After the osteopathic treatment, an improvement of the Visual Analogue Score (def: an increase of 10 points on the 100 point VAS scale for patients with an initial score of <50) on the question on the level of energy during the past week was found for 10/11 (91%) patients ($p = 0.02$). An equal improvement of the VAS score was found for the question on the ability to perform the daily work for 9/11 (88%)($p = 0.035$) and for the question on quality of life for 8/9 (80%)($p = 0.04$). Four typical "fatigue" questions gave a mean score of 9.3 points (range 0–15) prior to treatment. After the osteopathic intervention, the mean score decreased to 5.8 (p ⩽ 0.05). Two other specific fatigue questions gave a mean total score of 5 points prior to treatment. This score dropped to a mean score of 3 ($p = 0.34$). On the questions concerning the direct effects of fatigue, there were 6/13 patients that indicated an extreme need for help in daily activities prior to treatment. After treatment this was reported for only 2 patients. The need for bedrest during the day improved due to treatment. There was also an increase in the social activities.

Conclusion: Patients with PCF have signs of liver congestion and loss of liver mobility at initial diagnosis. Osteopathic treatment of these liver dysfunction results in a significant improvement of PCF. Normalisation of other dysfunctions in the parietal, visceral or craniosacranial system has also a significant positive effect on the fatigue complaints. Osteopathy has a worthy place in the total treatment of Post Cancer Fatigue.

1501 ORAL

Knowledge and experience of Greek family caregivers on cancer pain management: a pilot study

K. Papadopoulou, G. Kotronoulas, S. Katsaragakis, K. Antypas,
E. Patiraki. *University of Athens, Nursing Faculty, Athens, Greece*

Background: Greek family possesses a major role on cancer care provision, decision making, and patient's support. This pilot study was designed to explore knowledge and experiences of cancer pain management from the family caregiver's perspective.

Material & Methods: Researchers visited all patients admitted on Monday, Wednesday and Friday for a two month period (March-April 2005) at "St. Savvas" Oncology Hospital in Athens. Patients with a cancer diagnosis, who reported pain, were asked to name their primary caregiver. A Demographic Form and the Family Pain Questionnaire (FPQ-Ferrell BR, 2000, City of Hope) were used for data collection. FPQ is a sixteen item ordinal scale, including a subscale measuring knowledge (9 items) and a subscale measuring experience (7 items).

Results: Only 30 caregivers, from a total of 57 patients experiencing pain, accepted to participate. The greatest percentage of them were women ($n = 22$, 73.3%). Their mean age was 47.97 years (S.D.: 16.59). Among them, 16 were partners, 12 children, and 2 siblings. 23 participants (76.6%) were of primary and secondary education. A knowledge deficiency was detected in several aspects of pain management; particularly, 63.3% ($n = 19$) of participants stated that patients would become addicted to analgesic treatment and believed that analgesics should be administered only when pain was severe. 14 participants (48.3%) strongly agreed to give the lowest possible amount of medication in order to save larger doses for worse pain, whereas 13 caregivers (44.8%) strongly believed that analgesics would affect patient's breathing. Furthermore, 23 subjects (76.7%) comprehended pain deterioration as deterioration of cancer. However, the majority of caregivers ($n = 23$) claimed that cancer pain could be effectively relieved, and more than half ($n = 17$) were fond of a scheduled administration. Meanwhile, responses varied on the effectiveness of complementary therapies on pain relief. Spearman's correlation analysis indicated statistic significance between future perspectives and present level of pain ($p = 0.005$, $r_s = 0.512$), and pain relief ($p = 0.002$, $r_s = 0.559$). Comparing caregivers' estimation of pain as a distressing feeling both for themselves and for their patient, they found pain significantly more distressing for them ($p = 0.016$). No significant difference was found either between gender and knowledge, or educational level and knowledge.

Conclusions: Family caregivers hold limited knowledge about pain and pain management. Further research is needed to confirm these findings, before planning the most appropriate educational interventions.

