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Pediatric Nurses' Death Anxiety and Level of Comfort in Approaching Families of Dying Children

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PEDIATRIC NURSES' DEATH ANXIETY AND LEVEL OF COMFORT
IN APPROACHING FAMILIES OF DYING CHILDREN

By

Elizabeth June Cook

A THESIS

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ABSTRACT

PEDIATRIC NURSES' DEATH ANXIETY AND LEVEL OF COMFORT IN APPROACHING FAMILIES OF DYING CHILDREN

By

Elizabeth June Cook

The purpose of this study is to examine how demographics; bereavement education; personal death anxiety; and frequency of interaction with death and dying; impact the level of comfort pediatric nurses have in approaching families of dying children. Watson's Theory of Human Caring (n.d.) and the Quality Caring Model (Duffy & Hoskins, 2003) provide the theoretical framework for nursing actions and outcomes. The convenience sample of 165 pediatric nurses comes from a metropolitan children's hospital population of 425 pediatric nurses. Nurses are recruited by a mass e-mail to their work e-mails with a link to the online survey. Nurses' comfort level in approaching families of dying children is positively related to pediatric nursing experience; bereavement and emotionally charged communication education; choosing to interact with families of dying children; and frequency of interactions. Comfort level was not associated with total DAS score.

Dedication

This thesis is dedicated to Niki, a baby who lived to 14 weeks gestation, whose family tried for 10 years to have her, the families impacted by the death of a loved one, and all the nurses who care for them.

Acknowledgements

Thanks to God, my father in heaven for placing within me the desire and capacity to care for others. To Jason my husband for allowing me to work towards my masters degree and providing loving support as well as the “voice of reason” to my heart. To Nicki, my thesis chair, for being understanding and encouraging when the work felt overwhelming. To Nancy Kingma for emphasizing the importance of caring for families after they have lost a loved one. And to my mom for teaching me how to look into the soul of others and love them no matter where they are at in life.

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CHAPTER 1

INTRODUCTION

Life is full of changes. Small changes, changing the shade of a crayon color. Consistent changes, the setting of the sun. Drastic changes, the death of a child. Parents of dying children need to be supported by health care professionals caring for their child (Benkel, Wijk, & Molander, 2009). Pediatric nurses are often involved in notifying and supporting families when a child dies. According to Stewart, Lord and Mercer (2001) emotions evoked during the notification of the traumatic death of a child can affect one's ability to cope with grief. Ineffective coping can lead to mental health disorders that have adverse health outcomes such as post-traumatic stress disorder, anxiety, depression, somatic symptoms, and even death (Kersting et al., 2007; Prigerson et al., 1997; Stroebe, Schut, & Stroebe, 2007). Janzen, Cadell, and Westhues (2004) described how parents felt support from professionals who respected and cared for their child's body helping the parents say goodbye. These parents required less mental health support after the death of their child. On the other hand, parents who felt that health professionals did not care about the child found it more difficult to grieve (Janzen, Cadell, & Westhues, 2004).

Nurses feel as though they ought to have innate knowledge of caring for bereaved families, yet feel inadequately prepared to help families cope with death and dying (Deffner & Bell, 2005; Stewart, 1999). Comfortable, conscientious care in approaching families of dying children is neither intuitive nor thoroughly taught in nursing education

(Katz & Ferrell, 1999). Curriculum guidelines for baccalaureate nursing education from the American Association of Colleges of Nursing (AACN) require that nurses be prepared to care for patients and families at the end of life with respect to symptoms, rituals, and other preferences (AACN, 2008). Despite the requirement to be prepared for end-of-life care most commonly used nursing textbooks provide limited knowledge on care and interventions for the death and dying of patients (Katz & Ferrell).

Professional and community resources have recognized the need to further educate health care professionals. AACN's End of Life Nursing Education Course, Resolve Through Sharing Bereavement Services, and Harvard University's Center of Palliative Care program are training programs developed to deepen the knowledge of nurses and nurse educators in appropriate care of the dying patient.

