providers to obtain patient and carers opinions. Patient and carers experiences of participating in meetings were investigated and all parties were asked how participation could be improved and how its impact could be assessed. Results: –Patients in remission from cancer or attending palliative day care are those who are most commonly asked to participate –Forum meetings are commonly used to obtain patient and carers opinions. –Participants were motivated by a desire to give something back to the community and to help others –Patients at the end of life are less likely to have their views and opinions sought –Carers express different views to patients in a number of key areas -Dedicated time and skill is required to access patient and carers opinions and to utilise these in undertaking service change.Conclusions: –Often only the views of easily accessible patient and carers are sought –Opinion is dominated by the experiences of people attending palliative day care or by articulate patients who are in remission from cancer –The opinions of the very ill and dying are neglected –Creative approaches, dedicated time and effort are required to access the views of the very ill to ensure palliative care services and policies meet the needs of those at the end of life.

Abstract number: 225
Presentation type: Poster
Poster number: P117

Meaning of Life among Persons with Advanced Cancer
Susan Pope, Education, Bern, SWITZERLAND

The purpose of this study was to explore meaning of life among advanced cancer patients. Drawing on the philosophies of Heidegger and Gadamer, a qualitative design using a hermeneutic existential phenomenological approach to research was used with a sample of 12 participants, purposively selected from an oncologist’s practice and an in-patient clinic in German-speaking Switzerland. Interviews were conducted in the patients’ homes and/or in the respective clinics. The results suggested three divisions: (a) meaning in life – a conditional experience described as meaning, (b) meaning of life – an unconditional experience of ultimate meaning, and (c) a division in which meaning had little or no place within the patient’s frame of reference. Much work has been done to central symptoms associated with end-stage disease; however, few studies have addressed meaning of life in advanced cancer patients. Through the present study the researcher was able to step inside the mind of the participants and share a degree of their experience. Though more work needs to be done in this area of research, the findings suggest numerous implications for clinical practice, themes that emerged: dignity, coping, hope and hopelessness, sense of belonging, mission and commitment, and to the current policy issues of physician assisted suicide and euthanasia.

Abstract number: 226
Presentation type: Poster
Poster number: P118

How do Norwegian physicians define the term ‘terminal’?
Lotte Røgg, Dept. of Oncology, Oslo, NORWAY, Peter Kjaer Graugaard, Dept. of Behavioural Sciences in Med. University of Oslo, Oslo, NORWAY, Jon Håvard Loge, Dept. of Behavioural Sciences in Med. University of Oslo, Oslo, NORWAY

Background and Aims: The management of patients with life threatening illness is governed partly by the expected prognoses of the patient. There exist no clear definition of the term ‘terminal’, yet it is widely used in clinical practice. The present study explores Norwegian physicians’ understanding of how many weeks a terminal patient has left to live. Methods and Materials: A national representative survey was carried out, with 957 (60%) of the 1605 invited participants answering this actual question that was part of a larger postal survey. Results: Norwegian physicians greatly vary in their understanding of the term ‘terminal’, with a range of estimated weeks to live from one to twenty-six. The median estimation is two weeks survival, but there are differences between clinical specialties. More than twenty percent of the general practitioners (GP), psychiatrists and public health specialists define ‘terminal’ as having more than four weeks to live. Twenty percent of hospital-based clinicians define ‘terminal’ as having less than a week to live. Conclusion: Norwegian physicians greatly vary in their understanding of the term ‘terminal’. Some of the differences can be explained by differences in clinical practice. With understanding of terminality ranging from one to twenty-six weeks among physicians chances are that the planning of an end of patients’ last few days may come as a surprise to both patients and carers. The lack of a commonly agreed definition of terminal among physicians may have implications for the treatment of individual patients and the planning of health care services towards the end of life.

Abstract number: 227
Presentation type: Poster
Poster number: P119

Local impact of the Liverpool Care Pathway on patient care and its documentation in the dying phase. Local experiences of nurses and doctors delivering the LCP
Susan Crabtree, Royal Wolverhampton Hospitals Palliative Care Team, Wolverhampton, GREAT BRITAIN

This study uses a multi method approach to evaluate the use of the Integrated Care Pathway for the Last Few Days of Life in an Oncology Ward. The methods were stages of implementation Document Analysis with n=17 completed pathways, ongoing analysis with sub-sample of n=7 patients that had been receiving care for more than 3 days. Qualitative methods were Focus Group Discussion with n=15 (nursing team members) and Semi-structured Interview with n=1 medical member of the team. By comparing pre and post document analysis trends for improved documented care were identified. These were rationalisation of non-essential care for more than 24 hours peri death, prevention of drugs in anticipation of end-of-life symptoms and discontinuation of both nursing and medical intervention. Communication with regard to religious and spiritual needs of
Sedation of the patient in palliative homecare: The support from a multidisciplinary homecare team of a network in palliative homecare

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Introduction

Palliative sedation is the intentional administration of sedatives in the doses and combinations required to lower the consciousness as much as possible of the terminally ill patient in order to adequately control refractory symptoms. It is an acceptable treatment in medical decision-making regarding life-end were in View of this the network for palliative homecare gives advice and support to all involved carers in this field.

Aims

To make palliative sedation in the home possible. Support of both patient and all home carers during and after palliative sedation process. Giving of clear and understandable information regarding the patient, their family and those in the immediate environment.

Conclusion

Thanks to the support of the nursing expertise of the multidisciplinary support-team palliative sedation in homecare aims to apply quality and increase the possibilities of care-comfort.

Abstract number: 228
Presentation type: Poster
Poster number: P120

When Culture and Family Clash with Palliative Care

Sharon Kendall, La Trobe University, Bendigo, VICTORIA, AUSTRALIA

A large phenomenological study into the effects of the nurse–patient relationship on clinical learning in Cancer and Palliative Care was undertaken in three countries. The participants, 392 nurses, were asked to provide a vignette about a care episode from their practice of a patient with a diagnosis of cancer. The participants were asked to discuss the impact of this encounter on clinical learning and clinical practice. Some of the data collected in Hong Kong, dealt with conflict related to end of life issues and the right to decide care issues. Most commonly the conflict revolved around the wishes of families taking precedent compared to the rights of the patients. Family is of great importance in Chinese society and there still remain significant misconceptions about Cancer and Palliative Care. Other conflicts centred on nurse–physician relationships and a perceived lack professional respect for nurses’ opinions. In Hong Kong medical dominance is the norm. Nurses were required to participate in resuscitation efforts, for patients with end stage disease, against the patient’s previous requests. Some nurses struggled with caring for dying patients, who had never been told their diagnosis. Participants stated they believed firmly in patients’ rights and their own responsibilities to respect the patient’s wishes. They also had to juggle their medicine goals and current theoretical perspectives on the patient. In Hong Kong the word ‘carer’ is used by others compared to the ‘person’ (86,5%) and ‘judging how much sedation’. The identified care episode was a ‘burden’ and carers as victims of circumstances. The extent to which current palliative care policies in the UK recognise the separate needs of families as opposed to the preferences and needs of patients in planning and managing end-of-life care will be discussed.

Abstract number: 230
Presentation type: Poster
Poster number: P122

End of life communication: experiences and views of Pre Registration House Officers


Following the recommendation of the General Medical Council in Tomorrow’s Doctors (1993) sessions of communication skills, ethics and law are now required at most medical schools in Britain. In this paper we present the results of a survey among Pre Registration House Officers (PRHOs) regarding their experiences, knowledge and views with respect to the disclosure of bad news and different aspects of end of life communication. All PRHOs had received training in communication skills as well as in ethics and law applied to medicine. 104 PRHOs completed the questionnaire (response rate 78%). 95,2% of the junior doctors believe that patients should be informed about a serious life threatening illness. 78% have initiated breaking bad news to a patient at least once. 96,2% indicate that they have discussed bad news with the patient. 44,2% of the PRHOs have discussed with patients about a DNR order and 68,3% have discussed this issue with relatives. ‘Having discussed bad news with the patient’ (88,4%) and ‘judging how much information patients want’ (76,9%) are cited most frequently by the PRHOs as factors.
causing difficulties when discussing bad news with patients. The findings will be analysed on the background of strengths and weaknesses of the undergraduate training. In addition factors, other than the training of medical students which may be helpful for the implementation of good clinical practice of bad news and end-of-life communication will be discussed.

**Abstract number:** 233  
**Presentation type:** Poster  
**Poster number:** P125

**ATTITUDES TOWARDS EUTHAnASIA AND PHYSICIAN ASSISTED SUICIDE AMONG PAKISTANI DOCTORS**

Syed Qamar Abbas, Palliative Medicine, Hastingswood, GREAT BRITAIN; Syed Zafar Abbas, Muhammad Medical College and Hospital, Mirpurkhas, PAKISTAN

Objectives: In 2002, The Netherlands became the first country to legalise Euthanasia. After this, most of the world is discussing the attitudes towards Euthanasia. However, most data about the perceptions on Euthanasia is generated in the western world. We assessed the attitudes of Pakistani doctors towards Euthanasia and Physician Assisted Suicide with the help of case studies questionnaires.

Methods: A questionnaire was developed discussing two case studies. These case studies explained one patient each of Motor Neurone Disease and widespread malignancy. It was distributed, by hand, to a convenience sample of doctors from all specialties, who were trained in Pakistan with most of them still working in India. The distribution and collection of questionnaires was carried out within six months. Analysis and Results: 52/100 (52%) doctors returned the questionnaires. They belonged to Muslim (47) or Hindu (5) religions. The mean age of doctors was 42.8 (26–66) with mean experience 15 (2–40). 8/52 (15.3%) doctors agreed for Euthanasia. Their age of doctors was 42.8 (26–66) with mean experience 13.3 (3–30). Conclusion: Although there is understanding of Euthanasia and Physician Assisted Suicide, minority of doctors support the idea. The doctors supporting Euthanasia are likely to be males and belong to slightly less mean age and experience group.

**Abstract number:** 234  
**Presentation type:** Poster  
**Poster number:** P126

**INNOVATION IN ETHICAL GOVERNANCE: THE FORMATION OF A CLINICAL ETHICS COMMITTEE FOR A HOSPICE**

NIGEL SYKES, MEDICINE, LONDON, GREAT BRITAIN; VICKY ROBINSON, ST CHRISTOPHER’S HOSPICE, LONDON, GREAT BRITAIN

Introduction Research ethics committees are well established but clinical ethics committees are a newer concept. In 1996 the UK had 3 clinical ethics committees (CEC). By 2003 this had increased to 32 all based in National Health Service (NHS) hospitals. The St Christopher’s Hospice Clinical Ethics Committee Palliative care poses many ethical problems and is under increasing public scrutiny regarding issues such as sedation, rehydration and euthanasia. In response St Christopher’s Hospice set up the first hospice based CEC in 2003. The St Christopher’s CEC aims to: · Provide guidance to hospice clinicians in making decisions when ethical issues make the correct course of action uncertain. · Advise on hospice policies and protocols for ethical issues. · Be an educational resource on ethical issues. The CEC’s membership includes nursing, palliative medicine, social work, chaplaincy and psychiatry. External membership comprises an academic ethicist, an academic lawyer and a palliative physician qualified in medical ethics. Full meetings of the CEC occur quarterly but a mechanism exists for virtual meetings in urgent circumstances. Experience to date The Committee has now met five times. Presented cases have involved duress, suicide pacts, home discharge, and advance directives. The CEC has also new models in resuscitation and advance directives, advised on the legal implications for practice of a recent English court case and considered the ethical use of user feedback data. The CEC bases decision-making in clear academic, legal, philosophical and clinical thinking, and therefore minimises the risk of inappropriate outcomes for patients, families and the public. Already it has an established place in the hospice’s governance system and is becoming a valued resource for hospice staff.

**Abstract number:** 235  
**Presentation type:** Poster  
**Poster number:** P127

**Advance directives and palliative sedation: experience of a hospice in ITALY**

Adelaide Conti, Forensic Science Department, Brescia, ITALY, Paolo Delbon, Centre for Bioethics Research Forensic Science Department, Brescia, ITALY, P Borghetti, Hospice Domus Salutis, Brescia, ITALY, Giovanni Zaninotto, Hospice Domus Salutis, Brescia, ITALY

The Authors intend to make some consideration on the attitude of patients in a Hospice toward advance directives, i.e. to say what health care they would want to have in their possible future, were they to become incompetent, and toward possible contents of these recommendations. The Authors pay attention also to health care professionals’ tendency to patients’ earlier expressed wishes and to the possible contents of advance directives in decision-making process about medical treatments. In particular, with regard to possible contents of advance directives, the Authors intend to verify doctors’ attitude toward palliative sedation in the management of refractory symptoms, and possible changes of their opinion about this practice, after ‘illness’ appearance, as well as because of their admission to a Catholic centre. The study, perspective, will be carry out on 100 consecutive patients admitted to the Hospice. A questionnaire will be administrated to the patients or their relatives, to verify in particular the frequency of the practice of advance statements, the patients’ preferences between treatment options – be it the decision to allow admission – and physicians’ and patients’ attitude toward the role of these recommendations.

**Abstract number:** 236  
**Presentation type:** Poster  
**Poster number:** P129

**Terminal sedation in the Netherlands: practice and ethics**

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OBJECT - Terminal sedation has been defined as the induction, through medication, of a permanent coma in imminently dying patients suffering from refractory symptoms. Expectations are that this practice will grow in the future. However, there is much moral and conceptual confusion as to what terminal sedation is and how it relates to euthanasia. Our object is to lift up this confusion in view of a national guideline and possible policy regulations. METHODS - We sent out a questionnaire to GPs, as well as medical and nursing staff in hospitals, nursing homes, and hospices (n = 440). Furthermore, we held in-depth interviews with members of the same target groups (n = 42). Results - We evaluated indication, effectiveness, medication schedules, hydration and nutrition, decision-making, burden of care, and difference to euthanasia. RESULTS - A wealth of results include the following: Pain, dyspnea, and anxiety are the most common indications for terminal sedation. 49% of the physicians report that terminal sedation precedes a natural death. 5% of the patients still live after 7 days. 33% of the physicians suffer from stress associated with terminal sedation. CONCLUSIONS - Terminal sedation covers a heterogeneous group of practices, the fact that the patient is induced to sleep being a common denominator. Sedation is either acute and intended, or only gradually evolving as a side effect of treatment. Choices involved may be difficult, but are not commonly perceived as moral dilemmas. Terminal sedation should be viewed as normal medical treatment, if medication doses are proportionate. Guidelines help, but bringing terminal sedation sub judice is inappropriate. As physical suffering can be alleviated by terminal sedation, there is no medical indication for euthanasia, but most physicians accept identity and human dignity as valid arguments for euthanasia, too. Terminal sedation is then not an alternative.
the basis of P. Ricoeürs idea of life story); (2) activity and passivity of treatment in the terminal phase; (3) attachment and the relations with significant others; (4) guilt and life-balance; and (5) the quest for life’s meaning and trust. Central to this model is the concept ‘inner space’ as a metaphor for an attitude that helps dealing with emotions, as relevant for the interaction between caregivers, patient and family.

**Abstract number:** 238  
**Presentation type:** Poster  
**Poster number:** P131  
**Title:** A guideline for palliative sedation

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Background: Palliative sedation is increasingly an issue in palliative care. Sedation is estimated to be used in 12% of all patients dying in The Netherlands. We developed a guideline for palliative sedation, based on the literature and on our experience in a regional palliative care consultation team. Definition used: Palliative sedation is the intentional lowering of consciousness of a patient in the last phase of life by means of the administration of sedatives, with the aim to relieve severe suffering. Palliative sedation may vary from slight to deep. Conditions: 1) The presence of refractory symptoms, defined as symptoms which cannot be treated adequately by standard treatment due to lack of efficacy and/or intolerable side-effects, 2) Sufficient expertise and consensus of the team involved, 3) In case of deep sedation: life expectancy <1 week, and 4) Informed consent of the patient or proxy. Management: Sedation should be proportional, i.e. lowering of consciousness to the degree necessary to relieve the refractory symptom(s). Sedation is usually given continuously until death, but temporary or intermittent sedation may be considered in specific situations. Midazolam is the agent of choice. Depending on circumstances, a bolus injection of 5-10 mg sc is given, followed by 1-2.5 mg/hr sc, to be doubled every 1-2 hours. In case of lack of effect with a dose of 20 mg/hr, levomepromazine 4-8 mg/hr is added. In refractory cases, sedation with barbiturates or propofol is considered. If deep sedation is performed, parenteral fluids should be discontinued. Adequate documentation of the decision making process is essential.

Conclusion: We have been using the guideline in our team for the past two years. Although we have not evaluated it formally, it performs well in our consultations.

**Abstract number:** 240  
**Presentation type:** Poster  
**Poster number:** P133  
**Title:** Reanimation yes or no

Anika Prugovecki, Zagreb, CROATIA-HRVATSKA

XY 72 years old, female Medical History ca. ovaries since 2000. 2003. Anal neoplasm due to trm. metastases. Th. Tramadol retard 100 mg twice a day, sedative Palliative care not available. Social anamnese widow lives alone in comfortable flat. She has one daughter, no friends and relatives in town, no religion. One morning nurse has found her unconscious. Over the night she has taken twelve tablets of tramadol retard and left goodbye-letter. Nurse called the daughter and daughter called the EM. After psychical examination and consultation with the daughter EM doctor left the patient at home. Patient died few hours later at home. EM doctor initiated the discussion with her colleagues in EM center which ended up with the written question: Was the doctor wrong? 29 EM doctors participated and the result were: Yes 3 No 5 No answer 1 In conclusion: We should learn to stop reanimation terminally ill patients and to allowed them to die of their illness providing the palliative care for them.

Abstract number: 241  
**Presentation type:** Poster  
**Poster number:** P134  
**Title:** Symptom experience and symptom management in Dutch Palliative care units: what is the role of palliative sedation?

Patricia Claessens, Centre For Biomedical Ethics And Law, Leuven, BELGIUM, Kristel Maqness, Catholic University, Leuven, BELGIUM, Johan Menten, University Hospitals Leuven, Leuven, BELGIUM, Paul Schellong, Catholic University, Leuven, BELGIUM, BROECKAERT Bert, Catholic University Leuven, Leuven, BELGIUM

In Switzerland, the law does not prosecute someone giving personal assistance to another person who commits suicide if there are no selfish motivation. This procedure appears accepted to occur in willing nursing homes and should thus protect life. In addition, the hospital is not the legal home of patients. Suicide is therefore not provided in these institutions. However, as geriatrics, we sometimes receive many demands for death from our patients and a few of these will persist despite good symptom management leading the general care situation to a cul-de-sac. To illustrate this, we describe 2 different cases which occurred in our hospital and ended by a suicide at home on the day of the hospital discharge. The first case remained unclear and resulted in great frustration of the multidisciplinary team facing an uncompleted story. The second case was much better defined and discussed very clearly with the patient and all the carers. The active support of the institutional Ethic Clinical Council was available. The procedure provided respect for everyone involved with the patient including the patient herself and a follow-up-meeting was organized to give a proper end to this difficult story. In conclusion, the charge of a patient who requests suicide assistance is not an easy situation and requires open mind and trust in between the carers. In addition, external professional help may be useful. These precautions are a prerequisite to maintain the dialogue with the patient, to avoid a scission in the care team and to continue to work together whether the patient returns home to commit suicide or not.

**Abstract number:** 242  
**Presentation type:** Poster  
**Poster number:** P135  
**Title:** Demands for euthanasia and suicide assistance (E/SA). A prospective study in palliative care and geriatric units


In countries like The Netherlands, euthanasia has now been legalized under strict conditions whereas in others like Switzerland assisted suicide will not be prosecuted. In every circumstances, requests for E/SA should be the result of a process involving the patient him/herself in the course of either a disease or in front of great suffering. However according to our daily experience, this is not always the case. We thus conducted a prospective survey in order to quantify and qualify these requests made in our palliative and geriatric 104 beds academic teaching hospital during a period of 6 months. Approximately 800 patients are admitted each year, 800 among them will eventually die. Personal data of the patient, primary disease and co-morbidities as well as global symptom evaluation were recorded. In addition, notification of the person who has received the demand together with details and motivations of the demand were also recorded. Persistence or absence of the demand and final issue will be reported. Preliminary results show that demands for E/SA in the context of a specialized hospital come from more people than expected. Indeed the patient, but the
An interdisciplinary, bicentric research and consultation (sub)department on ethical, legal, historical and didactical issues in medicine is established at the university hospital of Schleswig-Holstein, Germany. This is affiliated to one of the departments for anaesthesiology, owing to the specific importance and the broad spectrum of the discipline’s intersection discipline’. Empirical and conceptual research on ethical and legal key-issues was carried out, which significantly influenced ongoing discussions on reforming professional guidelines and national legislation in Germany. On the clinical field, several hundred consultations have been carried out. Education programs on ethical, legal and palliative care issues were implemented and an interdisciplinary team was established for casework. Methodology: We provide an empiric survey on the over all incidences of the inquiries for consultation, the persons and professionals who seek advice, the issues on which consultation is most frequently asked for, different motives for seeking consultation, indicators for its success and acceptance and finally the inevitable limits of CES. Results: We suggest that the standard of a fully trained medical consultant (preferably one of the major clinical key-disciplines) is the most important education requirement for entry into the role of an ‘ethics consultant’. Continuing education on ethical and legal key-issues and the methodological spectrum of palliative care is also essential. Other important tools for practical needs are clear ‘guidelines’ transparent legislation. Concerning the third major alternative of CES, the ‘classical’ Clinical Ethics Committees, we do see increasing empiric data and conceptual reasons to question their effectiveness. Reference: M. Schmucker, Universitätsklinikum Schleswig-Holstein, Campus Lübeck., Lübeck, GERMANY, Volker Schmucker, Universitätsklinikum Schleswig-Holstein, Campus Lübeck., Lübeck, GERMANY

Abstract number: 243
Presentation type: Poster
Poster number: P136

Evaluation of the use of terminal sedation on a Dutch unit for palliative care
Lia Van Zuylen, Medical Oncology, Rotterdam, NETHERLANDS, Hetty Van Veluw, Erasmus MC-Daniel den Hoed Cancer Center, Rotterdam, Paul J. Lieverse, Erasmus MC-Daniel den Hoed Cancer Center, Rotterdam, Marjolein Bannink, Erasmus MC-Daniel den Hoed Cancer Center, Rotterdam, Carin C.D. Van Der Rijt, Erasmus MC-Daniel den Hoed Cancer Center, Rotterdam.

Introduction: Terminal sedation (TS) is a subject of national debate in the Netherlands. We evaluated the use of TS on the Palliative Care and Symptom Control Unit over the past 3 years. Method: In 2001 the Liverpool Care Pathway for the dying phase (LCP) was introduced on the Unit as an instrument to structure and evaluate the care in this final phase. Section one, initial assessment, and section two, ongoing assessment, of the LCP were studied on different items related to TS. Results: Problems in 2001 and October 2004 122 patients died, 83 (68%) on the LCP. Of these, 45 patients (54%) died after a period of TS. The median age was 57 (range 27–99) years, 22 males and 23 females. All patients had a diagnosis of cancer and were on opioids before TS was started. In 42% there was one refractory symptom, e.g. pain, dyspnoea or delirium; the remainder had two or three intractable symptoms. In most cases the decision to start TS was made during office-hours by the multidisciplinary team (91%) and with the infusion nurses as the patient and/or relatives. The median number of hours between starting TS and death was 21 (range 2-114) hrs. Midazolam was used for sedation in 91% of the patients with a median starting i.v. dose of 2 (range 1–10) mg/h after a median bolus of 3 (range 1–10) mg. A second sedative agent, mostly propofol, was needed in 26% of the patients. Conclusion: On this palliative care unit a substantial part of the dying patients died after a period of TS by midazolam because of intractable symptoms. It is possible to anticipate in the multidisciplinary team on the decision to start TS.

Abstract number: 244
Presentation type: Poster
Poster number: P137

Establishing a clinical Ethics Consultation Service (CES) and research department in anaesthesia and palliative care
Meinolfus Stratling, Klinik für Anaesthesiologie, Lübeck, GERMANY, Beate Sedemund-Adib, Universitätsklinikum Schleswig-Holstein, Campus Lübeck, Lübeck, GERMANY, Volker Edwin Scharf, Universitätsklinikum Schleswig-Holstein, Campus Kiel, Kiel, GERMANY, Peter Schmucker, Universitätsklinikum Schleswig-Holstein, Campus Lübeck, Lübeck, GERMANY

An interdisciplinary, bicentric research and consultation (sub)department on ethical, legal, historical and didactical issues in medicine is established at the university hospital of Schleswig-Holstein, Germany. This is affiliated to one of the departments for anaesthesiology, owing to the specific importance and the broad spectrum of the discipline. Empirical and conceptual research on ethical and legal key-issues was carried out, which significantly influenced ongoing discussions on reforming professional guidelines and national legislation in Germany. On the clinical field, several hundred consultations have been carried out. Education programs on ethical, legal and palliative care issues were implemented and an interdisciplinary team was established for casework. Methodology: We provide an empiric survey on the over all incidences of the inquiries for consultation, the persons and professionals who seek advice, the issues on which consultation is most frequently asked for, different motives for seeking consultation, indicators for its success and acceptance and finally the inevitable limits of CES. Results: We suggest that the standard of a fully trained medical consultant (preferably one of the major clinical key-disciplines) is the most important education requirement for entry into the role of an ‘ethics consultant’. Continuing education on ethical and legal key-issues and the methodological spectrum of palliative care is also essential. Other important tools for practical needs are clear ‘guidelines’ transparent legislation. Concerning the third major alternative of CES, the ‘classical’ Clinical Ethics Committees, we do see increasing empiric data and conceptual reasons to question their effectiveness. Reference: M. Schmucker, B. Sedemund-Adib, P. Schmucker (2004); Klinische Ethik-Komitees in Deutschland – Von Ende einer wohlehmendem Illusion? BPRAX 2004: 176 (Issue 5/2004).

Abstract number: 245
Presentation type: Poster
Poster number: P138

The revised guidelines of the German Chamber of Physicians on decisions to forgo life-sustaining therapy: Why yet another revision is unavoidable
Meinolfus Stratling, Klinik für Anaesthesiologie, Lübeck, GERMANY, Peter Schmucker, Universitätsklinikum Schleswig-Holstein, Lübeck, GERMANY

Last year the German Chamber of Physicians issued a revised version of its national guidelines on decisions to forgo life-sustaining therapy (DFLST) [1]. These have been criticised for failing to meet a variety of practical, legal and ethical requirements, which are of special importance for palliative care [2, 3]. Unlike the statements of e.g. the anglo-american counterparts [2], reflecting the results of international research and the present “physician’s art” in palliative care on these issues, the chambers’ guidelines do not provide sufficiently clear statements on artificial nutrition (tube feeding) and its serious limitations. The limitations of national debate in the Netherlands. We give patient who may not be aware of the request. Any member of the multidisciplinary team may be selected to receive the request. In conclusion, demands for E/SA sometimes appear in our practice as the result of requests made by other person than the patient, including health carers. This reality has to be accepted as such and we have now to understand the underlying reasons for these demands and how to deal with them in a societal perspective.
Terminal sedation in medical oncology

Jaime Sanz Ortiz, Servicio de Oncología y Cuidados Paliativos, Santander, SPAIN, Almudena García Caño, Medical Oncology Dept. Hospital Universitario M. Valdecilla, Cantabria University, Santander, SPAIN, Mª Victoria Rodríguez-Coto, Home Palliative Care Team. Hospital Universitário M. Valdecilla, Cantabria University, Santander, SPAIN

Background. It is define as the administration of drugs on purpose to get relieve, unachivable by other measures, of the physic and/or psychological suffering, by induction of unconscious that look set irreversible in a patient whose death is near due to illness, with their consent explicit, implicit or delegate. Objectives. 1) Analyse the incidence of terminal sedation during one year in a medical integral oncology unit in a teaching hospital with assistant home care included. 2) Identify the refractory symptom. 3) Survival time from sedation to death. 4) Drugs that has been given to induce sedation. Design. Descriptive retrospective study of incidence terminal sedation the inpatients and outpatients from 1 January 2002 to 1 January 2003. All of patients were asked about that in advance and they agree with this decisions. Results. 1) 365 patients were death in 2003 year. 176 (48,3%) dying at home and 189 (51,7%) in hospital ward. 141 (41%) with refractory symptoms were sedate. 64 (34%) were sedate at home and 82 (47%) in hospital ward. 2) Refractory symptoms were: 46% dyspnoea, 31% abdominal pain, 31% confusion and delirium, 26% anxiety, 13% digestive disorders (vomiting and intestinal obstruction). 3) Median time from sedation to death was 1.9 days (1 to 5). 4) Drugs use were: 80% midazolam, 75% morphine, 10% haloperidol, 2% ropinol. Propofol and fenobarbital were no necessary this year. Both were heavily sedated and oxygen saturation was considered satisfactory in all patients. We conclude that with a skillful combination of analgesics and small doses of benzodiazepines most cancer patients can be helped to die peacefully, making a positive last memory for their nearest family.

Euthanasia and end-of-life decisions: medical literature and public debate in Italy

Claudio Ritossa, Palliative Care ASL 5, Rivalta (Torino), ITALY, Eugenia Malininverni, Luce per la Vita Onlus, Palliative Home care, Turin, ITALY

Background: Data regarding medical opinions about euthanasia and end-of-life decisions in Italy are scarce and controversial. The aim of this study is to investigate the consistency of the debate among medical community and public opinion. Methods: We revised medical articles indexed in Medline in the last 5 years regarding the opinion of Italian doctors and their end-of-life decision-making practices. We also performed a research among Italian websites in order to explore the present state of public debate about euthanasia and end-of-life practices. Findings: Medline research resulted in 34 articles (key words: euthanasia, end-of-life, Italy, Italian doctors), 3 of them are European studies conducted in different countries, 5 of them are in Italian. A vast majority of doctors agree with statements consistent with preserving life, however relevant differences can be found among different specialties. In a study only 8% of doctors felt that do-not-resuscitate order should be applied in intensive care setting while in palliative care setting 32% of doctors interviewed thought that under certain conditions even euthanasia might be ethically ‘correct’. The WEB search found 80,800 Italian web pages regarding euthanasia or end-of-life decisions, and in particular several professional and public forum. Conclusion: There is a relevant difference between the consistency of medical literature and the real debate among public opinion about these themes. Furthermore most debates are conducted on media and are characterized by emotional and ideological positions. Further studies regarding practices of doctors and nurses are requested. We planned a study in North Italy which involves a large sample of doctors and nurses, the data of which will be available by the date of the congress.

Comparison of experience on euthanasia between two medical societies

Hristos Tsokanardis Drama, GREECE, C. Tsokanardis, E Nagy, K Aplexopoulou, A Tsikali, D Kosmidis, K Kopalioudou, E Mustheniotou General Hospital of Kavala, Greece

AIM: During the past decade the debate about euthanasia and assisted suicide has the potential to polarize our society. We have compared the experience on euthanasia between members of Drama Medical Society (D.M.S.) in Greece and Physicians from Michigan State in U.S.A. (P.M.S.) METHODS: The D. Doukas et al. questionnaire was mailed with self-addressed envelopes to 175 D.M.S. members and to 250 P.M.S. In our study we compared the answers on 10 items from the second part of the questionnaire. Respondents reported about their experience with passive euthanasia, assisted suicide and active euthanasia and they answered on a 3-point scale. We used SPSS v.11 package and applied chi square (X2). Data were expressed as mean ± sd. P<0,05 was considered statistically significant. RESULTS: The mean age of D.M.S. members was 50,8 years and 90% were men, and the mean age of M.S.S. were 49 years and 83% were men. The response rate of D.M.S. members was 29,14% (n=154) and the rate of P.M.S. members was 61,6% (n=154) (P<0,05). CONCLUSIONS: 1. The majority of the D.M.S. members in relation to P.M.S. members is against passive euthanasia. 2. No significant difference was noted in the answers about Physician-assisted death and active euthanasia. 3. Religious conviction may play a powerful role in euthanasia.
Abstract number: 252
Presentation type: Poster
Poster number: P145

Implementation of ethical case conferences in the palliative care unit of Nuremberg hospital: First experiences

Gerda Hofmann-Wackersreuther, 5. Med. Klinik, Palliative Care Unit, Nürnberg, GERMANY, Tobias Scherlin, see above GERMANY, Martin Wilhelm, see above GERMANY.

In 1999 a differentiated ethic project started in the hospital Nuremberg. First the ethical codex was defined that guaranteed the dignity of the patient during his whole stay in hospital. One part of the project was to establish clinical ethic consultation with the objective to sensitize the staff to ethical issues in clinical practice and to integrate ethical thinking into the personal qualification of each team member. From October 2003 until February 2004 a group of 16 members got a special training in ethics and communication to prepare them as clinical ethic consultants. In January 2004 ethical case conferences were introduced on a regular basis every 6 weeks in various interested clinical units. Since January 2004 in our palliative care unit 7 ethical case conferences have taken place. The consulting team consists of a nurse, a physician and a pastor. The reasons for triggering an ethical case conference were different. In 4 cases the team asked for help in ethical issues like patient’s autonomy and quality of life, the request for assistance in suicide or for active euthanasia. In 4 cases the team was asked for help in ethical issues like patient’s autonomy and quality of life, the request for assistance in suicide or for active euthanasia. In 2 cases the reasons for ethical case conferences were conflicts and distress in handling a very complex medical, psychological, and social situation with ‘difficult’ patients or family members and lack of a documented patient’s will. And one case was a therapy limiting decision that required a predictable and foreseeable patient’s wish. Ethical conferences represent further education for the staff in ethical issues and communication. The ability to perceive and reflect moral questions is improved. In complex and difficult case ethical case conferences are helpful in elaborating and separating the different aspects of a case: medical, social, economical, psychological, ethical, legal aspects. Thus decisions become transparent for all persons concerned.

Abstract number: 253
Presentation type: Poster
Poster number: P147

Euthanasia, Assisted Suicide, Terminal Sedation—Are They Compatible with Jewish Culture?

Michaela Becovitch, Oncological Hospice, Shoham, ISRAEL, Adunsky Abraham, Sheba Medical Center, Ramat Ha Sharon, ISRAEL.

The past decade has seen an abundance of literature on death and dying, with the issues of euthanasia and physician assisted suicide being among the main issues discussed. The issue of ‘mercy killing’ has been addressed from a Christian perspective, but only little attention was devoted to the needs of the terminally ill patient who is Jewish. Although the Bible recounts the story of the first murder early on, Judaism is a life-affirming religion. In the Jewish tradition, the life of each individual is of supreme value, and death does not represent the end of being. Our lecture will present: 1. Differences between Christian and Jewish spirituality regarding regard death, i.e. ‘mercy killing’. In particular, 2. Jewish thinking on euthanasia, 3. Attitudes of Jewish physicians toward ‘mercy killing’ and physician-assisted suicide is the physician the right address for killing in case of terminal disease? Terminal sedation, it may be considered a good compromise? We will conclude with some acceptable solutions, based on Jewish thinking, in facing terminal illness.

Abstract number: 254
Presentation type: Poster
Poster number: P148

Incidence, methods and outcome of palliative sedation before publication of a specific guideline in the Netherlands

Constant Verhagen, Medical Oncology/Palliative Care Consultancy Team, Nijmegen, NETHERLANDS, Eveline Cloin, University Hospital st Radboud, Nijmegen, NETHERLANDS, Selanya Achterberg, University Hospital st Radboud, Nijmegen, NETHERLANDS, Marjo Griling, Palliative Care Consultancy Team, Nijmegen, NETHERLANDS, Jeroen Fokke, Palliative Care Consultancy Team, Nijmegen, NETHERLANDS.

End of life decisions in palliative care varies from harmless treatments to potential toxic regimens and even the delivery of drugs shortening life. Confusion may occur between good clinical practise and ambiguity of intentions leading to hastening death. Euthanasia has been legislated in the Netherlands (3.6% of all deaths). More patients may encounter unacceptable refractory symptoms. Palliative sedation (PS) for intractable suffering seems to be the only acceptable alternative. Incidence, indications and methods vary widely suggesting differences in definitions and approaches towards PS. This forced the palliative care consultancy team to develop a guideline. We report a retrospective study of all patients seen before publication of this guideline. From January 1999 until May 2003, all 509 successive patient records have been reviewed. 248 files contained sufficient data to reconstruct end of life decisions. 149 patients were male; mean age was 63 (5–93) years; 221 patients had a malignant disease and 136 (55%) patients died at home. Local euthanasia (LE) was performed in 13 (5%), 42 (17%) died after PS and 23 (9%) patients died under anaesthetic medication (TM) without adequate indication that intention was either PS or LE. The indication for true PS was intolerable pain in 13 (31%), other physical symptoms in 16 (38%) and psychosocial in 8 (19%) cases. Survival after start of PS was less than 24 hours in 32 (76%), up to 3 days in 5 (12%) and more than 3 days in 5 (12%). In 19% patients were treated with adequate medication for sedation. Only 9 (39%) of the 23 patients who died under TM were sedated with adequate medication; many (11 or 48%) were intoxicated by high does of opioids. Nevertheless survival data in TM was not different from PS, the indication seemed to be more often psychosocial (10 or 43%) in TM. These data underline the necessity of guidelines for PS. Follow up data after publication of the guideline will be available during the congress.

Abstract number: 255
Presentation type: Poster
Poster number: P149

A Model to Guide Difficult Decision-Making: Responding to Ethical Dilemmas with the Tension of Hastened Death

Gary Buckholz, Center for Palliative Studies, San Diego, U. STATES, Frank Ferris, San Diego Hospice & Palliative Care, San Diego, U. STATES.

Objective: To provide an effective model to guide interdisciplinary teams when confronted with ethical dilemmas where the tension is hastened death of the patient. This process will facilitate team consensus building where there will be disagreement about how to proceed.

Method: After reviewing the literature on ethical principles guiding practice and reviewing all existing protocols, an iterative process was used to test and revise a model to guide interdisciplinary teams when faced with ethical dilemmas. Examples of these dilemmas include requests for withdrawal of ventilator support or artificial nutrition after chronic dependence, requests for sedation due to intractable suffering, suicidal ideation or requests for physician assisted suicide, and questions of abuse or neglect. Results: Through case examples, we will illustrate some of the ways to guide team members through these ethical dilemmas. This model includes four phases: planning, assessment, intervention, and implementation. 2) Clear definitions of ethical principles guiding practice and how these are integrated into the process. 3) How to integrate appropriate assessment and measurement tools into the process. Conclusions: This model ultimately leads to a comprehensive interdisciplinary plan of care that effectively addresses the dilemma in a way that is ethically sound and minimizes risk to the patient. This creates the highest likelihood of establishing safety and acceptability for patients, families, and staff.

Abstract number: 256
Presentation type: Poster
Poster number: P150

A bereavement service in light of the U.K. supportive and palliative care strategy: where do we stand?

Heino Hugel, Palliative Medicine, Liverpool L25 8QA, GREAT BRITAIN, Heather Wedderburn, HSPCT, University Hospital Aintree, Liverpool, GREAT BRITAIN, S Oakes, HSPCT, University Hospital Aintree, Liverpool, GREAT BRITAIN, A Tann, Community Palliative Care Team, Knowsley, Liverpool, GREAT BRITAIN, P Davies, Community Palliative Care Team, Knowsley, Liverpool, GREAT BRITAIN.

Aims: To examine current service provision for bereaved carers in different primary care and specialist palliative care settings within Merseyside/U.K. Method: A survey was conducted as part of the Merseyside and Cheshire Palliative Care Network Audit Group Programme. 29 out of 31 District nurse team leaders from two primary care trusts (PCTs) within Merseyside completed a telephone questionnaire. All (n=5) Community Palliative Care Nurse Specialists (CPSCNs) from the same PCTs and Bereavement Service Leads of a day hospice, an in-patient hospice and a hospital advisory team completed a postal questionnaire. Questions related to initial assessment, immediate post bereavement support, ongoing support, onward referral, provider education and service uptake. Results: None of the district nurses (DNS) used a bereavement assessment tool, 26 of 29 DNS provided immediate end of life follow-up. None made contact at 8–12 weeks post bereavement. Onward referrals were primarily to general practitioners (GPs) (n=21). 24 had training in bereavement support. CPSCNs had a higher level of training in bereavement support than DNS and 80% said they were involved with complex bereavement problems. All specialist services made written contact with bereaved carers at 8–12 weeks post bereavement. Uptake of some bereavement services was below 1% of total trusts (PCTs)(n=21). 24 had training in bereavement support. CPSCNs had a higher level of training in bereavement support than DNS and 80% said they were involved with complex bereavement problems. All specialist services made written contact with bereaved carers at 8–12 weeks post bereavement. Uptake of some bereavement services was below 1% of total trusts (PCTs)(n=21).
critical 8–12 week period post bereavement was lacking. GPs are central to bereavement care. Memorial services may provide a good basis to initiate bereavement support. Specialist bereavement services need to be coordinated well to guarantee efficient service provision.

Abstract number: 257
Presentation type: Poster
Poster number: P153

Long and winding roads: Stories of grief, loss and learning.
Susan Read, Nursing and Midwifery, Staffordshire, GREAT BRITAIN

Aim: To focus upon stories of grief and associated losses experienced by people with intellectual disabilities (ID). Bereaved people with ID have received increasing attention over recent years from a variety of interested professionals. However there are still many individuals who do not receive the psychosocial and emotional support required to healthily accommodate their grief. Consistency of support is variable, resources limited and access to various and appropriate therapeutic interventions remains difficult and rare. As part of a seven-year participatory action research study conducted within a voluntary bereavement counselling organisation in Staffordshire, England, bereaved clients were invited to tell their stories of their grief journey.

Method: Biographies and case studies are acceptable methods of gathering complex information pertaining to social phenomena for analysis and offer extremely powerful insights into sensitive areas. A series of biographies case studies (N=21) are analysed using a six themes that emerged from a previously conducted literature review. Results and conclusions: The results of the biographies powerfully illustrate the impact of death and the normality of the grief experienced and demonstrate the inherent challenges that people with ID have within this process.

Abstract number: 258
Presentation type: Poster
Poster number: P152

Bereavement and people with intellectual disabilities: A continuum of support
Susan Read, Nursing and Midwifery, Stoke on Trent, GREAT BRITAIN

Aim: The emotional needs of people with intellectual disabilities are often neglected (Arthur, 2003), particularly from a bereavement perspective. Yet it is recognised that people with ID do grieve, but, because of the nature of the intellectual disability itself (and often other associated disabilities), they may need additional help and considerations in order to explore their grief in a meaningful way. This positional paper proposes a model that describes the continuum of support required to support people with ID before, during and after a death. This model is designed to encompass a broad range of strategies offered at many different levels. Such strategies range from general preparation before loss or death (education); portraying loss and death as natural life events (participation); consistent support after death has occurred (facilitation) and the identification for specific help (therapeutic interventions). Such proactive responses should help to minimise the need for specialist therapeutic interventions.

Abstract number: 259
Presentation type: Poster
Poster number: P153

Psychosocial Care at St Joseph’s Hospice
Jenny Watmore-Eve, Department of Social Work, London, GREAT BRITAIN

The publication “Improving Supportive and Palliative Care for Adults with Cancer” (NICE, 2004), amongst other things, has highlighted the following: “Psychological distress is common among people affected by cancer – and – some patients are likely to benefit from additional psychological intervention”. “The social impact of cancer is considerable – and many patients do not receive a coherent integrated system of social support”; “Families’ and carers’ needs for support can be particularly profound around the time of diagnosis, at the end of treatment, at recurrence and most particularly around the time of death and bereavement”. St Joseph’s Hospice, Hackney, London, has one of the largest hospice based departments of social work in the United Kingdom. In addition to qualifications in social work, the department has a number of staff qualified in psychological therapies. This presentation describes the structure and activities of the department and the ways that staff attempt to meet the needs for psychosocial support outlined in the NICE guidelines. Examples are given of the department’s work in; amongst other activities, enhancing income and preventing poverty, family care planning, complex family work, counselling support for patients and their families, bereavement work for adults and children, creative writing and art therapy. The challenges of providing psychosocial support, evaluating and conducting research work in this area are explored.

Abstract number: 260
Presentation type: Poster
Poster number: P154

The hardest thing we have ever done: The social impact of caring for the terminally ill in Australia
Peter Hudson, Centre for Palliative Care and School of Nursing, Psychology and Social Work, UNIVERSITY OF WOLLONGONG, AUSTRALIA, Samar Aoun, Edith Cowan University, Perth, AUSTRALIA, Linda Kristjanson, Edith Cowan University, Perth, AUSTRALIA, David Currow, Flinders University, Adelaide, AUSTRALIA, John Rosenburg, Queensland University of Technology, Brisbane, AUSTRALIA

Purpose: Empirical evidence indicates that the role of supporting a dying relative adversely affects the well-being of many family caregivers. Palliative Care Australia (peak body representing Palliative Care in Australia) convened a working group to describe unmet family caregiver needs in order to plan strategies to enhance support. Method: A literature review was undertaken and individual submissions were invited from individuals, families and organisations in one or more of the following forms: (1) letters or case studies describing unpaid caregivers’ stories and experiences; (2) descriptions of unpaid caregivers’ needs and the extent to which they are being met by government, other institutions and the community; (3) policy statements and/or recommendations; and (4) copies of recent reports and published research data. A total of 131 organisations were contacted via letter and e-mail and were invited to make a submission. Advertisements were placed in the National newspaper and also circulated through several stakeholder newsletters. Results: 20 family caregivers, 6 volunteers in palliative care and 23 service providers, provided submissions that described caregivers’ experiences and unmet needs, all of which reflected findings from the literature review. Caregivers reported being unprepared for their role; socially isolated and many had financial difficulties. However, some caregivers were able to recognize rewarding aspects. Recommendations to address challenges fell into 4 categories: information and communication issues, financial and employment needs, increased services and community recognition. Conclusions: Findings from this project have informed a strategic national agenda aimed at enhancing the well being of family caregivers.

Abstract number: 261
Presentation type: Poster
Poster number: P155

PALLIATIVE CARE RESPITE AT HOME: A UNIQUE APPROACH TO SUPPORTIVE PALLIATIVE CARE
Anita Green, Primary Care, Stockport, GREAT BRITAIN, Ann Wakefield, The University of Manchester, Manchester, GREAT BRITAIN

This paper evaluates a local Palliative Care Respite at Home Service within the United Kingdom. The service was distinctive, in that it was staffed by a team of unqualified carers with a special interest in palliation. Although the findings are not meant to be generalisable to the wider community, they are considered worthy of further discussion in order to communicate good practice. Given the nature of the setting and subject matter the research was loosely based on a case study, as this offered the opportunity to explore a single ‘case’ and collect detailed information using deep descriptive data. The need to provide a comprehensive 24hr service to both patients wishing to die at home and their informal carers is both obvious and real. The use of unqualified ‘professional carers’ is in fact unique within the literature, yet the service proved valuable and worthwhile as evidenced by the following comment: ‘to go out of the house and leave your loved one with someone you know is capable, means so much’ (Partner of a patient). Despite the above, little information is documented in the literature regarding the richness of support such services provide; in particular details regarding the number of visits and the time spent with the patient are scant. Yet the service outlined here made a difference to patients’ lives because of its flexibility and lack of medicalisation suggesting this type of service is both wanted and needed by users and professionals alike. Nevertheless, it is only by undertaking studies of this kind that experience is gained ‘on the field’. One of the significant findings of the study therefore highlighted the need to recognise that each person’s experience of caring for someone at the end of life is different. However it is clear that what is required is individualised care and attention focused towards each family member when it is needed most.
Abstract number: 262
Presentation type: Poster
Poster number: P156

The use of volunteer counsellors for bereavement support in a study of bereavement services in UK hospices

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Aims 1) To identify the nature and extent of bereavement support offered by UK hospice and specialist palliative care services. 2) To examine the role of paid and volunteer staff in providing adult bereavement services and to solicit the views and outcomes of bereaved people who had and had not used these services. Method Five hospice services were selected from respondents to a national initial postal survey of hospice and SPCs using a range of variables (e.g. their size, organisation and geographical location). Two hospices used volunteer counsellors initially recruited from students completing diploma courses in counselling, some of whom continued to work as volunteers after they had completed their course. Twelve counsellors described their work to the researchers in open-ended interviews. Bereaved people using counsellors talked about their experiences either in focus groups (n=11) or interviews (n= 4). Findings This arrangement seemed to work adequately at the smaller hospice. At the second, substantially larger, hospice there were sometimes insufficient counsellors to meet the demand for bereavement counselling. A number of potential difficulties resulting from depending upon volunteers, especially trained, counsellors were identified. - The effect of the varying number of counsellors upon the availability of bereavement support. - The safety of both client and counsellor. - The potential isolation of volunteer counsellors. - The difficulty of coordinating and depending upon volunteers. - Potentially negative attitudes of potential clients to volunteers, who may be seen as less well trained.

Abstract number: 263
Presentation type: Poster
Poster number: P157

Approaches to offering adult bereavement support by Hospice Chaplains to people of diverse faiths in the UK

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Background: Formal adult bereavement support in UK hospices is an increasingly specialised activity, for example, with the rise of oncology as a appropriate resource for grieving relatives. This trend has been accompanied by the continued assertion that the UK is becoming a more secular society. Hospice Chaplains are associated with the provision of spiritual support in hospices, are expected to offer bereavement support to people with little or no Christian faith. Aims: - Report the main strategies for offering bereavement support to adults with little or no Christian faith identified by hospice chaplains. - Consider the effectiveness of these strategies by drawing upon the experiences of bereaved people who have received support from these chaplains. Methods: Organisational case-studies have been undertaken at adult bereavement services provided by five UK hospices. These services were sampled from a national survey conducted by the authors (n=247). This paper draws upon a thematic analysis of semi-structured qualitative interviews conducted with hospice chaplains (n=5) and bereaved people (n= 87). Results: Chaplains’ responses to diverse faith needs including renaming themselves as ‘spiritual care coordinators’, redesigning remembrance services to include secular readings, poetry and personal reflections and making themselves available to bereaved people in non-religious settings. Bereaved people with little or no Christian faith said Chaplains were approachable, knew them by their first name and were highly satisfied with remembrance service content. Conclusions: The Chaplains both acknowledged and acted to allay negative perceptions of their religiosity held by those with little or no Christian faith. Some bereaved people appreciated attempts by Chaplains to be inclusive; some with strong religious beliefs were dissatisfied with the lack of Christian content.
Support to family members is essential in palliative care, but there is limited literature concerning interventions during ongoing palliative home care. Therefore, support groups were started for family members of cancer patients referred to a palliative home care service. The aim of this study was to describe the family members’ experience of participation in such support groups. Four taped-recorded focus groups interviews were conducted (N=13) and a minor questionnaire was completed by 19 of 22 possible family members. The participants had experienced increased perception of support and knowledge and all would recommend a person in a similar situation to join a support group. Themes that emerged in the qualitative content analysis concerned ‘support facilitates decision to enter the group’, ‘being in the same phase contributes to cohesiveness’, ‘experienced and listening group leader as a catalyst’, ‘meaningful dialogue to solve everyday problems’ ‘cohesiveness increases security’, and ‘reflection increases strength’. Support groups for family members seem to be a valuable contribution during ongoing palliative home care. The findings are discussed in relation to recruitment to and ending of support groups.

**Abstract number:** 269  
**Presentation type:** Poster  
**Poster number:** P163

**History and Aims of the Bereavement Research Forum**

Christina Mason, Department of Research, London, GREAT BRITAIN

The Bereavement Research Forum (BRF) was established in 1990 as a small gathering of researchers aiming to support each other in the standard are used to demonstrate the practical implications of some of the literatures findings. Social support theory is also considered to offer an explanation as to why information is so important and where it fits with other support needs they may have. Five major themes were identified in the article and were: establishing that caring benefit from information, barriers that inhibit carers receiving information, topics that carers consider important, delivery methods and variables that may influence what information is required. The majority of the trials that were considered were qualitative in nature, some utilised a combination of qualitative and quantitative data and only one quasi-experimental study was identified. As in the case with many reviews conducted in palliative care there is a lack of what is considered to be strong evidence. There is certainly room for further research to be undertaken in this area and recommendations are made from the gaps that were identified in this review. Health care professionals should be aware of the needs of the carers that they are in contact with and should continually assess what information they require. Many of the strategies for providing support are straightforward and could be quickly incorporated into practice.

**Abstract number:** 271  
**Presentation type:** Poster  
**Poster number:** P165

**The Gifts of Grief Workshop**

Nancee Sobonya, Bereavement, Oakland, U. STATES

The Gifts of Grief is a unique film about the possibility of another side of suffering, told through the personal and moving stories of a special group of people who have embraced their pain and have found a way to transmute their grief into a greater understanding and fulfillment of life. We explore the possibility that grief while very painful, is one of the
closely guarded keys to true transformation and joy. Through these compelling interviews, we gain valuable insights from people facing, growing through, and transitioning through grief. The stories of ordinary and extraordinary people, including writer, Isabel Allende; Reverend Cecil Williams; Zen Monk/Vietnam Veteran, Claude Antignac; and Hindu mystic, Lee Mun Wau; celebrate and inspire healing and transformation. The film invites us to open, learn from loss, and teaches us about the preciousness of life.

OBJECTIVES:
1) To identify the physical, emotional and spiritual affects of death and grief.
2) For participants to identify the resources that help them through their losses.
3) For participants to discover for themselves the possibility of true gifts emerging from their own losses.

Abstract number: 272
Presentation type: Poster
Poster number: P166

A Chatroom For German Speaking Bereaved Adolescents In The Internet: www.allesistanders.de

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The hospice movement in the German university city of Freiburg (Hospizgruppe Freiburg e.V.) established itself as an association of benevolents in 1991 looking after terminally ill patients and their families. While there are mourning groups for adults there is little help available for children and adolescents. There is an increasing demand to support those young people. We started to offer mourning groups for various ages and discovered that bereaved adolescents did not like to participate spontaneously in a group. Therefore we tried to reach them via internet, a new communication means frequently and easily used by adolescents. Besides fora for adults and young people we started a chatroom in August 2003 for adolescents (teens, young adults). In this virtual room they can communicate with each other about their losses and griefs. Two specially trained adults supervise the chat. They participate, counsel and if needed may cut out an inverse chat if it is needed. German speakers every Wednesday from 8 to 10 p.m. There are 10–40 live chatters at a given time. They are frequently complaining that friends are not sharing their concerns nor coping with their griefs. The teenagers describe the situation at school as a real dilemma, e.g. explaining about concentration difficulties, sleep disturbances etc. and teachers having little understanding and respect for their concerns. Although internet seems to be a rather anonymous place to meet a high degree of intimacy is happening. It is impressive how adolescents are dealing with each other in a gentle, open and respectfulfull way. It looks that a traumatic experience like a loss of a dear person may lead to a personal growing and maturing. After one year of experience we are encouraged by the adolescents to carry on this project. The live chatroom is well accepted and offers new opportunities and challenges to reach and support bereaved young people.

Abstract number: 273
Presentation type: Poster
Poster number: P167

FEELING ALONE IN THE FACE OF THE DISASTER IS COMMON IN PATIENTS WITH ADVANCED CANCER DISEASE AND THEIR FAMILIES?

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Psychological distress and changes in patients and their families may be a serious complication during the final illness process. The diagnostic and the appropriate intervention may decrease the emotional suffering for all parts involved and may make more easily the family bereavement period. Death is a departure. Departure from all that is familiar and from all those that the dying person has known in life. Loneliness, which is so common in life, may be even more prevalent in the process of dying. The proposed paper will explore the loneliness experience, how it can best be faced and coped with by the dying, as well as addressed by those caring for the patient. Ways and techniques with which the medical staff can assist the dying and his or her caretakers to cope with loneliness will be discussed and demonstrated.

Abstract number: 274
Presentation type: Poster
Poster number: P168

Carers’ experiences around the Moment of Death at home

Sinéad Donnelly, Palliative Medicine Department, Castletroy, Limerick, IRELAND, Natasha Michael, Millford Care Centre, Castletroy, Limerick, IRELAND, Cliona Donnelly, Millford Care Centre, Castletroy, Limerick, IRELAND

Palliative care programmes continue to demonstrate that enlightened and dedicated care can markedly improve the suffering of patients and families. The time surrounding the moment of death, however, had become increasingly marginalised. The objective was to study, using qualitative enquiry, the experiences of families and carers about the events that occurred in the last hours and at the time of death. Those interviewed were asked to recall and describe the physical scene, the care, conversations, rituals and reactions of individuals around the moment of death itself.

Ten families based in the Mid Western region of the Republic of Ireland (urban and rural settings) were identified. Semi-structured interviews were conducted with the main caregiver a week to ten days after the patient’s death. The timing of the interviews with its proximity to death was a unique aspect of this study. Trust established between the interviewer (who is a doctor) and the families during earlier meetings allowed for this. The interviews were audio taped, transcribed and imported into non-numerical data indexing and searching and theorising (NUD.IST) for coding and content analysis.

Many, despite the urgency of the moment described death as a non-threatening event. There was a strong sense of family and community, as well as a need for proximity and physical contact especially at the moment of death. The presence of rituals was noted in the context of the family’s faith. There was evident reverence for the body after death and the significance of its removal from home noted. Carers were able to maintain a balance amidst chaos despite the many practical difficulties that arose when death occurred at home. There was a mystery that surrounded the significance of dates and times at which death occurred. These details are extremely moving. The phenomenon that is emerging is that people die well because of their own innate community strengths and support. At these crucial moments, families are hardest at work, in grief together. Professionals simply enable them at this important and sensitive time to use their strengths. From the findings of this study, we can focus on this critical time and ensure that optimal care is given in the physical, emotional, spiritual and social domain.

Abstract number: 274B
Presentation type: Poster
Poster number: P168B

A Listening Day


At St Christopher’s Hospice (SCH) regularly seeks patients’ and carers’ feedback, using questionnaires and a Users Forum. In July 2004, an innovative Listening Day was held for bereaved carers around 18 months after patient death asking in retrospect if they could see areas for improvement.

Method
The next of kin of all patients who died between October 2002 and April 2003 were invited to the day (n=649). The meeting was held on a Saturday. The agenda for the day was twofold 1) patient care, exploring clinical, psychological, social and spiritual care and hotel services and 2) carers’ experience, including carer support over three phases – during the patient’s illness, around the time of death, and since death, including views about the SCH bereavement service. The participants were divided into three groups, each having a facilitator and note taker. A record of all comments was produced and presented to the SCH Clinical Governance committee.

Results
In total 162 people (25%) replied to the invitations. There were 23 acceptances, and a total of 26 attendees, who were divided into three discussion groups.

Topics raised included information, communication and interface between the hospice and the NHS, feedback from the participants about SCH was generally positive, feeling that follow up at this stage was helpful.

Discussion
Whilst the numbers are small and this group was self-selecting, participants felt it was a worthwhile activity. For SCH some areas of need for staff development were identified. For the specialty it has highlighted some interesting challenges, namely how we gain the views of the silent majority and how we can use the Network structures in the NHS to improve the transition from NHS to hospice care.
A Phenomenological Investigation of the Lived Experience of Irish Palliative Home Care Nurses caring for the Non-National Population.

Geraldine Tracey, Day Hospice, Dublin, IRELAND

This study aimed to investigate the lived experiences of Irish palliative home care nurses in caring for the non-national population. Ireland, up to the mid 1990s, remained a predominantly homogenous society (Mac Enn, 2002) but since then there has been a huge increase in immigration for a variety of reasons. This change affects the provision of health care and since end of life care is strongly mediated by a person’s cultural and spiritual beliefs, it affects the delivery of palliative care. Thus, Irish Home Care Nurses are experiencing a new phenomenon in practice. This study is placed within a philosophical tradition, which proposes that people interact with a meaningful world guided by Gadamer’s hermeneutic philosophy, seven Irish palliative home care nurses, with experience of caring for non-national people, were interviewed. Gadamerian hermeneutic phenomenological investigation aims to interpret and understand the phenomenon rather than provide explanation of that experience. Four themes emerged from the interview transcripts. These were: challenges associated with ‘not standing on the same ground’ as these people, ‘communication both as a barrier and a gateway’, ‘bridging the gap’ and the ‘emotional highs and lows’ of caring for this population. The essence of this study is that home care nurses continually strive to provide care that meets the needs of non-national patients through the challenges of difference, language and emotions and relevance to practice. This can lead to an overwhelming sense of frustration on the nurses’ part and a lowered sense of achievement. The lack of clear understanding of what palliative care attempts to offer the patient and what the patient wants compounds this. Acknowledging the ‘difference’ has implications for not only those receiving care but also for those providing that care.

Abstract number: 276
Presentation type: Poster
Poster number: P171

12 YEARS EXPERIENCE OF THE PALLIATIVE PROGRAM OF Cudeca FOUNDATION


OBJECTIVES: The principal objectives of Cudeca are: to offer “specialised palliative care” to patients suffering from terminal illness and to support the family during the illness and in the bereavement process. To form a programme of study, training, investigation and awareness of Palliative Care. Our care is offered completely free of charge to those patients and families who need it and who live in the Province of Malaga. Spain. Cudeca is a Non-Governmental Organisation (NGO) and non profit making, depending on the support of the community for its finances.

We analyze 12 years experience of the palliative program of foundation Cudeca.

METHODS: We analyze the data of 2339 patients who entry, from July 1992 until May 2004, in the palliative program of foundation Cudeca, with the statistical program SPSS 11.0. A descriptive study was done of the following characteristics of the patients: sex, median age of the patients, median age of the caretaker, and time of permanence in program.

RESULTS: 52% Male (59,6%), Female (40,4%). Median age of the patients: 67 years. Median age of the caretaker: 55 years. Median time of permanence in program: 76 days.

CONCLUSIONS: The median age of the patients is high, due to the greater prevalence of tumours in older patients and also in relation to the aging of the population. The males predominate (59,4%), in relation to the greater prevalence of tumors, especially of lung, in men. The median time of permanence in program is not very long, 76 days, because the patients are derivated to the palliative care unit of the oncology departments in a very advanced situation of their disease, is necessary therefore, to improve the coordination between the units of palliative care and the oncology departments.

Abstract number: 277
Presentation type: Poster
Poster number: P172

Crossing Boundaries: The setting up of a National Network for the Palliative Care of People with Intellectual Disabilities in the UK


The NNPCPDL was set up in Great Britain in November 1998. The Network was set up in response to the experience of a small group of practitioners from within the fields of intellectual disability and palliative care. These practitioners had observed that people with intellectual disabilities were often diagnosed with cancer later than members of the public. The lack of awareness of the challenges and tensions of working as a Network. Case studies will be used to highlight the issues for people with intellectual disabilities. Time will also be spent thinking about the future of the Network as it finds a place within the changing policies and structures of the UK. eg The National Cancer Plan.

Abstract number: 278
Presentation type: Poster
Poster number: P173

Denial as an obstacle to palliative care: a discourse analysis

Camilla Zimmermann, Psychosocial Oncology and Palliative Care, Toronto, CANADA

Denial of death is perceived as a significant problem in palliative care practice. This study uses the qualitative method of discourse analysis and Foucauldian social theory to investigate the term ‘denial’ in the contemporary hospice and palliative care literature. A Medline search (1970 to 2001) was performed combining the text words ‘deny’ and ‘denial’ with the subject headings ‘terminal care’, ‘palliative care’ and ‘hospice care’ and restricted to English articles discussing death denial in adults. The 30 articles were analysed using a content comparison and emerging themes regarding the meaning and usage of the words ‘deny’ and ‘denial’ identified. The theme of denial as an individual psychological process has been one separate paper. This paper examines the theme of denial as an obstacle to palliative care. Denial was seen as an impediment to several different aspects of palliative care including discussion of dying, (2) dying at home, (3) stopping ‘aggressive’ treatment, (4) advance care planning and (5) control of symptoms. I suggest that rather than only reflecting a patient’s psychological state, denial may be a construct or label that is a result of a certain way of delivering health care services and providing palliative care. Different models of service delivery may provide alternate ways of dealing with ‘denial’.

Abstract number: 279
Presentation type: Poster
Poster number: P174

METHADONE PRESCRIBING: KNOWLEDGE, ATTITUDES AND PRACTICES OF PALLIATIVE CARE PHYSICIANS IN THE UNITED KINGDOM

Rachel Thorp, Palliative Medicine, Glasgow, GREAT BRITAIN, Miriam Tadjali, The Ayrshire Hospice, Ayr, GREAT BRITAIN

The purpose of this study was to quantify frequency and practices of methadone prescribing and to elicit beliefs about its use amongst palliative physicians in the UK. A questionnaire was developed, piloted and distributed to all members of the Association of Palliative Medicine in the UK. 55.4% of questionnaires were returned (402/725). 89% had prescribed Methadone. In the last year, 37% had prescribed it 1–2 times, 22% 3–5 times, 20%>5 times. 24% had initiated a prescription in an outpatient setting. Overall 7% would consider using Methadone 1st line, but 47% for patients on maintenance therapy, 25% and 65% respectively would consider it for 2nd and 3rd line use. Renal failure, neuropathic pain and loss of responsiveness to another opioid were the most common reasons for its use. 64% stop morphine abruptly before commencing methadone. 85% choose a potency ratio with morphine, with the most common being 1:4. 64% used conversion regime (77%) was Morley and Makin (1). 84% found methadone effective often or sometimes. Most people found side effects (50%), administration (45%), provision (63%) and titration (64%) problematic but manageable. Methadone was most commonly used for breakthrough pain but more than half used a variety of opioids, 37% had switched from methadone to another opioid and 82% of these were successful. Predominant difficulties identified with its use were titration, lack of experience and stigma, for patients and the palliative care staff. Most respondents commented on its efficacy, particularly in neuropathic pain and low toxicity and cost. There is a relative lack of experience in the use of methadone and it is mainly reserved for 3rd line use in in-patients. Education of health care workers and the development of guidelines may help build experience and confidence and also to support other opioids. References (1) Morley JS, Makin MK. The use of methadone in cancer pain poorly responsive to other opioids. Pain Reviews 1998;S.51–58.
Abstract number: 280
Presentation type: Poster
Poster number: P175

Development of Palliative Care in Zambia
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Palliative Care development through the home based care system is the result of the HIV/AIDS epidemic and has been in existence for years without recognition or support from the Ministry of Health (MoH). As a result of conditions in many villages (cramped quarters, no water or power) communities requested that hospice in-patient units be formed. The largest and oldest HIV/AIDS NGO in Zambia, Kara Counseling and Training Trust, currently has 3 hospices in the country and there are another 3 faith-based hospices and 2 faith-based paediatric hospices in development. In August 2004, following the first national palliative care conference sponsored, in part, by CARE International, Help the Hospices and Hospice Uganda, the Palliative Care Association of Zambia (PCAZ) was formed and has been recognized by the MoH. Its mission is to represent and advocate for palliative care training and excellence in Zambia, with the support of its members as well as donors and other outside organizations.

Abstract number: 281
Presentation type: Poster
Poster number: P176

Bordering on the impossible – Striving to combine quality and coverage in Africa
Kath Defilippi, Board Chair, Port Shepstone, S. AFRICA

This is the dream of the recently formed African Palliative Care Association (APCA). The inaugural AGM took place in Arusha, Tanzania in June, 2004 and was attended by 22 African countries, 7 of which are represented on the duly elected Board. In a continent beset by the HIV/AIDS pandemic and poverty with what is arguably, the greatest need for palliative care in the course of human history, only 5 African countries boast established palliative care programmes. South Africa and Uganda also have a comprehensive educational infrastructure in place. In keeping with WHO’s public health approach to palliative care, three Board Committees were formed – Advocacy, Education/Training and Standards. Each committee comprises skilled and experienced interdisciplinary African palliative care professionals. A team drawn from the board committees promotes culturally sensitive palliative care at Governmental and programme level, in countries requesting assistance. Activities include: Meeting key people in Health Ministries to advocate for the drugs and policy necessary to palliative care (morphine is currently illegal in parts of the continent); Conducting a situational analysis and providing training to draft palliative care onto existing home care programmes; Introducing clinical and non-clinical standards to enable organizations to provide quality palliative care that includes effective pain and symptom control, treatment of opportunistic infections and holistic support. APCA plans on scaling up existing best practice African models. Financially challenged organizations will be reimbursed for the time given to APCA by key employees via a development fund established for this purpose. Co-ordination by a highly motivated Board and Executive Director make the realisation of this dream a distinct possibility.

Abstract number: 282
Presentation type: Poster
Poster number: P177

How is spiritual care (SC) understood and practised at the end of life in the UK? A critical literature review.

