

# Caring for Dying Children: Assessing the Needs of the Pediatric Palliative Care Nurse

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Pediatric palliative nursing care, both stressful and rewarding, requires coping skills, confidence, and other attributes for successful patient care and nursing practice. Through a thorough literature review, clinical workshops, direct observations in pediatric palliative care settings, and personal nursing experience in the neonatal intensive care, pediatric intensive care, and oncology wards, this author confirmed the necessity for studies to clarify the needs of dying pediatric patients and their families, as well as the needs of nurses who provide their care. This article briefly reviews the history and current status of pediatric palliative care, describes the experiences of nurses caring for dying children, explores the impact of providing palliative care on the hospital staff, and seeks to discover possible interventions by the advanced practice nurse to influence more positive patient care and nursing staff job satisfaction and retention.

**S**umner (2006) used a children's book to poignantly describe the life cycle of nature:

There are lots of living things in our world. Each one has its special lifetime. All around us, everywhere, beginnings and endings are going on around us all the time. So, no matter how long they are, or how short, lifetimes are really all the same. They have beginnings and endings, and there is living in between (p. 909).

When a child dies, this cycle seems unnatural. Suddenly, human potential is lost, and dreams quickly become shattered. Parents, siblings, and health care providers are left to grieve the loss of the child. This dilemma has encouraged many nursing leaders to explore methods of research and evidence-based practice to promote bet-

ter outcomes for everyone involved in the palliative process.

Pediatric palliative care has become a topic of increasing study and discussion in the health care arena. In the past, most palliative care programs have focused on the adult population. Research has shown that pediatric palliative care programs and education are needed (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Further research shows that out of 3,000 hospice programs in the United States, fewer than 10% provide end-of-life care to children, and even fewer provide care for dying neonates (Romesburg, 2007).

Health care professionals face numerous obstacles and challenges while providing care to this unique population of clients and their families. Barnard, Hollingum, and Hartfiel (2006) suggest the care associated with terminal illness demands the qualities and skills that arise from compassion, reciprocity, professional commitment, and the ability to communicate with patients and their families. Professionals who witness the pain and suffering of children and their families may also experience pain and suffering themselves. Without comprehensive pediatric palliative care programs, nurses may lack the education and training needed to meet the challenges of this special care. Health care workers may experience emotions such as helplessness, anger, sadness, and anxiety while providing care to dying children. These feelings may quickly lead to nurse burnout and

increase turnover rates in the hospital setting (Weigel, Parker, Fanning, Reyna, & Gasberra, 2007).

## History of Palliative Care

The concept of palliative care originally evolved from the hospice philosophy of meeting gaps in care for seriously ill and dying patients. The Latin word *palliate* means "conceal or alleviate symptoms without curing" (Romesburg, 2007). The earliest recording of the word *palliate* can be traced to the late 14th century, where it originated in Elizabethan and Indo-European traditions (Morris, 1998). In 1967, Dame Cicely Saunders founded the first modern hospice program in the United Kingdom, which emphasized the importance of compassion and medical science (Georges, Grypdonck, & Dierckx de Casterle, 2002). Florence Wald, Dean of Yale University, invited Saunders to the U.S. to learn about her experiences, and in 1974, she founded the first home hospice program based in New Haven, Connecticut. In 1975, St. Luke's Hospice in New York was the first hospice in the U.S. incorporated into an existing medical center. In 1982, the first children's hospice center opened in England (Foster, 2007). Despite growth in hospice initiatives, researchers have only just begun to explore the unique aspects of pediatric palliative care.

Palliative care was first introduced in 1990 by the World Health Organization (WHO) (2004) and is currently defined as "an approach to

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Objectives and the CNE posttest can be found on pages 91-92.

care which improves quality of life of patients and their families facing life-threatening illness through prevention, assessment, and treatment of pain and other physical, psychological, and spiritual problems." WHO (2004) further describes palliative care for children as the active total care of the child's body, mind, and spirit, as well as a means of providing support to the family.