The AACN designed the End of Life Nursing Education Consortium (ELNEC) – Core course, a course composed of eight modules, to increase the knowledge of bereavement care with a focus on palliative care (ELNEC, 2011). ELNEC-Core modules include: nursing care at the end of life; pain management; symptom management; ethical/legal issues; cultural considerations in end-of-life care; communication; loss, grief, and bereavement; and preparation for and care at the time of death. According to ELNEC, over 12,000 nurses throughout the United States have completed the course. Approximately 65% of undergraduate nursing schools have an ELNEC trained faculty member. In 2003, ELNEC developed an End of Life Pediatric Palliative Care course that has trained 1,600 nurses who work with children.

In 1981, Resolve Through Sharing Bereavement Services (2011) developed a program to educate health care professionals concerning perinatal bereavement. As a

result, 30,000 healthcare professionals have been trained in perinatal bereavement care. These numbers represent less than 1% of nurses licensed in the U.S. (U. S. Health and Human Services: Health Resources and Human Services Administration [HRSA], 2006).

Harvard Medical School also recognized the need for physicians and nurses to be educated in palliative care and developed a Palliative Care Education and Practice Course which includes a pediatric track (Center for Palliative Care, 2011). The emphasis has begun on training and educating nurses on end of life care in general. The next step is to teach our nurses to care for special populations at the end of life.

Problem Statement

Much of the current pediatric death and dying research and education focus are on parental bereavement experiences. Some research studies were found on nurses' perception of care for families of dying adult patients, and even fewer concerning dying children. As a result, the evidence for pediatric nursing care of bereaved families is limited. The goal of this study is to assess pediatric nurses' perceptions of personal death anxiety and comfort level of caring for families of dying patients.

Caring for bereft and grieving families by helping them cope is part of health promotion and illness prevention. When nurses are uncomfortable around a dying patient they tend to avoid interacting and communicating with the family (Tse, Wu, Suen, Ko, & Yung, 2007). Deffner and Bell (2005) found that nurses who were older, who had more nursing experience or those who had education in communication had a higher comfort level when communicating with bereaved families. Deffner and Bell reported that nurses with higher death anxiety had decreased comfort in communicating with bereaved families.

Purpose

The purpose of this study is to examine how demographics, bereavement and emotional communication education, personal death anxiety and frequency of interaction impact the level of comfort pediatric nurses have in approaching families of dying children. These findings support the advancement of nursing knowledge concerning pediatric nurses' perceptions of working with families of dying children. Knowledge gained through this research will help inform nursing education concerning bereavement as related to assessed demographics such as age, gender, ethnicity, religious association, and level of nursing education.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

