

## **The Unspeakable Nature of Pediatric Palliative Care: Unveiling Many Cloaks**

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*In this article, the authors address the topic of pediatric palliative care and the unspeakable nature of the very practice of caring for children that are dying. This unspeakableness shows up in many ways around a silencing of the practice itself, a silencing of the topic of death within the practice, and ultimately, a silencing of children and families who are faced with one of the most profound life events of loss imaginable. The authors speak to this unspeakable nature and offer family systems nursing practices and the illness beliefs model as one way to give language and voice to the suffering and strengths that inhabit this often wordless terrain.*

**Keywords:** *pediatric palliative care; dying children; family systems nursing; illness beliefs model*

May you be wrapped in tenderness, my brother, as if in a cloak

*The Qur'an (Shakir, 1998)*

Children are not supposed to die, but they do. The death of a child is clearly out of the natural rhythm of life and death, and is a profound loss for the family as well as for those involved in the care of the child. Palliative care services for children and families are beginning to emerge to meet the special needs of children and their families who are facing death situations, but this type of comprehensive care has lagged behind the development of palliative care services for adults. In many ways, pediatric palliative care still struggles for acceptance and identity in the health care system. In this article, we describe the uniqueness of palliative care for dying children and their families. We examine the roots and meanings of the word *palliate* in a way that offers a better understanding of the relationship of nurses with dying children and their families. Finally, we speak to how a knowledge of family systems nursing (Wright & Leahey, 2000; Wright, Watson, & Bell, 1996, p.188), and specifically the illness beliefs model (Wright et al., 1996), can inform an understanding of *palliate* and can enhance advanced nursing practice in pediatric palliative care. At the heart of this discussion we address how these practices make room for “speaking the

unspeakable” (Wright et al., 1996) in the midst of a topic and practice in which unspeakability is deeply embedded.

## **CARING FOR DYING CHILDREN AND THEIR FAMILIES: PEDIATRIC PALLIATIVE CARE**

*Palliative care* is defined by the World Health Organization as the active total care of the patient whose disease is not responsive to curative treatment. Control of pain, other symptoms, and psychological, social, and spiritual concerns are paramount. The goal of palliative care is achievement of the best quality of life for patients and families (World Health Organization, 1998). The Canadian Hospice and Palliative Care Association (CHPCA) defines hospice palliative care as that which is aimed at the relief of suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved (Ferris et al., 2002).

Within the population served by palliative care, there is a unique and distinct group—namely, dying children and their families. Children requiring palliative care are a very diverse population; less than half have malignancies, and the remainder have a range of often rare conditions, including congenital abnormalities, chromosomal disorders, and neurodegenerative disorders (Goldman, 1998). In developed countries, the death of a child is now an uncommon occurrence, but this very infrequency makes it all the more difficult for families, communities, and health care professionals to accept when it does occur (American Academy of Pediatrics, 2000). Rolland (1997) wrote of the societal discourse of cultural avoidance in first-world countries that promotes patterns of relationships based on denial of illness and loss, romantically relegating them to later life and a peaceful, suffering-free death.

### **Uniqueness of Palliative Care for Children and Their Families**

Palliative care for children is only beginning to find its place in the spectrum of health care services (Davies & Howell, 1998). The Pediatric Palliative Care Special Interest Group (2001) in Vancouver, Canada defined *pediatric palliative care* as a philosophy of care, focused on the enhancement of the quality of life for a child and family (adapted from an adult definition of palliative care developed by the Canadian Hospice Palliative Care Association). This is achieved through the combination of active and compassionate therapies intended to comfort and support children and families who are living with a life-limiting illness. Family members, especially siblings, require attention and support. Palliative care strives to support children and families by assisting them in fulfilling their physical, psychological, social, and spiritual goals while remaining sensitive to their personal, cultural, spiritual, and religious values, beliefs, and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Pediatric palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team, which includes the child, family, caregivers, and service providers. It should be available to the child and the family at any time during the illness trajectory and bereavement (Pediatric Palliative Care Special Interest Group, 2001). Much of the focus and criteria for funding for palliative care services is structured for the last weeks of life. Children with progressive life-limiting illness and their families may require these services for many years. Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.

