

Caring for Caregivers: Assessing Grief and Coping of Pediatric Palliative Care Nurses

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A Senior Thesis submitted in partial fulfillment  
of the requirements for graduation  
in the Honors Program  
Liberty University  
Spring 2014

Acceptance of Senior Honors Thesis

This Senior Honors Thesis is accepted in partial fulfillment of the requirements for graduation from the Honors Program of Liberty University.

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## Abstract

The definition and implementation of pediatric palliative care has been increasingly studied in recent years. Within the United States, where children generally have adequate nutrition and access to advanced technology, the population of dying children is relatively small. Nevertheless, the number of pediatric patients suffering from both cancer and other chronic and life-threatening diseases has increased. While there has been a focus upon the need for support of the child and the family, the emotional response and grief of the caregivers, especially nurses, has often gone unnoticed. The five different kinds of loss that may be experienced by caregivers help to form a framework for research about the responses of healthcare professionals to pediatric sickness and death. The grief that these nurses experience can be influenced by their previous experiences with death, their support system, and additional interventions that may be used as they process the death of a patient. An extensive review of the literature interwoven with the responses from qualitative studies and personal interviews may promote awareness of nurses' grief and their need for support as they care for the children and families that make up the pediatric palliative care population.

### Caring for Caregivers: Assessing Grief and Coping of Pediatric Palliative Care Nurses

The nursing profession has a uniquely holistic perspective of the human person. Individuals are viewed irreplaceable members of society with physical, emotional, interpersonal, spiritual, and environmental components; this perspective lays the foundation for nursing care (Lewis, Dirksen, Heitkemper, Bucher, & Camera, 2011). In recent years, palliative care has been emphasized as a vital part of care for patients, since it provides comfort at a patient's most vulnerable time and often takes place during the transition from life to death. Research has reported the positive impact this type of care has had upon families (Bona, Bates, & Wolfe, 2011; Himmelstein, Hilden, Boldt, & Weissman, 2004).

Unfortunately, many healthcare professionals are uncomfortable providing palliative care and their grief was largely ignored in the research (Davies et al., 1996; Knapp & Thompson, 2012). Therefore, in an effort to alleviate some of the discomfort, it would be useful to describe pediatric palliative care, the grief process of nurses who care for this population, and the interventions that can be implemented for these nurses. In order to provide the best palliative care for pediatric patients and their families, nurses must be empowered to do so. Appropriate opportunities to express grief, to find meaning, and to receive support from peers can energize nurses and enable them to continue providing quality nursing care.

### **Pediatric Palliative Care**

Palliative care fits well with the nursing model of holistic care, since it takes into account all aspects of patient care. According to the World Health Organization (WHO, 2012):

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (para. 1)

Many people associate palliative care with hospice care, since they are alike in their focus upon maximizing comfort and quality of life. However, hospice care requires a six month prognosis for a referral, while palliative care can be implemented at any point during a patient's illness, including at the time of diagnosis. A multidisciplinary approach is employed in order to provide the best care possible. Palliative care is most effective when the family is involved and community resources are utilized. In the context of pediatric nursing, the family is an integral part of every patient's care (Johnson & Keogh, 2010). Curative care within hospitals and medical centers focuses upon doing every intervention that could possibly make a difference for the patient. While palliative care can be provided alongside this curative care, its goal is to maximize the quality of remaining life by offering pain and symptom management and support for families (Crozier & Hancock, 2012). The American Academy of Pediatrics has also emphasized the importance of compassionate palliative care throughout the entire course of illness, seeking to provide comfort and symptom management for everyone involved, whether the outcome ends in cure or death (Morrow, 2012).

Children do make up a large percentage of the United States population, but they tend to be remarkably healthy. For this reason, palliative care is often associated with other groups of people, and not typically with the pediatric population. Nevertheless, an

estimated 15,780 new cases of cancer will be diagnosed in 2014 with 1960 projected deaths for children between birth and the age 19 (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Additionally, it was estimated in 2012 that about 15-18% of children in the United States lived with a chronic illness, many of which can be debilitating or even life-threatening (Boyse, Boujaoude, & Laundry, 2012). As families and the children themselves receive care and make decisions amidst life-threatening injuries and diseases, their experiences are vital to the health of both families and their communities. Palliative care seeks to provide compassionate care amidst the suffering. Because the American Academy of Pediatrics (2000) believes “the goal is to add life to the child’s years, not simply years to the child’s life,” it supports the early implementation of palliative care (p. 353).

### **Implementation**

The Palliative Care Outcomes Collaboration (PCOC), a voluntary quality program, provides specific criteria to determine and evaluate the effectiveness of palliative care (Care Search, 2011). While not specific to pediatrics, several tools have been developed to describe the patient’s stage in his or her journey, to quantify and qualify the severity of symptoms, and to allow the patient (or a surrogate) to communicate the extent of distress related to the symptoms (Palliative Care Outcomes, 2012a). Not only do these tools allow the clinician to provide concrete and consistent documentation, but also they allow him or her to measure changes more objectively (Care Search, 2011). Furthermore, when multiple people are involved, these tools may help to promote continuity of care (Care Search, 2011; Palliative Care Outcomes, 2012b). In the care of children, these tools may need to be modified in order to appropriately assess a

child based on his or her developmental stage and ability to communicate (K. Little, personal interview, March 15, 2013).

Palliative care patients may be categorized into one of four phases: stable, unstable, deteriorating, and terminal. These stages do not always correlate with the patient's medical status and they may not be sequential since the patient may move back and forth between the phases. Following the patient's demise (a fifth stage known as post-death support), care is provided to the bereaved. When a patient's plan of care does not require changes and when his or her problems and symptoms are well-controlled, the patient is considered to be stable. A long-term plan of care may be established for anticipated changes to the patient's condition. Therefore, the patient would be considered stable until changes must be made to this existing plan (Palliative Care Outcomes, 2012a). When providing advance care planning in pediatrics, the healthcare professional must identify the decision makers. Honesty regarding the illness trajectory can help the patient and family to set realistic goals of care (Himmelstein et al., 2004).

When the necessary changes to an existing plan of care are *urgent*, then the patient is categorized as unstable. When a patient is classified as unstable, the required care plan changes may need to address one or more of the following: an unanticipated problem, a rapid increase in the severity of a current problem, or a sudden change in the family or caregiver's circumstances that impact patient care (Palliative Care Outcomes, 2012a). In the inpatient setting such as the pediatric intensive care unit, the nurse plays an important role in recognizing changes and recommending a palliative care consultant review. Because nurses do spend the most time at the bedside, pediatric palliative care

training for generalist nurses would greatly benefit the patients and families who receive their care (Shipman et al., 2008).