To provide this type of palliative care today, hospitals throughout the U.S. have increased initiatives to meet the unique needs of both adults and children. Although there are some commonalities, pediatric palliative care differs from adult palliative care in several ways that preclude the extension of existing adult services into the pediatric world (Sumner, 2003).

### Pediatric Palliative Care

Each year in the U.S., 55,000 children less than 20 years of age die, and many of these children experience a lengthy illness (Carter et al., 2004). Common diagnoses affecting the length of children's lives include prematurity, congenital anomalies, sudden unexpected infant death syndrome (SIDS), chromosomal defects, trauma, neurodegenerative disorders, acquired immunodeficiency syndrome (AIDS), and cancer. Cancer remains the leading cause of disease-related death in children and adolescents. It is estimated that 25% to 33% of children with cancer die; the average number of cancer deaths in children is 2,200 per year in the U.S. (Himmelstein, Hilden, Boldt, & Weisman, 2004). However, even with these statistics, children's palliative care programs are not as prevalent as adult programs.

A possible reason for lack of pediatric palliative care programs may be that most people are just unaware of the need or just do not want to accept that children die. Children, the hope and the future of our society, are not supposed to die. The concept of a child dying before a parent is just too unbearable to imagine. There is something especially tragic about a life with unrealized potential coming to an end. Thus, family members, as well as health care workers, often deny the approaching death. The death and avoidance of its surrounding issues may also be reinforced by the uncertainty of the treatment outcomes in the pediatric population (Rushton, 2000).

A unique aspect of pediatric palliative care is the need to tailor all care

around the developmental level or stage of each individual child. An example of this can be seen in the ethical and legal issues that arise in caring for a terminally ill teenager who, because of his chronological age, lacks the authority to make medical decisions, yet consensus supports giving him decisional authority because of his cognitive and emotional maturity (Freyer, 2004). Discussion of and advocacy for his life choices will look different from those offered to an adult, as well as those offered to a small child. Developmental level must be considered in pursuing effective communication with the younger child as well. The delivery of support and care must be age-appropriate and must be re-evaluated as children change through each developmental stage.

Another significant aspect of pediatric palliative care is the timing of its initiation. In adult palliative care, the patient must be considered terminal and in the last six months of life to qualify for palliative or hospice care programs. These requirements do not work well in the pediatric setting, as many of these children are still pursuing curative treatments at the time of their clinical deterioration and death. With the extended definition of pediatric palliative care to include care and support for life-threatening illness as well as for those who are at the end of life, pediatric palliative care should begin at diagnosis if death is clearly a possibility.

**Support for pediatric palliative care programs.** Literature identifies multiple and diverse barriers to good palliative care, including attitudinal, clinical, educational, institutional, regulatory, and financial barriers (Rushton & Catlin, 2002). However, significant change is on the way, as evidenced by the formation of national and even international task forces that are attempting to develop policies and protocols to address needs of children with life-threatening illnesses. The Children's International Project on Palliative and Hospice Services (ChiPPs), which is composed of leading international experts in the field of pediatric palliative care, was established to promote research in pediatric hospice and palliative care (Davies, Brenner, Orloff, Sumner, & Worden, 2002).

The year 2000 marked the formation of the nursing leadership academy in end-of-life care, which is composed of leaders from 22 national organizations, and was created by the Institute for Johns Hopkins Nursing

and funded by a grant from the Open Society's Project on Death in America. This group issued a statement that supported palliative and end-of-life (EOL) care across the lifespan (Bowden, 2002). The neonatal end-of-life palliative care protocol established a plan to create a protocol delineating the needs of patients, families, and staff necessary to provide a pain-free, dignified, and family/staff-supported death for newborns (Catlin & Carter, 2002). The National Alliance for Children with Life-Threatening Conditions brought together change agents and leaders in the field of pediatric hospice and palliative care (Sumner, 2003). This group is expected to evaluate current pediatric palliative care programs, identify problems, and work toward continuous program improvement.