Whilst general agreement exists that spiritual and religious needs are different, debate and confusion remain as to the definition and nature of SC. Aim To undertake a literature search to understand how SC at the end of life is understood and practised in the UK. The review sought to: explore the various definitions gain an understanding of the language used in academic studies; examine how SC is interpreted and practised in the UK at the end of life, and based on this, offer practical suggestions that will take health care professionals research forward in this area. Method Validated qualitative method to review the literature relevant to SC at the end of life. Results 17 studies met the inclusion criteria. a)Most were by nurses and/or chaplains. b) There was a lack of research in the medical literature. c) Broad agreement exists between professionals and patients that SC at the end of life is important. The notion of ‘being there’ for the patient and ability to give of oneself were particularly strong themes. The use of narrative in these papers was effective at emphasising the point. a) A universal weakness was an absence of authors’ declaration of their own beliefs and how these may have influenced the construction of their studies and conclusions drawn. Conclusion: Definitions of SC may be useful for professionals, but patients seem to talk of SC more as a concept. Some staff are better at giving SC than others. Stories told by patients and professionals might equip staff better to understand and provide SC at the end of life than conventional qualitative or quantitative studies of large populations. It seems mandatory that research in the area should be conducted. b) proxy carers (a) national and regional organized health care). Needs of severely ill and dying patients and their carers in Switzerland – results from part I, focus-groups interviews
Steffen Eychmueller, Palliative Care, St. Gallen, SWITZERLAND, Daniel Haegi, University Berne, Berne, SWITZERLAND, Livelotte Dietrich, Kantonsklinik, St Gallen, SWITZERLAND, Orest Weber, University Lausanne, Lausanne, SWITZERLAND

Aim: To determine the detailed needs of people in Switzerland suffering from far advanced disease and the needs of their professional and lay carers. To create a baseline for future interventions and planning on a local, regional and national level.
Method: In a first step, 26 focus groups (3–10 participants) in 3 different language regions (german, French, italian) with 3 different target groups (a) physicians and b) nurses from different working backgrounds, c) patients and proxy carers) have been performed in order to create a semi-structured questionnaire for the second part of the survey.
Results: The needs differ enormously not only between the target groups, but also within the same group, working background and language region. Common needs of all groups can be found in the area of information, cooperation and attitude. Interviewing a large number of severely ill patients may not turn out as feasible for the second part. The methodological development of the second part of the national survey has been changed in consequence. The findings indicate that choosing “indicator patients” and focussing on qualitative interview would probably be more appropriate. The following domains seem to be adequate and more reliable for the Swiss situation (lack of national databasis, regional organized health care).

Abstract number: 285
Presentation type: Poster
Poster number: P180

PROGRAMME METHODOLOGY AND EDUCATION IN THE PALLIATIVE CARE
Michèle Galluccio, Ospedale di Desio, Desio (Mi), ITALY, Arianna Cozzolino, UOCP ospedale di Desio, MILANO, ITALY, Maria Da CoI, Ospedale di Cuggiono – Legnano, Legnano, ITALY, Donato Di Pietropaolo, Azi L’Anciano – Vasto, Vasto, ITALY, Maria Borsari, Azi Modena, Modena, ITALY

Italian School of Medicine and Palliative Care, Milano (I.S.M.Pa.) The educational aim of the Italian School of Medicine and Palliative Care (SIMPa), that since 1991 has been organising post based courses for doctors and nurses, is represented by the Terminal Care. The SIMPa curriculum is divided in two sections, each of them composed by the following modules: clinical, organisation, ethics, communication, anthropology. Some of the advanced teaching methodology, used during the course, are showed in the below chart.
Each year some 25,000 (0.5%) of the 5.3 million people in the Hashimite Kingdom of Jordan die; and 70% of the 3,300 or more new patients with cancer present with stage IV disease. While the Al Na'Arah Foundation for Humanitarian Care has provided end-of-life care to more than 600 patients over the last decade, palliative care services have not been available to most of the Jordanian population. It is only recently that we could benefit from them. Since 2001, the Jordan Pain Relief and Palliative Care Initiative, a collaborative effort of the Jordan Ministry of Health, WHO Jordan, the King Hussein Cancer Center, Ikima Pharmaceuticals, San Diego Hospice & Palliative Care, Capital Hospice of Virginia, the EPEC and ELNEC Projects, and a visionary philanthropist, has been making a difference nationally. After an initial policy workshop in August 2003, the efforts of a National Committee working with the Jordan Ministry of Health has led to changes in opioid prescribing and dispensing regulations. To ensure adequate opioid availability, opioid importation has increased and local production and distribution of oral immediate release morphine tablets has begun. In March 2004, an international faculty presented the first 3-week introductory course in palliative care to 32 physicians and nurses from across the country. After 1 week of interactive sessions in the classroom based on the EPEC and ELNEC curricula, and 2 weeks of bedside mentorship the participants demonstrated significant changes in their attitudes, knowledge and skills. During the course multiple patients benefited from some of the first oral immediate-release morphine morphine delivered in the country. Since April 2004, the clinicians have returned home to provide palliative care to patients and families in their acute and cancer care facilities and develop palliative care services. As of October 2004, the first palliative care consultation service has been established at King Hussein Cancer and an inpatient hospice unit will open there shortly.

Abstract number: 287  
Presentation type: Poster  
Poster number: P182

Beyond Words: The Use of Creative Arts as a Coping Strategy for Palliative Care Professionals
Heather Wiseman, Specialist Palliative Care Team, Liverpool, GREAT BRITAIN
There is increasing interest in the use of creative arts in palliative care as a means of accessing the ‘deep level’ in the dying person (Mayo 1996). Little however is written about the potential benefits of such an approach as a coping strategy for palliative care professionals, despite the recognition that working with dying patients and their families presents challenges, stressors and difficulties and can lead to burnout. ‘Beyond Words’ is a collection of artwork created recently, mainly picture/word collage, crayon and paints which gives an insight into the world of a palliative care nurse specialist and some of the issues that health care workers encounter. The poems address themes such as grief due to anticipated death versus sudden death, grief due to death versus separation or exclusion, managing repeated losses in the workplace versus personal loss, the hiding versus openness of death, the philosophy of a ‘good death’ and the feelings that arise when reality falls short of the ideal, work versus leisure, we teach as professionals versus what we experience as people and communication issues including disclosure, denial, anger and collusion. Spiritual and philosophical issues are explored including the importance of hope and the concept of life after death. The creative arts enhance communication by making inner and emotional life accessible to consciousness and enable expression of feelings for which language alone may be inadequate. Such methods may be useful to individuals working in palliative care and in clinical supervision of palliative care staff. Reference Mayo S. Symbol, metaphor and story. Palliative Medicine 1996; 10: 20–21

Abstract number: 288  
Presentation type: Poster  
Poster number: P183

Welfare benefits service audit demonstrates high need and good outcomes
Malcolm Payne, Psycho-social and Spiritual Care, London, GREAT BRITAIN
An audit of a specialised palliative care welfare benefits advocacy service included three elements: a prospective study of all patients referred during a typical three-month period during 2003 to identify benefits dealt with and outcomes, and retrospective studies of samples of multiple referrals. The audit period was the period to assess appropriateness of referral and of a 50% systematic sample of all cases that received more than 20 contacts from welfare advice staff to assess needs in complex cases. The service is a specialised part of social work provision in a large UK hospice. The study demonstrated inconsistent referral by nursing staff, the main referrers, a large workload, including frequent complex cases involving from twenty to more than a hundred contacts and achievement of benefits and grants for patients, carers, and institutional patients, in excess of the cost of the service. Provision of specialised welfare benefits advocacy for palliative care patients is likely to meet a substantial need and to require specialist provision.

Abstract number: 289  
Presentation type: Poster  
Poster number: P184

Chemotherapy may not be of benefit for patients (pts) with non-resectable cancer of the bile duct system
Cristian Massacesi, Medical Oncology and Radiotherapy, Ancona, ITALY, Giordano Galeazzi, 2Oncology Institute of Marche for Supportive Care (IOM), Ancona, ITALY, Fabiana Marcucci, Medical Oncology and Radiotherapy, Ancona, ITALY, Lorenza Franciscio, Medical Oncology and Radiotherapy, Ancona, ITALY, Maurizio Bomsignori, Medical Oncology and Radiotherapy, Ancona, ITALY, Malcolm Payne, Psycho-social and Spiritual Care, London, GREAT BRITAIN
Background: In unresectable cancer of the bile duct system, both gemcitabine (GEM) and 5-FU/LV showed moderate activity. We studied an alternate regimen of GEM and 5-FU/LV. Material and Methods: From Jan 2002 to Aug 2003, 11 patients with non-resectable histologically or cytologically proven cholangiocarcinoma of the common bile duct, or gall bladder cancer, chemotherapy-naive, and with measurable disease were included in the study. The regimen consisted of GEM 1000 mg/m2 i.v. 30-minute infusion, on day 1, alternate with 5-FU, 400 mg/m2 i.v. bolus and 600 mg/m2 i.v. 24-hour infusion, and LV, 200 mg/m2, i.v. 2-hour infusion, on days 8 and 9; cycles every 2 weeks without rest. Results: Pts characteristics: M/F:5/6; ECOG PS 0/1/2 in 4/5/2 pts; median age 63 years (27–74); 4 pts had metastatic disease, and most patients had altered hepatic function. A total of 63 cycles were administered. NCI grade III/IV toxicities were (pts): VBC 1/0, NEU 2/0, platelets 1/0, SGOT/SGPT 2/0, diarrhea 1/0. One death due to sepsis and palliation after first cycle. Ten pts were evaluable for response: SD in 4 pts and PD in 6. Median time to progression was 3.8 months (1.6–11.5). According to Simon two-stage design (P1=0.30), with no objective responses observed in the first 10 pts, the study was terminated early. Conclusion: The regimen we employed did not show appreciable antitumor activity. Therefore a better selection of patients is needed, with a part of them that should be receive supportive care only.

Abstract number: 290  
Presentation type: Poster  
Poster number: P185

Patient access to palliative home care: the role of caregiver age
Gunn Grande, School of Nursing, Midwifery and Social Work, Manchester, GREAT BRITAIN, Meseg Faqghi, GPPCRU, University of Manchester, Cambridge, Cambridge, GREAT BRITAIN, Stephen Barclay, GPPCRU, University of Cambridge, Cambridge, GREAT BRITAIN, Chris Todd, School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, GREAT BRITAIN
Background: research has shown that older patients are less likely to receive palliative home care than younger patients. As the age of primary carers correlates positively with patient age, part of the reported bias in access may be due to carer age rather than patient age. Greater work commitments or effectiveness in advocacy may e.g. enable younger carers to obtain more help. Objectives: to investigate the relationship between both carer and patient age and access to palliative home care. Method: descriptive, quantitative analysis of 123 patients referred to a hospice at home service whose primary carer could be identified and agreed to an interview (57% response rate). Data were collected through linkage of electronic records of health service input and carer post bereavement interviews. Results: patients who received specialist nurse advice (Macmillan nurse) and palliative home nursing (Marie Curie care) were both younger and had younger carers than patients who did not. Of patients referred to hospice at home, those admitted to the service had younger carers (t-tests, all p<0.05). Logistic regression analyses controlling for cancer/non-cancer diagnosis, patient and carer sex and socio-economic status showed that carer age, but not patient age, independently predicted Marie Curie access alongside diagnosis. Both patient and carer age independently predicted access to Macmillan advice alongside diagnosis. Age of the carer was the only variable to predict admission to hospice at home (all p<0.05). The presentation will consider how carer employment, relationship with the patient and length of caregiving period inform patterns observed. Conclusion: Carer age may be a more important variable than patient age in predicting home care access. Thus we may need to consider the carer’s role more closely in order to improve access to palliative home care for older patients.
Abstract number: 290  
Presentation type: Poster  
Poster number: P186

The volunteers in the Home Hospice in Wroclaw  
Malgorzata Rosolowska, Palliative Medicine Clinic, Home Hospice, Wroclaw, POLAND, Renata Opalinska, Palliative Medicine Clinic, Home Hospice, Wroclaw, POLAND, Jolanta Zietek, Palliative Medicine Clinic, Home Hospice, Wroclaw, POLAND

Palliative Medicine Clinic and Home Hospice in Wroclaw is a part of the multidisciplinary team (doctors, nurses, psychologists, social workers, physiotherapists, chaplains), providing ambulatory and home care for about 1000 cancer patients per year. Their work is supported by volunteers. In Sept. 2004 there were 133 registered volunteers, 64 being active at that moment. These active volunteers were 11 men and 53 women aged 22–72, mean age 40. 80% of volunteers were persons with high education, different professions: economists, teachers (also at the university), lawyers, physicians, engineers, students (11 from Medical University). The work of volunteers is coordinated by social worker. The volunteers have different tasks: they care for the patients, provide respite care for families, help the families with everyday obstacles, help the children, provide bereavement service, and also help with some administrative work of the Team, help with organization of events, excursions and other events. All volunteers completed the course organized by the Team and meet at monthly meetings. They also take part in conferences and lectures concerning palliative and hospice care. Since 1997 the volunteers have been engaged in the care of 493 patients. In 2004 from June to August 20% of patients received help from the volunteers.

Abstract number: 292  
Presentation type: Poster  
Poster number: P187

GASTRIC CANCER AND PALLIATIVE CARE  

The Palliative Care Unit of Porto is integrated in an Oncologic Hospital. We evaluated the patients admitted in this Unit with gastric cancer, since the opening in October 1994 to December 2002. In a total of 2491 patients admitted in that period, there were 351 patients admitted with gastric cancer diagnosis. We report a retrospective study of 150 representative patients, chosen randomly. We focused their statement at the time of the diagnosis, the resection or not resection and bypass procedure. After the admission in this Unit, we evaluated the ECOG status performance, metastasis sites, symptoms and outcome (since the timing of the diagnosis and the admission in the Palliative Care). After the analysis of these 150 patients, we found that 72.6% were classified in stage IV (cancer staging), 32% had ECOG 3 and 36.7% had ECOG 4. Pain was present in 72%, dyspnea and 22% presented intestinal obstruction. The outcome patients since the timing of the admission was 62 days. The patients with gastric cancer whose evaluation of the patients admitted in our Unit and we found that a significative number of patients presented already advanced cancer at the time of the diagnoses. We believe that these results may suggest that these patients should be admitted in our Unit early, so that we could give them a better quality of life and control of symptoms till their death.

Abstract number: 293  
Presentation type: Poster  
Poster number: P188

COOPERATION WITH VOLUNTEERS IN THE PALLIATIVE CARE  
Jean Puyrin, Patient Care, Eindhoven, NETHERLANDS, Van den Eynde, Centre voor HuisartsenGeneeskunde, University of Antwerp, Antwerp, BELGIUM, Theo Koks, Comprehensive Cancer Centre South/IKZ, Eindhoven, NETHERLANDS, Annette Courtens, Comprehensive Cancer Centre Limburg/IKL, Maastricht, NETHERLANDS, Marijke de Hulst, Comprehensive Cancer Centre South/IKZ, Eindhoven, NETHERLANDS

In this project caregivers and researchers from Belgium and The Netherlands work together in order to improve the cooperation between volunteers and professionals in the palliative care. At this moment in The Netherlands about 5500 volunteers (organized in VITZ) are available in the terminal care. Earlier research indicates that in relatively few cases they are called on their help. The work of volunteers is rather unknown in professionals and some professionals do not see them as serious caregivers. Interventions are applied in 3 sub-projects and are: agreements about coordination of care (tasks and competences are discussed with caregivers and their managers), a training for volunteers to improve cooperation with professionals and interventions aimed at professionals to improve their attitude and skills to detect the need of help from volunteers. Finally, a very specific intervention is the construction and application of an interprofessional network of experts, including volunteers who have much experience with the care of patients in the palliative phase. This panel provides palliative consultation through the internet. The interventions are monitored and process evaluations take place. The main goal of the study is to identify factors that facilitate or inhibit the co-operation between professionals and volunteers. The results of the analyses will be used for (local) implementation and for further spread of knowledge to other regions and countries. Successful experiences and products (e.g. protocols, checklists, folders) in one country are shared with the other country and regions and, if possible, implemented there. In this way efforts of innovation in palliative care are brought ‘beyond the border’.

Abstract number: 294  
Presentation type: Poster  
Poster number: P189

The role of rehabilitation and physical therapy in the palliative care  
Stelmachowicz Miroslaw, Palliative Medicine Clinic, Home Hospice, Wroclaw, POLAND, Jolanta Gontlach-Worobiec, Palliative Medicine Clinic, Home Hospice POLAND, Magdalena Rhyback, Lower Silesian Oncology Center POLAND, Anna Sulkowska-Smolinska, Lower Silesian Oncology Center POLAND

Rehabilitation (RH) in the Palliative Care is the way of caring those who are terminally ill to give them the power control over being active as long as possible. RH allows expanding the ‘physical space’ of patients; therefore they do not need to be ‘confined to bed’. The rehabilitation process is an important element of the teamwork, to improve the quality life. There are several important targets in the field of RH in palliative care: – Prevention of the outcomes of being immobile and to minimize it – ‘Treatment of bed sores and lymphoedema – Providing patients with orthopedic equipment such as: orthopedic corsets, crutches, walkers – The results of a cancer are not need to be ‘confined to bed’. The rehabilitation programme the family or other caregivers are involved in the program after previous training. In the year 2003 the multidisciplinary team performed 15012 home-visits, and 3 physiotherapists – 1809 visits that is 12% of the overall number. The largest group of our patients are those with the cancers of the breast, colon, female sexual organs and lungs. Conclusions: Our rehabilitation offers to a patient a unique chance to be active in the last term the life. Additionally it makes possible to be independent to some extent which is deeply beneficial to patient well-being.
The authors present the case of a 67-year-old prostate cancer patient with brain secondaries. The prolonged treatment with relatively high doses of steroids (dexamethasone p.o. and s.c.) was necessary. Attempts to cancel or lower the dose resulted in impairment of consciousness and worsening of the patient. After 6 months' treatment with steroids, during routine bi-weekly control of blood glucose, the hyperglycemia 500 mg% was found. The patient was hospitalized to the Endocrinological Clinic and treatment with insulin was settled. The patient returned home, still taking steroids. His quality of life was good, he was fully conscious; in February 2004 he wrote an impressive letter about his existential feelings concerning coming death. The authors discuss the problem of using steroids in the patients with brain metastasis, comparing with diabetes in palliative care. They concluded, that palliative care doesn’t mean exclusion of intensive treatment of correctable symptoms that resulted in improving quality of life as well as can prolong life of the patient.

Abstract number: 297
Presentation type: Poster
Poster number: P192


Josep Porta-Sales, Palliative Care Service, L’Hospitalet-BCN, SPAIN, Maria Nahal-Vicuña, Hospital Universitari Arnau de Vilanova, Lleida, SPAIN, Jesús González-Barboteo, Instituto Català d’Oncologia, L’Hospitalet-BCN, SPAIN, Josep Planas-Domingo, Hospital de l’Esperança, BCN, SPAIN, Joan Carulla-Torrens, Hospital Universitat de la Vall de Hebron, BCN, SPAIN

Aim: Compare the prognostic capability of three prognostic models (PaP score, PPI, and IS) for a cut-off point of 30 days. Method: Unselected far-advanced cancer patients admitted in Palliative Care Units were enrolled consecutively. Were excluded younger than 18 y, treated with Chemotherapy 4 wks previously recruitment, haematological neoplasm, impending death, and participation refusal. The 3 prognostic models used were PaP score (Maiton), PPI (Mori), and IS (Porta). Follow-up as 12 wks because is the maximum time allowed in the Clinical Prognostic Score in the PaP score. Results: 99 prognostic evaluations (PE) were done in 85 patients; 8 patients had 2 PE, and 3 patients had 3 PE. Mean age was 66.6 y, and 65.9% were men. Mean survival of the sample was 23.7 days, with a median of 17 days. The PaP score classify correctly patients surviving more than 30 days with a sensibility (S)=1 and specificity (E)=0.32. The PPI reach a S=0.81 and E=0.55. The 3 models obtain a S=0.50 and E=0.71. ROC curves shown a area under curve in the PaP score=0.708, PPI=0.662 and IS=0.605. Conclusions: None of the model has a good S & E. PaP score has a great S for patients surviving more than 30 days, but its E is very low. In the other side, IS has an acceptable capability in prognostic survival less than 30 days. PPI has E > S among PaP and IS. Definitive data were required, but new models, universally validated are needed.

Abstract number: 298
Presentation type: Poster
Poster number: P193

Pathological Fractures in Cancer Patients: Can they be Prevented?

Helen Emmis, Wirral, GREAT BRITAIN, Nicholas Emmis, Wirral NHS Trust, Wirral, GREAT BRITAIN, Michael Hennessy, Wirral NHS Trust, Wirral, GREAT BRITAIN

Introduction: Prophylactic fixation of long bone metastases is generally easier for the surgeon and less traumatic for the patient. Risks associated with pathological fractures and their management in cancer patients are high. Could these risks be reduced in the clinical setting by early detection of bony metastatic disease requiring prophylactic fixation? Aim: To assess the number of pathological fractures presenting in a British district general hospital and whether these could have been prevented. Methods: A retrospective review of cases was performed on patients presenting with a pathological fracture in a 12 month period. Data was collected including cancer diagnosis, known presence of bony metastatic disease, site of fracture and preceding symptoms. Results: 16 patients were included; median age 71 years (range 38-90). The commonest primaries were breast 5/16 (31.3%) and lung 4/16 (25%). At the time of fracture 5/16 (31.3%) were known to have bone metastases. Prophylactic surgery had been considered but not performed in 1/5 (20%). In 2/16 the fracture was the presenting feature of their malignancy. 9/16 patients had a history of uninvestigated pain at the fracture site for a median of 8 weeks (range 2-26 weeks). There were 8 spine, 6 long bone and 5 femoral neck fractures. All spinal fractures were treated conservatively with analgesia and 4/5 patients had subsequent radiotherapy. Other all fractures were treated surgically and 11 were too unwell for post operative radiotherapy. 1/11 had previously had radiotherapy to the fracture site. Conclusions: We recommend that in cancer patients, reports of bony pain should be promptly investigated and managed in accordance with British Orthopaedic Association/ British Orthopaedic Oncology Society guidelines. Risk of fracture can be predicted using Mirels’ scoring system.

Abstract number: 299
Presentation type: Poster
Poster number: P194

Discharging terminally ill patients back to hospital from a hospice: A retrospective study

Lynette Ngo, Medical, Singapore, SINGAPORE, Noreen Chan, Dover Park Hospice, Singapore, SINGAPORE

Transfer of terminally ill patients back to hospital from the hospice has been viewed negatively as an event with adverse impact on the patient and his family. However, few studies have undertaken to determine the reasons for readmissions to hospitals, the outcomes of the hospital admissions and positive or negative predictors of patient outcomes. A retrospective analysis was performed on the discharge records of patients who have been discharged from Dover Park Hospice to hospitals between the period 1 September 2003 and 1 September 2004. There were 148 patients and 253 discharges with an equal number of male and female patients. The main reason for discharge of patients back to hospital was for specific therapeutic interventions which were not available in the hospice setting. Majority of patients were discharged back to the hospice after a short period of hospitalisation. Patient outcome with regards to mental status, place of death and need for intervention were all major factors in majority of patients after discharge from the hospital. Resolution of the symptom or problem requiring hospitalisation was achieved in most cases as well. However, mobility and activities of daily living remained the same after hospitalisation. Most patients survived 1 to 3 months after discharge from the hospital. It is thus concluded that there is a role for hospitalisation of terminally ill patients, especially where there is an acute medical problem with a clear indication for specific therapeutic intervention, where it is imperative that the goals of management in transferring patients back to hospitals are discussed and understood by the patient and his family to avoid unnecessary and futile medical treatment.

Abstract number: 300
Presentation type: Poster
Poster number: P195

The influence of NSAIDs, corticosteroid and prostogen therapy on selected parameters of cancer cachexia syndrome

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The aim of study was to establish the correlation between grade of cachexia and possible endocrine, selected non endocrine factors and type of therapy. The examined group included 60 patients with different grade of cachexia. In each patient, basic biochemical and selected hormonal parameters, serum level of cytokines (IL-6, TNF-a), insulin and IGF-1 levels were estimated. Parallely the personal card of symptoms control, type of therapy, activity (Karnofsky’s scale) and depression (HADS scale) was described. Disturbances of T4 conversion to T3 – low T3 syndrome, high re-vers-T3 values, low/normal insulin and IGF-1 levels, higher than normal cortisol values with abnormal regulation of secretion in hormonal examination were observed. The statistically significant, positive correlation between weight loss and anorexia, pain intensity, grade of depression and anxiety, higher values of cortisol was detected. Tendency to mild/moderate anaemia, hypoproteininaemia and abnormal regulation of glycaemia (higher then normal cortisol level together with cytokines leads to insulin resistance, tendency to postprandial hyperglycaemia, which inhibits appetite after small meal administration, following the evaluation was detected. The corticosteroid or prostogen therapy, especially used with NSAIDs, decreases TNF-IL-6 and high cortisol levels, increases appetite, but long-term treatment can inhibit hypothalamic–pituitary–adrenal axis. The cancer cachexia is the result of multiple factors. Chronic, higher then normal, cortisol level

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induces depression, protein degradation (together with TNF-a, especially in skeletal muscles mass), lipolysis, higher liver glucose production, glucocorticoids, and together with cytokines leads to insulin resistance. In our opinion pain control, treatment of nausea, anti-depression therapy (psychic state), nutritional support, improvement of appetite and progestogen therapy are the best way in the treatment of cancer cachexia.

Abstract number: 301
Presentation type: Poster
Poster number: P196

FOUR YEARS OF HOSPICE HOME CARE ACTIVITIES BY VOLUNTEERS
Matija Rimac, Vice-President of the Croatian Society for Hospice/Palliative Care, CMA, ZAGREB, CROATIA-HRVATSKA

In Croatia the single practical hospice unit is driven by health professionals acting voluntarily. The interdisciplinary home care team is made up of four medical doctors, nurses, social workers, psychologist and physical therapist supported by volunteers of other professions. The headquarters are at Regional Hospice Centre, Zagreb, Hrvceva 1, owned by civil association – Croatian Association of Hospice Friends. The administration, visits records and home care aids storage is there. There are also weekly consultation meetings held, and the education courses of different profiles, as well. The non health professional are trained at supervised at visits in an home for elderly and disabled. The most appropriate are selected for home care visits. They have also weekly supervision meetings conducted by volunteers coordinator. The number of new patients requiring for PC has increased from 45 in year 2000 to 207 during first 9 months in 2004. The time has come in which the voluntary activity must be changed into the full time engagements of the staff and the Institution for palliative care organized. The Committee for Palliative Care of Ministry of Health, succeeded in implementing into the Health protection law the institution consisting of three main units: Home care visits, Outpatient department for pain and palliative care, and Hospice day centre. It should be the solid base for further development of practical and educational issues.

Abstract number: 302
Presentation type: Poster
Poster number: P197

DEVELOPING THE PALLIATIVE THERAPY NETWORK OF THE LOCAL HEALTH AUTHORITY IN REGGIO EMILIA
Daniela Ricco, Health Management, Reggio Emilia, ITALY, Rosanna Carbognani, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Daniele Govi, Reggio Emilia Health Authority, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Cristina Pedroni, Reggio Emilia Health Authority, Reggio Emilia, ITALY

Background The development of a palliative therapy network is inherently tied to the acquisition of specific skills and tools that allow professionals to better orient their activity, centering it around the patient and his or her family, with a full grasp of the physical, psychological, and social repercussions that stem from the progression of the illness. Goals The primary goal of the work underway is to plan and test the cooperative creation of treatment plans for oncologic patients, from a procedural standpoint in which a palliative approach is useful even in earlier stages of the disease. Rethinking the treatment program, as a process that from the very beginning is developed around a co-opted empowerment of the patient and his or her family. Methods The working group ‘Palliative Treatment and Pain Therapy’ has agreed on the importance of tackling questions related to the care program of the patient, in all of their complexity. Stages of the project: 1) Theoretical reinterpretation of the care program for the patient 2) Sharing with professionals of the care network of the needs and the ‘theory-based’ planning of patient programs 3) The training sessions were a foundation for directing the work of professionals towards goals to be pursued in the development of the palliative therapy network, proposing work methods that unite organizational and professional outlooks. 4) The theory-based program was fitted into the local context in smaller working groups Evaluation Assessment on the basis of the indicators which have been identified is to take place six months from the beginning of the experiment.

Abstract number: 303
Presentation type: Poster
Poster number: P198

PALLIATIVE CARE NETWORK (PCN) IN THE DISTRICT OF LUOGO OF RAVENNA-ITALY
LUIGI MONTANARI, ONCOLOGY SERVICE, LUGO, ITALY, ILARIA STRADA, ONCOLOGY SERVICE, LUGO, ITALY, ANNA RITA FUGGETTA, ONCOLOGY SERVICE, LUGO, ITALY, MARIA CONSOLGINI-DEBOSCH, ONCOLOGY SERVICE, LUGO, ITALY, GIORGIO CRUCIANI, ONCOLOGY SERVICE, LUGO, ITALY

Purpose The Country of Ravenna has a population of 350.000 inhabitants. In this Country there are 3 Districts (Ravenna, Lugo and Faenza). Every year about 350 people die of cancer in the District of Lugo. In April 1993 a PALLIATIVE HOME CARE UNIT (PHCU) was activated in the District of Lugo to permit the terminally ill to spend their last days at home. Up to now, among the patients entered into PHCU (50% of terminally ill cancer patients) died at home, but 70% of all patients with advanced cancer in our province spent days of life in Hospice. We have proposed a project of Palliative Care Network connected with the Department of Oncology of Ravenna Objectives: to achieve a Program of Continuous Care in patients with advanced cancer; reduced hospitalization days; evaluation of Quality of Life; evaluation of symptom control and quality of assistance; realization of Video-Tele-Assistance Network and Computerized Clinical Chart Methods. Palliative Care Network Palliative Care Unit in Lugo Hospital (10 beds); Hospice in the District of Lugo (6 beds) Palliative Home Care Service in the Sub-District of Lugo (15 Patients) Home Care Service with Medical Practitioners Palliative Care Ambulatory Day Hospice Results. Actually is activate the Hospice of Lugo with 5 beds for Terminally Ill Patients, The Palliative Home Care Unit whist 15 patients simultaneously and Video Tele Assistance for patients with necessity of intensive care. The Palliative Care Network of Lugo: 1 Medical Doctor Head of Medical Oncology Department of Lugo, 1 Medical Doctors of Medical Oncology Department of Lugo and 5 Therapeutic Doctors of Oncology Institute of Romagna and National Association of Tumors of Bologna 1 Head Nurse and Nurses of A-URL of Ravenna and of Istituti Rumini of Lugo 1 Psychologist 15 Volunteers

Abstract number: 304
Presentation type: Poster
Poster number: P199

Palliative Care in the Emergency Department
Marian Conroy, Palliative Medicine Department, Dublin 4, IRELAND, Eoin Tiernan, St. Vincent’s University Hospital, Dublin, IRELAND, Joan Cunningham, St. Vincent’s University Hospital, Dublin, IRELAND, Aoife Gleeson, St. Vincent’s University Hospital, Dublin, IRELAND, John Ryan, St. Vincent’s University Hospital, Dublin, IRELAND

Though a majority of terminally ill patients prefer to be cared for and die at home, up to 66% of all Irish deaths take place in hospitals or institutions. Following a crisis at home, many patients attend Emergency Departments (ED). Objective: To examine ED attendances by palliative care patients; to determine their appropriateness; to identify any potential for improving systems. Methods: Those patients seen by the palliative care service over a 12-month period who subsequently attended ED were identified from hospital computerised databases. Patient notes were reviewed for details and outcome of attendances. Results: 67 of the 657 patients seen by the palliative care service over the study period subsequently attended ED. 37 were known to the palliative care homecare team; 30 were not, and had only been seen previously by the hospital palliative care team (HPCT). There were a total of 81 ED visits – 56 admissions to hospital, 20 discharges from ED, 3 deaths in ED, 1 patient did not wait and 1 unknown outcome. Only 4 patients were seen by the HPCT in ED. Average time in ED: 1 hour. Conclusions: Better availability and utilisation of community palliative care resources could reduce the number of terminally ill patients requiring attendance at ED and possible admission to acute hospital. Early review by the HPCT in ED may assist patients being admitted or discharged to the most appropriate service.

Abstract number: 305
Presentation type: Poster
Poster number: P200

PAIN THERAPY IN THE CARE OF THE ONCOLOGY PATIENT
Daniele Govi, General Care, Reggio Emilia, ITALY, Daniela Ricco, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Rosanna Carbognani, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Daniela Ricco, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Paolo Antonito Magnani, Reggio Emilia Health Authority, Reggio Emilia, ITALY, Cristina Pedroni, Reggio Emilia Health Authority, Reggio Emilia, ITALY

Pain is a symptom that frequently restricts the quality of life of the oncology patient in advanced stages of the disease. Attention to pain and its management are basic intervention that must be more widely fostered in the healthcare field, overcoming notorious prejudices about the use of opioids. It is necessary to work for the integrated involvement of different healthcare professionals in programs organized within the network of treatment which, in our context, envision the ongoing therapeutic responsibility of the General Practitioner 1. To widely foster a
Decision Support and knowledge driven collaborative practices in Palliative Care – PALLIANET

T Boez, Palliative Care, London, GREAT BRITAIN, Anne Carruthers, Guy’s & St Thomas’ Foundation Trust, London, GREAT BRITAIN, Frank Baldesare, Guy’s & St Thomas’ Foundation Trust, London, GREAT BRITAIN

The PALLIANET Project is co-funded by the EU IST Research Programme. This presentation addresses the role of improving communications and real time access to information amongst palliative care provider networks, to improve the quality of care. It reports on a research project, PALLIANET – Decision Support and knowledge driven collaborative practices in Palliative Care, which focuses on the improvement of collaborative practices in palliative care networks. It enables a Palliative Care Team (PCT) to support allied professional care providers, both medical & non-medical professionals, in – Better understanding the patient’s context (clinical, psychological & social dimensions). – Making information available anytime/anywhere to support decision making processes. The benefits expected from the approach are – Reduction of time spent & costs by PCT members to prepare for a patient’s discharge – following the role of the social worker in terms of: – providing and developing appropriate education for health professionals. – supporting all care providers at the point of care – providing and developing appropriate education for health professionals.

Abstract number: 306
Presentation type: Poster
Poster number: P201

Patients discharged from a palliative care unit: The role of the social worker

Luc Plassais, Palliative care, Paris, FRANCE, Annie Frapsauce, Hospital Cognacq-Jay, Paris, FRANCE

This prospective study analyses the evolution of the patients who were discharged from the palliative care unit of Cognacq-Jay hospital over the January 1st-September 30th period. During this period, 220 patients were admitted into this 20-bed unit, of whom 22 – that is 10% of all admissions – were eventually discharged. The discharged were 6 men and 14 women (one woman was discharged on three different occasions). All were terminal ill cancer patients in the advanced stages of the disease with short-term life prognosis (average stay in the unit is about three weeks). 3 patients were transferred to and other palliative care unit. 1 was transferred back the medical oncology unit. 1 was transferred to a retirement house. 2 discharged wanted to die at home went home with life spans that had not been considered viable upon their admission. The study aims at specifying the role of the social worker in terms of: – preparing for a patient’s discharge = following up the patient, mostly at home, after the initial ICU care and support provided by the palliative care unit staff as part of the end-of-life treatment. The study also points out the required conditions (which necessarily have to be) that all allowed the discharged patient to fulfill his or her desire to live.

Abstract number: 308
Presentation type: Poster
Poster number: P203

Morphine: Delusion and inexperience

Nataša Miljković, Oncology Dept., Belgrade, SERBIA AND MONTENEGRO, Jasmina Gutović, Medical Center, Belgrade, SERBIA AND MONTENEGRO

Serbia and Montenegro is one of the rare European countries where morphine hasn’t been established as a ‘gold standard’ for the management of severe chronic cancer pain. Aim: to explore the attitude of medical staff (doctors and nurses) towards the use of morphine for the relief of severe chronic cancer pain. Method: All doctors (n=131) and nurses (n=38) employed by University Medical Center ‘Bezanijska kosa’ were asked to answer a number of questions as a part of the larger questionnaire about palliative care. One of the questions was: do you think that the use of morphine is a drug of choice for management of severe chronic cancer pain? Results: All together 203 doctors (n=82) and nurses (n=121) completed the questionnaire. Among them 60 doctors...
ABSTRACTS OF THE 9TH CONGRESS OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE, AACHEN 2005

The provision of phlebotomy,

Abstract number: 311
Presentation type: Poster
Poster number: P206

PALLIATIVE CHEMOTHERAPY NEAR THE END OF LIFE: TOO LATE, TOO MUCH? A RETROSPECTIVE ANALYSIS OF 662 PATIENTS

Cataldo Mastromauro, Oncology, Venice, ITALY, Ottorino Nascimben, Department of Oncology, Mestre-Venice, ITALY, Michele Medici, Department of Oncology, Mestre-Venice, ITALY, Ardi Pambuku, Department of Oncology, Venice, ITALY, Adriano Paccagnella, Department of Oncology, Mestre-Venice, ITALY

OBJECT OF STUDY AND METHOD. We retrospectively reviewed 662 deceased patients (pts), out of 1105 treated with palliative chemotherapy from 01/01, 000 to 01/03/04 for locally advanced or metastatic cancer, in outpatient setting. Univariate and multivariate analysis (using Log rank test and Cox’s model) of pts characteristics were conducted to determine their effects on survival from the beginning of last chemotherapy (SURV LCT). Moreover we analysed duration (DUR) of LCT and residual survival (RES SURV) from last CT infusion to identify subset of pts treated for a short time and near the end of life.

POPULATION: sex (male: 382, female: 280); age (< 55yrs: 111, 55-70yrs: 314, 70yrs: 237), site primitive tumour (lung 231, colorectal 107, breast 101, other 223); N° previous chemotherapy lines (0: 324, 1: 177, 2-5: 3-45, >5: 23); PS of the date of disease at LCT (locally advanced 102, metastatic 560), performance status ECOG (PS) (0: 240, 1: 364, 2: 56, 3: 3). Median SURV LCT, DUR LCT and RES SURV LCT were respectively 47, 30 and 72 days treated respectively. RESULTS. At multivariate analysis the following factors influenced SURV LCT: FS (p < 0.004). AGÉ (p < 0.006), STATE OF DISEASE (0.04) and PREVIOUS CT LINES (p < 0.008). No correlation was seen with site or stage at diagnosis. LCT lasted less than 45 days in 290 pts (44%), 161 pts (24.3%) received last CT infusion within 30 days before death. This population had lower PS and shorter DUR LCT vs remaining pts (PS2 18% vs 5% and DUR LCT <45 days 74% vs 34%) CONCLUSIONS. In our sample we identified factors that were associated with shorter chemotherapy duration for palliative patients. Predicting pts likely to benefit from chemotherapy in terms of longer survival can help to optimize treatment and resource allocation. A needs assessment of patients under homecare during May to July 2004

Miriam Colleran

The object of study. A retrospective review of the homecare and inpatient charts was carried out on all the patients under homecare from May to July ‘04 inclusive. The aim was to determine the numbers of homecare patients who were receiving phlebotomy, bisphosphonates, red cell or platelet transfusion as outpatients in other institutions or in general practice. The purpose was to assess if patients may benefit from having these procedures available in day hospice. METHOD. The charts of 16 homecare patients were not available at the time of the retrospective review and hence, omitted. 14 homecare patients who were inpatients, in either the palliative care unit or a hospital and 2 patients who were ‘on hold’ the entire duration of their time in the study period were excluded. 197 patients with malignant and non-malignant disease were not included in the section of the review assessing the numbers of patients receiving intravenous bisphosphonates. Results: 32 patients had blood tests. 8 patients received either red cell or platelet transfusion was recorded. Of the 8 homecare patients who received transfusion during this three month period, 2 did not have recorded in their hospital notes that they were on full blood count. One patient was awaiting a red cell transfusion at the time of his first homecare visit. 193 patients with malignancy were included in assessing the numbers of patients who were receiving bisphosphonates. 16 patients received bisphosphonates, one of whom did not have any involvement recorded in her homecare notes. Of the patients with bone metastases, 13 died. Conclusion. The provision of phlebotomy, transfusion and the administration of bisphosphonates were not recorded in the charts. It means that the staff are not a record the full blood count on all the patients and it is not being documented in the charts.
Liverpool Care Pathway for the Dying Phase: implementation in the Netherlands by the Comprehensive Cancer Centre Rotterdam

Edith van den Aardweg, Comprehensive Cancer Centre, Rotterdam, NETHERLANDS, P Geurts, Comprehensive Cancer Centre, Rotterdam, NETHERLANDS, S.J. Swart, Nursing Home Antonius Ijselmonde, Rotterdam, NETHERLANDS, L van Zuylen, Erasmus MC-Daniel den Hoed Cancer Centre, Rotterdam, NETHERLANDS

Background – At the end of 2003 the research project ‘Care and quality of life in the dying phase’ started in the region of the Comprehensive Cancer Centre Rotterdam. Part of this project is the implementation of the Dutch version of the Liverpool Care Pathway for the Dying Phase (LCP). This abstract describes the co-ordinating role of the Comprehensive Cancer Centre in the implementation and use of the Dutch LCP.

Method – Following the general implementation method of the Comprehensive Cancer Centre the implementation process is supervised by a regional steering committee (RSC) in which a regional co-ordinator (RC) participates. The RC co-ordinates the implementation of the Dutch LCP in eight organisations. In each organisation a local co-ordinator (LC) is part of a local steering committee (LSC) that guides the local process. Local problems are discussed by the LSC with the RC on a regular base. If necessary the RSC is called in by the RC. The RC organises 3-monthly meetings during which LCs are educated and experiences are exchanged. A periodic newsletter informs all professionals involved.

Results – The organisations were prepared for implementation and use of the Dutch LCP by the RC. LCs and LSCs were appointed, local implementation plans were formulated and professionals involved were informed and instructed.

Discussion – During the process it became clear that LCs not only have a crucial function but also have a vulnerable position. Therefore input from the RC/Comprehensive Cancer Centre Rotterdam is an important factor in supporting and facilitating the implementation of the Dutch LCP. Thus a solid base is created for use of and research with the Dutch LCP.
ABSTRACTS OF INVITED LECTURES,
ORAL PRESENTATIONS AND POSTERS

9 APRIL 2005
Abstract number: 316
Presentation type: Invited
Poster number: 321

PHYSICIAN TRAINING IN PALLIATIVE MEDICINE

Marilène Filbet, Hôpital Geriatrique Du Val D'Auzergues, Aix, FRANCE, Frank Elsner, Universitätssklinikum Aachen, Aachen, GERMANY

The physician training in palliative medicine is a priority for provide the best quality of care for the patients and family. According to the core level of Care in palliative medicine, three level of training (A, B, C) will be defined. The objectives, the teaching methods and the content of the training programme will be proposed at the european level. For achieve this work an EAPC Task force is meeting since 2002. After a study of the situation in european country, for the pregraduate training and the post graduate training. The EAPC task force propose a recommendations for physician training in palliative medicine.

The objectives the content and the teaching methods for the pregraduate and post graduate programme will be discuss during the session.

Abstract number: 318
Presentation type: Invited
Poster number: 321

Centres of Excellence in Palliative Care – How to Define and How to Establish

Frank FERRIS, Medical Director, Palliative Care Standards/Outcomes, San Diego, U. STATES, Xavier Gómez-Batiste, Institut Catalá d’Oncologia, Barcelona, Spain

Around the world, palliative care has developed from many different roots. While everyone providing palliative care strives to relieve suffering and improve the quality of patients’ and families’ lives, there is considerable variability in the way palliative care is delivered. Some services provide care only at the end of a person’s life. Others provide care throughout the experience of chronic and life-threatening illness and bereavement. As palliative care becomes a recognized body of knowledge and skill, and it becomes much more prevalent throughout healthcare, the need for consistency and quality in the care that is provided and the need for ‘Centres of Excellence’ will grow. During this session, in addition to ‘meeting the experts’, participants will be challenged to consider: How do you define a ‘Centre of Excellence’ in palliative care? How and where should ‘Centres of Excellence’ be established? Are they built on quality improvement activities? Are there specific criteria or common examples from both Catalonia and Southern California will illustrate some of the possibilities.

Abstract number: 320
Presentation type: Invited
Poster number: 322A

Audit in Palliative Care – does it work?

Irene J Higginson, Department of Palliative Care and Policy, London, UK

Clinical audit is the systematic critical appraisal of the quality of clinical care, including the procedures used in diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient. Clinical audit can involve all professionals in the multidisciplinary team, and volunteers. A first question in the implementation of clinical audit is to ensure a proper implementation of the audit into practice. This involves not only issues related to selecting the correct method and mechanism of audit, according to the needs of the organisation. Second, there is the question as to whether the audit improves outcomes for patients and families.

However, audit can encompass a wide range of activities. These range from audits focussed on single topics, for example the use of postcards to aid communication, audit of out of hours activity, audits of the management of individual symptoms or of the use of particular drugs, to audits that focus on regional or national networks of organisations, or components of a particular service. Equally audits can measure aspects related to the structure (e.g. the resources and staffing), the process (e.g. the activities), or the outcomes (pain, symptoms, quality of life) of care. Different types of audit require different methods of implementation and have different effects on the staff.

This ‘Meet the Expert’ session will invite participants to discuss issues that they have encountered in implementing audits in these areas and review the potential effects of different types of audit.

Abstract number: 322B
Presentation type: Invited
Poster number: 322B

The EAPC recommendations on opioids treatment – part 2

Geoffrey Hanks, Bristol Haematology & Oncology Centre, Bristol, UK, Dr. Franco De Conno, National Cancer Institute of Milan, Milano, ITALY

The expert working group on opioids was reconvened to update its guidelines. Twenty new recommendations were produced and each one was graded according to the quality of evidence to support it. The recommendations are published in the paper: “Morphine and alternative opioids in cancer pain: the EAPC recommendations” British Journal of Cancer 2001; 84: 587–593. It is now more than five years since the recommendations were produced and it is appropriate to review them again and examine what is still relevant and what should be changed on the basis of new evidence.

For a percentage of patients (10–30%) the above mentioned recommendations do not achieve successful pain management, defined as adequate pain control without excessive adverse effects. A new expert working group was convened to consider the topic ‘What to do when oral morphine fails in treatment of cancer pain: Critical assessment of the strategies’. The group produced the paper “EAPC recommendations to manage the adverse effects of oral morphine: an evidence–based report” N. Cherry, C. Ripamonti et al and the Expert working Group of the Research Network of the EAPC. Journal of Clinical Oncology 2001; 19(9): 2542–2554. This work presents evidence-based recommendations for clinical practice and gives emphasis to careful evaluation in order to distinguish opioid induced adverse effects from comorbidity, dehydration, or drug interactions. Four different approaches to the management of opioid adverse effects are described, but overall it is apparent that the evidence-base for these strategies is poor. In these sessions we shall review the EAPC work on opioids and readdress the evidence base and progress in extending it over the last ten years since the first meeting of the Opioids Expert Working Group.

Abstract number: 322B
Presentation type: Invited
Poster number: 322B

The EAPC recommendations on opioids treatment – part 1

Geoffrey Hanks, Bristol Haematology & Oncology Centre, Bristol, UK, Dr. Franco De Conno, National Cancer Institute of Milan, Milano, ITALY

The expert working group on opioids was convened to consider the topic ‘What to do when oral morphine fails in treatment of cancer pain: Critical assessment of the strategies’. The group produced the paper “Morphine and alternative opioids in cancer pain: the EAPC recommendations” British Journal of Cancer 2001; 84: 587–593. Since 1996 there have been a number of significant changes in this field of therapeutics and in particular various alternative opioid analgesics have been introduced in different parts of the world.
Competent practice can only be achieved if education programs can be easily accessed. The role of a nurse practitioner in palliative care is an ongoing process that engages primarily in the clinical component of the role. The emphasis is on symptom management, patient and family education and counselling, coordination of care and maintaining continuity of care.

A recently completed UK study regarding clinical nurse specialists in palliative care, defines the effectiveness of being based on 5 distinct areas of concern: clinical, consultative, teaching, leadership, and research. Palliative nurses must adapt and develop services to suit local conditions. This requires a great deal of nursing expertise. A study undertaken by the Royal College of Nursing on expertise in nursing practice proposes that expertise tends to be understood from traditional and dominant discourses of medicine, management and technology which automatically involves competent nursing research.

Abstract number: 325
Presentation type: Invited
Poster number:
Research in Palliative Care – How To Get Started
Eduardo Bruera, Department of Palliative Care & Rehabilitation Medicine, Houston, Texas, USA

The majority of palliative care programs emerge as clinical programs. Some of these programs are based in academic institutions and others are predominately community based. Some of the most common barriers to research by palliative care program include limited time protection for planning, conducting, and reporting research, lack of methodological expertise and support, and lack of funding to conduct research. On the other hand, some of the major advantages include a unique patient population and the limited amount of previous knowledge. This allows palliative care programs to be able to conduct innovative research with limited resources. Initial projects should be conducted under the mentorship of experienced researchers so as to appropriate plan studies. Early projects should be limited to retrospective studies, literature reviews, case reports, and short pilot studies. Prospective clinical trials and complex interventions such as surveys or translational research should only be attempted after the research team has had some exposure to the research process. The availability of electronic communication has made it possible for mentoring to occur from great distance. This provides a unique opportunity for clinicians working in remote areas or communities to be able to conduct exciting research. Practical examples of barriers and solutions will be presented.

Abstract number: 326
Presentation type: Invited
Poster number:
Research in Palliative Care – Getting Started
Gian Domenico Borasio, Munich University Hospital – Grosshadern, Munchen, GERMANY

To paraphrase an old joke, research in Palliative Care is a little like teen-age sex: everybody talks about it, but nobody knows how to do it properly. Well, ok, it’s not quite so bad. There have been a number of pioneers like Eduardo Bruera who have greatly moved the field forward by doing magnificent studies on ‘a shoestring’. This seminar’s topic is ‘Getting started’. Here are some empirical rules of thumb: (i) find something that you are really excited about: be it symptom control, psychological distress, psychosocial or spiritual care – whatever truly catches your mind, that’s what you should do research on; (ii) ask a definite, concrete, clinically relevant question that interests you and that has not been answered previously by convincing, well-conducted studies (check your RCT’s carefully!); (iii) start with a small project (no project is too small, but a lot are too big; (iv) don’t let anybody discourage you with statements such as ‘This is interesting’ (no clinically relevant question ever is), ‘This subject can not be studied scientifically’ (why not?), ‘Lots of people have worked on this before’ (maybe, but if the question is still open, there must be a reason), ‘This will not advance your career’ (so what?); (v) if you can, go visit a place near you where they do good Palliative Care research – you will learn a lot and you will make valuable connections that will be helpful for your project; (vi) find allies in your institution – it’s hard to work alone – preferably from other professions as well as your own, and at all hierarchical levels (don’t be afraid to ask; (vii) be creative when thinking of who might sponsor the study. Depending on the local specifics, charities, research and talent donor, there provides a unique opportunity for clinicians working in remote areas or communities to be able to conduct exciting research. Practical examples of barriers and solutions will be presented.

Abstract number: 327
Presentation type: Invited
Poster number:
Bereavement, grief and the clinical response
DAVID KISSANE, PSYCHIATRY & BEHAVIORAL SCIENCES, NEW YORK, U. STATES

In their meta-analysis on caregiver and family outcomes from palliative care, Higginson and colleagues (2003) failed to identify any significant benefit [13 studies, weighted mean 0.17]. One Norwegian study randomized patients to receive a comprehensive program of palliative care or conventional oncological care and discerned no difference in bereavement outcome despite the effort of the palliative care program to achieve this (Ringal et al., 2001). Yet the public health consequences from bereavement in increasing mortality and morbidity have long been recognized (Stroebe & Schut, 2001). Harding & Higginson (2003) concluded that greater promise lies with targeted interventions that identify a significantly distressed or depressed subsample of carers and explore the benefits of intervention on outcome for these high risk individuals. This approach delivers continuity of care to the bereaved, and one of our model of targeting high risk families. In our Family Focused Grief Therapy (FFGT) trial, randomized assigned 53 families (233 individuals) to FFGT and 28 families (130 individuals) to usual palliative care. FFGT reduced distress significantly at 13 months bereavement (p=0,02), with highly significant reductions in measures of psychological distress, depression and hostility in hostile families. FFGT has the potential to prevent complicated grief, but care is needed to avoid greater conflict in hostile families. Palliative Care strives to support caregivers.
Abstract number: 328
Presentation type: Invited
Poster number:

The volunteer in palliative care: a clearly defined role?

Monica Muller, Zentrum für Palliativmedizin, Bonn, GERMANY

It is indisputably recognised that volunteers and voluntary work respectively one of the bedrocks of palliative medicine and hospice care. Voluntary work is part of all care concepts in this field, organisations and institutions proudly present their on average high numbers of voluntary workers to the public, and the degree of the contribution of voluntary work to an organisation serves as an indicator of its quality and a precondition for successful public grant applications.

In the field of voluntary work, however, some problems have been recently increasing, i.e.
- It is no longer self-evident, that services and institutions want to work with volunteers;
- Voluntary workers decline to take part in assessments and qualification measures (personal dedication vs. formal or professional requirements);
- Volunteers feel that their expectations are being disappointed and give up;
- Helper’s disease seems to become a new epidemic;
- Volunteers are being misused to replace professionals.

There are political tendencies with regard to an implementation of obligations for the improvement of the social security of volunteers;
- The dying and their family members do not wish to be exposed to too many caregivers; and many others.

It seems necessary to reconsider current concepts of voluntary work; appropriately by reflecting and adapting the self-image and the public image of voluntary work, re-defining its role and addressing the necessary aspects for qualification, control and care for the carers.

The guiding principle of this process should be an improvement of collaboration of volunteers and institutions in order to ensure the best possible care for those who are in need of the services of palliative medicine and hospice care.

Abstract number: 331
Presentation type: Invited
Poster number:

Reimbursement linked to conditions for care. An example from Norway

Dagny Faksvaag Haugen, Haukeland University Hospital, Bergen, Norway

DRG’s (Diagnosis Related Groups) classification is perhaps the best known and most widely used form of Casemix classification. As DRG reimbursement is based on average costs, specialist palliative care units may have difficulties due to complex patients in need of advanced medical and nursing care and often prolonged hospital stays. Accordingly, financial incentives are needed in order not to undermine access to care for this patient group.

The International Classification of Diseases (ICD-10) contains one category called "Palliative Care" (category Z51.5). This belongs to a group of categories intended for use to indicate a reason for care. In 2003, the Norwegian health authorities decided to grant a separate, additional reimbursement when this category was used in order to create a financial incentive to establish more palliative care teams and units in hospitals. However, despite advice from the palliative care community, no specific conditions were required for the hospitals to be allowed to use this category. As a result, the demands for reimbursement were excessive. To make the system work as intended, several criteria for the use of category Z51.5 were established in 2004. These criteria are based on the new Norwegian Standard for Palliative Care, and require that a palliative care service has been organised, and that specific specifications for staffing and clinical content.

Linking financial reimbursement to specific conditions for palliative care teams and units will hopefully encourage the development of new services, as well as improve the quality of the care.

Abstract number: 333
Presentation type: Invited
Poster number:

Pathophysiology and assessment emphasizing specific clinical formats

Neil MacDonald, Université McGill, Montreal-Quebec, CANADA

Anorexia–cachexia and the oft associated problem, fatigue, are the most common physical symptoms which afflict patients and families towards the end of life. There are common pathophysiological features which characterize anorexia–cachexia across a broad range of chronic illnesses. Aberrant inflammation and, less clearly defined, changes in the hypothalamic–pituitary–adrenal axis are often noted in wasting patients.

While anorexia–cachexia has devastating personal and societal costs and is a principal source of family distress, it has received little attention from researchers and health professionals. In some part this disproportionate approach reflects the common view that little can be done to combat cachexia. Today, while our understanding of its pathophysiology remains imprecise, sufficient knowledge is available to inform specific programmes targeted at anorexia–cachexia. These programmes, in order to be successful, must be available to patients with newly diagnosed anorexia-cachexia. Such programmes illustrate the WHO definition of palliative care which calls for efforts to identify and prevent sources of human suffering before they become manifest.

Abstract number: 334
Presentation type: Invited
Poster number:

Secondary anorexia and cachexia in cancer patients

Claudia Bausewein, Klinikum der Universität München – Großhadern, München, GERMANY

Based on etiological factors cachexia and anorexia are typically categorized as primary (metabolic) and secondary (starvation) in nature. Secondary cachexia develops as a result of a functional impairment patients ingestion of adequate calories and nutrients. Secondary cachexia can be divided in three groups. Starvation and malnutrition form the first group of secondary cachexia. They develop from impaired oral intake through gastrointestinal symptoms such as nausea, vomiting or constipation, other uncontrolled symptoms (pain, depression), impaired gastrointestinal absorption or significant protein loss. The metabolic features are different to those seen in primary anorexia/cachexia syndrome. The second group is characterised by loss of muscle mass through prolonged inactivity or microgravity, both defined as deconditioning. The third group describes several catabolic states caused by acute or chronic infections or chronic heart, lung or renal disease. Many patients with anorexia/cachexia present with several of the mentioned secondary factors and overlapping primary anorexia/cachexia syndrome. Despite the difficulty to sometimes separate primary from secondary cachexia it is important to recognize causes of secondary cachexia as many of them are reversible. In these patients nutritional support needs to be considered.

Abstract number: 335A
Presentation type: Invited
Poster number:

Clinical status – current measures (Presentation in the session)

Florian Strasser, Oncology & Palliative Medicine, Oncology/Hematolog, St-Gallen, SWITZERLAND

Among the nutritional issues in the palliative care context loss of appetite and malnutrition are important and frequent problems for both patient and relatives. The interdisciplinary outline of the patients’ actual and individual clinical status including patients’ views form the base to decide on current measures to alleviate anorexia and cachexia and their consequences. Measures include pharmacological (progestins, corticosteroids, prokinetics, omega-3-fatty acids, anabolic steroids, cannabinoids, anti-inflammatory agents, others), nutritional (oral supplements, enteral & parenteral nutrition), behavioural (relieve of eating-related distress [ERD]), and other non-pharmacological interventions (i.e., mouth care). With this presentation the participants should be enabled 1) to better understand the effects (and non-effects) and time required to achieve the desired outcomes of the main measures to alleviate anorexia, cachexia, and ERD in the palliative care context, 2) to depict a practical goal-directed care plan for the main types of primary and secondary anorexia/cachexia in advanced as well as terminal stage of the disease, 3) explain patients and relatives the main reasons for the (non-)elements of the plan and the main (non-) outcomes (ERD of both patient and relatives, symptoms [i.e., anorexia, nausea, fatigue, bothering edema], strength & function, complications of malnutrition [wound & mouth care], nutritional intake, body composition) targeted. The better understanding of the clinical status and of the effects and non-active effects in the expected time period of the main measures to alleviate anorexia, malnutrition, and ERD may help to avoid both futile hyperactivity and neglect and achieve a goal-directed best care until death.

Abstract number: 335B
Presentation type: Invited
Poster number:

Cachexia and Anorexia in palliative care

Florian Strasser, Oncology & Palliative Medicine, Oncology/Hematolog, St-Gallen, SWITZERLAND

The session on Cachexia and Anorexia in Palliative Care aims to attract a mixed-professional audience interested in practical
issues of patient and family care and in current research supporting the main messages. One third of the presentations and session time is assigned to review the patients. After an introduction and case presentation four presentations are given: 1) Pathophysiology and assessment emphasizing specific clinical care: by Neil MacDonald. 2) Secondary anorexia and cachexia’ by Claudia Bausewein, 3) ‘Clinical status – current measures’ by Florian Strauss, and 4) ‘From theory to practice: so what?’ by Steffen Eychmueller. The last part of the session is a round table of the 4 speakers, who discuss the case and two models (presented by the session chair) of approaching the problem together with the participants. The learning objectives of the session are 1) to understand the main pathogenic mechanism leading to loss of appetite and malnutrition and psychosocial factors contributing to eating-related distress in patients with advancing, incurable disease and distinguish specific clinical formats, 2) to describe practical assessments having the potential to influence multidimensional outcomes relevant for palliative care, 3) to understand the effects and time required to achieve the desired outcomes of the main measures (pharmacological, nutritional, behavioural, and other non-pharmacological) to alleviate anorexia, cachexia, and eating-related distress in the palliative care context.

Abstract number: 336
Presentation type: Invited
Poster number:

From theory to practice: so what?
Steffen Eychmueller, Head Palliative Care Unit, Dept Internal Medicine, St. Gallen, SWITZERLAND

The participant should be empowered to construct an own practical approach in the management of cachexia and anorexia by discriminating factors that are clinically relevant (and potentially reversible) and those of more scientific significance (knowledge level) - acknowledging factors of the clinical setting in which the patient is treated which may interfere with any decision making on nutrition (organisational aspects) - applying a practical approach how to proceed in the care of the patient (When, how, how long) (skills level) and by respecting factors that may influence any decision making about nutrition in far advanced illness (attitude level).

Abstract number: 337
Presentation type: Invited
Poster number:

SPIRITUALITY: INCLUSIVE AND IRRESSIPRESSIBLE?
Michael Wright, International Observatory on End of Life Care, Lancaster, GREAT BRITAIN

Background. In the debate surrounding the nature of spirituality, a view has emerged that spirituality is a universal human attribute which may be religiously or non-religiously experienced in the countries of Central/Eastern Europe (CEE) and the former Soviet Union (FSU), spiritually inclusive hospice and palliative care services have become established since the collapse of communism. Yet against a background of long-standing ideological repression of religion, little is known about how spiritual care is viewed and delivered by these services. Two questions emerge: What is the nature of spirituality? How is the spiritual dimension of palliative care being articulated and delivered in CEE/FSU countries?

Discussion. Building on a literature review and a phenomenological enquiry into the essence of spirituality, an inclusive conceptual model has been constructed of the spiritual domain. This model acknowledges: the dynamic relationship between Self, Others and the Cosmos that gives rise to the big questions of life; the spiritual activities of becoming, connecting, transcending and finding meaning; and the place or absence of religion. In the light of this inclusive model, the author has sought to identify the spiritual dimension of palliative care in CEE/FSU countries. Using a mixed-method design data were gathered by means of 51 recorded interviews with 42 ‘palliateurs’ and 19 email questionnaires; total countries n=14. The findings indicate: a) the presence of a continuing spiritual pulse b) a focus on death as a spiritual mystery c) a commitment to spiritual care from both religiously active and inactive ‘palliateurs’ d) the re-discovery of a spiritual memory among dying patients. These issues will be briefly explored in relation to three emerging themes: the irrepressible nature of human spirituality; transcendence in the face of mortality: and respect for the intrinsic value of human beings.

Abstract number: 338
Presentation type: Invited
Poster number:

Psychical and spiritual care of Holocaust survivor hospice patients at the Jewish Charity Hospital, Budapest
Katalin Hegedus, Dept of Bioethics, Budapest, HUNGARY

Introduction: Most of the Budapest’s 80 000 Jews are elderly people, Holocaust survivors, often ill and living alone. Neatling the end of their lives afflicted with disasters and humiliation, they have to face their deaths all-alone. In 2001 a mobile supportive hospice team was set up in the Charity Hospital of the Federation of Hungarian Jewish Communities in Hungary. Experiences: Earlier neither psychologist nor social worker were employed at the hospital. The hospice concept was completely unknown and the hospice team was received with suspicion by the hospital staff saying ‘hospice philosophy is against Jewish spirituality’. Members of the hospice team were face of the multiple traumas of Holocaust survivor hospice patients namely such as age, illnesses, fatal illness; horrible experiences, suppression, silences, non treated losses, crisis of Jewish identity during the communism; loss of home, loss of human dignity (control of body function, abilities etc.), loneliness, hopelessness. Most of members of the hospice team are from the second generation of Holocaust survivors, with some psychic, spiritual and identity problems also. It was a challenge for them to learn about their role or learn again approach of dying patient’s care of Judaism, to provide psychosocial and spiritual care, help the patients reviewing and evaluating their life, coping with emotional pain or restricting the radical change of their lives. New understandings can be used to challenge behaviour which is causing emotional pain or restricting the radical change in family life that is required when a family member is terminally ill. The author has extended her exploration about family belief systems to include the discussions about the family’s ideas about worth, value, suffering, the meaning of life and illness. The discussion will be illustrated by two case examples in which the patient and family members describe their family’s beliefs.

Abstract number: 339
Presentation type: Invited
Poster number:

Teaching and Providing Spiritual Care
Monika Muller, Malteser Krankenhaus Bonn, 19, Emmenweg 36, Germany

The spiritual dimension is indisputably acknowledged as one of the four main pillars of palliative care for the dying. There also seems to be a general understanding that spirituality is more than a matter of socialisation within certain cultures or the death-related rituals. Spirituality may also not be neglected to be linked with a person’s religious affiliation. It may even surpass it or be something very different. We also know that more than any other dimension of care, the spiritual dimension in particular has a major impact on the biography of professionals and other caregivers and it affects their individual concepts of meaning, their understanding of the world, their self-understanding of their life as well as their questions and answers with regard to the possible meaning of suffering.

The permanent challenge, however, is to address the following problems in a way that goes beyond cognitive understanding:
How can we communicate about these subjects without infringing a patient’s privacy and/or neglecting the protection of our own privacy in our role as carers? How can we possibly learn to communicate about these matters at all? And, for us lecturers, how can we possibly raise these questions and subjects in motley seminar groups in a sensitive manner, protecting our own personal space and allowing others to protect theirs as well, at the same time, enabling a kind of closeness and open relationship that achieves both spiritual and cognitive learning and balanced understanding for the members of the seminar group and ourselves?

Abstract number: 340
Presentation type: Invited
Poster number:

The spiritual care of the family, how can ideas from family therapy be developed to give help to family members
Pam Firth, Hertfordshire, GREAT BRITAIN

Introduction Spirituality is difficult to define but for the purpose of this presentation the author will focus on the idea that the spiritual dimension of a person’s life includes meaning, value and worth. However most hospices and specialist palliative care units provide family based care, so does that include the spiritual care of the family and if so, how can that be achieved?

Discussion Members of the multi-professional team who provide psycho-social and spiritual care increasingly use ideas from family therapy to help them understand generational patterns of behaviour and problem-solving. Commonly, families are encouraged to think about the rules and beliefs which govern how they live their lives. New understandings can be used to challenge behaviour which is causing emotional pain or restricting the radical change in family life that is required when a family member is terminally ill.

The author has extended her exploration about family belief systems to include the discussions about the family’s ideas about worth, value, suffering, the meaning of life and illness. The discussion will be illustrated by two case examples in which the patient and family members describe their family’s beliefs.

Insights gained from this exploration were then used by the patient, family and multi-discipline team to provide terminal care in a hospice in which all needs of the patient and the immediate family were addressed.

Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005

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SATURDAY 9 APRIL
Abstract number: 341
Presentation type: Invited
Poster number:
Using ethnography in palliative care research
Jane Seymour, School of Nursing and Midwifery, University of Sheffield, Sheffield, GREAT BRITAIN

A great deal of our knowledge about the experience of pain and suffering, understandings of death and dying, and the processes and organisation of clinical care, come from the stories told by patients rather than ‘on’ people (Heron & Reason 2001). The values that underpin action research it is difficult to get findings into academic knowledge but about the creative approaches. Although not classically considered as the theory/practice gap. The emphasis with research it is difficult to address using other research design and process.

care, looking particularly at issues of research how it may be used by researchers in palliative care needs often predominate. More recently, the approach has been applied in a focused way to produce mini-ethnographies of clinical areas. In all these, the stories of patients, carers, and staff are interwoven, giving a rich sense of the complexities that make up palliative care. This paper explores what is ethnography, and how it may be used by researchers in palliative care, looking particularly at issues of research design and process.

Abstract number: 342
Presentation type: Invited
Poster number:
Using action research to bridge the theory/practice gap in palliative care
Jo Hockley, Education, Edinburgh, GREAT BRITAIN

Action research is a relatively new research approach in health care. Its history has its roots in organisational development during the 1940s. However, over the last twenty years there has been a considerable re-awakening of its use in management, education, community work and nursing as the concept of ‘contextualising’ is realised. Some would argue that for all we have learnt through research it is difficult to get findings into practice and bridge what has come to be known as the theory/practice gap. The enthusiasm with action research is not just about gaining academic knowledge but about the creative action of people addressing difficulties within their own practice. This paper explores what is ethnography, and how it may be used by researchers in palliative care, looking particularly at issues of research design and process.