When considering a framework for pediatric palliative care, Hynson and Sawyer (2001) suggested the importance of sensitivity to the child's and the family's wishes; detailed care planning; the importance of a key worker; the continued involvement of the pediatrician; 24-hour access to medical support; utilization of clinicians, such as nurses and therapists with expertise in pediatric palliative care; and the importance of flexibility. The American Academy of Pediatrics (2000) developed an integrated model of care delivery that moves away from rigid distinctions between curative life-prolonging care and palliative interventions. This model allows for palliative care and curative therapies to coexist and challenges the dichotomy where health care professionals and families are forced to make the impossible choice of intervention directed at cure or supportive care (Frager, 1996).

### **The Unspeakability of Pediatric Palliative Care**

The very idea that a child and family are requiring hospice/palliative care services is difficult to accept and understand. The death of a child is profoundly out of the expected, natural progression of life for a family. A child is not meant to die before parents. Parents are not meant to bury their children. The magnitude of this particular kind of loss has an effect not only on the family but also on the community, the school, and the neighborhood. Health care providers who have known the child and family often for years also experience loss and grief with the death of a child. The loss of a child, in its very unspeakability, perhaps inadvertently contributes to a silencing of this particular loss and a diminishment of the profound voice of suffering that accompanies it.

### **UNDERSTANDING *PALLIATE* IN A NEW WAY: SHROUDS AND CLOAKS**

As nurses who find our way through winding, tortuous, and yet privileged journeys with families of dying children, we find ourselves at the root of what it means to palliate. *Webster's* dictionary defines *palliate* as "to ease without curing, to treat partially and incompletely" (Agnes & Guralnik, 1999). In many ways, it is this definition that has formed the basis of palliative care, moving from continued aggressive intervention to focus on comfort and supportive care. Yet,

this view of partiality or incompleteness does not seem to fit with the care of children with a life-limiting illness and their families. Can a parent ever consider something partial or incomplete in the care of their child? This viewpoint infers that something is missing, that something is left out of the utmost care for their precious child. This stance supports an either/or approach to care, which many families find unbearable (Frager, 1996).

The *Oxford* etymological dictionary (Hoad, 1986) indicates that the word *palliate* originated from the Latin word *pallium*, which means cloak or shroud. In ancient Greece and Rome, a pallium was a cloak that was draped over the left shoulder and around the body. Hence, to cloak, conceal, or hide comes from reference to this garment. *Pallium* was modified to *palliate*, an adjective meaning cloaked or concealed and a verb meaning to cloak, to clothe, and to shelter.

It is this metaphor of cloaking that seems to fit for a family systems approach (Wright & Leahey, 2000; Wright et al., 1996) in the care of dying children and their families. This metaphor of the ill child surrounded and cloaked by the family is useful. It envisions protecting and comforting the child while managing the pain and symptoms. It is this metaphor that prompts the inquiry, Who is the family? The *family* is defined as “a group of individuals bound by strong emotional ties, a sense of belonging and a passion for being involved in one another’s lives” (Wright et al., 1996, p. 45). Are we, as nurses, sensitive and curious enough to inquire, Who is the family? Who do the family identify as important in the child’s life and the life of the family? Do we consider the diversity of families, single mother families, and families from other ethnic backgrounds? Are we careful not to stand in judgment or get caught in society’s discourse of the “perfect family?”

Understanding palliative care from a family systems perspective allows us to view the family as a unit and focus simultaneously on interaction with the members of the family both as individuals and as a family (Wright & Leahey, 2000). The family is the unit of care. This approach to care fits for children and families as they carefully make the transition from aggressive intervention to supportive care. It is a time when families often want to regroup. For many years, their lives have been controlled by the health care system with treatments, appointments, and inpatient hospital stays. This transition is an important time to open up conversations about choice. What do the family identify as important for them? Where do they want to be? What are their goals? Nurses can play an important role in working with families around these decisions.