### Current Issues for the Palliative Care Nurse

Although much needs to be done to provide optimal palliative care programs for the patient and family, nurses caring for dying children also have many unmet needs that have an impact on the care they provide, their job satisfaction, and ultimately, hospital staff retention. A study conducted by Papadatou (1997) described the emotional distress experienced by nurses when a child dies:

Health care professionals are now, more than ever, directly confronted and affected by childhood death, since an increased number of children die in the hospital, usually after extensive efforts and heroic measures are undertaken to save their lives. As a result, it is not uncommon for health care workers to perceive the death of a child as a "triple" failure: first, because they did not have the means, skills, or abilities to save a life; second, because in their social role as adults, they were unable to protect the child from harm; and, third, because they "betrayed" parents who trusted them with the most valuable being in their life (p. 576).

Inevitably, this sense of failure increases grief reactions and intensifies feelings of helplessness, guilt, anger, and sadness. Providing care to dying children can increase the nurses' awareness of their own losses and vulnerabilities, thereby increasing anxiety and stress levels.

**Moral and ethical distress.** Moral and ethical distress can lead to feelings of helplessness and anger. This distress occurs when nurses are asked to act in a manner that is contrary to their beliefs. This disregard for personal and professional values can undermine the nurse's integrity. Nurses struggle with the dilemma between their obligation to follow physicians' orders and their duty to provide a comfortable death (Davies et al., 1996). Barriers may occur when health care providers are prevented from acting according to their personal values and professional standards. These barriers may be external or internal in nature. External barriers may occur when a nurse's opinion is neither sought nor valued in the workplace. Internal barriers may result when a nurse has poor communication skills or lacks the knowledge and skill to appropriately provide palliative care. Resolution of these barriers must be achieved to maintain job satisfaction as well as appropriate patient care.

Literature suggests that when nurses feel they can no longer help the terminally ill recover, they begin to experience a deep sense of sadness, ambivalence, and helplessness. They do not know how to cope with the dilemma of providing palliative and curative care (Yam, Rossiter, & Cheung, 2001). Pain management and case management issues are good examples of this. The bedside nurse who is with a child for a 12-hour shift is probably the best person to assess the effectiveness of the current pain medication regimen and other end-of-life needs. However, the nurse may report poor pain control or the need for a patient care conference, and the request may not even be considered. When nurse input is ignored, nurses may become angry, frustrated, and resentful about the care being provided to patients. Performing aggressive treatments is difficult when the child is actively dying. At times, children who should be in the palliative phase of care are still receiving painful, aggressive procedures, which may be performed with limited assessment and suboptimal management of the patient's pain. These aggressive measures take up precious time needed by the family, siblings, and staff to prepare the child for death. Children, as well as adults, need time to finish tasks, say good-byes, and find closure. The author's conversations with nurses in the clinical setting confirm that nurses agree that children want to feel their lives

have purpose and meaning, and are faced with many challenges when trying to meet the holistic needs of dying children.

**Personal pain.** During the course of the author's many clinical conversations with nurses in pediatric palliative settings, recurrent themes of personal pain evolved. Nurses reported feeling extreme sadness when dealing with deaths of children. One nurse finds that her sadness is compounded when she is providing care to a dying child that is the same age as one of her own children. Another nurse spoke about the cold, dark stares of a mother after losing a child. The nurse reported there is nothing more disappointing or devastating than watching the overwhelming grief on the face of a mother who has just lost a baby, especially if the parents had tried repeated fertility treatments to have a child.

An oncology nurse reported on her most painful experience while taking care of a dying child. She was taking care of a 10 year-old girl one day when the child's physician arrived with his head down and everyone knew the news was not going to be good. The child's cancer was out of remission and the child was told she was going to die. The nurse recalled the little girl screaming and repeatedly saying that she was not ready to die. The nurse stood silently almost in shock from the news and fear for the child. She did not know what to say. She just held the child's hand and silently said a prayer.

These few poignant anecdotes selected from many clinical conversations show that nurses suffer emotionally from the termination of established relationships with patients and families. Nurses sometimes protectively keep themselves busy with physical care and try to minimize interactions with families as much as possible in an effort to avoid distress (Yam et al., 2001).