Abstract number: 343
Presentation type: Invited
Poster number:
Issues in multi-lingual Qualitative Research
Phil Larkin, Dept.Palliative Medicine, Galway, IRELAND

Despite advances in the development of translation/ validation of research tools to measure and quantify aspects of health care in a multi-lingual context, very limited literature is available which considers the issues of conducting qualitative interviews in multiple languages. The nature of such research indicates the specific problems of translation and back-translation, sensitivity and specificity of the interview question, and the role of interpreters for both data collection and analysis. Although the literature has highlighted some of the problems in these issues (Bradly 2002, Kapborg & Bertens 2002), little is offered by way of solution and particularly when researching a palliative care population with the additional problems that may arise in interviewing patients at the end of life.

This presentation focuses on practical issues of conducting multi-lingual research arising from an ongoing doctoral study, which explores and describes the transition experiences of 100 patients in 6 EU palliative care centres. In particular, the limitations of the standard translation/back-translation method will be critiqued and a different method proposed, based on the issue of cultural competency” (Birbili 2003). The challenges of using interpreters and the subsequent linguistic analysis will be described as well as the issues of qualitative validity and reliability which arise. A case will be made that the potential benefits of multi-lingual interview data about patient’s experiences in palliative care outweighs the challenges of this type of research at the end of life.

Abstract number: 344
Presentation type: Invited
Poster number:
How can discourse analysis be used in palliative care?
SHELLA PAYNE, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN

This paper will introduce discursive approaches from the perspective of health psychology, presenting two major positions: 1) an approach derived from ethnomethodology and conversation analysis concerned with how everyday social interactions are negotiated and managed, and 2) Foucauldian discourse analysis which draws upon post-structuralist writers including Foucault. In this language constitutes social and psychological experience. Discursive approaches regard interview responses as evidence about how people use language to represent a particular situation at that particular time. Discursive approaches make no assumptions about consistency of responses in other situations, no inferences about intra-psychic processes (how people think or feel), and explain talk as representing a repertoire of ways that people have of dealing with questions in social situations and interact as discursive agents. In discursive approaches, analysis of talk is concerned with individuals’ attempts to deal with their current situation (for example in an interview maintaining their credibility as a ‘good’ patient, trying to ‘help’ the interviewer or complaining). To illustrate these differences, I will use examples taken from research about bereavement support provided by general practitioners and counsellors in the UK, and a study of the way death is described by palliative care practitioners in medical records in the UK. A further example will be provided by an analysis of the discourse of the hospital in Australia, which revealed how nurses enact the transition between life and death. The talk was multi-modal and involved the use of language towards the live patient and dead body. Discourse analysis has not been used much as an analytic approach in palliative care research. This presentation explores the limitations and advantages in revealing taken-for-grANTED aspects of social interactions embedded within language.
Abstract number: 346
Presentation type: Oral
Poster number:

Prognostic disclosure: does the information provided allow cancer patients to be aware of the evolution of their disease?

Marie-Claude Blais, Psychiatry (psychoncology), Québec, CANADA, Pierre Gagnon, Centre de Réch. Hôpital-Dieu de Québec, Québec, CANADA

Background: While a body of literature and clinical experience (Loprinzi et al., 2000) suggest to improve patients’ awareness of their prognosis, some studies underline the low amount of usefull information in regards to many aspects of their disease. Chances of survival (Loprinzi et al., 2000) are discussed in only 60% of cases, while a majority of patients (80%) express a preference for such information. Moreover, 55% of patients still indirectly state their aware of their disease, which is particularly true among patients having a poor prognosis.

Discussion: Given the importance of prognosis awareness for enabling patients and relatives to make informed treatment and life decisions, these results call for the development of innovative tools to improve, systematize, and facilitate prognostic communication without inducing unnecessary distress.

Abstract number: 347
Presentation type: Oral
Poster number:

DNR-DECISION MAKING ON ACUTE GERIATRIC WARDS IN FLANDERS, BELGIUM

Cindy De Gendt, End-of-Life Care Research Group, Brussels, BELGIUM, Johan Bilsen, End-of-Life Care Research Group-Vrije Universiteit Brussel / Centre for Environmental Philosophy and Bioethics-Universiteit Gent, Brussels / Ghent, BELGIUM, Margareta Lambert, Geriatric Unit-AZ VUB, Brussels, BELGIUM, Nele Van Den Noortgate, Geriatric Unit-University of Ghent, Ghent, BELGIUM, Cindy De Gendt, End-of-Life Care Research Group-Vrije Universiteit Brussel / Department of Public and Occupational Health-EMGO-Institute-VU Medical Centre (The Netherlands), Brussels / Amsterdam, BELGIUM

Objective: According to good clinical practice physicians making do-not-resuscitate decisions (DNR) should previously and in time consult the patient, his/her family members and other healthcare workers. In this study we investigate the characteristics of the DNR-decision-making process on acute geriatric wards.

We gather information about when the decision was made, and who previously was consulted. Method: A structured mail questionnaire was sent to the 91 geriatricians, responsible for acute geriatric wards on all hospital campuses in Flanders, Belgium. We asked them about the decision-making process concerning their last patient for whom a DNR-decision was made. Results: The questionnaire was returned by 66 geriatricians (73% response rate). All reported about their latest DNR-decision. In 29% of the cases the decision was made before or at time of the patient’s admission, in 8% after diagnosis, and in 63% when the condition of the patient declined (44%) or became critical (29%). The physician previously consulted at least one person in 80% of the cases. In 81% of these cases the head-nurse of the geriatric ward was involved, in 55% another physician, in 8% the Specialist for Nephrology and/or the Head of the ward, in 26% the GP of the patient, in 43% another physician, in 19% the patient him-/herself and in 77% the patient’s next of kin.

Conclusions: Seemingly, geriatric wards in Flanders, DNR-decisions are mostly made when the condition of the patient declines or becomes critical. (Head-)nurses and the patient’s next of kin are often consulted, the patient and his/her GP rather rarely. Further research is needed to explain these findings and to investigate if low patient participation is the result of the clinical condition (e.g. incompetence) of the patient at the time of the decision making.

Abstract number: 348
Presentation type: Oral
Poster number:

Consultation of the parents in actual end-of-life decision-making in neonates and infants: a population study

Veerle Provost, Department of Medical Sociology, Brussels, BELGIUM, Filip Coobs, Department of Paediatrics, Academic Hospital, Free University of Brussels, Brussels, BELGIUM, Freddy Mortier, Centre for Environmental Philosophy and Bioethics, Ghent University, Ghent, BELGIUM, Armand Van Veldenplaas, Department of Paediatrics, Academic Hospital, Free University of Brussels, Brussels, BELGIUM, Luc Deliens, Department of Medical Sociology, Free University of Brussels, Brussels, BELGIUM

Background: In the treatment of critically ill neonates and infants, the parents are the patient’s next of kin and are frequently on quality-of-life considerations. Expectations and wish to prevent suffering are prominent determinants of the parents’ decisions about treatment and life. Because of the vulnerable status of the neonates and infants, discussing DNR-decisions with parents is especially important.

Methods: A 6-month ethnographic study was undertaken with 41 staff, 20 patients, 7 carers and 34 parents at the children’s hospital of the University of Brussels in a neonatal department and a NICU, which is specialized in neonatal and infant intensive care. The retrospective study of all deaths of live born neonates and infants was conducted in Flanders, Belgium. For 292 of all 298 deaths in a one-year period (1-8-1999 until 31-7-2000) the attending physician could be identified and was sent an anonymous questionnaire. Results: The response rate was 86.6% (253/292). The end-of-life decision was discussed with parents in 83.8% (114/136) of all cases where one was made. For cases where treatment was withheld or lethal drugs were used, parents more frequently had an explicit request, compared to cases where treatment was withdrawn, or opioids were used (in dosages) with a potentially life-shortening effect (14/29 versus 21/107, p=0.012, and 9/17 versus 26/119, p=0.015). When lethal drugs were used, parents initiated the discussion more frequently, compared to cases of institutional decision (8/14 versus 18/102, p=0.003). When parents were not consulted, the decision was based less frequently on quality-of-life considerations (2/2 versus 39/39), and there were more cases where there was probably no life-shortening due to the decision (according to the estimation of the physician) (15/22 versus 13/14, p=0.05), and the cases where parents were consulted. Conclusions: Parents are frequently consulted in end-of-life decision-making for their child, especially for decisions based on quality-of-life considerations.

Abstract number: 349
Presentation type: Oral
Poster number:

Does social support work as a buffer against reactions to external stressful life events such as terminal cancer?

Gerd Inger Ringdal, Department of Psychology, Trondheim, NORWAY, Kristen Ringdal, Department of Sociology and Political Science, NTNU, Trondheim, NORWAY, Svein Brun, University of Applied Clinical Research, NTNU, Trondheim, NORWAY, Steen Kaasa, Unit of Applied Clinical Research, NTNU, Trondheim, NORWAY

The main aim of this study is to examine the relationship between social support and anxiety and depression, and coping with stress. Our hypothesis is that patients who reported high degree of social support will do better in terms of coping with stress and experience less anxiety and depression, than patients with low degree of social support. Methods: The sample comprised of 434 patients at the Palliative Medicine Unit (PMU), University Hospital of Trondheim. The patients completed a questionnaire monthly including questions about social support, based on the MacAdam’s Scale of assessment of suffering; coping with stress, measured by the Impact of Events Scale (IES) and QoL. Results: Regression analyses showed that dependent variables at two time points were performed. Although our hypothesis was not supported at the baseline assessment, it was supported at the second assessment, two months later. The results show that the regression coefficient of the social support variable has the predicted sign for all three dependent variables and the relationships are statistically significant at the 0.05 level for the emotional functioning subscale (b=0.21, p=0.03, and for the IES avoidance subscale (b=0.19, t=–2.25, p=0.03), but not for the IES intrusion subscale (b=0.011, t=1.35, p=0.18). Thus, patients with high social support experienced significantly less anxiety and depression and they reported significantly better coping, in terms of lower scores on the avoidance subscale, than patients with low degree of social support. Conclusion: Our results on the second assessment indicate that social support might work as a buffer against reactions toward external stressful life events such as terminal cancer.

Abstract number: 350
Presentation type: Oral
Poster number:

Getting the message across: adaptive communication strategies in palliative care

Anita Sargeant, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN

Background: Effective communication between hospice, hospital and community teams is essential for good quality care. UK government policy seeks to improve care through improved communication. Aim: identify how different communication strategies are used and adapted to provide information and support to patients, families and carers, and to community and acute hospital settings.

Method: A 6-month ethnographic study was undertaken within a NHS specialist palliative care service in the UK. Observations of communication including verbal, non-verbal and written took place within the hospice, community and hospital teams. Interviews were undertaken with 41 staff, 20 patients, 7 carers
Abstract number: 351  
Presentation type: Oral  
Poster number: 

Discourse of prognostic information – differences between female and male physicians?  
  
Lotte Rogg, Dept. of Oncology, Oslo, NORWAY, Peter Kjær Graugaard, Dept. of Behavioural Sciences in Med. University of Oslo, Oslo, NORWAY, Jon Håvard Loge, Dept. of Behavioural Sciences in Med. University of Oslo, Oslo, NORWAY,  

Background and Aims: The manner in which physicians communicate an estimated prognosis may be of importance for the patient’s future life, as well as the physician–patient relationship. The aim of this study was to explore Norwegian physicians’ attitudes towards the disclosure of prognostic information. Material and methods: Seventy percent of a representative sample of 1605 Norwegian physicians who received a postal questionnaire responded to a set of questions related to prognostication and communication of prognostic information. Results: Physicians find it more difficult to formulate a prognosis than a diagnosis, and more than 50% think they have had too little practice in prognostication. More than 60% stated that most of their patients didn’t know their prognosis. Differences between the genders were found: women found prognostication more difficult than male doctors, and felt they lacked training in formulation and communication of prognoses to a greater extent than their male counterparts.  

Conclusions: Norwegian physicians generally regard prognostication to be a difficult task. A greater uncertainty among female doctors towards communication of prognostic information might have implications for how they communicate with their patients. The physicians’ attitudes towards communication of prognostic information may impact on their actual communication with patients and on their clinical management of their patients. The findings in this study may have implications for the education of future medical students and for establishing communication skills training for specialists.

Abstract number: 352  
Presentation type: Oral  
Poster number: 

Pain therapy for cancer patients in the palliative phase – a systematic review  
  
Sebastian von Hofacker, Region. Centre of Excellence for Palliative Care, Bergen, NORWAY, Ulf Kongsgaard, Dept. of Anaesthesia and Intensive Care The Norwegian Radium Hospital, Oslo, NORWAY, Anita Lynngtaadas, Norwegian Health Services Research Centre, Oslo, NORWAY,  

Objectives: Seventy to 90% of cancer patients have pain in the palliative phase of their disease. Pain severely impairs health related quality of life and is the single most feared symptom in cancer patients. The main objective was to assess the clinical effectiveness of medication and radiotherapy in the palliative treatment of cancer-related pain addressing pain relief, pain prevention and adverse effects as the outcome measures. Methods: A systematic literature search was undertaken to identify systematic reviews and newer studies published between 2001 and 2003. Two reviewers assessed each publication according to criteria defined by protocol for evaluating relevance, quality, and validity. Two systematic reviews from the US-Agency for Healthcare Research and Quality, 10 Cochrane reviews and 54 articles were identified as relevant publications. The quality of the systematic reviews was assessed as acceptable, thus, relevant RCTs and metaanalyses contribute to the documentary basis of this systematic review. From the updated literature search RCTs and metaanalyses were included, as well as comparative case series where studies of a higher evidence level were lacking. All included studies were systematised into three subgroups according to the quality of the study design in question and the validity of the Results: a) high, b) moderate, and c) low. Results: This systematic review is part of a health technology assessment (HTA) report performed by an interdisciplinary review group appointed by the Norwegian Health Services Research Centre planned to be finished in December 2004. The results of current available best evidence in relation to pain therapy for cancer patients in the palliative phase will be presented.

Abstract number: 353  
Presentation type: Oral  
Poster number: 

Opioid Rotation in Cancer Pain: A Prospective Longitudinal Study  
  
Mellar Davis, Hematology/Oncology, Cleveland, U. STATES, Declan Walsh, MSc, FRCP, The Cleveland Clinic Foundation, Cleveland, U. STATES, Kavassalam Estfan, The Cleveland Clinic Foundation, Cleveland, U. STATES, Susan B. LeGrand, MD, FACCP, The Cleveland Clinic Foundation, Cleveland, U. STATES, Philip Salminen, MD, The Cleveland Clinic Foundation, Cleveland, U. STATES,  

Background: Cancer pain can be adequately controlled using around-the-clock analgesics and rescue dosing. Some develop major side-effects or do not respond to the initial opioid and require opioid rotation. Reports suggest 24-72% of patients may require opioid rotation.  

We prospectively evaluated the number, reason and sequence of opioid rotation from referral until death. Method: 238 consecutive patients were followed by the palliative service in a two month period, 195 (85%) had cancer. Initial opioid, the reason for rotation, the number and sequence of opioid rotations and route of administration were recorded. Some who entered the study were on multiple opioids or given opioids by multiple routes. Results: 132 of 195 (67%) cancer patients had pain; 54 of 132 (39%) had a second rotation, 4 a third and 1 a fourth rotation. Reasons for rotation were: 1) ineffective pain control (31%), 2) opioid side-effects (25%), 3) both (21%), 4) contraindication (12%), 5) cost (10%), 6) neuropathic pain (10%). The pre-rotation opioid was oxycodone (48%), morphine (27%), fentanyl (19%), hydromorphone (3%), methadone (2%) and other opioids (10%). Most rotations were to morphine (54%) or methadone (31%). 13 second rotations were to morphine (7), methadone (3), or fentanyl (3). Routes of administration were usually either oral or intravenous; 2 patients received subcutaneous infusions. Conclusion: Opioid rotation were required in nearly 40% of our patients due to reasons of ineffectiveness, side-effects or both. Most were rotated once.

Abstract number: 354  
Presentation type: Oral  
Poster number: 

EFFICACY OF GRANISETRON AND DEXAMETASONE FOR ANTIEMETIC CONTROL IN NO SURGICAL MALIGNANT BOWEL OBSTRUCTION: PHASE II CLINICAL TRIAL  
  
Albert Tuca-Rodriguez, Palliative Care Service, L'Hospitalet-BCN, SPAIN, Rosa Roca, Hospital Sta Caterina, Girona, SPAIN, Carmen Sala, Hospital St Llatzer, Terrassa, SPAIN, Jesus Gonzalez-Barbotes, Institut Catala d'Oncologia, L'Hospitalet-BCN, SPAIN, Xavier Gomez-Batiste, Institut Catala d'Oncologia, L'Hospitalet-BCN, SPAIN,  

Aim: Determine the antiemetic efficacy of granisetron and dexametosone in no surgical malignant bowel obstruction. Method: Multicentre prospective phase II clinical trial. Inclusion criteria: advanced cancer patients who presented malignant bowel obstruction, with a clinical and radiological diagnosis and no indication of surgical treatment. Granisetron efficacy was assessed by means determination of every day nausea severity (VAS 0–10), continuous and colic pain (VAS 0–10), vomiting number, and the need of antiemetic drug rescues, and before and after starting granisetron 3 mg/24h and dexametosone 4 mg/24h. The global efficacy was assessed after 3 days of treatment. The patients with a good control of nausea continued the treatment until complete a maximum of 7 days. We exclude patients previously treated with antagonist of SHT3 or on nasogastric tubes for aspiration. The protocol was approved by Ethic Committee of all centres. Preliminary results: The final estimated recruitment will be 30 patients. Until now, 23 patients have been included. The majority of them have been previously treated with standard antiemetic drugs. The initial results are significant improvement of nausea, number of vomiting and control pain in more than 50% of patients. The majority of patients who had a good control at third day of treatment, keeping this response until seventh day. Conclusion: The antagonist of SHT3 receptors granisetron with dexametosone bring a good antiemetic control in non surgical malignant obstruction even while the standard palliative treatment failed.

Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005  
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005
Audit of the management of breakthrough cancer pain in a hospital setting

Claire Littlewood, Palliative Care Medicine, Liverpool, GREAT BRITAIN, Rebecca Conlon, Liverpool University Medical School, Liverpool, GREAT BRITAIN, Sushila Sarker, Liverpool University Medical School, Liverpool, GREAT BRITAIN, Jenny Wiseman, Willowbrook Hospice, St Helens, GREAT BRITAIN

Objectives 1. To audit prescription of opioids for breakthrough pain relief. 2. To assess training needs of Junior doctors toward opioid use. Method 1. A retrospective study using medical records & drug cardexes of 100 cancer inpatients at Whiston Hospital, U.K. in 2003. The following criteria were collated from internationally approved guidelines & used as standards: ~ 100% patients on long acting opioids should be prescribed opioids PRN. ~ The PRN dose of opioid should be 1/6th of the total daily dose of a long acting opioid. 2. A questionnaire of PRHOs at the same hospital. Results 1. Audit 59 of the 100 patients were female & the age range 39 to 91. 45 patients (45%) were prescribed long acting opioids. Of these 45 cases, 20 (45%) were prescribed opioids PRN. Of those 20 cases 32 (60%) were referred to a palliative care team. Of those 45 cases, 20 (40%) were given the appropriate dose for breakthrough pain. 2. Questionnaire 20 questionnaires were completed. All the respondents had received training in prescribing opioids, mainly during a palliative care placement as Undergraduate but out of 20 said this training was inadequate. All agreed additional training during junior doctor induction programmes would be beneficial. 10 (50%) calculated the wrong opioid dose for PRN use. Conclusion Knowledge of appropriate prescribing amongst junior doctors is limited. The standards for prescription of PRN opioids were not met. Where the palliative care team was involved, the standards were met. This demonstrates a need for multiprofessional education amongst hospital medical, nursing & pharmacy staff.

Abstract number: 355
Presentation type: Oral
Poster number:

Neuropathic Pain in Cancer: A Prospective Study of Current Management and Development of Clinical Guidelines in a Cancer Network

Helen Emms Wirral, GREAT BRITAIN, Claire Douglas, Marie Curie Centre, Liverpool, GREAT BRITAIN, Mathew Makin, Nightingale House, Wrexham, GREAT BRITAIN, John Ellershaw, Marie Curie Centre, Liverpool, GREAT BRITAIN

Background: One third of cancer patients are affected by neuropathic pain. 50% of these patients will achieve pain control using the WHO analgesic ladder. Regional guidelines for management of neuropathic pain exist but there is limited evidence based guidelines. Objectives: To assess current management of neuropathic pain in cancer across a local cancer network and to further develop evidence based guidelines. Methods: A prospective multi-centre study was performed over 4 months with a comprehensive literature review. All patients with new onset or uncontrolled neuropathic pain were eligible for inclusion. Data was collected including cancer diagnosis, pain description and previous management. New drugs commenced and drug measures tried and outcomes including side effects were recorded over 7 days. Results: 89 patients were observed. Hot burning (23.4%) and electric shock (19.6%) were the commonest descriptors of pain. Lower limbs were the commonest site of pain (30.3%). The median number of previous drugs was 2 (range 0–5), 37.1% had tried non-steroidal anti-inflammatory drugs (12.4%) and TENS (11.2%). The most frequently prescribed new drugs were gabapentin (56.2%), clonazepam (22.5%) and amitriptyline (20.2%). Buprenorphine was the most frequently reported side effect in all patients (19.1%). Anaesthetic intervention occurred in 5.6% patients. 38.2% patients had a complete response to treatment during the 7 day follow up period. Conclusions Neuropathic pain can be controlled in cancer patients by a combination of non drug, drug and local nerve block measures. The choice of drug should be evidence based. As a result of this study our cancer network standards and guidelines have been revised.

Abstract number: 357
Presentation type: Oral
Poster number:

Errors in Opioid Prescribing: A Prospective Survey

Mellar Davis, Hematology/Oncology, Cleveland, U. STATES, Bassam Estfan, MD, The Cleveland Clinic Foundation, Cleveland, U. STATES, Declan Walsh, MSC, FRCP; The Cleveland Clinic Foundation, Cleveland, U. STATES, Philip Shaheen, MD, The Cleveland Clinic Foundation, Cleveland, U. STATES, Ruth Lagman, MD, The Cleveland Clinic Foundation, Cleveland, U. STATES

Background Cancer patients experience both chronic and intermittent pain. Analgesic prescribing must consider pain severity, quality and temporal pattern to be successful. Prescribing errors can occur with dosing strategy, opioid conversion, opioid rotation, and adjunctive analgesic use. Such errors result in poorly controlled pain and opioid side effect side effects. This prospective study evaluated opioid prescribing using a palliative medicine program. Method 14 principles were derived from published resources (Agency for Health Care Policy and Research, European Association of Palliative Care, World Health Organization, American Pain Society). Deviations were categorized into 1) errors of dosing strategy (10), 2) opioid conversion or rotation (2), 3) dose titration (1) & 4) use of adjunctive analgesics (1). Results In a 2-month period 195 of 238 (85%) consecutive patients evaluated had cancer. 132 of 195 (67%) had pain 95 (78%) had at least one error. In total 166 errors were identified; 142 strategy errors, 6 due to adjuvants and 5 due to inappropriate conversion or rotation; 13 had other errors. 57% had 1 error, 24% 2 and 19% 3 or more. Common errors were 1) failure to use continuous oral or parenteral opioids (29 patients), 2) undertreatment of opioid side effects (24 patients) 3) simultaneous use of multiple opioids (16 patients). 163 recommendations were made; low dose continuous opioid doses (23 patients), opioid rotation (19 patients) and drug titration for incident pain (16 patients) and treatment of opioid side effects (14 patients) were most common. Discussion Most cancer patients with pain referred to a palliative medicine program have one or more opioid dosing errors. Most involve failure to prescribe according to pain pattern or severity and failure to treat opioid side effects. This study demonstrates the continued importance of teaching cancer pain control and identifies where educational activities should be focused.

Abstract number: 358
Presentation type: Oral
Poster number:

OUTLINE OF THE SECOND STEP OF THE WHO ANALGESIC LADDER IN THE TREATMENT OF CANCER PAIN

Wojciech Leppard, Chair and Department of Palliative Medicine, Poznan, POLAND, Slawomir Pawziak, Palliative Care Department, Down Silesian Oncology Centre, Wroclaw, POLAND, Jacek Luczac, Chair and Department of Palliative Medicine for Lower Silesian University of Medical Sciences, Poznan, POLAND

Aim of the study: To assess the usefulness of the second step analgesic ladder in the treatment of cancer pain. Material and methods: Retrospective analysis of the use of analgesics of the second step of analgesic ladder during last year from clinical notes. We analysed data of 1411 patients treated by Chair and Department of Palliative Medicine in Poznan (650 patients) and Palliative Care Department in Wroclaw, Poland (761 patients). Results In the analysed group of patients 1010 (72%) were treated by weak opioids. The rest of the patients who had were treated by strong opioids (50% morphine) or non-opioid analgesics. Among weak opioids tramadol in different preparations was the most commonly used analgesic – orally in 721 (51.1 %): in immediate release drops and capsules in 525 (37.2%), in controlled release tablets in 75 (5.3 %) subcutaneously in 106 (7.5%), and rectally in 15 (1%) of patients. The other analgesics of the second analgesic ladder were oral codeine (in tablets or water solution) used in 153 (11%) patients and dihydrocodeine administered in 15 (1%) patients. The treatment with weak opioids lasted on average 35 days and after that period it was necessary to substitute weak with strong opioids because of inadequate analgesia in 515 (51%) of patients treated with weak opioids. Good analgesia (VAS < 4) was achieved in 677 (67%) of patients; partial effect (VAS 5–5) in 121 (12%), unsatisfactory pain relief (VAS > 5) was noted in 111 (11%) of patients treated with weak opioids. No serious side effects were noted. Conclusions: 1. The use of weak opioids allowed achieving satisfactory pain relief in majority of treated patients without serious side effects. 2. Half of treated patients demanded change for strong opioids after mean time of 35 days of the treatment. 3. The second step of analgesic ladder seems to be important in the treatment of cancer pain of moderate and sometimes severe intensity.

Abstract number: 359
Presentation type: Oral
Poster number:

Respiratory Tract Secretions in the Dying Patient: A comparison between Glycopyrronium and Hyoscine Hybridoside

Heino Hugel, Palliative Medicine, Liverpool L25 8QA, GREAT BRITAIN, J Ellershaw, Marie Curie Hospice, Liverpool, GREAT BRITAIN, RM Kass, Marie Curie Hospice, Liverpool, GREAT BRITAIN, M Gambles, Marie Curie Hospice, Liverpool, GREAT BRITAIN, S Foster, Marie Curie Hospice, Liverpool, GREAT BRITAIN

Introduction and aim of the study: The evidence for the management of respiratory tract secretions (RTS) in dying patients with...
Invited lectures and oral presentations

**Multimodal analgesia to treat pain in patients with advanced cancer:**

The use of multimodal analgesia has been shown to provide effective pain relief in patients with advanced cancer. This approach involves the combination of different analgesic modalities, such as opioid antagonists and non-opioid analgesics, to target multiple pain pathways. The benefits of multimodal analgesia include reduced opioid use, improved pain control, and decreased adverse effects. However, the optimal combination of analgesics and the timing of their administration remain important considerations to achieve effective pain management.

**Poster number:** 361

**Presentation type:** Oral

**Abstract:**

Multimodal analgesia is a complex and evolving field in the management of pain in patients with advanced cancer. Recent advances in pain management have emphasized the importance of understanding the underlying mechanisms of pain to tailor treatment effectively. This talk will provide an overview of the current state of multimodal analgesia, including its clinical applications and future directions.

**Abstract number:** 362

**Presentation type:** Oral

**Poster number:**

**Abstract:**

The use of multimodal analgesia in patients with advanced cancer is becoming increasingly popular. This approach aims to provide effective pain relief by targeting multiple pain pathways. Several studies have shown that multimodal analgesia can improve pain control and decrease opioid use compared to monotherapy. However, the optimal combination of analgesics and the timing of their administration remain important considerations for effective pain management.

**Abstract number:** 363

**Presentation type:** Oral

**Poster number:**

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Pharmacokinetics of transdermal buprenorphine (Transec)® in patients with renal insufficiency

Johannes Philipuz, University Hospital Erlangen, Erlangen, GERMANY, J Hiltz, University Hospital Erlangen, Erlangen, GERMANY, Reinhard Sittl, University of Erlangen, Pain Clinic Erlangen, GERMANY, Norbert Griesinger, University of Erlangen, Pain Clinic, Erlangen, GERMANY, Rudolf Likar, General Hospital Klagenfurt, Klagenfurt, AUSTRIA, Wolfgang Boecker, University Hospital Erlangen, Erlangen, GERMANY

The reduced physical state of terminally ill patients is often accompanied by diminished organ functions resulting in severe renal or hepatic insufficiency. However, with most of the currently used opioid analgesics there is a risk of accumulation of either parent compound or metabolites resulting in drug-related tolerability problems in a number of patients. In contrast the pharmacokinetics of buprenorphine show only very slight changes in patients with renal failure, making it especially suitable for pain treatment in these patients.

To investigate the impact of haemodialysis on the plasma concentrations of buprenorphine (bup) and its metabolite norbuprenorphine (norbup) ten patients were asked to provide blood samples immediately before and after haemodialysis. The mean age and weight of the patients were 63 years and 65 +/- 9 kg, respectively. The patients had to be sufficiently informed and gave their written consent. Bup and norbup plasma concentrations were analysed as described by Ceccatto et al. Reduced plasma concentration of buprenorphine were 0.35 ng/ml before and 0.38 ng/ml after haemodialysis. This result correlates well with the average daily dose of 0.18 µg/kg, confirming that buprenorphine plasma levels are not altered in patients with renal insufficiency. A significant correlation between plasma levels and administered doses could also be observed. In these patients with renal insufficiency, the slightly increased plasma concentrations in the second blood samples could be attributed to the decreased plasma volume after haemodialysis, but the concentration of bup is not increased by dialysis which is consistent with the observation that there had been no differences in pain relief before and after haemodialysis. Regarding norbup plasma concentrations, it is notable that 7 out of 10 patients did not have any detectable norbuprenorphine plasma concentrations, i.e. plasma levels were below 0.05 ng/ml before as well as after haemodialysis. The other three patients had norbup plasma levels still lower than the concentrations of the mother compound.

Conclusion: This investigation shows no clinically significant increase of either bup or norbup plasma levels in patients with renal insufficiency. Consequentially transdermal buprenorphine can easily be administered to patients with renal insufficiency without dose adaptation and without increased risk of side effects.

Abstract number: 364
Presentation type: Oral
Poster number: 79

Lidocaine 5% patch in the treatment of neuropathic pain of diverse origin.

Eriphili Argyra, Anaesthesiology - Palliative Care Clinic, Athens, GREECE, Ioanna Siakalak, Athens University, Athens, GREECE, Elefni Moka, Arateioio Hospital, Athens, GREECE, Athina Vadolouca, Athens University, Athens, GREECE

Background: Neuropathic pain syndromes are difficult to treat. Commonly used combinations of anticonvulsants, antidepressants and opioids are often ineffective, whereas side effects especially in older or very sick patients preclude their use. Results of invasive therapy are still controversial. An old local anesthetic, lidocaine has been produced in the form of patch, recommended for treatment of post herpetic neuralgia. Recently it has been used for the treatment of other painful neuropathic syndromes as well. Aim of the study: An observational study to evaluate the long-term efficacy and adverse effects of Lidocaine 5% patch in resistant to therapy neuropathic pain of diverse origin. Method: Lidocaine 5% patch (Lidoderm®) was applied to the skin in 36 patients suffering from chronic pain syndromes: Postherpetic neuralgia 17, Postherozymopathy syndrome 6, Post mastectomy pain 4, Diabetic neuropathy 2, Complex regional pain syndrome 5, Peripheral ischemia due to autoimmune disease 2. Two patches were used every 24 hours. Length of therapy, Pain intensity score and after treatment, Pain intensity difference, Global therapy assessment, adverse effects and reasons for treatment stopping were recorded. Results: Length of treatment was 2 months to 4 months (mean 18 months). Pain relief 10-50% (mean 33,4%), patient assessment: fairly good result 30%, good 30%, very good 20%, no result 20%. Local erythema was observed in 5 patients, (13,8%) Treatment was abandoned by 1 patient due to local erythema and by 3 due to difficulty in obtaining the patch. Conclusion: Lidocaine 5% patch was safe and well tolerated even as long term therapy (up to 4 years). The various adverse effects attributable to treatment were not observed. 1 Rowbotham MC, et al Pain 1996; 65:39-44 2 Meier T, et al Pain 2003; 100:151-158.

Abstract number: 366
Presentation type: Oral
Poster number: 367

When you cannot use an RCT – the value of using evaluation research to assess the improvement of cancer patient’s insight into their disease following the impact of the hospital palliative care team

Barbara Jack, Faculty of Health, Liverpool, GREAT BRITAIN, Valerie Hillier, University of Manchester, Manchester, GREAT BRITAIN, Anne Williams (1), Swanso, SWANSEA, GREAT BRITAIN, Jackie Oldham, University of Manchester, Manchester, GREAT BRITAIN

Background: It is reported that cancer patients want as much information as possible about their diagnosis and prognosis. This input regarding patient’s insight into their disease is undoubtedly a major part of providing optimal palliative care. Despite this there is little information regarding the impact of hospital based palliative care teams on patient insight. A study was done to assess the effect of the hospital palliative care team on patient’s insight to their disease. Methodology An evaluation study comprising a non-randomised control group design, using a quota sample, investigated 100 cancer patients admitted to hospital for symptom control. 50 patients received hospital palliative care team intervention compared with 50 patients receiving traditional care. Outcome was assessed using the IPAQ assessment tool on 3 occasions (within 24 hours admission/diagnosis or referral to the team, day 4 and day 7) measuring the patients self reported understanding of their illness.

Additionally a qualitative approach including 31 semi structured interviews with doctors and nurses to explore their perception of the palliative care team impact on cancer patients insight in to their disease was undertaken. Results and Discussion The results indicated that cancer patients admitted to hospital for symptom control demonstrated an improvement in their insight scores (between initial and final assessments) with a 95% confidence interval of 0.4 to 5.6 (mean score). The difference was significant (p<0.01). Those patients who had the additional input of the palliative care team had a greater improvement in their insight scores (between initial and final assessments) with a 95% confidence interval of 2.0 to 2.02 (mean score), compared to the standard care group that displayed an improvement from 4.86 to 4.26. This input was reported by the doctors and nurses as being invaluable to the patients. The value of using an evaluation research approach combining methodologies will be discussed and potential explanations for the results will be explored.

Abstract number: 367
Presentation type: Oral
Poster number: 578

Action research in palliative care: An overview of the literature

Kashifa Mahmood, Centre for Primary Health Care Studies, Coventry, GREAT BRITAIN, Dr Daniel Munday, Warwick University Medical School, Coventry, GREAT BRITAIN

Aims and objectives: Action research promotes an educative and empowering approach to modifying clinical practice and facilitating organisational change. Service delivery and research are closely linked with actions being undertaken by practitioners using a cycle of reflection, action and evaluation. Although it is increasingly utilised in health services research, no reviews of action research in palliative care are available. A review of published literature was therefore undertaken to investigate the use of action research in palliative care. Methods: A search of databases in MEDLINE, EMBASE, Cinahl and the Web of Science was performed from their inception to June 2004. MESHL and free text searches were used to identify articles, qualitative, cancer and action research as key terms. Palliative Medicine (1999–2004) and the Journal of Advanced Nursing (1993–2004) were also scanned in detail. Emerging Findings: Eleven action research studies (published 1996–2003) were found, addressing palliative care (8) or focusing on cancer services (3). Projects were conducted in the UK (4), Australia (4), Switzerland, (5), Sweden, (1) and the USA (1). Studies were based in the community (7) and in a hospital setting (4). Projects focused on changing practice (4), strengthening service organisation (1), designing staff education programmes (4) or raising health awareness amongst patients (2). Qualitative and quantitative methods were employed including questionnaires, focus groups, interviews.
Physical exercise intervention in palliative cancer patients: a phase II study. Effects of the exercise programme

Line Merethe Oldervoll, Department of Cancer Research and Molecular Medicin, Trondheim, NORWAY, Jon Håvard Loge, Department of Behavioural Sciences in Medicine, Oslo, NORWAY, Unni Vethei, Hospice Loviseng, Oslo, NORWAY, Palitei Hamne, Palliative Unit, St Olavs Hospital, Trondheim, NORWAY, Kaara Stein, Department of Cancer Research and Molecular Medicin, Trondheim, NORWAY

Background: Despite growing interest in palliative cancer patients’ quality of life, little attention has been directed toward preservation and/or recovery of their physical function. Purpose: To examine the effects in objective physical function of a structured exercise programme of a walk test and ‘sit to stand’ test, subjective emotional and physical functioning, fatigue and sleep in incurable cancer disease patients with short expected lifetime undergoing a physical exercise programme. Patient population: Patients from an oncological and a palliative care outpatient clinic. Exercise intervention: The patients participated in an exercise programme twice a week for 50 minutes each time over a six week period. Methods: Assessments were carried out prior to the intervention and at completion of the exercise period. ‘Objective’ physical function were measured by a 6 minutes walk test and ‘time repeated sit to stand’. Fatigue was measured by Fatigue Questionnaire (FQ), physical- and emotional function, fatigue and sleep by the European Organisation of Research and Treatment in Cancer Core Quality of Life Questionnaire (EORTC-QLQ-C30). Results: In FQ physical fatigue was significantly decrease from 12.6 to 10.7 (p<0.02). Of the EORTC emotional functioning was increased from 69 to 78 (p=0.002), physical functioning from 67 to 67 (p<0.010), fatigue scale decreased from 51 to 43 (p=0.07) and insomnia from 44 to 36 (p=0.02). Walk length increased significantly from 481 to 510 meters (p=0.007) and the time repeated sit to stand was reduced from 5.1 to 4.2 seconds. Conclusions/implications: Structured physical exercise is feasible for objective physical function, fatigue and subjective physical functioning in incurable cancer disease patients. Future randomised trials are needed to confirm the results.

Abstract number: 369
Presentation type: Oral
Poster number:
South Thames were asked to complete confidential questionnaires, including demographic details and the MBI, as part of a larger study. The questionnaires were also sent to doctors present at the inaugural meeting of the APM who had continued in the specialty. 49 (86%) Registrars, 60 (76%) Consultants and 15 (40%) founder members responded. This is 36% of all SpRs and over 28% of all UK consultants. In Palliative Medicine and is not significantly different from the national sample in gender or qualifications. The results show personality profiles that are distinctly different from other specialties and may help in career advice. Comparing the Thames Registrars with the Consultants suggests that the personality profile of the specialty is changing. Combining all the results shows a distinct difference in the group type of those who have been working in the specialty 10 years or more, compared with their junior colleagues. The senior group type is INTJ, compared with ESFJ in the others. INTJ’s have long range vision, planning skills, and are good at problem solving at an analytical level. ESFJ’s have good people skills, can maintain and preserve what works and are skilled at building consensus. Will the specialty be able to develop and thrive in a field that we have lost our visionaries?

Abstract number: 373
Presentation type: Invited
Poster number:

Biology and pharmacology of the older patient – Start low – go slow

Ola Dale, Department of Anaesthesiology, Trondheim, Norway

A person is considered old when above 65 yrs of age. Social and medical advances have changed the age composition of advanced industrialized countries. The number of persons above 65 years of age increased from 8% of the total American population in 1950 to about 13% in 2000 and is expected to reach about 20% in 2030. A consequence is that the number of patients in need of palliation will increase substantially during the next decades, as the older patient also has more cancer than younger. Aging is a continuous process that starts after puberty. Aging causes reduction in functions, and reduce the capability to master the daily activity of living as complex actions such as driving. Old people may present symptoms such as pain differently than younger people, and more often cognitive changes such as confusion are nonspecific symptoms of stress or disease. Aging causes changes in the pharmacology of drugs, usually resulting in a more pronounced action, for instance for opioids. Old people often suffer from more serious adverse drug effects than younger, for instance for NSAIDs often used for pain in palliative medication should ‘start low’ and dose titration should ‘go slow’. Moreover, repeated evaluation of the treatment with respect to desired effects or troublesome adverse effects is required. Stopping of treatment is often required to evaluate whether the patient benefits from pharmacotherapy or not.

Abstract number: 375
Presentation type: Invited
Poster number:

When all is said and done: interpreting the language of caring

Phil Larkin, Galway, IRELAND

As the development of palliative care progresses within mainstream healthcare, a tension may exist between the need for technological advancement and the need to meet the basic needs expressed by patients; to be cared for, comforted and consoled. The role of nurses in this caring role has, by and large, been well articulated in the literature, although possibly the nursing contribution to modern conceptions of palliative care still requires further explanation. In this presentation, an overview of the construct of palliative caring will be given, with a focus on the value of attention to practical detail. The intuitive nature of caring will be discussed in terms of the use of physical senses (sight, hearing, touch, smell, and taste) as a way of exploring the practical dimension of care and suggests that such an approach compliments rather than contrasts the technology of palliation, when applied in the professional context of assessment and evaluation.

Abstract number: 376
Presentation type: Invited
Poster number:

The use of MEOPA (ENTONOX) in the relief of pain

Leila Measson-Bouhafs, Lyon, France

This presentation will discuss the use of self-administered analgesia using ENTONOX. The history and development of the gas will be discussed as well as the physiological actions indications for use and practical procedures necessary for its safe use. The Nursing care of the patient, before, during and after the procedure will be described as well as the relevant side-effects, and contra-indications. This presentation will suggest that MEOPA (ENTONOX) is a valuable tool to assist in the care of palliative patients.

Abstract number: 377
Presentation type: Invited
Poster number:

Holistic care of patients with breathlessness

Beate Augustyn, Bavarian, München, GERMANY

Holistic care of patients with breathlessness Breathlessness is a subjective symptom causing suffering in patients, relatives and carers. Patients experience breathlessness as distressing and react with anxiety. Dyspnoea reduces the patients’ ability to communicate, his mobility and his ability to take part in social life. Relatives feel helpless and powerless. Nurses react either with reservation or with increased activity. Breathlessness is causing anxiety in all parties. This anxiety is passed on from patients to relatives and nurses and backwards. Thus anxiety is increasing breathlessness. To interrupt this vicious circle it is not only important to know the causes of breathlessness but to explore the patients’ subjective experience of breathlessness and mechanisms that help best in this situation. Thus breathlessness is what the patient says it is and not what we observe or measure. To treat breathlessness different levels – physical, psychosocial and spiritual – have to be considered. The care of a patient with dyspnoea is challenging for nurses as there are different forms of dyspnoea (chronic dyspnoea, acute respiratory attack, death) and appropriate medical and therapeutic measures the following nursing interventions can be helpful for the patient: measures to reduce anxiety, different positioning strategies, fresh air, mouth care, guidance for power reduced movements (kinaesthetics) and massage. Dyspnoea can be successfully relieved through careful and competent cooperation of all carers.

Abstract number: 378
Presentation type: Invited
Poster number:

Care of the body at the end of life: A double challenge for the carer

Brigitte Eugene, Soins Palliatifs, Lyon, FRANCE

Care for the body at the end of life enables the practitioner to return to the roots of their caring profession and to demonstrate their skills at the deepest level of practice. One of these challenges is the ability to be present to the suffering body and enable the patient to see that such changes in their body as the end of life approaches do not detract from their humanity.

This may be difficult, not least because of the physical assault on the senses of bodily process; odour, sweat, stools, wounds. Gently, the carer must move both patient and family through these changes, support guide and console. This presentation looks at the intrinsic value of caring for the body and its role in the broader practice of care at the end of life. The specific needs of care in the terminal phase will also be discussed.

Abstract number: 379
Presentation type: Invited
Poster number:

The EAPC Task Force Development of Palliative Care in Europe

Carlos Centeno, Programa de Medicina Palliativa, Pamplona (Navarra), SPAIN

The information relating the develop and provision of Palliative Care in the whole Europe is very few, dispersed and uncompleted. Besides the EAPC feels the responsibility to cooperate to collect and spread the information available about the provision of Palliative Care in Europe, the implementation dilemmas that we are finding and the success in attending better more patients every year. All of this, thinking that it could be a good stimulus for all and to help to advance in this area. The EAPC intends for the first time to carry out a comprehensive overview of the palliative care situation in each European country. Such work will allow us to make some assessment of the current state of development of palliative care across many countries. With this goal in mind, in June, 2003 the EAPC Board agreed to the creation of creation of a Task Force on palliative care development in Europe. The work of the Task Force will be of great importance for activities at the policy level and will make use of important collaborations with other institutions and national and professional associations. This study will be carried out in a systematic way and with a well defined method. In the introductory presentation the actual situation of this International study will be described.
Abstract number: 380  
Presentation type: Invited  
Poster number:  

Palliative care development  
David Clark, International Observatory on End of Life Care, Lancaster, GREAT BRITAIN  

Global interest in palliative care development has never been greater. Nevertheless, we still have only a rudimentary understanding of the factors that shape and influence policy and service innovation in palliative care. Why are some countries quite well endowed with palliative care services, whilst others are not? Is it a question of economics, wider resources, human development index rating, or particular barriers within the health care system? What is the role of charismatic leaders and product champions in promoting palliative care innovation? How can we set about building and then sustaining a palliative care workforce, forging a field of specialization, and creating the academic and evidence base that will strengthen the claims of palliative care protagonists? These and related questions will be explored in this teaching session on palliative care development.

Abstract number: 381  
Presentation type: Invited  
Poster number:  

Palliative care development  
Carl Johan Fürst, Stockholms Sjukhem Foundation, Stockholm, Sweden  

Comparing the WHO definitions of 1990 and 2002 reflects recent development and future challenges for palliative care. In most societies there is an increasing prevalence of patients with cancer and an increasing cancer incidence compared with a reduction of oncology and other hospital beds. The challenge is to develop flexible and competent palliative care organizations in order to integrate the care of cancer patients with a need for supportive care with those at the end of life. Palliative care has through the team approach and focus on symptom control and quality of life issues to take on the challenge from this large group of patients. A parallel challenge is to loose the history and soul of the hospice movement. An increasing need for palliative care competence is also seen in the care of elderly in nursing homes and other similar non hospital institutions.

Abstract number: 382  
Presentation type: Invited  
Poster number:  

Legal background of palliative care development in Hungary, strength and weak points  
Katalin Hegedus, Dept of Bioethics, Budapest, HUNGARY  

Object of study: To present the legal background of the Hungarian palliative care development and to clarify results and some typical mistakes from the point of view of the national palliative association (HHPA).  

Methods: Analysis and comparison of some important documents: Hospice and patient’s right chapters of the Health care act (1997); National Guidelines (2002); Minimum Standards (2004) and analysis of role of the HHPA as a coordinator of this process.  

Results:  
Strong points of the legal documents: strengthening the knowledge of palliative care; introducing structures for implementation of palliative care services; improving relationship with policy makers of the Ministry of Health, and the NHS during the working up (consensus conferences; control of professional level).  
Weak points: lack of precise clarifying of the aims of Professional Guidelines (putting too much in it, textbook function); few contacts with professional physician societies and clinics; lack of need assessment and researches; lack of harmonizing of different actions of the NGO-s. Conclusion: Legal background is essential condition of palliative care development. It is necessary to complete it with a well-defined and coordinated policy activity.

Abstract number: 383  
Presentation type: Invited  
Poster number:  

Introduction - Research - design of clinical studies  
Franco De Conno, National Cancer Institute of Milan, Italy  

Palliative Medicine (PallMed) is growing rapidly towards a medical speciality. Good assistance is the first goal, but there are also two other predominant aspects: education and research. In PallMed the potential subjects of research are two: the patient and his/her family. But attention! Palliative care patients differ from traditional patients.  

Pain for example that in other fields is considered as physical suffering is "total pain" (physical, psychic, social and spiritual). Many patients prefer to control pain totally and maintain their cognitive function.  

There is an agreement on 4 dimensions of quality of life (Qol): Physical dimension, psychological well being, social relation and all the symptoms related to illness and to therapies. The role of spirituality, economical impact, sexuality and body image are still debated topics. Some dimensions may present specific problems of definition and measuring. Assess Qol means assess what the patient thinks, feels, wishes: this is subjective. Qol assessment is very difficult in advanced patients, and is impossible in terminal patients.  

The presence of poli-pathology is frequent; particularly in elderly patients. There may also present complex situations derived from the great number of drugs. An important challenge are drug interactions.  

The short survival and the difficulties in the diagnosis, obstacles the research projects, and the particular vulnerability of the patients induces in care givers the fear of exposing them to scientific over treatment and/or transmitting them unrealistic hope by including them in a study.  

Two fundamental aspects are acquired: The multidimensional nature of the problems and subjectivity. For this reason also qualitative research is important in PallMed. We ask directly to the patient! Last but not least the need to approach research in a multidisciplinary way must be considered.  

Due to the above the importance of the scientific methodology in Palliative care must be more thoughtful.

Abstract number: 384  
Presentation type: Invited  
Poster number:  

Choosing the right research design  
Irene J Higginson, Department of Palliative Care and Policy, London, GREAT BRITAIN  

A badly analyzed study can always be reanalyzed, but a badly designed study will not be saved by the analysis; instead another study will be needed. Study design usually refers to the 'type' of study and includes a brief outline of what will be done. They can be categorized according to four central questions: (1) will you collect the information or used other sources? (2) what is the time sequence between study of the input (e.g. the important intervention) and output (the effects), (3) what is the philosophy and nature of data = numbers, or describing the nature of things and themes? (4) are you trying to 'test' whether one thing causes another (e.g. whether a treatment improves fatigue).  

Using examples from recent palliative care studies we will consider the relationships between study aims and Design. We will then appraise the alternative designs of clinical studies including experimental and quasi-experimental studies. Finally we will consider appropriate study designs to assess complex interventions, using models such as the Medical Research Council Framework for the evaluation of complex interventions.

Abstract number: 385  
Presentation type: Invited  
Poster number:  

How to set up a protocol in Palliative Care  
Declan Walsh, The Cleveland Clinic Foundation, Cleveland, Ohio, USA  

Development of systematic research is dependent on a disciplined approach to protocol development. This requires the commitment of energy, money, staff time and other resources to this process. It is essential that there is a regular research meeting. This serves as a forum for the generation of new ideas, constructive criticism of new ideas and protocols, reviews of studies in progress, and analysis of studies completed. This meeting should be multidisciplinary and include clinical staff who are not involved in the research process. The meeting services to develop new research but also to educate staff about the complexities and challenges of conducting research in palliative medicine. It is important that new ideas are brought forward in a positive atmosphere which encourages general participation. The emphasis should be on refining the questionnaire which is being asked and encouraging simplicity of thought and Design.  

Careful consideration should be given to avoiding complexity. The approach to the design of clinical palliative medicine has significant ethical, practical, operational and statistical challenges. Rigid exclusion criteria can destroy a study. Over emphasis on complex or randomized studies may prevent any research being accomplished. Practical considerations of the design of recording forms, and using a protocol template help the process. Study diaries are very important to avoid patient burden. Many review boards are unfamiliar with the issues of research in palliative medicine; it is important to explain the rationale for the design carefully to avoid rejection. Accrual to well designed studies can be a challenge, as is attrition during the study and these issues should be accounted for in study design and biostatistical advice.
Pain trials in palliative care

Christoph Osgathe, Klinikum der Universität zu Köln, Köln, Germany

Pain is one of the most common symptoms in patients suffering from a progressive disease and treatment is a challenge to physicians, nurses and all the other professions involved in the patients care.

According to its importance pain should be one of the main focuses of research in palliative care. But like in other issues palliative care patients and the palliative situation itself complicate the design of studies that are able to show valid and specific results as well as to clinical advances in pain management. Ethical issues and methodological problems (with high drop out rates, unspecific or fast change in patients general condition, the difficulty to establish controls, low patient numbers) are the barricades for this necessary research. Down to the present day the activity for (pain) research in palliative care is still too low. The advances in pain therapy are mostly adopted from other fields of pain research. But the patient in palliative care is specific so these results are useful only in some degree. We need research that considers the particular requirements associated with a progressive disease and with the patient in an existential situation.

To overcome these obstacles of pain research in the palliative care setting collaborations of researching units, concise research questions, clear study designs and appropriate methodologies are fundamental.

Dyspnoea in Palliative Medicine – What’s New? Introduction and some pathophysiological aspects

Eberhard Klaskich, Zentrum für Palliativmedizin, Bonn, GERMANY, Kati Elina Clemens, Malteser Krankenhaus Bonn Hardtberg, Bonn, GERMANY, Friedemann Nauck, Malteser Krankenhaus Bonn Hardtberg, Bonn, GERMANY

Dyspnea is the term for the sensation of breathing difficulties (air hunger). Since it’s a subjective experience, only the patient himself is in a position to judge its severity. There is no monocausal explanation for the occurrence of dyspnoea. The following factors are essential triggers of dyspnoea: increased breathing effort, disproportionally high breathing labour in relation to oxygen uptake, gas exchange disorders, irritation of the respiratory centre, subjective factors. General functional disorders which are common in various diseases of the lung and normally accompanied by dyspnoea are the following: alveolar hypoventilation, obstruction, restriction, diffusion disorders, intrapulmonary shunt. While in case of obstruction and restriction, dyspnoea is mainly due to increased breathing effort, in case of hypoventilation it is to be explained by the increase of pCO2 but not by the decrease of pO2. In case of diffusion disorders, the breathing effort increases as a consequence of reduced compliance, but not to an extent that could explain the occurrence of dyspnoea in itself. In hypoxemic patients, the application of oxygen may reduce or eliminate dyspnoea. In patients with increased intrapulmonary shunt but no changes in the respiratory mechanics, most likely dyspnoea may be caused by hypoxemia. This cannot be fully counterbalanced by the application of oxygen, particularly in patients with an intrapulmonary shunt greater than 25 per cent. Some strategies for the treatment of airway obstructions in palliative care medicine can be deduced from these pathophysiological considerations. These are, above all, measures which serve to reduce increased breathing labour and facilitate pCO2 elimination and have a positive impact on individual distressing factors such as anxiety and fear which may influence the perception of the symptom of dyspnoea.

Dyspnoea in neurological diseases

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Dyspnea caused by terminal neurological diseases such as amyotrophic lateral sclerosis or muscular dystrophy, results from a progressive weakness of the respiratory muscles whilst maintaining a normal gas exchange rate. As the muscles weaken the tidal volume diminishes, causing alveolar hypoventilation. This results in insufficient oxygen supply which leads to arterial hypoxia, whereas the reduced exhalation of carbon dioxide generates hypercapnia. Dyspnoeic symptoms are increasing daytime fatigue, morning headaches, cognitive impairment, and sleep disturbances – and ultimately hypercapnic coma and central apnæa may occur.

An effective drug therapy of primary neuromuscular respiratory dysfunction is currently not available. The intervention of choice is the use of ventilatory support (non-invasive ventilatory support). The administration of oxygen is to be considered for cases of hypoxia which do not respond to NIV. Frequently the mucus from the upper and lower airways cannot be appropriately expectorated because of the weakened respiratory muscles. The ensuing accumulation of thick airway secretion is to be treated stepwise: At first mucolytic drugs and breathing exercises should be initiated. Subsequently, devices for intratracheal mobilization of mucous by a pulsed air stream and for nebulizer therapy may be used.

Expectorated sputum is a marker of the effectiveness of the overall therapy that aims to maintain and protect respiratory function in such patients. As long as a patient is still able to obey commands, he should be involved in the therapy decision making process.

As these therapeutic interventions improve the patient’s quality of life and potentially prolong survival they should be offered to all symptomatic individuals.

Dyspnea in Palliative Care – What’s New?

Eduardo Bruera, Department of Palliative Care & Rehabilitation Medicine, USA

In recent years there have been significant advances in our understanding of the aetiology and management of dyspnea. Dyspnea in palliative care is progressively recognized as an incidental syndrome. Most patients suffer acute short-lasting exacerbations. The nature of this syndrome explains the limited success of pharmacological interventions. The frequent association between dyspnea and cognitive failure or overwhelming fatigue explains the difficulties with patience accruals to clinical trials. Recent studies have demonstrated the possibility of conducting studies including response to exercise even in the palliative care setting.

The role of oxygen, pharmacological interventions, and non-pharmacological interventions has been better clarified by recent clinical trials. The results of some of the trials research and future studies in the area of dyspnea will be discussed.

Dyspnea in Palliative Care – What’s New?

Carla Ripamonti, Istituto Nazionale Dei Tumori, Milano, ITALY

Some RCTs have been carried out on the use of systemic opioids in the treatment of dyspnea associated with cancer or COPD. Most of the studies found that systemic opioids of different types, given in different dosages and by various routes of administration, are capable of relieving dyspnea. However, a randomized, double-blind, crossover trial carried out to compare the efficacy and tolerability of sustained-release morphine compared with placebo in 16 COPD patients with dyspnea showed no differences in the dyspnea score before oral morphine and placebo. Moreover, almost all the subjects experienced morphine-related adverse effects. A number of possible mechanisms have been postulated, but the exact mode of action is unknown. Morphine exerts a depressant action on the respiratory centers. The depressant effect is thought to be compensated by respiratory reserve, so that respiratory failure does not occur. As well as a central effect, a peripheral action of morphine may be involved. Controlled clinical trials on the symptomatic effect of nebulized opioids in COPD and in cancer-related dyspnea have been carried out, but the results have not been published. Pharmacokinetic studies suggest that the systemic bioavailability of nebulized morphine is extremely poor, varying from 4 to 8%. A single-dose randomized controlled trial of nebulized morphine in cancer patients with dyspnea showed no symptomatic benefit of nebulized morphine over placebo. In patients with COPD only two studies showed some positive Results. An increase in exercise endurance with morphine-6-glucuronide 4 mg compared with morphine 12.5 mg and placebo was observed. This may reflect potency of the nebulsed opioids as a determining factor for the efficacy. A patient required assisted ventilation after the 1st dose of nebulized morphine (4 mg) * dexamethasone.

Risks and benefit of opioid therapy

Carla Ripamonti, Istituto Nazionale Dei Tumori, Milano, ITALY

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Abstract number: 386
Presentation type: Invited
Poster number:

Pain trials in palliative care

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Pain is one of the most common symptoms in patients suffering from a progressive disease and treatment is a challenge to physicians, nurses and all the other professions involved in the patients care.

According to its importance pain should be one of the main focuses of research in palliative care. But like in other issues palliative care patients and the palliative situation itself complicate the design of studies that are able to show valid and specific results as well as to clinical advances in pain management. Ethical issues and methodological problems (with high drop out rates, unspecific or fast change in patients general condition, the difficulty to establish controls, low patient numbers) are the barricades for this necessary research. Down to the present day the activity for (pain) research in palliative care is still too low. The advances in pain therapy are mostly adopted from other fields of pain research. But the patient in palliative care is specific so these results are useful only in some degree. We need research that considers the particular requirements associated with a progressive disease and with the patient in an existential situation.

To overcome these obstacles of pain research in the palliative care setting collaborations of researching units, concise research questions, clear study designs and appropriate methodologies are fundamental.
Abstract number: 392
Presentation type: Oral
Poster number:

Managers’ Perspectives on Death and Dying in Care Homes for Older People

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Care homes in the UK provide long term care for frail older people. Whilst care homes are a home for life for many of these older people die in this care setting. These deaths require support for the older person, their family and staff. Aim: A postal survey of care home managers in South Yorkshire was undertaken to: • establish the nature of deaths within the care homes • identify managers' perspectives of the needs of residents and family • describe the resources available to the home • describe managers’ priorities for improving end-of-life care. Methods: The managers of 261 care homes in South Yorkshire were surveyed using a postal questionnaire. The data was analysed using descriptive statistics. Responses to open questions were coded using the N-VIVO package. Results: Responses were obtained from 46% (n=115) of the managers surveyed. The response for useable questionnaires was 33% (n=81). A third of deaths in 2003 occurred in hospital and 1% in a hospice. The vast majority (85%) of deaths were from non-cancer conditions. 13% of homes had at least one resident with an advanced care plan. 65% of homes had accessed training relevant to the care of dying people. The main provider of education were in-house staff, specialist palliative care and funeral directors. 65% of homes had access to 24 hour palliative care and funeral directors. 65% of homes had accessed training relevant to the care of dying people. The main provider of education were in-house staff, specialist palliative care and funeral directors. 65% of homes had access to 24 hour palliative care and funeral directors. 65% of homes had accessed training relevant to the care of dying people. The main provider of education were in-house staff, specialist palliative care and funeral directors. 65% of homes had access to 24 hour palliative care and funeral directors. 65% of homes had accessed training relevant to the care of dying people. The main provider of education were in-house staff, specialist palliative care and funeral directors.

Abstract number: 393
Presentation type: Oral
Poster number:

The circumstances, experiences and preferences of older people at the end of life

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Background and aim In the developed world, 84% of deaths occur among people aged over 65, and this is likely to rise across the next three decades. This study was commissioned by a major UK charity, Help the Aged, to review evidence regarding the circumstances, experiences and preferences of older people in relation to end of life care, and to make recommendations for the improved care and support of older people who are approaching death and their carers. Method The project has involved three activities: a literature review; secondary analysis of data; and a consultation exercise. Literature review: a review of primarily UK policy and research based literature relating to palliative and end of life care, ageing, chronic illness and informal carers. Secondary data analysis: a targeted secondary analysis of data from a study of 77 older adults views about end of life care. Consultation exercise: a presentation of a summary of key issues and conclusions to key stakeholders and carers, followed by a structured discussion.

Abstract number: 394
Presentation type: Oral
Poster number:

Palliative Care in Community Hospitals in the UK: An under recognised resource for older people

Sheila Payne, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN; Sheila Hawker, University of Southampton, Southampton, GREAT BRITAIN; Chris Kerr, University of Southampton, Southampton, GREAT BRITAIN; David Seakam, The Honiton Group Practice, Honiton, GREAT BRITAIN; Carol Davis, University of Southampton, Southampton, GREAT BRITAIN

Background There are 478 community hospitals in the UK, most provide end-of-life care. They have the advantage of being located within easy reach of family members, are staffed by local people and in many hospitals general practitioners can maintain continuity of care. It is unclear the extent to which these hospitals have the resources, facilities, personnel and skills necessary to offer general palliative care. Aim: This project aimed to identify the extent to which community hospitals were involved in providing palliative and terminal care to older people with end stage cancer and non-malignant diseases. Method Organisational case studies were conducted in six South of England community hospitals to identify how care was delivered from the perspectives of staff (n=125), older patients (n=10) and bereaved carers (n=51) and approximately 900 hours of non-participant observation. Data were analysed using descriptive statistics of staff questionnaires and content analysis of users’ interview transcripts and field notes. Results Patients and carers valued the accessibility, flexibility, and personal care afforded to them. Bereaved carers were largely satisfied with care for themselves and their relative but some commented on the noisy environment and pressures on staff. Staff indicated confidence in their knowledge about communication, pain, equipment use and symptom control but lacked education in spiritual, psychological and bereavement support. Key issues were competing priorities between different types of patients, problems with skill mix, an emphasis on terminal rather than palliative care. Conclusions The Community Hospitals of the UK: a way that leads to good quality care for these dying residents.
place of death as part of the research question were included. Data was extracted to standardised forms and contrasted between studies. Results: N ranged from 56 to 1.3 Million) from 10 different countries that assessed this. The studies were all observational, except one which used a randomised controlled method. 12 of the studies increasing age among adults was found to be associated with place of death; 9 reporting a higher proportion of care home deaths and 3 died in hospital. Of these, 7 recorded deaths with increasing age. In contrast 2 studies, from Canada and Italy, demonstrated an increase in home deaths with increasing age. Hospital death was found to be equal reporting of increased and reduced deaths in hospital with aging. The overarching trend was for institutional death to increase into older age. One study specifically assessed the factors which influenced place of death in older people. Conclusions: Resources and research needs to be targeted to ensure that appropriate end of life care is available for older people, who appear to be likely to die in institutions.

Abstract number: 396
Presentation type: Oral
Poster number:

The Palliative Care Needs Of Elderly Patients in an Acute General Hospital

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Aims This study is a review of the management of elderly patients approaching death in an acute general hospital. An emphasis was placed on examining the documentation of both medical and nursing staff and to whether the patients could have been managed and have died in the community. Methods A retrospective review of the casenotes of the 25 patients who died under the care of a medicine for the elderly (DME) service during November 2003. Data collected included basic demographics, circumstances of admission and details of end of life care. Results The patients were 72% female with a mean age of 81.4 years, 64% from their own homes, 20% from nursing homes and 8% each from another family home and from sheltered accommodation. Admission may have been avoidable in 24% of cases. One patient had an active malignancy. In 16% no acknowledgement of a terminal phase was documented, in 20% there was no documentation of a discussion with the patient or family regarding dying and 43% of DNAR decisions were made in the last 48 hours of life. Of those patients recognised to be in pain, 50% had no prn analgesia prescribed, 67% of those agitated had no prn anxiolytic prescribed, 75% of patients with known nausea and vomiting had no prn anti-emetic charted and 35% of patients with pharyngeal secretions were not prescribed an appropriate agent. Conclusions This study reveals improvements to be made in the terminal care of elderly patients dying from non-malignant disease. There is a need for acute medical care, many of which could be addressed by a programme of education in the palliative care principles of communication, symptom control and advance care planning. The growing involvement of palliative care and DME professionals in community care should help to limit unnecessary admissions of terminally ill elderly patients to hospital.

Abstract number: 397
Presentation type: Oral
Poster number:

Physical exercise intervention in palliative cancer patients; a phase II study. Are the patients able and willing to participate?

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Objectives: To assess the current state of end-of-life care in Canadian long term care (LTC) facilities. Methods: All licensed LTC facilities within the province of British Columbia were included in the postal questionnaire survey. Survey questionnaires were mailed to the designated Directors of Care at each facility. The instrument collected information about mortality patterns, provider and organizational characteristics, end-of-life care practices, staff and family education needs, and LTC policy recommendations. Results: 125 LTC facilities from 426 (76% response rate) licensed LTC facilities completed the postal survey questionnaire. Substantial challenges were identified in staffing levels, education and training, and staffing ability in providing quality of end-of-life. Respondents also identified concerns relating to attending physicians and their provision of end-of-care planning. Conclusions: The findings of this survey analyses identified the best predictors of providing quality care for dying residents: 1) consensus in the facility about what constitutes quality of end of life care, 2) management expertise for quality care of the dying, 3) having staff in the facility that are able to accurately assess when a resident is dying, 4) having attending physicians in the facility that have the necessary knowledge and skills to provide quality care, 5) having less than 100 beds in the facility, 6) having staff that have the ability to address multi-cultural preferences, 7) having good communication among facility staff regarding care. Conclusion: The findings revealed serious problems in the care of the dying resident in LTC facilities. The information contributes to the current discussion on policies for the meeting the care needs of residents in LTC facilities.

Abstract number: 399
Presentation type: Oral
Poster number:

Systematic 'ethnographic' review of palliative care professionals' experiences of caring for people with cancer at end-of-life

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Aims: To (systematically) review and analyse palliative care professionals’ written accounts of caring for people with cancer who are knowingly facing death in order to provide another source of knowledge or ‘evidence’ about patients’ needs and views and responses to them. Method: Systematic review methodology and qualitative research techniques were utilized to locate a range of material written by palliative care professionals in a variety of disciplines across different institutional settings. The search strategy was designed to find published reflective narratives (not original research) in the English language from 1975 onwards, which focused on the experiences of health professionals caring for patients with cancer as they approached their death. The extensive search included electronic databases (e.g. Medline; CINAHL), journals, archives, research networks and the internet. The data analysis was conducted using a thematic analysis; a qualitative analysis and a qualitative discourse thematic analysis. Results: The search strategy yielded 2224 possible articles, books and book chapters. The inclusion/exclusion criteria were then applied independently by two researchers; and 204 pieces of literature met the criteria for inclusion in the review, with physician (34%) and nurse (25%) authorship predominating. Discussion: Over the last 30 years, palliative care professionals have been steadily writing about their experiences of caring for people with cancer at end-of-life. Research on cancer patient and professional practice have shifted from views of the individual as an ‘object’ of medical care, to those of a person who desires autonomy and self-determination.
However, preliminary analysis from this study suggests that palliative care professionals’ understanding of patient autonomy is partial, and as a consequence expectations and practice surrounding end-of-life care for cancer patients may place limits upon the way in which they face death.