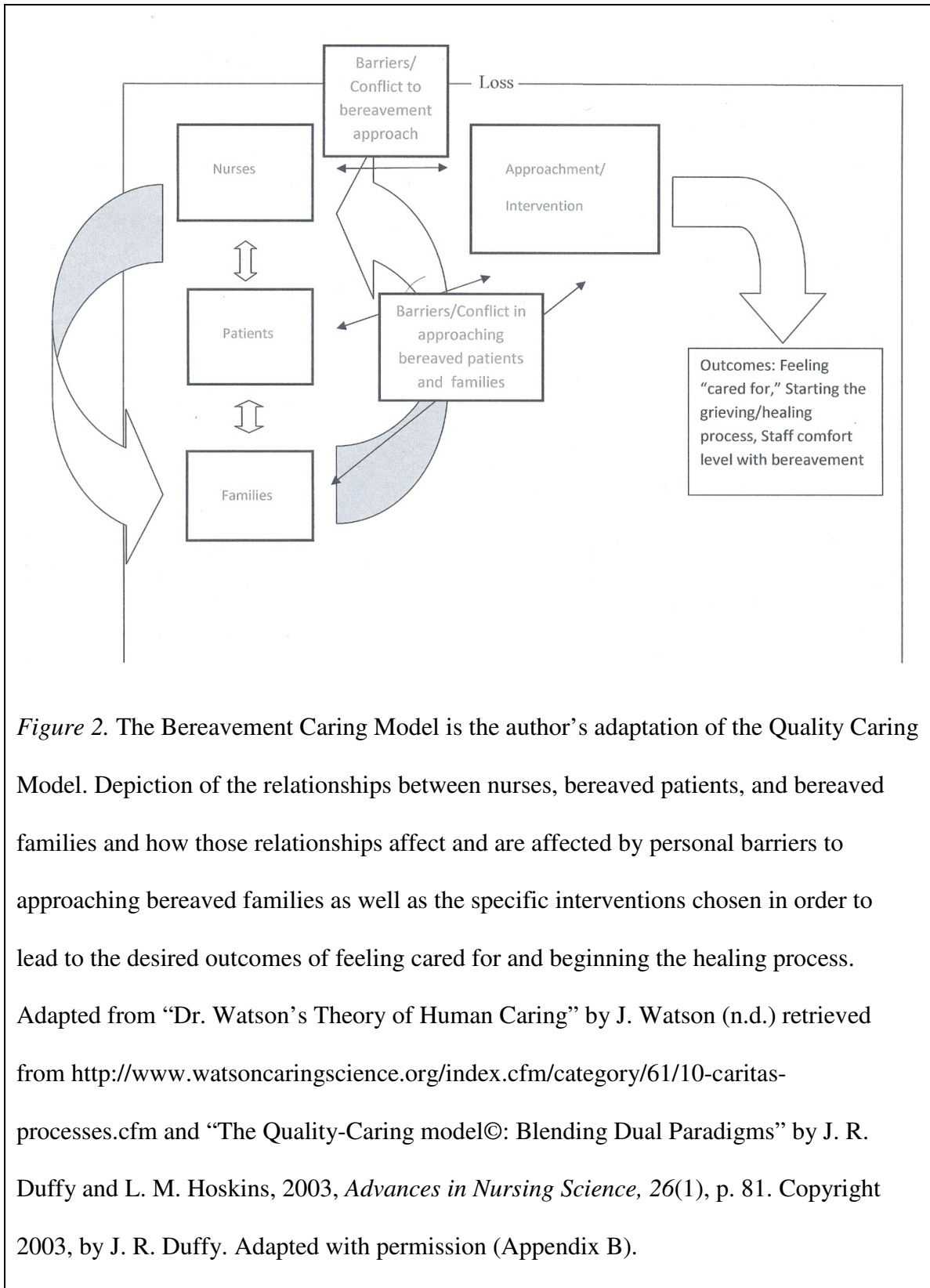
The assumptions of this research stemmed from Watson's broad range Human Caring Theory (n.d.), while the more concrete process was extracted from Duffy's middle-range theory, the Quality Caring Model (Duffy & Hoskins, 2003; Appendix A). The Human Caring Theory addressed three major concepts: the ten caritas, transpersonal caring, and the caring moment achieved through a caring/healing consciousness. The ten caritas described how a nurse should embrace him or herself as well as patients and their families (Caring Science 10 Caritas Process, n.d.). The ten caritas are listed in figure 1.

1. Embrace altruistic values and practice loving kindness with self and others.
2. Instill faith and hope and honor others.
3. Be sensitive to self and others by nurturing individual beliefs and practices.
4. Develop helping – trusting- caring relationships.
5. Promote and accept positive and negative feelings as you authentically listen to another’s story.
6. Use creative scientific problem-solving methods for caring decision making.
7. Share teaching and learning that addresses the individual needs and comprehension styles.
8. Create a healing environment for the physical and spiritual self which respects human dignity.
9. Assist with basic physical, emotional, and spiritual human needs.
10. Open to mystery and allow miracles to enter.

Figure 1. The 10 Caritas of Dr. Jean Watson’s Human Caring Theory. Caring Science 10 Caritas Processes. (n.d.) Retrieved from <http://www.watsoncaringscience.org/index.cfm/category/61/10-caritas-processes.cfm>

The transpersonal relationship could be described as seeking a deep, spiritual connection with a patient or family member through authenticity and openness. The caring moment is the moment in which the spiritual connection is made between nurse and patient. The healing process of caring begins in consciousness of this moment.

Duffy’s Quality Caring Model provided the practical, adaptable framework on which to utilize the theory of human caring for research. The major concepts of participants, caring relationships, and terminal outcomes correlated with the human caring concepts of the ten caritas, transpersonal relationships, and caring moments respectively. The researcher adapted the quality caring model to more succinctly reflect Watson’s theory of Human Caring and the Quality Caring Model, see figure 2.