When we think of shrouding and cloaking, we think of how illness affects the whole family. The whole family is together under the cloak or shroud of illness, affected profoundly, individually, and together. “At no time are family and individual beliefs more affirmed, challenged, or threatened than when illness emerges” (Wright et al., 1996, p. 23). Having a dying child affects all members of the family, including parents, siblings, grandparents, and those close to them. Wright et al. (1996) suggests that how they manage, cope, and adapt arises from

their beliefs, and at the heart of a family's beliefs lie core beliefs that profoundly influence behaviors. It is important for nurses to be curious about the core beliefs of the family. What matters most? What does the child and the family members believe about the illness and about themselves? How would they prefer to "live alongside" (Wright et al., 1996, p.172) the illness?

Cloaking also raises the issue of keeping something covered or hidden and how there are things that nurses prefer not to see in families and other things they choose not to see. Such an example lies in the following example: A single mother and four children moved to the city from a rural community as one of her children was diagnosed with a very aggressive cancer and would be in and out of hospital frequently. Through her outspokenness and lobbying for her child, the mother became labeled as difficult and challenging. There was a distancing by staff members, indicating a desire to remove themselves from much involvement with the child or the mother. This distancing begs the wondering if space was made to consider what it would be like to move from a small town to reestablish a life for a family in a low-cost housing development in a big city and to care for an ill child and three other small children. Can we move away from this labeling of dysfunction to see a family in a unique way with unique viewpoints? The term *dysfunctional* trivializes and minimizes problems, setting the clinician in a privileged position to look for pathology instead of strength (Bell, 1995; Wright et al., 1996). Worse, it blinds one to recognize the uniqueness, capacities, and struggles of a family to make sense of a senseless event, an unspeakable event of being faced with the loss of a child.

"All families have strengths, often unappreciated and unrealized" (Wright et al., 1996, p. 50). In a health care system that is based on a medical model of care delivery, decisions are often made from a patriarchal stance, a "we know best what you need" philosophy. Medicine is focused on investigation, diagnosis, treatment, and cure, sometimes at the expense of caring for pain and suffering. Suffering is viewed as a problem to be conquered rather than a mystery to be understood and a moral challenge to be lived. Death and suffering are regarded as a form of failure and medical embarrassment (Kane, Barber, & Jordan, 2000). Some children in the terminal phase of illness are known to suffer significantly from inadequate recognition and treatment of symptoms and aggressive attempts at cure (Wolfe, Grier, et al., 2000). There is not much time given to carefully listen to the family's story, to their perspective on the illness, and how they are living with it. "Illness narratives include stories of sickness and suffering that need to be told" (Wright et al., 1996, p. 61) and that need to be heard. These are stories of great courage and strength. People tell stories of their illness to make sense of suffering, and when they turn their disease into story, they can find healing (Frank, 2000).

It is our experience that families welcome the opportunity to share their stories. Recently, the first author spent some time with a family whose 19-year-old daughter died at home. She had been ill for many years with severe cerebral

palsy. On visiting the family the day following her death, there were many stories told—stories of sadness and sorrow and stories of great courage. The family spoke of the challenges of the intense physical care and not having a break from the relentless demands of her care throughout the many years. They also spoke of how the family embraced the child's illness throughout the years and lived alongside it. They went camping, attended ball-games, and went out for dinner and to the movies. The child was part of it all. One of her younger siblings spoke of taking her sister in her wheelchair to school for show and tell. This is a story of suffering but also of great strength, and we believe it will be part of the ongoing healing of this family as they continue in the journey of grief.