1502 ORAL

High prevalence of psychosocial distress in cancer patients treated in the outpatient clinic

N. Tonglet. *Oosterschelde Hospital, Medical Oncology, Goes, The Netherlands*

Background: In the Oosterschelde Hospital a psychosocial support program is being developed for patients treated in the medical oncology department. This program encompasses accurate screening of all patients at different stages of the treatment process and definition of the psychosocial support needed.

Purpose of the study: In order to estimate the need for psychosocial support, we screened all cancer patients who visited our outpatient clinic on 2 consecutive days. The Distress Thermometer (DT, *www.nccn.org*) was used as screening tool. A DT-score of at least 4 positive items was considered as an indication for psychosocial support.

Results: All patients asked ($n = 26$) filled in the DT-questionnaire; 16 were female and 10 male. The patients were treated for breast ($n = 6$), colorectal ($n = 8$), ovarian ($n = 2$), gastric ($n = 1$), renal ($n = 2$) and lung ($n = 1$) cancer or a hematological malignancy ($n = 6$). The treatment setting was palliative in 22 and curative in 4 patients. Twenty two patients had a DT-score of at least 4 (range 4–20). Out of these 22 patients, 10 wished to receive help if indicated, 12 did not. Two out of 4 patients treated with curative intention had a DT-score of at least 4.

Conclusions: In 85% of the cancer patients screened in our outpatient clinic psychosocial support appeared to be indicated. The greater part of these patients however preferred to remain untreated. Psychosocial distress appears to be a significant problem, not only in the palliative setting, but also in the curative setting.

1503 ORAL

What do newly-diagnosed patients with lung cancer report as most distressing during the first year post diagnosis?

E. Doukkali[1,2], C. Tishelman[1,2], K. Bertilsson[1,2], S. Runesdotter[1,2],
J. Öhlén[1], E. Broberger[1,2], H. Leveälahti[1,2]. [1]*Karolinska Institute, Department of Nursing, Stockholm, Sweden;* [2]*Stockholms Sjukhem, R&D unit Foundation, Stockholm, Sweden*

The patient perspective on distress associated with lung cancer is important, yet understudied. The study reported here was part of a large-scale project to help clarify distinctions between symptom intensity and symptom distress in patients with lung cancer. The aim of this study was to explore what patients diagnosed with inoperable lung cancer spontaneously report as most distressing during the first year post diagnosis. Inductive, structured data has been collected from 400 men and women consecutively diagnosed with primary lung cancer through two university hospitals in the Stockholm area of Sweden, using a 'free-listing and ranking' method. The patients were asked to respond to an open question "What do you find most distressing at present"? This data was collected close to diagnosis (median 23 days) and prior to treatment (T1), and after two weeks (T2), one month (T3), three months (T4), six months (T5) and one year (T6). The responses were categorized by two members of the research team, based on content.

Fifteen categories of distress were identified, which were structured under the three dimensions: bodily distress; distress related to living with lung cancer, and iatrogenic distress, defined as distress described as triggered by contact with the health care system. Patients reported, on average, approximately two distressing problems per person and time point. Distress associated with the body comprised between 57% and 72% of the issues reported, and increased steadily during the first year. Difficulties with breathing, pain and fatigue were responsible for nearly half the bodily distress reported, although even symptoms not generally assessed were reported. Distress related to living with cancer decreased steadily from 34% at T1 to 23% at T6. Iatrogenic distress accounted for approximately 8% of the reports during the first six months and decreased to <5% after one year.

Implications for care of this group of patients, with numerous and complex problems will be discussed. Strengths and weaknesses of this inductive approach versus structured questionnaires as means of collecting data on distress will also be addressed.

1504 ORAL

Train-the-trainer method for a prospective oral mucositis audit (POMA): a report from the collaborative EBMT nurse/physician mucositis advisory group

B. Quinn[1], R. Stone[2], S. McCann[3], N. Blijlevens[4], M. Uhlenhopp[4]. [1]*Royal Marsden NHS Trust, School of Cancer Nursing & Rehabilitation, London, United Kingdom;* [2]*Nottingham City Hospital NHS Trust, Nottingham, United Kingdom;* [3]*Trinity Centre, Durkan Building, Dublin, Ireland;* [4]*Amgen (Europe) GmbH, Luzern, Switzerland*

Background: Oral mucositis (OM) is a frequent and debilitating consequence of cancer treatment (Eilers 2004). The true incidence and duration of OM are largely unknown due to inaccurate assessment and underreporting. Unlike assessment of neutropenia or anaemia, the presence and severity of OM requires routine physical assessment by an individual. In addition, multiple OM scoring systems exist, with no current standard of care.(Rubenstein et al, 2004) Experts have shown that proper training can lead to substantial improvement in consistency and accuracy of OM assessment. Accurate assessment is important for the conduct of clinical trials to evaluate new therapies to manage OM, ultimately improving patient care.