According to the Palliative Care Outcomes Collaboration (2012a), the phase of a patient should be assessed at least once a day in the inpatient setting. For outpatient palliative care, like so many areas of nursing practice, patient education is the key component to ensure the health of a patient. Lewis et al. (2011) spent an entire chapter outlining the responsibility and opportunity that nurses have to teach their patients. For a child with a chronic or life-threatening illness, effective patient teaching is crucial. For example, a pediatric palliative care program was started in Massachusetts that provided resources in the community. A nurse was on-call for emergency symptom management 24-hours a day (Bona et al., 2011). However, parents need to know the signs to which they need to be attuned and these signs need to be communicated in a way they can understand. One parent who responded to a satisfaction survey stated: “The program will be better when you talk to the family with their own language” (Bona et al., 2011, p. 1221). In the care of children the communication with parents and child is especially important, since the entire family is a unit and the relationship of healthcare personnel with the child is often mediated by the parent (Hockenberry & Wilson, 2009). Furthermore, giving permission for a palliative care patient, his family, and caregiver(s) to contact the palliative care team when changes occur facilitates high-quality care.

The third phase, though not as urgent as the unstable phase, does require periodic review of the plan of care. This phase, known as the deteriorating phase, often correlates with the declining overall functional status of the patient. The deteriorating phase may be assigned to a patient when a new but anticipated problem occurs, when there is a gradual

worsening of an existing problem, or when the family or caregiver experiences gradual worsening distress that affects the patient's care. Because it is difficult to witness the deterioration of a child, a nurse may be at risk for developing a nontherapeutic relationship, in which the boundaries that separate the nurse from the child and family become blurred. However, it is important for the nurse to maintain these boundaries in order to serve the family's needs appropriately and to encourage open communication (Hockenberry & Wilson, 2009).

The patient may return to any of the other three phases if his condition plateaus (stable phase), if an urgent change or emergency occurs for either the patient or family (unstable phase), or if death is likely within days (terminal phase). This terminal phase is then followed by post death support (as mentioned above) and the closure of the case (Palliative Care Outcomes, 2012a). During each time period, it is especially important to provide the patient and family with the information necessary to make informed decisions. In the pediatric intensive care unit (PICU), the rapid changes—especially regarding pain and symptom management—may rightly cause healthcare professionals to work quickly (Jones et al., 2007). However, communication in the midst of these changes helps to facilitate a therapeutic relationship which promotes the family's control over the child's healthcare (Hockenberry & Wilson, 2009). Additionally, the nurse can endeavor to provide a peaceful environment for the patient and family (Jones et al., 2007).

### **Tools Utilized in Pediatric Palliative Care**

Within the context of each phase, the nurse or the palliative care specialist can use the two tools given by the Palliative Care Outcomes Collaboration (2012b). These

include the Palliative Care Problem Severity Score (PCPSS; Appendix A) and the Symptom Assessment Scale (SAS; Appendix B). The first, PCPSS, is a score given by the clinician. The purpose of the PCPSS is to evaluate the overall severity of the pain, symptoms, psychological and spiritual problems, and family or caregiver problems. The scoring used for this test gives a number value to each domain: absent (0), mild (1), moderate (2), and severe (3). In using this tool, the evaluator uses a measureable and consistent scale when documenting symptom severity (Palliative Care Outcomes, 2012b). Regardless of the tool used, it is important to identify the child and family's fears and concerns along with the child's coping and communication styles. In order to do so, the nurse may discuss previous experiences with death, dying, and other traumatic life events and may perform a spiritual assessment (Himmelstein et al., 2004). As will be explored later, these conversations may be difficult for a nurse who has been greatly affected by the deterioration of the child. In order for the nurse to adequately assess the child's and family's emotional and spiritual state and provide care, he or she must have the ability to cope (Papadatou, Bellali, Papazoglou, & Petraki, 2002).

In contrast, the symptom assessment scale (SAS) is designed to capture the patient's perspective. By allowing the patient to rate the degree of distress due to each symptom, the medical professional can evaluate which problem is most important to address when developing a plan of care. Furthermore, this scale provides feedback regarding the efficacy of interventions, measures changes, and tracks individual symptoms over time. The seven most common symptoms include the following: appetite problems, difficulty sleeping, breathing problems, nausea, bowel problems, pain, and fatigue. Of course, symptoms may be added that are specific to the patient. The

symptoms are rated numerically 0-10, where 0 is absent and 10 is the worst possible experience with that symptom (Palliative Care Outcomes, 2012b). The scale or the method used to obtain ratings from the patient will differ depending upon the development and cognitive ability of the child. Although this particular scale may be beneficial for older children and adolescents, its use in young children would be limited at best due to the abstract nature of a number rating.

Ideally, the patient performs this assessment, but a patient with a life-threatening disease may only have limited participation or no participation at all due to unconsciousness, confusion, delirium, or undeveloped cognitive ability in the case of a young child. If this is the case, a proxy (one who answers on behalf of the patient) may be used. Often the nurse will combine discussion from the family with objective data she collects when recording her assessment. If a family member is used as the proxy, then it is best to use the same member each time. When using a proxy, the proxy must strive to complete the assessment from the patient's perspective. The utilization of a proxy may be appropriate for very young children who are unable to complete the assessment for themselves. The two tools (PCPSS and SAS) are to be used in combination in order to determine the severity of problems and the amount of distress the patient is experiencing because of each problem. The Palliative Care Outcomes Collaboration points out that a patient may be experiencing severe pain, but may not be overly distressed by it. If this is the case, then the two scales will display different results with regard to pain. These assessments should be completed daily in the inpatient setting and at each contact (either phone or face-to-face visit) in the consultative or community settings. Whenever the

patient changes phases, the assessment should also be repeated (Palliative Care Outcomes, 2012b).

While these assessment tools are available, those caring for the patient do not need to be overly focused upon the technique of delivering palliative care. As palliative care has developed into a specialty, a number of scales have been developed in order to effectively determine and document pain levels and symptom severity. Consistent, systematic evaluation is crucial since the alleviation of symptom distress is a priority of palliative care, but the exact tool used is less important (Nelson & Hope, 2012). As mentioned above, the scales used for young children will differ from those used for older children and adults.

### **Goals and Foci of Pediatric Palliative Care**

The focus of palliative care is similar to that of atraumatic care. Hockenberry and Wilson (2009) defined atraumatic care as “the provision of therapeutic care in settings, by personnel, and through the use of interventions that eliminate or minimize the psychologic and physical distress system” (p. 11). The definition of atraumatic care incorporated prevention, treatment and palliation of chronic or acute conditions using a variety of interventions. Ideas specific to pediatric nursing included preparing the child adequately for a procedure and providing space to allow the parent to room in with the child. Prevention of psychological and physical distress includes minimizing the following: anxiety, fear, anger disappointment, sadness, shame, guilt, pain, sleeplessness, immobilization, bright lights or darkness (Hockenberry & Wilson, 2009).

The goals of pediatric palliative care, as put forth by Crozier and Hancock (2012), are aligned with the goals of atraumatic care. Pediatric palliative care seeks to meet

spiritual, mental, and bodily needs while providing developmentally appropriate and family-centered care. Ideally palliative care would be implemented early in the disease trajectory, even upon diagnosis. It would be used concurrently with curative therapies and would be continued after these interventions have been stopped. The primary goals include symptom management and improvement of the patient's quality of life throughout the disease process. However, these goals are much more easily attained in theory than in practice.

