474 Nursing Programme

1640 ORA

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

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-Westohalia.

Results: More than 60 per cent of children with malignancies died as inpatients 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.

642 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