Living in a World Without Closure: Reality for Parents Who Have Experienced the Death of a Child


These investigators examined factors that cause variation in healthcare providers’ level of comfort about providing pediatric palliative care. In particular, they tested the hypothesis that nurses who are more inclined toward hopeful ways of thinking and feeling are also more comfortable providing palliative care. A cross-sectional survey of all the nurses at Children’s Hospital of Philadelphia was conducted during the spring of 2005. The response rate to the survey was 44% (410 out of 932 eligible nurses), which the investigators noted was higher than that reported in comparable surveys of nurses. The Web-based survey incorporated questions regarding nurses’ knowledge, attitudes, practices, and experiences regarding various aspects of palliative care. The Adult Dispositional Hope Scale was included as part of the survey to measure hopeful thinking. Most respondents were women who were younger than 40 years of age, had a decade or less of nursing experience, and had four or fewer hours of previous palliative care-specific education. Nurses reported feeling most competent regarding pain management and least competent regarding talking with children and families about dying. The results indicated that greater numbers of years in nursing practice, more hours of palliative care education, and higher scores on the Hope Scale were each associated with significantly higher levels of comfort working with dying children and their families, higher levels of palliative care competency, and lower levels of difficulty talking about death and dying. Among the predictors, the hours of palliative care education was the most substantial explanatory variable. Although further research is needed to substantiate these associations, the results suggested that provision of palliative care education is an important factor in enhancing nursing competence and level of comfort. Furthermore, the development and testing of hope-enhancing interventions for nurses who provide pediatric palliative care may be warranted.

Comment by Maureen Heaman
Palliative Care Delivery in the NICU: What Barriers Do Neonatal Nurses Face?


Despite a well-established and universally accepted protocol (Catlin & Carter, 2002) and support for neonatal palliative care by the World Health Organization (Maginnes, 2002) and the American Academy of Pediatrics (2000), it is rarely and certainly inconsistently practiced in most NICUs today. This interesting article presented an extensive and systematic review of the literature on barriers for neonatal nurses to providing palliative care. The author systematically searched several databases (CINAHL, Medline, PsychINFO, and PsychArticles) and reference lists of several significant articles for a total of 35 articles. The author was surprised to find few articles that specifically related to neonatal nursing. Several themes emerged from the literature indicating that barriers for neonatal nurses may be attitudinal, clinical, educational, institutional, regulatory, and financial. The author discussed literature that spoke to the perception that neonatal death is often viewed as “unnatural” to both nurses and families, who often have unrealistic expectations for medical intervention with sick and dying neonates. These unrealistic expectations are further exploited by the media and, in combination with providing what is perceived as futile aggressive treatment, may result in a sense of moral distress for the nurse. Ethical dilemmas also exist for the nurse because there is little, if any, consensus in the research literature as to what neonatal outcomes should be considered beneficial versus detrimental. The literature also revealed that neonatal nurses with more experience and advanced education experienced less moral distress during and after the death of a patient. Other significant barriers to providing neonatal palliative care include the NICU environment, which offers little or no privacy and comfort for the family, and a lack of formal training in palliative care and palliative care skills. The author, a doctoral candidate at Queensland University of Technology in Australia, has developed a survey instrument that explores both barriers and facilitators to palliative care practice by neonatal nurses. She plans to administer this instrument to NICU nurses in Australia and eventually—after testing for validity and reliability—to an international sample of NICU nurses. The Neonatal Palliative Care Attitude Scale (NPCAS) surveys the following key barriers: (a) neonatal death viewed as a failure, (b) adjustment from a curative to palliative care approach, (c) difficult communication with parents of dying neonates, (d) previous and traumatic exposure to neonatal death, (e) conflicts among providers around end-of-life decision making, (f) NICU environment, (g) lack of support for nurses providing end-of-life care, and (h) lack of formal training for nurses. The NPCAS is included in a sidebar of the article and would be useful for neonatal nurses exploring their own attitudes on palliative care. As a start in the development of a more formalized approach to the education of neonatal nurses on this topic, the palliative care protocol (Catlin & Carter, 2002) is a must read!