### **Barriers to Pediatric Palliative Care**

In order to achieve effective pediatric palliative care, the barriers must be understood. Two important barriers include the feelings of the family towards palliative care and the attitudes of the healthcare professionals involved in each case. Knapp and Thompson (2012) cite the two greatest barriers to pediatric palliative care as reported by 303 pediatricians in Florida and California: families' reluctance to accept palliative care (95%) and families viewing palliative care as giving up (94%). Additionally, Jones et al. (2007) emphasize the focus of both families and providers upon curative treatments and aggressive life-saving approaches. Because the death of a child is unnatural and emotionally difficult, even considering the possibility is sometimes avoided by the patient, family, and healthcare team. Jones et al. (2007) surveyed 118 PICU healthcare professionals with 38% of them nurses, 45% physicians, and 17% other roles such as chaplains and physical, respiratory, or occupational therapists. The results from the nurse subgroup in the study showed that nurses may gain confidence in providing palliative care, especially spiritual care, when they have greater than 8 years of experience. However, there was no correlation between years of experience and comfort with

palliative care based upon the survey scale. Jones et al. (2007) speculated that a healthcare professional may spend years within the PICU and gain confidence in providing palliative care, but the encounters with life-threatening illnesses and the death of children do not necessarily become more comfortable. Knapp et al. (2011) found that prior training in palliative care could alter nurses' attitudes towards palliative care. Nurses who have a positive perspective of palliative care have the potential to greatly impact the number of referrals to and earlier implementation of palliative care, since nurses are often the first ones to communicate with the family about palliative care as a possibility (Knapp et al., 2011).

A pediatric intensive care unit (PICU) itself can present some challenges to palliative care. The focus in a PICU naturally includes life-saving measures, many of which are invasive and often painful procedures (Jones et al., 2007). The number of monitors, intravenous lines, and tubes may be intimidating for family members, making them uncomfortable. The nature of palliative care may not appear to be compatible with the PICU. Because of the connotations associated with palliative care, families often view it as giving up (Knapp & Thompson, 2012).

The incorporation of palliative care into pediatric medical practice is a balancing act. The goal is not necessarily to cease curative therapies. Instead the goals of palliative care are to maximize the comfort of the child throughout the treatment process, including after curative interventions are stopped. There is tension when seeking to do everything possible to save a child's life and to avoid needless suffering. Choices must be made that may have a long term effect upon one's feelings. For example, a healthcare professional may recommend an additional procedure that causes pain for the patient and family,

which could lead him or her to question whether it was the right action. Conversely, parents may decide to stop curative therapies, such as chemotherapy for a child with cancer. In retrospect, the parents will most likely wonder what would have happened if they made another choice. Healthcare professionals, especially the physicians and the nurses, must assist parents in making decisions regarding their child's care, knowing that they may have enduring regrets and doubts about their choice. The responsibility that comes with counseling families while they make such difficult decisions ought not to be taken lightly. Because of the complex situations that can occur, more training may be needed for nurses and other healthcare professionals (Jones et al., 2007). Implementation of individual case evaluations that include the family and members of the interdisciplinary team would be beneficial (Rushton et al., 2006).

### **Components of Effective Care**

Quality pediatric palliative care requires a number of skills on the part of the healthcare professional. One qualitative study done by Meyer, Ritholz, Burns, and Truog (2006) identified components of effective pediatric palliative care in the PICU according to 56 parent reports. The provision of honest and complete information was listed as the first priority, followed by ready access to staff. Next, parents reported that communication and care coordination were important. Finally, families mentioned emotional expression and support from staff members as crucial, while the nurses and other staff members continue to preserve the parent-child relationship (Meyer et al., 2006). In other words, parents want nurses and physicians to be involved in the life of their child and in the decision making process. However, parents also want to maintain a healthy relationship with their child while he or she is in the hospital and to retain their

right to make choices that they as parents believe to be in their child's best interest. All of these qualities—complete information, ready access to staff, communication, care coordination, and emotional expression—demonstrated the need for an open relationship between nurses, physicians, and families, especially at the end-of-life (Meyer et al., 2006). However, open, honest, and interactive communication can be extremely difficult when a child's life is threatened.

Nevertheless, Malloy, Virani, Kelly, and Munevar (2010) cited communication as the cornerstone of nursing practice and illustrated its importance in palliative care through a number of case studies. One nurse described a conversation with a 17-year-old child dying of bone cancer with the complication of a lung infection. The family members were grateful for the nurse's ability to support them at the bedside while they were honest with their daughter about her situation and voiced their love and care for her (Malloy et al., 2010). Lastly, faith was identified as an essential part of effective pediatric palliative care. Clearly, Christian nurses have an opportunity to share the light of Christ with patients and their families. A spiritual assessment is certainly part of the palliative care approach (Himmelstein et al., 2004), and has been identified as an essential element to nursing care in general (Ackley & Ladwig, 2011; Lewis et al., 2011).

A number of themes were addressed in another study that evaluated 22 patients and 22 nurses and explored their perspectives of quality palliative care (Johnston & Smith, 2006). In depth interviews, thematic content analysis, and interpretation were utilized to draw out themes. The authors sought to provide a consensus among healthcare professionals about what qualities constitute a *good death* from the viewpoint of both nurses and patients. Connecting was a major theme found in answers given by both

patients and nurses. Nurses who were effective listeners not only served the needs of patients, but also found meaning in the relationships they formed with patients. To describe a good palliative care nurse, one patient stated: “One that can sit down and talk to you, hold your hand and give you a wee bit of confidence” (Johnston & Smith, 2006, p. 704). Other desirable qualities included kindness, warmth, compassion, and genuineness along with effective interpersonal communication skills (Johnston & Smith, 2006). Hope, humor, order, openness, safety, freedom from pain, and individuality have also been reported as needs of dying patients that can be provided by nurses and others who interact with patients who are near death (Malloy et al., 2010; Obershaw, 1992). As will be addressed below, this connection in the nurse/patient relationship can play a key role in the grief experienced by the nurses.

### **Grief Process of Nurses Providing Pediatric Palliative Care**

Palliative care, particularly in the area of pediatrics, can be challenging and heartbreaking. Parents and healthcare professionals alike desire that children would enjoy happy and healthy lives well in to adulthood. However, disease, pain, and suffering are a reality, even in the lives of children. A significant amount of research had been done regarding the need for palliative care and bereavement support for pediatric patients and families (American Academy of Pediatrics, 2000; Himelstein et al., 2004) but within the last twenty years researchers have shifted their focus to include the healthcare professionals who provide this care (Davies et al., 1996; Gerow et al., 2010; Papadatou et al., 2002). Understanding the complex grief process can help these professionals to mourn and to seek appropriate support.