When the word *palliate* is considered from its etymological origin of cloaking, it can also raise a notion of concealing and hiding the illness. We believe this, too, is part of the family experience of living with a child with a life-limiting illness. It has long been believed that children have an awareness that they are very ill and dying (Bluebond-Langner, 1978). Despite this awareness, children often maintain a silence out of a desire to protect their parents and, in this act of protection, they can become painfully isolated (American Academy of Pediatrics, 2000). Parents can suffer also in a cloak of concealment. In a recent conversation with a mother whose child died 10 years ago of a cardiac condition, she spoke of her longing for a normal child. She spoke of the hesitancy of taking her baby out in public, encountering the stares and inappropriate comments. As well as the protectiveness and comfort of the cloak, there is the secrecy and hiding of the illness, and it is here that the unspeakability of dying children finds its home. Wright and colleagues (1996) suggested that nurses are in a privileged position to help children and families to speak the unspeakable and, in doing so, to uncover beliefs that are central to the problem and from which the family is struggling. Helping families to speak the unspeakable, to put words to the suffering, can reduce the power and grip that illness has on the family and can take away the conspiracy of silence (Wortman & Dunkel-Schetter, 1979). Perhaps the cloaking and shrouding of the child and family silences the family's voice and hampers the ability to talk openly and creatively about the situation.

Those who work in the health care system can cloak the family *with* the illness, refusing to see past the face of the illness to find the family that suffers within it. Alternately, they can cloak the family *from* the illness or its stage, erroneously believing, like the small child, that they are protecting the family. In a recent study, when health care professionals failed to define a child as requiring palliative care, their main concern was that the mother would lose hope if the probability of the child's death was openly acknowledged. Health care professionals believed that talking about the palliative status would focus attention on the child's death to the detriment of their quality of life during the limited time remaining (Davies & Steele, 1996). Yet, in this benevolently intended act, not approaching the subject deprived the family of the opportunity to make their own decisions. For those families who had an opportunity to openly acknowledge the probability of the death, there was an opportunity to participate

in discussion. In our practice experience, families do not want staff to avoid the sensitive topics. Davies and Steele (1996) suggested that families may not want to dwell on the outcome, but they do not want to avoid the conversations. Speaking the unspeakable then does not try to eliminate hope but allows families to refocus the target of their hope.

In a recent study in the United States with pediatric oncology families, Wolfe, Grier, and colleagues (2000) reported that parents' understanding for cure often delayed/lagged behind the documentation by the oncologist by 3 months. When both the parents and the oncologist recognized earlier that there was no chance for cure, hospice care was introduced, and the primary goal shifted to lessen suffering (Wolfe, Klar, et al., 2000). Perhaps this cloaking of the family in secrecy and silence is born of fear, fear to speak the unspeakable, fear to say the words that the child is dying, fear to stand in the midst of great suffering. The imminence of death has a silencing effect on individuals and families. Instead of new stories being sought to meet the new reality, old silences are reinforced (Frank, 2000).

### **SPEAKING THE UNSPEAKABLE IN NURSING PRACTICE WITH DYING CHILDREN: THE ILLNESS BELIEFS MODEL**

The illness beliefs model (IBM; developed by Wright et al., 1996) can provide a useful advanced nursing practice framework in family systems nursing for working with families in pediatric palliative care. The model is not only useful in work with families but also helpful for nurses working in partnership with other nurses and health care professionals who are involved in the care of children with life-limiting illnesses and their families. The IBM was developed as a specialty area of graduate study of advanced practice in family systems nursing. Although the model is used to guide the acquisition of specialty skills and knowledge, the basic ideas and concepts are applicable for all palliative nurses in building and maintaining therapeutic relationships with families.

In the role as pediatric palliative care coordinator, the first author came to believe that an important initial step in the referral of a family to palliative care is to identify the health care providers who are most involved in the care of the child and family. Who is most important from the family's perspective? Who do they trust? Many of these children have lived with a life-limiting illness for many years, and they and their families have close contact with a pediatrician and/or a specialty service at the Children's Hospital. In some cases, it is the community health nurse; sometimes it is the nurse in the intensive care unit or the outpatient primary nurse in the oncology clinic. In these situations where there is a significant bond with another nurse or health care professional, it is important to work alongside these practitioners, to support and encourage them in their work, and to indirectly ask the questions and influence the coordination of care for the child and family. It is important to respect these relationships. However, the role

of pediatric palliative care coordinator can provide the family with a different relationship, a new perspective in which an aggressive search for cure is no longer the goal. There is a safe ground for the family to raise issues that they may find difficult to discuss with other staff involved in active treatment.