Comment by Judy Beal

References


Interdisciplinary Interventions to Improve Pediatric Palliative Care and Reduce Health Care Professional Suffering


An interdisciplinary committee at Johns Hopkins Children’s Center began their initiative to improve the quality of care given to dying children by assessing the knowledge, attitudes, beliefs, and concerns of healthcare professionals regarding end-of-life care. Healthcare professionals reported significant levels of distress and many believed that the care provided was not optimal. The committee then initiated a quality improvement program of professional education and support that consisted of four interdisciplinary activities: a forum for networking and education, palliative care rounds, palliative care conferences, and bereavement debriefing sessions. The program was based on an empowerment, facilitation model and was designed to help healthcare professionals (a) increase their competence and confidence in providing pediatric palliative care, (b) increase their ability to manage responses of grief, and (c) restore and maintain their sense of professional integrity. This article reported the feasibility and utilization, content, and participants’ views of usefulness. One hundred one sessions were conducted for 950 participants. All four activities were positively evaluated. The authors concluded, “A comprehensive approach that includes clinical skills, psychosocial support, meaning making, and offering opportunities to integrate palliative and end-of-life knowledge and skills is critical to meeting the diverse needs of the interdisciplinary health care team” (p. 930). Although additional evaluation is needed to evaluate the impact of this program on the quality of palliative care provided to children and their families, a program such as this may be helpful in educating and supporting healthcare professionals in providing end-of-life care and can be applied in diverse pediatric healthcare settings.

Comment by Maureen Heaman
It is well documented that recent advances in neonatal medicine have increased the sustainability of life and improved neonatal outcomes. However, it remains fact that more infants die in the first 27 days of life than any other period during childhood (Kochanek, Murphy, Anderson, & Scott, 2004) and that neonatal palliative care is rarely offered. This ambitious systematic review of 51 research articles published since 1996 using OVID, MEDLINE, PsychINFO, CINHAL, and PubMed yielded 10 articles that the authors reviewed for the purpose of synthesizing research on end-of-life care in neonates. A clear and concise literature review of the overview of palliative care and end-of-life care during the neonatal period preceded the presentation of the integrative review. The inclusion and exclusion criteria for article selection were not well described in the article. It was interesting to note that the authors stated that there are no universal standards for treating neonates at the end of life and did not cite the Catlin & Carter Neonatal-End-of-Life Palliative Care Protocol published in 2002. Findings of this study were summarized in four categories: practices of withdrawing or withholding life-sustaining treatment, pain management during ventilator withdrawal, parents and the decision-making process, and the dying process. Research has shown that there has been an increase in the number of neonates for whom treatment was either withdrawn or withheld and that most NICU deaths occurred after the decision to withdraw or withhold treatment. The use of palliative care services is low in the NICU despite the high number of deaths during the neonatal period. Research on pain management during ventilator withdrawal was inconsistent, ranging from a study that showed that most infants received pain management to another study that indicated that although pain management was given during ventilator withdrawal, it was rarely continued. Parental involvement with decision making during the neonatal period has been well researched (previously reviewed in this column) and has shown that parents are involved in the decisions to withdraw or withhold treatment but that their level of involvement varies and that their experiences and perceptions with providers during this period of tough decision making clearly have an impact on what they decide. Although the research shows that most parents are present when their infant dies, they are not well prepared for the dying process itself. These authors make a strong case for enhancing palliative care and end-of-life services in the NICU, arguing that the use of such services would go a long way to solving issues related to inconsistent pain management and parental decision making and support. They concluded with the recommendation that palliative care services should be offered as soon as life-sustaining treatment has been initiated, regardless of anticipated outcomes.

Comment by Judy Beal

References

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**Neonatal End-of-Life Care: A Review of the Research Literature**