Because the nature of this research sought the perspectives of the nurses and other palliative care providers, the majority of studies have been qualitative. Papadatou et al. (2002) conducted interviews with 14 oncologists and 16 pediatric oncology nurses in Greece, while Gerow et al. (2010) limited her study to 11 registered nurses using a qualitative phenomenological approach. Morgan (2009) conducted a literature review and presented an overview of pediatric palliative care and the individual experiences of nurses who provide this care. Some symptoms described by these professionals included the following: intense fear, increased feelings of helplessness, sadness, anger, and recurring thoughts of the dying conditions or the death of a child (Gerow et al., 2010; Morgan, 2009; Papadatou et al., 2002). The professionals who provide palliative care not only witness the pain and suffering of others, but also experience it themselves throughout the process of providing care (Morgan, 2009; Papadatou, Martinson, & Chung, 2001). However, these feelings may go unexpressed since nurses are expected to be strong for their patients and to maintain composure in the face of pain and suffering. One nurse stated: "We just didn't really talk about it" (Gerow et al., 2010, p. 126). Instead, some nurses learned to put up boundaries (Gerow et al., 2010).

### **Subjective Losses**

Papadatou (2000) developed a model in order to describe the complex grief process of healthcare professionals. The model was developed as a result of the author's extensive past experience within a large pediatric hospital in Athens and transcultural research in Greece and Hong Kong (Papadatou et al., 2001). She found that it is important to address the subjective loss that occurs for each person involved, since this may vary based upon the relationship that existed with the patient and family. The death

of a patient affects the nurse's life in a different way than would the death of a personal friend or family member. In the pediatric population, a nurse may face challenges to the assumptions of his or her worldview, since the death of a child is rare and is considered to be abnormal and unfair, especially in Western culture (Crozier & Hancock, 2012; Papadatou, 2000; Papadatou et al., 2001; Reid, 2013). For those who work in a setting where palliative care is often implemented and where deaths occur more frequently, the dying process must be faced more regularly. Because healthcare professionals who provide palliative care may experience numerous encounters with death, there may be a number of different losses contributing to a person's grief (Papadatou, 2000).

The first type of loss addressed by Papadatou (2000) occurs because of the loss of relationship with the patient and family. Depending upon the nature and length of the relationship with that patient, the nurse may experience varying degrees of grief (Papadatou, 2000). In one interview, a nurse related: "There are some that even in a day's time, they just speak to your heart" (Gerow et al., 2010, p. 125). Other patients, especially those with cancer, developed a relationship with nurses over months or even years. Nurses often found it difficult to toe the line when determining appropriate boundaries between a professional relationship and one that transcended these boundaries. This balancing act was found to be even more exaggerated in pediatric palliative care (Reid, 2013). When nurses identified with the patient and family, their grief intensified. When comparing nurses and physicians, Papadatou et al. (2002) found that nurses were more likely to point to the loss of the relationship while physicians experienced a loss of their unmet goals and expectations. This finding is not a great surprise, since many nurses reported great involvement in their work and in the lives of

patients at the beginning of their careers (Gerow et al., 2010). When a nurse cannot bring healing to a patient she has cared for, this can result in a deep sense of sadness and helplessness (Morgan, 2009).

The close relationship with a patient, even though it caused increased grief on the part of the nurse, was cited as a reward (Gerow et al., 2010; Zadeh, Gamba, Hudson, & Wiener, 2012). When reciprocity existed in a relationship with a patient, the nurse not only gave the gift of excellent care, but also gained something from the patient and family, such as recognition for her care. Nurses built relationships that had lasting impact upon them, their patients, and their families and valued the way these relationships changed them (Gerow et al., 2010; Zadeh et al., 2012). One nurse articulated it this way:

If we didn't love and become attached and have relationship, then we...we wouldn't have to have grief. So I view it as very positive even though it is painful. But what it means to me is that I was involved with that person...there was a connection. There was a relationship. (Gerow et al., 2010, p. 125)

When the nurse was able to find meaning in the nurse/patient relationship, this helped him or her to continue to invest in future patients and to provide quality care. When a nurse recognized the contribution she had made to the patient's comfort at the end-of-life, she was able to find satisfaction in her work (Gerow et al., 2010).

A second type of subjective loss occurred when a healthcare professional identified with the pain of the family members (Papadatou, 2000). If he or she had a child close in age to the dying child, this type of identification with the parents was more likely. A third type of loss was closely related to the identification loss; past unresolved losses or anticipated future losses also caused the nurse grief or anxiety (Morgan, 2009;

Papadatou, 2000). Sometimes a nurse associated the current loss of a child in her care with either a previous loss or a future one, comparing it in her mind to the death of her own family member (Papadatou, 2000).

The fourth type of subjective loss focused upon unmet expectations or the failure of the provider. Loss related to unmet expectations or failure was found to be more prevalent in physicians, but occurred in nurses as well. The professional grieved because his or her own ability and knowledge were not enough to cure the child. One female pediatrician in Togo, West Africa spoke to this author of her journey through grief. She spent time wondering whether there were cues she missed or more treatments she could have implemented, but eventually found it necessary to sacrifice her pride since she could not be the ultimate savior for her patients. She related how intensely she wrestled with God because of her many face-to-face encounters with dying children. She found herself crying often, angry with God because He had not acted as she prayed and hoped. The struggle with grief required a worldview shift on her part, in which she attributed all power to God. From a Christian perspective, she was able to surrender this grief to God with the belief that He had all things in His control (K. Faber, personal communication, January 11, 2014). She vividly described what the literature refers to as a spiritual quest for meaning that occurs when caring for a dying child (Papadatou et al., 2002).

This worldview shift reflects the fifth type of loss, loss related to one's personal system of beliefs and assumptions about life (Papadatou, 2000). Prior to the experience of caring for a dying child, many of the healthcare providers considered life to be orderly and the world just. The death of children and adolescents goes against what people perceive as right and fair and may be seen as an outrage (Reid, 2013). Following an

immersion experience in Togo, one nursing student related her distress at the suffering of young children when juxtaposed with the availability of medical care in the United States and the long life that many enjoy. As she mourned her eighty-six year old grandfather's death, she also felt grief for the children she had met in Africa who would never reach that ripe old age (K. Paulus, personal communication, January 19, 2014).

Nurses who provide palliative care to the pediatric population must make sense of these assaults to their belief systems in order to continue their care and avoid burnout. As a result of these challenges to their beliefs, the 11 nurses who had been chosen based on their experience with the death of a patient reported a spiritual transformation (Gerow et al., 2010). In her book, *One Thousand Gifts*, Voskamp (2011) openly questioned the goodness of God when she thought of her young sister's death and then later in life heard of the tragic death of her neighbor's child. She asked how these tragedies could be a measure of grace. She searched out the Scriptures and found meaning in her ability to give thanks, first for small things and eventually for hard things. Her tumultuous struggle poetically portrayed the intense grief that many nurses experienced and the way they were changed as a result of this journey (Voskamp, 2011). As a response to the writing of Voskamp (2011), this author also portrayed her walk through grief in poetic language (Appendix C). One staff nurse in Togo indicated her increased intimacy with God as a result of the face-to-face encounters with ill children and death, far more common in Africa than in the United States (B. Mason, personal interview, January 2, 2014). Several nurses cited faith as a major element in how they coped, but others noted they felt uncomfortable when families asked the nurse to pray with them (Cook et al., 2012; Malloy, Thrane, Winston, Virani, & Kelly, 2013).