In other situations, there is not a strong connection with the treatment team or the community physician. In these cases, the members of the palliative care team take a more direct role with the child and family, continuing to develop a relationship with them through the weeks and months of the illness and after the death. Whether directly involved or in a consultative role with other staff, the important consideration is that there is a right “fit” with the family (Wright et al., 1996).

Beliefs are lenses through which the world is viewed; beliefs are embedded in stories of families and are intertwined with stories of nurses (Wright et al., 1996). Wright and colleagues further suggested that families have facilitating beliefs and constraining beliefs that affect and influence their lives and behaviors. There are no correct beliefs for families, only beliefs that are more freeing, useful, and facilitating. The relationship that develops with the nurse and family allows for many individual descriptions of family beliefs and family meanings, and it is important to acknowledge that each is valid. This relationship can open possibilities for healing.

The IBM is presented in the language of therapeutic “moves” occurring in the relationship between nurses and families. It is, in part, based on the concept of structural coupling (Maturana & Varela, 1992), the coming together of the nurse and family in a relationship. Working within the domain of “objectivity in parenthesis” (Maturana, 1988), the nurse must set aside the imposition of her or his own beliefs to allow space for the understanding and listening to the beliefs of the other. The relationship that coevolves is mindful of “fit” and diminished hierarchy and is based on reciprocity (Wright et al., 1996). Power and control are set aside and replaced with respect, wonder, and curiosity.

The four macromoves of the IBM are creating a context for changing beliefs; uncovering and distinguishing illness beliefs; challenging, altering, and modifying constraining beliefs; and distinguishing change through identifying, affirming, and solidifying facilitating beliefs. Each of these macromoves is composed of micromoves or interventions (Wright et al., 1996).

### **Macromove: Creating a Context for Changing Beliefs**

The dance of structural coupling (Maturana & Varela, 1992), engagement, or joining is very important to form the basis of the relationship with the family (Wright et al., 1996). When mindful of “fit,” it can open up conversation with what the family wants. When a nurse in an advanced practice role in palliative care



first meets a family, it is often at a very difficult time, a time when the family is in the midst of decision making, making a shift from aggressive intervention to supportive care. Often, this first meeting happens in the privileged places of their own homes. Here, in their own environments, in the sacred place of home, stories come naturally as words move to offer some shape to experience. Embedded in these stories is information offered by the medical team, the hopes and values of the family, and dreams lost and remaining. This initial meeting provides an opportunity to set the stage for work together, to explain the role of the coordinator and the palliative care team, and to reassure the family that the team will work alongside other nurses, doctors, and caregivers. This time of setting the groundwork, sharing with one another, and beginning a relationship of trust is important in the ongoing process of structural coupling (Wright et al., 1996). This important beginning work creates a space for unspeakable words and experiences to begin to be spoken and heard.

### **Macromove: Uncovering and Distinguishing Illness Beliefs**

Nurses in advanced practice can play an important role in uncovering and distinguishing illness beliefs in the areas of etiology, diagnosis, healing and treatment, and prognosis (Wright et al., 1996). In pediatric palliative care, conversations about prognosis often arise with families. These conversations are important to determine what the family has been told by the medical team and what they understand from their own perspective. How does the information fit with their beliefs? The prognosis has been “given” to them by the medical team from their own perspective. Carefully listening to the family about what they believe about prognosis, how they concur with each other and with health care professionals’ beliefs, or if they have other ideas can open up possibilities that reflect what is important to them, and may influence how they live the remaining time with their child.

