

- Access to 24-hour specialist advice and expertise
 - Emotional, spiritual and practical support for all family members
 - Respite care, with medical and nursing input, when required
- The challenge for health care services is to develop a system to provide safe, high quality care, able to meet the multifaceted needs of patients and their families in their place of choice until the end of life.

This paper will consider the obstacles to the expansion of complex care at home and describe the underlying principles and a model of care that has evolved to support palliative and end of life complex care. As an example of the expansion of care at home, the use of patient controlled spinal analgesia via a tunnelled subarachnoid catheter will be highlighted. A case study will illustrate indications for use of spinal analgesia, titration, monitoring, affect on patient function, quality of life and preparation for death.

1644

INVITED

The importance of place of death for young adults with cancer

A. Grinyer. *Lancaster University, Institute for Health Research, Lancaster, United Kingdom*

This paper addresses issues relating to place of death in young adults with terminal cancer, through the perspectives of their parents. Evidence suggests that the majority of terminally ill cancer patients would prefer the option of a home death, but little is known about preferences among young adult cancer patients and their families. Through retrospective reflection by bereaved parents of young adults with cancer, this paper aims to understand the importance of place of death to this age group. The empirical data drawn on in this paper consist of accounts written by the parents of 13 young adults who died of cancer. A death at home is reported as a strongly held preference of the majority of young adults, and was supported by their parents. Eight of the 13 young adults were able to die at home, another wished to do so but died in a hospice. However, narratives describing death in places other than home signal that home may not always be the preferred or 'best' place to die. Life-stage factors do appear to play a role in determining both preference for, and the actual achievement of, a death at home, but if life stage issues are understood and respected a 'good' death can take place in other environments.

Special Lecture

1645

INVITED

Nutrition and physical activity for individuals living with cancer

J.K. Brown. *University at Buffalo, School of Nursing, Buffalo, NY, USA*

Individuals with cancer commonly experience nutritional problems such as anorexia and weight change that are strongly associated with functional status, quality of life, and potential recurrence of disease. The purpose of this presentation is to: (1) describe a conceptual framework that guides analysis of nutritional problems and related evidence as well as design of nutrition and physical activity interventions; (2) discuss evidence based nutrition and physical activity interventions across the cancer trajectory; and (3) describe the levels of evidence for nutrition and physical activity interventions for selected cancers. Nutrition and physical activity are integrally related in the pathophysiology and management of nutritional symptoms. Weight change is caused by imbalance between food intake and energy expenditure, and weight loss may be accompanied by the loss of muscle mass. Nutrition and physical activity symptom management strategies should address patient unique needs across the phases of living with cancer and should be based on the best scientific evidence and clinical judgment. During cancer treatment, increased caloric needs are common, and food choices should be adjusted to individual needs. A small number of studies have tested physical activity interventions during treatment, and all reported findings of reduced treatment-related symptoms and improved quality of life. During recovery from cancer treatment, a nutritionally balanced diet and physical activity to regain muscle strength and endurance are needed. Although evidence is limited for advanced cancer patients, good nutrition and physical activity, to the extent possible, are important to reduce symptoms such as anorexia, constipation, and fatigue and improve feelings of well-being and quality of life. Researchers are now beginning to report positive effects of nutraceuticals on nutritional status of patients during treatment and living with advanced disease. Cancer survivors are concerned about preventing recurrence and second primary tumors. There is substantial evidence that recurrence of breast cancer is strongly related to obesity, so maintaining a healthy weight through a combination of healthy food choices and physical activity is important for breast cancer survivors. In conclusion, the levels of evidence for nutrition and physical activity interventions is variable, so the current

evidence for nutrition and physical activity interventions in breast, prostate, colorectal, and lung cancers will be described.

EONS symposium

TITAN: education with dissemination

1646

INVITED

A visual tool to educate patients: improving understanding and early detection of side effects of chemotherapy

S. Verhage¹, V. Keijsers², N. Golsteijn³, C. Kuijpers¹, J. Graat⁴. ¹*Jeroen Bosch Hospital 's-Hertogenbosch, The Netherlands;* ²*Amphia Hospital Breda, The Netherlands;* ³*Tweesteden Hospital Tilburg, The Netherlands;* ⁴*Elkerliek Hospital, The Netherlands*

In order to manage side effects of chemotherapy optimally, it is crucial that patients and their relatives are able to access information easily. The purpose of this project was to develop a picture-based tool that helps nurses to communicate medical information to people who have a preference for pictorial information, such as the elderly or people with reading disabilities. A major advantage of a picture-based tool is that it is language independent, and so it could be used across the whole of Europe and also to communicate with patients who do not speak the local language.

A picture-based flipover tool has been designed that can be used when giving information to patients in concert with a treatment guide for chemotherapy. It includes a general introduction to cancer and chemotherapy and lists the side effects of anaemia, neutropenia and thrombocytopenia.

It was a challenge for us to see which manner of graphic illustration we could use other than the usual drawings. We started with the help of a graphic designer. We also sought photographic material which spoke for itself and could be used as a visual support for the above mentioned side effects.

The next step is to evaluate the tool in daily clinical practice.

In September we are going to test the flipover application on 25 patients. Also the nurses who participate in giving this test will be asked to evaluate their experiences. The result of this pilot will be presented at the ECCO and shall give direction for further development of this flipover.

Following successful results, this tool could be used as a benchmark example for the development of additional visual tools that would explain other side effects of chemotherapy such as mucositis, fatigue and nausea. *This project was nominated as the best Dutch TITAN dissemination project during the pilot phase of the TITAN initiative, which is an innovative educational program being implemented by EONS. More information about TITAN can be found on the EONS website at <http://www.cancereurope.org/> or by contacting Jan Foubert at eons@village.uu.net.

1647

INVITED

A flow-sheet protocol for febrile neutropenia

S. O'Connor, C. Duggan. *Oncology Day Unit, Portiuncula Hospital, Ballinasloe, County Galway, Ireland*

The format of our existing febrile neutropenia protocol is difficult to follow, and this hinders the identification of patients who are at risk of neutropenic sepsis. The aim of our project was to make this protocol more user-friendly so that medical and nursing staff would be better equipped to identify high-risk patients and to manage common infections more efficiently in the future.

Background: On Friday, 26th March 2004, we attended a Training Initiative in Thrombocytopenia Anaemia and Neutropenia (TITAN), which was held in Dublin. The aim of the course was to improve the prevention, detection and management of haematological toxicities in patients with cancer. On completion of the course we were required to complete a dissemination project.

We have designed, produced and pilot-tested a flow-sheet that will help medical and nursing staff to make a comprehensive assessment of a febrile neutropenic patient. The flow-sheet was adapted from the West of Ireland Cancer Care protocol for febrile neutropenia, with permission from Dr Maccon Keane, Consultant Medical Oncologist, University College Hospital Galway and from The Nursing and Midwifery Planning and Development co-ordinator in Portiuncula Hospital.

A 3-page written document was reduced to a single page and transformed into an easy-to-navigate flow-sheet. Once a consensus was reached on a final version of the flow-sheet, it was pilot-tested at the Accident and Emergency Unit, Intensive Care Unit and medical and surgical wards of Portiuncula Hospital, County Galway during July 2004.