**Lack of support and collaboration.** In addition to experiencing personal pain and ethical distress, nurses also report feeling a lack of support from peers, administrative personnel, and other health care team members. This lack of support was a source of stress for nurses with whom the author spent time in palliative care clinical sites. Some hospitals employ supportive staff, such as clinical nurse specialists, social workers, child life personnel, and chaplains. These collaborators provide much needed services to families. They explain procedures and provide distractions for children undergoing painful treatments, meal

assistance for families, and spiritual guidance. If these collaborators are not present, then the nurse must address the responsibility of meeting these needs while reassuring and comforting the patient and family. As patient advocate, the nurse often is asked to coordinate palliative care services for the child.

**Burnout.** Given the moral and ethical distress, personal pain, and lack of support experienced by pediatric palliative care nurses, it is not surprising that employee turnover rates were affected. In one large children's hospital, average length of employment for nurses was 2 to 3 years in the neonatal intensive care unit (NICU), 3 to 7 years in the pediatric intensive care unit (PICU), and 2 to 5 years in the oncology ward. In one facility, 12 new registered nurse graduates were hired the previous year for the NICU, and only 4 of the nurses were still employed in the NICU one year later. The reasons given for their leaving were ethical dilemmas and burnout. The high levels of stress in these areas contribute to large staff turnover rates. One nurse indicated that the nursing supervisor did not consider the level of acuity for each patient when making assignments. It is overwhelming to have a patient who is actively dying and have several other patients to care for at the same time. The nurse was new to the unit and did not feel that she was receiving adequate support. She also thoughtfully considered the legal liability of malpractice with her perceived inability to adequately care for her other patients. Such a patient assignment will easily leave the nurse feeling overwhelmed and highly stressed. The nurse may feel like a failure to patients and coworkers. This lack of control and frustration will lead many nurses to seek less stressful work environments.

**Lack of professional collaboration and education.** Many articles in the literature address the issue of limited professional collaboration and appropriate education for dealing with pediatric end-of-life care. Health professionals are increasingly exposed to the dying process and death with little prior education to help deal with the particular needs of the young patient and minimal preparation in recognizing and handling their own personal reactions in the face of death. Contro and colleagues (2004) addressed a survey to hospital staff and parents to obtain their perspectives of pediatric palliative care. The goal was to

improve services and address staff needs. Some staff members reported feeling inexperienced in communicating with patients and families about end-of-life issues, transition of patients into palliative or hospice care, "do not resuscitate" status, and pain management issues. The study indicated that staff were insufficiently trained and incompetent in symptom management and communication skills. This may exacerbate staff member stress and affect quality of care. Although inexperienced nurses may look to physicians for guidance in end-of-life care, a study reported that 43% of attending physicians and 56% of residents also felt inexperienced in managing end-of-life symptoms (Contro et al., 2004).

Nurses in some clinical settings reported having inadequate knowledge, expertise, and skills to comfort grieving parents. They felt uncomfortable when parents cried, and most did not know to handle the situation (information obtained from the author's group study sites, January 2008). Some nurses feared saying something that would be inappropriate and offensive to parents (Yam et al., 2001). Clearly, this perceived lack of skill must be addressed if the dying patient and family are to receive appropriate care.

### Role of the Advanced Practice Nurse

In an effort to reduce pressures related to clinical activity and high patient acuity, as well as to increase staff education, the role of the advanced practice nurse (APN) has been operationalized in many clinical settings (Chang, Kicis, & Sangha, 2007). Advanced practice nursing extends the traditional scope of nursing knowledge and contributes to the development of the profession. An inherent function of the APN is that of a change agent, involving collaboration and consultation with other health care providers. The APN can provide this service through constant education, research, personal development, and organizational leadership (Bryant-Lukosius, DiCenso, Browne, & Pinelli, 2004).

APNs can serve as knowledgeable advocates for patients and nurses in a palliative care setting. APNs can serve as frontline nurses to carefully coordinate care and implement new strategies to provide services to patients as well as nurses. APNs can assist staff nurses with complex patient care procedures, provide hands-on education at the bedside, and support staff in

managing challenging situations (Chang et al., 2007). It is essential for APNs to work collaboratively with nurse managers to have ideas accepted and enhance the professional development of staff (Hürlimann, Hofer, & Hirter, 2001). Perhaps the most important role of the APN is to serve as a mentor to novice nurses. This role may help to increase the comfort level of the novice nurse, which will increase job satisfaction and decrease chances of burnout.