This macromove finds a place in the story of a young woman of 18 years who had experienced several relapses of leukemia and had been told that she had weeks to live. When asked what she thought about this, she was able to share that she understood what the doctors believed, but she wanted to live for a few more months so she could graduate from high school with her classmates. By carefully listening to her wishes and beliefs, a collaborative decision was made. She chose to take a mild oral chemotherapy medication to keep the disease under control and allow her to achieve her goal. Families can be invited into the role of expert, and Wright et al. (1996) suggested that it is the intersection of the shared expertise of the family and the nurse where healing can occur. When these conversations are encouraged, even when facing death, families can put illness in its place and find creative ways to live alongside it (Wright et al., 1996).

### **Macromove: Challenging, Altering, and Modifying Constraining Beliefs**

This macromove includes asking interventive questions, speaking the unspeakable, and offering hypothetical beliefs or alternative beliefs to a family in a partnered effort to change constraining beliefs. One important area of conversation in this area of practice involves speaking with families about what to expect at the time of death, what the actual physical changes may look like, and what the family can do for themselves and for their child at this time. This is especially important when the family is caring for a dying child in the home. These conversations are not easy and often begin by saying, "If we were to think ahead about what to expect, what it might be like at the time of Jimmy's death. . . . " Even though these conversations are difficult, families have mentioned later that it was helpful for them to have thought through those moments together ahead of time. Speaking the unspeakable gives the family an opportunity to identify their fears, to discuss their beliefs, to be comforted in the sharing of unspeakable things, and to assist in their ongoing healing (Wright et al., 1996).

The practice of therapeutic letter writing (Epston, 1994; Moules, 2002; 2003; White & Epston, 1990; Wright et al., 1996) is a significant part of the IBM. Writing a personal letter to the family after the death of their child allows an opportunity to make commendations, to offer comments about the strength of the family, their courage, and the care they provided for their child. It offers an opportunity to comment on the relationship between the nurse and the family and how that relationship has influenced the nurse's own practice, for it is their stories and experiences that are often the greatest teacher.

### **Macromove: Distinguishing Change: Identifying Affirming, and Solidifying Facilitating Beliefs**

Change is an ongoing and constant process that needs to be recognized, encouraged, and celebrated (Wright et al., 1996). Beliefs about the care of the child change and need to be validated. A mother spoke about the death of her child 11 years ago, of taking her child home to die, of how terrified she was, of how she was not sure if she and the family would be able to provide the care, to witness the death at home and still survive. Reflecting on the experience, she said it was just like it happened yesterday. Caring for her dying child at home was the most difficult experience she has ever had, and yet she views it as the most important contribution she ever made, helping her child to die at home. She spoke about how the experience changed her life; she could not go back to her work as a legal secretary as it seemed meaningless. She started a small nonprofit organization in her basement to help children with serious illness attend summer camp; it has grown into a large organization that supports clinical care and research in pediatric oncology. Change in families is not always so dramatic and life changing, yet there are countless opportunities throughout the course of the child's illness to validate and affirm facilitating beliefs that can foster change.

## SUMMARY

Pediatric palliative care is emerging and evolving; it is beginning to find its place within a health care system that continues to value the medical model of managing illness, highly technical care, and a push for cure at all costs. Caring for dying children and families is an area of practice where nurses can make a difference, and this difference is built on relationships with children, families, and their caregivers.

Understanding advanced practice nursing within a context of family systems nursing and the IBM can benefit children and families living with life-limiting illness. Speaking the unspeakable, opening up opportunities for difficult and sensitive conversations with staff, with children, and with families can assist in the healing process. In the midst of great suffering, the cloak of illness and the cloak of death can be lifted a little. The relationship of the advanced practice nurse with the child, the family, and the caregivers can be embraced, not in a cloak of secrecy and silence but rather with great sensitivity, respect, and curiosity as a blanket of comfort and security. This relationship can assist families to embrace the illness and dying experience in a way that is based on their own beliefs and what is important for them. The unspeakability of children dying should not be relegated to the shoulders of family members, for it is something we all must bear and, as nurses, we are obligated to bear. Children die and families suffer, and nurses need to be there alongside to mediate the unspeakableness of it, to ameliorate the suffering that accompanies it, and to embrace the privilege and obligation of being a part of such profound events in the life of a family.

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