Abstract number: 400
Presentation type: Oral
Poster number:

INTERRUPTS UNTIL DEATH AMONG CANCER PATIENTS REFERRED TO A PALLIATIVE CARE PROGRAM IN A COMPREHENSIVE CANCER CENTER

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In recent years, the number of advanced cancer patients referred to palliative care programs has increased in the United States. The purpose of this retrospective study was to investigate the intervals between cancer diagnosis and death, and the interval between the palliative care initial consult and death. The charts of 340 patients with advanced cancer initially referred to the palliative care program at The University of Texas M. D. Anderson Cancer Center between September and December 2003 were reviewed. Available demographics, date of cancer diagnosis, date of diagnosis of advanced disease, date of death, and other available data were determined for this study. The study included 175 males and 167 females with median age of 62 years (range, 3–90 years). The four main reasons for referral to palliative care were pain (76.2%), fatigue (68.5%), depression/anxiety (47.7%), and loss of appetite (46.5%). The median time from the date of primary cancer diagnosis to death was 33 months (95% CI, 26–42). The median time from the date of diagnosis of advanced disease to death was 9 months (95% CI, 8–11). The median time from the date of palliative care referral to death was 58 days (95% CI, 47–66). All these medians were estimated using the Kaplan-Meier method. 340 values were used for each of the above estimates; 226 deaths and 114 censored survival values. We conclude that advances in referral to palliative care programs often occur late in the history of their illness. Joint oncology/palliative care is required in order to facilitate earlier patient access.

Abstract number: 401
Presentation type: Oral
Poster number:

Delirium in the outpatient clinic in palliative care service in an institute of cancer

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AIM: Epidemiology of delirium is poor studied in outpatient clinics. We wished to know the frequency of delirium in our clinic, its aetiology and its evolution after 7 days of treatment. METHIOD: We designed a descriptive study, enrolling patients consecutively who attended the palliative care service outpatient clinic from April to August 2004. Delirium diagnostic was made using DSM IV criteria. Apart from demographic data, the cognitive status was checked for using MME-30. When indicated complementary test were used (blood sampling, pulsoxymetry and others). RESULTS: During the study period 236 patients were visited. Twenty eight (13.8%) patients were diagnosed of delirium; the mean age was 66.6 y and 57.1% were men. Regarding the primaries in 26.8% of patients was lung, 10.7% breast, 10.7% prostate, 10.7% digestive, 7.1% head & neck, and 21.5% others. All patients with delirium fulfil DSM IV criteria, and at the moment of diagnosis 90% of them had a diagnosis MME-30, in 10% was impracticable. Regarding the main aetiology; in the 42.9% the main cause were psychotropic agents (75% strong opioids, 16.6% weak opioids and 8.4% antidepressants), in 25% was unknown, in 17.8 dehydratation and in 14.3% brain metastasis. After 7 days of treatment 46.5% were completely reversed, 32.1% partially reversed, 14.3% had no clinical changes, 7.1% deteriorates. Ten (83.3%) patients with delirium of pharmacological cause obtained a complete reversal and 2 (16.7%) a partial one. CONCLUSIONS: Delirium is a relevant condition in patients, in our milieu, could be considered quite high. The main cause involved is the use of opioids. Due to the general good response to treatment, when the cause of delirium is due to drugs or dehydration; early diagnosis through regular cognitive screening and a high level of suspicion should be recommended.

Abstract number: 402
Presentation type: Oral
Poster number:

Existential loneliness and existential coping in palliative home care

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Do palliative care patients and their relatives use existential and spiritual coping strategies even if they are not religious? How are they expressed and what are their functions? Informants and methods: Type I qualitative study included 175 males and 167 females with median age of 62 years (range, 3–90 years). The four main reasons for referral to palliative care were pain (76.2%), fatigue (68.5%), depression/anxiety (47.7%), and loss of appetite (46.5%). The median time from the date of primary cancer diagnosis to death was 33 months (95% CI, 26–42). The median time from the date of diagnosis of advanced disease to death was 9 months (95% CI, 8–11). The median time from the date of palliative care referral to death was 58 days (95% CI, 47–66). All these medians were estimated using the Kaplan-Meier method. 340 values were used for each of the above estimates; 226 deaths and 114 censored survival values. We conclude that advances in referral to palliative care programs often occur late in the history of their illness. Joint oncology/palliative care is required in order to facilitate earlier patient access.

Abstract number: 403
Presentation type: Oral
Poster number:

Specialists' religion and actual end-of-life decisions in neonates and infants

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Objective: To study the relation of physicians' religion with their actual end-of-life decisions (ELDs) in neonates and infants (method). All physicians who signed a death certificate of a live born neonate or infant in one-year period (1 August 1999 until 31 July 2000) in Flanders, Belgium, received an anonymous questionnaire regarding their attitudes toward ELDs and their actual ELDs in neonates and infants. Results: Of all 175 physicians who received a questionnaire, 121 responded (response rate: 69.1%) for a total of 253 deaths. The unit of analysis is the death certificate where an ELD was made by a specialist (N=142). There is no significant relation between physicians’ religion and the occurrence of ELD, but there is between religion and selfreported intention and type of ELD. Physicians who do not find religion important in ELD-making and in ELDs in neonates and infants. Method: All significantly more often explicitly intended to hasten death (p=0.002 and p=0.001) and used lethal drugs more frequently (p=0.048 and p=0.004). Physicians who find denomination important in ELD-making had significantly less explicit intention to hasten death (p=0.001) and did not use lethal drugs. They more often opted for the use of opioids for the alleviation of suffering then for other forms of ELDs. No significant relation was found between physicians’ religion and whether the consultation of a religious or religious counselor in the hospital setting – baseline data

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Objective: This paper describes from national and local perspectives, experiences and expectations of citizens, staff and community as they relate to people dying in hospital settings. The data presented here are part of a larger programme focusing on cultural, attitudinal and tangible change in one hospital setting. Methodology: Mailing national and local perspectives were employed to create a baseline of information. A nationally representative telephone survey (n=1,000) investigated care preferences, impressions of hospital care for dying patients

Abstract number: 404
Presentation type: Oral
Poster number:

Expanding the boundaries of care in the hospital setting – baseline data

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and the extent to which Irish citizens had made plans or discussed with others arrangements around care at the end of life. Nine focus group discussions were held with staff from clinical, professional and household sectors explored local observations around good and poor practice in caring for dying patients and their families. An end to end thematic analysis recording to examine the physical and symbolic environment of the hospital. Summary of Results: Similar to other Western countries the majority of Irish people would want to die in hospital. Our survey results show that 67% of respondents felt that was scope for improvement in hospital care for people who are dying or terminally ill. Over a quarter of those surveyed said that someone close to them had died in a hospital during the previous 12 months. Focus group discussions uncovered discipline-specific and common challenges in providing humane care for dying patients and their families. Video taping and photographs of the hospital illustrate the patient’s journey and are supplemented by the chaplain’s comments. These data directly input to the knowledge change program being developed for the hospital. Conclusions: Change in an individual hospital is being framed relative to national public opinion and qualitative.

Abstract number: 405 Presentation type: Oral Poster number:

Crossing the Threshold: A study of hospital doctors and nurses clinical decision making in the terminal trajectory

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Abstract number: 407 Presentation type: Oral Poster number:

Managing diabetes at the end of life: current practices of doctors and nurses

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Purpose: The incidence of both diabetes and cancer is anticipated to increase. Minimal empirical evidence describes or guides health professionals practice about diabetes and cancer management at the end of life. The aim of this research was to explore the current practices of doctors and nurses who provide care to patients with advanced cancer and diabetes and to make recommendations for improved patient outcomes. Methods: Three strategies were used: (1) A review of the literature; (2) Two focus groups with palliative care nurses, palliative care physicians, diabetes nurses and endocrinologists; (3) Sixty seven nurses and doctors completed a questionnaire about current practice related to diabetes at the end of life. Results: The literature identified that there is minimal published data describing or guiding practice in this area. Results of the focus groups and questionnaires showed that health professionals perceive diabetes patients at the end of life to be very challenging due to a lack of guidelines to support clinical decisions. When patient death appeared imminent health professionals found it difficult to: (a) the optimal frequency of blood glucose monitoring; (b) what might be considered a normal blood glucose range, and (c) to ascertain appropriate anti-hyperglycaemic medication doses. Participants recognised the importance of greater collaboration between palliative care health professionals and diabetes specialists. Conclusions: Findings from this research suggest that guidelines and education are required to assist health professionals as they care for patients with diabetes at the end of life.
Abstract number: 409
Presentation type: Oral
Poster number:

**The Association Between Anemia and Fatigue in Palliative Care Cancer Patients**

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Fatigue has been reported associated with chemotherapy-induced anemia in patients with advanced cancer. Correction of anemia using erythropoietin has been reported to decrease fatigue and increase the quality of life of these patients. The purpose of this study was to determine the association between the intensity of anemia as determined by the hemoglobin (Hgb) levels and the intensity of fatigue, depression, anxiety, well-being in terminally ill cancer patients receiving palliative care. The charts of 177 consecutive patients seen by palliative care specialists were reviewed. Complete blood count was available in 147 (83%) patients. Median Hgb within 4 weeks of palliative care consultation was 11.6 g/dl (range 7.5–16). Eighty-two (56%) patients had Hgb levels < 12 g/dl. 125 (85%) had Hgb level ≥ 12. Median fatigue score in patients with Hgb level ≥ 10 g/dl vs. < 10 g/dl. Hgb did not show significant univariate correlation with fatigue, depression, anxiety, or well-being. In a regression analysis between the intensity of fatigue and other clinical variables, 3 variables remained in the stepwise elimination analysis: depresssion (P = 0.007), albumin (P = 0.006), and well-being (P = 0.006). The overall r2 for this model was 0.22. We conclude that anemia is not one of the major contributors to fatigue in palliative cancer care patients. More research is required to identify correlates of fatigue other than mood.

Abstract number: 410
Presentation type: Oral
Poster number:

**Follow up of volunteers activity in urban and rural areas of Ancona district, Marches, Italy**

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Background: From 1997 to 2002, 75 volunteers were trained to join IOM Palliative Care Unit, and 40% of them were available. A 15 volunteers education module was held each year. Age, sex, education, previous volunteer experiences, neoplastic disease in relatives and motivation were recorded at registration. By the end of 2004 reason of withdrawal was investigated. Result: Overall attendants: sex F 80% (60 vs 15), mean age (range 15–65) 47 ± 11, previous volunteers 31%, neoplastic disease in relatives 64%, university education 28% (53% high school, 19% primary). Solidarity is a motivational category more represented (49%) out of five. 55 volunteers withdrew (75%) with 13 never started, 20 are still working. Study/work, lack of motivation, family reasons represent 25%, 20%, 25% of withdrawal reasons respectively.

Withdrawal rate (w.r.) from home care and in-hospital activity is 75% and 50% respectively. W.r. for age < 35, 35–50, 50–65 is 95%, 64% and 49%. W.r for primary, high school, university education is 46%, 84%, 70%. Conclusion: under 35 attendants are more likely to withdraw, as well as home care volunteers and highly educated ones. Selection, specific training and psychological supervision should be reconsidered..

Abstract number: 411
Presentation type: Oral
Poster number:

**IMPACT OF MUSIC THERAPY IN PALLIATIVE MEDICINE**

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Background Complementary therapies are palliative and augment conventional treatment. Music therapy as a complementary therapy has been used to reduce anxiety and improve quality of life. We wished to prospectively study the effect of music therapy on multiple symptoms experienced in an inpatient palliative medicine unit. Methods A visual analog scale, a Happy/Sad Face Assessment tool and behavioral scale were utilized as a measured outcome pre and post music therapy. Anxiety, depression, dyspnea, mood, pain, and verbalization were assessed by both patients and families. A computerized data program was used and statistical analysis performed using the Wilcoxon signed rank test. Results Two hundred cancer patients participated, 59% were females, the median age was 62 (range 24–87 years). Mood, pain, anxiety, depression, dyspnea and verbalization all improved by patient assessment (P < 0.001). Mood (P < 0.001) but not anxiety (P = 0.50) improved by family assessment. Discussion Music therapy has a beneficial effect on multiple symptoms. This is one of the few few studies conducted. Among the shortcomings of this study was that future data will be presented at the meeting.

Discussion: The data suggest that music therapy is effective in over 50% of patients. As the data needs to be considered in hospitalization. The data also suggest that music therapy may be effective in palliation and further randomized controlled trials require.

Abstract number: 412
Presentation type: Oral
Poster number:

**Antifungal drug resistance in patients with advanced cancer**

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Background: Oral candidosis is common in cancer patients. The need to consider the risk of fungal infection and resistance often makes antifungal drugs (e.g. fluconazole). However, recent studies suggest that antifungal drug resistance may be becoming common in patients with advanced cancer. Aim: (1) To determine the prevalence of antifungal drug resistance; (2) To determine specific risk factors for the development of antifungal drug resistance. Methods: The population studied were patients attending a specialised palliative care unit of advanced cancer attending hospice day centres within the South West region of England. Basic demographic and antifungal prescribing data were recorded. Unintentional and psychosocial data were collected (for isolation of yeasts). Isolated yeasts were identified using the standard API method, and tested for antifungal sensitivity using the standard NCCLS method. Results: 285 patients have participated in the study. Resistance to polyene drugs (amphotericin, nystatin) was rare, although resistance to azole drugs was common. For example, 24% of isolates were resistant to fluconazole, and a further 6% sensitive to higher doses of fluconazole. Similar levels of resistance occurred to itraconazole, but lower levels of resistance occurred to ketoconazole and voriconazole. Resistance was not related to previous exposure to azole drugs or to antifungal drugs per se, but was associated with colonization with non-Candida albicans species (27% isolates) and with salivary gland dysfunction. Further clinical and pathological data will be presented at the meeting.

Discussion: The data suggest that azole drug resistance is common in patients with advanced cancer. Thus, health professionals should consider other treatment options in this group of patients (e.g. polyene drugs). The data also suggest that salivary gland dysfunction may predispose to colonization with azole-resistant organisms.

Abstract number: 413
Presentation type: Oral
Poster number:

**Respiratory effects of buprenorphine compared to fentanyl: dose-response assessments in healthy volunteers**

Albert Dahan, Department of Anesthesiology, Leiden, NETHERLANDS

Long-acting opioids are important tools in the treatment of cancer pain. When selecting one of the available compounds the analgesic properties as well as the safety profile of the drug needs to be considered. Among the opioids with long-acting properties as well as the safety profile of the drug needs to be considered. Among the opioids with long-acting properties as well as the safety profile of the drug needs to be reconsidered.

[Abstract text continues with detailed study methodology and conclusions, not transcribed here.]
to fentanyl with respect to their effect on the ventilatory control system. Buprenorphine has only little impact on respiratory function with ceiling effect at high dose. In contrast, fentanyl causes dose-dependent respiratory depression with apnea at high dose.

Abstract number: 414
Presentation type: Oral
Poster number:

OUT-OF-HOURS PALLIATIVE CARE NEEDS IN THE COMMUNITY

CHI-CHI CHEUNG LONDON, GREAT BRITAIN, CATHERINE O’DOHERTY, BASILDON AND SOUTHEND HOSPITALS, ESSEX, GREAT BRITAIN

Studies have shown that 50–90% of terminally ill patients wish to die at home. The focus of palliative care has therefore shifted towards enrolling patients to remain at home, if this is their wish. Patients should be well supported not only during normal working hours, but also during the remaining 75% of the week (‘out-of-hours’) when staffing levels are lower. Aims: This study looks at the needs of patients during the out-of-hours period, by assessing the calls made to an emergency GP (‘general practitioner’) service in South Essex, England. Methods: We analysed calls sheets regarding terminal illness patients, over a 3-month period, and documented when and why they called, what action was taken, and what prescriptions were required. Results: 1.8% (132) of all calls were regarding patients who were terminally ill. Most calls were made at the weekend; only 16% of these calls occurred between 2300 and 0700. 90% of calls requested either assessment, and/or symptom control. 53% were managed by giving telephone advice alone. 15% attended the primary care centre for consultation; 25% required a home visit. Nearly a quarter of calls resulted in secondary care input. Specialist palliative care telephone advice was not sought for any of the cases. Nearly one third of patients required new prescriptions. 7 patients needed controlled drugs; 4 of these were for opioids and 3 were for benzodiazepines. There were no documented problems in obtaining these drugs. Conclusions: Although most calls were managed by the on-call GP, nearly 1 in 5 patients attended hospital. Anticipating crises and communicating information with on-call services may help to reduce this figure. Most calls were made during waking hours at the weekend. Specialist palliative teleadvice was not utilised, we question whether a visiting service at these times may help to keep patients at home.

Abstract number: 415
Presentation type: Oral
Poster number:

THE SEIQoL-DW: outcome measure and psychosocial intervention?

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The SEIQoL-DW (Schedule for the Evaluation of Individual Quality of Life – Direct Weighting) is a well-validated quality of life instrument. In this study, we investigated whether the SEIQoL-DW may furthermore be a helpful intervention for palliative care patients, their primary caregivers, and the palliative care team. Patients and methods: 32 patients and their primary caregivers were asked to complete the SEIQoL-DW at admission and after 2 weeks. Additionally, patients rated their own perceived helpfulness, distress and validity of the SEIQoL-DW on 10-point visual analogue scales (VAS). The palliative care team received summarized feedback on the SEIQoL-DW for every patient and caregiver, and was asked to rate on a VAS the helpfulness of this information for their work. Results: 20 patients, 7 primary caregivers, and 16 team members took part in the study (after 2 weeks: 9/4/6). The median age was 62.5 years in patients and 57.9 years in caregivers. The median SEIQoL-DW index (0–100) was 55.9 in patients and 51.4 in caregivers (2 weeks: 54.9/61.1). The SEIQoL-DW was rated as valid (6.2/6.7; 2 weeks: 7.3/7.0), hardly distressing (2.5/1.7; 2 weeks: 3.0/1.3) and quite helpful (5.3/4.4; 2 weeks: 6.3/4.8; 47.4% of patients had a rating of 6 or more at baseline, 70% after 2 weeks). The palliative care team reported a benefit through the SEIQoL-DW feedback, especially at the beginning of the palliative care treatment (admission: 5.9; 2 weeks: 4.8). All measures did not differ significantly between patients and caregivers or over time. Conclusion: This preliminary study appears to be a helpful instrument for the palliative care team to optimize the treatment at admission, i.e. at a time when the patient is not yet well known. For the patient and the primary caregiver the SEIQoL-DW is hardly distressing and quite helpful to a sub-group of patients. Further research should verify whether the SEIQoL-DW may facilitate a higher degree of preparedness in some patients and primary caregivers.

Abstract number: 416
Presentation type: Oral
Poster number:

Health-related quality of life in caregivers of dying cancer patients: a comparison between a specialist palliative care unit and a home care setting

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Background: Little is known about the distress of caregivers while caring for dying relatives. In order to capture health-related quality of life, questionnaire surveys were conducted. The SF-12 health survey were sent out to the families of cancer patients who either died in the palliative care unit at Goettingen University or in a home care setting in the surrounding region. Results: Out of 146 included relatives we obtained a total of 87 (60%) answers. The relatives of both collectives showed drastically lowered MCS-12 scores in comparison to the normal population (psychological quality of life: palliative unit group: 28.1, home care group: 30.7, normal population: 52.3, p < 0.001) and moderately reduced PCS-12 scores (physical quality of life: palliative unit group: 43.7, home care group: 40.9, normal population: 49.6). In the subgroup palliative unit relatives with an average length of care of more than six hours per day showed especially low MCS-12 scores (21.6; p < 0.001). Sole caregiving relatives without support by other persons, and a total length of care of more than six hours per day showed a significant with low SF-12 scores. The relatives of both collectives showed a mean age of 55.9 years in patients and 57.9 years in caregivers. The median SF-12 index (0–100) was 55.9 in patients and 51.4 in caregivers (2 weeks: 54.9/61.1). The SEIQoL-DW was rated as valid (6.2/6.7; 2 weeks: 7.3/7.0), hardly distressing (2.5/1.7; 2 weeks: 3.0/1.3) and quite helpful (5.3/4.4; 2 weeks: 6.3/4.8; 47.4% of patients had a rating of 6 or more at baseline, 70% after 2 weeks). The palliative care team reported a benefit through the SEIQoL-DW feedback, especially at the beginning of the palliative care treatment (admission: 5.9; 2 weeks: 4.8). All measures did not differ significantly between patients and caregivers or over time. Conclusion: This preliminary study appears to be a helpful instrument for the palliative care team to optimize the treatment at admission, i.e. at a time when the patient is not yet well known. For the patient and the primary caregiver the SEIQoL-DW is hardly distressing and quite helpful to a sub-group of patients. Further research should verify whether the SEIQoL-DW may facilitate a higher degree of preparedness in some patients and primary caregivers.

Abstract number: 417
Presentation type: Oral
Poster number:

Action Research: A feasible method for service development in palliative care?

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Introduction: The complex nature of community palliative care makes action research a potentially valuable approach for service development. By this method health professionals engage in research using a cyclical process of reflection, action and evaluation to explore and enhance local practice. We present initial findings of an ongoing study in which professionals and researchers are using this approach to develop a palliative care service. Although we explore the feasibility of using action research to develop a home care nursing service (HCNS) provided by health care assistants (HCA). Methods: The work of the HCNS in one year was surveyed retrospectively by key informant interviews to explore issues for service improvement. Results were presented to a focus group of relevant stakeholders to allow a developmental strategy to emerge. Continuous reflection regarding the research process was made at a theoretical and practical level to assess the feasibility of its application to palliative care. Results: Findings revealed that whilst the HCNS was highly valued and effective, organisational deficiencies and lack of professional support for HCAs existed. The solution of employing a senior nurse as co-ordinator is currently being developed. Process issues identified included: conflict between time spent in research and service activities, differing time-scales for service development and research, and failure to engage HCAs sufficiently in the project. Conclusions: Action research may provide a robust and transparent model for service development. However conflicts between service and research requirements may compromise the rigour of the method and power relations may threaten its emancipatory nature. Continuous reflection and flexibility of the process are vital to its success.

Abstract number: 418
Presentation type: Oral
Poster number:

The analysis of the causes of hospitalization of patients with advanced cancer

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In the integrated model of palliative care patients with advanced cancer diseases have free access to both ambulatory care and hospital care. At present, the Bydgoszcz Home in Bydgoszcz take care of almost 200 patients every day: 160 patients in home care, 20 patients in outpatient department and 20 patients in 24 beds inpatients department. Since 2000 which is the moment of home care start we have noticed lower interest in long stay in the inpatient department. Patients are sent to inpatients department mainly from home care, palliative outpatient department and nearby oncological hospital. Other hospitals sent a smaller number of patients (15%) to our centre. The aim of the research was the quantity of hospitalizations and their reasons.
Centralised palliative care units in remote areas: an obstacle to future home care?

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Background: Inpatient palliative care units at university hospitals serving remote and rural areas are rare. In 2003 a Palliative Medicine Inpatient Unit (PMIU) was established within the Cancer Department at the University Hospital of Northern Norway. The aim of this study was to explore whether centralised inpatients palliative care units in remote areas are necessary to provide good palliative care and whether such centralization unnecessarily keeps the patients far away from their family and home community. Methods: We retrospectively reviewed our computerised database for clinical and demographic information during the first year of PMIU service. Additionally, 100 consecutive inpatients from the rest of the Department of Oncology (OD) were analysed. Results: Sixty-seven patients were admitted to the PMIU during the study period. Twenty-one had more than one admission (range 1–7) and the total number of admissions was 119. Median age was 60 years (range 16–82). The main cancer diagnoses were gastrointestinal (30%), genitourinary (23%) and breast (16%). The median length of stay at the PMIU was 7 days (range 1–52). Chemotherapy or radiotherapy was administrated in 66 out of 119 admissions. Median survival of the PMIU patients was 8 weeks vs. 13 months at OD. Twenty-six (39%) patients died while at PMIU. Most patients (81%) were discharged to their home community and 42% of the patients lived more than 300 kilometres from the PMIU. Conclusion: A centralised PMIU in a remote area is beneficial in order to give advanced palliative care to selected patients, of whom many are in need of chemotherapy or radiotherapy. Despite long travel distances, centralization of advanced palliative care in remote areas seems not to inhibit these patients' possibility to spend most of their time at home.
Abstract number: 421  
Presentation type: Poster  
Poster number: P1

Refractory pain-depression syndrome treated with Tianeptine: case report

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It is well known that refractory chronic pain is strongly associated with anxiety and depression symptoms in advanced cancer patients. The concomitance of the two conditions raises clinically difficulties symptom control and seems to create a noxious feedback mechanism in which: uncontrolled and/or chronic PAIN (leads to) > DEPRESSION (losser the capacity to cope with pain) > more PAIN (worsen) > DEPRESSION > and so on. We call this feedback circle as Pain-Depression Syndrome. Mr RA, is a 68-years-old male Caucasian. At the age of 66 an advanced prostatic adenocarcinoma was diagnosed, and radiotherapy was initiated. Bone metastases were concomitantly found. The improvement of the prostatic cancer was small and the metastases were multiple. A mild bone pain was treated with paracetamol. After a year, the pain worsened and tenoxicam 20 mg/day was added, but the pain became more severe. We initially treated the pain with 400 mg/day of tramadol with partial response. A decision to start morphine was discussed. The patient had no history of mental disorder and this family had no history of mood or anxiety disorder. He was examined by a psychiatrist who diagnosed a major depressive episode (DSM-IV-TR) associated with chronic pain syndrome (Clinical Global Impression-GG, severity = 5). He was prescribed with amisulpride starting with 25 mg/day and increasing up to 75 mg/day at which he experienced severe anticholinergic side effects and mild confusion. Then amisulpride was thus halted, and he was prescribed with tiapine 12.5 mg three times a day. After a 2 week period he described a remarkable improvement of pain control (75% on a analogue visual scale of pain), mood, anxiety and depressive symptoms were also improved (CGI severity = 2; CGI improvement = 1). At 6 months follow-up he had very mild pain complaints and no significant mood or anxiety symptoms. His quality of life had improved greatly and he has also returned to many of his daily activities.

Abstract number: 422  
Presentation type: Poster  
Poster number: P2

Levobupivacaine vs Bupivacaine: effectiveness in Malignant Pain

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Bupivacaine is a racemic (50:50) mixture of the S- (+) and R (-) enantiomers, Levobupivacaine and Dextrobupivacaine, respectively. However there has been a large amount of data on the clinical characteristics of levobupivacaine, and the pharmacological and central nervous system toxicity associated with rac-bupivacaine (1,2). In recent study Levobupivacaine has demonstrated less toxicity, while retaining comparable analgesic efficacy and analgesic potency (3). The aim of this study was to investigate the analgesic effectiveness of Levobupivacaine during a continuous epidural infusion (4). The Levobupivacaine group was 67 years, 21 females and 18 males, with cancer pain were randomized to receive either Levobupivacaine 2.08 mg/ml (L Group), or Bupivacaine 2.08 mg/ml (B Group). Morphine 0.83 mg/ml was given to each group. Up-down epidural catheter implantation for epidural infusion was performed under X-ray control. Efficacy was measured according to: 1. Pain using visual analogue scale (VAS) and verbal Assessment 2. Spontaneous or induced paresthesias. Our follow-up study was three months. Data was analyzed using standard statistical tests and p-value of <0.05 was considered significant. Results: T-test proved that L (Levobupivacaine) group and B (Bupivacaine) group's patients were homogeneous (t=1.460; p=0.152). We observed: L Group 66,6% and B Group 61,1% presented pain relief 80% to three months follow-up study (VAS = 0–3). However L Group 79,7% and B Group 28% presented pain relief 60% to two months follow-up study (VAS =4–6), than controlled analgesia (PCA) was effective. Object examination showed spontaneous or induced paresthesia more evident in Bupivacaine group. Conclusions: Since B (Bupivacaine) Group’s Pearson factor was 0,3, analgesic effectiveness Levobupivacaine seemed be limited. L (Levobupivacaine) Group did not present undesirable influence (factor Pearson=0.17). In L Group consistent analgesia came true without spontaneous or induced paresthesia.

Abstract number: 423  
Presentation type: Poster  
Poster number: P3

Topical application of morphine-gel in inflammatory mucosal and cutaneous lesions

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Aim The aim of this study was to demonstrate a peripheral local opioid effect using case examples involving inflammatory mucosal and cutaneous lesions. Methods A 0.1% morphine gel, mixed in the hospital pharmacy, was applied several times daily to inflammatory mucosal lesions (oral, anogenital and in one patient to a skin ulcer). The effects and side-effects were documented. Results All patients experienced a significant reduction in pain with the use of topical morphine gel and no side-effects were seen. Conclusion Topical peripheral application of morphine gel is a simple, effective method that can be carried out by patients several times a day with few side effects. Key Words peripheral opioid receptor, inflammatory skin-mucosal lesions, morphine gel.

Abstract number: 424  
Presentation type: Poster  
Poster number: P4

Meeting the Analgesic Requirements of Radiotherapy Outpatients

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Object of Study: to assess the impact on the pain control of radiotherapy outpatients following a 12-month project. The project involved placing a Controlled Drug Cupboard in the radiotherapy-planning department (following the RCP guidelines, see home Office). A specialist nurse is contacted by bleep (according to a rota) to check and administer the analgesia. Previously, a prescription had to be taken to the pharmacy, then brought by a radiographer. A ward nurse would then return to the planning department with the analgesic and administer it to the patient. Method used: quantitative audit - comparing number of analgesic episodes (outpatients identified to have pain) & time taken (identification of pain to administration of analgesia) both before and after the project was set up. Results obtained: the number of patients identified to require analgesia increased (from 1 to 5 times a month) & the time those patients waited for analgesia decreased significantly (from 20 to 5 minutes). Conclusions reached: 1. The new system did not take ward staff away from inpatients 2. Providing the service increased awareness of the analgesic requirements of outpatients 3. Those outpatients now spend significantly less time in pain.

Abstract number: 425  
Presentation type: Poster  
Poster number: P5

Use of the Micro-Electronic Monitoring System for the measurement of adherence to analgesics in cancer outpatients

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Pain is one of the most prevalent and feared symptoms in cancer patients. Adherence for pain medication may contribute to pain relief, but is hardly studied in oncology outpatients. Until now, no ‘gold standard’ exists for the measurement of adherence. In this study we investigated the feasibility of a new method for adherence measurement known as the Micro-Electronic Monitoring System (MEMS). The MEMS consists of electronic circuitry that registers each time the tids of medicine containers are opened. In an ongoing study 45 patients are being included (15 patients with one, 15 patients with two, and 15 patients with three prescribed analgesics). During a four-week period in each patient the MEMS will be used for the measurement of adherence, which is defined as ‘taking adherence’ (% of total prescribed medicines taken), ‘correct dosing’ (% days correct number of doses taken), and ‘timing adherence’ (% prescribed doses taken on schedule). At the moment 20 patients were evaluated, 6 patients with one analgesic, 9 patients with 2 analgesics and 5 patients with 3 analgesics. 80% of the patients were (very) satisfied using the MEMS, 95% had no problems using the MEMS and 90% used only medication from the MEMS containers. Mean percentages of taking adherence of patients with one, two, and three analgesics were resp. 98, 83, and 84%; mean percentages of correct dosing were resp 93, 77, and 66%; mean percentages of timing adherence were resp. 74, 55, and 44%. Final results will be presented. In conclusion, the measurement of adherence with the MEMS seems feasible, and it provides objective and detailed information.
Introduction and Objectives: Radiation therapy is a well known and common method of treatment of bone pain due to metastases with pathological fracture risk. Material and Methods: 13 patients with different kinds of tumors and bone metastases. The ones who received beam radiation therapy poorly responded to opioid pain treatment previously. Single radiation of 6 Gy and 8 Gy was used achieving analgesic effect. Results: Patients described pain using NRS scale: before radiation as follows: 48% – 4, 36% – 5, 12% – 3, 14% – 6, than on 2nd day, 7th . and in 2nd . week. Radiation was effective in better pain control in all patients (60% showed 2 in NRS and 40% – 1). It is difficult to estimate the research because of small group of patients (n=13) and subjective perception of pain. Conclusions: Single beam radiation therapy is a well known and common method of treatment of bone pain in palliative patients. It turned out that single beam radiation is equally effective as long term radiation but more comfortable and less exhausting for patients. The research should be continued with more reliable validation methods.

Abstract number: 427
Presentation type: Poster
Poster number: P7

Encapsulation of an intrathecal catheter

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Summary: Adequate pain relief may not be achieved with oral opioid administration in some patients with cancer pain. Spinal administration of opioids is an alternative for some of these patients. While encapsulation is a well-known complication of long-term epidural morphine administration, it has not only been reported for intrathecal catheters. We report a case of an encapsulated and infected intrathecal catheter tip. The successful identification and treatment of the infection as well as the subsequent intravenous pain regimen are described. Case report: A 47-year old patient with cancer pain with buprenorphine implantation of an intrathecal drug delivery device. When the patient suffered from an infection with fever, pain on injection into the catheter and an elevated number of granulocytes in the cerebrospinal fluid 7 weeks later, radiological examination showed an encapsulation of the catheter tip. Systemic and cerebrospinal fluid concentrations of morphine and its metabolites suggested transport of morphine into the systemic circulat ion via the vascularisation of the encapsulating membrane. After antibiotic therapy and removal of the catheter, morphine was administered intravenously with a one to one conversion ratio resulting in adequate pain relief. The patient died more than six months after removal of the catheter.

Abstract number: 428
Presentation type: Poster
Poster number: P8

The use of Tramadol as an adjuvant in cancer related bone pain: prospective case series

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Background: Tramadol is a synthetic centrally acting analgesic with opioid and non-opioid properties. Tramadol has moderate affinity for mu- and weak affinity for delta and kappa- opioid receptors. The non-opioid properties include increased release of serotonin and reduced pre-synaptic uptake of noradrenaline and serotonin. Due to its favourable side-effect profile and good effect, tramadol is used commonly in postoperative pain management of orthopaedic surgery patients. Bone pain is a common problem in cancer patients and is often difficult to manage with standard analgesic regimes including non-steroidal anti-inflammatory drugs and strong opioids. This preliminary case series intends to study the effect of a tramadol slow release formulation as an add-on to maximal opioid therapy in the treatment of cancer-related bone pain. Method: Patients with cancer-related bone pain as diagnosed by the treating clinician, who have been titrated onto oral morphine sulphate and appropriate co-analgesics until dose-limiting side effects occur will be started on Tramadol SR 50mg bd as an add-on if deemed appropriate by the treating clinician. Breakthrough doses of strong opioid will be allowed as needed and recorded. If pain persists tramadol SR will be increased in 48 hour intervals in steps of 50mg bd up to a dose of 200mg bd. Endpoints are decreased dose of concurrent opioid dose, pain control and side effect profile. Pain, drowsiness and nausea will be measured at baseline and once daily for five days with a four-point categorical scale ranging from 0 to 1 (0=no pain, 1=minimal pain, 2=moderate pain, 3=severe pain).

Abstract number: 429
Presentation type: Poster
Poster number: P9

Pain treatment in the palliative home care - use of opioids


Introduction: Palliative Medicine Clinic (PMC) and Home Hospice (HH) in Wroclaw provides home and ambulatory care for about 1000 cancer patients per year. The aim of the study was to estimate the use of opioids in treatment of cancer pain. Material and Methods: On one day, 15th March 2004 all medical records of patients being currently under the care of PMC and HH were checked, looking at the treatment with opioids on that day. 269 records were checked. The VAS score less then 5 was recorded in all patients. 24% of patients were without opioids, either without any analgesics, or taking NSAIDs or paracetamol. Opioids were taken by 76% of the patients, 43% of them were receiving tramadol, 26% morphine (mph), 28% Durogesic, and 3% buprenorphine. Very often different opioids

Abstract number: 430
Presentation type: Poster
Poster number: P10

BUPRENORPHINE IN TRANSDERMAL SYSTEM IN CANCER PAIN - OUR EXPERIENCES

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Introduction and Objectives: Buprenorphine is a low molecular weight, lipophilic, opioid analgesic, available also as patch formulation designed to release buprenorphine over 72-hours period. In Poland buprenorphine patches are available from the beginning of 2004. Partial agonist in opioid receptors and an antagonist at K - opioid receptors, buprenorphin is 23-50 times more potent than an equivalent dose of morphine. Following the cessation of buprenorphine therapy, withdrawal symptoms may occur. The peak may be reached at about 2 weeks. Buprenorphine is placed on the three-step pharmacological ladder of analgesia. Material and methods: The observation involved 10 patients (6 women and 4 men) in range of age 50 to 82 treated of cancer pain with buprenorphine as TDS of dose 35 µg/h. For breakthrough pain patients were administrated buprenorphine in tablets on demand. In the study side effects were also considered. Results: At the beginning side-effects were observed, and gone after few hours. All patients experienced pain relief. Patients also described patches as easy and comfortable in use. Observed side effects were as follows: in 40% - sleepiness, 10% – worse concentration, 10% - dizziness and 10% - none. Conclusions: Use of buprenorphine patch system confirms its efficacy and safety in cancer pain. It is also easy and comfortable in use and excpets patients from remembering of taking tablets.
Abstract number: 431
Presentation type: Poster
Poster number: P11

Strontium 89 and samarium 153 in palliative therapy of painful cancer bone metastases – comparison of effectiveness

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The painful cancer bone metastases are usually detected in 60–80% of patients with advanced prostate cancer and breast cancer. The aim of this study was to evaluate the effectiveness of Sr 89 and Sm 153 therapy in the group of prostate and breast cancer patients with multiple bone metastases. The study included 40 prostate cancer patients and 40 breast cancer patients with multiple bone painful metastases detected by scintigraphy and by radiogram or CT or MRI determined in the course of their metastatic disease. 40 patients (20 with prostate and 20 with breast cancer) received a standard dose of Sr 89; others received a individual dose of Sm 153 (the randomization). For assessment of therapy effectiveness; pain relief, a reduction in analgesic requirements and motor activity were evaluated. During follow-up after 4 and 10 weeks of the end of Sr 89 therapy we noticed pain relief effects as follows: “good” (VAS) in 8 patients (2 with prostate and 6 with breast cancer). During follow-up after 4 and 10 weeks of the end of Sm 153 therapy we noticed pain relief effects as follows: “good” in 16 patients (8 with prostate and 8 with breast cancer), “moderate” in 18 patients (9 with prostate and 9 with breast cancer), “no effects” in 6 in patients (3 with prostate and 3 with breast cancer). We have observed that the analgesic requirements decreased to 50% of dose on average. The motor activity of the points evaluated according to EOCG scale and Karnofsky’s scale was much better. We conclude that palliative therapy using radioisotopes (both Sr 89 and Sm 153) is effective (80–85% “good” and “moderate” response rate). In breast cancer bone metastases (more cases with oestolecic – osteoblastic metastases), tendency to better results of Sm 153 therapy was observed.

Abstract number: 432
Presentation type: Poster
Poster number: P12

Opioid rotation for the relief of refractory pain: Assessment of prevalence and effectiveness during global natural history of cancer

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Aim: To assess the need for opioid rotation (OR) through the natural history of neoplasms and evaluate the analgesic response. Methods: Retrospectively the medical records were studied of all patients who received S-ketamine orally at the start and those in whom the administration was converted from parenteral to oral administration. Results: The patients were in the palliative phase of advanced cancer and pain was managed multidisciplinary. All received S-ketamine adjuvant to a parenteral/transdermal opioid. Four patients received S-ketamine primarily parenteral and showed a good effect. S-ketamine was converted after 4 to 8 days into oral administration, with good effect in 3 patients. It was also possible to decrease the dose of opioids, and even to stop opioids, in one of these patients. Four patients started with S-ketamine orally for 2 to 13 days with no favourable effect. Administration was continued parenterally with satisfying effect in 3 patients. Conclusion: S-ketamine is a good adjuvant to opioids in complex pain problems. It seems rational to titrate the dose parenterally and then convert into oral administration, which is more convenient for the patient. Further prospective research is necessary.

Abstract number: 433
Presentation type: Poster
Poster number: P13

Use of Samarium-153 in the relief of cancer pain in a palliative care service: preliminary results

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Aims: To assess the characteristics of the patients in whom samarium-153 (Sm153) is prescribed in our service and mainly its analgesic benefit. Method: We designed a descriptive prospective longitudinal study, from January 2003 to February 2004. Patients enrolled were those in whom was prescribed Sm153 in an attempt to relieve bony pain due to multiple metastasis, insufficiently relieved with other means; drugs, radiotherapy or even surgery. The reduction in analgesic requirements was the parameter used to evaluate the analgesic response.. Sm153 was administered at the Service of Nuclear Medicine in an standardized way. Results: Nine patients have been enrolled, 3 of them died within the next 3 months after Sm153 treatment and there were not assessable by long term pain response. Six patients could be assessable: the mean age was 61.1 y, and 2/3 were men. One third of patients had breast cancer and the other two thirds prostate cancer. Before Sm153 administration the mean Equivalent Daily Oral Morphine Dose (EDOMD) was 130 mg with a rescue mean EDOMD of 25 mg. After 15 days of Sm153 injection the mean EDOMD could be reduced by 30% and the other 30% reduced the doses were reduced by 10%. The mean of the analgesic response was 3 months. No patient presented severe (grade IV) haematological side effects. Conclusions: Our experience Sm153 offers a good, early analgesic response (reduction of analgesic requirements) and long lasting. In despite of these good results, more experience is needed to define the patient’s profile which will best benefit. Further assessment of Sm153 in palliative care should be include improvement of functional status and QoL parameters.

Abstract number: 434
Presentation type: Poster
Poster number: P14

S-ketamine as an adjuvant analgesic: effectiveness of oral administration

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Introduction: S-ketamine (Ketanest®) is increasingly popular as an adjuvant to opioids in the treatment of cancer pain. In case reports and studies it is mostly administrated parenterally, but there are some reports about oral administration, which is more convenient for the patient. However, actual benefit of OR. We are now conducting a prospective national multicentre study.

Abstract number: 435
Presentation type: Poster
Poster number: P15

The incidence and measurement of pain in Dutch nursing and residential homes

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Introduction The prevalence of pain among the elderly is high. This study aimed to ascertain 1) the prevalence of pain among residents in Dutch nursing and residential homes, and 2) the effect of the implementation of daily pain registration on pain intensity. Method In 3 nursing homes and 1 residential home all nurses were trained in pain treatment and pain measurement. They were also instructed to ask the pain intensity of the residents on a daily basis using a numeric rating scale (0–10). Before the start of the program nurses’ knowledge on
pain management was measured by a survey and all residents were asked to indicate their pain intensity. Both measurements were repeated 3 times a day after the implementation of daily pain registration. Results 477 residents participated in the study (mean age 79 years, mean stay 22 months). 25% of them were unable to report pain intensity; 69% of the residents experienced pain (mean intensity 3.9) of whom 58% suffered substantial pain. Of the residents with pain 31% were offered no pain medication or only medication PRN. 38% of the residents did not mention their pain to the nurses. Education improved the knowledge of nurses on pain treatment with respect to fear of addiction, habituation and administration of pain medication. After implementing pain registration the percentage of residents suffering substantial pain decreased from 58% to 49%. Conclusion Pain is a major problem in residents of nursing and residential homes. Educating nurses and implementing pain registration increases knowledge of pain treatment and decreases the percentage of residents suffering substantial pain. Pain registration is a useful tool in improving pain control in these homes.

Abstract number: 436
Presentation type: Poster
Poster number: P16

LOCALLY ADMINISTERED OPIOIDS – CLINICAL PRACTICE
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The opioid receptors located on the peripheral sensory nerves are responsible for an analgesic effect after a local administration of preparations containing opioids. For the last 4 years, our clinical centre has carried out the research of locally administered preparations containing morphine in the treatment of painful malignant skin and mucosa ulcerations. Materials and Methods: The study comprised 24 patients with neoplastic pain (13 women and 11 men aged 44–87 years). Time of treatment: 30–210 days. Buprenorphine TDS–patches were applied (35 µg/h – 105 µg/h). Patients with incidental pain were additionally given intakes of Paracetamol, Tramadol, and sublingual Buprenorphine. Additional Paracetamol, Tramadol, and sublingual Buprenorphine intake were allowed. Conclusion Pain scores showed substantial decrease from 58 % to 49%. A few years ago Buprenorphine TDS–patches were also available for patients with neoplastic pain. Aim: The aim of the research is to evaluate the effectiveness of Transdermal Buprenorphine in patients with neoplastic pain and to gain clinical practice.

Abstract number: 438
Presentation type: Poster
Poster number: P18

Nursing experience of caring patients with advanced cancer at home with spinal analgesia: preliminary experience
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Aim: Describe our experience in the management of advanced cancer patients at home with spinal analgesia. Method: We enrolled patients with the diagnosis of advanced cancer, cared for our palliative service wearing a catheter for spinal analgesia. We collect data related to the complications and specific nursing care. Results: From March to September 2004, 4 patients were enrolled, 3 (75%) were men. It have been placed 5 catheters 3 intradural and 2 epidural. Mean follow up at home was 59.3 days (20–120 days). Pain relief in all cases was very good (VAS < 4) allowing a high degree of autonomy for the Daily Life Activities (Mean Barthel of 85). Three hospital admission were needed for catheter related complication, mainly skin infections. None case was necessary to remove catheters to control the complication. Overall evaluation of patients, families and team was fairly good allowing caring patients at risk of potential heavy complications at home. Using a close system of analgesia and a careful patient supervision was most valued by patients and nurses. Conclusions: This initial experience has been helpful to us to realize the feasibility of caring complex patients at home, since till now patients like this needed long hospital admissions.

Abstract number: 439
Presentation type: Poster
Poster number: P19

A PILOT STUDY TO DEVELOP A BEDSIDE PAIN DOCUMENTATION CHART AND ESTABLISHING THE EFFICACY OF THE CHART
Katherine Clark, Palliative Care, Sydney, AUSTRALIA, Paul Glare, Royal Prince Alfred Hospital, Sydney, AUSTRALIA, Martin Stockler, Royal Prince Alfred Hospital, Sydney, AUSTRALIA, Emily Sung, Royal Prince Alfred Hospital, Sydney, AUSTRALIA, Judi Greaves, Royal Prince Alfred Hospital, Sydney, AUSTRALIA

Background: Cancer pain a problem in Australia, despite guidelines indicating that documentation may improve pain management, boosting staff & patient satisfaction. Little evidence exists that pain scores improve. In our institution, pain scores aren’t documented so a study was undertaken to: 1. Develop an acceptable bedside pain documentation chart 2. Assess the efficacy of the chart to improve pain scores Methods: A collaborative approach was used to devise a pain chart. Cancer patients with pain are identified on admission & asked to complete a Brief Pain Inventory (BPI), calculate the Pain Management Index & commence the pain chart. During the day, numeric pain scores are regularly recorded. After 7 days or when discharged the BPI & PMI are repeated plus questions regarding satisfaction with pain control. Results: 96 patients have so far been identified with study ongoing. 53% not enrolled as they were too unwell, had language barriers, were cognitively impaired, declined interviews or were pain free when approached. 44 patients recruited with 15 patients completing all questionnaires. Non-response too low, had language barriers, were cognitively impaired, declined interviews or were pain free when approached. 44 patients recruited with 15 patients completing all questionnaires. Non-response too low, had language barriers, were cognitively impaired, declined interviews or were pain free when approached. Conclusion: This initial experience has been helpful in assessing discharge, not wishing to answer more questions, becoming too unwell or dying. The 15 all have advanced cancers. Initial pain scores were greater than 6/10 in 9 patients. On completion, 9 had improved their scores, 3 had worsened & 3 unchanged. Regardless, 14 expressed satisfaction with their pain control & 15 expressed satisfactions with the staff’s approach to analgesic management. Conclusion: Preliminary results suggest that visible pain documentation is efficacious in improving pain scores & ensuring patient satisfaction with analgesic management in a cancer unit. Review of the completed pain charts indicates that an inpatient hospital setting would be the most appropriate setting for staff to be able to adequately assess patients and provide adequate pain relief.
Multicenter descriptive and longitudinal study on opioid rotation (OR) or changes of route administration in advanced cancer patients: preliminary results

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Aim: To know the natural history of the use of opioids in far advanced cancer, the effectiveness of OR and the causes to do it. Method: We designed a descriptive, longitudinal and multicenter study, enrolling advanced cancer patients from their first visit in a Palliative Care, Medical Oncology or Radio-Oncology Services and followed up till 6 months. We record any switch of opioid, considering or changing of route of administration and its effectiveness using VRS (0–10) at day 0 and 7. Evaluation was done even by phone or visit in the clinic. Time lasting till new change was also recorded. Results: From June to September 2005 60 patients have been enrolled, 36 (60%) were men. In 34 (56,6%) patients opioids were started and in 26 (43,3%) OR initially were done, with 40 OR. Mean 1.5 OR per patient. Starting opioid in naïve patients were: Fentanyl (15), Buprenorphine (6), Tramadol (6), Morphine (5), Methadone (2). In OR opioid used to switch were: Morphine (20), Buprenorphine (9), Fentanyl (5), Tramadol (3), Methadone (2), Oxycodon (1), Codeine(1). Principal cause of OR opioid pain was un relieved. Mean Equivalent Oral Morphine (DEOM) before OR was 99.9 mg and first day after OR 90.8mg (p=0.897). DEOM between day 1 and 7 were 90.8 mg and 116.5, respectively (p=0.019). After 7 days of OR, basal VRS were reduced 2 or more points in the 65% of ORs, in the case of breakthrough pain reduction was found in 42.4% and in the average of both pains reduction was in 57.5%. In 63,2% OR in which pain was well relieved DEOM was increased and in 52.6% was unchanged (p=0.511). Change of route was done 9 times. We show the preliminary results of this study. This project is the continuation of a retrospective study made in our service about OR. Initial result seems to indicate that at the end of OR is related with the switch opioid in it self rather than the change of the opioid dose.

Abstract number: 441
Presentation type: Poster
Poster number: P21
THE ROLE OF TRAMADOL IN THE TREATMENT OF CANCER PAIN – RESULTS OF 10 YEARS OF CLINICAL EXPERIENCE

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Aim of the study: Assessment of analgesia and side effects of tramadol immediate (drops and capsules 50 mg, ampoules 50 and 100 mg, suppositories 100 mg) and controlled release (100, 150 and 300 mg) in cancer pain. Patients and Methods: 1101 patients (879 moderate, 222 severe) with visceral, somatic (bone) and neuropathic cancer pain, 1035 patients were treated with tramadol orally (57% controlled release tablets, 960 immediate release drops or capsules), 51 subcutaneously, and 15 rectally. Initial dose 12.5–50 mg, then titrated, usually by 50% increments. 1036 patients received metoclopramide as prophylaxis of nausea and vomiting. Results: Time of treatment 1 – 687 (mean 35) days, daily doses 50 – 900 (mean 325) mg, 25 patients were monitored for 600 mg. Good analgesia (VAS < 4) in 826 (75%) patients: in 774 (88%) with moderate, in 52 (23%) with severe pain, partial effect (VAS 4–5) in 143 (13%): in 79 (9%) with moderate, in 64 (29%) with severe pain, unsatisfactory analgesia (VAS > 5) in 132 (12%): in 26 (3%) with moderate and in 106 (48%) with severe pain. Good analgesia in 76% patients with moderate, in 64 (29%) with severe pain, unsatisfactory analgesia caused substitution tramadol with strong opioid after mean 35 days. Conclusions: 1. Tramadol administered by different routes (oral, subcutaneous, rectal) is an effective analgesic in the treatment of cancer pain of moderate intensity. 2. The efficacy of tramadol is highest in visceral pain. 3. The tolerance of the treatment is good, provided prophylactic use of antihistamines is made, by using increments. 4. 51.5% of patients after mean time 35 days need substitution of tramadol with strong opioid because of unsatisfactory analgesia.

Abstract number: 442
Presentation type: Poster
Poster number: P22
THE DEVELOPMENT AND IMPLEMENTATION OF A PAIN ASSESSMENT TOOL

Chris Terwel, Pain department, Arnhem, NETHERLANDS, Sylvia Verheugt, Hospital Jeroen Bosch, Horrithgenbosch, NETHERLANDS, Jaap Gootjes, Hospice Kuria, Amsterdam, NETHERLANDS, Rianne de Wit, Erasmus MC, Rotterdam, NETHERLANDS, Wendy Oldenemenger, Erasmus MC, Rotterdam, NETHERLANDS

Introduction: Measurement of pain intensity, by means of a Numeric Rating Scale, is more and more used on a daily basis in hospitals and home care. In case of moderate to severe pain, the various multidimensional aspects of pain should be evaluated and used for providing adequate pain treatment. To register the effects and side-effects of pain we use a pain assessment tool. Comparison of tramadol in 58 (5.3%) patients because of side effects, respiratory depression not observed. In 567 (51.5%) patients unsatisfactory analgesia caused substitution tramadol with strong opioid after mean 35 days. Conclusions: 1. Tramadol administered by different routes (oral, subcutaneous, rectal) is an effective analgesic in the treatment of cancer pain of moderate intensity. 2. The efficacy of tramadol is highest in visceral pain. 3. The tolerance of the treatment is good, provided prophylactic use of antihistamines is made, by using increments. 4. 51.5% of patients after mean time 35 days need substitution of tramadol with strong opioid because of unsatisfactory analgesia.

Abstract number: 443
Presentation type: Poster
Poster number: P23
P.A.I.N. Quality – Outcome-related pain management

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Chronic pain is a major European healthcare problem. Appropriate pain management is still not available to the majority of patients. Concerted action could lead to improvement. Objective of the P.A.I.N. Initiative is to elaborate outcome-oriented concepts for a continuous quality improvement in routine clinical practice. P.A.I.N. methodology is based on a Plan-Do-Check-Act (TDQm) circle. ‘Evidence based’ guidelines are often ignored or not relevant for routine practice. As a consequence experience based ‘educated guesses have been made to describe and compare the ideal and the real conditions, based on measurable indicators, having threshold values, usable to indicate designated measures, suitable to realise desired results. These results will be re-evaluated, what could lead to changes in practice. Prerequisite is an instrument for a valid documentation.

Abstract number: 444
Presentation type: Poster
Poster number: P24
Continuous sc infusion of Ketamine as an adjuvant analgesic in difficult to control cancer pain

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18 patients with poor pain control because of dose connected intolerable opioid side effects were treated by CSII of Ketamine as an adjuvant analgesic. All patients had more than 10 tablets in opioid pain 18 patients. 12 /66%) had more than one neuropathic pain, somatic pain = 13/72%, visceral pain = 10/53%. All patients had pain score >30-80 and IBS –6 >5 and performance score PSIP2=42%. All were converted from oral to CSII of morphine = 3/1 (the dose of the CSII was fixed and remained the same through the time of treatment) + sc rescue doses /Fixed mg /

Abstract number: 445
Presentation type: Poster
Poster number: P25
PAT is a useful help for nurses to systematically register the complaints and effects of pain. It is suitable for adult patients without cognitional disorders. The national PAT is legally for introduction in The Netherlands.

Abstract number: 446
Presentation type: Poster
Poster number: P26

SATURDAY 9 APRIL

Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005

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Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005

Poster number: P25

Endoscopic sphenopalatine ganglion (SPG) block for head and neck cancer pain

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The analgesic efficacy of sphenopalatine ganglion (SPG) block although well documented is yet to receive wide application. Several techniques are in vogue for the block the most recent one being the transnasal endoscopic approach. Although surface blocks of SPG with local anesthetics have been studied transnasal infiltration of anesthetics is yet to be popularized. The authors present their updated series of endoscopic infiltration of 2% lignocaine and 6% phenol (neurolytic agent) for patients with advanced malignancies of the head and neck region whose pain was not adequately controlled with conventional medications including oral morphine. SPG block is effective in alleviating pain due to advanced head and neck cancers. Nasal endoscopy is a valuable adjunct to accurately localize the sphenopalatine ganglion. The block is relatively safe and can be used safely carried out as an office procedure.

Abstract number: 446

Presentation type: Poster

Poster number: P26

PROMPT RELEASE OF ORAL MORPHINE USE AND TRANSDERMAL FENTANYL, USED FOR ADVANCED ONCOLOGICAL PATIENTS TREATMENT, DURING THE INDUCTION PHASE AND BREAKTHROUGH PAIN

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Goals: Demonstrating their use practicality in homecare and the patients’ compliance. Methods and Materials: It has been analysed data on an number of 763 patients, assisted during 2003. Results affirm that in the 80% of the cases it has been applied an 'analgie therapy'; it has been given oral morphine and transdermic fentanyl in 258 cases and both have been used in 116 cases. It has been analysed 1059 daily medical survey, highlighting the use of two opioids in the therapy; more exactly oral morphine in 537 survey and transdermic fentanyl in 483; only in the 3% of the cases the supply has been interrupted for controllable side effects. That is really important underlining how the morphine use has been useful, especially in cases of severe pain (testified by 170 daily medical survey). The authors have carried out researches on the data given by a palliative care organization who acts in the homecare of advanced oncological patients. Conclusions: The use of these two drugs and the low presence of side effects affirm that the subministration and the patients compliance are really efficient for the invalids treatment in homecare.

Abstract number: 447

Presentation type: Poster

Poster number: P27

ELECTROPHONOPHORESIS - ADMINISTRATION IN LONG-STANDING PAIN

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If the pain is situated on a small area of the skin and the tissues that are close to this area, the systematic pharmacotherapy is usually ineffective. Toxicity of human body organs and many side effects are the serious barrier to applying this method of treatment, especially during long-term treatment with high doses of medicine. The physiotherapeutic methods of therapeutic menagement like ultrasounds and ionotherapy are commonly used in applying analgetics (mainly in non-neoplastic long-standing pain). Therapeutic value of these methods is the subject of interest in reference to possibilities of modulation the receptor pain. Such methods like ultrasounds and or facadic current make the penetration of medicine by the undamaged skin easier. The aim of this paper was to evaluate the effectiveness of analgetics using Lignocainhydrochloricum 1%, Diclofenac sodium gel 10% and 3% of morphine gel with the help of electrophonophoresis. The research involved eight patients from Sue Ryder House in Bydgoszcz that suffer from long-standing pain. The pain was both neoplastic and non-neoplastic and it was localized on a small area and difficult to control with medicines given systemically and locally. The medicines were passed in the form of gel. They were given according to the instruction for "Sonoter" machine that characteristics are constant current and the special head used to electrophonophoresis with the frequency of 1MHz. The procedures had been made for four days. Six patients treated with this method reached the soothing of pain. The best effects were reached among the patients with the pain connected with osteolytic metastases, 23% had neuropathic pain only and 19% had mixed pain. In all cases advice was given regarding drug therapy and specific non-drug advice was given in 10. 31 patients reported having less pain, requiring lower doses of fewer analgesic medications and/or were able to go home. 12/32(38%) of the patients underwent 15 anaesthetic pain control procedures: epidural catheterization, coeliac plexus neurolaxis(3), epidural phenol instillation(2) or percutaneous cordotomy(2). 92% had significant analgesic benefit from their procedure. 55% of all patients died during the study and mean survival following first anaesthetic intervention was 45 days.

Conclusions: Our study emphasises the vital role of a Pain Specialist in the management of the difficult pain problems we regularly meet in our work. We stress the importance of patient access to the opinion of a specialist pain service and found that although only 38% underwent a formal anaesthetic procedure, all 32 patients benefited from combined review.

Abstract number: 449

Presentation type: Poster

Poster number: P29

CLINICAL PHARMACOLOGY OF HYDROMORPHONE HCL EXTENDED-RELEASE (HHIR) CAPSULES q24h FOLLOWING MULTIPLE-DOSE ORAL ADMINISTRATION

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Once-daily (q24 h) HHIR (Palladone XL in U.K.; Hydalg UNO Retard in Austria) capsules have been developed in strengths of 12, 16, 24 and 32 mg to simplify and ease the frequent administration of immediate release hydromorphone (HHIR) needed to maintain analgesia. A multiple-dose, crossover study was conducted in healthy volunteers. One HHIR 12 mg capsule was administered q24h for 45 days while HHIR was administered q6h for 5 days. Steady-state pharmacokinetics (PK) and safety following HHIR and HHIR dosing were determined. Plasma concentrations were

Abstract number: 448

Presentation type: Poster

Poster number: P28

Collaboration in Pain Control – It's good to talk

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Aim This study was undertaken to assess the outcomes of regular discussions between Palliative Care patients with difficult pain problems by a Specialist Palliative Care Team and a visiting Consultant in Pain Medicine. Methods A detailed log of 25 meetings that took place over an 8-month period was maintained. Relevant information regarding all patients discussed was collected. These patients were hospital inpatients, day hospice or outpatient attendees of our service. Results 71 discussions were held regarding 32 patients, 56% female, mean age 61yrs. 81% were inpatients, 94% had a malignancy, with the GI Tract and lung disease predominant and 45% were discussed on multiple occasions. 59% had nonocceptive pain due to primary or recurrent disease, distant or bone metastases, 23% had neuropathic pain only and 19% had mixed pain. In all cases advice was given regarding drug therapy and specific non-drug advice was given in 10. 31/32 patients reported having less pain, requiring lower doses of fewer analgesic medications and/or were able to go home. 12/32(38%) of the patients underwent 15 anaesthetic pain control procedures: epidural catheterization, coeliac plexus neurolaxis(3), epidural phenol instillation(2) or percutaneous cordotomy(2). 92% had significant analgesic benefit from their procedure. 55% of all patients died during the study and mean survival following first anaesthetic intervention was 45 days.

Conclusions: Our study emphasises the vital role of a Pain Specialist in the management of the difficult pain problems we regularly meet in our work. We stress the importance of patient access to the opinion of a specialist pain service and found that although only 38% underwent a formal anaesthetic procedure, all 32 patients benefited from combined review.
assessed pre-dose (trough values) on days 1 through 5 while full PK profiles were obtained on day 5 for 24 hours following HHER and HHIR dosing. Plasma concentrations of hydromorphone were determined using a LC-MS/MS assay. Safety including vitals, laboratory and adverse events were monitored during the study. Four hundred and sixty-one patients were randomized to receive HHER or HHIR. The total daily exposure (AUC) of HHER and HHIR formulations were equivalent based on equal daily doses. The plasma concentration profile of HHER, resulted in steady-state Cmax which was lower, tmax occurring later, and steady-state accumulation. Adverse events noted in the study were mild in severity with the overall incidence of nausea and dizziness less in the HHER group.

Abstract number: 450
Presentation type: Poster
Poster number: P30

MORPHINE HYDROCHLORIDE 0.1% IN POLYETHYLENE-OLEOGEL FOR IMPROVED TOPICAL ACTION

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Lesions and ulcerations of the mucosa and the skin can be very painful. The treatment of those painful alterations tends to be quite difficult. Systemic painkillers especially opioids often induce dose-limiting side-effects without achieving sufficient pain relief. Since the sixteenth century ayurvedic physicians successfully use topical preparations containing opium as therapeutic conditions. In Europe William Heberden described in 1774 the use of an opium paste to treat haemorrhoids. This simple mixture of morphine and polyethylene-oleogel is easily covering the wound. This mixture of morphine and polyethylene-oleogel is easily done by the pharmacist.

Abstract number: 451
Presentation type: Poster
Poster number: P31

TENS as adjuvant for pain relief in palliative care

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Introduction. 70% of all terminal ill patients suffer from moderate to severe pain. Pain treatment is often difficult in terminally ill patients, especially in case of neuropathic pain. The effect of the use of Transcutaneous Electric Nerve Stimulation (TENS) as adjuvant treatment in pain relief may be simple and often forgotten method. The purpose of this study was to evaluate retrospectively the efficacy of TENS in terminally ill patients in hospice Kuria. Methods. In consecutive patients suffering from myofascial and neuropathic pain in the hospice Kuria the physiotherapist or trained nurse applied TENS and explained the procedure. During two years 149 outpatients received TENS as adjuvant treatment. The nurses continued to give regular instructions. If possible, the patients apply TENS by themselves or with help of relatives. Results of all patients gave their comments on the use of TENS. 51 (70%) Patients expressed some beneficial effect and continued to use it as long as possible. The patients were content, that they could do something themselves to achieve better pain control. Conclusion The use of TENS in terminally ill cancer patients is a useful adjuvant for pain relief in palliative care.

Abstract number: 452
Presentation type: Poster
Poster number: P32

EVOLUION AND CONSUMPTION OF ANALGESICS IN A UNIT OF PALLIATIVE CARE

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Introduction: The Unit of Palliative Care was inaugurated in December 2000. It consists of 15 beds and after 3 years of functioning it seems to us to be interesting to know the evolution of the consumption of analgesics and his distribution. Objective: To know the consumption and distribution of the analgesic medications in the Unit of Palliative Care and the evolution throughout these three years. Method: There are analyzed the analgesics consumed by all the patients distributed during the period understood between January 1, 2001 and December 31, 2003. Results: During this period 657 patients were treated with an index of occupation of 92.4, one average stay of 20.2 and one index of mortality of 72.4. The consumption of analgesics in the year 2003 distributed in the following way: 12.6% of the patients uses analgesics of the first step, 27.2% of the second one and 60.2% of the patients of the third one. Of the first step 87% of the patients use Tramadol, of the second one 98 % to the Tramadol and of the third one 45% to the Morphine. The total number of prescribed drugs increased in time and most drugs were prescribed for cancer patients. Conclusion Almost all patients are prescribed drugs near end of life. Two months before death GPs prescribe mostly drugs from step 1 of the WHO analgesic ladder. In the last two weeks before death the total number of prescriptions and the proportion of strong opioids were significantly more indicating more and stronger pain near end-of-life. The low proportion of drugs from step 2 indicates that either GPs move quickly from WHO-step 1 to WHO-step 2. 51 (70%) of the patients apply TENS by themselves or with help of relatives. Results Most patients gave their comments on the use of TENS. 51 (70%) Patients expressed some beneficial effect and continued to use it as long as possible. The patients were content, that they could do something themselves to achieve better pain control. Conclusion The use of TENS in terminally ill cancer patients is a useful adjuvant for pain relief in palliative care.

Abstract number: 453
Presentation type: Poster
Poster number: P33

Drug prescription for pain control in the last 3 months of life in general practice

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Introduction In the Netherlands, the general practitioner (GP) has a central role in providing palliative home care. Drugs are an important tool for pain control in end-of-life. In this paper we explore drug prescribing during the last 3 months of life. Method Of all patients who died, ATC-coded prescriptions were divided according to the three steps in the WHO analgesic ladder. Drugs were analysed over the total period of the last 3 months and in 3 time frames of 2 weeks. Results Almost all patients (97%) were prescribed at least one drug, with a mean of 25 prescriptions per patient. Most prescriptions were for the nervous system (21,6%), mostly opioids and psycholeptics. Of all prescribed pain medication, WHO-step 1 (paracetamol/NSAIDs) took 61% 8–9 weeks, 54% 4–6 weeks and 27% 2 weeks. For step 2 (weak opioids) the proportions were respectively, 20%, 11% and 9%. The proportions of step 3 (strong opioids) were 19%, 33% and 64%. The total number of prescribed drugs increased in time and most drugs were prescribed for cancer patients. Conclusion Almost all patients are prescribed drugs near end of life. Two months before death GPs prescribe mostly drugs from step 1 of the WHO analgesic ladder. In the last two weeks before death the total number of prescriptions and the proportion of strong opioids were significantly more indicating more and stronger pain near end-of-life. The low proportion of drugs from step 2 indicates that either GPs move quickly from step 2 to step 3 or that they skip 2 totally.

Abstract number: 454
Presentation type: Poster
Poster number: P34

The effectiveness of amoxapine as an adjuvant analgesic for cancer pain

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Objectives: We retrospectively investigated our experiences with amoxapine, a tricyclic antidepressant (TCA), to determine whether it is reasonable to be tested in future trials as an adjuvant analgesic for difficult cancer pain. Background: TCAs are commonly used in cancer patients as adjuvant analgesics, especially for cancer pain with neuropsychiatric complications. These practices are based on the evidence that TCAs are beneficial in a number of non-cancer neuropathic pain syndromes. However, very few clinical trials have specifically evaluated the efficacy of TCAs for cancer pain. It is also important to consider the balance between subcutaneous Morphine and the stabilization of the Fentanyl. Conclusions: 1. More than the half of the patients they consume analgesics of the third step. 2. The Morphine is undoubtly, most used in her corresponding step. 3. The Fentanyl transdermal places secondly after the Morphine subcutaneous and ahead of the Oral Morphine.
analgesic effects and adverse effects related to the use of TCAs with opioids because of overlap of similar side-effects. Amodin is a TCA that has a longer half-life and is associated with an earlier onset of action for depression than other TCAs. There is no report of the use of amoxapine as an adjuvant analgesic for cancer pain. Method: A retrospective review of all patients who had amoxapine prescribed as an adjuvant analgesic for opioid treatment for cancer pain with neuropathic components from January 2003 to August 2004. Results: Among 24 patients identified in this term, 14 patients (58%) reported their pain relief within 3 days (Median=1.9 days). There were only 2 patients (8%) who stopped its use because of the possibility of adverse effects. Conclusion: Amodin has a favorable side effect profile and the onset of the analgesic effect seems to occur within a few days. Based on these results, we will conduct a prospective trial to establish evidence for the effectiveness of amoxapine as adjuvant analgesics for cancer pain.