From a Christian perspective, this world cannot be understood apart from the truth presented in Genesis 1-3. The earth was created perfectly and deemed *good* by God. The curse was pronounced when Adam and Eve chose disobedience. Disorder, pain, suffering, and death exist because sin is present in this world. Ecclesiastes 3:19 illustrated the perspective of one who does not fear God. The author wrote, “Man’s fate is like that of the animals, the same fate awaits them both. As one dies, so dies the other. All have the same breath...everything is meaningless” (New International Version, 1984). However, this passage from Ecclesiastes did not point to a God who is unfeeling or one who is pleased at the suffering of His creation. In fact, this God made the ultimate sacrifice in order to pay for the sins committed against Him. He allowed His own Son to suffer as a guilt offering (Isaiah 53:10) and then provides hope for those who believe in Him because He has power over death (1 Corinthians 15:55). Christians may take solace in the truth that God has not distanced Himself from the suffering that these parents and healthcare professionals experience when they care for suffering and dying children.

Additionally, the Bible can provide a strong foundation when nurses face the sixth and final loss in the Papadatou (2000) study, the loss that addresses one’s own mortality. Each time a nurse entered into the emotional turmoil of a patient who is dying, he or she experienced the fear “of being overwhelmed by suffering, chaos, and disintegration” (Papadatou, 2000, p. 63). This fear was exaggerated in multiple studies when the nurse found him- or herself alone on the hospital unit when a patient died (Gerow et al, 2010; Papadatou, 2000; Papadatou et al, 2002). The need for mutual support when a nurse experienced this kind of loss can be seen in the following: “A dead child and you are

alone—unable to talk about it, not even to say a word to some other person” (Papadatou et al, 2002, p. 349).

### **Conflicting Aspects of Grief**

As a result of the losses that nurses experience with the deterioration and death of a patient, they may react with conflicting aspects of grief, including focus upon the loss and detachment from it. One aspect of grief involves an intense focus upon the loss experienced (Papadatou, 2000). During times of focus on that loss, characteristic symptoms include sorrow, depression, anger and guilt (Papadatou, 2000). Nurses may find themselves thinking of the person lost and of the family. One stated: “I sit there with a cup of coffee and I think, think, and think of the child, of what happened...for hours” (Papadatou, 2000, p. 63). Periods of short withdrawal from other people may coexist with a need to process the experience with others who understand. The funeral may be a place where one can openly grieve her loss and find closure (Reid, 2013).

For some nurses in the Papadatou et al. (2002) study, this type of grief became long-lasting and all-consuming. A male nurse illustrated the ongoing nature of grief in the following quote:

Grieving over the death of the child does not end the day after his or her death.

Every day something the child did or said comes to our mind. There is a continuous relocation of the loss; there is a continuous stirring. (Papadatou et al., 2002, p. 350)

Unfortunately, this depth of sorrow can negatively impact the lives of professionals outside of work. One professional described it this way:

It is the accumulation of so many experiences over so many years. I don't laugh easily. I am not enjoying myself. I am no longer carefree. I feel overwhelmed.

It is as if I have taken in so much sorrow, a sorrow which is not concrete or tangible in a way that you could place it opposite you and kill it. (Papadatou et al, 2002, p. 351)

For this reason, nurses emphasized their need for alienation from the grief that they have experienced (Conte, 2014).

The opposing aspect of grief involves the tendency of nurses to detach from the loss in order to cope, called *alienation* by Conte (2014). Conte (2014) studied 11 oncology nurses and their experiences with work-related loss and grief. A nurse may avoid being overwhelmed by loss and grief, which can be necessary when he or she faces the death of patients regularly. The nurse may experience anger and frustration at being unable to meet all of the demands of the patient and family (Pereira, Fonseca & Carvalho, 2012). As a reaction, nurses may revert to a purely task-oriented mindset rather than address the nearness of death and interact with the patient and family (Morgan, 2009). Unfortunately, this coping mechanism may prevent the nurse from adequately ministering to the patient and family. One professional expressed: "Sometimes I catch myself avoiding talking to them (grieving parents). I pass in front of them as if I did not exist, as if I were not there" (Papadatou, 2000, p. 66). Furthermore, the coping mechanism of avoidance may not only have a negative impact upon the nurse's care for his or her patient, but also create a higher risk for the nurse to develop burnout (Pereira et al., 2012).

Perhaps the most important characteristic of the grieving process for healthcare professionals is the continual fluctuation between avoiding and experiencing the feelings of grief. When this fluctuation did not occur in the Gerow et al. (2010), Papadatou (2000), and Papadatou et al. (2001) studies, the nurses experienced immobilization and impairment in functioning. Papadatou (2000) communicated the great variety of responses to loss in her study, which ranged from withdrawal to open crying or anger. Another study by Davies et al. (1996) interviewed 25 nurses in a Canadian pediatric hospital who had cared for at least one child with a chronic illness who then died. The nurses in the Davies et al. (1996) study described grief as a “devastation,” an “emptiness,” or a “blowing apart” followed by disorientation and behavior that was out of character for them (p. 506-507). A nurse’s reaction to loss could last anywhere from a few hours to a few months, especially if the nurse was deeply invested in the relationship. Conversely, professional and personal responsibilities may prevent the nurses from grieving immediately, causing them to purposely suppress feelings of grief in order to continue caring for other patients. Later the grief may again weigh heavily (Conte, 2014; Davies et al., 1996).

The fluctuation between the focus and avoidance characterizes grief that is adaptive and healthy. In fact, when healthcare professionals reported just one extreme or the other, they were more likely to avoid similar situations and to burn out more quickly (Gerow et al., 2010; Papadatou, 2000). On the other hand, if the nurses were able to fluctuate between the two and come to terms with the loss of their patients, then nurses were able to find satisfaction in their work (Conte, 2014; Davies et al., 1996; Gerow et

al., 2010; Pereira et al., 2012). The following quote from one nurse illustrated this reality:

There are moments we share with the family and that are... important moments... and, although we are delivering bad news sometimes, and despite the fact that we are working in a difficult period of their lives, we have lots of feedback... we have the feedback of the patient immediately after some procedure we make for symptom control... and when we see a smile in their faces... and we have the feedback of the family who becomes calmer. (Pereira et al., 2012, p. 377)

Obershaw (1992), a grief counselor for healthcare professionals and patients for many years, also emphasized the importance of allowing people to work through grief in an individual manner. He used a canoe ride as an analogy and asserted that the grieving person has the right to steer. Others in the canoe could only point out obstacles and dangers while the journey through grief occurred. For some, the process was more difficult, especially if a person chose to point his or her canoe upstream. Nevertheless, he wrote that it was important to allow time and space when appropriate and support when that person met rough waters (Obershaw, 1992).