There are many ways APNs can help make the workplace function more efficiently for staff and patients. APNs can coordinate support groups for nurses working in pediatric palliative care setting. Research has shown that employees may benefit from brief interventions, called debriefing, when exposed to traumatic events (Hanna & Romana, 2007). APNs can bring together staff members to identify areas of stress, teach coping mechanisms, and identify staff members who may need additional individual counseling. These activities will help alleviate the grief, anger, and feelings of helplessness that nurses experience during periods of stress.

APNs can organize monthly inservices to help staff stay current on research and evidence-based practice related to pediatric palliative care. These meetings could involve guest speakers from other professional disciplines. Proper communication and collaboration with professional disciplines can help with the implementation of care.

Patient care conferences could also be implemented during these meetings. These conferences help educate caregivers on each patient's current status and assist with continuity of care. The use of new educational programs related to death and dying could be very beneficial. These programs should be specifically designed for each developmental age. For example, the developmental needs of dying neonates would require nurses to possess a different knowledge base and set of skills than for young children or teenagers. Such programming would help nurses achieve better communication skills with patients.

APNs can help develop policies that provide guidance for issues, such as pain management. APNs can perform audits on pain assessment records in patient charts, which can help APNs monitor trends in pain levels and management. APNs can determine if pain management is being adequately maintained and coordinate referral services if indicated.

Finally, APNs can be used as advocates for better staffing of nurses and other disciplines to meet the demands on evenings, weekends, and holidays. Through careful observations of care and conversations with staff, APNs can identify areas that are negatively affected by low staffing. APNs can work through administration to increase staffing to meet these needs and better serve clients. APNs can also make definite improvements in the care of dying children by implementing research to provide nurses with evidence-based practice strategies. This knowledge will enable nurses, to meet the unique needs of children and help staff provide more holistic care.

### Areas for Future Research

There is much to be done by nursing professionals to secure the future of pediatric palliative care programs. Many barriers exist that must be overcome to further research that will provide evidence-based practices geared toward the specific needs of children. The first task is to increase awareness of pediatric palliative care programs and the special needs of nurses who care for dying children. Further research studies are needed to explore strategies to decrease work-related stress in nurses caring for dying children. Another beneficial study could involve clearly identifying the role of the APN in pediatric palliative care programs and establishing protocols for staff development. These studies may also discover other innovative ways to increase satisfaction of patients, family members, and nurses overall.

### Conclusions

A child's death may seem like a long, scary pathway. Nurses have the power to create a brighter journey for these patients and families, as well as for themselves. The provision of pediatric palliative care can be both stressful and rewarding. By acknowledging the work of past historians, APNs can acquire a strong foundation to build future evidence-based programs. The use of these programs will hopefully influence positive patient outcomes and nursing staff job satisfaction.

### References

- Barnard, A., Hollingum, C., & Hartfiel, B. (2006). Going on a journey: Understanding palliative care nursing. *International Journal of Palliative Nursing*, 12(1), 6-12.