Abstract number: 455 Presentation type: Poster Poster number: P35
Long-Term Administration and Safety of Once-Daily Oral Extended-Release Hydromorphone MA Kwarcinski, Medical Services Department, Stamford, CT, U. STATES, B Buckley, Purdue Pharma L.P., Stamford, CT, U. STATES

Long-term administration of oral extended-release hydromorphone (HHIR) capsules (e.g. Palladone® XL Capsules, UK) was assessed in 143 patients with cancer-related pain who had participated in either of 2 previous double-blind active-controlled studies of HHIR. Patients received open-label once-daily HHIR for up to 8 weeks in this extension study. Supplemental analgesic (immediate-release hydromorphone [HHR]) was available pm for pain exacerbations. The HHIR dose could be titrated Q24-48 hours. Average weekly pain intensity, measured on a 0–10 numeric rating scale, total daily doses (mg) of HHR and HHIR, number of doses of HHIR, number of patients titrating the HHIR dose and adverse events were the efficacy and safety variables. Efficacy measurements remained relatively stable over the entire 8-week treatment period. The mean ± SE weekly pain intensity was 2.9 ± 0.16 at baseline, 3.1 ± 0.16 in the 1st week and 3.0 ± 0.18 in the 8th week of treatment. The mean ± SE daily dose of HHIR was 36.2 ± 2.10 mg at baseline, 36.8 ± 2.12 mg in the 1st week and 43.6 ± 4.33 mg in the 8th week of treatment. The HHIR dose increased in 48 patients (34%) while 88 patients (62%) required no titration, and 7 patients reduced their dose during 8 weeks of treatment. The average daily dose of HHR was 10.4 ± 1.35 mg (mean ± SE) in the 1st week and 11.1 ± 2.01 mg in the 8th week of treatment, while the mean ± SE number of doses of HHR per day was 1.5 ± 0.12 in the 1st week and 1.3 ± 0.13 in the 8th week of treatment. Common adverse events were opioid-related side effects: somnolence, constipation, nausea, vomiting, and dizziness. Conclusions: Once-daily HHIR provided sustained effective pain control, with tolerable adverse events, over 8 weeks of treatment in patients with cancer pain.

Abstract number: 456 Presentation type: Poster Poster number: P36
Conversion from Previous Opioids to Extended-Release Oral Hydromorphone Hydrochloride MA Kwarcinski, Medical Services Department, Stamford, CT, U. STATES, M Shi, Purdue Pharma L.P., Stamford, CT, U. STATES, B Buckley, Purdue Pharma L.P., Stamford, CT, U. STATES

The optimal schedule of opioid administration provides pain control with a minimal number of daily doses. The efficacy of a once-daily, extended-release hydromorphone hydrochloride (HHIR) capsule (Palladone® XL Capsules, UK) was evaluated in patients who were switched from a given opioid regimen using a 8:1 conversion ratio of oral morphine to oral hydromorphone. 344 patients with persistent moderate to severe pain due to cancer (79%) or nonmalignant causes were enrolled in either of two identically designed studies with an initial open-label conversion and titration phase followed by a double-blind phase. Eligible patients had been treated with single entity and/or fixed combination opioids at a total daily dose equivalent to at least 90 mg oral morphine. During the open-label phase, the previous opioid dose was converted to an equianalgesic dose of morphine, and the starting dose of HHIR was then calculated at 1/8 of the morphine total daily dose using standard dose conversion factors. The efficacy of the conversion dose was evaluated using mean average pain intensity (API) (pain scale 0 = no pain; 10 = pain as bad as you can imagine) at 48 hours compared to baseline. 333 patients had complete data. Following conversion mean ± SD API scores at 48 hours remained within 1 point of baseline, decreasing from 5.3 ± 2.13 at baseline to 4.6 ± 2.16 ± 0.5 48 hours. Relatively unchanged pain scores were observed regardless of previous opioid or pain type. Results suggest patients can be effectively switched from previous opioid regimens to a once-daily hydromorphone capsule using an 8:1 ratio or oral morphine to oral hydromorphone to calculate the conversion dose.

Abstract number: 457 Presentation type: Poster Poster number: P37
Assessment of Once-Daily Extended-Release Hydromorphone (Palladone® XL Capsules) With 7-Days Treatment At Stable Doses B Moehring, Medical Services Department, Stamford, CT, U. STATES, B Buckley, Purdue Pharma L.P., Stamford, CT, U. STATES, P Lacouture, Purdue Pharma L.P., Stamford, CT, U. STATES, S Rosen, Purdue Pharma L.P., Stamford, CT, U. STATES

Hydromorphone hydrochloride extended-release (HHIR) capsule (e.g. Palladone® XL Capsules, UK) is a new oral analgesic for once-daily dosing. Two randomized controlled studies assessed the efficacy and safety of HHIR compared with immediate-release hydromorphone (HHR). Two randomized, double-blind, crossover studies with identical designs compared HHER administered q24h and HHR administered qid to patients with persistent moderate to severe pain. Previous opioid analogues were converted to HHER and the doses titrated for up to 21 days to stable pain control as determined by average pain intensity (API) scores 65 years, and elderly patients receiving HHER and HHR, except for vomiting which occurred almost 3 times more frequently in patients administered HHR first. HHER dosed q24h provided comparable pain control to HHER dosed qid in the elderly. HHER was associated with less vomiting.
Disclosure of diagnosis to HIV children and adolescents-foundations for effective palliative care

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Background:A specific trend for Romania is the maintenance of a high number of paediatric cases (7% in vertical transmission. In our Day Clinic we have registered 985 cases, 610 of them being active cases and the mean age is 14 years old. Disclosure of diagnosis is not a priority when life expectancy is poor. With ARV therapy, most of children should at least reach adolescence and adulthood, so it has become much more plausible. The disclosure of diagnosis is a very sensitive moment for children living with HIV/AIDS. Emotional problems and psychological distress associated this process of telling. A good palliative care involves options and in order to do this, HIV infected children will need to be aware of the extent of their disease. At the beginning of the study only 27% of children knew the diagnosis. Started with 2001 we included 98 infected children in the process of telling. We applied art-therapy methods, emotional self-identification in different techniques, systemic therapy. The child’s parents many times assume the worst and their is often a reluctance to give information about illness. Although parents are reluctant to fully disclose the child’s HIV diagnosis, they may partially disclose by giving information about HIV, without naming it. Conclusions:After disclosure the psychological adaptation of the child was better, and the adherence and compliance to ARV, which improved. Most parents found it a positive experience and gave them the chance to think about things they would not have done. The acquired results confirmed the opportunity and necessity of disclosure. Children are capable to cope with multiple losses involved by a sever diagnosis, before to install the final symptoms of AIDS.

Transdermal Buprenorphine for Pain Treatment in Ten-year-old Girl with Neuroblastoma

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Introduction: A ten-year-old girl was to receive outpatient palliative treatment for a stage IV neuroblastoma. She had already been treated in the pain clinic for three years during her chemotherapy, cancer irradiation and antibody therapy. Case report: After cancer irradiation of the head, the patient was presented to the outpatient department with continuous sharp pain in the lower left jaw and in both of her legs (NRS 6-8). Oral medication was no longer possible, due to neuropathy caused by an irradiation mucositis. An intravenous access wasn’t accountable and a Hickman catheter or rectal administration were refused by the patient. Treatment started with a quarter of a Transcet® 35 µg/h patch (transdermal buprenorphine) providing satisfactory pain relief down to NRS 2-3. In the course of five weeks the dosage was raised gradually to a full Transcet® 70 µg/h. During this time no side-effects were reported. The adherence of the patch was so good, that the girl was even able to bath. However she consented removal of the patch every three and a half days to be unpleasant. With the deterioration of her illness, she complained of severe legs pains and increasing headaches (NRS 7-9). She agreed to an implantation of a Hickman catheter. The treatment was continued intravenously with a PCA pump for ten weeks until she passed on. The girl died peacefully in the patient’s home. The family decided to avoid interventions of any kind. Conclusions: Transdermal buprenorphine is another option when treating cancer pain in children. The patch can be divided, providing an excellent dose titration. Yet more studies are necessary to investigate the efficacy and safety of using transdermal buprenorphine with children.
availability of care. During the quick scan most parents interviewed had a child died of cancer. The question is if their needs differ from parents of children with non-malignant diseases.

The aim of this study is: To get insight in the needs and problems of children with a non-malignant life-threatening illness and their parents during the phase of palliative care. To propose possible solutions to improve palliative care for the children and their parents.

Method
In-depth interviews are conducted with bereaved parents of children with a non-malignant life-threatening illness. The interviews are analysed following the method of grounded theory.

Results
Data collection is still ongoing. The results of this study will be compared with the results from the quick scan (Molenkamp, et al., 2002). Final results will be available in February 2005.

Conclusions
During the presentation the results of the quick scan and the final results of this project will be presented. These results will provide information on the needs for palliative care services for children. Recommendations to improve the quality of palliative care and for additional research will also be made.

Reference

Abstract number: 465
Presentation type: Poster
Poster number: P45

Evaluation of Palliative Care for the Elderly
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Nizhny Novgorod region is one of the five areas, where demographic aging level is among the highest in Russia. Our sociological research was carried out by a method of interview of the terminally ill persons 60 years and over, living in Nizhny Novgorod. The purpose of interrogation was to study the need of the elderly in palliative care and the kinds and amount of care, which they really receive. Our questionnaire has been made on the base of the questionnaire developed in Russian Academy of Sciences Institute of Sociology on the international sample. The interrogation was carried out at patients’ homes and in the outpatient medico-social department of a city polyclinic. It contains questions on medical and hospital care. The need is identified as provision and symptom control, patients’ satisfaction with his or her communications with a doctor and a nurse, availability of different services and the need to pay for investigations and medical interventions which must be made free of charge. Besides we examined the availability of strong opioids and other end-of life drugs for cancer patients. Quantitative data were analysed using SPSS-program. The data received reflect the general unsatisfactory condition of palliative care services for the elderly with life threatening diseases. The findings will be presented at the conference. The results of our study have been submitted to the City Public Health Minister in order to make some positive decisions on palliative care promotion, including palliative care for the elderly people. After that we managed to organize the first home palliative care team in the city. The comparative analysis of the quality of medical and social care for the elderly in this district before and after the beginning of the team’s work is the subject for further investigation.

Abstract number: 466
Presentation type: Poster
Poster number: P46

Barriers to geriatric continuing and palliative care
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Palliative care (PC) represents good medical practice for all clinicians and should not be restricted to oncology patients. Their still exist many barriers to good PC in general and in geriatrics in particular. The present study aimed to identify these barriers. During the six months study period, patients hospitalized in a Belgian geriatric hospital and benefiting from PC were compared to those who died without PC. Out of 229 patients hospitalized, 20 died (8.7%), 9 of whom had not benefited from PC. 45% of these patients. Compared to the 23 patients who had received PC, these patients showed less often pain (11% vs 73%) and more often dyspnea (66% vs 30%) as main symptom. There were no differences in age (87.2 vs 84.7 years), social status, co-morbidity, level of autonomy (as measured by the Katz scale) nor nutritional status (as assessed by prealbumin levels). Antibiotics were used in all patients who died without access to PC and in 61% of PC patients. Analgesics, sedatives and anxiolytics were used less frequently compared to PC patients. In patients who died without PC, communication with the patient and communication with the family was scored much lower than in PC patients. The former group showed more cognitive impairment, social isolation, and a more rapid, unanticipated death. There were more advance directives (both from family and health-care workers) in the PC patients. In the geriatric hospital, nearly half of the patients died without access to good PC. A comparison with patients who did benefit from PC in the same time-period permitted to identify the following risk factors: absence of pain syndrome (real or missed); presence of dyspnea (cardiac or pneumologic in origin), cognitive dysfunction and an unexpected death. More efforts should be made to recognize and implement PC as a fundamental concept in the management of ill and frail hospitalized elderly.

Abstract number: 467
Presentation type: Poster
Poster number: P47

REIKI and Alzheimer’s disease in Nursing Homes
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Introduction: Alzheimer’s disease is a form of presenile dementia. It is characterised by memory failure for recent events and lack of spontaneous activity and initiative. Loss of spatial orientation is common. Restlessness is very common in all forms of dementia especially in early stages. REIKI is an ancient system of energy healing which utilizes universal life force energy for natural healing process; it unlocks the inner flow of vital KI energy, works in harmony with medicines and medical procedures, is safe as it cannot be used to nurture more. More than 50% of all patients in nursing homes suffer from dementia – most of them have Alzheimer’s disease in different stages. Restlessness is a worrying problem for these patients, sometimes preventing proper nursing care and disturbing relatives and inmates. Sedation is often required to calm down the afflicted. An alternative can be REIKI treatment – beginning once daily up to twice a week by a REIKI practitioner (preferably a trained nurse). In our experience with old people even with senile dementia REIKI leads to deep relaxation without sedative drugs and promotes trust and human warmth. Patients feel accepted and looked after. It is possible to reach these patients on their level of living and do without sedative drugs. It is still to early to present hard data but we are confident to report about our results within the next two years.

Abstract number: 468
Presentation type: Poster
Poster number: P48

A Regulatory Perspective on the Management of Dying and Death in Care Homes for Older People
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Background: Care homes provide a home for older people to live in until they die. Regulatory frameworks, such as the National Minimum Standards (Department of Health 2000) in the England and Wales, shape the provision of care in care homes, to ensure quality care. Although there is increased interest in meeting the needs of people dying in care homes, little attention has been paid to the role of inspection and regulation in the management of death and dying in care homes. Aim: In this paper the way dying and death are constructed in regulatory policy and by inspectors is presented. Methods: A discourse analysis was undertaken of the Standard 11, ‘Dying and Death’, and its twelve sub-clauses. In addition, the Standard 11 section from the inspections, undertaken in 2003, for 273 care homes in one English county, were analysed. Content analysis was undertaken to explore the relative importance of the different aspects of the Standard within the inspection reports. The language used by the inspectors was also examined to explore the underlying discourses held by the inspectors, concerning dying and death. Findings: Regulatory policy Standard 11 is a representation of a ‘good’ death. The elements outlined in the Standard indicate how this ‘good’ death can be achieved. The process of inspection brings to the fore certain aspects of the dying and death process for older people and the staff that care for them, for example the control of pain. These elements will be identified and explored further. Factors that shape the inspectors’ practice will also be outlined. Conclusions: The inspection process influences care provision in care homes. Understanding how dying and death is constructed in regulations, and by inspectors, will inform initiatives seeking to develop good care for older people dying in care homes.
Abstract number: 469  
Presentation type: Poster  
Poster number: F49

**Palliative care for elderly people: assessing the quality**  
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Introduction: Palliative care for geriatric patients is not systematically inventorized, studied and evaluated on its quality. The literature is rather scarce. This study wants to answer the question what the problems are caregivers are confronted with in caring for palliative residents of the nursing home Immaculata. Methodology: Using data found in the literature a questionnaire was constructed. This questionnaire tries to draught a picture of the manner in which people living in a nursing home pass their terminal phase. The questionnaire is filled in by caregivers supporting and surrounding a resident: physical, emotional, social and existential factors and aspects are mentioned and requested. At the latest one week after decease of a resident the questionnaire is presented to the caring nurse head and filled in during a team meeting. Results: One hundred thirty one patients could be evaluated. A quantitative analysis was not simple. Nevertheless a number of data concerning age, sex, diagnosis, duration of the terminal phase, the frequency of different symptoms as well as the evolution of the functional status and of the quality of life could be derived. These figures are compared with a small pilot-research of forty patients in the past, focusing on residents suffering from advanced cancer. Conclusions: The problems the team in a nursing home caring for palliative patients encounters, are mainly situated in the field of (inter)professional communication and relationships. General practitioners play a key role which they not always fill in on a constructive and creative way. Strong and weak points will be explained.

Abstract number: 470  
Presentation type: Poster  
Poster number: F50

**An effect of morphine on cognitive function in terminally ill patients in the elderly - Preliminary report**  
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Despite of common use of morphine and tramadol in medicine, the knowledge about its pharmacokinetic characteristics and side effects is still insufficient. There is few information about their use and tramadol on human cognitive function in the elderly. The aim of the study is to determine the effect of morphine commonly used as analgesic medication on the cognitive function in terminally ill in the elderly. Material and Method: 20 female and male and terminally ill patients aged 65 or older with good abilities being not curred with morphine during last four weeks with good liver and kidney efficiency were examined: We used following methods of examination: 1. Cognitive functions: memory tests, attention, concentration test, comprehensive test. 2. Psychomotoric functions: reaction time. 3. Laboratory blood and urine sample test of M1 and metabolites (M6-glucuronide and M3- glucuronide). 4. General state: ESAS scale (used every day). The examinations 1, 2, 3, were performed before therapy and after two days of good analgesic effect. 5. Demographic and social characteristics. Conclusion: In our small pilot-study for chosen test and measurement, the study indicates that patients aged 65 or older in terminal state treated with Morphine 2) making the most information relating M1 impact cognitive function efficiency in terminally ill patients aged 65 or more. 

Abstract number: 471  
Presentation type: Poster  
Poster number: F51

**Providing palliative medicine in seniors homes and dement outpatients**  
Matthias Passon, Pain & Palliative medicine, Berlin, GERMANY

Palliative medicine, originally developed to care for cancer-patients, has taken great success because of it's holistic approach and it's concept of integrating special knowledge of various medical disciplines and of course because of it's teambased, multiprofessional organisation, as described by WH0 definition. Because of it's open concept structure special competence in managing difficult situations palliative medicine becomes more and more interesting for various other specialties as for instance geriatric patients. Spreading it's work field into geriatrics can cause trouble for the carer because special competence needs to be developed, for instance to cope with the pain problem in dement patients. There is very little knowledge about pain diagnosis in dement patients, who are not able to communicate adequately. So it might become very difficult to distinguish between anxiety and pain. Disturbances in sensation and orientation might alter the body image also, leading to the trial-and-error-method rather than rational reasoning. Therefore special skills in describing and communicating the residents health state have to be developed and compared with managing and ethical implications. Based on his work with the Berlin home-care-project the author will describe his experiences in "translating" palliative medicine to dement geriatric patients and to develop pathways for rational reasoning together with their carers.

Abstract number: 472  
Presentation type: Poster  
Poster number: F52

**Prevention of falls and fall-related injuries - A challenge for palliative care**  
Jorun L. Helbostad, Section of Geriatric Medicine/Dept. of Neuroemod., Trondheim Stein Kaupanger, Section of Geriatric Medicine and Technology, Trondheim, NORWAY, Olav Sletvold, Norwegian University for Science and Technology, Trondheim, NORWAY

Falls and subsequent injuries is a major cause of morbidity and mortality in older people, but have up till now not been paid attention to in palliative medicine. About 30 % of home dwelling persons more than 65 years of age fall annually, while as much as two thirds of those living in residential care facilities and nursing homes fall each year. Between 50% of those who fall suffer injuries that reduce mobility and independence and increase risk of death. Falling is caused by interacting factors. A history of falls, co-morbidity, polypharmacy and interaction and cognition, use of multiple medications, muscle weakness, balance problems, fear of falling and environmental hazards are all risk factors for falls. Successful interventions directed towards high risk groups have been described. These are individual and multifaceted and include medical review, training of muscle strength, medication and modification of environmental hazards. A newly published observational study with palliative care patients in hospices found that falls occurred almost four times as often as in nursing homes. Cognitive impairments, low blood pressure, age over 80 and visual impairments were risk factors for falling. The results indicate that falls and subsequent injuries also may be a problem in palliative medicine. Knowledge gained through fall studies and clinical practice with older people may be applied to understand the risk of falling, and to design interventions aimed at preventing falls and fall related injuries in palliative care patients. The paper discusses how knowledge from research and clinical guidelines for fall prevention in older people can be applied in palliative medicine.

Abstract number: 473  
Presentation type: Poster  
Poster number: F53

**Biography Management: an assessment of the quality of life as a measure for the quality of care of elderly people with cancer**  
Bart Van den Eynden, Chair of Palliative Medicine, University of Antwerp, Mortsel, BELGIUM, Sandra Vertongen, RVT Immaculata, Edegem, BELGIUM, Claus Myriam, RVT Immaculata, Edegem, BELGIUM, Annick Vanderoot, Centre for Palliative Care Gasthuis Sint-Camilus, Antwerp, BELGIUM, Paul Van Royen, University of Antwerp, Antwerp, BELGIUM

Introduction: Many people live for years in their nursing home, most of them being frail and chronically ill, some of them also suffering of cancer. A goal-oriented approach (Mold) allows patients to reach their individual goals, adding the maximum of desired and attainable quality of life. In the Biography Management model, information about the resident is collected in a core booklet and presented in the core booklet and presented in the daily management, which contains the necessary, the corresponding domains of life and the quantity of services the elder person needs. Research question: Does the Biography Management model deliver a contribution to the evaluation and the adjustment of elderly people with cancer, living in a nursing home? Methodology: This research project is based on observations from the daily management of patients suffering from cancer. A careful registration made a quantitative analysis possible. The researchers made also an in-depth study of the dossier of a number of cases and of the observational data from the multidisciplinary meetings of the caring team. Results: The overall quality of life of people with cancer, living in a nursing home, improved significantly. Implementing the Biography Management model has many advantages: the involvement of caregivers increases; residents and family express their satisfaction explicitly; the process of interprofessional teamwork grows; consultation with elder people, family and relevant others happens systematically; measures are developed and adapted in a...
Abstract number: 475
Presentation type: Poster
Poster number: P55

A phenomenological investigation into the need for palliative care in end stage heart failure

Margaret Kendall, Delamere Centre, Cheshire, GREAT BRITAIN

Over the last 25 years an upsurge of interest and research into the care of dying people has resulted in improved symptom control and support. Yet even with these welcome developments, not all dying patients benefit from the expert services of palliative care teams. The World Health Organisation, in its definition of palliative care, articulates an approach associated with life-limiting illness. However, access to these services outside the diagnosis of cancer is limited. This phenomenological study explores the lived experience of patients with End Stage Heart Failure and attempts to ascertain whether these patients would benefit from a Palliative Care intervention. Using a qualitative approach, a purposive sample of patients whose disease was classified as ‘NHYA IV’, were interviewed using an unstructured interview technique. The interviews were tape-recorded and transcribed verbatim. The transcripts and researchers’ field notes were analysed following Giorgi’s methodological interpretation. The essence which emerged from the data were: ‘The need to protect partner and/or family’, ‘The burden of everyday living’, ‘Regret’, ‘Waiting to die.’

Similarities to the experiences of cancer patients were identified in the course of the study, leading the researcher to conclude that a palliative care intervention may be of benefit to the patients with Heart Failure. However, the current model applied to cancer would not be appropriate, due to the difficulties associated with diagnosing dying in non-malignant disease. The necessity for further research has been identified, to create a model of intervention that would be suitable for non-malignant disease.

Abstract number: 476
Presentation type: Poster
Poster number: P56

Palliative care for psychological distress of patients living with progressive neuromuscular illness

Mitsuko Ushikubo, Division of Nursing, Department of Health Sciences, Tokyo, JAPAN and unmet needs, and the holistic palliative care approach

Purpose: Progress in medical technology and treatment has led to patients with progressive neuromuscular illnesses surviving for longer periods of time. This project, in partnership with the Cheshire & Merseyside Cardiac Network (CMCN) set up a subgroup to address the Specialist Palliative Care (SPC) needs of these patients. This subgroup concentrated on issues associated with end-stage heart failure patients, in collaboration with the Cheshire & Merseyside Cardiac Network (CMCN). The lack of knowledge of the SPC services available for heart failure patients in different parts of the region was identified. A directory of current services was compiled to address this. Methodology: A questionnaire was posted to the chairperson of the 7 Integrated Clinical Networks (ICNs) within the MCPCCNG to identify in-patient and outpatient services available for patients with end-stage heart failure. It asked about referral criteria and the number of referrals for patients with end-stage heart failure received within the last year. The same questionnaire was conducted by telephone with Community and Hospital SPC teams. Results: Responses were received from 86% services. All accept referrals for patients with non-malignant disease with restrictions, some assess cases on an individual basis. Greater access to psychology and lymphoedema services was highlighted. The results are presented and have been compiled into a directory format. Conclusion: A directory of SPC services available for patients with end-stage heart failure is available to facilitate collaboration between SPC and cardiology, aiming to improve symptom control for this group of patients and more appropriate referral.

Abstract number: 478
Presentation type: Poster
Poster number: P58

A Network Approach to Formulation of Guidelines for End Stage Heart Failure Care

Jennifer Smith, Department of Palliative Care, Liverpool, GREAT BRITAIN, Emma Richards, Willowbrook Hospice, Prescot, GREAT BRITAIN, Clare Littlewood, Whiston Hospital, Prescot, GREAT BRITAIN

Introduction: Heart failure patients often have unmet needs and uncontrolled symptoms. Palliative Care, with its emphasis on the holistic approach, may be of benefit. The Merseyside & Cheshire Palliative Care Network Group (MCPCCNG) set up a subgroup to address the Specialist Palliative Care (SPC) needs of these patients. This subgroup concentrated on issues associated with end-stage heart failure patients, in collaboration with the Cheshire & Merseyside Cardiac Network (CMCN). The lack of knowledge of the SPC services available for heart failure patients in different parts of the region was identified. A directory of current services was compiled to address this.

Methodology: A questionnaire was posted to the chairperson of the 7 Integrated Clinical Networks (ICNs) within the MCPCCNG to identify in-patient and outpatient services available for patients with end-stage heart failure. It asked about referral criteria and the number of referrals for patients with end-stage heart failure received within the last year. The same questionnaire was conducted by telephone with Community and Hospital SPC teams. Results: Responses were received from 86% services. All accept referrals for patients with non-malignant disease with restrictions, some assess cases on an individual basis. Greater access to psychology and lymphoedema services was highlighted. The results are presented and have been compiled into a directory format. Conclusion: A directory of SPC services available for patients with end-stage heart failure is available to facilitate collaboration between SPC and cardiology, aiming to improve symptom control for this group of patients and more appropriate referral.
approach has much to offer. This has been recognised in such national documents as the National Service Framework for Coronary Heart Disease and the NCHPCCP report, ‘Reaching Out: Specialist Palliative Care for Adults with Non-Malignant Diseases’. The Mersey and Cheshire Palliative Care Cancer Network (MCPCCCN) comprises 7 integrated clinical networks in which different local projects were taking place in an uncoordinated way. A network sub-group was established in collaboration with the Cheshire and Merseyside Cardiac Network (CMCN) and CHD Collaborative (CHDC), aiming to improve service provision for end-stage heart failure patients through the region in a coordinated manner. Methodology: A ‘Think-tank’ event was held, attended by doctors and nurses from Cardiology and Specialist Palliative Care (SPC), GPs and managers. This aimed to identify the SPC services these patients require, effective models of service delivery and issues for SPC. This highlighted the need to develop symptom control and referral guidelines, to establish joint nurse-led clinics and to organise joint educational events. It was also recognised that formulation of a directory of SPC services available for end-stage heart failure patients would be very useful. A working party has formulated symptom control and referral guidelines. A service directory is being developed by means of telephone and postal questionnaires. The Way Forward: A one-day partnership conference of the MCPCCCN, CMCN and CHDC is due to take place and a follow-up event next year is planned.

Abstract number: 479
Presentation type: Poster
Poster number: P59

CONTINUING AND PALLIATIVE CARE IN VEGETATIVE STATE, MINIMALLY CONSCIOUS STATE AND LOCKED-IN SYNDROME

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Palliative care (PC) focuses on helping patients with any terminal illness, that is a disease likely to result in death. It is a symptom-based care approach designed to maintain a good quality of life (QoL). We here focus on devasting neurologic conditions that occur following severe acute brain damage and dramatically impair cognition (vegetative state VS & minimally conscious state MCS), or produce complete physical dependency without cognitive deficit (locked-in syndrome LIS). Few data are available concerning the care given to VS patients and whether this affects the incidence of medical complications or life expectancy. If the diagnosis of VS is beyond doubt, the passage of a year or more has greatly reduced the chance of recovery, withdrawal of artificial hydration & nutrition can be considered. There are no existing guidelines regarding the care of the MCS, an entity only defined two years ago. Future research should tell us more about the best PC and curative care. But in all circumstances, the patient should be treated with dignity, and caregivers should be aware of the patient’s potential for understanding and perceiving pain. In LIS, patients can live as long as 26 yrs, emphasizing the need for a renewed ethical and medicolegal framework. Who speaks for the LIS patient? With the initial handicap of communicating only through an eyelink, who can decide whether the patient is competent to consent or to refuse treatment? Healthy individuals and medical professionals too often assume that QoL in LIS is poor and that such a life is not worth living. Data from the French Association for LIS show that in chronic LIS, mental well-being is close to that of the general French population. Suicide thoughts and refusal of life sustenance by VS patient exist but are infrequent. We believe that patients suffering from LIS should not be denied the right to die – and to die with dignity – but also, and more importantly, they should not be denied the right to live – and to live with dignity and the best possible pain and symptom management.

Abstract number: 480
Presentation type: Poster
Poster number: P60

A prospective study to assess the palliative care needs of patients with severe heart failure

Paul Paes, Palliative Medicine, Oxford, GREAT BRITAIN

Aim: To prospectively assess the symptoms (physical and psychological) and quality of life of patients with severe heart failure. Method: Patients with NYHA III or IV heart failure filled in 3 questionnaires to assess their symptoms and quality of life: EORTC-QLQ-C30, Kansas City cardiomyopathy and HADS scales. Results: 11 patients completed the questionnaires. The biggest physical symptom problems were dyspnoea, insomnia, fatigue and pain. Depression was clinically significant in 45% of patients and anxiety in 18%. Overall quality of life was scored at 33%. Poor social role, role and physical functioning were major contributors to this score. Conclusions: Patients with heart failure have considerable physical and psychological problems and quality of life issues that need addressing. These palliative care needs are comparable to those patients with cancer.

Abstract number: 481
Presentation type: Poster
Poster number: P61

Prognostication in older people who are dying from diseases other than cancer. Can it be done?

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Background: most people in contemporary western society die of chronic circulatory, respiratory and neurological diseases in old age. Whilst palliative care is appropriate for elderly patients with chronic, non-malignant disease few of these patients access such care compared with cancer patients. One of the referral criteria based on accurate estimation of survival may facilitate more timely referral of non-cancer patients most appropriate for palliative care. Objective: to identify key and predictor variables that might aid clinicians estimate survival and assess palliative status in non-cancer patients aged 65 years and older. Methodology: retrospective review and quality assessment using criteria modified from the literature. Results: from 85 initial papers, 11 studies that evaluated prognoses in hospitalised and community-based older adults with non-malignant disease were identified. Only 3 studies validated their results in a second, independent test set. Key generic predictors of survival were increased dependency of activities of daily living, presence of comorbidities, poor nutritional status and weight loss, and abnormal vital signs and laboratory values. Disease specific predictors of survival were identified for dementia, COPD and CHF. No study evaluated the relationship between survival and palliative status. Conclusion: prognostic models that attempt to estimate survival of ≤6 months in non-cancer patients have generally poor discrimination, reflecting the unpredictable nature of most non-malignant disease. However, a number of generic and disease specific predictor variables were identified that may help clinicians identify older, non-cancer patients with poor prognoses and palliative care needs. There is a need for simple, well-validated prognostic models that provide clinicians with objective measures of palliative status in non-cancer patients.

Abstract number: 482
Presentation type: Poster
Poster number: P62

Recruiting older people with heart failure into a longitudinal study exploring palliative care needs

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Objective: To examine the methodological issues encountered in recruiting older people with HF into a longitudinal study exploring their palliative care needs. Method: Electronic records in 16 GP practices in 4 UK locations were searched for patients aged ≥60 with HF. Patients were recruited by letter and follow-up phone call. Questionnaires are being sent 3 months for 2 years to all participants (NYHA 2–4) and their informal carers where appropriate. Qualitative data are also being collected including through post-bereavement interviews with carers. Results: Of 1826 patients extracted from the searches, 19% were ineligible, 51% were excluded or refused and 30% participated, of which 42% nominated a carer. Participants were younger (median age 77), and more likely to be male (54%) than non-participants, 69% reported 2+ comorbidities. To date all participants have been sent 2 questionnaires, 92% and 90% respectively have been returned completed (reasons for drop-out include ill-health and deaths). Initial self-reported NYHA was: 2: 65%, 3: 29% and 4: 6%, with 3 and 4 increasing to 32% and 7% respectively by questionnaire 2. Conclusion: A high number of HF patients need to be identified from GP records to recruit participants. Issues uncovered during searches included poor record coding and gate keeping. Preliminary data indicate the importance of a longitudinal element to explore the palliative care needs of people with HF.
Abstract number: 483  
Presentation type: Poster  
Poster number: P65  
Do Patients with Alcoholic Liver Disease Need Palliative Care?

Libby Ferguson, Palliative Medicine, Glasgow, GREAT BRITAIN, Kathleen Sherry, The Ayrshire Hospice, Ayrshire, GREAT BRITAIN, James D R Rose, Medical Directorate, The Ayr Hospital, Ayrshire, GREAT BRITAIN

Background. Palliative care aims to improve the quality of life of patients with incurable illnesses, an increasing cause of morbidity and mortality in Scotland. Scoring systems such as the Maddrey Discriminant Function (MDF) and Glasgow Alcoholic Hepatitis Score (GAMS) aid identification of patients with poor short-term prognoses. Scant research is available about the last phase of life for these patients. Aim. To describe systematically the physical and psychosocial needs of patients with severe alcoholic liver disease admitted to a District General Hospital. Subject and Methods. A prospective study of patients with alcoholic liver disease admitted to The Ayr Hospital over a six-month period. Cases selected had severe alcoholic hepatitis by MDF and GAMS criteria or end stage cirrhosis. Patients were interviewed and the following data collected: demographics, medical interventions and outcomes.

Symptoms were assessed using the Palliative Care Outcome Scale (PCOS) and the Hospital Anxiety and Depression Scale (HADS). Results. 11 patients were reviewed, 9 males, 2 females, mean age 48 years (range 31–66). Physical symptoms reported included fatigue (100%), pain (73%), anorexia (64%), nausea (55%) and breathlessness (18%). Other symptoms mentioned were hiccoughs, itch, sweating and increasing tiredness. Psychological symptoms were prevalent with anxiety reported in 82% of cases and moderate to severe depressive symptoms prevalent with anxiety reported in 82% of cases. Symptoms were assessed using the Palliative Care Outcome Scale (PCOS) and the Hospital Anxiety and Depression Scale (HADS). Results. 11 patients were reviewed, 9 males, 2 females, mean age 48 years (range 31–66). Physical symptoms reported included fatigue (100%), pain (73%), anorexia (64%), nausea (55%) and breathlessness (18%). Other symptoms mentioned were hiccoughs, itch, sweating and increasing tiredness. Psychological symptoms were prevalent with anxiety reported in 82% of cases and moderate to severe depressive symptoms reported in 45%. Issues of spirituality, body image, addiction, guilt, family and financial concerns were also raised. An improvement in physical symptoms excluding fatigue and anorexia was demonstrated in those who completed serial PCOS. 6/11 patients died, mean duration of 6 days from initial review. Conclusion. Patients with severe alcoholic liver disease suffer physical and psychological symptoms, which may be addressed by a multidimensional, palliative care approach.

Abstract number: 484  
Presentation type: Poster  
Poster number: P66  
Specialist Palliative Care in Non-malignant Disease in an Acute Hospital

Norma O’Leary, Department of Palliative Medicine, Dublin, IRELAND, Eoin Tiernan, St. Vincent’s University Hospital, Dublin, IRELAND

Objectives: Up to 66% of all Irish deaths take place in hospitals or institutions. Hospital Palliative Care Teams (HCPT) have been established to meet the needs of patients dying from malignant and non-malignant conditions. This study examined all the non-malignant cases referred to the team over an 18-month period.

Method: A retrospective chart review was carried out. Information from the first HCPT assessment was gathered. Results: There were 864 referrals to the HCPT over the 18-month period. 14% referred for non-malignant disease; 53% were female; average age was 70 years. Most common non-malignant diagnoses: Stroke 26(23%), respiratory disease 25(22%), neurodegenerative disorders 14(12%), dementia 11(10%). 70% of patients were referred for terminal care, 50% for symptom control, 33% for pain control. This contrasts with cancer patients where 52% were referred for pain control and only 22% for terminal care. At assessment by the HPCT, patients with non-malignant disease had multiple symptoms. Pain was the most common (57%), ‘chestiness’ (47%), agitation (25%), dyspnoea (22%). The average length of involvement by the HPCT was 8 days. 80% of patients died in hospital. This contrasts with cancer patients where only 42% died in hospital and 39% were discharged home. Conclusion: Patients with non-malignant disease have multiple symptoms and are referred late in the disease trajectory – terminal care was the most common reason for referral to the HPCT. Non-malignant disease is characterised by prognostic uncertainties. Rather than just resorting to palliative care in the terminal phase, we recommend earlier referral so that the HPCT can support the acute team in maximising symptom control and quality of life.

Abstract number: 485  
Presentation type: Poster  
Poster number: P67  
Multi-disciplinary COPD Clinic Poster

Deirdra A Sives, Palliative Medicine, Airdrie, GREAT BRITAIN

Chronic Obstructive Pulmonary Disease (COPD) is a major public health problem. The growing recognition that many healthcare providers and patients take a nihilistic view of the therapy of COPD has led to the inception of The Global Initiative for Chronic Obstructive Lung Disease (GOLD). Palliative care is traditionally linked to cancer but it is now recognised that palliative care has a role in non-malignant conditions such as COPD. Recent British Thoracic Society guidelines recommend a multi-disciplinary approach to COPD. In response to these observations a pilot monthly multi-disciplinary COPD Clinic was set up in December 2003. This clinic has, as its core staff, a respiratory nurse specialist, a respiratory physiotherapist, a senior palliative care physician and a consultant chest physician. Other medical and para-medical professions have facilitated slots available during COPD. Patients as required. Patients are given the opportunity to explore any relevant issues such as the impact of COPD on their quality of life. Structured assessment tools are completed including the HADS and St. George’s Hospital Respiratory Questionnaire. Thirty-five appointments were analysed over 6 months representing 24 new attendances. Subjects had severe airflow obstruction, a high level of symptoms and high scores in the St. George’s Hospital Respiratory Questionnaire. Thirty-five appointments were analysed over 6 months representing 24 new attendances. Subjects had severe airflow obstruction, a high level of symptoms and high scores in the St. George’s Hospital Respiratory Questionnaire.

Abstract number: 487  
Presentation type: Poster  
Poster number: P67  
Evaluation of Clinical Supervision at St Christopher’s Hospice

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Aims Clinical supervision was offered to nurses at St Christopher’s Hospice from September 2002. The groups were organized to ensure nurses from both the wards and the home care unit. Ten months after its introduction, an evaluation was carried out, in order to examine the nurses’ needs of taking part in clinical supervision, and whether it was perceived to be a worthwhile activity.

Method The evaluation was carried out by anonymous questionnaire to all who had been taking part in clinical supervision. The questionnaires contained fourteen questions asking for responses to various statements using a 5-point Likert scale from “Strongly agree” to “Strongly disagree.” There were also open questions asking respondents how many sessions they
had attended, to identify two items that were liked and disliked about clinical supervision, and reasons for non-attendance where appropriate. Responses were input to and analysed on an SPSS computer programme.

Results
There were 67 returned questionnaires (68% response rate).

There was an average of 74% positive statements about clinical supervision, ranging from 91% agreeing to finding out what clinical supervision is about, to 54% agreeing that it has kept them motivated at work. Main reasons for non-attendance were holidays and off duty items liked best were mainly time away to reflect on clinical practice and help/encouragement/support from others. The two items most disliked were that it is sometimes difficult to leave the ward/office and small groups or low attendance.

Analysis/Conclusion
These results show a very positive view of clinical supervision. The hospice has therefore decided it should be offered to all nurses. Other points for consideration were whether it could be widened to include the multi-professional team, whether it should be compulsory or mandatory, and how to ensure maximum attendance.

Abstract number: 488
Presentation type: Poster
Poster number: P68

A vision for the future palliative care development in Russian Regions

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In Russia, palliative care has generally been developed by enthusiasts and volunteers — although its success is heavily dependent on the attitude of the local authority, which may respond differently in different regions. Generally, new services are being linked to institutions already operating in the health system. In future, the shape of palliative care developments may be influenced by: a rise in economic growth over the next four years with an expected increase in the health care budget; economic growth over the next four years with an anticipated increase in the health care budget; a palliative care vision for the whole of Russia; the development of national guidelines for palliative care; the availability of opioid drugs; the ability for hospitalised patients to receive palliative care in the same setting; an anticipated enhancement to home care; an awareness-raising programme for government officials and the public. In Nizhny Novgorod Region like in many other regions through over the country, opportunities for palliative care development include the following: an awareness-raising programme for government officials and the public; directors of medical institutions who are becoming sympathetic to the establishment of palliative care units; the linking of palliative care to geriatric services (for non-cancer patients); expanded sources of funding; the integration of palliative care training into medical colleges and universities as well as into the schedule of postgraduate education; a palliative care official leader (Heads of Palliative Care) for the region, who is responsible for palliative care services; the development of the head hospice as a regional clinical and training establishment; a network of local palliative care with the aim of forming the basis for palliative care; growing resources within the voluntary sector; a religious awakening which is leading to the acceptance of humanitariin support and changing attitudes towards patients with incurable diseases.

Abstract number: 489
Presentation type: Poster
Poster number: P69

Difficulties of Palliative Care in Lithuania

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Our country can’t boast about advanced Palliative Care. It is known that some practitioners don’t pay enough attention to Palliative Care. Such restricted understanding of man’s health from the scientific and treatment point of view doesn’t satisfy the society anymore. Besides, it’s not usual in our country to talk about death openly in the families. This topic is usually a taboo. Such conception makes acceptance of the fact of loss of the patient even harder and he has to leave without a sincere talk with the loved ones about his feelings concerning death. Weaknesses of Palliative Care: – We only recently started teaching the students about palliative care at the university level; – There's no hospice network, no grief service; – There's a lack of social workers, although we already have this kind of education at the university level; – There’s strong fear in most families to talk about death. Strengths of Palliative Care: – We have highly qualified specialists doctors working in the area of oncology, who had studies or training in advanced foreign countries.

Abstract number: 490
Presentation type: Poster
Poster number: P70

Adult cancer patients with incurable disease: an exploration of continuity of care

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Background: Cancer patients with palliative care needs are becoming more numerous, as the changing demographics of the population. However, the number of professional caregivers from a range of provider agencies (NICE 2004). Good continuity of care is crucial if the care patients receive is to be appropriate. Responses were input to and operationalised this in their work. Study Aims and Objectives: 1. To explore how palliative care professionals conceptualise continuity of care in terms of their working practice and role 2. To identify barriers to and facilitators of continuity of care from the professional caregiver standpoint 3. To investigate if and how commissioners of palliative care services address continuity of care in business plans and service level agreements. 4. To map the conceptual development of continuity of care in the palliative healthcare context. Method: Case study strategy. A variety of data collection techniques will be used including: document analysis; group and individual interviews; non-participant observation. The study will be carried out in 3 PCTs in the Greater Manchester & Cheshire Cancer Network. Findings/Conclusions: Study is at the design stage. Reference: National Institute for Clinical Excellence (NICE) 2004, Improving supportive and palliative care for adults with cancer, The Manual. NICE, London. Available at http://www.nice.org.uk/pdf/csgpmanual.pdf

Abstract number: 491
Presentation type: Poster
Poster number: P72

Improving the communication in a Home Palliative Care Network

Carlo Perusselli, Palliative Care Unit / Oncology Dept., Biella, ITALY, Pella Alessandria, Fondo, Biella, ITALY, Grubich Sergio, Palliative Care Unit, Biella, ITALY

An element of criticality in the activity of a Home Palliative Care Network (HPCN) is the difficult sharing of the information about patients. A lot of information, available in the patients’ home, is not organized in a way to be easily interpreted and above all it is not shared. All the members of the team must be able to share and exchange the information about the patient’s condition in real time. We have therefore defined and made operative a project (‘GerasiM’ Project) with the following main objectives: –Organizing a monitoring system of a HPCN, activating a computer network for communicating. –Organizing a system of information sharing among the operators in the network, (GPs, PC, doctors and nurses, emergency services). We have defined a minimum data set, referred to the clinical situation of the patients, to the monitoring of the Qol., to the treatments in progress and their effectiveness. Some data are fixed, while others are variable and continuously updated. We have selected a group of GPs willing to participate in the initial project, to be extended later to all GPs. A specific formation has been organised for these doctors. We defined the hardware for the project (mobile/palm) and a web-based appliance, which provides the means for each operator in the HPCN to log-in and navigate in Internet. The platform was developed in web-based technology, which permits the managing and organizing of the flow of information of the patients’ data, through the use of a browser and a medium-large band connection. The main advantages provided by the application of the project are: –The opportunity to continuously monitor the data now inserted in the patient’s database. –The opportunity, for all the HPCN operators, to give immediate and targeted answers on the effective needs of the patients and/or their family – The possibility of defining projects in order to improve the quality of care, based on the criticality which emerged from the system of continuous monitoring.

Abstract number: 492
Presentation type: Poster
Poster number: P73

Evaluation of the national policy on palliative care in the Netherlands

Wim J.J.ansen, Agora, Bunnik, NETHERLANDS, Jo A.H. Baekel, BMC, Leusden, NETHERLANDS, Gert Cazemier, BMC, Leusden, NETHERLANDS

Introduction
In 2000 ten regions in the Netherlands participated in a pilot-project ‘Development of local networks palliative care’. Based on the results of this pilot a nation-wide development of about 70 local networks palliative care started in 2003. All institutions and organisation involved in palliative care in a certain region should collaborate to achieve a higher level of quality of palliative care. The state finances network-coordinators to develop these
Abstract number: 494
Presentation type: Poster
Poster number: P74

Palliative care in the Kemerovo region, Russia.

Olga Usenko, Hospice, Kemerovo, RUSSIA, Olga Berezikova, Kemerovo Regional Hospice, Kemerovo, RUSSIA

The Kemerovo region has a population of 2,919 million. The elderly make up 20% of the population. In 2003, the morbidity rate from cancer was 284.4 per 100,000, the mortality rate from cancer was 197.3 per 100,000 in the region, and there were 5,759 deaths due to cancer. The average percentage of advanced cancer was 15.4%. At the present time, 4 Hospices operate in the Kemerovo region.

The number of beds is 147 or 0.50 per 10,000. 1,803 patients with advanced cancer (31.3%) received palliative care. The number of palliative care centers in the region is 6. The Kemerovo region Hospice is equipped with 40 beds. It served a population of 2,918,900 in 2003. 319 patients were admitted to the hospice; 229 (44.1%) of those patients died. The home care team visited 642 patients. The Hospice is the methodological centre of palliative care in the region. Another hospice for the residents of Kemerovo city is the Kemerovo City Hospice. It has 60 beds. Hospice served a population of 523,110 in 2003. 811 patients were cared as inpatients, 162 (20.0%) died. 501 patients were visited at home. In 2003, the Nuzhnetsk Palliative Care Unit served a population of 577,700. It was equipped with 22 beds. 238 patients were cared for as inpatients; 116 (48.5%) died. The new Hospice with 25 beds was opened in Prokopyev in 2003. It served a population of 225,884. 235 patients were admitted to the hospice, 76 (32.9%) of them died. Patients with advanced cancer in the Kemerovo region receive free treatment and care. The Hospices’ financing is stable and gradually increases. Most hospice staff obtained information about the advances in palliative care from training courses provided by local, national and international medical and nursing specialists. As a result, the awareness of palliative care in the Kemerovo region gradually increases.

Abstract number: 495
Presentation type: Poster
Poster number: P76

Managing the delivery of a palliative care service to patients with advanced respiratory disease

Martin McCormack, Social work department, Dublin, IRELAND

Quality of life for people dying from advanced respiratory disease is often suboptimal, as access to services can be limited to symptom management in the acute phase of their illness. This is in stark contrast to the panopty of services that cancer patients have access to in Ireland. Progress made with advanced respiratory disease is poor, and it is increasingly accepted that such patients need good palliative care. With increasing requests for palliative care provision for all, irrespective of their diagnosis, professionals within specialist palliative care services need to consider how they will respond. This research examines the implications of managing the delivery of a palliative care service to patients with advanced respiratory disease. This is achieved through a combination of semi-structured interviews with key groups and use of the Delphi method, with a panel of experts to develop a consensus statement on the management of the delivery of a palliative care service to patients with advanced respiratory disease. This is the first research of this kind in Ireland. The research indicates that there could be a clear benefit to patients with advanced respiratory disease from having specialist palliative care services available at an earlier stage, than is currently being offered. Some of the barriers to this service being offered to patients are well documented in the international literature. However this research highlights willingness by the specialist respiratory and palliative care teams to collaborate, which indeed is different. There are some recommendations for further research that may influence the development and expansion of hospice and palliative care services in Ireland in the future.

Abstract number: 496
Presentation type: Poster
Poster number: P77

Where there are no borders: Providing an integrated seamless specialist palliative care service

Karen Groves, WL, S&F Palliative Care Services, Merseyside, GREAT BRITAIN

In an ideal world a palliative care service should be seamless to the patient and family. However, in reality, due to the fact that different parts of the service may be provided and managed by different organisations, both NHS and independent, this may not be so easy to achieve. In an attempt to overcome the borders and hurdles which obstruct seamlessness of the patient experience, West Lancs, Southport and Formby has developed a virtual single service consisting of all elements of palliative care, owned and managed by different Trusts and organisations. The service works to joint organisational and clinical guidelines and protocols, sharing a single electronic multiprofessional clinical record. This poster describes the nuts and bolts of the integrated service and how the pieces of the jigsaw fit together to provide benefits for the patient, family and the health professional who care for them, both within and without the team.

Abstract number: 497
Presentation type: Poster
Poster number: P78

St. Christopher's Hospice (SCH) @ Home (H@H) - Year 1 evaluation

Sara Burroughs, Home Care, London, GREAT BRITAIN, Pam Bale, GREAT BRITAIN, Penny Hansford, GREAT BRITAIN, Vicky Robinson, GREAT BRITAIN

Introduction There is growing evidence that people prefer to be at home at the end of life. H@H intends to fulfil these wishes, providing skilled nurses and carers. In the UK there are 103 adult H@H services, largely funded by the voluntary sector. In the area served by SCH personal and nursing care is given by agency staff commissioned via NHS continuing care funds. Staff are not trained in palliative care. Recognising these gaps in statutory services SCH raised voluntary funds to provide H@H. This began in May 2003. Aims To enable patients to remain at home for as long as possible and to die in their place of choice. Methods Comprehensive information captured at referral, duty shifted re-hospitalisation rates. A questionnaire completed by H@H nurses. Descriptive statistics used to review service Objectives. Results 140 patients were referred, median age 72 (range 33–93). 90% had cancer. Reasons for referral were patient deteriorating and/or carer in need of a break (70%), and psychological support for the carer (30%). 47% of duties undertaken were physical nursing care.
From April to improve ‘grassroots’ were to determine (a) extent of experience and families in the last 48 hours. H@H should be purchased as part of statutory care.

4 (3%) were admitted to SCH before H@H (11%) died before 1st visit, 6 (4%) are still alive, as their chosen place, 7 (5%) in hospital, 15 as their chosen place, 7 (5%) in hospital, 15

49% (95% CI=3.1–3.0) in another home, 37.2% (95% CI=31.5–42.9) in hospital, 0.6% (95% CI=0.4–1.1) in hospice, 7.1% (95% CI=5.0–9.2) in a nursing home, and 0.3% (95% CI=0.3–0.7) in an ambulance during the transport to the hospital. Wide differences can be observed between different geographic areas of Italy. The proportion of patients choosing home, hospital, 49.9% (95% CI=15–35.7) in NE, 55.5% (95% CI=39.3–71.7) in the centre, and 93.5% (95% CI=68.8–98.2) in the south. According to what the caregivers about the preferred place of death of the patients, an homogenous preference for dying at home was present in all areas of the country. More specifically 88% of the patients in NW, 87% in NE, 93% in the centre, and 98% in the South preferred to die at home. 5.4% of the sample preferred to die in a hospital, more in the North of Italy than in the South. The reported reasons for preferring hospital were ‘not to be a burden for the family’ and ‘to prefer a safer setting of care’. Conclusions: This study, conducted on a representative nationally based sample, shows that where people die is strongly influenced by where people live, and not by their preference.

Abstract number: 501
Presentation type: Poster
Poster number: P82
Palliative Care Services and Irish Travellers – Barriers to Service and Training Needs
Regina McQuillan, Medical Director, Dublin, IRELAND, Onja Van Doorslaer, St. Francis Hospice, Dublin, IRELAND
Irish Travellers, an ethnic minority are recognized as having poor health and poor access to health services. As part of a study exploring relationships between the Travellers and palliative care services, a questionnaire was sent to palliative care service providers. The aims were to determine (a) extent of experience of palliative care service providers caring for Travellers, (b) if Traveller ethnicity was routinely recorded, (c) extent of training on Travellers issues and (d) identify providers views of Travellers accessing palliative care. 215 questionnaires were sent; the response rate was 38%. In the previous year 86% of staff had not cared for a member of the Travellers and over the previous five years over 80% of staff had not cared any Travellers. 88% had never received any training or education about Travellers. Traveller ethnicity was not routinely recorded. The barrier to delivery of specialist palliative care to Travellers that was most often identified was that the respondents was traveller mobility, leading to poor continuity of care. Lack of awareness of the different beliefs and cultures held by Travellers and prejudices held by the public and service providers were the second and third most commonly identified barriers. Additional issues identified were large family networks which may hinder care because of overcrowding when Travellers are admitted to hospices and the isolation experienced by Travellers in hospital or hospices. Needs of health care providers include training and education about the customs, cultures and beliefs of Travellers. Many respondents believe greater knowledge of these issues would improve their ability to care given to the Travellers. This study showed that specialist palliative care staff had little experience caring for Travellers; they identified their own training needs and suggested barriers to Travellers accessing services.

Abstract number: 499
Presentation type: Poster
Poster number: P80
Palliative Access Links (PALs) as ambassadors for Palliative Care: Moving information beyond the provider-community border and taking volunteering into new territory
Peter Whan Chermside West, AUSTRALIA
Background: The PALs project is funded by the Caring Communities Program of the Australian Government’s Department of Health and Ageing. It aims to ‘move ‘grassroots’ awareness of the underlying concepts of Palliative Care and the availability of local services within the Bundaberg region. A network of ‘information volunteers’ is being recruited, resourced, trained and supported to inform people about Palliative Care generally, and local Palliative Care options specifically, in community settings such as workplaces, schools, churches and social clubs. Objective: To analyse processes undertaken so far by the 23 PAL volunteers currently active. Method: Qualitative and quantitative review of PALs’ activity diaries. Results: Activities were of two broad types, with approximately equal numbers of each. 1) Talks given by PALs to groups of about 20 people on average, in church, school, social and community settings. 2) Responses by PALs to requests for information from community members (often in response to a poster). About half of these were of a general nature, the other half relating to the specific (and occasionally urgent) need of a dying person. Key themes were a lack of community awareness, and concerns about the relationship between dementia care and Palliative Care. Conclusion: The PALs project takes Palliative Care volunteering into yet another territory. Rather than providing person to person care or playing a supporting role in a service, PALs serve as a link point where information can be shared to encourage those in contact with a dying person to be aware of the nature and availability of Palliative Care services, and to access them in a timely way. This analysis reveals that PALs are doing this by engaging in a wide range of structured and opportunistic activities in a variety of settings.

Abstract number: 500
Presentation type: Poster
Poster number: P81
PREFERRED vs. ACTUAL PLACE OF DEATH OF THE CANCER PATIENTS. RESULTS FROM AN ITALIAN MORTALITY FOLLOW-UP SURVEY
Monica Beccaro, Unit of Clinical Epidemiology, Genova, ITALY, Costantini Massimo, National Cancer Institute, Genova, ITALY, Minciccesi Guido, CSPO, Firenze, ITALY, Grimaldi Maria, National Cancer Institute, Napoli, ITALY
STUDY OBJECTIVE: to describe and analyse actual and preferred place of death of Italian terminal cancer patients, and their determinants. METHODS: this is a mortality follow-back study of 2000 adults who died in 1997 - 1998 of cancer deaths, identified with a 2-stage probability sample representative of the whole country. Information on patients’ experience was gathered from the non-professional caregivers with an interview conducted by trained professionals. A schedule covered information on the actual and preferred place of death of cancer patients. RESULTS: valid interviews were obtained for 63.5% (n=1.271) of the theoretical sample. It can be estimated that in the whole country, 52.5% (95% CI=46.6–58.3) of the cancer patients died in their own home, 2.2% of patients died in their place of choice. Most were referred in the last days of life. H@H is a vital source of skilled nursing care for patients and families in the last 48 hours. H@H should to be purchased as part of statutory care.

Abstract number: 498
Presentation type: Poster
Poster number: P79
Palliative care is needed before the last months of life
Unni Marie Rekkedal, Faculty of Medicine, BODØ, NORWAY
Background: Late referral to palliative care is a cited obstacle to care improvement, but the extent to which such services are needed in early palliation (survival expectancy > 3 months) is not extensively explored in non-selected groups of cancer patients. Aim: Systematic symptom assessment of advanced cancer patients in early palliation to explore their palliative needs. Methods: From April 2002 to December 2003, all patients with advanced cancer consecutively admitted to a one-specialist medical oncology outpatient clinic, reported their symptoms using a slightly modified Edmonton Symptom Assessment Schedule including 9 symptoms and general well-being. Constipation was added ad hoc. All symptoms were scored on a 0 (best) – 10 (worse) numerical rating scale. Scores above 3 were defined as a problem requiring intervention. To enable reports on time from assessment to death, only patients who died within August 2004 were included. Results: Overall 145 patients died, median time from assessment to death was 24 weeks. Median age was 69 years, 57% were men and 43% women, 35% lived alone, 60% with spouse, 5% with others. 38% had 41%, gastrointestinal system 30%, breast 10%, prostate 4%, and others 15%. For 85%, tumour treatment was the reason for admission. General well-being excluded, 45% of the patients reported 3 or more intervention requiring problems. Overall, 10% had scores above 3 for constipation, 10% for nausea, 15% for pain at rest, 28% for pain with movement, 22% for anxiety, 22% for depression, 26% for dry mouth, 35% for dyspnea, 40% for appetite loss and 43% for fatigue. Only 23% had no such problems. Conclusion: A large number of patients had severe symptoms indicating that palliative care services should be an integrated part of oncology clinics providing palliative tumour treatment. The importance of later intervention, better tools for symptom assessments is advocated.
DYING OF CANCER: THE IMPACT ON THE FAMILY. RESULTS FROM AN ITALIAN MORTALITY FOLLOW-BACK SURVEY

Paolo Giorgi Rossi, Agenzia di Sanità Pubblica, Roma, ITALY, Beccaro Monica, National Cancer Institute, Genova, ITALY, Miccinesi Guido, CSPO, ITALY, Borgia Piero, Agenzia di sanità Pubblica, Roma, ITALY, Montella Maurizio, National Cancer Institute, Napoli, ITALY

STUDY OBJECTIVE: to describe the impact of terminal cancer disease on patient’s families. We analyse the economic burden and the impact on daily activities. METHODS: this is mortality follow-back survey of 2,000 adults cancer deaths, identified with a 2-stage probability sample, representative of the whole country. Information on patients’ experience was gathered from the non-professional caregiver with an interview conducted by trained professionals. A schedule covered information on the impact of managing care on finances and on the daily activities of the family. RESULTS: The main non-professional caregiver was the child (41.7%), the spouse (36.4%), a sibling (5.8%), a parent (1.9%), another relative (10.2%), or a friend (1.5%). The mean age of the caregiver was 53.9 and 70 % were female. 9% of caregivers of young aged reported difficulties in managing their work, and 71% difficulties in managing their spare time. Most families (68%) had to pay for some of the care: drugs (38%), physician (23%), nurse (19%), assistant (17%). The multivariate analysis showed that families living in the south of Italy had to pay for some of the care more than families living in the north (OR 3.2, 95% CI 1.1–9.3), and that the age of the patient was significantly associated with the costs for the family (OR for unit of age: 1.06; 95% CI 1.00–1.13). Families attending old patients have to pay more frequently than families attending young patients. Age and gender of the caregiver had no effect on the cost of the care for the family. To cover the costs of the care to the patient has been reported as somewhat or very difficult for the families by 25.4% of the caregivers. The multivariate analysis showed that difficulties to cover the costs of care were more frequent when the caregiver was female (OR: 1.5 95% CI 1.1–2.0). Conclusions. Families must pay only marginal aspects of care but the impact on savings and daily life is heavy.

Abstract number: 503
Presentation type: Poster
Poster number: P84

Comprehensive Palliative Care: Successful Integration of the Palliative Care Service

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St Mary’s Hospital Center is a community-based hospital which offers comprehensive care to the multietnic population of Montréal. Since 1996, palliative care team has joined the oncology staff. The in-patient unit welcomes oncology patients as well as palliative care patients. Two years ago, the nursing staff of the in-patient unit and the out-patient clinic were combined in the same administrative entity. Therefore, the nursing staff is involved with all patients. The patients benefit from a timely consultation of the oncologist and the palliative care physician during the same visit at the out-patient clinic. This workshop will describe the activities of this program as well as the pros and cons of this model of practice. Results of patient satisfaction survey will be presented. Nurses were also asked to express their opinion regarding the merger of their activities. Integrating palliative care physicians and oncologists within the same program allows a comprehensive approach to the treatment of cancer patients, favoring improvement of their quality of life.

Abstract number: 504
Presentation type: Poster
Poster number: P85

Caring for patients dying in hospitals – pioneering a process

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Objective: To develop an integrated and multi-perspective approach to care of people dying in an acute hospital setting with a view to demonstrably improving all aspects of care and organisational culture. Method: Using an action research methodology, the process occurs over two years under continuous review. Focus group discussions were used to isolate local and discipline-specific issues. A staff survey on knowledge, attitudes and beliefs is planned. Video and web based media were developed early on to trace the project. The structure detailed below ensures continuous feedback to hospital staff. Summary: Holistic care demands that specialist care is supported by two levels of care - referred to as ‘general’ and ‘an approach’ in palliative care. A partnership between a not-for-profit organisation (Irish Hospice Foundation) & health authority (North Eastern Health Board) was initiated and one hospital site identified with the aim of examining and improving all facets of care for patients dying in hospital. Operational structures were designed at macro level (project committee) to ensure hospital & community representation; and at micro level (working groups) to ensure focussed consideration of issues impacting on patient, family & staff during care at the end of life. National & local media were used to build a profile for the project and raise awareness. A nation-wide survey was conducted on care preferences for dying to provide an opinion context for the project. Government partnership funding was attained to focus on staff support & patient experiences.

Conclusions: Specific goals have been generated concerning communications, information and physical environment. Investigation of staff support issues & support systems has been initiated & patient review systems are being planned. The project time-line ceases in March 2006 with structure reviewed in Dec 2004. This presentation details the process and will include survey data and video reviewed.

Abstract number: 505
Presentation type: Poster
Poster number: P86

Establishment of a palliative care competence network in Helse Fonna, Western Norway

Anne Lis Ersland, Pain clinic, Haugeoisund, NORWAY, Eli Neshem Ronnevik, Vardaljell Hospice, Haugeoisund, NORWAY

Background: National hearings have recommended that palliative care should be an integrated part of the public health care system. We observe that the health care system surrounding the patient is often lacking, and that competence within palliative care benefits only some of the patients. A coherent interdisciplinary competence within this area should be established. Since 2001 our goal has been to establish a competence network consisting of resource groups and/or persons within our region across administrative levels. Methods: Marketing of the competence center – Mapping out the existing available competence and palliative care within the primary health services and the hospitals – Take initiatives for inter-communal cooperation – Theme meetings and courses within palliative care – Focussing on the importance of palliative work at the different levels of care – Stimulate further education – Marketing of other palliative care centers within the region – Focus on quality control in planning, establishing routines and procedures – Document other progress in these processes. Results: There has been established a palliative care competence network within Helse Fonna which involves three hospitals and 19 of 20 local authorities. There have been 13 inter-communal meetings, several courses and monthly meetings for resource personnel at Haugeoisund Hospital. Six nurses on further education in oncology and one in palliative care. ESAS is used in the hospitals and in most of the local authorities. One authority, Etne, has received national funding for palliative care. Evaluations indicate increasing awareness concerning quality control. Conclusion: Establishment of a competence network in palliative care places focuses on this discipline and promotes communication and cooperation across administrative levels. Improved competence and quality control of routines contributes to a better offer for both patients and relatives.

Abstract number: 506
Presentation type: Poster
Poster number: P87

National associations – a global overview

Nick Pahl, Development, London, GREAT BRITAIN

An update on a recent event for national associations in hospice and palliative care, held in Korea, March 2005. Initiated by Help the Hospices (UK), the meeting was held in the Hague, and was attended by 40 representatives from 53 national associations work in isolation and find themselves re-inventing what has been developed elsewhere. This seminar will share experience about how other associations have contributed to the development of palliative care. It will also cover: ● The possibilities for international e.g. standards sharing has occurred between the US and Europe● Advocacy opportunities e.g. working with Government ● Organisational issues e.g. structure, governance. By the end of the seminar participants will have increased their...
knowledge of what other national associations have achieved; and the possibilities for international collaboration.

Abstract number: 507
Presentation type: Poster
Poster number: F88

World Hospice and Palliative Care Day – 8th October 2005 – Awareness raising events as a way of advocating for improved care


A review of plans for world hospice and palliative care day – 8th October 2005, including a pre launch of the ‘state of the world’ publication linked to this. Initiated by a number of national and pan national organisations and in partnership with Voices for Hospices, the workshop will run through – The key messages of the day to raise awareness of hospice and palliative care to the outside world – What can be achieved through a day of action – Resources available on the website worldday.org The second section of the seminar will share experiences of how national organisations have run awareness and fundraising events and how this has contributed to the development of palliative care, for example, it will cover activities now being carried out in Australia, Canada and India. By the end of the seminar participants will have increased their knowledge of what can be achieved by such events.

Abstract number: 508
Presentation type: Poster
Poster number: F89

Do healthcare workers confronted with patients nearing the end of life suffer? Implications for patient care and for services organization.

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Object of the study: The relief of suffering is recognized as one of medicine’s most fundamental purposes. However, little is known of the suffering of healthcare providers being confronted daily with patients at the end of their life, nor of its consequences. The aim of our study was to explore the response of healthcare providers to the suffering of patients nearing the end of life. In this communication we report results bearing on the suffering being induced in the healthcare workers themselves. Methodology: Semi-structured interviews, recorded for later transcription, were conducted among healthcare providers involved in the care of palliative patients in a teaching hospital. Focus-groups were also led in order to validate the emerging theory. Analysis using constant comparison of cumulative data yielded initial thematic classifications which were later condensed and organized into conceptual categories. Results: The chaos and helplessness associated with the ultimate phase of existence are shared by the professionals and auxiliaries who care for patients nearing the end of life. Added to constraints brought on by the healthcare system’s organization and management subject healthcare providers to a level of suffering which interferes with their capacity to respond to the suffering of patients. Conclusions: Consideration of healthcare providers’ own suffering is essential in identifying needed adjustments in healthcare delivery and management, in any attempt to improve and foster a lasting ability to respond adequately and alleviate the suffering of the terminally ill.