Nurses must address the question of how much emotion to allow when interacting with patients. Of course, it is inappropriate for the family to console the nurse, a situation which was cited by Cook et al. (2012) in a study of 22 nurses using interviews and focus groups. However, the nurse was often expected to “suck it up” by mentors and fellow nurses and to continue to care for her same patient load (Cook et al., 2012, p. e17). This author had one nurse relate a story illustrating this fact. The nurse, who worked with adults, had just experienced her first death when another patient called the nurses’ station

for a soda. He grew impatient and the nurse requested that another staff person bring this to him while she sought to provide closure for the spouse and postmortem care for her other patient. Her coworker condescendingly asked why she could not care for that herself, since her patient was already dead. Unfortunately, this nurse barely received a few minutes to debrief in the supply room later in the shift with a fellow staff nurse (R. Mills, personal interview, January 20, 2014). In addition to this example, Conte (2014) interviewed 11 nurses who also spoke about the negative impact upon their practice when forced to continue working after the loss of patient. The responsibilities that nurses have toward other patients do not go away, requiring them to take control over their emotions (Conte, 2014).

### **Interventions to Help Nurses Cope with Grief**

#### **Self-Care**

In order for a nurse to work effectively with the pediatric palliative care population, he or she must know his or her own lifestyle and limitations. Papadatou (2000) defined lifestyle as the set of beliefs, values, and assumptions developed early on in life. When people are able to understand the experiences they have had, how they attach meaning to different events, and why they may alter their behavior, they can more effectively step back and process. Because it does demand emotional output to be an expert palliative care nurse, it is important that the nurses have awareness of their own needs and take care of themselves (Johnston & Smith, 2006). Self-care must be a dynamic process that includes adaptation, but for nurses “the daunting task of consistently balancing professional roles can leave little time, energy, or enthusiasm to care for self” (Richards, 2013, p. 198). Nevertheless, taking care of their own needs and

making time for rest helped nurses to prevent emotional exhaustion, depersonalization, and burnout (Pereira et al., 2012). It also allowed nurses to grow and to change as human beings throughout their time of caring for dying patients (Gerow et al., 2010).

Self-care is differentiated from self-indulgence, which would include the use of immediate fixes such as “vegging” and obeying cravings for unhealthy foods (Richards, 2013, p. 199). In contrast, self-care requires commitment to the development of habits such as regular exercise, getting enough sleep, and drinking water (Richards, 2013). Nurses recognized self-care as vital for those who provide nursing care and understood “the importance of being well rounded, taking time off for reflection and rest, and caring for needs outside the institution” (Malloy et al., 2013, p. 105)

Nurses may also create balance in their lives by scheduling breaks and vacations, with just one week of vacation a year reported by nurses as a tangible way to provide self-care (Malloy et al., 2013). However, it can be difficult to schedule longer breaks or vacations when nurses have busy schedules and have a number of other responsibilities in their personal lives. Therefore, consistent choices must be made in their day-to-day lives to promote nurses’ health. Richards (2013) wrote: “By taking care of ourselves first, we bring positive energy and vitality to work that positively affects others and influences the overall landscape” (p. 199).

Based upon previous research and her experience within a large pediatric hospital, Papadatou (2000) found that when nurses were able to find fulfillment within their personal lives and truly to invest once again in life and living, they demonstrated their ability to accept loss and to move through grief. From a Christian perspective, a movement back into abundant life requires more than re-centering and re-connecting with

oneself as Papadatou (2000) suggested. Instead, nurses are able to find true rest in the One who offered to bear their burdens (1 Peter 5:7). By taking time to study the Bible and to pray, nurses can develop a deeper relationship with Jesus Christ, who urged them to come (Matthew 11:28). This is the day-to-day practice by which one undergoes the spiritual transformation mentioned above (Gerow et al, 2010).

A study by Desbiens and Fillions (2007) evaluated 117 nurses in three different areas of Quebec. The nurses in the study spent an average of one third of their working time with patients in the palliative phase of their illness. Desbiens and Fillions (2007) found that nurses who turned to religion and who used positive reinterpretation of events in their lives and nursing practice had a higher spiritual quality of life. Richards (2013), in an article directed to nurses, wrote that her method of spiritual renewal involved a walk outdoors with her dogs each morning before addressing the tasks of the day, but that the goal of this practice was mindfulness. When a person practices mindfulness, he or she takes notice of positive moments throughout the day rather than focusing on the negative ones. Ultimately, nurses must learn to practice self-care that benefits their mental, physical, and spiritual health (Richards, 2013).

### **Open Communication**

Open communication with all those involved in patient care proved to be another important intervention to promote the health of nurses. Hatano, Yamada, and Fukui (2011) conducted an in depth case study about a young Japanese boy with Asperger's syndrome who presented to the hospital with a tumor in his liver that had metastasized. The child's parents did not wish to tell him about his terminal illness, but later he did receive information from the physician. It was very difficult to gauge the extent of his

understanding. Hatano et al. (2011) concluded that because of their direct involvement with the patient and family, nurses are often the best mediator. Additionally, nurses have the ability to assess the pediatric patients' knowledge and how much they may want to know about their diagnoses and care (Clemente, 2007). When the nurse had the opportunity to participate in conversations and decisions, this improved her ability to process the grief and helped her to feel as though she had done everything possible to provide optimal care (Davies et al., 1996; Gerow et al., 2010; Hatano et al., 2011). When open discussion did occur, this collaboration empowered nurses and increased their autonomy by giving them input. Both empowerment and autonomy decreased nurses' stress in the workplace (Wright, 2014). Conversely, when organized communication did not occur, nurses were frustrated in their work (Pereira et al., 2012).

As part of a quality improvement program, Johns Hopkins Children's Center recently implemented one aspect that incorporated monthly palliative care rounds and patient care conferences when potential palliative care cases were noted. The purpose of this program was to facilitate greater interdisciplinary communication for selected patients, ensuring that the patient, parents, physicians, and nurses had input. The program was based on the following premise: "professionals will provide better care and support to seriously ill children and their families when they feel supported personally and professionally in their work" (Rushton et al., 2006, p. 924).

The palliative care rounds utilized specific cases as tangible examples for the staff of patients who would benefit from intentional palliative and end-of-life care. In these situations, nurses and physicians were able to address potential ethical issues and talk through these, increasing the percentage of professionals who felt these were adequately

discussed (Rushton et al., 2006). As a result of the palliative care rounds, a number of follow-up activities were implemented including patient care conferences, family meetings, and referrals for services like pastoral care or social work consults. Patient care conferences, led by a trained staff member, helped to facilitate open communication. As a result, the patients and families were more likely to be well-informed about the illness. By creating an opportunity to summarize the child's illness, to address concerns, to create a palliative care plan, and to identify the next steps, the patient care conferences removed barriers and increased the quality of care that these clients received (Rushton et al., 2006).

