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 a sense of loss of control, there are a multitude of relationships involved which may help or cause distress to the person dealing with cancer, the health care team while often supportive sometimes failed to see the needs of those they cared for, while people with cancer value the expertise and knowledge of the health care team they also want the team to demonstrate compassion and sensitivity while delivering care and information, while a few people had found particular meaning to aspects of their experience all recognised that the ongoing process of searching to find meaning continues after treatment finishes. It is hoped that by listening to the experiences of these individual people living with cancer the insights gained will support the health care team in their efforts to help those undergoing treatment for cancer.

Frankl, V.E. (1959) Man's Search for Meaning. London. Hodder & Stoughton

### 1508 INVITED
### The sense or nonsense of isolation

P. Crombez. *Institut J. Bordet, Onco-Hematology Department, Brussels, Belgium*

Infectious complications are a major cause of morbidity and mortality after haematopoietic stem cell transplantation (HSCT). Protective isolation (PI), especially in laminar airflow (LAF)- and/or high-efficiency particulate air (HEPA)- rooms remains still a controversial issue.

Numerous studies have assessed the effect of these measures with conflicting data. Most are descriptive, with only 9 prospective randomised studies, or tested several prophylactic interventions simultaneously making it difficult to determine the impact of PI alone.

The established guidelines concerning isolation practices are based on opinions of respected authorities or expert committees without evidence on the usefulness of PI. Only some airborne infections like nosocomial Aspergillosis can effectively be prevented by the use of LAF or HEPA filtration. But what about the preventive effect of these measures against endogenous bacterial or viral outbreaks? These cannot be prevented by strict isolation and led together with other factors; like financial costs, psychological burden, and the change in supportive care, newer concepts of HSCT and a remarkable change in the epidemiology of infections; to the reconsideration of isolation practices.

In addition, several reports, although non-randomised, describes the feasibility of outpatient care after high-dose therapy and HSCT. The pooled statistics suggest that protective environments provided no benefit in decreasing mortality for the transplant patient.

Furthermore the risk of opportunistic infections is not limited to the period of neutropenia but continues during the whole phase of immunodepression until about 1 year after HSCT and while the patient is not hospitalised.

Despite lack of sufficient evidence regarding the sense of PI it could be recommended for inpatient care of high risk allograft patients, especially if there is a history of high incidence of Aspergillosis or if there are frequently (re) construction activities in the hospital. It is of great importance to incorporate in the hospital an infection control program with ongoing assessments to identify risks for the acquisition and transmission of nosocomial infections.

For other patients there is less or no sense of PI but several isolation measures remain primordial to be respected like strict hand disinfection.

Only the results of a prospective, randomised study of sufficient power will enable definitive conclusions to be drawn regarding the sense or nonsense of PI.

## Special Lecture

### 1509 INVITED
### Centering care: patient's perspective

S. Rozman. *Europa Donna European Breast Cancer Coalition, ED Slovenia, Ljubljana, Slovenia*

In the lecture we want to highlight the patient as an important role in the organization and planning of care. Nowadays more and more diseases become increasingly chronic and we are faced with different problems: issues of patient compliance to treatment, of patient participation in decision making, of patient being a member of the multidisciplinary team, the doctor-patient relationship, as well as the patient advocacy movement, are becoming increasingly the center of our attention. On the other hand, there is striving for professional excellence in health care management, and systems of quality assessment demand feed-back from the customers, in this case the patients. Patients find themselves also in the increasingly powerful role of consumers and there are consumer rights that need to be taken into account, warranted by customer protection charters. Most countries have endorsed patient's rights, too, but how to implement them is something yet to be discovered.

We no longer take it for granted that what the caretakers think is best for the patient is the best that can be done. We ought to know what the patients really want. A research has shown that patients want three main things: competent care, person-centered care, organized around patient's needs and holistic care that extends beyond basic clinical care to address wider patient needs and wishes. Within these themes are ten things that patients want: practical support-knowing how their everyday lives will be affected, and how they can cope; emotional support, provided in a systematic fashion; being treated as people, not as patients, numbers, or diagnoses; involvement in decision making, services as close to home as possible, provided that clinical quality is not compromised; less waiting for diagnosis, during treatment procedures, and in outpatients; follow-up to be as well planned and patient centered as the initial treatment; but they also want easier access to complementary therapies as a supplement to conventional therapies; skilful staff and specialist nurse support; as well as appropriate "hotel services".

Patients are often the last to be consulted when services are being designed, assuming that they are unable to cope with that role while in the middle of their struggle for recovery. When searching for a competent partner, one should take into account the long term survivors who are well informed, organized, able and ready to act as patient advocates in the planning activities.

## *Joint EONS/AFIC symposium*
## Evidence based management of adverse events

**1510** Abstract not received

### 1511 INVITED
### Hand–foot syndrome – evidence based management

C. Courtiol. *Cadre de Santé, Centre Alexis Vautrin, Nancy, France*

The hand–foot syndrome was described for the first time in 1974 in relation to a treatment with Mitotane. After Burgdorf (1982), observed the hand–foot syndrome during a high dose chemotherapy for acute myeloid leukemia, several cases followed and were named differently, like acroerythema, hand–foot syndrome, palmar plantar erythrodysesthesia syndrome, Burgdorf reaction, palmar plantar toxic erythema. It is a painful erythema located on the palmar and soles. In 1984, 5 fluorouracil (5FU) was reported as implicated agent : from 400 patients, 18 presented this syndrome, and 17 of them were treated with 5 FU; later other chemotherapeutic agents were related to this syndrome just like Caelyx.

In my presentation I will address various questions such as how many patients suffer from this syndrome ? How to prevent it? What advice should be given to the patient? What is the implication for nurses?

### 1512 INVITED
### Skin problems – evidence based management

L. Lemmens, H. Marsé, E. Van Cutsem. *University Hospital Leuven, Digestive Oncology Unit, Leuven, Belgium*

New therapies targeting the epidermal growth factor receptor (EGFR) are active in the treatment of several types of cancer. Amongst the agents targeting the EGFR are monoclonal antibodies (e.g. cetuximab, panitimumab) against the extracellular ligand-binding domain of the receptor and small molecules (e.g. gefitinib, erlotinib) that inhibit activation of the receptor tyrosine kinase. Targeted therapies have a specific mode of action and as they are focused they usually affect fewer normal cells than cytotoxic drugs do. This gives a better side effect profile than that of cytotoxic drugs. However, EGFR-inhibitors often cause signs of skin toxicity, most often acneiform eruption. After an acute phase of acneiform eruption, patients can gradually develop dry skin, sometimes resembling atopic eczema. After several months of treatment, in 10–15% of the patients, nail changes can be seen: paronychia can be painful and mimics an ingrown nail. There are also some other minor effects, such as the growth of long curly and rigid eyelashes, teleangiectasia and hyperpigmentation, all usually appearing after several months of treatment. Several retrospective analyses suggest a correlation between the severity of rash and the activity of the EGFR-inhibitor. Prospective studies are ongoing to better understand these findings. Dermatologic side effects of EGFR-inhibitors should be taken seriously since they can cause physical and cosmetic discomfort, that may compromise compliance to therapy if left untreated. Although the number of large trials on the treatment of skin toxicity is limited, the experience is growing on the best management