Abstract number: 509
Presentation type: Poster
Poster number: F90

A Good Death in nursing homes – is it possible

Gunhild Jakobsen, The Palliative Medicine Unit, Trondheim, NORWAY, Mette Ronning, The Palliative Medicine Unit, Cancer Unit, St. Olavs Hospital HF, University Hospital of Trondheim, Trondheim, NORWAY, Finn Gutvik, The Palliative Medicine Unit, Cancer Unit, St. Olavs Hospital HF, University Hospital of Trondheim, Trondheim, NORWAY

Background Studies suggest that palliative patients suffer from poor symptom control. The question to be addressed is whether the phenomenon can be explained among other things by lack of competence by health care professionals. Another cause may be related to the organisation of palliative care services. The PMU was the first academic palliative care unit established in Norway. The PMU, in addition to running a clinic, also is responsible for education, research and the enhancement of skills and knowledge in palliative care. The PMU has initiated a project called ‘Improving palliative care in nursing homes in Mid-Norway’ based on national and international recommendations. The project’s main objective is to further develop and improve the palliative services at a local level within the Mid-Norway Regional Health Authority, hereunder establishing guidelines for patients requiring palliative care in the region’s nursing homes. Methods The objectives can become reality through activities directed towards increasing the general skills within the palliative field as well as improving the way palliative care is organised. To improve palliative care services, several aspects need to be addressed. The PMU contribute to the development of these aspects through different channels and methods. Results so far – Established special collaboration with central authorities in Mid-Norway related to the project. Several projects and 8 hospitals in Mid-Norway are contacted and informed about the project – Agreements have been made with communities on bed-side learning programmes – An educational programme is started in several regions, both in hospitals and nursing homes – Joint meetings arranged with communities on how to establish palliative beds in nursing homes Conclusion The quality of palliative care services in communities (and hospitals) will most likely improve by the PMU intervention as described and ‘a good death’ in nursing homes could be possible.

Abstract number: 510
Presentation type: Poster
Poster number: F91

A Century of Palliative Care: St Joseph’s Hospice 1905–2005

Mary Teresa Clarke, Chief Executive, London, GREAT BRITAIN, Christina Mason, St Joseph’s Hospice, London

On January 15th 2005, St Joseph’s Hospice celebrates its centenary; the arrival from Ireland of the small band of Sisters of Charity that founded St Joseph’s. Their mission at that time was to care for the sick and poor of Hackney, East London and initially they did this from a large house that had been given to the Sisters by a Jewish benefactor. Now in 2005, patient and family care takes place in a newly completed and substantial four storey building. In this presentation, the key story of St Joseph’s history will be outlined and the way in which changing social and health conditions influenced these stages and the decisions that were taken to implement change. Emphasis will be given to the last of these stages, the decision to rebuild the hospice in order to provide the most up to date facilities for palliative care of patients and their families. Emphasis will be made on the substantial number of challenges in considering this building programme. Attention will be focused on the following: the many different ethnicities, languages, faiths and cultures of the population served by the hospice; the provision and maintenance of choice for patients and their families; the care of families; the balance between the in-patient facilities and the service given to patients at home; the integration of physical, emotional, social and spiritual aspects of care; the provision of special facilities for infection control. The presentation will also consider project management, how members of staff were involved in the decision making process, the practical considerations of available space, and the balance between medical and aesthetic aspects of a large C21st palliative care facility. There are lessons to be learned for all who are attempting to provide a palliative care for the present and the future.

Abstract number: 511
Presentation type: Poster
Poster number: F92

What do patients in the palliative phase value in a lung cancer service?

E. Tim Peel, Department Of Palliative Medicine, North Shields, Tyne And Wear, GREAT BRITAIN, Sue Longstaff, North Tyneside General Hospital, Tyne and Wear, GREAT BRITAIN, Karen Hanson, North Tyneside General Hospital, Tyne and Wear, GREAT BRITAIN, San Dogan, North Tyneside General Hospital, Tyne and Wear, GREAT BRITAIN

Most published guidelines on lung cancer management reflect professional opinions, sometimes evidence based. These tend to concentrate on efficient time scales and medical aspects of management that promote survival outcomes. In the context of an illness, which is fatal in more than 90% of people, we have undertaken a qualitative analysis of the experiences of 6 patients in the later stages of lung cancer. The study used interpretative phenomenological analysis (IPA) of transcribed taped semi structured interviews of 6 patients with progressive lung cancer. The key themes that were identified were: (1) Adjustment and coping along disease pathway (2) Person centred style of service delivery and staff attitude (3) Co-morbidities may be more frustrating than the cancer (4) Need health professionals’ emotional and physical Isupport in addition to family’s (5) Families need support too (6) Good communication is straightforward language, matching patient’s needs (7) Frustration than the cancer (8) Meaning of life (9) Coping with the future – different people have different strategies (10) Right to continue smoking (11) Spiritual support is a personal choice As the majority of lung cancer patients will die from their disease, listening to their needs is vital for planning a lung cancer service.
Special palliative care unit in a nursing home—evaluation and description of a new model

Gunnhild Jakobsen, Faculty of Medicine, Trondheim, Norway; Trondheim, NORWAY, Helge Garåsen, Chief Medical Officer, Municipality of Trondheim, Trondheim, NORWAY, Stein Kaasa, Pain and Palliation Research Group Norwegian University of Science and Technology, Faculty of Medicine, Trondheim, NORWAY

Objective: To describe and evaluate a new model of palliative care as a part of an integrated model in Norway. Background: The Palliative Medicine Unit (PMU), University Hospital of Trondheim was established in 1994, with an acute inpatient unit (12 beds), a multidisciplinary consultation team, an outpatient unit and a teaching program for the primary health care system. A joint project between the PMU and the municipality of Trondheim has been running for the last 6 years. As a result of the experiences through a randomized controlled study, a permanent palliative care service has been established at Haavsten nursing home. Since Jan 2003 the nursing home has assigned 12 beds for palliative care. The unit is meant to be a model for further establishment and planning of palliative care services and needs to be evaluated and further described. Methods: Descriptive medical and sociodemographic comparison of patients dying in a special palliative care unit in nursing home (n=86) and patients dying in the PMU (n=192) in 2002–2003. Results: Death in nursing home was significant associated with higher age with a mean age of 76 yrs, range 45–92, versus 67 yrs, range 29–91 (p<0.01). Furthermore, the existence of non professional health care providers, i.e. living with spouse, was also significant different with 24% of patients dying in a nursing home not living with spouse as compared to 49% in the PMU (p<0.01). Patients dying in nursing home had a significant longer institutional time, mean time 46 days range 2–207, as compared to patients dying in the PMU with a mean of 15 days, range 1–71 days (p<0.01). Conclusion: As an integrated model this gives the patient an opportunity to stay at home for as long as possible, and when needed acute care is offered at the PMU. The patients dying in a nursing home stayed there for a longer time, were older and had less support from spouse. Further development of such models is necessary to meet the care of seriously ill patients.

Abstract number: 512
Presentation type: Poster
Poster number: P93

ORGANISATION OF PALLIATIVE CARE IN BOSNIA AND HERZEGOVINA

Nermina Obralic, Oncology Institut, Sarajevo, Bosnia, in the midst of a war torn Bosnia and Herzegovina. Although palliatively ill cancer patient had started in the mid-eighties in Sarajevo, or even earlier in other European countries, Bosnia, in the midst of a war 1992–1995, had been prevented from developing this area of care. Addressing palliative care needs of patients and their families the philosophy of palliative care had to be introduced, education in palliative care improved, palliative care services set in such a way as to fit into the current model of care provided by local health services, analgetics and other drugs, medical devices and equipment and supply provided. In an attempt to address some of these issues 10 conferences for doctors, nurses, social workers and health authorities since 1997 was held. Education is also progressing well by publishing books and guidelines with and doctors and nurses recruited to the project and undergoing intensive training at St. Gamma’s Hospice in London or Palliative Care Home Service for the terminally ill patients suffering from cancer was opened in Sarajevo 1998, first hospice in Sarajevo in 2000, and second in Tuzla in 2003. Although a great deal has been achieved, there is a need for more effective and more broaden services for palliative care. The situation of shortage of same analgetics, specially different forms and concentrations of oral morfin preparations should be relieved, graduate and post-graduate education in palliative care provided. But the key goal should be to grow awareness and promote concept of quality of live and introduce palliative care as an integral part of comprehensive health care by facilitating the understanding and application of the principles of care based on the WHO (1990) definition of palliative care. Palliative treatment and care hav to be available at all stages of health care, particularly in family medicine.

Abstract number: 514
Presentation type: Poster
Poster number: P95

Shared responsibilities in palliative care

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Of all the patients treated on the Department of Medical Oncology of the University Medical centre of Utrecht fifty percent are incurable ill. A lack of knowledge and competencies on the principles of symptom management and good palliative care was obvious. For this reason we developed a strategic plan and an educational program to improve symptom management and overall quality of palliative care. Semi-structured interviews and a survey among medical doctors, oncology nurses and paramedics have been done. Improvement of the multidisciplinary collaboration between the outpatient-clinic, day-care centre and clinical ward showed to be the most important issue. The multidimensional approach of the suffering of patients and the decision making process are other priorities. The main operationalization of the strategic plan is the structural involvement of the clinical nurse specialist in direct and indirect care and the introduction of senior nurses. The educational program stimulates discussion and creates the structural involvement of the clinical nurse specialist in direct and indirect care and the introduction of senior nurses. The educational program stimulates discussion and creates the opportunity for interdisciplinary exchange of knowledge and competence (e.g. what is needed to give good terminal care; what does it mean to be responsible in palliative care). Increased knowledge and changed attitude resulted in most cases of effective collaboration between disciplines about topics in palliative care and a multidimensional approach of complex questions. Available consensus guidelines are better applied, principles of palliative care are leading in the development of patient care plans. Evaluation of the outcome of symptom management is the main topic of multidisciplinary research.

Abstract number: 515
Presentation type: Poster
Poster number: P96

There is no place like home—I.V. Home Therapy for Cancer Patients

Mali Kusha, Central District – Community Palliative Oncology Unit, Rishon Lezion, ISRAEL, Sara Ben-Ami, Clalit Health Services-Tel-Aviv District ISRAEL, Vicky Oz, Teva Medical L.A.B. ISRAEL

Today patients leave hospitals quicker and sicker to the community. The health care providers must supply continuity of care to those patients in their homes. One of the treatment modalities to cancer patients includes Intra Venous home therapy of chemotherapy, Antibiotics and T.F.N. An intervention plan was developed between two Clalit Health Services districts and Teva Medical Home Care as the treatment supplier in Israel. The aims were: To provide a safe alternative to hospital stay, to make it as simple as possible in order that the patient and family could participate in the care and to provide a cost effective service. During 2003, 979 patients received 3.915 days of I.V treatments at their homes, 638 patients received chemotheraphy treatment by intusers mostly with SFU. 162 patients received Antibiotic treatments and 36 patients received 322 day treatment of T.F.N at home. The home care nurse responsabilities are: To assess the patient’s readiness and ability to receive the I.V. therapy in the home environment, to connect and disconnect him to the treatments., to provide him with relevant information and written instructions about the medications and to be available by phone or immediate visit should the need arise. Results: - Increased Quality of Life as reported by patients and their families. - Increased (Higher) Satisfaction of patient & family. - Increased in the number of patient receiving I.V. home care Services Decrease of 86% in cost of treatment. In this presentation, we will present the significant improvement in these areas that were achieved in the joint project with Tel-Aviv & Central District of Clalit Health Services and Teva Medical Home Care.

Abstract number: 516
Presentation type: Poster
Poster number: P97

The Palliative care in France: a Palliative step moving

Laurent CHAUSIGNOL, ardeche, PRIVAS, FRANCE, LE DIVENAH Aude, Project leader of palliatif Care, DHOS, Ministry for Health, Paris, FRANCE

That of way traversed since Circular LAROUQE, 26 August 1986, which recommended the assistance with dying. The development of the palliative care intensified under the impulse of the Law of 9 June 1999, launched and supported by Dr. Bernard KOUCHEMER, then minister for the health, by promoting the access to the palliative care and an accompaniment for any person whose state requires it. In order to support the application of this law, a first territorial plan was put in luvre of 1999 to 2001, primarily stressing the development of the palliative care in establishments. The circular relating to the organization of the palliative Care, February 2002 stresses the missions and the procedure of the
Palliatif process: a new legislative concept in France
Philipp COLOMBAT, indre et loire, TOURS, FRANCE, CHASSIGNOL Laurent, CH VALS D’ARGEUIL, PRIVAS, FRANCE, D’HEROUVILLE Daniel, Past president SFAP, PARIS, FRANCE, DEBECK Jan, responsible especially in Europe, national follow up palliative care, PARIS, FRANCE, LE DIVENAH Aude, project leader of the palliatif care, ministry for Health, Paris, FRANCE

Since 1980, many palliative care units, palliative care teams and palliative care networks have been created in France. However patients die in all types of institutions and a good palliative care is a necessary whatever the care unit where they die. So the concept of palliative process was developed. It was postulated that a better quality of life of hospital staff could improve management of end of life patients and their family. This concept of participative management of patients (five main points: 1) internal process of formation for the staff of the care units which allows to educate each member of the staff, 2) Elaboration of team project after assessment of caring dysfunctions in the care unit, propositions are made by small groups to optimise the management of the team consequently of the patient, 3) Promotion of staff meetings where are discussed with all members of the team, the psychological and ethical problems of the patients or their family, 4) support of hospital staff with their suffering either as individual support, either as debriefing or regular meetings, 5) Resort to specialized structures such as palliative care units, pain units, specialized in dying patients. This model was published by Health Ministry in February 2002. A more detailed circular has just been published on next June. This model could be generalized in other countries.

Palliative care policy development in Hungary 1991–2005
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Objectives In Hungary hospice groups provide palliative care for cancer patients since 1991. Though Hungary leads WHO cancer death statistics and death and dying belongs to the taboo topics palliative care is not recognised in the country. 80% of the people die in poor conditioned hospitals without an adequate symptom control. Legal background was inefficient for palliative hospital. It was provided mainly by NGOs that constantly need to raise funds, while the National Health Insurance Fund made only limited contribution. Methods From 1996 a palliative care policy was developed to improve the attention on dying people and hospice awareness increased enormously. An interpellation in the parliament raised the awareness and hospice approach was supported by the government. A policy conference was organised in 2004 for the integration of palliative care into the national health services. Due to an active lobby of the past years the National Insurance Fund and the Ministry of Health strongly contributed to create legal and financial background for palliative care. Results In 2004 a new national strategy and a demonstration project was created. Minimum standards and the hospice code serves as a legal background for the care. A two year pilot model extends palliative care in the whole country. The conference made recommendations for the next five years to make palliative care an integrate part of national health services available for all types of patients. A national body, the National Palliative Council is to be set up in 2005 with delegates of policy makers, health authorities, universities and palliative care providers. In Hungary a palliative national plan for the next five years. Conclusion We hope that palliative care policy development will lead to provision of palliative care services available for half of those in need with a 70% covering from NHS by 2009.

Pharmacist prescribing exploring new territories in Palliative Care
Margaret Hook, St. Peter’s Hospice, Bristol, GREAT BRITAIN

The health service in the United Kingdom is moving towards increasing the roles of healthcare professionals. Prescribing has been the domain of doctors and dentists for many years. The extension of prescribing to include other healthcare professionals is a key part of the government’s agenda to modernise the National Health Service (NHS). It is part of their plan to design the NHS around the needs of the patient. There are now two categories of prescribers: a) independent prescribers,a doctor or dentist, are responsible for the initial patient assessment and deciding a treatment plan. b) Supplementary prescribers, a registered nurse, registered midwife or registered pharmacist are authorised to prescribe for patients whose condition had been diagnosed or assessed by an independent prescriber. Their prescribing is within an agreed clinical management plan. Qualifying as a supplementary prescribing pharmacist has extended the care I can provide patients but the challenge is to introduce the new way of working in the palliative care setting to improve patient experience and strengthen the clinical team. Palliative care should embrace this change and find new ways of working to maximise expertise. My story helps to start the debate and covers the following questions:
● Who should become supplementary prescribers?
● Is it worth the effort for the individual and the organisation?
● What are the implications?
● What are the benefits?

REGIONAL AND INTER-TEAM VARIATIONS IN THE USE OF PALLIATIVE CARE CONSULTATION IN THE MID-EASTERN PART OF THE CERMEDIX
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Background: Palliative care teams are relatively new in the Netherlands. They are directed to caregivers working in all sectors of health care: general practise, homecare, hospitals, nursing and elderly homes, hospices. Their main task is to advise and support primary caregivers. In the mid-eastern part of the Netherlands, four palliative care teams are active, each in his own local network / region. They are connected to and supported by the Comprehensive Cancer Centre East. In this study, regional and inter-team variations in use of palliative care consultation was evaluated. Methods: Information concerning patients who were registered on a registration form developed by the Dutch Association of Comprehensive Cancer Centres (VIBC). Results: In the first six months of 2004, 7.5% of all patients were registered. Per team 109 to 326 consultations. 74% of all consultations came from general practitioners, whereas 31% came from hospital caregivers. These data varied considerably between teams: from 23% to 78% for general practitioners and from 3% to 64% for hospital caregivers. Almost ninety percent of all patients were diagnosed with cancer, almost 3% had a heart failure, 3% a neurological disorder. Almost 60% of all patients were at home during the consultation, 19% stayed in hospital, 4% in a hospice and 6% in a nursing or elderly home. These numbers differed between teams, for example in one team 90% of all patients stayed at home and in another team 60% of patients were hospitalised. The number of patients was 65 in all teams. Conclusion: Variation in characteristics of consultations between local consultation teams and regions may be explained by different diseases, stages and origins of the teams. More streamlining of the working processes of the teams is necessary to assure that each caregiver (and thereby each patient) can account on the same kind of support from specialised teams in each local region.
of these answers to sex, age, occupation and faith will be presented in detail at the Congress. Conclusion: In the country where palliative care is reimbursed by the social security system for terminally ill cancer patients and where there are no services specialized for this care, the medical staff opinion concerning the place where the patient should spend the last days of life can be used for planning this kind of services. Key words: Palliative cancer care, settings and services, terminal care.

Abstract number: 522
Presentation type: Poster
Poster number: P103
The integrated development of the complex hospice–palliative care in inpatient and home care in Hungary – The pilot program of the National Health Insurance Fund

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Obj:In May 2004 the National Health Insurance Fund (NHIF) in conjunction with the Ministry of Health and the Ministry of Finance after consultations with the professional associations invited applications for the integrated development of the complex hospice–palliative care. This tender was the first step of a two-year pilot program. The pilot program started in September 2004 in order to expand this essential provision form in Hungary. Meth: The accepted candidates both home care providers and hospitals obtain an additional reimbursement for the hospice–palliative care. The hospice–palliative care providers have to meet special professional and contractual requirements: elaborated professional and financial plans, references, infrastructural, personal and mental conditions and quality management. The main elements of the monitoring are the professional and operational indicator-system, bimannual reports and process control. The NHIF stipulated the integrated form of the provision: in-patient and home care providers had to operate in intensive cooperation with each other. Res: The NHIF determined the limits of the so-called hospice-days for the home care providers and the number of hospice-beds for hospital patients. The hospitals had to convert operating beds into hospice-beds because this pilot program has close connection with the aim of the restructuring of hospice-beds. The findings and analysis presented here aim to stimulate the development, the improvement of the structures, user and service profiles and performance of hospice–palliative care in Hungary.

Abstract number: 524
Presentation type: Poster
Poster number: P105
Forlì Palliative Care Unit: report of the first year’s activity

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The Palliative Care Unit of the Department of Medical Oncology of Pierantoni Hospital in Forlì runs the palliative care network comprising Home Care Service, Day Hospital and Valerio Care Home. The Hospice began operating in October 2002 and has 10 in-patient facilities. It is seen as a trait d’union between hospital and district services for the clinical and organizational management of terminally ill cancer patients. In the first 12 months of its activity (1/1/2003–31/12/2003), the hospice registered 312 admissions for a total of 247 patients hospitalized. Of them 53% (130) were males and 47% (117) were females. Median age was 68 years (range 27–96 years). 42% (132) of patients were admitted from home, 24% (75) were referred from the Department of Oncology, 29% (90) came from other hospital departments, and 5% (15) arrived from private, residential or long-term clinics. The Health and Social Services used were 82% (255) of them. Palliative Care, 17% (52) SSS in the region of Emilia-Romagna (ER), and 1% (5) outside the region. The mean number of hospitalizations days was 12, and of 312 hospice discharges, 36% of patients went home and 22% were referred to other health professionals.

Abstract number: 526
Presentation type: Poster
Poster number: P107
Home Care for the Dying – Results of an exploratory study in NRW / Germany

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This presentation reports on a three year evaluation study completed in March 2003 investigating the structures, user and service profiles and performance of 16 palliative nursing home care services in North-Rhine Westfalia, Germany. After outlining the scope and design of the study, the presentation focuses on the user and service profiles and performance documented within this study, questioning how palliative nursing home care services are designed for patients in North-Rhine Westfalia. The findings and analysis presented here aim to provide an insight view of the current situation of palliative nursing home care services, the organizational obstacles which they need to overcome and the complex dynamics at play in working with the (potential) users demands. Challenges are highlighted in the hope, that understanding of the palliative nursing home care services face is increased and appropriate action is taken to develop services which are both efficient and designed to meet the needs of the Dying and their families.
Abstract number: 527
Presentation type: Poster
Poster number: P108

Quality of life after radical cystectomy: An evidence-based analysis of published reports

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It has been assumed that new methods for urinary tract reconstruction (continent cutaneous diversion; CUD and orthotopic bladder substitution; OBS) are superior to the standard ileal conduit (IC) in improving quality of life after cystectomy for bladder cancer. Objective: The aim was to critically examine published reports to find out if there is any evidence that CUD and OBS provide better quality of life than IC. Method: A Medline search using the terms ‘bladder cancer’, ‘cystectomy’, ‘urinary diversion’ and ‘quality of life’ was performed. Retrieved publications were assigned levels of evidence according to the system proposed by NICE (National Institute for Clinical Excellence) in UK based upon study design (prospective, retrospective), number of patients enrolled, if the cohort consisted of all patients available or not, type of assessment tool and its psychometric properties, Respectively. Twenty-nine studies met the criteria. Many of them had urologists only as authors. Only 3 studies were prospective, comparing all three methods of reconstruction. In 9 studies ad hoc questionnaires were used. There was no randomized controlled trial. Three studies met the criteria for level 2 evidence, the rest being level 3 evidence. 5 studies which compared OBS and IC, only one, a retrospective study, showed superiority for OBS. No differences were found in the other studies and this was true also for the 9 studies which compared CUD and IC. The 5 studies comparing OBS, CUD and IC and the 3 studies which compared OBS and CUD. Conclusion: The scientific quality of the published literature on quality of life after radical cystectomy is rather low and flaws in patient selection and methodology are common. Published evidence does not support advantage of one type of reconstruction over the others with regard to quality of life.

Abstract number: 528
Presentation type: Poster
Poster number: P109

Individual quality of life evaluation in palliative care: experience with the SEIQoL-DW

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A complete Quality of Life (QoL) evaluation in terminally ill patients should include an assessment which respects the personal values of each individual, without imposing a system of values predetermined externally. SEIQoL-DW is an instrument to evaluate individual QoL, developing these guidelines, and measure how the patient is able to manage the important areas of his life, which he himself has defined. We used an Italian version of the SEIQoL-DW, in a sample of 24 advanced cancer patients (10 males, 14 females), aged between 37 and 82, with an average K.P.S. of 66.2 (min.30, max.90). 54.1% of the patients were in therapy with strong opioids. 22 patients were able to identify all the areas of the QoL: the average time of administration of the instrument was 27 minutes (min.10, max. 70). The patients identified as most important subject matters correlated to the QoL, which were grouped into 7 general areas. For each area, the average level of functioning, the average weight and the product of the functioning multiplied by the weight were calculated. The weights assigned and the levels of functioning are referred to a scale from 0 to 100. These data give an indication of the impact of each area on the overall quality of life of the patients: the higher the product, the higher the contribution of that area is in improving the quality of life. The area which seems to have the highest impact on the quality of life is the one related to the communication aspects. The psychometry data indicates that the patients were good judges of their own QoL and that their judgements were reliable. Basing on a biometric model of illness, it is often assumed that the QoL inevitably worsens by degrees as the end approaches; in our study, despite the fact that the patients were in the terminal phase of their life and aware of being so, many patients showed a good QoL. The individual evaluation of the patients’ QoL must take on a greater importance in palliative care.

Abstract number: 529
Presentation type: Poster
Poster number: P110

Physical and psycho-social problems in female breast cancer survivors: Focus on chronic/long-term pain. An epidemiological study

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Recent research found a considerable high prevalence of chronic/long-term pain following breast cancer surgery, ranging between 12.7% and 65%. However, to our knowledge there are no representative epidemiological studies that have identified prevalence rates of chronic pain and associated conditions in breast cancer survivors. Aim of the study: The aims of the study are to epidemiologically investigate chronic pain and associated physical and psychosocial conditions in a representative population of female breast cancer survivors at least five years after breast cancer surgery. Methods: 2000 women at the age of 18 years or older who have survived breast cancer surgery for at least five years have been included. Prevalence rates of chronic pain and psychosocial complications will be determined through questionnaires and compared to a sociodemographically matching Danish female population obtained through the 2000 Danish Health and Morbidity Survey. Hypothesis: Women who have survived breast cancer surgery for at least 5 years experience a higher prevalence of long-term/chronic pain, reduced work ability and daily function as well as self-rated health as compared to a sociodemographically matching Danish female population. Status of the study / September 2004: 10,462 women met the inclusion criteria out of which 2000 have been selected and randomly sampled as described. Participants will be contacted shortly in order to obtain informed consent. As soon as informed consent is obtained, participants will receive the questionnaires. The project is financially supported by the Danish Cancer Society.

Abstract number: 530
Presentation type: Poster
Poster number: P111

The Lifelines Project – a multi-professional approach to creative care and communication which can promote quality of life in palliative care


Clinical governance in specialist palliative care involves a number of processes, which can measure the effectiveness of the patient experience. One of the goals of care is to achieve the best quality of life for people with life-threatening illnesses. Quality of life is easy to say, hard to define and difficult to evaluate or research with rigour within the modern healthcare. Modern medicine has increased life expectancy for many people with a life-limiting illness but does living longer on its own contribute to the individual’s quality of life? Putting life into days rather than just days into life – ‘releasing the creative spirit’ marked the start of the Lifelines Project, a collaboration between palliative care staff, users, a theatre company, and R & D Department at Salisbury Hospital. The setting up of the project was presented at the EAPC 6th Annual Congress. Evaluation of the first three years has led to the development of a toolkit for introducing and sustaining creative arts activities. The next phase of the Lifelines Project relates to implementation of the Supportive and Palliative Care IOG (2004). It will produce a professional video of The Great Escape to use as an advanced communication skills training tool for health care professionals. It is also due to deliver a two year training programme of interactive drama to a network of hospices and provide an annual forum for participants in the project and other interested parties to share learning and experiences. Crucially, it will be supported by an independent researcher to measure the impact of creative care on the patient experience. Progress on this project will be included in the presentation.
patients at various stages of disease and treatment inconsistencies. Aims of this study were to identify and better understand relevant issues affecting the management of nutrition in advanced cancer and palliative care patients by exploring the views of health care professionals working in this specialist field. Method Mixed qualitative and quantitative methods used consisting of a focus group and in-depth interviews to collect information from clinical nurse specialists, dietitians, consultants in oncology/hematology and GPs. Discussion The poster will report on the key issues emerging from this study including health professionals’ levels of awareness of nutrition intervention and care; how health professionals differed in the relative importance they placed nutrition. The study suggests this is influenced by: awareness of evidence to support nutrition interventions in palliative care particularly rehabilitation strategies understanding roles of other health professionals including dietitians and their contribution to multidisciplinary teams protocols that are effective in identifying patients at risk of malnutrition given by health professionals to manage the needs of patients and their carers, managing psychosocial symptoms regardless of physiological improvement. These issues give rise to many implications at a local level to influence professionals’ decisions so that more timely and appropriate nutrition strategies may occur.

Abstract number: P113
Presentation type: Poster
Poster number: P113

An analysis of palliative rehabilitation needs in Chiba Cancer Centre

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Introduction: We study the impact of palliative cancer rehabilitation which we have experienced for nine years at Chiba Cancer Centre have largely focused on the reviews and interpretations of needs analysis as an example of Japanese situation about palliative rehabilitation of the cancer patients. Method: Subjects: were analysed statistically. We gather 900 cases of M and F, 500 cases of Mar 2003. Results: There were needs of palliative cancer rehabilitation in Chiba Cancer Centre. 51% of the rehabilitation goals were some kind of walking, 41% increasing activities of daily living including transfer technique and 10% psychological support for the patients and 15% others. Conclusion: We understand there were needs of palliative rehabilitation in a cancer center in Japan. We should expand the result of our studies into our country. When this information spread over the country, many patients would have more comfortable quality of life in their last times.

Abstract number: P114
Presentation type: Poster
Poster number: P114

FACIAL MASSAGE RELAXATION FOR CANCER PATIENTS

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Introduction Patients with cancer often suffer from a loss in quality of life. In combination with the regularly standard therapy, complementary care could increase the well-being. This study aims to determine the effects of facial massage relaxation (FMR) on the quality of life of patients with cancer, and to compare the differences between patients from in- and out-patient units of a cancer clinic. Methods The study has been carried out at an out-patient Chemotherapy Unit and two clinical units, Radiotherapy and Palliative Care and Symptom Control Unit. The study is a randomised-controlled trial with a control group receiving no FMR and an experimental group receiving two treatments of FMR. Patients from both groups completed a pre- and after measurement questionnaire about QoL. The questionnaires were composed of standardised instruments measuring several aspects of QoL, and the physical and mental state. Nurses of the unit completed the biographical and medical data. Results At both clinical units together, 32 patients were included in the control as well as the experimental group. At the out-patient unit 18 patients were included in the control and 20 in the experimental group. Both questionnaires were completed by 49 hospitalised patients (77%; 23 control/26 experimental) and 30 out-patients (80%; 13 control/17 experimental). The FMR has been appreciated by the participants, as indicated by the school mark of 8.5 (range 1–10). Variance analysis shows that the experimental out-patient group decreased in angry feelings. On the clinical units pain is decreased more in the experimental group and they perceived their joy of life retrospectively to be improved. Conclusions FMR is highly appreciated by cancer patients. It improves the QoL of hospitalised patients with regard to pain and joy of life, and decreases feelings of anger for the out-patients.

Abstract number: P115
Presentation type: Poster
Poster number: P115

A Multiprofessional Approach to The Management of Cancer Related Fatigue

Anne Finn, Palliative Care Team, Belfast, GREAT BRITAIN

Introduction: Cancer related fatigue (CRF) is a general weakness combined with mental or physical fatigue which can occur as a result of the cancer or the cancer treatments (Sheehan, 1997). It is a new universal symptom, which many patients perceive as the most distressing cancer symptom. Research now supports a non-pharmacological approach to symptom management encompassing exercise, lifestyle pacing etc. This multiprofessional approach is not routinely available. Method: An institutional needs assessment reflected an urgent need to address fatigue management, specifically in the oncology/haematology directorate. This necessitated the formation of a multiprofessional group of clinicians whose aim was to design, pilot and initiate a holistic programme of care. Results: To date, the group has produced objectives, standards and a screening and treatment care pathway. To raise awareness, an educational package has been developed which includes patient information and guidance, posters and booklets, formal staff education and an awareness project launch. Discussion: Feedback from the group has been submitted to provide the resources required to take the project forward. The group was also one of the three finalists in the Roche Oncology Project of the Year 2003 (MEANDER, AWARD FOR DISTINGUISHED CANCER CARE). The commitment and drive of the group has resulted in backing from the All Ireland Fatigue Coalition (AIFC), whose remit is to champion the proactive management of CRF. The skills of each profession have been utilised and coordinated to provide effective screening and treatment, which demonstrates true holistic service provision. Conclusion: Institutional management of CRF is minimal at present (Miller and Kearney, 2002), however this research based multiprofessional service development will facilitate the management of this distressing and debilitating symptom. The AIFC has identified this project as a unique initiative in cancer management.

Abstract number: P116
Presentation type: Poster
Poster number: P116

THE INFLUENCE ONCOLOGICAL THERAPY FOR QUALITY OF LIFE FOR PATIENTS WITH CERVICAL AND OVARIAN CANCER

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INTRODUCTION & OBJECTIVES: Measuring quality of life in patients (pts) with gynaecological cancer (GC) has a great importance. The level of pts quality of life depends not only on physical status, but other factors play important role like coping mechanisms, self-respect, family relations, support from friends and medical staff, meaning of life and spiritual values. MATERIAL & METHODS: This paper assess QOL for 33 pts with GC (23 ovarian cancer – group A and 10 with cervical cancer – group B) before, during and after oncological therapy, treated in University Hospital in Wroclaw. In Group A, all pts undergoing surgery and chemotherapy (CHT), in group B all pts were after brachytherapy, 20% of them undergone CHT and 90% surgery. Assessment was made using the Rotterdam Symptom Checklist, Edmonton Symptom Assessment System, Depression Zung Scale and the new questionnaire invented by authors. Results: Pts during and after CHT reported worse QOL then pts during and after brachytherapy. The QOL in the grope A (ovarian cancer) was generally lower then for the group B. During the treatment pts depression is increased. Cancer impacts financial status of the pts and the family. Most frequent psychological symptoms were: anxiety, depression, tension and worry. Most frequent physical symptoms were: fatigue, loss of energy, sleeps problems, constipation and abdominal pain. Conclusions: Cancer decreases QOL in pts with GC. Cooperation with family members could scientifically improve quality of care. Many psychological and emotional problems during the treatment could be avoided by involving psychologist in treatment process.

Abstract number: P117
Presentation type: Poster
Poster number: P117

Living with localised or local advanced prostate cancer

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Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005
The study focuses on men living with prostate cancer where curative treatment as surgery or radiation therapy is not an option due to the advanced stage, high age, poor performance status or other causes. The aim of the study is to illuminate their experience of getting the cancer diagnosis, information given by healthcare providers and how they follow up regimes either at out-patient services or at their GP meets their needs. Method. Ten men were interviewed 3 to 36 months (median 9.5 months) after they were diagnosed. The interviews were tape-recorded, transcribed into text and analyzed using a phenomenological-hermeneutic approach inspired by Ricoeur’s philosophy. The patients’ medical journals were studied in order to find what information they and their GPs where giving regarding their disease and treatment. Results. The disease was described as a threat to their lives. Both the disease and the treatment gave sexual and urinary problems that could be perceived as threatening to their manhood. They described ambivalence in how to handle the new situation in their lives, e.g. with openness or by keeping it to themselves. Despite good information at the time of diagnosis they had many question after discharge to home. They felt alone, and because contact with the health care system was limited many had difficulties getting information and help regarding communication with their family, sexuality etc. Conclusion. The health care services should pay attention to individual needs for information, and to facilitate conversing conversation and counseling about the disease, treatment, side effects and the prognosis. Spouses are often the closest every day support and should be involved at an early stage. It also seems important to improve patient organisation and to establish a special nursing service.

Abstract number: 537
Presentation type: Poster
Poster number: P118

The Significance of Celebration of Life Boxes in Day Therapy
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Aim To give patients opportunity to reflect on their own story, explain the impact the security, significance & self worth. Introducing Volunteers and staff at the hospice provide extensive pre-bereavement support to the patients. When a patient dies, it has a profound effect on the other patients, volunteers and staff. In view of this, it was decided that we needed to openly explore the feelings of the other patients and also reflect on that person’s life. Our concern is whether or not we have provided the opportunity for dying patients to also celebrate and/or reflect on their own life. Method The Paternal is given an introductory letter giving ideas they may be able to use to start off their own project. This is followed by a discussion with their key worker who assesses their thoughts around this subject. Centre to this discussion is the alleviation of any fears or misconceptions, reinforcing the positive aspects. They then choose what format e.g. books/box/photo-album etc. and then they begin to personalise it. Results Since the start of the project six patients have completed their own Celebration of Life. This has varied from scrapbook to C.D., malignant wound. Patients have chosen to produce ‘one-off’ pieces of work such as paintings or cards/letters that have particular significance for them. Conclusion The project has provided opportunities for dying patients to reflect on their lives in a meaningful manner. It has also helped them to feel able to enter the final stage of their life with a feeling of resolution. This has also helped assist the grieving relative/carer in coming to terms with the patients’ death.

Abstract number: 538
Presentation type: Poster
Poster number: P119

Health Related Quality of Life (HRQOL) of patients with cancer and a reference population in different age groups
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Object of the study HRQOL is increasingly important for (cancer) patients as many patients live longer with their disease. The aim of this part of the study was to compare HRQOL of different age groups of cancer patients with the different age groups of a reference population from the general population. Methods The Rand-36 questionnaire (a Dutch version of the SF-36) was used. Patients (6–24 months after diagnosis, age older than 18 yrs, no carcinoma in situ) were randomly selected from the population based cancer registration of our institute. Response rate was 47%(N=2885). In the reference population study 1063 people were included. Summarized results In older age-groups of cancer patients (65–74 yrs and 73–84 yrs) there was no difference in HRQOL compared to the same age groups of the reference population. In younger age-groups significant differences were found for functional status and general health evaluation but not for mental health. Conclusion: The influence of cancer on HRQOL is related to age. In our study population above the age of 65 years we did not find a difference in HRQOL between cancer patients and a reference population. This means that to improve HRQOL, which groups concentration should be on treating or relieving the effects of the cancer diagnosis and treatment. In older age groups probably HRQOL is not so much depending on an own cancer diagnosis and treatment of cancer. This implies probably that aspects of all the different diseases and their effects on the life of the patient should be taken into consideration in an effort to achieve improvement of HRQOL.

Abstract number: 539
Presentation type: Poster
Poster number: P120

A Phenomenological Study into the impact on the life of a patient with a fungating wound
Diane Laverty, Palliative Care, London, GREAT BRITAIN

Using an interpretative approach within the framework of hermeneutic phenomenology, the aim of this study was to gain an understanding of the views, perceptions and impact on the life of an individual with a fungating wound. Six patients with advanced cancer participated in an individual, unstructured interview with the researcher where they shared their experiences. As part of the findings the researcher completed a reflective diary throughout the course of the study. This formed an integral part of the analytic process. The emerging themes clearly demonstrated the peaks and troughs of adapting to the cancer diagnosis, living their life with cancer and its associated treatments and life changes and then the emergence of their fungating wound which was a continual visual reminder of their cancer and its progression. Through each stage of the wound’s extension the participants referred to the process of adapting to the changing boundaries that their wound imposed on them and the consequent alterations they needed to make to their life. Each stage of adaptation became more difficult, and often more lengthy, due to the implications this presented in the way of possible impending death. This process has been likened to a rollercoaster ride with its peaks and troughs and associated emotions. The results of this study will inform and influence delivery of care to this vulnerable group of patients.

Abstract number: 540
Presentation type: Poster
Poster number: P121

Psychiatric disorders in a Palliative Care Unit

Objective: To evaluate the frequency of psychiatric disorders in 50 impatient sample at the Palliative Care Center of the National Cancer Institute(INCA). Method: We select 50 subsequent subjects referred to the impatient unit. Psychiatric diagnoses was assessed with the version 4.4 of the Mini-International Neuropsychiatric Interview (MINI), a short structured questionnaire designed to explore each of the necessary criteria for the main diagnoses of DSM-IV, Axis I (Americcan Psychiatric Association). The parameters for exclusion was coma, mental confusion or any incapacity to understand and anwer the questionnaire. Results: From the overall sample of 54 patients, four were excluded due difficulties in understand the standard instrument used (MINI). The sample was composed by 28 women(56%) and 22 men(44%). The mean age was 53.6(Sd 13.3) years. Twenty-three patients (46%) of the total met the criteria for at least one diagnosis. The most common diagnoses explored by the MINI. The frequency of major depression was 32% (n=16), generalized anxiety 14% (n=6), panic disorder 6% (n=3), agoraphobia 6% (n=3), alcohol abuse 4% (n=2), bulimia 4% (n=2), suicidal ideation 4% (n=2), manic episode 2% (n=1), obsessive-compulsive disorders 2% (n=1), somatization 2% and psychotic syndromes 2%. Seven patients (14%) fulfilled more than one diagnoses. No patient met the criteria for adjustment disorder. Conclusion: Comorbid psychiatric disorders are clinically significant in palliative care patients, and may alter symptom control strategies as well worsening the patient’s quality of life, mostly if underdiagnosticated and treated. Clinical Staff in Palliative Care must be aware and prepared for psychiatric diagnoses in their daily practice.
PALLIATIVE CARE AND PSYCHOPHARMACOLOGY: MORPHINE IN PATIENTS ADVANCED CANCER – ASSESSMENT OF COGNITIVE EFFECTS


Aims: To assess acute effects on everyday cognitive requirements of immediate release morphine in patients on stable doses of long acting opioids. Method: A double blind cross over study: 14 patients randomly allocated to treatment order tested on 2 days no less than 7 days apart. Morphine dose individually calculated as usual breakthrough dose; same percentage increase in all patients. Patients completed cognitive assessments just before then 45 minutes after single oral dose of morphine. Obtain test battery: assessments of cognitive function (e.g. spot the word, speed of comprehension, prose recall, map location, digit span, speed of processing), of alertness and psychological pain and mood. Analysis: Repeated measures ANOVA using SPSS. Results: No significant interactions for mood factors. Despite not complaining of pain pre test dose, pain relief following test dose morphine was significantly greater than placebo (t (13)=2.38, p=0.033). Immediate recall of prose showed a trend towards interaction between condition and time (F(1,13)=4.566, p=0.037). Immediate recall of pre-treatment story unaltered but recall of post-treatment story poorer after morphine than placebo. Delayed recall of prose showed a highly significant effect of treatment but not time. In individual comparisons morphine significantly impaired recall of the pre-drug story [F(1,13)=6.528, p=0.024] and the story presented post morphine [F(1,13)=13.012, p=0.003]. No significant effects on verbal fluency, everyday attention (map and telephone searches). Befian’s trails tests for psychomotor speed and conceptual flexibility showed significant improvement after acute morphine. Conclusion: Acute short acting morphine has a significant impairment after acute morphine. Delayed recall of prose showed a highly significant effect of treatment.

Abstract number: 542 Presentation type: Poster Poster number: P123

Nurses’ views on their involvement in euthanasia: a qualitative study in Flanders (Belgium)

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Background: Although nurses worldwide are confronted with euthanasia requests from patients, the views of palliative care nurses on their involvement in the care process surrounding euthanasia remain unclear. Objectives: In-depth exploration of the views of palliative care nurses on their involvement in the care process surrounding euthanasia. Methods: A qualitative Grounded Theory strategy was used. In anticipation of new Belgian legislation on euthanasia, we conducted semi-structured interviews with 12 nurses working in a palliative care setting in the province of Vlaams-Brabant (Belgium). Results: Palliative care nurses unanimously asserted that they have an important role in the process of caring for a patient with a euthanasia request, a role that is by no means limited to assisting the physician when he/she is administering life-terminating drugs. Nurses’ involvement starts at the moment the patient expresses a euthanasia request and ends with supporting the patient’s relatives and friends. Colleagues after the potential life-terminating act. Nurses stressed the importance of having an open mind and of using palliative techniques in dealing with a euthanasia request, as well participating in decision-making regarding euthanasia. Concerning the actual act of performing euthanasia, palliative care nurses saw their role primarily as assisting the patient, the patient’s family, and the physician by being present, even if they could not reconcile themselves with actually carrying euthanasia. Conclusions: Based on their professional nursing expertise and unique relationship with the patient, nurses participating as full members of the interdisciplinary expert team are in a key position to provide valuable care to patients with a euthanasia request.

Abstract number: 543 Presentation type: Poster Poster number: P124

ASSESSMENT OF NALTREXONE ANTAGONISM OF BUPRENORPHINE


Background: buprenorphine (BUP), a semi-synthetic opioid, is used as an analgesic in patients, the type of more frequent tumors in a palliative patient population. So, we considered the objective to present scores below the median Various hypotheses accounting for this difference will be commented on.

Abstract number: 545 Presentation type: Poster Poster number: P126

EPIDEMIOLOGIC STUDY OF THE HISTOLOGIC TYPE OF TUMOR OF A POPULATION OF 2539 PATIENTS FROM THE CUDECA FOUNDATION PROGRAM OF PALLIATIVE CARE

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OBJECTIVES: There are very few studies in the literature, with a significant number of patients (pts), that analyze the histologic type of more frequent tumors in a palliative patient population. So, we considered the objective to analyze in our database, that includes 2539 patients, the type of more frequent tumors. METHODS: The data of 2539 pts were processed with the statistical program SPSS 11.0. The differences in morbidity between the different histologic types of tumors were assessed by the Chi-square test. RESULTS: The most frequent histologic type of tumors were: lung cancer: 626 pts (24.6%), Colorectal cancer: 330 pts (13%), Head and Neck cancer: 259 pts (10.2%), Breast cancer: 208 pts (8.2%), Thyroid and Parathyroid Cancers: 25 pts (1%).
Pancreatic Cancer: 86 pts (3.4%), Esophageal Cancer: 52 pts (2%), Gastric Cancer: 148 pts (5.8%), Prostate Cancer: 122 pts (4.8%), Urothelial and Kidney Cancer: 129 pts (5.1%), Ovarian Cancer: 158 pts (6.2%), Melanoma and Other Skin Cancers: 48 pts (1.9%), Soft-tissue Sarcomas: 21 pts (0.8%), Acute Leukemias: 2 pts (0.1%), Carcinoma of Unknown Primary Site: 119 pts (4.7%). Conclusions: Lung cancer was the most frequent cancer with a 24%. Followed by the colorectal cancer with a 14%, and head and neck tumors with a 10%. The data of high frequency of lung cancer correlates well with the data described in the literature, since Lung cancer is the most frequent cancer due to high tobacco consumption. In our population there is a high frequency of head and neck tumors, in possible relation to the tobacco and alcohol consumption.

Abstract number: 546
Presentation type: Poster
Poster number: P128

Bereavement research: towards to common understanding of methodological and ethical issues
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Background: It is widely recognised that research involving bereaved people and services for them raises complex methodological and ethical concerns. Such research is usually defined as 'sensitive research'. Aims: This paper considers the sensitive nature of bereavement research and the sensibilities of 'gatekeepers' - ethical review boards, professionals and organisations working with bereaved people – in allowing research access to bereavement support services and the people using them. We draw upon our current experiences of conducting in-depth organisational case studies in five UK adult hospice based bereavement support services. Research design: Five in-depth organisational case studies of adult bereavement services in England. Data were collected from bereaved people (n=87), bereavement support workers (n=115), using focus groups and interviews. We encountered a number of methodological and ethical issues in conducting this research: Discussion 1. defining what constitutes a bereavement support service 2. defining when bereavement support begins 3. recruiting bereaved people and determining those who do or do not use services 4. observing actual support sessions, especially one-to-one bereavement support or counselling 5. obtaining informed consent 6. providing appropriate support for bereaved people and the researchers Conclusion: The paper suggests strategies for researchers which balances the need to protect vulnerable people with the requirements for gaining access and recruiting people in an ethically sensitive way.

Abstract number: 547
Presentation type: Poster
Poster number: P130

RESEARCHING PALLIATIVE CARE DEVELOPMENT IN RESOURCE POOR SETTINGS
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Aims: The International Observatory on End of Life Care aims to promote comparitive, research-based information on palliative care development in the international context. Projects are currently being undertaken in Eastern Europe and Central Asia; Africa; India; and the Middle East. In many resource poor regions, access to information about palliative care services may be problematic due to: uneven communications; patchy record-keeping; indigenous and Western health care systems operating in tandem; varying definitions of palliative care. Methods: The Observatory adopts a spectrum of methods to access a broad range of sources. We have developed a) criteria for service identification; b) a template for comparing epidemiological, demographic and health systems data across countries c) a structure for in-depth qualitative interviews; d) a review method for published sources; grey literature e) a template for individual country reports f) a country database of palliative care services and educational programmes g) case study analysis of palliative care success stories h) an international network of collaborating colleagues i) a system for validation of findings j) a website for dissemination (www.eolc-observatory.net). Results: Reports have so far been generated for a total of 5.3 countries. We have made cross-country comparisons on the following dimensions: types and numbers of palliative care services and workforce capacity; national and professional organisations; education and training; opioid availability; case studies and ‘success stories’; public health and health care system context; ethical themes. Discussion: In global and resource poor contexts, multi method and interdisciplinary approaches are essential if we are to generate accurate data and worthwhile analysis. Conclusion: The research methodology adopted by the Observatory provides flexible, comprehensive and valid ways to review palliative care services across countries.

Abstract number: 548
Presentation type: Poster
Poster number: P131

The role and training needs of Occupational Therapists working in specialist palliative care in the UK.
Mark Hall, Specialist Palliative Care Team, Denbigh, GREAT BRITAIN

Introduction: Occupational Therapy posts have, in recent years, increased in specialist palliative care services (SPCS) in the UK. Current government recommendations on the role of the Occupational Therapist (OT) in these services. Given this and the lack of any previous research in charting OTs in SPCS in the UK, this study had a timely contribution. Objectives: What is the extent of OTs’ team membership SPCs? What is their level of teaching, training and research involvement in palliative care services and links with regional cancer networks? Method: A multi-centre study using a descriptive survey methodology. A postal questionnaire was sent to 369 OTs nationwide – all members of a national specialist interest group of OTs working in palliative care. The response rate was 73%. Results: SPCs have seen an increase in Occupational Therapy input but many of these are insufficient; only 22% stated they are employed full-time within SPCs. Many others have split clinical roles, frequently with great input to SPCs – though no formal membership. It is perceived that multi-disciplinary team colleagues have a poor understanding of Occupational Therapy and its rehabilitative role in palliative care. Conclusion: Of a postgraduate training pathway, there is a failure in gaining clinical specialist status. OTs have a poor presence on cancer networks and are often, instead, representatives of clinical pressures, lone working and part-time employment are contributing factors for little time or interest in performing teaching and research. Conclusion: OTs need increased, strategic presence on regional cancer networks. SPCs are asked to review their Occupational Therapy provision and employ designated OTs. Occupational Therapy colleges/governing bodies need to introduce palliative care training pathways at under- and postgraduate levels.

Abstract number: 549
Presentation type: Poster
Poster number: P132

PROVISION OF PALLIATIVE CARE: INTERFACE OF LUNG CANCER AND PALLIATIVE CARE SERVICES
Stephanie Gomm, Hospital Palliative Care Team, Salford, GREAT BRITAIN, Zenia Kasim, Hospital Palliative Care Team, Salford, GREAT BRITAIN

Background: 75% of lung cancer patients will be treated by palliative intervention only, requiring timely access to Specialist Palliative Care (SPC). The role and interface of these multi-disciplinary teams (MDTs) was assessed in their provision of palliative care by postal questionnaire. Method: Questionnaires were completed by lung cancer and palliative care practitioners from 15 Lung Cancer Units across a Cancer Network (popn.3,200,000) in NW England. Manpower, roles, referral criteria, MDT working and database information on palliative care were collated. Results: 62% (42/68) response rate. Most of units identified a Lead Lung Cancer Physician, but only 9 had input from a Palliative Care Consultant; 28 Lung Cancer Nurse Specialists (LCNS) and 34 Hospital Palliative Care Nurse Specialists (HPCNS). One site had no LCNS. 60% of units provided palliative care only within the Cancer Network. LCNS/ HPCNs only referred criteria between teams. LCNS/ HPCNs employed full-time within SPCS. Many others are insufficient. All sites had formal referral criteria, but 20% had no formal pathway. Clinical liaison occurred in two thirds, but < 50% within MDT meetings. Database information on referrals to palliative care by lung cancer teams was limited. Significant community support was provided by LCNS. Communication between teams is paramount for seamless care requiring expansion of lung cancer and palliative care workforce.

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Resilience, hardness, and coping in palliative care: a qualitative study of nurses’ experiences of work

Janice Ablett, Division of Clinical Psychology, Liverpool, GREAT BRITAIN

Recently there has been increased recognition of the stress that affects healthcare professionals. High levels of stress and depression have been found in NHS staff. This has an impact on individual and organisational levels. Yet, working in a stressful job does not inevitably lead to physical illness or psychological distress. In addition to organisational variables, it is highly likely that interpersonal factors have a significant role in moderating the effects of stress. This has led to attempts to identify factors that buffer the effects of stress and promote resilience. One such buffer is the concept of hardness, which is thought to be important in influencing how people cope with stressful life circumstances. In palliative care settings, levels of stress have been found to be lower than in many other healthcare settings, although significant numbers of staff do still experience psychological distress. Again, personality variables in palliative care staff have been identified as important in dealing with stress. The concept of hardness, however, does not appear to have been studied in palliative care staff. This study used interpretative phenomenological analysis to investigate palliative care nurses’ perceptions of their work, particularly the personal characteristics help in buffering the effects of stress and promoting resilience. The participants were palliative care nurses working in an integrated palliative care team in hospital, hospice and community settings. During the analysis themes emerged describing the factors that palliative care nurses found helped them to cope with workplace stresses. In the discussion these were compared with the concept of hardness. Implications for palliative care services were discussed.

Caresearch: A literature and research database for palliative care

David Currow, Department of Palliative & Supportive Services, Adelaide, AUSTRALIA, Amy Abernethy, Duke University Medical Center, Durham, U.S.A, Belinda Faekas, Flinders University, Adelaide, AUSTRALIA, Jennifer Tieman, Flinders University, Adelaide, AUSTRALIA

CareSearch: A literature and research database for palliative care D Currow1, A Abernethy1,2, B Faekas1, J Tieman1 1Department of Palliative and Supportive Services, Flinders University, South Australia, 2Duke University Medical Center, Durham, NC, USA Background: Much research work in palliative care has been hard to locate and studied in isolation in community settings. Previous studies suggest that the AKPS may be superior to the KPS in palliative care; the AKPS has not been validated. Methods: Performance status was measured using all three scales for participants in a large RCT in South Australia. Care occurred in a range of settings. Raters were trained in each scale. Survival was defined from enrollment to death. Results: All three ratings were collected at 1600 timepoints for 275 participants over 21 months; 251 participants died with mean survival 99 days. The median score on all three scales was 60. The RPs and AKPs agreed in 87% of ratings, and 80% of disagreements occurred within one level. The AKPs and TKPs agreed in 85% of ratings, and 94% of all disagreements occurred within one level. The strongest level of agreement of the AKPS with the KPS and the AKPS occurred in the highest performance levels, with greatest disagreement in the middle levels; similar patterns were seen with the TKPS and KPS. Spearman correlations of KPS, TKPS and AKPS with survival were 0.297, 0.294 and 0.301, respectively. Face validity was greatest for the AKPS; nurses reported the AKPS was easiest to use. Conclusion: The AKPS is a useful modification to the TKPS that is more appropriate for palliative care clinical and research settings that include multiple venues of care.

Abstract number: 554
Presentation type: Poster
Poster number: P137

What are the problems in recruiting patients in palliative care research: An observational study

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Background: A large study to develop a new palliative care screening measure is being conducted in the UK. As part of the process of recruiting patients to the study, field researchers observed and reported a number of problems influencing the recruitment of palliative care patients. Objective: To explore the various factors affecting the recruitment of patients receiving palliative or specialist palliative care to a large research study. Methods: The observational study was conducted at seven sites including hospital out-patients, palliative care inpatient units, day care centres and primary care in the North Midlands (UK). Field notes on issues relating to recruitment were recorded. Results: A number of factors affected the recruitment of patients including — reluctance to sign consent form; patient decision influenced by other patient’s experience; interruption by family members at the time of taking consent; death of patient...
before the interview; patient having medical treatment on the day of the interview; patient requesting the presence of their partner at the time of interview; having visitors; preferring not to disclose personal feelings. Exclusions included: (1) patients preferring to do another activity rather than take part in a research study, particularly at the day hospice and patient preferring not to disclose personal feelings;

Recruiting patients for palliative care research was difficult and influenced by (1) healthcare professionals acting as gatekeepers, (2) family members exerting influence on the patient, (3) the patient receiving treatment or being too ill to take part or (4) patients and their carers’ attitude toward research. We were unable to explore some of the reasons for not taking part as patients do not have to provide a reason for refusal according to standard ethics guidelines. Information about these recruitment issues and the number of patients that may be expected to be recruited may be useful to other researchers planning palliative care studies in the future.

Abstract number: 555
Presentation type: Poster
Poster number: F138
Symptom Assessment Instruments – A Systematic Review – Pitfalls and Shortcomings

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Objectives: Electronic databases provide the bulk of references for systematic literature searches. However, it is recognised that many relevant articles are missed. The ‘related articles’ link in PubMed identifies articles that address similar topics quickly, but is not included in guidelines for carrying out a systematic review. We wished to determine the usefulness of incorporating the ‘related articles’ link in PubMed as part of a systematic review. Methods: As part of a systematic review of symptom assessment instruments in cancer patients, PubMed and EMBASE searches were undertaken using a defined search strategy. Two independent examiners screened the citations and a final list of relevant articles was agreed. The references of these articles were hand-searched. A ‘related articles’ link search was also performed on the relevant articles identified by PubMed. Results: A total of 1181 citations were identified through the PubMed search. 10 articles met the inclusion criteria. A further 21 articles were identified through hand searching the references of these 10 articles. 51 articles were identified through the ‘related articles’ link; 43 of these articles were new. In total, 74 relevant articles were identified. A total of 154 citations were considered. Conclusions: The ‘related articles’ link in PubMed is a useful tool and should be a routine part of any systematic review.

Abstract number: 556
Presentation type: Poster
Poster number: F139
Palliative Care for Head and Neck Cancer Patients, a challenge


In the Netherlands each year 2400 patients are diagnosed with head and neck cancer. In the ErasmusMC 550 of these patients are treated. Since the five-year survival of head and neck cancer is about 50%, caregivers should be able to give adequate support during palliative stage. Recent literature review shows few attention is paid to palliative care for head and neck patients. Caregivers in first line medicine have little knowledge of treatment of specific symptoms these patients cope with, such as speech-, airway- and swallowing-problems. Patients need systematic screening, follow-up and support. Therefore an Expert Centre of Palliative Care for head and neck cancer patients (ECPC) is developed. Because of a general preference to outpatient treatment of palliative patients, the centre supports patients and caregivers in a home situation, aiming at consultation towards first line and short admissions when necessary. It has furthermore set as objective a structural support of patient and family; good symptom control and specific information. Systematic registration of palliative patients, consultation by a specialised nurse and screening of symptoms are necessary for structural controlling of these patients.

Research and education of medical employees of the hospital could optimise the quality of the centre. One of the research projects is an ongoing study on the experience of general practitioners in their care of palliative head and neck patients before start of the centre. 55 general practitioners, who had a patient treated for head and neck cancer and whose patient died as a result of this were included in this study and asked to fill out a questionnaire on care of their patients. Communication between first and second line and actions of both general practitioners and the hospital. There is a response-rate of about 70%. In this presentation we will present preliminary results of this study and discuss the procedure of the ECPC.

Abstract number: 557
Presentation type: Poster
Poster number: F140
The L.O.A.D. (Level OfAwareness of Disease) code for disease awareness in palliative care cancer patients and caregivers

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Objective: To evaluate the L.O.A.D. (Level Of Awareness of Disease) code as a tool newly developed for the level of disease awareness in palliative care cancer patients and caregivers both. Method: The L.O.A.D is a two digits code where the list is referred to the patient, the second to the caregiver. Independently from the evaluation method applied, the number 0 is used when the patient/caregiver has no diagnosis and prognosis awareness both, 1 when awareness is limited to diagnosis, 2 when the patient/caregiver is aware of diagnosis but overestimates prognosis, 3 when awareness of poor prognosis is present with no diagnosis awareness, 4 when full prognosis awareness is present. Codes 7 and 9 are used respectively when no evaluation is possible and, code 9, when the level of awareness is doubtful. The L.O.A.D code has been tested in May 2004 in a prevalence study in the 4 Hospices of Piedmont (Northern Italy) using a physician based evaluation to assess awareness in patient and caregiver both. Patients with a hospice length of stay longer than 7 days have been excluded. Results: No difficulties have been reported using the L.O.A.D. code. 31 patients out of 38 had been enrolled. Full disease awareness in patient and caregiver both (LOAD 44) was present in 35,38% (11). Patients were completely aware of diagnosis and prognosis in 45,16% (14) while caregivers were in 80,65% (25). Other results will be presented. Conclusions: The L.O.A.D. code is a research and working tool newly developed to define the level of disease awareness in palliative care cancer patients and caregivers simultaneously. It can be used with any method of assessment and has shown to be quick and easy to apply in clinical practice. The results of the first trial show a limited disease awareness in Hospice cancer patients in Piedmont.

Abstract number: 558
Presentation type: Poster
Poster number: F141
Shared decision making as a controlled process on the basis of precise clinical data and individual needs – a clinical study in radiotherapy for head and neck cancer

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Background: Shared decision-making (SDM) is increasingly advocated as an ideal model of treatment decision-making in the medical encounter. Essential for SDM is that both, physicians and patients, share information and take steps to build a consensus about the preferred treatment. In the model of radiotherapy for head and neck cancer we recorded and investigated acute therapy side effects and their risk factors as a basis for patient information and for estimating patients’ individual need for supportive care. Potential benefits of a SDM model in the context of Palliative Care are discussed. Patients and Methods: Prospectively collected data of 144 patients undergoing head and neck radiotherapy were evaluated through EMBASE. No relevant articles were identified. Conclusion: Only 13.5% of relevant articles were identified using the original PubMed search. This would suggest deficiencies in the indexing system for articles related to symptom assessment in PubMed. Over 50% of all relevant articles were identified using the ‘related articles’ link. We propose that ‘related articles’ link is a useful tool and should be a routine part of any systematic review.
Abstract number: S59
Presentation type: Poster
Poster number: P143

THE CLASSIFICATION OF APPETITE LOSS: A PROSPECTIVE EVALUATION IN CANCER PATIENTS

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Background: Anorexia is common in cancer, which reduces quality of life. Characteristics of appetite loss include anorexia, early satiety, taste and smell changes. Patients with anorexia probably experience a number of these characteristics. We surveyed patients with cancer and anorexia to further understand the experience of anorexia and to develop an approach to classifying the symptom. Method: A twenty-two question empirical questionnaire was prospectively completed by patient interview. The questionnaire surveyed anorexia severity, diurnal variations, GI symptoms, taste and smell changes, possible relationship to cancer therapy and patient concerns about anorexia. Results: 49 patients were surveyed over six weeks. The mean age, 65 ± 13 years, male/female 20/29. Anorexia was present for months in 40/49 (82%). 16/49 (33%) had anorexia for 20+ months. 16/49 (33%) had anorexia for 20+ months. Most had constipation, nausea and weight though only 16/49 (35%) were clinically moderate and 25/49 (51%) severe anorexia. Taste changes occurred in 29/49 (59%) were common. Taste changes (except hiccups and abdominal symptoms (except hiccups and abdominal pain). Altered food preference 24/49 (69%) and taste 29/49 (59%) were common. Taste changes were evenly divided between bitter, salt, sour and sweet. Altered smell occurred in 20/49 (41%). 26/49 felt anorexia worsened with chemotherapy. Reduced appetite occurred in 12/30 on radiation, 10/49 (20%) were not personally concerned about the anorexia. Discussion: Appetite loss can be present without the appearance of cachexia. GI symptoms were common with anorexia. Patients attributed appetite loss to GI symptoms. Taste changes occurred in most and changes in smell in nearly half. Anti-tumor therapy was associated with worsening anorexia in most. A minority were not concerned about the anorexia despite its prevalence and severity.

Abstract number: S60
Presentation type: Poster
Poster number: P144

Fatigue in advanced cancer: really a multidimensional phenomenon

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Introduction: Fatigue is one of the most frequently encountered symptoms in advanced cancer with major implications for quality of life. Fatigue has been described as a multidimensional phenomenon with physical, affective and cognitive expressions. In palliative care, quantitative studies on fatigue dimensions have not been performed in advanced cancer patients. The Multidimensional Fatigue Inventory (MFI) is a validated psychometric instrument measuring the dimensions General Fatigue (GF), Physical Fatigue (PF), Reduced Activity (RA), Reduced Motivation (RM) and Mental Fatigue (MF). This study determines fatigue levels in cancer patients admitted for palliative care using the MFI and assesses internal consistency of the different dimensions. Methods: Fatigue was measured using the MFI in 94 advanced cancer patients within 48 hours after admission to the palliative care unit of a cancer centre. Results: Internal consistency was good for each subscale with Cronbach’s alpha values of 0.77, 0.67, 0.72, 0.77 and 0.84 for GF, PF, RM and MF, respectively. Median GF, PF and RA scores were 18–19 out of a maximum score of 20, indicating extremely high fatigue for most patients; the percentages of patients with the maximum MF subscore were 35%, 47%, and 35% respectively. Median RM and MF scores were much lower (15 and 12), and differed significantly from the GF, PF and RA scores (p=0.001, Friedman test). RM and MF scores varied widely between the lowest and the highest possible score (4–20).

Conclusion: Most cancer patients who are admitted to a palliative care unit experience extreme physical fatigue. Motivation and mental functioning vary widely and seem to be less impaired. The purpose of this study is to show that these patients are relatively capable and willing to perform mentally taxing tasks, but unable to carry out physical demanding roles.

Abstract number: S61
Presentation type: Poster
Poster number: P145

the influence of different kind of opioids on cognitive functions

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The proposed research are planned between 09.2004 to 04.2005 at Sue Ryder’s Palliative Care Hospital in collaboration with Department of Neuropsychology and Behavioral Genetics, Institute of Psychology, Warsaw University. The purpose of the study is to improve quality of clinical research, protect trial subjects, ensure credible results and create conditions conducive to the effective co-ordination of clinical trials in the European Community. The directive’s provisions will apply to all clinical trials involving medicinal products and do not distinguish between commercial and non-commercial trials. Trials sponsored by government, research council, charity or university are also covered. The need for more high-quality randomized trials in palliative care is well known. Therefore an overview will be given how drug trials in palliative care can be conducted according to Good Clinical Practice (GCP). The history of the development of Good Clinical Practice (GCP) guidelines is well known. The Good Clinical Practice (GCP) guidelines and the International Conference on Harmonization (ICH) will be discussed. It will be described how ICH GCP applies to the Sponsor, Monitor, Investigator and Ethics Committee. A ‘dummy study’ all relevant steps to undertake a clinical trial according GCP requirements will be represented and the responsibilities of the investigator will be discussed. Finally, the complex requirements will be simplified into a collection of ‘golden rules’ where GCP compliance is most important.
Abstract number: 563
Presentation type: Poster
Poster number: P147

Statistical quantitative analysis of symptoms among patients with advanced cancer disease admitted to Palliative Care Department

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Patients with advanced cancer disease present various kind of somatic symptoms. Because of wide kind of these symptoms quantitative statistical analysis was conducted – to prove medical care in Palliative Care Department and to research somatic and psychological needs of patients. Main aim of the research: Statistical analysis of symptoms among patients in the day of arrival to the hospital. Method: Research was conducted between 1st of January 2003 and 30th of June 2004 among 448 patients with advanced cancer disease admitted to PCD. During the procedure of admitting physicians were asked to report on somatic symptoms and clinical problems choosing them from wide list of symptoms in computer software. Results: Average number of symptoms: 7.6. Most common symptoms were: – Pain (215) – Lack of appetite (197) – Exhaustion (171) – constipation (168) – dyspnoea (154) – lowered mood (145) – Lack of energy (140) Conclusions Three groups of symptoms were identified: Cahexia-anorexia symptoms, Alimentary canal symptoms, Psychological symptoms. These results show that pain is in no longer most important symptom, other symptoms are getting more common – especially among last few years. This shows that pain is better controlled than few years ago. It is obvious that medical procedures and procedures in Palliative Care Departments must be changed. Results also shows great importance of multi-disciplinary team.

Abstract number: 564
Presentation type: Poster
Poster number: P148

Health care utilization at the end of life and problems in the organization of end of life care


In many countries, palliative care has developed in the last decades. We studied the utilization of palliative care from the perspective of patients and bereaved relatives. Patients with various types of advanced cancer were asked to fill out a questionnaire every half year. When patients were undergoing the research period, we asked their bereaved relatives to participate in a personal interview at the home. The use of care and problems in end of life care were assessed. Until now 38% are most patients who participated in the study have died. Seventy-seven of these patients filled out a questionnaire about end of life care in the last half-year of their lives. Most patients had received care from their general practitioner and one or more clinical specialists during this period. About half of the patients had seen an oncology nurse. The district nurse was most often involved during the last three months of the patients’ lives. In the last half-year of life, the mean number of health care professionals involved with one patient was 4.5, while bereaved relatives reported that this number was 6.4 in the last three months before death. The care provided by health care professionals was in general evaluated as good. Patients and bereaved relatives mentioned the same problems in end of life care. These problems concerned difficulties in fine-tuning the care of different professionals and different care settings. The problem most often mentioned in the last months before death concerned the quickness of responding to acute problems (26%). We conclude that patients need to be sure that patients are in general satisfied with the quality of end of life care, although the acute response to problems and the mutual fine-tuning of many involved health care professionals remain important issues.

