1640 ORAL

The daily debrief: an innovative method to manage emotional burden in palliative care nursing

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Background: A consistent therapeutic relationship between nurses and patients is required to facilitate the provision of high quality cancer and palliative care. Previous research has revealed that nurses can benefit from "resent-less self care" and has highlighted the importance of using colleagues as a supportive learning resource. A short daily debrief for nurses working in specialist palliative care was introduced that was grounded in the principles of reflection, lateral thinking and problem solving. The sessions provided a safe place, guaranteed equality *between* group members and ensured that issues were explored *and* action planned.

Materials and Methods: By using skilled group facilitation, the nurses are encouraged to reflect on the shift, articulate problems, concerns and dissatisfaction, describe what has gone well and what has not. This encourages nurses to express anxieties and allows the team to enhance collaborative practice by thinking through solutions together away from the practice setting. At the end of each session each nurse shares with the group something that they have either done well or achieved that day. Evaluation of the value of the daily debrief has been conducted by collecting narratives from individual team members during routine staff development interviews conducted by senior staff every 6 - 8 weeks. Also a review of the daily debrief was conducted at two time out days for the nursing team.

Results: One of the recurring themes at the staff development interviews is the degree of support gained from the daily debrief and how it has encouraged nurse to look for solutions as the problems arise rather than leave problems unresolved. Review of debrief at two time out days this year and last year has highlighted how it has become fundamental part of the day. Staff regularly seek out a member of the senior team saying 'we are ready for debrief!' Staff state that they feel they can leave the shift behind and then look forward to returning, rather than feel drained by unresolved issues.

Conclusions: The daily debrief is a valuable method of reducing the stressors of the day before leaving the unit thereby minimising the effects of the emotional labour associated with palliative care work in patients with advanced cancer. This has in turn affected the encouraging the nurses to take action toward resolving problems that arise as well as providing support for members of the team. The next step is to develop the tool further for use within the multidisciplinary team and to test in other practice settings.

Joint EONS/SIOP symposium
Palliative care in young people

1641 INVITED

Palliative care in young people in Germany: the magnitude of the problem and diversity of symptom profile

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Background: More than 22,000 young people suffer in Germany from a terminal or life-threatening condition. Every year 1,500–3,000 of those young people die, one-third of them due to cancer. In three nationwide studies we studied i) the provision of palliative care at home and on the children's cancer units ii) pediatric palliative care by nurse-led home care services for children with cancer and non-cancer life limiting conditions and iii) the symptoms at the end of life in children with cancer and parents' perception of the dying child's quality of life.

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 132 German nurse-led home care services for children identified 37 services which have gained experience in caring for dying children between 2000–2002. iii) A third survey among parents of deceased young people, formerly patients of six pediatric oncology units in North Rhine-Westphalia.

Results: More than 60 per cent of children with malignancies died as in-patients in 2000, less than 40 per cent at home. Twenty-nine pediatric cancer departments were able to provide comprehensive medical palliative home care, nine units incorporate a designated palliative care team or person. The most common symptoms were pain (82%), fatigue (76%), poor appetite/weight loss (70%), dyspnoea (62%), constipation (44%), anxiety (44%) and nausea/vomiting (38%). Of those children who received a specific treatment for their symptoms, 37% were treated successfully, 30% with some success and 20% without success.

Conclusion: Symptom control in children with terminal conditions in Germany is at the moment not sufficient. The majority of dying children in Germany do not have access to comprehensive palliative care services at home. While nurse-led home care services for children cover a substantial part in the provision of pediatric palliative care in Germany, their reimbursement by health insurance is poor.

1642 INVITED

Decision making and transition to palliation

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Despite remarkable progress in curative treatment approaches the prognosis of about one third of childhood and adolescent cancer patients is very limited. Each year, thousands of children in Europe die ultimately of progressive incurable cancer. In the majority of these children, due to disease progression, the primary curative treatment will be changed into palliative care to prevent and treat unnecessary suffering of these patients on their way to a premature death.

When cure seems no longer possible, the goals of treatment and the tools to meet them have to be clearly adjusted which is a difficult task to accomplish.

When to shift to palliative care and which treatment and care options have to be initiated or stopped, has to be decided very individually based on the physical, psychological, social and spiritual needs and desire of the patient. This situation differs remarkably from a curative approach in which standardized treatment protocols clearly set the direction to follow and individual needs of the patient are of less importance. The duration of palliative care is indefinite, possibly many months or years, and comprises the end-of-life period when patient's death is imminent. The problems the patient and caregivers face in this period are typically complex with medical, social and ethical aspects and are changing in the time. Decision making is therefore a complex, almost continuous process in which the needs and interest of the patient, on one side, and the benefits and the impact of the treatment and care given, on the other side, have to be assessed and the treatment/care has to be adjusted accordingly, if necessary.

Transition into palliative care is mainly triggered by absence of an effective therapy. However, the exact chance of cure is mostly difficult to define and other factors, such as the patient's performance status, the impact of side effects, request by patient/parents etc., have to be considered as well. Consequently, thorough knowledge of the individual patient, the course of the disease and treatment results in comparable situations (data from literature and studies, personal experience etc.) is required for an appropriate recommendation.

In the terminal stage, end-of-life issues, such as 'no resuscitation' and management of pain with narcotics, should be discussed in order to clarify the patient/parent's needs and explain the expected impact of the selected approach.

1643 INVITED

Expanding complex palliative care at home for young people

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Despite improvements in survival for children and young people with cancer, approximately 25% will die as a consequence of their disease. When cure is no longer possible, care should be tailored to the unique needs and personal choices of the patient and family. As curative therapies are no longer indicated, approaches are focused on 'holding' the disease and/or optimizing symptom care.

In our experience, the palliative stage of the patient's journey is extending, not least due to advances in palliative chemotherapy, radiotherapy, and symptom management strategies. For some, the symptomatic phase of their illness can be long and may require complex symptom management. Given appropriate and adequate support, home is invariably the families preferred choice of place of care and death.

Recently published guidelines (August 2005), Improving Outcomes in Children and Young People with Cancer, by the National Institute for Health and Clinical Excellence, identifies core elements of palliative care as:

- Timely and open communication and information
- Choices/options in all aspects of care, including complementary therapies
- Death in the place of choice
- Coordination of services at home, where this is the chosen place of care, including provision of specialist equipment
- Expert symptom management, including radiotherapy and chemotherapy

- Access to 24-hour specialist advise 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

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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

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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

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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 pictoral 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 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 photografic 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.uunet.be.

1647 INVITED

A flow-sheet protocol for febrile neutropenia

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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.