Background: Oral mucositis (OM) is a frequent and debilitating consequence of cancer treatment (Eilers 2004). The true incidence and duration of OM are largely unknown due to inaccurate assessment and underreporting. Unlike assessment of neutropenia or anaemia, the presence and severity of OM requires routine physical assessment by an individual. In addition, multiple OM scoring systems exist, with no current standard of care (Rubenstein et al, 2004). Experts have shown that proper training can lead to substantial improvement in consistency and accuracy of OM assessment. Accurate assessment is important for the conduct of clinical trials to evaluate new therapies to manage OM, ultimately improving patient care. EBMT initiated a prospective oral mucositis audit (POMA) of 200 patients in approximately thirty hematology transplant units across Europe. Data on OM incidence, severity and duration, and associated costs are collected.

Material and Methods: To streamline and standardize OM assessment across participating POMA centres, a 'Train-the Trainer' approach was established to optimize inter-evaluator concordance by ensuring consistent assessment methodology. Trainers were selected on geographical location, language and/or participation in the audit. Twenty-two nurses and physicians were trained on OM assessment and scoring using the World Health Organization (WHO) Oral-Toxicity Scale which includes evaluation of alimentation (solids, liquids only or oral intake not possible), presence of oral pain/discomfort, and evaluation of eight specified sites for erythema or ulceration. Trainers are then dispatched to POMA sites to train the nursing staff on OM assessment through education, training materials and practice assessment of OM slide images. Trained staff then perform daily OM assessment and collect data for the OM registry.

Results and Conclusions: By May 2005, a total of nine sites received training, with the remaining centres scheduled in time for site initiation. Collection of OM data is ongoing and results of a quality assurance review to assess inter-rater reliability will be presented. This process will demonstrate how joint physician/nurse training on a European level can aid clinical research in OM and ultimately patient care.

References

[1] Eilers, J. (2004) Nursing Interventions and Supportive Care for the Prevention and Treatment of Oral Mucositis Associated with Cancer Treatment. Oncology Nursing Forum 31 94) 13–23.

[2] Rubenstein, E.B. et al (2004) Clinical Practice Guidelines for the Prevention and Treatment of Cancer Therapy-Induced Oral and Gastrointestinal Mucosits. Cancer 100. 2026–20461. 31–42.

Joint EONS/EBMT symposium

Innovations in nursing care, cancer and transplantation

1505 INVITED

Educational activities for stem cell transplant nurses: an European approach

M. Fliedner. *Inselspital, BHH R DOLS, Bern, Switzerland*

The strategy of the European Blood and Marrow Transplantation – Nurses Group (EBMT-NG) aims at promoting and developing specialist education and training within the field of Blood and Marrow transplantation and hematology (Strategy 2004–2009). The underlying background is to reflect the objectives of the JACIE (Joint Accreditation Committee of ISHAGE-Europe and EBMT) accreditation criteria. Hematological diseases are often very complex and difficult to understand. Together with other organizations, the EBMT-NG strives for offering educational programs, that are easily accessible for bedside nurses and other professionals involved in care.

At the EBMT Conference in Prague (Czech Republic) in 2005, the first study day for nurses and allied health professionals was organized. This study day was especially designed to meet the needs of the new European countries. To enable as many nurses as possible to attend many companies helped by providing financial support. Interesting topics related to bedside nursing care were presented and opportunities for open discussions were offered.

In 2004, a program to develop an educational resource for European nurses managing patients with Non Hodgkins Lymphoma (NHL) was launched. The aim is to educate nurses on the best practice and care for patient with NHL. A "meeting in the box" together with a "self-learning guide" is currently being developed.