Abstract number: 565
Presentation type: Poster
Poster number: P150

The development of a new department and a strategy for research in a well established hospice

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For many years research has been an important feature at St Joseph’s Hospice, Hackney, East London. It was here that Dr. (now Dame) Cicely Saunders conducted some of her foundation research work on the management of pain and distressing symptoms in the early days of palliative care. In recognising this and the importance of research in all disciplines relevant to palliative care, the hospice decided to appoint a Director of Research to build up and lead a research department. This development has coincided with preparing for the centenary celebrations of St Joseph’s Hospice, which was founded in 1905. In this presentation some of the key challenges and opportunities of this new development will be outlined. Amongst the challenges are the following: encouraging research activity in all disciplines; dealing with the suspicion that sometimes surrounds research; the balance of research and service; the difficulty of securing new research projects in a voluntary organisation. In the environment of St Joseph’s hospice there are many opportunities for research in every discipline. The hospice is the only one in the UK with a large in-patient unit with 61 palliative care beds and many more patients who are being cared for at home; patients and families from a large multi ethnic community with many different languages, cultures and faiths; a vibrant staff group with a balance of age and cultural backgrounds. The Research Department with its new Director came into existence early in 2004. The presentation will describe the results of this first year of co-ordinated research activity and some of the plans for future developments.

Abstract number: 566
Presentation type: Poster
Poster number: P152

Physical exercise intervention in palliative cancer patients; a phase II study. Effects of the exercise program

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Background: Exercise interventions for palliative cancer patients are few and the procedures are often poorly described. Purpose: Describe the intervention program used in our phase II intervention study. Location: Group exercise (3–8 patients per group) in the gymnasium at the hospital or in the living room at the palliative outpatient clinic. Symptom registration: Prior to each exercise session each patient filled out a symptom questionnaire, Trondheim palliative assessment tool (TAPAT) to monitor changes. Alterations in the program, caution or restrictions were then implemented. Method: Intervention: The patients participated twice a week, 50 minutes each session for a six week period. The program consisted of a warm-up session (10 minutes), circuit training with six stations (30 minutes) and a relaxation/stretching session (10 minutes). At each of the 6 stations, exercises were performed for 2 minutes, with a 30 second break moving on to the next station. The exercises could easily be duplicated in the home. Main focus was on lower and upper limb muscle strength, standing balance and aerobic endurance. Each station had a ‘set’ series of exercises, with the possibility for adjustments to the individual patients’ physical function. Warm up: Upright/sitting position or exercise bicycle. Station 1: Strength lower limb: ‘step up’: step up and down on a step. Station 2: Balance. Trampoline/thick mat: weight transfer. Station 3: Pull down, resistance for arms. Station 4: Start in standing position, descend to the floor, lie on back, then roll from side to side, and then stand up again. Station 5: Sit on bench, stand up and sit down again. Station 6: Exercise bicycling. The session ended with relaxation/stretching. Conclusion: The group exercise program was found suitable for this patient population. Main gains were: increased physical function, increased social contacts.

Abstract number: 567
Presentation type: Poster
Poster number: P153

HOSPITAL MOBILE PALLIATIVE CARE TEAMS: STRUCTURAL AND DEVELOPMENTAL GUIDANCE FOR EUROPE

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Background: The European Community provided a grant, in order to research the development of hospital based mobile palliative care teams (PCMT’s). A network of mobile palliative care teams are in different stages of development, working in a variety of institutional, cultural and political contexts. Aim: The aim of the project was to face the challenges faced in establishing and running hospital based Palliative Care Teams. It was finalised by providing guidelines for the development of mobile exercise for cancer patients. Process: Mirroring some of Palliative Care’s core values, decisions were taken inclusively, in that clinicians and researchers prepared an inventory to evaluate the structure, ethics and clinical activities of 8 PCMT’s across Europe together. Subsequently, sociological, psychological and ethical research teams examined the functioning of the mobile teams.
Based on these results, the educational consultant presented a design of an education programme, from which 2 items were chosen and piloted as tools. In September 2004, a publication was issued by the European Community and distributed to the 25 European countries. Highlights of process, research and educational results will be presented.

Abstract number: 568
Presentation type: Poster
Poster number: P154

The impact of the disease on the family that looks after a terminally ill oncological patient, in Italy

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Introduction: the Italian studies concerning the impact of the disease on the family of terminally ill oncological patients are few. Aim of the study is to throw light on this matter on national survey. Method: 74 Italian Palliative Care Centres (PCC) proposed to the caregivers of the in charge patients, a questionnaire concerning the impact of their own attending work on their own quality of life, on the economic conditions and on the support obtained by PCC. Total care on the privacy has been taken on patients, on caregivers and PCC. Results: to OICP, 454 questionnaires totally arrived. The caregiver resulted as a medium aged woman, strictly relative to the patient that, in about 70% of the cases, dedicates to the patient from 12 to 24 hours per day, depending on a partial help from other relatives, acquaintances or paid personnel. Over 80% of the caregivers declare that their own life has basically changed since when they look after the patient: in various percentages, psychological troubles, reduction of the time for himself and for his own relationship life, further direct or indirect economical expenses. As far as concerns the relationship with the patient, the worries to face the pain, to be physically and emotionally taking care of him, to face a direct conversation about the disease or the death, to be unable in hiding the own worries, to be afraid that the patient dies in front of you or to be unable in realize the death moment, are often reported. As far as concerns the PCC support, almost all the caregivers expressed a substantial positive judgment, even underlying some organizing and structural lacks. Discussion: in PC, the tendency is overall to pay attention to the problems of the terminally ill patient. This study analyses and points out the difficulties in the family, both relative to the quality of life and to the economical expenses to be faced.

Abstract number: 569
Presentation type: Poster
Poster number: P155

SUBCUTANEOUS INFUSION OF TRAMADOL AND DEXAMETHASONE: COMPATIBILITY AND STABILITY

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The aim of the present study was to evaluate the compatibility and physical stability of binary admixtures composed of tramadol hydrochloride and dexamethasone sodium phosphate destined to subcutaneous administration to terminally ill patients followed at home by staff of Palliative Care Units. The doses assayed in the study were 100, 200 and 400 mg/day for tramadol hydrochloride and 4, 16, 20 and 40 mg/day for dexamethasone sodium phosphate. All doses tested are usually administered in our Palliative Care Unit. Twelve different drug admixtures were prepared in triplets in saline and stored at 25°C protected from light exposure. At pre-determined times; 0, 5, 7 and 15 days all samples were checked for volume and colour changes, cloudiness and/or precipitation and pH determination. Moreover, all admixtures containing tramadol hydrochloride and dexamethasone sodium phosphate were analysed by high performance liquid chromatography (HPLC). None of the samples showed changes in colour, precipitation or measurable loss of volume due to evaporation. The pH values ranged from 7.11 to 7.69 at time zero and from 7.06 to 7.65 at the end of the study. The losses of tramadol and dexamethasone occurred after 5 days were lower than 10% at 25°C and increased up to 20% at the end of the study period (15 days). It can therefore be concluded that dexamethasone sodium phosphate (concentration range 1.7 to 6.7 mg/ml) can be safely combined with tramadol hydrochloride (concentration range 0.2 to 4.2 mg/ml) to prepare 5-day infusion pumps with no significant losses of both drugs found when kept at 25°C.

Abstract number: 570
Presentation type: Poster
Poster number: P156

A Bit of Heaven for the Few? An oral history of the hospice movement in the United Kingdom

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Background This work seeks to explore the development of the modern hospice movement through the words, experiences and perspectives of some of those involved, and represents ten years of research. It includes the voices of eighty researchers and carer experience, however, is best captured as hindsight accounts which do not necessarily reflect greater accuracy. Discussion This situation has deep implications for historical representation, and is one which the authors have had to consider carefully. Through this presentation of extracts from A bit of heaven for the few? and a review of contributors responses, this paper aims to generate discussion of the issues surrounding historical representation of hospice and palliative care development.

Abstract number: 571
Presentation type: Poster
Poster number: P157

Which methods best gain the views of people affected by cancer about end-of-life issues?

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Background The objective was to assess the utility of both established and innovative methods and approaches to end-of-life research. Research questions included issues of recruitment, challenges faced by researchers and research ethics.

Methods A systematic review of the relevant cancer literature, 31 semi-structured interviews with an international sample of researchers and 4 focus groups with people affected by cancer. Interviews and focus groups were analysed thematically using NVivo.

Results Interviews with researchers revealed that a mixed method approach has become more popular. While qualitative methods gain in-depth data on patient and carer views, quantitative methods reach a larger sector of the population, and may facilitate wider inclusion. While researchers seek to widen recruitment, however, ethics committees may deny patients the right to choose whether or not to participate. The importance of sensitivity, respect, ethical conduct and emotional demands placed on researchers were shared concerns.

Focus groups revealed that people affected by cancer do not want to be treated differently and generally welcome the opportunity to share their experiences. Similarly, some researchers felt that health research in general brings challenges that are not the exclusive domain of the cancer field. We therefore looked beyond cancer to draw on methods that have been applied in other areas that require innovative approaches to facilitate both communication and dissemination.

Conclusions This study reveals that a diversity of methods, from research-based drama to postal questionnaires, can enhance participation in end-of-life research. An in-depth understanding of patient and carer experience, however, is best captured through qualitative methods.
This paper will introduce discursive approaches from the perspective of health psychology, presenting two major positions: 1) an approach derived from ethnomethodology and conversation analysis concerned with how everyday social interactions are regulated and managed, and 2) ‘Foucauldian discursive analysis’ which draws upon post-structuralist writers including Foucault to examine how language constitutes social and psychological experience. Discursive approaches regard interview responses as evidence about how people use language to construct that particular situation at that particular time. Discursive approaches make no assumptions about consistency of responses in other situations, no inferences about intra-psychic processes (how people think and feel), and explain talk as representing a repertoire of ways that people have of dealing with questions in social situations, such as that of an interview. In discursive approaches, analysis of talk is concerned with individuals’ attempts to deal with their current situation (for example in an interview maintaining their credibility as a ‘good’ patient by ‘telling the truth’ (the interviewer or complaining). To illustrate these differences, I will use examples taken from research about bereavement support provided by general practitioners and counsellors in the UK, and a study of the way death is described by palliative care practitioners in medical records in the UK. A further example will be provided by an analysis of ‘Last Offices’ in the procedure manual of a hospital in Australia, which revealed how nurses enact the transition between life and death in their behaviours and language towards the live patient and dead body. Discourse analysis has not been used much as an analytic approach in palliative care research. This paper will discuss its limitations and advantages in revealing taken-for-granted aspects of social interactions embedded within language.

Abstract number: 574
Presentation type: Poster
Poster number: P160

The usefulness, and ethics of Practitioner-Centred-Research in examining knowledge and practice with regard to the marriage of palliative care and care of the older person

Jo Wilson, London, UK

Against a context of increasing medicalization of the dimensions of the Clinical Nurse Specialist (CNS) role, and to attend to practice-development, I work one day / week (of a four day week) on a ward caring for older people. A study was undertaken that addressed whether it was ‘possible for me as a CNS (Supportive and Palliative Care), to develop a role on a ward that could provide a responsive, timely, accessible and equitable palliative care service whilst developing the palliative care practice of the clinical staff, and at the same time grounding and developing my own nursing practice.

From the paradigm of Practitioner Centred Research, the methodology of reflexive action research was chosen. The model used was ‘action = evaluation = understanding’ (Rolfe 1998). A reflexive diary was recorded for five weeks before a break (Period 1). It was decided (action) to support only those patients requiring symptom management / dying care who were in my own ward (as opposed to caring for a team of patients). The diary was kept for five weeks afterwards (Period 2).

The diary was regarded as narrative and analysed (McLeod and Balmououth 2000) to yield a narrative of both periods, which were compared. The analysis showed that the action resulted in a role that allowed me to start providing a responsive, timely, accessible and equitable palliative care service. Additionally by understanding better the marriage of Palliative Care and the Older Person, practice (both my own and that of CNS) was developed. A commitment to reflexivity was maintained, and the reliability and validity of this work is in its authenticity and its emphasis on action.

The present study presents the usefulness of this methodology to highlight knowledge gained from practice. Examples of the knowledge gained regarding the Palliative Care / Older Person Care interface will be included.

Arguments related to the ethics of using this methodology are presented with respect to patients and team members, and with particular regard to the practitioner - researcher relationship.

References
A Prospective Regional Audit of the Management of Cancer-Associated Hypercalcaemia in Palliative Care

Jennifer Smith, Palliative Care Department, Liverpool, GREAT BRITAIN; Jennifer Doherty, Whiston Hospital, Prescot, GREAT BRITAIN; Andrew Dickman, Whiston Hospital, Prescot, GREAT BRITAIN

Introduction: Cancer-associated hypercalcaemia is an uncommon and poorly managed condition and is a cause of significant morbidity and mortality amongst palliative care patients. Within the Merseyside and Cheshire Palliative Care Network Audit Group (MCPCNAG) evidence-based guidelines and standards for the management of hypercalcaemia were developed and clinical practice was audited against these.

Methodology: A literature review was initially undertaken to update previously-existing standards and guidelines for the management of cancer-associated hypercalcaemia. Over a three-month period a prospective audit was performed of management of hypercalcaemia in cancer patients within hospice in-patient units and known to Specialist Palliative Care Teams in hospital and community settings across the region in order to assess whether management was in accordance with the guidelines and standards achieved. Within the audit severity of symptoms of hypercalcaemia was recorded before and after treatment using a 4-point scale of severity and potential indicators of a poor prognosis were also examined. Results: A total of 55 patients with cancer-associated hypercalcaemia were included in the audit. Aspects of practice deviating from the guidelines and standards were identified. Due to poor recording of symptoms of hypercalcaemia it was not possible to confirm symptomatic response to treatment. Among the patients who died within the audit period a statistically significant correlation was identified between the time to death and pre-treatment serum albumin, but no association was identified between time to death and severity of hypercalcaemia prior to treatment, serum sodium, age or mobility. Conclusion: Evidence-based, evidence and standards for the management of cancer-associated hypercalcaemia are presented and aspects of management regionally that deviated from these are discussed.

Posters

Abstract number: 576
Presentation type: Poster
Poster number: P162

Improving palliative care in the community: an evaluation of the first phase of the Gold Standards Framework

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Object: Most of a patient’s last year of life is spent at home under the care of the primary care team. More patients prefer to die at home than are able to do so. A managed framework of care, the Gold Standards Framework (GSF) was developed to improve the organisation of palliative care in the community. The framework consists of the standards as well as a support programme to aid their implementation. The national programme of dissemination is underway and GSF is being used by over 1,500 UK practices. The aim of this study was to evaluate the first phase of GSF in terms of its acceptability to primary care teams, effectiveness in changing practice and professionals’ views on the consequences for patient care. Methods: Focus groups of members of the 12 participating practices at baseline and six months. Questionnaires to 12 participating practices and 12 matched practices at baseline and six months. Questionnaires to 18 other practices in the area at six months. Semi-structured interviews with a GP from each participating practice one year after introduction of GSF. Results: Participating practices reported that the GSF was acceptable and time efficient. Standards were achieved more often by participating practices compared to matched or other practices in the area. Registries, teams and co-ordinated care were thought to have improved communication, teamwork, patient identification, assessment and care planning in participating practices. Conclusions: The GSF appears to be acceptable and its early introduction to a limited number of primary care teams appears to have changed practice. Participating GPs and district nurses were positive about the effect on the quality of care provision. An evaluation of the national uptake of GSF and further research into its effectiveness is required.

Abstract number: 578
Presentation type: Poster
Poster number: P164

How do symptoms interfere with quality of life in advanced cancer patients?

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Introduction: Patients with advanced cancer experience an impaired quality of life (QoL) due to symptoms related to the disease itself or the toxicities of treatment. We have developed the following grades of QoL impairment as compared to a population of controls: mild (25% or less QoL decrease from controls), moderate (25-50% decrease), severe (50-75% decrease) and critical (more than 75% decrease). The goal of this research was to study the severity of main symptoms in advanced cancer patients with different grades of QoL impairment. Patients and Methods: 201 advanced cancer patients (male/female 80/121; mean age 61.5) were enrolled in the study. The Russian versions of SF-36 and M.D. Anderson Symptom Inventory (MDASI) were used for QoL and symptom assessment, respectively. To obtain QoL indices the integral profile method (MIP) was used. Results. The majority of patients experienced critical (42%) and severe (20%) QoL impairment. Moderate, mild, and no QoL impairment were recorded in 10, 12, and 10 % of patients, respectively. The QoL indices differed significantly between the groups (0.04 vs 0.12 vs 0.2 vs 0.28 vs 0.47; p=0.00002). Moderate-to-severe fatigue, sleep disturbance, and pain were observed in patients with critical and severe QoL impairment; one third of patients exhibited 3 or more moderate-to-severe symptoms. Conclusion: The majority of patients with advanced cancer exhibit severe to critical QoL impairment as compared to a healthy population. They experience moderate-to-severe fatigue and sleep disturbance. Grading of QoL impairment and symptom assessment in these patient groups is worthwhile to provide adequate management of advanced cancer.

Abstract number: 579
Presentation type: Poster
Poster number: P165

Initial results of implementing the system of quality management (ISO 9001:2001) in the Regional Center of Palliative Care– Sue Ryder Home

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Focusing on patients and the quality of medical service is one of positive aspects of health service reform that has been introduced in Poland since 1999. The principle of palliative care groups before those reforms was implementing the idea of comprehensive care, in accordance with the definition of WHO. Good quality of medical service is in great demand and palliative care responds to this demand. After many years of experience our team set a question how to develop and improve the standard of care. The strategy of our development focuses on the organization of specialist palliative care for larger group of patients thus far. To achieve this aim we decided to introduce a system of quality management. After preparation of the managerial staff and the personnel we began the process of implementation of the system of quality management according to the ISO 9001. An essential element of the implementation was the appointment of quality and team, as well as interior checkers. The whole process was taking place there were examined in relation to the requirements of the ISO 9001 norm. Policy of quality, mission, quality aims, maps of processes, procedures and standards of conduct were defined in a ‘Book of Quality’. The results of those actions include: new quality within the scope of medical and administrative documentation, reduction of activity costs, defining standards of medical conduct, introduction of checking patients’ satisfaction. Another result of the implementation of the system is constant monitoring of the management. The Quality Branch constantly monitors and assesses the standards, at the same time it updates procedures. Interior checkers will review the conformity of procedures. However the most important control will be the analysis of examinations patients’ and their families’ satisfaction. The system will result in the decrease of accidental events and increase of safety for patients and their families under our care.

Abstract number: 580
Presentation type: Poster
Poster number: P166

Is 'dying at the desired place' an indicator for preference-oriented palliative care?

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Although most people want to die at home, the most probable place of death is hospital or a nursery home. We know that preferences may change near the end of life and that patients sometimes prefer to spend their last time in hospital, a hospice or a nursery home. Within a national study about ‘patients as partners – tumor patients and their participation at medical decisions’ we have explored the relative’s and physician’s perspective concerning the dying place desired.
by the patients. Method: From March 2002 to June 2004, a standardized questionnaire was sent to GPs and surviving relatives of the patients. Of these all surviving relatives of the patients, who were in contact with the newly established palliative counselling team. Results: 88 GPs and 109 relatives answered the questionnaire. 34 (36,9 %) of the patients died at home, 54,8 in hospital and 11,1 % in a nursery home. On the one hand, 52 GPs (57,1 %) and 59 relatives (54,1 %) said, the patient died at the nurses’ desired place. But on the other hand, 18 GPs (18,1 %) and 33 relatives (30,2 %) said, the patient did not want to die at the place, he or she actually did. All patients, who died at home, 20 GPs and 17 relatives said, the patient wanted to die in hospital (34,2 % of all patients, who died in hospital) and 10 persons mentioned, that the patient wanted to die in a nursery home. 40 patients died against their own wishes in hospital (20,3 % of all patients and 37,0 % of the patients, who died in hospital). Named reasons were deterioration of the disease, poor symptomcontrol at home, hope until the last time and to late planned discharge of the patient. Conclusion: The desired place of dying seems to be an indicator for preferences oriented palliative care. In the presentation, the patients’ perspective will be contrasted with relatives’ and GPs’ view. Communication before the beginning of the dying process needs to be improved.

Abstract number: 581
Presentation type: Poster
Poster number: P167

Nursing in palliative care: specialism or not?
Angelique De Wit, Erasmus MC, rotterdam, NETHERLANDS, Arianne Brinkman - Stoppelenburg, Agora, Bunnik, NETHERLANDS, Janneke Rongingswood-tten Hove, Hospice Calando, Dirkland, NETHERLANDS, Mathilde Van der Breggen, Verpleeghuis Antonius IJssemonde, Rotterdam, NETHERLANDS

Introduction: Among nurses working in palliative care, the conviction is held that working in palliative care asks for specific requirements of these nurses. The question is whether palliative care really asks for specific requirements and whether the nurses can meet these demands. The care given by the nurses must be organised in such a way as to guarantee and strive for measurable quality of care for incurable ill human beings in the last phase of their lives. Methodology: From September 2003 until July 2004, several members of the Dutch Association of Nurses working in Palliative Care (Nederlandse Vereniging voor Verpleegkundigen werkzaam in de Palliatieve Zorg) have busied themselves with the development of a profile for that professional sector. According to a recognised method, the specificity of the nurse working in palliative care is visualised. One of the most important analyses was addressed to the quality of palliative care. Results: Seventeen core tasks have been identified, subdivided into three different groups, that is the person in need of care, profession-related tasks, and organisation-related tasks. Along with every core task, the corresponding competences are described. Proceeding from these competences, the concrete conduct and behaviour of the nurse working in palliative care are named. Specific core tasks are, among others, to ‘develop, guarantee and adjust quality of palliative care’, ‘to guide’, ‘co-ordinate’, ‘consult’ and ‘care for the caregivers’. Conclusion: The description above makes it possible to assess whether the expertise is specific compared to that of a basic nurse. If defects have come into existence, it is justified to set up a separate specialism with corresponding educational requirements.

Abstract number: 582
Presentation type: Poster
Poster number: P168

Nursing care - what is the optimal standard?
Sheila Payne, Palliative & End-of-Life Care Research Group, Sheffield, GREAT BRITAIN

Nurses have helped shape palliative care by establishing and developing services, leading educational, and research programmes. Most palliative care nursing is delivered by general qualified nurses. These nurses need to be aware of the principles of palliative care; including attention to the physical, psychological, social and spiritual care of patients and their families, and know how to access additional support in dealing with complex problems. Nurses with additional qualifications and expertise in palliative care are described as specialist palliative care nurses. These nurses may work in hospitals, hospices or in the community both to provide direct care to patients and families. Many of these nurses work independently but some are part of multidisciplinary teams. The role of specialist palliative care nursing is varied and complex and includes symptom control and supportive care for patients and families, co-ordination and communication between other services, empathy and respect to the dignity and preferences of those in their care. Nurses need to be aware of cultural diversity and the social implications of death, dying and bereavement. In this session, we will discuss: Roles and competencies of a specialist palliative care nurse, including: Palliative care expertise – Knowledge and application of knowledge. Communication – Skills with patients, families, and multidisciplinary team. Collaboration – Working with multidisciplinary team members, family carers and other professionals. Advocacy – For patient and family and for palliative care services. Evidence based practice – Participation in continuing professional development, education and research. Professional nursing – Practising honestly, honestly and delivering ‘best practice’ to all.

Abstract number: 583
Presentation type: Poster
Poster number: P169

Diagnosis and management of spinal cord compression - what's the urgency?
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Aims: To establish guidelines for diagnosis of malignant spinal cord compression (MSCC) referral criteria to surgical/oncological services and to assess outcome regarding discharge, functional status and survival. Methods: A retrospective questionnaire-based audit was carried out including all patients identified via MRI reports with a diagnosis of MSCC at two university hospitals in Liverpool from 31.5.01–1.6.03. Results: Of 237 patients, 31.5% used of high-potency opioids. All patients were treated with oral calcium and vitamin D3 supplementation; we also performed evaluation of serum creatinine and serum calcium before and after the intervention with ZA. Results: 32 pts received 104 courses of ZA ( mean 3.3, range 1–6). 4/32 pts reported asymptomatic hypocalcaemia ( 1 patient with pregressed hypocalcaemia), 4/32 pts experienced transient fever, fatigue and myalgia. There was no evidence for renal or haepatic toxicity, based on renal and liver function tests. A randomized raised serum calcium intervention was observed in 3/32 patients(< 0,4 mg/dl to baseline values). Conclusion. The results of this small trial support an expanded role for ZA in the hypercalcemia management of patients with advanced cancer disease and bone metastases.

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SATURDAY 9 APRIL

Posters
Oral morbidity in cancer patients. A pilot study

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Introduction: Oral health problems are common in cancer patients. Physicians and nurses show less attention to the mouth than to other parts of the body (Öhrn 2001). Xerostomia, mouth pain and oral candidiasis may cause considerable distress, compromise nutrition and influence proper cancer therapy. Improved identification of oral morbidity, documentation in medical records and mouth care are needed. Aims: To screen the prevalence of oral morbidity in cancer patients admitted to a department of oncology, receiving curative or palliative therapy mostly outside the head- and neck region. Investigate the information given on oral morbidity in medical records and patient interviews, compare to xero-/oral parameters and the Edmonton Symptom Assessment System (ESAS) (Aas et al. 1999).

Methods: A prospective face-to-face questionnaire was performed. Results: Of the 62 patients, forty were females, age 33–83. Twenty-two were males, age 31–82. Some of the 54 questions were not answered by all patients of different reasons. Forty-five of 62 patients revealed chemotheraphy less than one month before screening. Forty-four were on medication contributing to dry mouth. Xerostomia, reported by fifty-three of the 62 patients, was ranged as the most significant problem (VAS, mean 5.6) over pain, nausea, dyspea, anxiety and appetite. Ten of 31 patients showed oral pseudomembranous candidiasis. Twenty-four of the 62 experienced oral discomfort and mouth pain. Mean 9.3 of the 30 patients reported halitosis. Thirty-eight of 58 complained of missing information and treatment of oral side effects. Patients wanted dental consultation. Conclusions: Patients with cancer outside head-and neck need increased information on oral morbidity and improved mouth care. Oncology teams should include dental referrals. Further studies are needed to increase the attention to oral morbidity.

Hydromorphone, Morphine, and Constipation: are there Differences?

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Introduction Aim of this investigation was to assess the symptoms constipation in cancer pain patients with transdermal buprenorphine (b), fentanyl (f), or oral hydromorphone (hm). Methods and patients After ethical approval of the local ethics committee and patients written consent we enrolled 107 cancer pain patients into this prospective comparative and observational study. Using standardized interviews and questionnaires we assessed central symptoms as day time sedation, dizziness, jerks, and sleep disturbances as sleep onset and maintenance insomnia, nightmares by Numerical Rating Scale and categorical variables. Other variables comprised demographic and medical data. Analysis were performed by descriptive and confirmative statistical methods. Results Mean age was 66 (b), 64.6 (f), and 60.4 (hm) years. Cancer diagnoses were lung cancer, gastrointestinal and urogenital tumours, mostly. Mean dosage of opioids were 51.5 g/h (b), 82.3 g/h (f), and 27.5 mg/d (hm), mean NRS (pain) ranged from 2 (b, f) to 3.6 (hm). Day time sedation (NRS 4.7 f, 4 b, 2.7 hm), dizziness (NRS 1.7 b, 1.6 f, 1 hm), were most severe with transdermal opioids. Myoclonus was most frequent with b (mean value 0.5, range 0.2–2.2), sleep maintenance insomnia with f (mean value 0.5/night) (b, 0.3, hm 0.4). Nightmares occurred more often with f and hm (group mean value 0.8/night in patients with b). Differences were seen for sleep onset insomnia (b, f 0.2 b, h 0.24). Conclusion Compared with oral hydromorphone, the transdermal administration of buprenorphine or fentanyl revealed higher rates and severity of several central symptoms.

By the criteria stool free interval, defeation rate, a Numerical Rating Scale of the subjective feeling of being constipated (NRS constipation) for a period of five consecutive days. Results Mean age was 57.5, (MG) resp. 60.4 years (HMG). Cancer diagnoses were lung cancer (MG 50%, 14% HMG) and urogenital tumours (MG 13.3%, HMG 67.5%), mostly gastro-intestinal cancers (HMG 24%). Daily mean dosage of morphine was 104.9 mg (sd ± 100.5), and of hydromorphone was 27.5 mg (sd ± 23.4). Mean NRS for pain was 3.6 (HMG). Defecation rate were 0.94 per day (MG) and 0.9 (HMG). The stool free interval > three days (15% MG – 4% HMG) (p = 0.007), and NRS for constipation differed (3.94 MG – HMG 2.2). Patients used laxatives, and patients. Laxative use comprised polyethylene glycol (HMG 40 %, MG 65 %), sodium-picosulphate (HMG 24 %, MG 25 %) (p > 0.08), mostly (multiple answers possible). Conclusion Constipation signs were more frequent in patients with a morphine therapy. In comparison with morphine hydromorphone seems to have less constipating effects.

Methylenediphenilamine as needed for Fatigue in Patients with Advanced Cancer – A prospective double blind controlled study

Lise Pedersen, Department of Palliative Medicine, Copenhagen, DENMARK, Mogens Groenovild, Bispebjerg Hospital, Copenhagen, DENMARK, Morten Aa Petersen, Bispebjerg Hospital, Copenhagen, DENMARK

Background: Fatigue is a highly prevalent symptom in patients with advanced cancer and has a strong negative impact on patients’ daily life. Medications capable of improving the subjective symptoms of fatigue would be useful, but insufficient evidence exists. The WHO fatigue trial in HIV patients and one phase II in cancer patients have indicated that methylenediphenylamine, a psychostimulant, can improve fatigue.

Aim To evaluate the efficacy of Methylenediphenilamine as needed for the management of fatigue in patients with advanced cancer.

Methods: A prospective controlled double blind

Abstract number: 585
Presentation type: Poster
Poster number: P171

Central Effects of Transdermal Buprenorphine, Fentanyl, and Oral Hydromorphone: a Prospective, Comparative Evaluation of 107 Patients with Cancer Pain

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Methods: A prospective controlled double blind

Abstract number: 587
Presentation type: Poster
Poster number: P173

Posters

Abstract number: 588
Presentation type: Poster
Poster number: P174

Non-recteal Malignant intestinal obstructions: 3 successive therapeutic phases over 80 cases

Guillemette Laval, Hôpital Andre Michallon, Grenoble, FRANCE, Catherine Arveux, CHU Grenoble, Grenoble, FRANCE, Marie-Laure Ney, CHU Grenoble, Grenoble, FRANCE, Jean-Philippe Mestrallet, CHU Grenoble, Grenoble, FRANCE, Laetitia Stefan, CHU Grenoble, Grenoble, FRANCE

A prospective medicosurgical protocol was implemented for 80 episodes of intestinal obstruction in 75 patients followed for 4 years at the Grenoble University Hospital. All 80 episodes resulted from unrecteal peritoneal carcinomatosis. An endoprosthesis was proposed whenever feasible. The protocol involved three successive therapeutic phases: the first phase involved a five-day attempt to relieve the obstruction with corticosteroids and to control the symptoms with antiemetic agents, anticholinergic, antiseretatory agents, and analgesics as needed. In the event of refractory nausea or vomiting with greater than 1.25 L gastric secretion, the second phase was initiated using somatostatin analog. If this treatment was ineffective after three days, phase three was undertaken with gastrostomy. Outcome showed that for the 80 episodes of obstruction, medical treatment enabled relief in only 28 cases (35% in phase I and 4 in phase II) and that symptoms were controlled despite persistent obstruction in 32 episodes (25 in phase 1 and 7 in phase II). Ten patients were relieved by the gastrostomy providing symptom control without a long-term nasogastric tube for 72 of the 80 episodes (90%). The remaining patients experienced persistent vomiting and acute gastric aspiration until death. Fifty-eight episodes (72% of overall total) were controlled for 10 days or less. Median time to gastrostomy was 20 days. Median survival was 30 days. These very positive results could be optimized by using somatostatin analog as first intention treatment instead of anticholinergic agents. The cost-effectiveness ratio remains however to be evaluated. In any case, this multidisciplinary work between palliative care and specialized medical and surgical teams demonstrated its usefulness for the management of terminally ill patients.

Abstract number: 589
Presentation type: Poster
Poster number: P173

Methylenediphenilamine as needed for Fatigue in Patients with Advanced Cancer – A prospective double blind controlled study

Lise Pedersen, Department of Palliative Medicine, Copenhagen, DENMARK, Mogens Groenovild, Bispebjerg Hospital, Copenhagen, DENMARK, Morten Aa Petersen, Bispebjerg Hospital, Copenhagen, DENMARK

Background: Fatigue is a highly prevalent symptom in patients with advanced cancer and has a strong negative impact on patients’ daily life. Medications capable of improving the subjective symptoms of fatigue would be useful, but insufficient evidence exists. The WHO fatigue trial in HIV patients and one phase II in cancer patients have indicated that methylenediphenylamine, a psychostimulant, can improve fatigue.

Aim To evaluate the efficacy of Methylenediphenilamine as needed for the management of fatigue in patients with advanced cancer.

Methods: A prospective controlled double blind
paired design, where the patient is his/her own control, has been used. Patients with advanced cancer and a fatigue score > 50 on a 0-100 VAS scale were included. The patients were given a box with 10 placebo tablets and 10 methylphenidate tablets wrapped in little plastic bags, individually numbered from 1 to 20 and packed in black boxes (10 placebo and 2 placebo, randomly arranged). When patients had taken at least 3 tablets they were regarded as evaluable. Primary effect parameters are the mean difference in the VAS scale for tiredness evaluated after 2 and 5 hours and secondary effect parameters are the other VAS scales in the "The Edmonton Symptom Assessment System" (ESAS). With a planned sample size of 14 evaluable patients the study has a power of 0.90 to detect a mean difference of 15 on a scale from 0-100 between active and placebo tablets. Results: Thirty-eight patients were included in the study. Twenty-six patients are assessed evaluable, 9 non evaluable, 2 patients have not handed in their papers and 1 is still being treated. The results of the statistical analysis will be presented at the congress.

Abstract number: 590
Presentation type: Poster
Poster number: P176

Feasibility of managing malignant pleural effusion by a chronic indwelling catheter at home
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Introduction: Malignant pleural effusion (MPE) is a common complication in metastatic cancer. In case of dyspnea, thoracocentesis and pleurodesis are considered standard palliative treatments. However, thoracocentesis frequently has to be repeated regularly and pleurodesis requires hospitalization. Furthermore, pleurodesis fails in a subgroup of patients. The PleurX Pleural Catheter – an indwelling catheter to drain MPE intermittently – is a relatively new option that allows for the diagnosis and planned placement in hormone resistant prostate cancer patients with spinal cord compression treated with radiotherapy. Patients and Methods: Consecutive patients treated at the Norwegian Radium Hospital from May 1996 to October 1999 participated in the study. Daily life activities were assessed at start and discontinuation of radiotherapy and 2 and 6 months thereafter using a questionnaire based on a slightly modified Barthel activity of daily living Index. The patients were followed to death. Results: 49 patients were evaluated. Time from debut of neurological deficits to start of radiotherapy was median 4 days. Median target dose was 30 Gy. Overall survival from start of radiotherapy was median 3.5 months. No complications were observed. Conclusion: Definite treatment of spinal cord compression should be considered in all hormone resistant prostate cancer patients in good general condition irrespective of the neuronal deficit.

Abstract number: 592
Presentation type: Poster
Poster number: P178

The Use of Bedside Sonography in a Palliative Care Unit
Otto Gehmacher, Palliative Care Unit, Hohenems, AUSTRIA, Alois Wüstner, Landeskrankenhaus Hohenems, Hohenems, AUSTRIA, Franziska Wagner, Landeskrankenhaus hohenems, Hohenems, AUSTRIA, Gebhard Mathis, Landeskrankenhaus hohenems, Hohenems, AUSTRIA

Introduction: Palliative care patients are severely ill and suffer from multiple complaints. On the one side unnecessary diagnostic procedures should be avoided, on the other side exact diagnosis is important to provide best symptomatic relief. We examined the use of bedside sonography in the set up of a palliative care unit. Methods: 100 examinations were performed on 62 patients. 83 patients underwent bedside sonography, whereas 17 cases were referred by the US lab of the medicine department. There was an emergency indication in 25 patients, 75 investigations took place under routine conditions. Results: 113 diagnostic procedures were performed. The most common indications for sonography were: abdominal discomfort (50%), ascites (39%), pleural effusion (35%), abdominal pain (28%), thoracic US (23%), tumor staging (26%), follow up (11%), internal jugular vein catheter (4%), and others (4%). Results: The examination lead to US guided interventions in 29 patients, drainage of pleural effusion 13 patients, ascites 6 patients, abcess 5 patients, central venous line, suprapubic catheter etc. 7 patients. In addition the findings of the US examination influenced the management in 37 patients, mainly by changing the drug therapy (26%). Others were placing of a urinary catheter or gastric tube and removal of drains. The US findings lead to cessation of life prolonging procedures in 2 cases. Conclusion: Bedside sonography is a well tolerated, cost effective diagnostic tool for severely ill patients. It helps to assess the patients condition and allows immediate therapeutic intervention. The diagnostic findings influence the therapeutic management and help to safe other investigations like x-ray and CT scans.

Abstract number: 593
Presentation type: Poster
Poster number: P179

Assessment and Treatment Ubedret of Constipation After Opioids in Palliative Care Patients
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Introduction and objectives: Patients with advanced cancer can suffer from pain and chronic received opioid treatment. Constipation is very common side effect. Usually doctor prescribing opioids should at the same time provide anti constipation treatment. But long term laxative drugs causes addiction. Material and Methods: Research involved 40 patients suffering from post opiod constipation and 40 patients with chronic non cancer pain after 65 years old. All of them had been previously treated with laxatives with poor Results. Afterwards patients were administered Ubedret – long acting cholestyramine inhibitor twice daily 1 tablet. Results: After use of Ubedret in patients with different kinds of cancers, chronic non cancer pain and opioid caused constipation – satisfying effect was achieved (normalization of intestinal activity). Moreover Ubedret protects from flatulence, normalizes urethra and bladder, improves quality of life. Conclusions: Palliative patients with diagnosed cancer and with non cancer pain in age of 60 and over treated with opioids should take preventively laxatives. Ubedret seems to be the best solution for alleviating guts activity.

Abstract number: 594
Presentation type: Poster
Poster number: P180

When nothing helps: Propofol in sedation and intractable nausea, ten years of clinical experience
Steffan Lundström, Palliative Medicine, Stockholm, SWEDEN, Carl Johan Fürst, Stockholm, SWEDEN

Background: When there is a need for sedation in end of life, benzodiazepines, neuroleptics and barbiturates are commonly used to achieve symptom control. In difficult cases, there are a few reports on the use of propofol. Also in intractable nausea propofol has emerged as an interesting alternative. We report on the use of propofol in 34 patients during the last ten years. Method: Since 1993 we have prospectively followed a Pfeil patient receiving propofol at our unit and collected demographical data, information on tumour burden, medication, lab parameters, symptom distress, subsequent death. Results: 21 patients were given propofol in order to obtain conscious sedation during the terminal phase when rapid dose escalation of diazepam, midazolam and neuroleptics was ineffective in achieving...
Abstract number: 596
Presentation type: Poster
Poster number: P182

A Strip Against Dyspnea

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RATIONAL: ENDS (external nasal dilator strips) are adhesive bands which contain a central elastic strip which provide a spring action. The possibility of recruiting ENDS in an uncontrolled effort of continuous breathing or decreasing the perception of exertion would be of major benefit in oncological dyspneic patients, namely in presence of a cachexia-asthenia-complex. METHODS: We present the preliminary results of a pilot study on the application of ENDS in oncological dyspneic patients. Patients with asthma or chronic obstructive pulmonary disease were excluded. Nine dyspnea complaining patients were included in this pilot study. The ENDS were applied at 8 AM and at 4 PM. Perception of dyspnoea was assessed after 12 hours after the first application of the ENDS, using a Likert scale: 0 = no efficacy, 1 = little, 2 = moderate, 3 = good. The tolerability of the ENDS was assessed by 0 = no tolerability, 1 = little, 2 = moderate, 3 = good. Finally, we also asked the patients whether they wished to carry on using the ENDS. The therapy with ENDS application was simply added and any other treatment provided was not changed otherwise. RESULTS: As a result of the application of ENDS one patient perceived a good improvement of dyspnea, three moderate, two little and three none. Tolerability was good for four patients and moderate for another one. One patient complained of a moist rhinopharynx but decided to continue. Seven out of nine patients decided to carry on with the application of ENDS afterwards. CONCLUSIONS: ENDS may be useful in cancer patients with dyspnoea. However further research is needed. With regard to the favorable cost/benefit profile a trial with ENDS may be considered as an adjunctive treatment regimen in patients suffering from dyspnoea related to muscle weakness in the astenia-cachexia syndrome.

Abstract number: 597
Presentation type: Poster
Poster number: P183

Calcium Conundrum: Not all hypercalcaemia in malignancy is hypercalcaemia of malignancy

Marjitle Drifhout, WL, Stf Palliative Care Services, Southport, GREAT BRITAIN, Karen Groves

This poster depicts four patient histories. All four were referred to the palliative care services with hypercalcaemia. 1. A patient who had the classical presentation and pathology associated with hypercalcaemia of malignancy. We discuss his treatment, response and outcome. 2. A patient with hypercalcaemia and atypical symptoms who turned out to have primary hyperparathyroidism. We discuss follow up, referral to endocrinologist and outcome. 3. A patient with hypercalcaemia and no symptoms, who was found to have vitamin D intoxication. This was the consequence of the medication prescribed to his renal impairment due to renal failure. We discuss treatment, follow up and outcome. 4. A patient who had hypercalcaemia and renal failure. He had a low phosphate level suggesting secondary hyperparathyroidism but proved to have hypercalcaemia of malignancy after all. We discuss his response to treatment and outcome.

Abstract number: 598
Presentation type: Poster
Poster number: P184

Sublingual atropine effectiveness in inadequate control of salivary flow: a randomized placebo-controlled, double-blind crossover study

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Objective: Inadequate control of salivary flow (ICSF) occasionally appears in cancer patients, leading to drooling or choking, and impairing the quality of life. Usual treatments include anticholinergic drugs, although there is lack of scientific evidence supporting it, and further controlled studies have been recommended. A randomized placebo-controlled, double-blind crossover study was designed to evaluate the effectiveness of sublingual atropine in the relief of ICSF in patients with upper digestive cancer. Methods: Twenty two consecutive patients with upper digestive cancer (11 women, 11 men) with ICSF >3/10 (VAS 0–10), no longer receiving oncologic treatment, were admitted to the study and randomized to receive atropine sulphate 0.5mg q6h (two drops) or equivalent drops of placebo during 48h. After a wash-out period of 48h patients were crossed over to the alternate regime for 48h. Impact of salorhoia (primary outcome) and choking, increased daily and social activities and global impact from ICSF (secondary outcomes) were evaluated by VAS at the beginning of the study and at the end of each intervention period. Adverse effects and patients’ preference were evaluated too. Results: No statistically significant difference between groups (atropine and placebo) was found for the impact of salorhoia nor any of the secondary outcomes. Mean score for salorhoia were 59.68 (S.D. 28.52) and 34.95 (S.D.27.68) at baseline and after atropine; 62.19 (SD. 27.59) at baseline and 40.07 (S.D. 30.53) after placebo (p=0.38). No differences in patients’ preference nor severe toxicity were reported. Conclusions: We conclude that in this population the atropine drops used failed to produce an improvement in subjective measures of the symptom when comparing with placebo, both in terms of relieving salorhoia and choking and of reducing the interference of the symptoms on daily activities and social relationship.

Abstract number: 599
Presentation type: Poster
Poster number: P185

Clinical and translational research in palliative care: a phase 1 study of the use of Infliximab (Remicade®) for fatigue in advanced cancer

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Background: Fatigue is common in palliative care patients. The inflammatory cytokine Tumour Necrosis Factor alpha (TNF-a) may be a mediator. Infliximab (Remicade®) is a chimeric monoclonal antibody to TNF-a licensed for treatment of Crohn’s disease and rheumatoid
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Implementation of Computerised Tools in Health Care Units – a systemic review

The Pat C - Project

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Background: Symptom treatment is one of the primary goals in palliative care. There are data showing that lack of systematic symptom assessment hinders optimal symptom relief. Symptom assessment can be facilitated by the use of computer based registration. However, the attitude to use new technology and computers varies. Previous studies have indicated that resistance among health care providers is a major obstacle. The goal of the present study is to obtain knowledge about different factors that can promote or hamper the process of introducing new technology in routine clinical practice.

Methods: During a literature study we have identified and described categories of importance. A systematic search was conducted employing the following search terms: barriers, computers, doctors, nurses, new technology, attitudes, health, palliative, pain, oncology, cancer, man-machine systems. Eleven studies met the inclusion criteria (description of implementation of computerised technology in a hospital ward, systematic approach, evaluation of the implementation) and were included in the review.

Results: Barriers against computer technology were reported as negative attitude or resistance (N=5). A concern was fear of reduced quality of patient care (N=3), however significant improvement in quality of care planning after the implementation was reported (N=1). The challenge of the role adjustment process can be related to disturbance of traditional patterns and changes in established routines (N=6). Knowledge about the process and both skills and utility must be considered, lack of training was reported (N=3) and understanding was connected to user acceptance (N=3).

Conclusion: There is an imperative need for development of a training program if implementation shall be successful.

Abstract number: 601
Presentation type: Poster
Poster number: P187

Permanent Percutaneous Drainage of Ascies in the Palliative Phase

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Introduction: In the palliative phase 15-50% of cancer patients develop ascities. Treatment is symptomatic. Technical options are a peritoneovenous shunt, high volume paracentesis and a permanent percutaneous drain (PPD). The use of a PPD is a relatively new option. We evaluated our experience with the PPD over the last two years. The catheter was placed percutaneously for permanent drainage. Patients may drain the ascites intermittently or continuously. Patients were followed after placement, however ascites was never recorded after death. Results: Since June 2002 13 patients received a PPD, 12 of them had been treated with regular paracenteses before (1–5, every 1–3 days). One patient drained the ascites continuously, the others intermittently (varying from once daily to once a week). Eleven patients were treated by a PPD until death (mean 45 days, SD 84). Replacement was necessary in 3 patients. In one of these 3 patients the PPD was replaced twice, because of dislocation and ascites leakage, respectively. The reasons for replacement in the other 2 patients were occlusion and insertion of the PPD in a pocket. Complications, which could be treated conservatively, occurred in 5 patients: ascites leakage in one and occlusion in 4 patients. In these 4 patients the PPD could be re-opened by flushing it. In 2 patients the PPD was removed: in the first because ascites production had stopped, in the second because of high viscosity of the ascites. In the last patient intermittent punctures were performed successfully thereafter. Conclusion: Permanent percutaneous percutaneous drainage can be a useful intervention for advanced cancer patients in the palliative phase. It enables patients to limit the hospital visits.

Abstract number: 603
Presentation type: Poster
Poster number: P189

TREATMENT OF NAUSEA AND VOMITING BY THE THREE STEP ANTIEMETIC LADDER IN PATIENTS WITH ADVANCED CANCER

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Introduction: We propose three step antiemetic ladder: the first step metoclopramide, haloperidol and tiethylperazine, the second step dimenhydrinate, dexamethasone, levoempropamozine and hyoscine butylbromide, the third step: setrons, octreotide and benzodiazepins. Aim of the study: Assessment of the usefulness of the three step antiemetic ladder in the treatment of nausea and vomiting in patients with advanced cancer. Material and Methods: Assessment of the treatment of N & V from different causes in 420 patients with advanced cancer. The intensity of N & V was measured by verbal scale: 0 - lack, 1 - weak, 2 - moderate, 3 - high N & V intensity of N & V. Symptoms were assessed three times: (1) at the beginning of care, (2) during the treatment and (3) at the last week of life. The treatment was beneficial if there was decrease or no change in the intensity of symptoms when there was no or mild intensity of N & V. The treatment was effective if increase in N & V intensity or no change in moderate or strong N & V was observed. Results: In comparison of (2) to (1) assessment, beneficial results were in 345 (82 %) patients: N & V intensity of N & V was reduced in 345 (82 %) patients: N & V remaining constant in 28 (6 %) patients. Lack of effect (N & V remaining unchanged) was observed in 75 (18 %) of patients. In comparison

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of (3) to (2) appraisal, beneficial effects were achieved in 357 (85%) patients; improvement in 118 (28%), no N & V in 105 (25%), no change (mild N & V) in 33 (8%). Lack of effect was observed in 63 (15%) patients. Conclusions: 1. The treatment of N & V according to the proposed three step antieptic ladder, is effective in 80% of patients with advanced cancer. 2. In above 15 % of patients control of N & V was unsatisfactory. More intensive treatment including drugs with supportive therapies and the symptoms were in effective antieiotics in this group of patients is recommended.

Abstract number: 604 Presentation type: Poster Poster number: P190

THE EFFECT OF COMPLEX DECONGESTIVE THERAPY (CDT) ON ADVANCED CANCER PATIENTS WITH LYMPHEDEMA (LE).

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LE is a common symptom in patients with advanced cancer. CDT (manual lymph drainage [MLD], compression therapy [CT] and physical/breathing exercises [PE]) is an effective management of radically treated cancer patients (e.g. postmastectomy). The aim of this study was to assess the effect of CDT on patients with progressing lymphatic insufficiency of advanced cancer. 15 patients (aged 48–82, median 60 years) of Karnofsky Performance Status median score 60 (20–60) were treated with a 2-week course of CDT (Monday–Friday). In one case CDT consisted only of CT due to discomfort. Within the treated upper limb edema group there were 6 cases of advanced breast cancer and 1 with malignant melanoma of the thumb. In the lower limb edema group there were 3 cases of cervical uterine cancer, 3 cases of malignant melanoma spreading to the inguinal nodes, 1 case of skin cancer of the lower abdomen and 1 case of hepatocarcinoma also spreading to the inguinal nodes. On both (upper or lower) limbs symmetrical circumstances measurements were taken every 4 cm, then the volume of the limbs was calculated using a simplified formula for the frustum. The effect of the CDT was measured by comparing the volume of the affected limb before and after the last session of the physotherapy and also by comparing the volume of the edema (difference between the ill and the healthy limb). Additionally, Quality of life (QoL) was assessed using the ESAS scale. A marked reduction of the affected limb (from median 8260.9 ml to 7681.1 ml; Wilcoxon paired test, P<0.05) and also of the size of the edema (from median 2521.5 ml to 1189.4 ml; P=0.001) was seen. In the QoL the mean ESAS level (1–10 points) decreased from 3.2 points to 2.7 points; P<0.01. We did not observed marked correlations between volume changes and CDT. CDT plays an important role in the hospice care. It markedly reduces the affected limb volume and decreases the edema Vlysin 134 (without worsening the QoL).

Abstract number: 605 Presentation type: Poster Poster number: P191

ASSESSMENT OF PREVALENCE OF SYMPTOMS AND EFFECTIVENESS OF SYMPTOM RELIEF for 803 PATIENTS WITH ADVANCED CANCER

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INTRODUCTION & OBJECTIVES: Clinical experience suggests that optimal palliative care can effectively control symptoms of cancer patients (pts) during most of the course of the disease. PATIENTS & METHODS: This paper assesses the incidence and prevalence of 14 symptoms and effectiveness of symptom control for 803 pts with advanced cancer treated in Palliative Care Team in Wroclaw during two years. Pts were divided on subgroups related to the previous stage of the cancer: gastrointestinal, gynecological, urological, head and neck, lung, breast and others. Results: Pts were admitted late, with significant impairment in physical (activity) efficiency, 25% died within 3 weeks; in many cases it was the cause of problems in symptom control. Pts with advanced cancers were polysymptomat. Most frequent symptoms were: weakness - 96%, pain - 89%, loss of appetite - 81%, insomnia - 63% and constipation - 61%. Mean number of symptoms per patient was 6, 7. Factors that contributed to the symptoms were: age, performance status, and primary site of cancer. Five symptoms were related to age: confusion, pressure sores, breathlessness, loss of appetite and dysuria. (median score in pts >65 yrs). Pressure sores, confusion, urinary symptoms, dysphagia, anorexia, constipation and weakness were related to impaired physical activity (ECOG ≥3). In the each of the six groups of primary site cancer some related symptoms were detected. Symptom control was effective in the treatment of bleeding, insomnia, constipation, nausea/vomiting, confusion, diarrhea and loss of appetite. Pain treatment with the WHO ‘analgesic ladder’ was effective in 82% CONCLUSIONS: The management of multiple symptoms in pts with advanced cancer is one of the most challenging aspects of care. Multidisciplinary approach and individualization is required.

Abstract number: 606 Presentation type: Poster Poster number: P192

Non-pharmacological management of end stage breathlessness

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Non-pharmacological breathlessness programmes have been advocated for a number of years, and usually follow 1.1 sessions over 3–6 weeks in an outpatient setting (i). We report our 2 year experience of a community based flexible programme for breathless patients with advanced disease. 43 patients (14 female) were included: mean age 71 (range 50–83). Most had intra-thoracic malignancy (23 lung cancer, 8 mesothelioma, 9 other secondary cancer) and 3 had end stage disease. ‘First stage’ breathlessness was tumour related in 24, due to other medical conditions in 15, anxiety related in 22 and treatment related in 4. Interventions included advice on cognitive strategies, breathing techniques and relaxation. In addition information about other services (social work, psychology, occupational therapy and support groups) was given. Of the patients referred 7 were not seen (6 died, 1 refused), 19 received some or all of the interventions described above and were subsequently discharged (though they may have since died), 16 were seen and advised but disease progressed and they died during follow up and 9 needed other support. The mean number of interventions was 3 (1–12). Mean survival from first intervention was 98 days (1–358). 7 patients are still alive. Although all patients described subjective benefit from the interventions, objective symptoms appear to be difficult to obtain because of the progressive nature of their disease. This should not deny such patients receiving this type of programme. (ii) Corner et al. Non-pharmacological intervention for breathlessness in lung cancer Palliat.Med 1996; 10:299–305.

Abstract number: 607 Presentation type: Poster Poster number: P193

Depression – Grief – Demoralization: what means sadness in terminally ill patients?

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The development of a major depression occurs in nearly one third of all patients with cancer in different stages of their disease with increasing frequency during progression of disease. Despite of good therapeutic options and effectiveness of medical therapy, only few of these patients receive an adequate therapy. Several reasons cause this phenomena. One cause could be, that feelings like grief and anxiety or symptoms like demoralization and fatigue are very difficult to distinguish from the clinical diagnosis of a major depression for physicians and other medical staff without special psychiatry knowledge. There exist some strategies for differentiation between the normal process of grieving, physical symptoms and the diagnosis of a major depression. This trial wants to point out the differences between these symptoms. These strategies could be helpful for assessment of the patient’s situation which lead to a sufficient therapy and psychological support. Especially in terminally ill patients with short life expectations it is very important to have good instruments for diagnosis of psychiatric disorders. This can lead to a sufficient therapy to improve quality of life of our patients.

Abstract number: 608 Presentation type: Poster Poster number: P194

Treatment of paroxysmal nausea and vomiting in a patient with meningococcal sepsis

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Paroxysmal syndromes are well-known in neurology, e.g. as manifestations of multiple sclerosis (MS). The literature reports a few cases of paroxysmal nausea and vomiting in MS patients. These symptoms appear to be difficult to distinguish from the normal process of grieving, physical symptoms and the diagnosis of a major depression. This trial wants to point out the differences between these symptoms. These strategies could be helpful for assessment of the patient’s situation which lead to a sufficient therapy and psychological support.
Nausea and vomiting stopped after a first dosage of 100 mg. The EEG showed paroxysmal excitations. The next day the syndrome returned, and we started a medication with 400 mg of carbamazepine per day. This allowed the patient to sit and eat without vomiting. Thus, paroxysmal syndromes can be the cause of apparently therapy-refractory nausea and vomiting in patients with cerebral tumor involvement, and respond well to anticonvulsant medication.

Abstract number: 609
Presentation type: Poster
Poster number: P196

Nausea and Vomiting – the development of clinical guidelines based on current practice and literature

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Background Nausea and vomiting are common symptoms in palliative care and can have a significant impact on quality of life. However, there can be wide variation in how these symptoms are managed. Objectives 1. To review current management of nausea and vomiting by palliative care specialists. 2. To develop practice and evidence-based guidelines for the management of nausea and vomiting. Method A multicentre prospective study, over a two-month period, of palliative care patients from the community, hospital and community. A doctor or nurse completed a proforma on each patient with symptoms of nausea or vomiting during this period. The proforma recorded patient demographics, the underlying cause of the symptoms, investigations undertaken, and pharmacological management. Symptoms were scored over a ten-day period. The scale used was based on the PCA tool. Any changes to the management of the symptoms were documented. Results Proformas were completed on 90 patients. In 39% the cause of the nausea and vomiting was felt to be multifactorial. The majority of patients (91%) had their biochemistry checked. There was wide variation in the drugs used for specific causes of the symptoms. The majority of patients (91%) had symptoms that were managed with moderate or mild symptoms were receiving their medications by the parenteral route. After 4 days of specialist intervention, symptoms were controlled in 32% of patients. Conclusion This study, along with a review of the current literature, has lead to the development of standards and guidelines for the management of nausea and vomiting, which have been disseminated across the cancer network.

Abstract number: 610
Presentation type: Poster
Poster number: P197

Unbearable and intractable suffering in terminally ill patients

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Introduction In palliative care direct symptom management has to be one of the priorities in treating terminally ill patients. Nevertheless symptom management may be uneventful and the patient is suffering to a great extent. The quality of symptom management may vary: the knowledge and experience of the medical and paramedical personnel, the possibilities to perform adequate treatment are important factors. The purpose of this study was to investigate when patients, medical and paramedical personnel are convinced of a situation of unbearable and intractable suffering in terminally ill patients. Methods A still going study, according to the Delphi methodology, is performed in a panel of 20 persons, non-medical, medical and paramedical practitioners, spread across the Netherlands. Their reasoned opinions are expressed in three written rounds of questioning. The main questions are around formulating concepts to define unbearable and intractable suffering. Results and Discussion The results will be presented at the conference. The preliminary results show that the panelists have different intuitions is difficult. However, defining unbearable and intractable symptoms in terminally ill patients is crucial in taking medical decisions.

Abstract number: 611
Presentation type: Poster
Poster number: P198

Pre-emptive breath therapy in combination with rich nutrition therapy at terminal cancer patients in a hospice

Jacob Van Den Broek Amsterdam, NETHERLANDS, Jaap Gootjes, hospice kuria, Amsterdam, NETHERLANDS, Wouter Zuurmond, hospice kuria, Amsterdam, NETHERLANDS, Corry van Tol – Verhagen, hospice kuria, Amsterdam, NETHERLANDS

Introduction: During the last six weeks at the terminal phase about 70% of all cancer-patients are suffering from respiratory problems. Dyspnoea is a very difficult to treated symptom. Studies also show that there is a need for a method to prepare patients and caregivers for this kind of dyspnoea. It is assumed symptom in different kind of situations and to increase(in this way) the quality of life. Respiratory problems are distressing and frightening for both the patients and the caregivers. Method: In three hospices in the Netherlands 100 cancer-patients with a life expectation less than six weeks will be treated by a physiotherapist. The method contains a specific individualized intervention, especially breath therapy in combination with relaxation therapy, advices and instructions. To increase the interdisciplinairy character, members of an interdisciplinary team (for example a physiotherapist, a doctor, a psychologist) are involved in these methods. Specific functional instructions for these interventions are given by a physiotherapist to all members of the interdisciplinary team. The control group contains a dossier-research of 100 comparative cancer patients, which had not been treated in this way. Results and Conclusions: First outcomes shows that pre-emptive breath therapy and specific individualized advices and instructions gave the patients more self-control during both resestitations and activities. Moreover, the patients developed more self-confidence and less fear in situations of dyspnoea or related symptoms. Pre-emptive breath therapy seems to show an increased quality of life by better breathing and energy consumption.

Abstract number: 612
Presentation type: Poster
Poster number: P199

Algorithm for stepwise approach of the patients with ileus in palliative care

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Many patients in palliative care may encounter episodes of nausea, vomiting, abdominal pains and constipation mimicking a bowel obstruction. But complete (obstructive) ileus is an infrequent problem (3%) in the palliative setting. Some patients will be cured by surgery, but many will not improve after laparotomy and may benefit from non-surgical interventions. Often it remains unclear which factors may have lead to a final medical decision. We developed an algorithm (A) to aid the doctor in the diagnosis of true ileus and in the discussion which terminal ill patient should be treated either by surgery or conservative measurements initially. The different steps were based on literature search and completed after discussion with professionals. Secondly A was tested in all successive patients admitted for suspected ileus in an intervention palliative bed of a university hospital during a 3 months period. The registrar of the unit was instructed in the use of A; the treatment was based on his decision and was discussed daily with a senior palliative care doctor (author). Seven patients were identified fulfilling the criteria. The mean age was 61 (42–75) years, 3 males; one patient suffering abdominal metastases of lung cancer, 3 had primary gynaecological tumours and 3 a maligancy of the digestive tract. Six patients benefited directly from this stepwise approach, 1 patient developed alarming symptoms of bloo-out of the coecum and was referred to a surgeon who needed surgery. Relief was reached with a mean of 3.5 (2–5) days. Overall survival was 21 (3–120) days with 3 patients dying from other causes (3, 10 and 120 days) and 4 dying from ileus (7, 16, 30 and 60 days). The registrar was confident in his decisions and felt comfortable during discussions with consultants. This confirms the initial question that using an algorithmic stepwise approach of a patient presenting with ileus in the palliative care settting will be of benefit for both doctor and patient.

Abstract number: 613
Presentation type: Poster
Poster number: P200

SUBCUTANEOUS ANTI-TUBERCULAR THERAPY WITH INJECTED GENERATION CEPHALOSPORINS. A PROSPECTIVE STUDY WITH HOSPITALIZED AND HOME-BASED Palliative PATIENTS.

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The objective of this prospective study was to evaluate the feasibility and tolerance of subcutaneous ceftriaxone in terminal patients both hospitalised and home-based. In two previous pharmacokinetics articles already published. Ceftriaxona Combino Pharm 1–2g EFG was administered, from ampoules for intramuscular use (ceftriaxone 1g, sterile water 5.3 ml) and lidocaine hydrochloride 35mg), diluted in 50–100cc saline solution, administered over 10–20 minutes using a 21G subcutaneous butterfly needle exclusion of administration on abdominal region. The group at the Palliative Care Unit at the Hospital Los Montalvos, Salamanca (SA) treated 12 hospitalised cancer patients (10–4–4.5 days). The Group from

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Odivelas, Lisbon (L) treated 32 patients (9 with cancer, 23 without) in their homes (3+/–1.88 days). Parenteral antibiotherapy was indicated in the majority of cases for respiratory infections with fever (38º+/–1 in SA, 37.7º C+/–1.2 in L) or, only in L group, for symptomatic treatment of respiratory secretions. The subcutaneous route was indicated where patients presented veins in a poor state (9 patients), agitation which advised against IV administration (4), rejection of IV treatment (5), deterioration of the patient, making the IV route unadvisable (19) or for home based patients (32). A total of 128 infusions were studied in SA and 96 in L. In no instances was treatment suspended due to local intolerance and signs of local irritation (12 of 224 infusions) were managed without complications by changing the injection site (reddening (7), indurations (1) or bleeding (4)). Local discomfort was 0/10 in SA and 1/10 in L. The temperature at the end of study was SA 37 ºC, L 37.3. In terminal phase patients, when it be indicated, subcutaneous ceftiraxone administration is an alternative to intravenous administration, both for hospitalised and home-based patients.
ABSTRACTS OF INVITED LECTURES,
ORAL PRESENTATIONS AND POSTERS

10 APRIL 2005
Invited lectures and oral presentations
Confusion with confusion: Delirium or not?
Raymond Voltz, Department of Palliative Medicine, Germany

One of the most prevalent neuropsychiatric syndromes in oncological patients in palliative care is confusion. ‘Confusion’ is not a disease entity, but a symptom. It can be a sign of an epileptic seizure (non-convulsive status), delirium, psychosis or – which is the most prevalent reason in palliative care – delirium. In the terminal phase, delirium is described in up to 80% of oncological patients. In 2/3 it is not recognised and therefore not treated adequately. In up to 50%, a reversible cause can be identified and treated (e.g. drugs, hydration). Symptomatic treatment consists of general measures (communication, environment) as well as of drugs (e.g. haloperidol, low-potency neuroleptics, benzodiazepines, which must be used in a differentiated according to the probable causes).

In single cases, it may be very difficult to treat an agitated delirium using conventional measures. Therefore, besides severe pain and nausea, delirium is one of the most frequent causes for the necessity of palliative sedation. This may be an ethically, medically and legally justified measure in these exceptional patients. Several studies have shown that if done correctly, this palliative sedation does not hasten death, and can therefore be distinguished clearly from any form of active euthanasia.

Delirium in palliative care, diagnosis and treatment
Augusto Caraceni, National Cancer Institute of Milan, Italy

The problems and the opportunities posed by delirium to palliative care clinicians are unique. Delirium is a syndrome which crosses the borders between, at least, neurology, psychiatry, geriatrics, intensive care, and internal medicine. Palliative care can bring an original contribution to the definition and therapeutics of delirium, due to the high incidence of delirium in advanced progressive illness and to the specificity of taking care of dying patients: delirium has been indeed described as a way of dying. Delirium is a complex syndrome and requires accurate assessment, diagnostic ability and experience. It also has psychological and management implications which should involve nursing and support expertise for the patient and the family. Accurate evaluation of risk factors and causes is paramount and in particular palliative care specialists are called to evaluate the avoidance of causes of delirium, their pathogenic role and the strategies to avoid it. Pharmacological management is also very important it can range from the conservative treatment of slight to moderate situation with neuroleptics to sedation. In conclusion, palliative care clinicians have learned early on to master pain control. Cicely Saunders already pointed out at the beginning of the hospice movement, that other symptoms, and delirium in particular, were going to be as challenging and important in the clinical armamentarium of palliative care, and still today delirium remains one of those.

OPIOID ROTATION – DOES IT WORK?
Sebastiano Mercadante, La Maddalena Cancer Center Italy

While morphine remains the opioid of choice for its familiarity, availability, costs rather than proven superiority, a substantial minority of patients do not have a successful outcome because of excessive adverse effects, inadequate analgesia, or a combination of both. Individual patients may not respond in their response to different opioids. Patients with poor analgesic efficacy or tolerability with one opioid will frequently from the administration of another opioid. Sequential opioid trials may be needed to identify the drug that yields the most favourable balance between analgesia and adverse effects. The biological basis for the individual variability in sensitivity to opioids is multifactorial. The frequency of opioid switching is increasing in acute palliative care units, probably as a consequence of a better knowledge and improved monitoring of the cognitive function in patients who receive higher doses of opioids. Available equianalgesic tables assist physicians to estimate the adequacy of the doses when switching opioids. However, these tables derive from the results of earlier studies or relative potency ratios using single dose crossover Design. Moreover, differently from what happens in cancer management, these studies focused on patients with a limited opioid exposure, both in duration and dose. Thus, the applicability of these equianalgesic ratios during chronic and terminal opioid administration has been questioned in the last years, also on the basis of a better knowledge of the basic mechanism of opioid tolerance.

Unfortunately, most studies regarding opioid switching have been including different indications, such as intolerable adverse effects with good pain control, convenience, poor pain control and adverse effects, uncontrolled pain with increasing doses of opioids, among others, so that the conversion ratios are hard to apply. Relatively large series published on opioid switching have reported a clear benefit using different opioid sequences, with an improvement in adverse effects in 70-80% of cases, using, lower doses of opioids than expected, when considering the questioned tables of conversion. Despite the lack of controlled studies, opioid switching seems a relevant instrument in cancer pain management.

Opioid rotation – does it work?
Andrew Davies, Royal Marsden Hospital UK

"Opioid rotation" ("opioid switching", "opioid substitution") is a strategy that is used to try to improve analgesia and/or reduce side effects from opioid analgesics. Contrary to popular belief, the strategy is not a new one. Indeed, the strategy was being utilised by palliative care physicians in the late 1960s/early 1970s (and probably beforehand). Nevertheless, the term "opioid rotation" was only introduced in the early 1990s.