The importance of therapeutic communication cannot be overstated. Continual evaluation of the words used and the manner in which information is communicated between team members and the patient and family can help professionals to improve their care (Crozier & Hancock, 2012). As Mark Twain (1890) said, "The difference between the *almost right* word and the *right* word is really a large matter—'tis the difference between the lightning-bug and the lightning" (p. 88). However, listening and silence are often equally as important when caring for dying patients and their families (Crozier & Hancock, 2012). One nurse described her experience with a drown victim child who was brain dead. For the sake of the child's parents, she spoke to the child, bathed him, and held him as though he were sleeping. These actions brought comfort to the parents, upheld the dignity of this child, and helped the nurse to find meaning in her care (Malloy et al., 2010, p. 169).

A good palliative care nurse was described by the 22 patients and 22 nurses in one study as one who listened and looked for the things a patient may not be saying outright,

but who learned to sense his or her patients' needs (Johnston & Smith, 2006). Another study that surveyed 333 registered nurses attending an End-of-Life Nursing Education Consortium (ELNEC) program found that when communication occurred between the nurse and the family and with everyone involved in the care, the nurse was less likely to experience moral distress and more likely to identify positive elements of care (Malloy et al., 2010). Because communication can be difficult and uncomfortable, interventions for nurses such as role play to allow nurses to practice their skills have been suggested (Malloy et al., 2010).

A study done by Steven, White, Marples, and Atkinson (2014) paired eight different nurses with palliative care specialists to mentor and support them during a seven month period. To collect data, a training needs analysis (TNA) was utilized, along with interviews with both the nurses and their mentors. The learner-centered approach allowed them to acknowledge their own deficits, to create action plans and to schedule time with their mentors. At the beginning of the study, all 8 nurses rated a low level of confidence with communication about end-of life care. The mentorship with experienced nurses had a positive impact upon the nurses' confidence in communicating about end-of-life concerns (Steven et al., 2014).

### **Mutual Support**

Nursing was neither designed nor intended to be practiced alone. The Johns Hopkins Children's Center and the newly implemented program addressed the great need for support of healthcare professionals (Rushton et al., 2006). The nurse as the collaborator is expected to communicate with a great number of team members, to advocate for the patient, and to provide the best care possible. However, for many new

nurses, palliative care is unfamiliar since nursing education is lacking with regard to generalist palliative care (Gerow et al., 2010). While the overwhelming sentiment in the literature emphasized the great benefits that would result from earlier implementation of palliative care and its use alongside curative therapies, this still tends to be an area wrought with misunderstandings. However, with an increased focus upon “helpful and constructive role modeling and improved educational experiences for nursing students and new nurses,” many of these could be remedied (Gerow et al., 2010, p. 128).

Gerow et al. (2010) emphasized the great impact that the nurse’s first experience has upon future care for dying patients, especially when he or she has a positive role model. She wrote: “Nurses who felt supported, mentored, and not alone were able to learn and experience a death in such a way that it did not devastate them emotionally; this provided a healthy basis for future death experiences” (Gerow et al., 2010, p. 125-6). Both positive and negative experiences were shared by nurses. The researchers found correlations between the nurses’ perceptions of their first experiences and their willingness to again enter a situation where they may face the death of a patient (Davies et al., 1996; Gerow et al., 2010; Papadatou, 2000).

Many barriers to a reduced patient load to allow a nurse to spend more time in caring for a dying patient and family do exist, such as lack of staff, inexperienced staff, and high acuity levels of patients (Davies et al., 1996; Gallagher & Gormley, 2009). Gerow et al. (2010) found that there was a great benefit when the nurse who experienced a death was given time to follow through with the family, especially as it pertained to her willingness to face another situation involving the death of a patient. Many nurses have reported personal accomplishment when working with acute patients despite the

stressors. In one study of 30 staff nurses on a bone marrow transplant unit, a positive outlook and a sense of personal accomplishment were positively correlated with the nurses' perceptions of available support systems in place on the unit (Gallagher & Gormley, 2009). Conversely, when nurses did not follow through with the family, did not have opportunities to process the emotional impact of a given situation, or did not resolve the thoughts of self-blame, they were more likely to remember the experience negatively and to avoid future situations where they might be exposed to dying children (Davies et al., 1996, Gerow et al., 2010). Therefore, when nurse leaders and educators help new nurses to process encounters with death, they take advantage of the opportunity to influence the next generation.

Often the only other people to truly understand the experience of pediatric palliative care nurses are others who have walked through an experience with terminally ill children themselves. One participant stated: "I can't see that people on the outside who know me would understand what I do here" (Cook et al., 2012, p. e17). Conte (2014), Papadatou (2000) and Papadatou et al. (2002) found that many nurses referred to their need to share experiences with colleagues as an emotional outlet. The nurse who was present at the time of death may share the experience with other nurses who had also cared for that patient. The time of sharing about the patient's death enabled nurses to work through their grief and to be comforted knowing that the patient was comfortable and at peace. In this way colleagues became a "surrogate family in which one has to find one's place, and learn how to work with and depend upon others" and found a sense of belonging (Papadatou, 2000, p. 74). One nurse from the qualitative study done by Conte (2014) shared the following in an interview: "If I need support, it has always just been

with my own colleagues on the floor because they understand the most exactly what is going on. Everybody supports everybody else even if it's informally" (p. 42). A culture of mutual support was found to be especially important for new nurses who often felt underprepared for practice. In a qualitative study of six new nurses who had remained in their original unit for at least 24 months, the nurses attributed their success in the transition to the willingness of other nurses to go out of their way and to be patient (Zeller, Doutrich, Guido, & Hoeksel, 2011).

The task of meaning making is a major part of mutual support and is central to working through grief (Desbiens & Fillion, 2007; Papadatou, 2000). When professionals are able to recount the patient's illness and death, to affirm that they did all that they could to care for that patient, and to process the impact the patient had upon the unit and on the staff members individually, this can help them to address their grief (Conte, 2014). In order to move on from a situation, it is important that the nurses perceived that they had contributed to a peaceful and meaningful death (Davies et al., 1996; Gerow et al., 2010). When nurses provided their patients with quality psychosocial and physical care near death, they recognized their work as something unique (Conte, 2014; Desbiens & Fillion, 2007; Papadatou et al., 2002). One nurse shared: "There are days, most of them...days when I really feel very satisfied...I couldn't feel better elsewhere...days when we notice that a detail...a small detail was just enough to make all the difference and this makes me feel absolutely delighted" (Pereira et al., 2012, p. 379).