For the current study the variables under the concept of participants were nurses, patients, and families. The system participant was excluded as this study was concerned with the comfort level related to approaching families of dying children. The nurse-to-patient-to-family relationship dynamic included both direct and indirect influences (e.g. nurse-patient was a direct relationship that indirectly affected the family, nurse-family directly affected the family and indirectly affected the patient). The concept of the independent caring relationship in this research was the approach and interaction of the nurse toward the patient/family. The potential barrier or conflict variable to approaching families was the nurse's death anxiety. An additional barrier or conflict could have been infrequent interactions or lack of interaction with families about death and dying due to discomfort in communicating a difficult subject. The final concepts included in this model were the outcome variables of patients/families feeling "cared for," starting the grieving process, as well as the staff comfort level with death and dying care. However, as this research was a descriptive survey the outcomes of an intervention were not assessed.

Summary

In summary this research culminated from the belief that nurses have the capacity to engage in healing, caring relationships with families of dying children that could lead to improved patient care and family grieving. The research question addressed whether a nurse's demographics, bereavement education or emotionally charged communication education, personal death anxiety, or frequency of interacting with families of dying children were related to his or her comfort level in approaching families of dying children.

Literature Review

A literature review was performed to establish the current state of nursing knowledge concerning nurses' perceptions of comfort level when approaching families of dying children. Databases were searched with the library search engine Summon and included the Cumulative Index to Nursing and Allied Health (CINAHL), PubMed, and Medline. Terms used to identify appropriate studies included bereavement; pediatric bereavement; death AND dying; pediatric bereavement; nurses AND families AND dying; traumatic death; health care professionals AND bereavement; communicating with families AND death; end-of-life care; nurses AND grief. Research on bereavement in pediatrics was limited. The bulk of available bereavement research focused on family responses to end of life care for adults, pediatric oncology, and perinatal death, with some studies on nursing response to bereavement and end of life care. As a result literature reviewed for this study included bereavement studies in the adult population, pediatrics, and traumatic loss. Traumatic loss was included in the review because according to the Centers for Disease Control and Prevention (CDC) (2007) the top three causes of pediatric death in the U.S. are accidents (43%), homicide (11%), and suicide (9%). Additionally, Stroebe, Schut and Stroebe (2007) found traumatic grief as a grief response to a variety of non-traumatic situations. The traumatic grief studies described the impact of death and dying on families and nurses; the impact of nurses on families of dying patients; nurses' knowledge of end-of-life care; nurses' personal death anxiety; nurses' attitudes toward death and dying; and death anxiety.

Impact on Families

In pediatric nursing the family was always present and often considered the second patient. The following studies have demonstrated how the family was impacted by the death of a family member. Some authors did not study pediatric patient deaths, but they were included because they assessed aspects of bereavement that could be generalized to a family of a dying child.

Janzen, Cadell, and Weshues (2004), in their original qualitative research, interviewed parents whose children had died suddenly, to determine through the parents' experiences what all professionals involved in the death and dying care of the children could do to help parents achieve healthy grieving. The study stemmed from heuristic inquiry. The authors interviewed 20 parents, one to seven years after the sudden death of a child, asking an open ended question concerning the experience of losing a child and what professional actions had been or would have been helpful in the grieving process. The population sampled was white, European-Canadian, Christian, middle-class, and middle aged. The data were transcribed from cassette tapes and coded to two levels.

Janzen et al. (2004) identified five major themes of parental needs during the grieving process: to reconstruct the death scene; regain control; say good-bye; understand the meaning behind the death; and develop a new and continuing relationship with their child. Parents were thankful to any professionals who allowed the parents some control through the process of dying to burial. Particularly of nurses, parents found it helpful when the nurses explained what was going on, made the patient and family comfortable, empathized, validated feelings, and recognized a stillborn as a child. The authors explained that professionals involved in the care of a child from dying to burial can help

parents to attain a healthy grieving pattern by using professional's actions toward the family.

Strengths of Janzen et al.'s (2004) study included a focus on pediatric patients, bereaved parents' description of what was helpful, and a large qualitative sample size. Weaknesses identified by the authors included the involvement of all participants with the Bereaved Families of Ontario organization and the limited diversity of the sample. Despite its limitations, this study provides excellent insight into how families were affected by professionals' responses at the crisis point of the death and dying of their children.