Opioid rotation has become an established management strategy. However, the evidence base to support the strategy is limited. In particular, there is little evidence that this strategy is more effective than other strategies, e.g. dose reduction (for opioid toxicity).

Furthermore, at the current time, the results of opioid rotation are completely unpredictable. Indeed, patients not infrequently deteriorate following opioid rotation.

Further research is required to determine the role(s) of opioid rotation in clinical practice. One important strand of research is pharmacogenetics, where researchers are attempting to identify specific genotypes that will predict the response (analgesia / side effects) of individual patients to individual opioids. However, clinical studies are also required, including clinical studies comparing opioid rotation to other strategies.

Social care – how important is it?
David Oliviere, Education and Training, London, GREAT BRITAIN

The "social" introduces the wider context in which palliative care operates. This brief presentation will locate "social" pain within “total” pain model and will conceptualise social care as incorporating individual, family, group and community relationships.

This includes society’s institutions, which determine not only the quality of housing, finance, recreation and care provision but also issue of discrimination and exclusion. The integration of social aspects with all other dimensions of the holistic approach is emphasized. The process of assessing and intervening with social aspects must respect the symbiotic nature of socio-cultural, psycho-social and professional-patient partnerships. The complexity of working in the area of social care will be demystified in the interaction with the session’s participants.
family, and everybody involved
- Psychosocial rehabilitation of the patient and family through identification and activation of existing resources
- Facilitating grief and bereavement interventions.

There is a dire need for psycho-social research in palliative care: theoretical clinical background for social work in palliative care is lacking, and little research has been conducted on this topic so far. In times of diminishing resources, it becomes more and more important to demonstrate the efficacy of social work in this field. Moreover, research findings can help to develop interventions that can be tailored to the specific needs of the patients and families.

Abstract number: 620
Presentation type: Invited
Poster number: 620

The Changing Face of Opiate Consumption in the USA
Declan Walsh, The Cleveland Clinic Foundation, Cleveland, Ohio, USA

The rapid increase in the use of morphine in the United States has been overshadowed by the large increase in the prescription of oxycodone and fentanyl. In specialists practice methadone is rapidly finding favor and this is likely to influence non-specialists and community prescribing in the near future. Progress has been made in working with state medical boards and other regulatory bodies in encouraging physicians in prescribing opioids appropriately. Notable advances have also occurred in the education of pharmacists, nurses, and physicians in safe opioid use.

Challenges remain (even amongst cancer specialists) to ensure high quality opioid use. Errors in opioid prescribing are frequent and multiple. Poly opioid use is common, partly because of the general increased acceptance of opioid use. Recent acceptance of the role of methadone will challenge education, research, and clinical practice because effective use requires very different strategies to those taught for other opioids over the last 20 years.

The development of alvimopan and dextromethorphan may influence prescribing significantly if they are officially approved. Availability of methadone is a continuing problem. Parenteral oxycodone is unavailable in the United States. A sustained release formulation of hydromorphone has just been approved. Intravenous oxymorphone and other opioids are under continuing investigation for utility in clinical practice.

The clinical, regulatory, and legal controversy concerning oxycodone has raised old fears and prejudices concerning opioid use. The final effects of this are still unclear and unpredictable. Appropriate use of opioids has improved substantially, and the future for further progress appears bright. This must be accompanied by appropriate continuing education. Clinical research, systematic education, and political wisdom.

Abstract number: 621
Presentation type: Invited
Poster number: 621

Opioid consumption - trend and changes
Rainer Sabetowski, Pain Clinic, Cologne, GERMANY

The options for opioid therapy have expanded considerably within the last decade. New drugs and new drug application forms such as transdermal fentanyl, oral transmucosal fentanyl and s.r. oxycodone and hydromorphone have been released in the recent years. Opioids are accepted as a cornerstone in the treatment of cancer pain. The recent national drug report describes a constant increase of opioid consumption in Germany over the last years, indicating an improvement of pain management. Turkey is a part of drug prescription 1.6 million defined daily doses (DDD) of s.r. morphine had been prescribed in 1990 and this number had increased to 15.6 million DDD in 2001. While the introduction of the DDD of s.r. morphine decreased slightly, the amount of other opioids prescribed increased even more. However, these data do not differentiate between prescription for cancer and non-cancer pain. Therefore, conclusions on the impact of overall increased opioid consumption on pain management can not be drawn. In fact, results of a representative regional health insurance survey gave evidence of major drawbacks. Predominately WHO-step 2 opioids and opioids with non-modified release were prescribed and most patients received opioids only for short periods of time. Continuous therapy with WHO-step 3 opioids was rare. The analysis of opioid prescription for cancer patients who died of their disease, demonstrated that those patients received less than one DDD per day for pain treatment in the last year of their life. These data suggest a non-adherence of existing guidelines. The procedure of prescribing WHO-step 3 opioids, even though a special tripartite prescription form is still necessary, has undergone several revisions in the last years. Several restrictions have been lifted. Despite of increasing opioid consumption and alleviation of governmental regulations, undertreatment of cancer pain is still a significant problem for many patients.

Abstract number: 621B
Presentation type: Invited
Poster number: 621B

How to establish palliative care programs
Stein Kaasa, Department of Cancer Research and Molecular Medicine, Tromso, Norway, Kathy Foley, Memorial Sloan Kettering Cancer Center, New York, USA

There has been an discussion for several years on how to optimise educational programs in palliative care. This challenge is solved differently in various countries. In several European countries the strategy has been first to establish educational programs and then to formulate guidelines on how to organise palliative care within each country. Quite often have these initiatives been guided by individual pioneer programs.

Ten years ago a university based palliative care unit was established in Tromsø, Norway. During the development process we have been able to complete the program with an outpatient consultation/homecare program and recently a chronic unit/hospice in a nursing home as a part of the close collaboration between the hospital and the community service. We have developed a comprehensive research program with its base at The Medical Faculty with close collaboration with basic scientists, clinicians and in several groups in the social and drug sciences.

On the one hand individual initiatives are important, however on the other it is important to see programs as a part of the public health care plan in order to have palliative care included as a part of the entire health care program. In order not to be too vulnerable for political and/or economical shifts a long term strategy not only building up a program full; and there is growth, but also on pre- and postgraduate formal teaching within palliative care seems appropriate.

Another example of ways to foster the development of palliative care programs has been initiatives developed by the Project on Death in America, a nine-year foundation supported effort in the United States to transform the culture of death in America. This initiative supported the development of physician, nursing and social work leaders, who would serve as role models to develop and sustain palliative care programs in academic centers and in a variety of clinical settings.

In this initiative, 87 Faculty Scholars, predominantly physicians and 6 nurses, developed programs within their academic institutions ranging from palliative care services to palliative care units to clinical research programs and policy institutes. Forty-four social work leaders were appointed, which bridged the gap between clinical and academic social work programs serving as leading authorities on the role of social work in end-of-life care.

Nursing leadership was fostered through the development of educational programs among nursing associations, who supported broad educational initiatives for nurses in undergraduate, graduate and advanced level training programs.

By creating role model leaders in palliative care in the medical, nursing and social work professions, the Project on Death in America has left a legacy of committed individuals who form a formal and informal network collaborating to address research and programmatic aspects of palliative care within the United States.

Abstract number: 622
Presentation type: Invited
Poster number: 622

PALLIATIVE CARE IN EUROPE: A VIEW ACROSS THE BORDERS
Michael Wright, International Observatory on End of Life Care, Lancaster, GREAT BRITAIN

Reviewing European palliative care development presents methodological challenges due to various understandings of ‘Europe’, different interpretations of ‘hospice’ and ‘palliative care’ and disputed evidence on the ground. Currently, several groups are engaged in such projects including an EAPC task force. A study that focused on central and Eastern Europe and Asia received the support of the International Observatory on End of Life Care, formed in 2003 (www.eolc-observatory.net). In western Europe, most founding services were established before the mid-1970s and in the central and eastern Europe (CEE), they emerged after the collapse of communism. Alongside the development of palliative care services has been the growth of organisations designed to provide support: WHO has advocated for pain relief since the early 1980s; EAPC represents over 50,000 members; ECEPT promotes palliative care development in CEE; OSI has worked towards changes in health care policy; the UK Forum has brought together worldwide national associations; and NPHCO has assisted in standards development. These initiatives have been guided by individual pioneers. There has been an increasing recognition of the issues involved and the need for sustained political commitment.
Pain arising from nerve injury is a major challenge for clinicians to treat and neuroscientists to unravel. It can be divided into peripheral and central neuropathy for example cancer induced brachial plexus (peripheral), metastatic lesion in spinal cord (central).

Neuropathic pain has cardinal features clinically, allodynia, hyperalgesia, hyperpathia, spontaneous pain and negative features including areas of numbness. Animal models attempt to mimic the symptoms of neuropathic pain and offer a means of investigating the peripheral and central pathophysiological changes. In addition they offer a means of investigating the efficacy of drugs, although the correlation between animals and humans is never exact. This part of the symposium will concentrate on the basic pathophysiology of neuropathic pain. The majority of animal models are not necessarily cancer related, except for the chemotherapy induced peripheral neuropathies and the unique features of cancer-induced bone pain. Few models of cancer induced central neuropathy exist and information is extrapolated from other animal models and symptoms from clinical states. A general review of animal models as correlates with clinical efficacy will also be presented.

Definition and diagnosis of neuropathic pain in cancer

Raymond Voltz, Department of Neurology and Interdisciplinary Palliative Care Service, München, Germany

Neuropathic pain refers to pain mechanisms thought to be related to pathology in the somatosensory pathway, both in the peripheral and/or central nervous system. Diagnosis of neuropathic pain in cancer relies on clinical examination (most important in palliative care), laboratory tests and invasive procedures (helpful in palliative care). The clinical examination relies on (1) symptoms reported by the patients (spontaneous pains, such as dysesthesia, paresthesia; stimulus-evoked pains, such as hyperalgesia, allodynia, etc.), (2) the neurological findings (pattern of sensory disturbance, associated findings, bedside tests such as pinprick, thermal, vibration, etc.), (3) quantitative sensory testing (Frey hairs, vibrometer, weighted needles), (4) pain quality and intensity scales (VAS, Likert NRS, VRS, MPQ, LANSS), (5) assessment of other dimensions (Qol, mood, sleep, anxiety, depression). Laboratory tests may encompass (1) standard electrophysiological studies, (2) microneurography, (3) nociceptive reflexes, (4) laser-evoked potentials, and (5) functional neuroimaging. A biopsy will most likely not add to the treatment in palliative care.

Neuropathic pain may be differentiated into predominantly peripheral and predominately peripheral (polyneuropathy or mononeuropathy). Mononeuropathies may be divided into lancing neuropathies, activation of nociceptive nerve fibrils, and aberrant activity in injured neural structures. Neuropathic pain in cancer differs from neuropathic pain in chronic neurological disorders, regarding time aspect mechanism and associated nociceptive pain. Therefore, treatment flowcharts should differ between those two scenarios.

Pharmacological treatment evidence-based review of drug trials. Do we have clinical guidelines to offer?

Augusto Caraceni, National Cancer Institute of Milan, Italy

Data on the efficacy of drugs for neuropathic pain derive mainly from controlled clinical trials (CCTs) on non malignant chronic neuropathic pain conditions. In this area several metaanalyses of CCTs support the efficacy of tricyclic antidepressants (amitriptyline, imipramine desipramine) and of anticonvulsants (carbamazepine, phenytoin, lamotrigine, gabapentin), recently also opioids were tested in CTR for neuropathic pain syndromes. These metaanalyses specifically addressed the effect of pharmacological therapy in cancer pain with neuropathic pathophysiology. One of the limitation in this field is the definition of neuropathic pain due to cancer, that is discussed by another speaker in this session. Another only partially resolved question is: is neuropathic cancer pain less responsive to treatment than neuropathic pain due to cancer. Only two clinical trials of good quality are available to show a modest effect of amitriptyline in improving neuropathic pain due to cancer and a clinically significant effect of gabapentin in 51% of the days of administration, comparing with 37% of response days with placebo, when this drug is combined with opioids in patients with neuropathic cancer pain. The problems posed by designing, performing and evaluating this type of analgesic trials will be discussed.

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Invited lectures and oral presentations

institutional implications will be mentioned to be explored in subsequent papers.

Abstract number: 630
Presentation type: Invited
Poster number:
Individual and Institutional Stress
Tine De Vlieger, Universitaire Instelling Antwerpen

Introduction: A good managed team is the key to deliver good work. Caregivers in palliative care are daily confronted with all aspects of life and death. Social skills help us to deal with patients, their family and colleagues in care. Managing a team in palliative care is create forum for reflection about care ethics, support and offer education and training in communication, teamwork, self-care and stress management.

Objectives: It is a challenge for management to create a team spirit that lead to high quality of care, improvement of teamwork, recognition and reduction of stress factors and personal growth.

Methods: Give recognition and valuing to each team member and the team. Invite the team members as an individual and group to reflect upon work-aims, teamwork, inconveniences in work and personal work needs as guidance, motivation, education, stress.

Plan regular workmeetings were care experiences can be exchange and vision and guidelines can be made or followed up. Invite minimal twice a year each team member to participate at an employee evaluation with the manager to receive functional feedback. Oblige participation to regular intervention. This method give utterance to care for the caregivers as an important part of management and a method of support. Oblige to follow courses in stress management and self-awareness.

Setting: Network for palliative Care Antwerp, Flanders, Belgium

Conclusion: Teamwork is an essential tool to provide palliative care. The team members are the key in the organisation to reflect about the quality of offered care, organisation – and work structures. They are also important to balance the effectiveness of the management. For the manager of the team it is a continual challenge to be aware of the needs and growing pains of a team. Learn the team and the team members to achieve a deeper understanding in interpersonal relationships and management possibilities is an important task.

Abstract number: 631
Presentation type: Invited
Poster number:
Teamwork as a central concept in palliative medicine
Martina Pestinger, Universitätsklinikum Aachen, Aachen, GERMANY, Saskia Jungfer, Klinik für Palliativmedizin, Aachen, GERMANY, Frank Elsner, Klinik für Palliativmedizin, Aachen, GERMANY, Lukas Radbruch, Klinik für Palliativmedizin, Aachen, GERMANY

Teamwork is well accepted as a central instrument for the comprehensive approach of palliative care. Non-hierarchical structure, competence in the own area of work, estimation of the other team members and high esteem for professional team a vast range of different backgrounds and know-how has been merged. Different stages of integration in the team have been established with central members, liaison and counseling from other services and volunteers. Team forming procedures as well as the organisation of working procedures are in development. Finding a group identity and a collective strategy is of major importance for effective cooperation, especially in the forming phase. This is closely related to the ability of the team to get involved in emotional learning procedures. On the other hand team forming may build up pressure towards group conformity with typical risks such as loss of profile of those team members with specific expert knowledge or loss of tolerance for diversity for example for different priorities in the therapeutically approach. This raises the question about the decisive factors of a good palliative care team. Further on what kind of resources and supportive measures are needed to meet the challenges of multi-professional work? The study represents results of a qualitative action-research oriented approach.

Methods of investigation were semi-structured interviews and participant observation as well as specific interventions such as consensus workshops towards the common operational aims of the team. First results of the organisational development are presented and experiences with methods of staff support are reported.

Abstract number: 632
Presentation type: Invited
Poster number:
Palliative care research: ethical issues
Jane Seymour, School of Nursing and Midwifery, University of Sheffield, Sheffield, GREAT BRITAIN

This presentation will introduce the teaching session ‘Research – ethics’. In palliative care research, ethical issues feature in two ways: first, in debates about the ethics of research conduct in palliative care (ethics in research) and, second, in attempts to acquire a better understanding of ethical dilemmas and perspectives involved in the delivery and receipt of palliative and end of life care (research on ethics). Ethics in research. In considering ethical issues in palliative care research, one area that has been neglected is that of the ethical issues involved in qualitative studies. With the development of research ethics review mechanisms in Europe, formal attention is now being directed at qualitative research in health care fields. However, many ethical problems and dilemmas in qualitative research are unanticipated and involve issues of collaboration, trust and the management of interpersonal relationships over which ethical review committees have no jurisdiction. These involve moral choices and dilemmas that require ongoing reflection and support to resolve. Research on ethics. With advances in medical technology and changes in demography and epidemiology, palliative care faces a range of ethical challenges that require both empirical study and ongoing critical debate. At the moment qualitative research in these challenges are particularly visible. Questions about: how to manage the dying process, the best way to make clinical decisions, and how to relate to dying people and their families have been issues of intense debate across Europe. This draws attention to the way in which death is both a socially organised and a physical transition.

Abstract number: 633
Presentation type: Invited
Poster number:
The EU - clinical trial directive and research in palliative care: Research obstacle or facilitation?
Ola Dale, Department of Anaesthesiology, Trondheim, Norway

"Directive 2001/20/EC of the European Parliament and of the Council of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct or clinical trials on medicinal products for human use" (EU-clinical trial directive) was implemented May 1. 2004. It has created debate in many member countries for several reasons such as increased bureaucracy, consequences for research ethics committees, and not least the issue of including persons lacking capacity for giving informed consent.

Bureaucratic rigidity: The directive requires that clinical trials should be conducted according to principles as "for instance reflected in the 1996 version of the Helsinki Declaration". Does this mean that later versions of the Helsinki Declaration applies in all other biomedical research, but is not valid in clinical trials?

Ethics committees: Required to consider investigator's brochure, suitability of investigator and his staff, the quality of facilities and economic arrangements between sponsor and investigator. In some countries this is a new burden, and one may ask if the committees have capacity for this expansion of duties.

Positive is that a response is required within 60 days, and that multi-center trials shall be approved at one site in a country.

Inclusion of incapacitated persons: Many subjects relevant to research in palliative care may not be able to give an informed consent.

The directive gives detailed instructions for inclusion of such persons. Foreseeable risk and benefit must be assessed for each trial individual. Also, a "legal representative", a non existing person/body in some countries, must consent. One can ask if anybody, not knowing the individual patient at all, can protect person better than clinicians who care for their patients?

Abstract number: 634
Presentation type: Invited
Poster number:
How can Empirical Research be carried out in Clinical Ethics? The Embedded Researcher as a methodological Approach
Uwe Fahr, Medical Department of the University of Basel, Basel, SWITZERLAND, Stella Reiter-Theil, Institut für Angewandte Ethik und Medizinethik, Basel, SWITZERLAND

The concept of the embedded researcher has been developed by the research groups in Freiburg and Basel [1]. It was stimulated by two questions. (1) How can we safeguard that research in bioethics will yield valid and meaningful results for practice? (2) How can we convince clinical colleagues that medical ethics offers relevant contributions to the analysis and solution of ethical problems in clinical practice? Firstly, this presentation will inform about the general features of the concept of the embedded researcher as it has been applied in Geriatrics and Operative Internal Medicine. We will show how an embedded researcher gathers information about a selected case and how this information contributes to an integrative case study. Secondly, we will discuss the approach of
the embedded researcher in the context of the widely discussed issue of ‘principilism versus casuistry’. The concept of the embedded researcher should be seen in the context of this methodological controversy as a bottom-up approach trying to stimulate ethical discussions oriented at the same time at the collection of objective data. Thirdly, it will be shown how the concept can be used for research in clinical ethics. For this purpose a series of case studies in a Geriatric Unit will be described. The ten cases vary in general features such as patient age, ethical problem and the course of treatment. We will point out how the concept of the embedded researcher is useful to gather thick information. To sum up, the concept of the embedded researcher is a strong instrument of research in clinical ethics. It can be used to scrutinise the clinical and ethical details of a case very thoroughly, and it enables researchers to discuss medical cases in a way that has been shown to be very useful to clinicians. [1] Reiter-Theil S (2004) Does empirical research make bioethics more relevant? ‘The embedded researcher’ as a methodological approach. In: Medicine, Health Care and Philosophy 7:17–19, 2004.

Abstract number: 635
Presentation type: Invited
Poster number:

End of Life Ethics: Hindu, Muslim and Buddhist Perspectives
Bert Broeckaert, Belgium

In ethical discussions on end of life issues, whether in the scientific literature or in the political debate, usually only two voices are heard: those of people speaking from a secular, non-religious perspective and those of people referring implicitly or explicitly to a Christian framework. When in ethical end of life discussions the religious factor surfaces it is nearly always wrapped in Christian cloth. People refer to the biblical thou shalt not kill, to the teaching of the church, the pope etc, agreeing or disagreeing with the positions taken. European societies however have changed dramatically over the last few decades. From societies with an often exclusively christian religious heritage they have evolved into multicultural and multireligious societies in which for instance Islam, nearly totally absent before, has become the second largest religion, involving millions of Europeans. This fact cannot be ignored by bioethicists and must certainly not by people involved in palliative care.

If palliative care claims to put the patient at the centre, it cannot disregard the cultural and religious sensitivities of a buddhist (or hindu, or ...) patient when difficult ethical decisions have to be taken. In this paper an overview is given of how Islam and Buddhism look at ethical issues at the end of life. Is sedation allowed in Buddhism? What about euthanasia in Islam? Can life-sustaining treatment be withdrawn in a hindu patient? While discussing the attitudes and positions of the religious traditions involved regarding end of life decisions, the richness and complexity of each tradition is taken very seriously.

Abstract number: 636
Presentation type: Invited
Poster number:

Measurement of subjective symptoms: depression
Julia M Addington-Hall, School of Nursing and Midwifery, Southampton, GREAT BRITAIN

Although some symptoms of depression may be understandable in advanced disease, and there are arguments to avoid medicalisation of distress, more severe forms of psychological distress are common, frequently overlooked, and our understanding of their nature and course is limited. More research is needed. A key decision is how to measure depression. A good measurement tool for depression in palliative care needs to be short and easy to understand; it must take into account the fact that many of the symptoms of depression may be caused by the underlying cancer diagnosis; and it must measure clinically significant depression rather than depressed mood (although it is difficult to know where understandable distress related to diagnosis ends, and where depression begins). Popular tools, including Chochincher’s single item ‘are you depressed?’ question, will be reviewed in terms of their reliability, validity and feasibility in palliative care, and a way forward discussed.

Abstract number: 637
Presentation type: Invited
Poster number:

Measuring breathlessness
Claudia Bausewein, Klinikum der Universität München – Großhadern, München, Germany

Breathlessness is a common symptom in patients with cancer, chronic obstructive airways disease and chronic heart failure. As breathlessness is subjective and often correlated with other symptoms such as anxiety, depression or fatigue it is difficult to measure. Various breathlessness or dyspnoea scales exist for measuring breathlessness but there is no gold standard against which the validity of an instrument can be assessed. Breathlessness scales can be divided in scales measuring multiple symptoms where breathlessness is included or dyspnoea specific questionnaires. Global scales include the Edmonton Symptom Assessment System (ESAS), the Support Team Assessment Schedule (STAS), the Rotterdam Symptom Checklist (RSCL) or the Memorial Symptom Assessment Scale (MSAS). Dyspnoea specific questionnaires include the Modified Borg Scale, the Baseline and Transitional Dyspnoea Index (BDI and TDI), the Medical Research Council dyspnoea scale (MRC), the Shuttle Walking Test or the Oxygen-Cost diagram. The choice will be chosen depends on the objective of measurement, e.g. research or outcome of an intervention. For patients with respiratory disease relatively little research has been done on the correlation of breathlessness and dyspnoea. However they correlate poorly with other general quality of life measures. Furthermore it has been shown that dyspnoea measures are not strongly correlated with objective measures of pulmonary function.

Abstract number: 638
Presentation type: Invited
Poster number:

Response Shift in Studies Assessing Quality of Life: should we abandon all measurement?
Irene J Higginson, Department of Palliative Care and Policy, London, GREAT BRITAIN

The results of evaluations of palliative care services have been disappointing as far as quality of life (QoL) is concerned. Salisbury et al’s systematic review of alternative models of specialist palliative care concluded that services showed little or no effect on QoL(1), whereas other reviews found improvements for different outcomes(2). A cluster randomized controlled trial found no difference between 235 palliative care patients with 199 controls, using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30) questionnaire.(3) There are three possible interpretations of these studies Results: palliative care services make no different to QoL, insensitive measures of QoL are used, or that in response to events, many individuals adapt to their circumstances and alter their evaluation of self, wellbeing, goals and expectations, thus changing the way they respond to assessments. These changes, often called ‘response-shift’, may result in the contradictory findings in many studies. Response-shift can occur in three dimensions: (a) re-calibration, (b) re-prioritization and (c) re-conceptualization (4). This session will define response shift, discuss its components and ways to assess it. Using examples from recent palliative care studies we will consider the extent of response shift, and how it may be affecting research findings and clinical assessments. References: 1. Salisbury C, Bosanquet N, Wilkinson E.K., Franks PJ, Kite S., Lorentzon M et al. Palliat Med 1999;15:3–17 2. Hearn J, Higginson J. Palliat Med. 1998;12:317–32. 3. Jordhoy MS, Fayers P, Loke JH, Ahlner-Elmqvist M, Kaasa S. J Clin Oncol 2001;19:3884–94. 4. Schwartz CE, Merriman MP, Reed GW, Hammers BJ. J Palliat Med. 2004 April 7/2:233–45.

Abstract number: 639
Presentation type: Invited
Poster number:

Outcomes in prospective clinical studies – how to choose?
Stein Kaasa, Department of Cancer Research and Molecular Medicine, Trondheim, Norway

In clinical studies in palliative care most studies will aim at symptom improvement and/or improvement of quality of life, meaning that the outcomes in most cases are of subjective nature. In general, during the planning process of a study one need to clearly define the primary and secondary outcomes(5) based upon the research questions. A regiosus sample sized estimation should be based upon the primary outcome.

There are many considerations to take before the use of instrument is decided upon. First, one must decide which domain/area is of most importance, thereafter one may consider also the need for secondary or tertiarly outcomes. However, it is important to underline that outcomes must be based upon the clinical research questions in mind. A valid and internationally accepted instrument are to be recommended in most cases. The number of questions given to the patients must be weighted against the burden to each individual by completing the instrument.
Invited lectures and oral presentations

Abstract number: 640
Presentation type: Oral
Poster number:

**Consent Issues Recruiting Dying to Randomisation Studies in Palliative Care**
Andrew Fowell, Palliative Care Dept, Caernarfon, GREAT BRITAIN, Ros Johnstone, North West Wales NHS Trust, Caernarfon, GREAT BRITAIN, Ian Russell, University of Wales Bangor, Bangor, GREENLAND, Ilora Finlay, University of Wales College of Medicine, Cardiff, GREAT BRITAIN, Daphne Russell, University of Wales Bangor, Bangor, GREAT BRITAIN

Guidelines in palliative care exist, but evidence underpinning these is weak. There are known difficulties surrounding recruitment of palliative care patients to trials/research studies. Dying patients have significantly less energy, are easily fatigued or exhausted at the slightest exertio, accomplishing physical problems may be pain, dyspnea, excess respiratory secretions or vomiting. Approaching dying patients to participate in research is not always defendable though vulnerable, dying patients remain valuable to research. A feasibility study (ISRCTN66924384) exploring two types of randomisation, cluster and randomised consent (Zelen) were utilised following a crossover design at two hospitals within the North West Wales NHS Trust. All patients admitted to the two sites and being cared for on the Integrated Care Pathway (ICP) for the last days of life were approached for consent to access medical records prior to the palliative care assessment. Each site was allocated to one method for 3 months and then crossed over to the other method for 3 months. A pro-forma was developed for consent to access medical records this maintained consistency across the sites. Initial resistance by staff to utilise the pro-forma on admission was resolved by informing staff of the study resulting in improved patient consent. Sites using ‘Zelen’ had a total of 29 deaths over 6 months, 11 of these were ICP patients, 9 of the 11 gave consent. Sites using cluster randomisation had 25 patients dying over 6 months, 11 of these were ICP patients, consent was recorded for 8 patients. Failure to acquire consent was attributed to the central role that General Practitioners (GPs) cannot be recommended as a substitute for the health impact of caregiving is well recognized; maintaining health of caregivers should not be limited to the services (PCS) should not be limited to the palliative care patient. Sixty percent had not used a syringe driver with a patient over the last 12 months. Conclusions: The finding that over half of all GP Registrars surveyed did not feel confident in using a syringe driver nor had practical experience in this area. Further training in this area would be beneficial. There also appeared to be a call for further training in bereavement care.

Abstract number: 643
Presentation type: Oral
Poster number:

**Palliative care services are associated with improved caregiver outcomes**
Amy Abernethy, Division of Medical Oncology/Department of Medicine, Durham, NORTH CAROLINA, U. STATES, Beate Konzmann, Michaela Kastner, Sarah character, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA, Maggie Kuchibhatla, Duke University Medical Centre, Durham, U. STATES, David Currow, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA

Background: Outcomes of palliative care services (PCS) should not be limited to the impact on people with the life-limiting illness (LLI). The health impact of caregiving is wel recognized; maintaining health of caregivers during and after the terminal phase has to be a focus of end-of-life services. Methods: Pilot questions were included in the 2001–2003 annual face-to-face health surveys of 9,052 South Australian residents on the need for, uptake rate of, and impact of palliative care services. The survey was representative of the SA population by age, gender and region of residence. Analyses concentrated on respondents who reported that they cared for a terminally ill person. Results: Of the population, 37% (3,341) indicated that someone close to them had died of LLI in the preceding 5 years. Overall, 949 (29%) reported that they provided some level of hands on care for the deceased individual, with 329 (3%) providing day to day care (31% intermittent care, and 253 (8%) rare care). Caregivers were more likely to be first degree relatives and female, and 46% provided care for more than one year. Few (13%) reported PCS involvement in care. Comparing the experiences of caregivers when patients did or did not receive PCS, more carers who had PCS indicated that they could ‘move on’ with their lives (93% vs. 87%, p<0.005). (From pilot data, moving on incorporated stopping dwelling on past, life returned to normal, accepting death as part of life, looking to the future, past crying and realizing that grieving ends.) This effect was strongest in the first 12 months. Hands-on caregiver benefit was even greater at 6 months (82% vs. 67%, p<0.004). Conclusions:

It is experienced in many studies that too many questions may reduce the compliance. A special challenge in palliative care is to collect data on these patients with Questioned cognitive function. There is no international consensus for example on how to measure pain in the cognitively impaired. It is most often recommended staff. Reasons, however, how these data correlates with data from patients is still questionable. Therefore, it is a main research area to establish how to collect data from the cognitively impaired patient. Without outcomes it is difficult to perform research during end of life care.

Abstract number: 641
Presentation type: Oral
Poster number:

**Comparison of patients’ and physicians’ assessment of the health related quality of life of palliative care patients**
Morton Aa. Petersen, Department of Palliative Medicine, Copenhagen, DENMARK, Henrik Larsen, Department of Palliative Medicine, Copenhagen, DENMARK, Per E Pedersen, Department of Palliative Medicine, Copenhagen, DENMARK, Nan Sonne, Department of Palliative Medicine, Copenhagen, DENMARK, Lars M Grønvoel, Department of Palliative Medicine, Copenhagen, DENMARK

Objective: Research in palliative care is complicated by the poor condition of the patients. Hence, if equivalent information could be obtained from other sources than the patients this would often be preferable; this may improve the compliance, the applicability of results, and the range of studies ethically feasible. Few proxy studies have been carried out in specialist palliative care units. Therefore, we investigated whether physician assessments could be used to evaluate the health related quality of life of palliative care patients. Study Design and Setting: Patient and physician assessments of EORTC QLQ-C30 items and scales were obtained once a week for up to 13 weeks in consecutive patients admitted to a department of palliative medicine. Seven methods for comparing responses were used to investigate the agreement at first contact T0 (N=115) and for the following time-points T1: T13 combined (total N=263). Results: At T0 average differences between patient and physician scores ranged from 7 to 18 (0–100 scale), exact agreements ranged 21–62%, and kappa coefficients were 0.07–0.70. The best agreements were observed for nausea/vomiting and constipation symptoms and the poorest for social functioning. The analyses for T1–T13 generally confirmed the findings for T0 with a tendency to slightly poorer agreement. Conclusion: The agreement between patients and physicians was poor across most domains and for most items. Using physician assessments might bias findings and cannot be recommended as a substitute for the patients’ own assessments in palliative care.

Abstract number: 642
Presentation type: Oral
Poster number:

**A UK Wide Survey of GP Registrars’ Palliative Care Education**

Background: In the UK, there is recognition of the central role that General Practitioners (GPs) play in providing care to patients in the last year of their life. There is some concern about GPs’ ability to provide this care. The aim of this study was to assess how these gaps in palliative care knowledge develop, it is important to evaluate the level of training received by GP Registrars. Aim: to evaluate: (1) GP registrars’ perceptions of the coverage and quality of their palliative care education (2) GP registrars’ perception of their confidence and skill in caring for patients with palliative care needs. Method: Questionnaire, all GP Registrars in six UK deaneries (London, Eastern, Wales, West Midlands, Northern Ireland and North East Scotland) via their administrative staff. Results: 320 out of 498 GP Registrars completed the questionnaire, giving a response rate of 64%. Most respondents were female (219/320) with a median age of 32 years (IQR: 28 to 35). Over half of GP Registrars felt that communication skills, pain control and control of other symptoms were satisfactorily covered and felt confident in these areas. Fewer felt that syringe driver use (38%) and bereavement care (36%) was satisfactorily covered. One expressed lower confidence in the area of bereavement care, and over half expressed low confidence in using a syringe driver with a palliative care patient. Sixty percent had not used a syringe driver with a patient over the last 12 months. Conclusions: The finding that over half of all GP Registrars surveyed did not feel confident in using a syringe driver nor had practical experience in this area. Further training in this area would be beneficial. There also appeared to be a call for further training in bereavement care.

Abstract number: 643
Presentation type: Oral
Poster number:

**Palliative care services are associated with improved caregiver outcomes**
Amy Abernethy, Division of Medical Oncology/Department of Medicine, Durham, NORTH CAROLINA, U. STATES, Beate Konzmann, Michaela Kastner, Sarah character, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA, Maggie Kuchibhatla, Duke University Medical Centre, Durham, U. STATES, David Currow, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA

Background: Outcomes of palliative care services (PCS) should not be limited to the impact on people with the life-limiting illness (LLI). The health impact of caregiving is well recognized; maintaining health of caregivers during and after the terminal phase has to be a focus of end-of-life services. Methods: Pilot questions were included in the 2001–2003 annual face-to-face health surveys of 9,052 South Australian residents on the need for, uptake rate of, and impact of palliative care services. The survey was representative of the SA population by age, gender and region of residence. Analyses concentrated on respondents who reported that they cared for a terminally ill person. Results: Of the population, 37% (3,341) indicated that someone close to them had died of LLI in the preceding 5 years. Overall, 949 (29%) reported that they provided some level of hands on care for the deceased individual, with 329 (3%) providing day to day care (31% intermittent care, and 253 (8%) rare care). Caregivers were more likely to be first degree relatives and female, and 46% provided care for more than one year. Few (13%) reported PCS involvement in care. Comparing the experiences of caregivers when patients did or did not receive PCS, more carers who had PCS indicated that they could ‘move on’ with their lives (93% vs. 87%, p<0.005). (From pilot data, moving on incorporated stopping dwelling on past, life returned to normal, accepting death as part of life, looking to the future, past crying and realizing that grieving ends.) This effect was strongest in the first 12 months. Hands-on caregiver benefit was even greater at 6 months (82% vs. 67%, p<0.004). Conclusions:
Abstract number: 644
Presentation type: Oral
Poster number:

Training Needs of Canadian Palliative Care Researchers: A National Survey
Jose Luis Pereira, Palliative Medicine, Calgary, CANADA, Kim Fisher, Palliative Care Research Initiative, Calgary, CANADA, Vicki Baroco, University of Alberta, Edmonton, CANADA; Lisa van Wijk, Alberta Palliative Care Research Initiative, Calgary, CANADA, Monica Faria, Alberta Palliative Care Research Initiative, Calgary, CANADA

Background: Capacity to conduct palliative care research (PCR) needs to be enhanced. Methods: A national online survey was conducted to identify Canadian health professionals involved in or interested in participating in PCR. Results: 153 respondents were either active in PCR (64) or considering coming involved (89). Of these, 60 (46%) had no formal training in research; 35 (23%) had a Masters degree and 5% had PhD degrees. 86/153 (56%) considered their training inadequate. Low comfort levels were reported in % of respondents indicating low comfort levels; n=148): critiquing research papers (62%); designing studies (74%); selecting appropriate measurement tools (75%); and statistical methods (79%); and conducting qualitative research (74%). High levels of interest for further training were reported in (n=143): critiquing research papers (35%); designing studies (42%); selecting appropriate measurement tools (42%) and statistical methods (34%); writing research proposals (43%); managing research projects (36%); and conducting qualitative research (44%). 26%/36% of respondents (n=140) expressed high interest in attending short courses (1-2 weeks) on research methods & training. 21% expressed interest in Masters degrees. Lack of research training, mentors, time and funds to hire trained staff was perceived as significant barriers. Conclusion: Lack of training in conducting and participating in PCR is a major barrier to improving PCR in Canada. There exists a high level of interest in receiving further training.

Abstract number: 645
Presentation type: Oral
Poster number:

Changing goals, disentangling the treatment goals of Palliative Chemotherapy
Susanne de Kort, General Practice, Amsterdam, NETHERLANDS, Prof. dr. Dick Willems, Academic Medical Center, University of Amsterdam, Amsterdam, NETHERLANDS, Prof. dr. Dick Richel, Academic Medical Center, University of Amsterdam, Amsterdam, NETHERLANDS

Background: The objective of this study is to clarify what is and what should be the main goal of palliative chemotherapy (PCT). Oncologists disagree whether PCT is intended to improve Quality of Life (QoL) or to prolong life/tumour response or, like some people say, both. If the goal of PCT would be clear, this would have important clinical consequences, as one could better indicate and evaluate cancer care. By studying the results of phase III research of PCT, we tried to settle the discussion. Methods: To see what authors consider to be the primary goal of PCT, 29 phase III trials of PCT in colorectal cancer were selected for a review. From every single article that presented a trial, the results on the different endpoints were compared to the advances given by the authors in the discussion section. Results: We found that, in trials, in their study design and results, were focussed on both life prolonging and QoL-outcomes. However, authors clearly gave more (often positive) advice on basis of life prolonging results – even if the results of the experimental arm were equal to the control arm – than they would on basis of QoL. Results. Conclusion/Discussion: In our review we can hardly find a reason to choose a specific PCT for QoL-improvement, because the advances based on phase III trials are mainly focussed on life prolonging Results. To disentangle the discussion, we need to recognize the two meanings of the word ‘palliative’, namely in palliative care (which only focuses on QoL) and palliative chemotherapy (which just is in contrast with curative treatments). Probably it would be better to use the term PCT only in the few cases when the goal of palliative chemotherapy is QoL. Otherwise we suggest that the term ‘life prolonging chemotherapy’, according to its intention, would be clearer.

Abstract number: 646
Presentation type: Oral
Poster number:

Recruitment of 461 patients into a longitudinal randomised controlled trial in the palliative care setting. How can it be done?
Amy Abernethy, Division of Medical Oncology/Department of Medicine, Durham, North Carolina, U. STATES, Tania Shelby-James, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA, Christine Lillie, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA, Alexandra, AUSTRALIA, David Currow, Southern Adelaide Palliative Services, Adelaide, AUSTRALIA

Background: Authors argue that large randomised controlled trials (RCTs) in palliative care are not possible due to the limitations of participating patient populations. Palliative Care Trial (PCT) is a RCT of educational outreach care. Objectives:1. To evaluate the tolerability and safety of transdermal buprenorphine 2. To evaluate the effectiveness, (degree of pain relief) 3. To collect information on its patterns of use in clinical practice 4. To evaluate the effects of treatment on the patients’ quality of life. Methods:The study was designed as a prospective, non-interventional 3-month follow-up study. 58 Palliative Care and Oncological Units participated and 207 oncological patients were included. Pain relief was determined by means of a five-category Verbal Rating Scale and quality of life by the EuroQol SD questionnaire. For safety measurement all adverse events were coded by MedDRA 6.1 and a statistical analysis was performed. Results: 61.65% patients were male and 38.35% female with an average age of 65.72 (TD 12.73). At baseline 89.27% of patients were prescribed 35 µg/h transdermal buprenorphine and the proportion of patients using higher doses (52.5 or 70 µg/h) increased during the first follow-up month (31.55%) and until the end of the study (48.08%, p<0.001). Regarding the Pain Relief Scale, 4.86% of patients experienced good or very good pain relief at the baseline evaluation. This percentage improved to 89.19% in the third month. The mean score for the EUROQOL scale throughout the study rose from 44.83 ± 16.99 to 66.018 ± 18.42, 36.71 % of patients experienced adverse events, but only 4.92% of patients reported adverse events. The prevalence of constipation, vomiting and nausea was 8.7%, 3.86% and 3.38% respectively. Local adverse events were pruritus (1.45%) and dermatitis (0.97%).

Conclusions:1.Transdermal buprenorphine is an effective drug for chronic, moderate to severe oncological pain 2. Excellent safety and tolerability profile 1. Almost half of patients used higher doses after 3 months of treatment 4. Transdermal buprenorphine improves quality of life in oncological patients.

Abstracts of the 9th Congress of the European Association for Palliative Care, Aachen 2005
Résumés du 9ème Congrès de l’Association Européenne de Soins Palliatifs, Aix la Chapelle 2005
Invited lectures and oral presentations

SUNDAY 10 APRIL
Efficacy and safety of Buprenorphine (BPN) patches in far-advanced cancer patients: preliminary results

Gala Serrano-Bermudez, Palliative Care Service, L’Hospitalet-BCN, SPAIN, Jose Porta-Sales, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN, Albert-Rodriguez, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN, Eulalia Alburquerque-Medina, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN, Xavier Gomez, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN

AIM: To evaluate the analgesic efficacy and safety of BPN patches in patients with far-advanced cancer. METHODS: We enrol a consecutive sample of ambulatory patients with a pain score (VAS: 0–10) greater than 4, and already been treated with weak analgesics. We always started with BPN half patch of 35 mcg. Patients were randomised to rescue with morphine 10 mg p.o. or tramadol 50 mg p.o. in case of episodic pain. Basal pain and episodic pain scores were evaluated, as well as the last time before the increase the patch dose was needed. Side effects were also recorded.

RESULTS: From 26.04.2004 to 29.07.2004, 13 patients have been enrolled and 10 were assessable. The mean age was 66.3 years, and 8 (80%) were men. The main neoplasm were: 30% lung, 20% pancreas, 20% prostate, 15% bladder, and 10% others. The mean pain score before BPN were 6.3, at 3, 7, and 15 day were: 2.3, 1.7 and 2.1 respectively. Mean BPN dose at 3, 7, 15 days were 17.5, 31.4 and 41.6 mg respectively. The mean time before the increase the patch dose was 4.8 days. The mean pain score of episodic pain before BPN were 7.5, and at 3, 7 and 15 day were 5.5, 4.1 and 4.6 respectively. The mean number of rescues per day before BPN were 3.7, and at 3, 7 and 15 day were 2.3, 1.7 and 2.1 respectively. Significant side effects, were only seen in 2. Patients had a delirium (reversed) and the other dermatitis (grade IV), in both BPN was withdraw. CONCLUSIONS: In our patients Buprenorphine patches produce a good and long lasting analgesia, with few side effects. Rescue pain crisis with morphine or tramadol offers similar efficacy and not more side effects.

Abstract number: 649
Presentation type: Oral
Poster number:

EFFECTS OF AGE, GENDER, BODY WEIGHT, RACE AND RECURRENT FUNCTION ON THE PHARMACOKINETICS (PK) OF HYDROMORPHONE HCI EXTENDED-RELEASE (HHER) q24h CAPSULES IN PATIENTS WITH PERSISTENT PAIN
V Vashi, Department of Clinical Pharmacology, Stamford, U. STATES, S Harris, Purdue Pharma LP, Stamford, U. STATES, A Cipriano, Purdue Pharma LP, Stamford, U. STATES, A Tinti, Purdue Pharma LP, Stamford, U. STATES, D Wu, Purdue Pharma LP, Stamford, U. STATES

To compare the PK of a once-daily HHER (Palladone XL in UK; Hydral Unio Retard in Austria) capsules in patients with stable moderate to severe pain, mainly associated with cancer. Patients were enrolled on age, gender, body weight, race and renal function. Patients were administered HHER capsules to a stable daily dose of 12 mg to 84 mg. After their final HHER dose, patients provided blood samples for PK over 6 hours. A total of 135 patients were evaluated for their steady-state dose-normalized PK metrics, AUC and Cmin. For age, young: 32–64 y [n=89]; old: 65+ y [n=51], very elderly: >75y [n=15]; AUC and Cmin increased approx. 31% and 22%, for elderly versus young, and approx. 52% and 63%, respectively, for the very elderly versus young. There was significant overlap among and variability within the groups. Comparing gender (64 males vs 71 females) resulted in AUC in Cmin values 20% to 21% higher in men. There was no correlation between body weight and dose-adjusted exposure or dosage of HHER. There were no apparent differences in PK observed based on race (nonwhite vs white, black, Hispanic), although the small percentage, 12.5%, of nonwhites precluded statistical comparisons. PK parameters increased with decreasing renal function-creatinine clearance (Ccr <80 mL/min vs >80 mL/min). The mean pain score of episodic pain before BPN were 6.3, and at 3, 7 and 15 day were 4.3, 3.1 and 2.7 respectively. The mean pain score of basal pain and episodic pain scores were evaluated, as well as the last time before the increase the patch dose was needed. Side effects were also recorded.

RESULTS: From 26.04.2004 to 29.07.2004, 13 patients have been enrolled and 10 were assessable. The mean age was 66.3 years, and 8 (80%) were men. The main neoplasm were: 30% lung, 20% pancreas, 20% prostate, 15% bladder, and 10% others. The mean pain score before BPN were 6.3, at 3, 7, and 15 day were: 2.3, 1.7 and 2.1 respectively. Mean BPN dose at 3, 7, 15 days were 17.5, 31.4 and 41.6 mg respectively. The mean time before the increase the patch dose was 4.8 days. The mean pain score of episodic pain before BPN were 7.5, and at 3, 7 and 15 day were 5.5, 4.1 and 4.6 respectively. The mean number of rescues per day before BPN were 3.7, and at 3, 7 and 15 day were 2.3, 1.7 and 2.1 respectively. Significant side effects, were only seen in 2. Patients had a delirium (reversed) and the other dermatitis (grade IV), in both BPN was withdraw. CONCLUSIONS: In our patients Buprenorphine patches produce a good and long lasting analgesia, with few side effects. Rescue pain crisis with morphine or tramadol offers similar efficacy and not more side effects.

Abstract number: 649
Presentation type: Oral
Poster number:

Bioavailability Comparison of a Once-A-Day Hydromorphone HCl Extended-Release (HHER) Capsule Swallowed Whole Vs. Sprinkled Capsule Contents On Soft Palatable Food
V Vashi, Department of Clinical Pharmacology, Stamford, U. STATES, S Harris, Purdue Pharma LP, Stamford, U. STATES, A Cipriano, Purdue Pharma LP, Stamford, U. STATES, D Cilla, Purdue Pharma LP, Stamford, U. STATES, J Miotto, Purdue Pharma LP, Stamford, U. STATES

Oral administration of opioid analgesics in the treatment of cancer pain is a preferred route. In patients with difficulty swallowing solid dosage forms, q24h HHER (Palladone XL in UK & Hydral Unio Retard in Austria) capsules offer an alternate option, the capsule can be opened and contents sprinkled on soft palatable food for easier swallowing. A single dose, crossover bioavailability study of 24 mg HHER capsule dose was compared to a 24 mg capsule dose by sprinkling the contents on a tablespoon of applesauce just prior to ingestion in a study involving 26 male and female subjects. Following each dose, pharmacokinetic blood samples were taken serially over a 72-hour period and analyzed for plasma hydromorphone by a GC/MS assay method. Twenty-four subjects completed the study and were in the pharmacokinetic analyses. The
mean areas under the concentration-time curve (AUC) for HHER sprinkled on applesauce and HHER swallowed whole were 58.4 and 55.6 ng*h/ml, respectively, with an AUC ratio of 105.0%, 90% confidence interval (CI): 102.6 to 108.6%. The mean maximum plasma hydromorphone concentration (Cmax) for HHER sprinkled was 1.41 ng/mL, compared to 1.36 ng/mL for HHER swallowed whole, Cmax ratio 103.7%, 90%CI: 98.1 to 111.5%. HHER was generally well tolerated and most adverse events were those associated with opioid use. Based on AUC and Cmax, HHER dosed by sprinkling capsule contents on applesauce prior to ingestion is equally bioavailable to HHER capsules swallowed whole. Administration of HHER capsules not only provides patient and caregiver convenience, but offers the option of sprinkling capsule contents on applesauce for easier swallowing by debilitated cancer patients.

Abstract number: 653
Presentation type: Oral
Poster number:

Transdermal buprenorphine in the treatment of cancer related pain
Bart Van den Eynden, Chair of Palliative Medicine, University Antwerp, Mertiel, BELGIUM, Paul Van Boyen, University Antwerp, Centre for General Medicine, Antwerp, BELGIUM

AIM OF INVESTIGATION: To collect data on the use of transdermal buprenorphine (TRANSTEC®) in daily practice. METHODS: This is a subset interim-analysis on the data from 3,200 patients treated with TRANSTEC® of which 296 patients were suffering from cancer related pain. In this non-interventional trial, data was collected at the start of treatment, after 2 weeks (optional) and 6 weeks of follow-up. More than 700 physicians participated from December 2002 until December 2003. Primary efficacy variable was pain intensity measured on a 11-point numeric rating scale. Secondary efficacy variables were: patient satisfaction with pain relief, tolerability, user-friendliness and comfort of the patch measured on a verbal rating scale. RESULTS: In the subset of 296 cancer patients the mean age was 70 years (17–98); 52% of the patients were males. Previous treatment mainly consisted of tramadol (28%), NSAIDs (8%), paracetamol (20%) and paracetamol/codeine (15%). Pain intensity decreased from 7 at baseline to 3 after 6 weeks (p<0.0001). Doses of TRANSTEC® used at baseline were 75% for 35µg/h, 19% for 52,5µg/h, 5% for 70µg/h. After 6 weeks dose distribution was 35%, 38% and 19% respectively (7% were other doses or missing data). 92% of patients were ‘Satisfied’ to ‘Very Satisfied’ with the user-friendliness and comfort of the patch. TRANSTEC® is an effective and well tolerated treatment for cancer related pain.

Abstract number: 654
Presentation type: Oral
Poster number:

A shorter version of the Mini-Mental State Examination (MMSE) can be used to screen for delirium
Marianne Hjørnestad, Institute for Behavioural Sciences in Medicine, Oslo, NORWAY, Peter Fayers, University of Aberdeen, Aberdeen, GREAT BRITAIN, Anette Ranhoff, Ullevål University Hospital, Oslo, NORWAY

Background. Delirium is common in palliative care, but poorly recognized and therefore under-treated. The Mini-Mental State Examination (MMSE) is commonly used for assessment of cognitive impairment (CI), (case: <23 of 30) and delirium, and has become a reference instrument. Besides being cumbersome for daily clinical practice, little is known about its validity in advanced cancer. The study objectives were to investigate the performance of the MMSE items for predicting delirium in delirious patients and to explore whether a shortened version would have suitable properties for screening in palliative care patients. Methods. 507 complete MMSE scores were available from two data sets. Sample A included 290 general medical patients (median age 80 yrs), of whom 142 had delirium (ICD-10) and 148 were matched controls (score >24 on the MMSE). Sample B included 217 palliative patients (median age 62 yrs). Mepwise logistic regression was used for identification of the best discriminatory items for delirium, while linear regression was used for prediction of the overall MMSE score. Results. Most MMSE items were too easy for screening purposes. Four items were predictive (92% sensitivity) of delirium in sample A: ‘current year’, ‘date’, ‘backword spelling’, ‘copy a design’. These items correctly identified 99% MMSE-cases (<23) in sample A and 96% in sample B. Adding two items: ‘recall 3 objects’ and repetition of a proverb reduced the standard errors. Conclusions. The MMSE appears to function similarly in palliative and delirious patients. Caseness could be fairly accurately screened for by using four of the original 20 MMSE items, while using six items greatly improved the discrimination.

Abstract number: 655
Presentation type: Oral
Poster number:

Prospective validation of the Palliative Prognostic Index in palliative care patients
Carol Stone, Palliative Medicine, Cork, IRELAND, Eoin Tiernan, St. Vincents University Hospital, Dublin, IRELAND

Object: The Palliative Prognostic Index (PPI) was developed in patients with advanced malignant disease in Japan. It relies on assessment of performance status and clinical symptoms and does not incorporate or require a clinical prediction of survival or laboratory investigations. The PPI categories into one of 3 groups, predicting survival of shorter than 3 weeks, shorter than 6 weeks, or greater than 6 weeks. We set out to validate the PPI in a wider patient population, including cancer patients receiving chemotherapy or radiotherapy and those terminally ill due to non-malignant conditions. METHODS: 223 patients referred to a palliative medicine consultancy service based in a large teaching hospital and therefore home care service and a 6 bedded hospice inpatient unit over a 6 month period were included. A PPI score was assigned to each patient at first assessment, and followed until death or time of census. Results: 87% of patients had a diagnosis of cancer; 13% had non-malignant conditions. 43% of cancer patients were receiving palliative chemotherapy and/or radiotherapy. 3 week survival was predicted with positive predictive value (PPV) of 87% and negative predictive value (NPV) of 75% (sensitivity 64%, specificity 92%). 6 week survival was predicted with PPV of 92% and NPV of 63% (sensitivity 68%, specificity 91%). Conclusions: The PPI is highly specific and may facilitate redirection of scarce resources to palliative care patients identified as having a short prognosis. Our study demonstrates that its applicability extends to patients receiving chemotherapy and/or radiotherapy and those referred to palliative care services with non-malignant conditions. The PPI is a tool that is quick and easy to use and does not require specialist knowledge to ensure accuracy.

Abstract number: 656
Presentation type: Oral
Poster number:

Use and cost-efficiency of palliative care services in Spain: A national wide multcenter prospective study
Xavier Gómez-Batiste, Palliative Care Service, L'Hospitalet-BCN, SPAIN, Albert Tuca-Rodríguez, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN, Esther Corrallez-Baz, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN, Jose Porta Sales, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN, Maria Amor, Institut Catala d’Oncologia, L’Hospitalet-BCN, SPAIN

AIM:Describe the use and cost of health care resources for advanced-terminal cancer patients attended by specialist Palliative Care Services (PCS) in Spain and to compare them with a population-based previous study, in order to look at their efficiency. METHODS: Descriptive, prospective, multcenter study. Patients’ recruitment was done consecutively during 15 successive days, with a follow up of 16 wks. A weekly questionnaire was used. Results were compared with an historical study (1992), when PCS were initially implemented. RESULTS: 101 PCS participated, 52.6% home care teams. Participant teams were based in 14 out of 18 regions of Spain which is a representative sample. 393 cancer patients were recruited. Median survival after recruitment was 6 wks with a 2.1 health care intervention (HCl)/patient/week. The most frequent HCl were home care visit, hospital admission and phone call. The majority of the hospital admissions were scheduled. PCS provided 67% of all services and intervened as consultant services for 54% of patients. Compared with historical data, there was a large shift from the use of conventional hospital beds towards palliative care beds, a lower length of stay, 5.5 to 19.9 days (p<0.0001) and percentage of hospital admissions 72% to 57.8% (p<0.0001), an increase of death at home, 31% to 42% (NS), and a lower use of hospital casualty rooms, 52% to 20.6% (p<0.0001), along with the use of services under programmed rather than emergency manner. The cost of all hospital stays per patient was 1,795 euros. The preliminary analysis and comparison with the previous use and cost of hospital beds per process can estimate a savings of 3,286 euros per patient/process. CONCLUSIONS: PCS have been promoted a radical change in the use of health care resources at the end of life, with a reasonable cost per process, and have been improved efficiency in the care of advanced and terminal cancer patients in Spain.
Abstract number: 657
Presentation type: Oral
Poster number: 

The PAT-C project Quality of life questionnaires for palliative care: is physical function neglected?

Marit Jordhøy, Pain and Palliation Research Group, Bodo, NORWAY, Gerd Ringdal, Department of Psychology, Norwegian University of Science and Technology (NTNU), Trondheim, NORWAY, Jorunn Helbostad, Dept. of Neuroscience, Norwegian University of Science and Technology (NTNU), Trondheim, NORWAY, Håkon Hauglo, Department of Behavioural Sciences in Medicine, University of Oslo, Oslo, Stein Kaasa, Inst of Cancer Research and Molecular Medicine, NTNU, Trondheim

Introduction: Physical dysfunction, experienced by all palliative care patients, affects most aspects of life and is among the most distressing concerns. Thus, physical function (PF) is a crucial domain for quality of life (QoL) assessments. Purpose: To review PF assessments of QoL instruments developed for palliative care Methods: For instrument identification, a Medline search (PubMed) was performed (April 2004) using the terms (palliative care OR end of life care OR terminal care) AND quality of life AND assessment OR instrument OR questionnaire). Of 1189 hits, 878 were excluded as irrelevant (e.g. case reports, educational papers). Among the remaining 311, named instruments were detected in 203 abstracts and included in this report. Results: Of 133 individual instruments detected, 35 were identified as developed for palliative care. The contention was explored. 7 tools assessed symptoms, 2 satisfaction with care, 5 existential/emotional issues, 1 was a global unidimensional. 5 multidimensional instruments had no PF scores. For 3, only brief descriptions indicating no PF assessment were obtained. 12 instruments included PF assessment, 2 were comprehensive palliative performance scales for staff’s assessment, 10 were multidimensional including 2 to 8 PF items. Items’ content was non-consistent, 2 instruments used the ECOG/WHO performance scale, the others included various aspects of selfcare, mobility, help needs or participation in activities (work, hobbies, transportation). Conclusion: Despite its importance, the PF assessment seems a minor part of palliative care instruments. Clear definitions and conceptualisation of PF are needed, as well as a consensus on relevant aspects, and improvement of instruments. Performance scales already developed should be further tested

Abstract number: 658
Presentation type: Oral
Poster number: 

Study to test the psychometric properties of the ‘Meaning and Motivation Scale’

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Background: Studies have suggested that religious involvement or spirituality is associated with better health outcomes. Many instruments measuring spirituality are unsatisfactory because of the difficulty of definition and need to consider spirituality apart from religion. Following on from feasibility work, a self-assessment questionnaire to assess spirituality has been developed. Aim: To test the psychometric properties of the ‘Meaning and Motivation Scale’ Method: 300 patients and staff from various sites (Marie Curie Hospice Harrogate, Marie Curie Head Office, Royal Free Hospital, St Joseph’s Hospice, 3 North London general practices, London Metropolitan University) are completing the questionnaire over two separate occasions two weeks apart to test for test/re test reliability. Factor analysis will identify which items should remain in the tool. Preliminary results: Preliminary analysis of data (244 complete data sets – quantitative analysis) showed that internal reliability/consistency of the scale was high. Test-retest reliability revealed moderate/good strength of agreement for 46 out of the 47 items on the questionnaire. Three main factors were identified through factor analysis. Some respondents commented on certain questions being unclear/ ambiguous in meaning (371 single questionnaires – qualitative analysis). Conclusions: The instrument appears to have face validity, is acceptable to patients and is reliable. Our aim is to apply it in clinical and population studies to understand how spirituality contributes to health and health care.

Abstract number: 659
Presentation type: Oral
Poster number: 

Piloting the Palliative Care Screening Scale with patients who have an advanced illness

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Background: The Palliative Care Screening Scale (PCSS) has been developed to assess the palliative care needs of patients with an advanced cancer or non-malignant illness. Such a measure may help professionals to make an appropriate referral to palliative care. Objective: (1) To identify the palliative care needs of patients who are very ill and (2) To reduce the number of questions on the PCSS. Method: The PCSS was developed psychometrically and consisted of 59 questions paired with two response formats about frequency and distress plus one open-ended question. A minimum of 61 patients were required to test for feasibility and redundancy. Questionnaire data were recorded in SPSS and an item analysis was performed for each section on the measure. Qualitative data from the feedback form were content analysed. Both types of data were used to make a decision about which questions to change, remove or keep on the measure. Results: Sixty-three patients were interviewed. Nine questions were removed because of low correlation and 37 questions were combined as they were measuring similar concepts (sadness and depression). Three questions were added two about sleepiness (morning and evening) and one about bladder problems. Two open-ended questions were added because the question was not specific to palliative care or did not pick up differing levels of distress or had low correlations. Two questions were combined as they were measuring similar concepts. Conclusion: Data collection was completed in 174 patients and 420 assessments. The instrument seems difficult to use in hospital PC teams but is better suited for inpatient service. More research is required to adapt it to geriatric than advanced cancer patients. Besides population-based information on PC services in Iceland we have collected valuable information that will help guide further improvement and development of the instrument.

Abstract number: 660
Presentation type: Oral
Poster number:

Assessment of Patients in Palliative Care Services using the Minimum Data Set for Palliative Care – (MDS-PC) Instrument

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The Minimum Data set for Nursing Home care is valid and reliable instrument used internationally and introduced in Iceland since 1994. A MDS-PC is now under development. During six months a clinical epidemiological study of this instrument was conducted in three different types of PC settings in Reykjavik, PC team, free standing home hospice units and hospital palliative inpatients units. The purpose was: 1) to test the instrument in palliative situations in Iceland and to participate in international development. 2) To get detailed information on the patients’ population receiving PC services. 3) To develop quality indicators. 4) To search for prognostic factors regarding death at home, discharges and hospitalisation. A nurse and a doctor filled out the instrument three times during the study period for all new patients: at the beginning of service, 2 weeks later and at discharge. Following aspects were enlisted: Health conditions, oral/nutritional status, skin condition, cognition, communication, mood and behaviour, psychosocial well-being, physical functioning, continence, medications, treatments and procedures, responsibility/directives, social relationships, discharge. This is the first attempt in Iceland using MDS-PC resulting in 174 patients and 420 assessments. The instrument seems difficult to use in hospital PC teams but is better suited for inpatient service. More research is required to adapt it to geriatric than advanced cancer patients. Besides population-based information on PC services in Iceland we have collected valuable information that will help guide further improvement and development of the instrument.

Abstract number: 661
Presentation type: Oral
Poster number:

Introducing systematic symptom assessment in a large geographical area: Clues to success

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Background and Aims: A valid assessment is a prerequisite for good symptom relief. Since 2001, the Regional Centre for Excellence for Palliative Care, Western Norway, has been conducting a developmental project aimed at introducing systematic symptom assessment for all palliative care patients in the region. The
Western Norway Health Care Region covers a population of 0.9 million. The area is served by 11 somatic hospitals and 86 local authorities, and has approximately 2,100 cancer deaths per year. ESAS (Edmonton Symptom Assessment System) was chosen as the symptom assessment tool. Methods: Strategies used to introduce ESAS: i) A project nurse travelling extensively in the region to provide teaching resources; ii) Project locations at hospitals which serve as bases to reach nearby districts. New locations have progressively been included each year, giving a total of 14 in 2004. iii) Designated nurses in charge of the project at each location; iv) Close follow-up of staff at the project locations, via telephone, e-mail, and visits; v) Multidisciplinary teaching sessions; vi) Project information provided on the internet. Patient information leaflet; vii) ESAS included in the form for referral to the regional palliative medicine unit; viii) ESAS-lunches with case discussions; ix) ESAS presented in all relevant health care educational courses. Results: ESAS has been introduced into routine clinical work at all project locations, as well as in nursing homes and municipal home care. An evaluation performed by 68 health care workers in November 2003 showed that the systematic use of ESAS is a useful tool, but that the registration may be even more widely used. A new evaluation will be performed in October 2004. Conclusions: This project demonstrates that systematic symptom assessment may be implemented in a large geographical area. The process is time-consuming. Systematic follow-up, motivation, and repeated provision of information/education are clues to success.

Abstract number: 662
Presentation type: Invited
Poster number:
Paediatric palliative care in the UK: a working model?

Richard Hain, Department of Child Health, Wales, UK

In the United Kingdom, palliative medicine in adults has evolved largely along a hospice model. St Christopher’s Hospice was the first institution to try to bring a high degree of specialist medical and nursing expertise to bear, not on the cure of a condition, but on the relief of symptoms in a supportive emotional, social and spiritual environment. This model has, we believe, been effective in adults. In children, however, the model is much more complicated. Delivery of palliative medicine to children is based on an assumption that, where possible, the child should be managed at home. The model has also to be flexible enough to allow delivery of specialist palliative medicine on the ward, the school and the children’s hospice. Paediatric palliative medicine in the UK is therefore a specialty that aims to deliver specialist care to the child wherever it is needed, irrespective of location. In this respect, paediatric palliative medicine may have more in common with the experience in some European countries than with the adult specialty in the UK. This talk will describe the UK model of paediatric palliative medicine, and consider what can be learnt from its weaknesses as well as its strengths.

Abstract number: 663
Presentation type: Invited
Poster number:
Pediatric Palliative Care in France: a recent approach

Chantal Wood, Hôpital Robert Debré, Paris, France

The need for palliative care in children seems a recent necessity in France. Up to now, most of the teams thought that they could deal correctly with the patient, his family and siblings. Palliative care had been developed for cancer patients or patients with AIDS. But little was done for other chronic diseases and for the bereaved families and siblings. In France, 2500 to 4000 children die every year due to a disease. Different aspects are to be approached:
- Units or hospices:
- There are no pediatric palliative care mobile units in France
- Must there be beds in certain hospitals?
- Is there a need for hospices as there are in the UK?
- Must a network with the adult palliative world be created due to the few number of pediatricians and nurses specialized in children?
- How to improve the return to their homes of children?
- Create a network with the general practitioners?
- Develop home care?
- Have the help of voluntary workers?
- How to educate the doctors and nurses?
- Special courses in palliative care developed in university diplomas
- Creating a medical speciality of “pain and palliative care”
- How to work with other french speaking countries:
- Sharing expertise and congresses with Canada
- Creating a documentation center for pediatric palliative care
- Palliative care in children is slowly being developed in France.
- A reflexion is taking place to choose the best system for our country and it’s culture.

Abstract number: 664
Presentation type: Invited
Poster number:
Status Quo of Pediatric Palliative Care in Germany

Boris Zernikow, IJF, Datteln, GERMANY, Stefan Friedrichsdorf, Christine Wansler, Andrea Menke, Wilma Henkel

In two nationwide studies we studied i) the provision of palliative care at home and on the children’s cancer units and ii) pediatric palliative care by nurse-led home care services for children with cancer and non-cancer life-limiting conditions. Methods: i) A survey of 71 (of 73) German pediatric oncology units (response rate 97 per cent) provided the information presented. ii) A second survey among 1,322 German nurse-led home care services for children identified 37 services which have gained experience in caring for dying children between 2000–2002. Results:

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Invited lectures and oral presentations

SUNDAY 10 APRIL

Ulrika Kreibergs, Clinical Cancer Epidemiology, Stockholm, SWEDEN, Unnur Valdimarsdottir, MEB, Stockholm, SWEDEN, Erik Onelöv, Oncology and Pathology, Stockholm, SWEDEN, Olle Bjork, Women and Child’s Health, Stockholm, SWEDEN, Gunnar Steineck, Oncology and Pathology, Stockholm, SWEDEN, Jan-Inge Henter, Institution Women and Child’s Health, Stockholm, SWEDEN

Background: Little is known about how care-related factors affect bereaved parents in a long-term perspective. We conducted a population-based, nationwide study to identify potential stressors among parents 4 to 9 years after losing a child to cancer. Conclusions: In 2001, we attempted to contact all parents in Sweden who had lost a child to cancer in 1992–1997. The parents were asked, through an anonymous postal questionnaire, about their experience of the care given and to what extent these experiences still affect them at follow-up.

Results: Information was supplied by 449 (80%) of 561 eligible parents. Among 196 parents of children whose pain could not be relieved, 111 (57%) 62% among mothers and 48% among fathers) were still affected by it 4 to 9 years after bereavement. Among 138 parents reporting that the child had a difficult moment of death, 78 (57%) 67% among mothers and 44% among fathers) were still affected by it at follow-up. The probability of parents reporting that their child had a difficult moment of death was increased (RR 1.4, 95% CI 1.0–1.8) if staff were not present at the moment of death. Ten per cent of the parents (25/251) were not satisfied with the care given during the last month at a paediatric haematology/oncology centre; the corresponding figure for care at other hospitals was 20% (33/168). Conclusions: The moment of death are important to address in end-of-life care of children with cancer in trying to reduce long-term distress in bereaved parents.

Abstract number: 665
Presentation type: Invited
Poster number:
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