In summer 2004, a small-scale project to develop a training program for nurses was initiated to develop an educational support package to better understand the complex disease of Multiple Myeloma, its treatment and care issues. Again, this program is aimed to meet the needs of bedside nurses and is intended to be translated into several European languages. Established organizations for patients with Myeloma are involved.

Major pharmaceutical companies are supporting these two projects with unrestricted educational grants.

Obviously, nurses play a vital role in educating patients and their family about the underlying disease and its treatment and side effects, and offering the best supportive care for the patient. To do this, they need to understand the disease, patho-physiology and best care options. A glance at currently running projects, reflections on the study day prior to the EBMT conference in March 2005 and ideas for future projects will be presented.

1506 INVITED

The benefits of reduced intensity transplants

M. Ni Chonghaile. *St James's Hospital, Hope Directorate, Dublin, Ireland*

Care of the Haematopoietic Stem Cell Transplant (HSCT) patient is a complex and challenging area of practice (Chouinard 2003) and the rapidly evolving field of HSCT increases the challenges for the nurses, patient and families involved in the process. The greatest challenge that has faced haemato-oncology nurse and health care professionals in the last 5 years is the advent and development of Reduced Intensity Transplantation.

Reduced Intensity Transplantation arose out of a "conceptual revolution in conditioning regimen design" (Barrett 2000) which developed from the major lessons learned from the last 3 decades of HSCT.

The benefits of Reduced Intensity Transplantation have been simply listed as being a low toxicity and mortality rate; low anticipated late effects; that the treatment of older patients is feasible; that the treatment of patients with co morbid conditions feasible, that they can be carried out on an out-patient basis and there should be a fast recovery with fewer complications and less infection.

The number of Reduced Intensity Transplants has steadily increased over the last 5 years and the shift to this method of transplantation is a critical point for nurses and health care professionals not only when planning and delivering care but also in the education and training of nurses and health care professionals. The aim of this session is to define the theoretical basis and give an overview of Reduced Intensity Transplantation; to separate the truth from the myth with regard to complications and toxicities showing what is comparable to and what is different from conventional myeloablative HSCT and what toxicities and complications are truly reduced. The future directions and challenges of Reduced Intensity Transplantation are manifold with implications not only for patients and their families but also for the education and development of nurses and health care professionals, as well as the management, development and financing of HSCT programmes with the expansion of the patient cohort with respect to age, diagnosis and co-morbidity. The traditional premise that HSCT is the remit of the haemato-oncology nurse is no longer so with the need to expand our knowledge but also increase the greater involvement of health care professionals and disciplines that previously had minimal involvement.

Reduced Intensity Transplantation offers hope and therapeutic options to patients and families that were previously limited and while serious and life threatening complications can occur, the care afforded to these patients can dramatically influence the outcome for these patients and their families offering a very successful treatment and in some cases the only chance of cure for various haemato-oncology conditions.

1507 INVITED

Making sense of cancer and its treatments

B. Quinn. *Royal Marsden Hospital – NHS Trust, School of Cancer Nursing & Rehabilitation, London, United Kingdom*

This presentation discusses the findings of an ongoing doctoral study that arose as the result of my own clinical experience, earlier studies and ongoing reflection. Having originally worked as a priest and more recently working as a nurse I noted that while working in a variety of health care contexts (hospice, hospital, community), both roles required me to support people who were trying to make sense of their illness and the treatments they had to undergo. Talking to my colleagues I knew this support was something many of us were involved in. Building on the work of Frankl (1959) this study explores the search for meaning in the context of living with cancer. In this study people with cancer share their experience of trying to make sense of their disease and the treatments they underwent. From first noticing a change in their body, (finding a sore, a lump, feeling tired, breathless, pain) each person began to make sense of their experience and went on to be told of a medical diagnosis of a malignancy bringing multiple changes to themselves and those close to them. Some of the findings that have begun to emerge include: the search for meaning is ongoing, multifaceted and may be lived out in a variety of ways, living with cancer and the treatment it demands brings many changes some of which lead to