Stroebe, Schut, and Stroebe (2007) systematically reviewed correlational research studies concerning (mental/physical health) outcomes of bereavement. The purpose of their study was to improve understanding of mortality, psychological symptoms, medical implications, risk factors and intervention efficacy related to bereavement in order to prevent adverse bereavement outcomes.

The study was a systematic review of studies with adequate sample size which used standardized measurements and appropriate analytical techniques to better understand bereavement. The sample included 16 studies, 13 of which focused primarily on spousal bereavement. The studies reviewed included those with a non-bereaved control group, longitudinal studies, prospective studies, and the authors' previous publications. Assessments included bereaved individuals mortality/suicide risk, bereavement onset, racial backgrounds, and a twin study. One study assessed spouses/cohabiters and parental bereavement. Two studies focused on parents' risk of mortality and suicide after a child's death.

The variables of interest in this study included the relationship of bereavement with mortality, psychological symptoms and ill health, physical symptoms, risk factors that led to poor coping, and the effectiveness of interventions in preventing negative health outcomes. Stroebe et al. (2007) were careful to select articles that had control groups in order to strengthen the review of studies. Additionally, the articles chosen had follow-up results ranging from 4 years to 18 years. Sample sizes ranges from 237 widows to a national longitudinal survey of 50,000 households. The ages of the subjects ranged from 18-84 years old. Investigators reported found that mortality of bereaved individuals was higher in the first few months after the death of a loved one, and more often related to accidents, violence, and alcohol than natural causes of death. Mothers, who had lost children, were affected more than fathers. However, fathers were at a higher risk of unnatural death close to the time of the child's death. Researchers found that suicidal deaths held a higher risk of spouses and parents committing suicide.

Psychological symptoms were diverse spanning affective, cognitive, behavioral, physiologic-somatic, and immunologic reactions. Psychological symptoms were found to be present at least during the first six months of bereavement. Most researchers found that the bereaved were resilient and recovered over time, although some individuals had a heightened level of depression long-term. Occasionally, individuals experienced complicated grief which led to delayed grief expression and healing.

The authors found that bereaved individuals were more likely to have had new or exacerbated illnesses, took more medications than non-bereaved individuals, had high levels of grief and functional impairment and used fewer health care services. Additional

symptoms expressed by bereaved individuals included negative changes in eating habits, social and work situations, relationships, and memory difficulties.

The researchers suggested factors influencing some bereaved individuals to cope better than others. Variables related to coping included differences in adjustment, cause of death, caregiver strain, quality of relationship lost, robustness/fragility of the bereaved individual, attribution process – making sense of what is happening, emotional regulation, predisposing vulnerabilities (mental illness, medical health, etc.), secondary stressors, and interpersonal resources. How these variables interplay and lead to maladaptive coping was not described.

Stroebe et al. (2007) focused on effective psychological interventions and found that three levels of bereavement intervention were appropriate. Primary interventions should be provided to every bereaved individual. Secondary interventions should be reserved for individuals found to be more vulnerable. Tertiary interventions should be focused on individuals with complicated grief.

Strengths of this study include large sample sizes, careful selection of research studies, and varied styles of research (longitudinal, prospective, cross-sectional, and a twin study). Limitations of this study included confounding factors such as health of individuals prior to the loss of a loved one and inclusion of a minimal number of studies of non-spousal bereavement. Grief was considered complicated when it fell outside the societal norms for grief. As a result, this study does not address cross cultural grief or grieving patterns: the cultures represented in this meta-analysis include Europe and the United States. Therefore, there was limited evaluation of the effectiveness of the interventions described in the article. Additionally, the authors mentioned that although

the studies met inclusion criteria there were some methodological weaknesses in the studies reviewed including high dropout rates and poor response. This article suggested that bereavement could lead to serious negative physical and psychological outcomes, and further suggests that research was needed to evaluate other populations of interest and the efficacy of bereavement interventions.