Several practical ways to remember a patient and to facilitate closure were included in the research. Often, nurses attended the funeral in order to gain closure. However, in a study about seven nurses who provided palliative care in the home found

that attending the funeral was not always an effective measure due to the distress of the family members that also caused distress for the nurse who had built a relationship with them (Reid, 2013). The Pereira et al. (2012) study utilized both quantitative and qualitative methods by requesting the involvement of 15 palliative care teams throughout Portugal; nine palliative care teams agreed to participate. A researcher met with each of the participating teams to provide quantitative questionnaires and to perform semi-structured interviews with the 73 palliative care professionals who made up the study sample. A number of different interventions were reported by the generalist (37), graduate (28), and head nurses (8) in this study. Those involved in the patient's care often took time to light a candle in memory of that patient after he or she died. Booklets were given to nurses to allow them to write down the experiences they had and "to spill out [their] feelings" (Pereira et al., 2012, p. 378). Some nurses made a point to say goodbye to a patient before going home at the end of a shift. One nurse shared that this was something she learned over time to avoid the sense of emptiness that came when she did not have the chance to bid him or her farewell at the time of death. Overall, the promotion of social support among professionals and a strong sense of cohesion helped nurses to develop trust, to cope with the losses they experienced day to day, and to decrease the risk of burnout (Pereira et al., 2012). This finding was consistent with the Zeller et al. (2011) study that promotes mutual support as a key intervention for retaining new nurses.

In accordance with these findings in the literature, the major quality improvement program implemented at Johns Hopkins Children's Center also included bereavement debriefing sessions (Keene, Hutton, Hall, & Rushton, 2010; Rushton et al., 2006).

Bereavement debriefing sessions were implemented as a formal method to facilitate discussion among the staff and to create opportunities for mutual support. Each session followed a pattern that introduced the staff members and how they had cared for the patient, addressed appropriate facts surrounding the patient's death, and presented a chance for the staff to share their memories about the patient and family. After the staff shared memories, the facilitator opened the floor to talk about coping strategies. The discussion of coping strategies provided an excellent opportunity for newer staff to glean wisdom from and to make connections with experienced staff members. These sessions were especially beneficial when the patient's death was unexpected or when the staff built a relationship with that patient and family over a length of time (Keene et al., 2010).

However, the authors of the study emphasized the need for support from nursing leadership in order to make such a program successful. When considering such a program, it is important to consider the potential increase in staff retention and satisfaction. This type of intervention does require a staff person who is willing and able to facilitate the sessions. Extensive training is essential in order to lead group processing effectively, to recognize when staff members may be experiencing complicated grief, and to create a therapeutic environment. The conversations in bereavement debriefing sessions are vulnerable, meaning that staff must feel safe and believe the facilitator to be trustworthy. Based on the data, the bereavement debriefing sessions were interdisciplinary, but especially beneficial to nurses. Of the 676 healthcare professionals who attended, 374 were nurses (Keene et al., 2010). Since this particular study utilized participant self-report as the method of data collection, objective data regarding staff retention was not available to Keene et al. (2010).

However, another report by Huff (2006) evaluated a new graduate mentorship program in a Chicago children's hospital that paired new nurses with mentors outside their unit. Since new nurses may be uncomfortable demonstrating their vulnerability within their unit, they were more open to sharing when paired with mentors. The first year the mentorship program was implemented, the turnover rate was cut in half (Huff, 2006). Additionally, 90 hospitals have been trained by the Kenneth B. Schwartz Center to implement emotional debriefing sessions similar to the bereavement debriefing sessions at Johns Hopkins Children's Center (Huff, 2006; Keene et al., 2010; Rushton et al., 2006). While many programs have developed, emotional care and mutual support for nurses will remain a priority for medical institutions, nurse educators, and nurse leaders in the future.

### **Conclusion**

Nurses who deliver pediatric palliative care face great challenges. Palliative care itself is a field that is greatly misunderstood but certainly needed in the pediatric population. Furthermore, the pediatric population has unique needs including age- and developmentally-appropriate interventions, effective communication with the family, and wisdom when making ethical decisions throughout the caregiving process. Additionally, encounters with suffering and death in young patients threaten the worldview and the spirituality of many professionals, shaking their very foundation. As a result, many nurses experience grief while caring for these patients. A proper understanding of this grief and the potential types of loss may help nurses to process successfully and to become stronger and more refined. Since grief is an individual process, nurses who know themselves and care for themselves accordingly will likely have positive outcomes. Self-

care is an ongoing process that requires the individual to find and to consistently implement strategies to help him or her cope.

While grief is an individual experience, it was also found to be a social experience. Nurses affirmed that those who had assistance in working through grief were far more likely to make meaning and to identify purpose when providing pediatric palliative care. Mutual support within the healthcare system played an important role in upholding nurses and preventing burnout. The programs recently implemented at Johns Hopkins Children's Hospital and other medical centers may be a model for future developments. Regardless of the method, nurses who receive care for their own needs will be equipped to serve their patients, families, and fellow nurses when providing pediatric palliative care.

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Appendix A

Palliative Care Problem Severity Score (PCPSS; Palliative Care Outcomes, 2012)

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Appendix B

Symptom Assessment Scale (SAS; Palliative Care Outcomes, 2012)

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## Appendix C

## A Poem and Prayer from a Biblical Perspective

Written by Sophia Undseth

Lord God, I pray that Your love would abound  
And Your Presence in this place would continue to astound.

I know days get long and we get worn out  
And we have little things and big things to complain about.

I've been there—as have they—living in stress  
When everything around us seems such a mess.

When the pain is real and our hearts are raw  
Could this truly be the picture that You meant to draw?

Or maybe on the outside it all looks “just so”

But deep in our hearts we cannot let go

Of that little, painful question on the inside  
That asks: “Does God even see?” or “Has He lied?”

Perhaps it's not a question we would ever say:  
“Is God holding out on me?” or “Where is He today??”

The answers don't come easy, maybe not at all  
Feels like You have left us here, all alone to fall  
Regardless of our questions and our nagging doubt

I praise You that You're here—even in drought!

You treasure, You cherish our tender hearts  
And offer living water; You give us new starts

*John 4:14 ~ John 8:11*

Every single day You call us back to Yourself,  
 Knowing only You can offer us true wealth.  
 And our offerings of thanks for Your endless grace

Usher us into Your Presence, bring us to a place

*Psalm 100 ~ Philippians 4:4-7*

Of freedom, of joy, of love, and of strength  
 Of perfect steadfast peace no matter the length  
 Of trials or of suffering, of loneliness or pain  
 Because of the offering, of Blood's crimson stain,  
 And the working of that power that brought Christ to life  
 That enables us to persevere in the midst of great strife.

*Ephesians 1:19-20 ~ James 1:2-4*

You may not change the situation or circumstance we're in  
 This world in which we live is still horrifically marred by sin  
 But Lord, how grateful I am that You do hold our hearts  
 And You know each thought and feeling in the very deepest parts

You long to sit with us and You can truly listen

You hear our deep laments; You see our eyes glisten

*Psalm 139:1-2, 16-18 ~ Psalm 56:8 ~ Lamentations 1:16; 3:19-33*

You process with us and You feel our pain

You wait for us to ask how we can dance in this rain

Because You know, as do we, life is not only sunshine

And for so many things we wish and we pine  
We may fear the future and we question our past  
We cry out to You, God: “How long will this suffering last?”  
Might You give us Your vision, brand new eyes  
To come to see more clearly the One far above the skies.  
Help us to place all things in Your capable hands  
Since You know even our hair and have counted its strands!  
May we come to find true joy and in You take delight  
May we trust that in Your time You will make all things right.