- Bowden, V. (2002). End-of-life: A priority issue for pediatric nurses. *Journal of Pediatric Nursing, 17*(6), 456-459.
- Bryant-Lukosius, D., DiCenso, A., Browne, G., & Pinelli, J. (2004). Advanced practice nursing roles: Development, implementation, and evaluation. *Journal of Advanced Nursing, 48*(5), 519-529.
- Carter, B.S., Howenstein, M., Gilmer, M.J., Throop, P., France, O., & Whitlock, J.A. (2004). Circumstances surrounding the deaths of hospitalized children: Opportunities for pediatric palliative care. *Pediatrics, 114*(3), 361-366.
- Catlin, A., & Carter, B. (2002). Creation of a neonatal end-of-life palliative care protocol. *Journal of Perinatology, 22*(3), 184-195.
- Chang, A., Kicis, J., & Sangha, G. (2007). Effect of the clinical support nurse role on work-related stress for nurses on an inpatient pediatric oncology unit. *Journal of Pediatric Oncology Nursing, 24*(6), 340-349.
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H.J. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics, 114*(5), 1248-1252.
- Davies, B., Brenner, P., Orloff, S., Sumner, L., & Worden, W. (2002). Addressing spirituality in pediatric hospice and palliative care. *Journal of Palliative Care, 18*(1), 59-67.
- Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J., et al. (1996). Caring for dying children: Nurses' experiences. *Pediatric Nursing, 22*(6), 500-507.
- Foster, T.L. (2007). Pediatric palliative care revisited: A vision to add life. *Journal of Hospice and Palliative Nursing, 9*(4), 212-219.
- Freyer, D. (2004). Care of the dying adolescent: Special considerations. *Pediatrics, 113*(2), 381-388.
- Georges, J.J., Grypdonck, M., & Dierckx de Casterlé, B. (2002). Being a palliative care nurse in an academic hospital: A qualitative study about nurses' perceptions of palliative care nursing. *Journal of Clinical Nursing, 11*(6), 785-793.
- Hanna, D.R., & Romana, M. (2007). Debriefing after a crisis. *Nursing Management, 38*(8), 38-42, 44-45, 47.
- Himmelstein, B.P., Hilden, J.M., Boldt, A.M., & Weisman, D. (2004). Medical progress: Pediatric palliative care. *The New England Journal of Medicine, 350*(17), 1752-1762.
- Hürlimann, B., Hofer, S., & Hirter, K. (2001). The role of the clinical nurse specialist. *International Nursing Review, 48*(1), 58-64.
- Morris, D.B. (1998). The cloak and the shield: A thumbnail history of palliation. *Illness, Crisis, and Loss, 6*, 229-232.
- Papadatou, D. (1997). Training health professionals in caring for dying children and grieving families. *Death Studies, 21*(6), 575-600.
- Romesburg, T.L. (2007). Building a case for neonatal palliative care. *Neonatal Network, 26*(2), 111-115.
- Rushton, C. (2000). Pediatric palliative care: Coming of age. *Innovations in End-of-Life Care, 2*(2). Retrieved February 19, 2009, from <http://www2.edc.org/lastacts/archives/archivesMarch00/editorial.asp>
- Rushton, C.H., & Catlin, A. (2002). Pediatric palliative care: The time is now. *Pediatric Nursing, 28*(1), 57-60.
- Sumner, L. (2003). Lighting the way: Improving the way children die in America. *Caring Magazine, 22*(5), 14-18.
- Sumner, L. (2006). Pediatric care: The hospice perspective. In B. Ferrell & N. Coyle, *Textbook of palliative nursing* (2nd ed.) (pp. 909-924). Oxford, United Kingdom: Oxford University Press.
- Weigel, C., Parker, G., Fanning, L., Reyna, K., & Gasberra, D.B. (2007). Apprehension among hospital nurses providing end-of-life care. *Journal of Hospice and Palliative Nursing, 9*(2), 86-91.
- World Health Organization (WHO). (2004). *WHO definition of palliative care*. Retrieved February 19, 2009, from <http://www.who.int/cancer/palliative/definition/en>
- Yam, B.M., Rossiter, J.C., & Cheung, K.Y. (2001). Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong. *Journal of Clinical Nursing, 10*(5), 651-659.

Palliative care for children involves all-inclusive and compassionate care aimed at preventing and relieving suffering for those with life-threatening illness. Pediatric palliative care is family-centered care, with the child and family enwrapped in the center of a circle of professionals addressing spiritual, social, psychological, and physical needs. Available resources designed for the care of adults with life-threatening illness do not fit the needs of dying children. Also, despite recent increases in interest in adult palliative care and hospice philosophy, a parallel increase in pediatrics has not occurred—80 percent of children dying with cancer in this country are still suffering, and their symptoms are not being adequately palliated (Wolfe, 2000).