Traumatic grief, grief that was debilitating and not necessarily caused by traumatic death, was another example of how families are impacted by death. Shear et al. (2001) performed a pilot study intervention of therapy focused on improvement of traumatic grief symptoms. The authors explained that individuals meeting traumatic grief criteria had no resolution of grief symptoms with standard medical and interpersonal psychotherapy interventions. The authors explored how these individual's grief intensity decreased and the ability to enjoy good memories of the dead individual increased through exposure therapy as well as how the participant was better able to re-engage in activities of daily living and relationships.

Shear et al. (2001) began with 21 participants who met criteria for traumatic grief. All participants were rated on the DSM-IV initially, and all completed three inventories weekly (Inventory of Complicated Grief; Beck Depression Inventory; Beck Anxiety Inventory) throughout the 4-month session. Participant mean age was 51 years old. Thirteen participants completed all 16 therapy sessions. The authors found that all groups – completers (13), non-completers (8), and total (21) – had lower mean scores on each inventory after the sessions. Those who completed the therapy sessions had the largest drop in mean scores.

The strength of this study was that it demonstrated how debilitating grief can be, and emphasized that traumatic grief was not well understood and required further treatment. Weaknesses of this study include that it is a pilot study, and therefore has a small sample size. Many of the participants faced traumatic bereavement of their spouses, and not their children.

Impact on Nurses

Nurses enter their profession to help and care for individuals in need. They care for individuals at every stage of life, from birth to death, and become emotionally invested in their patients. Every death, personal and professional, affect the nurse and her care of other patients.

Ratner (2010) expressed her own personal experience managing her grief as an intensive care unit (ICU) nurse. She described how the loss of her mother changed how she cared for older patients who reminded her of her mother. She felt more connected to them, and used that connection in managing her own grief. After her son died in a motorcycle accident, Ratner felt a connection to young patients who reminded her of her son. As part of her continued to grieve she searched for connections with her patients. She found that these connections provided her with welcomed reminders of her mother and son. This article demonstrated how personal losses impacted a nurse's interactions with her patients and that these interactions with her patients helped this nurse grieve.

Education on appropriate end of life care can impact a nurse's ability to cope with grief related to the death of a patient. Mallory and Allen (2006) examined how a staff guided experience with the care of a dying patient could positively impact a student nurse's attitude toward death and dying. The authors argued that the majority of nurses

felt that good end of life care was important, but felt that their nursing education did not adequately prepare them for appropriate end of life care. Mallory and Allen also explained that education and more frequent exposure to end of life care has improved nurses' attitudes toward caring for the dying. The authors used the theoretical framework of the Transformative Learning Theory. In this study, the participant was a 20 year old female nursing student placed in a clinical experience with a palliative care nurse. The student was described as hesitant and uncomfortable with care of the dying patient. The palliative care nurse was able to provide knowledge concerning appropriate care and role play with the student to increase her comfort level in caring for a dying patient and the grieving family.

Two other students' experiences were also reported in this study. One explained how after completing the end of life course she felt honored to be present during the death of the patient. Another student described how after the course she was able to advocate for her father to have a peaceful death at home.

The strength of this end of life care study was the expertise of the authors, the thorough literature review, and a clear description of a positive experience in caring for a dying patient. The weaknesses of this study include the lack of follow up of the nurse's clinical experiences of death and dying after the study. The experience may have been different if caring for a family with the death of a child.

Other nursing experiences aside from coping with grief related to the death of a patient were also an important part of the studies reviewed. Davies et al. (1996) performed a qualitative study using grounded theory with the purpose of discovering the experiences that nurses have when caring for dying children. The inductive grounded

theory approach allowed theory development from qualitative answers using non-guiding, open ended questions that highlight the concepts of the study. The authors used three recruits to pilot the questions which were then revised and applied to the remaining sample.

The population for this study came from a tertiary care pediatric hospital in Western Canada. The sample of 25 female nurses involved in pediatric patient care had cared for one or more chronically ill child(ren) who had died. Ages of nurses ranged from 23-45 years with nursing experience from 2-24 years. About half of the sample were married and half had children. Time since the death of the child ranged from three weeks to 19 years, and ages of the patient who had died ranged from newborn to 18 years old.

Concepts that surfaced through the interviews included recognizing the pending death of the child, having a relationship with the child, grieving, experiencing moral distress, finding meaning, letting go, being honest, sharing with coworkers, seeking support, receiving support from family and friends, briefing, debriefing, taking charge, following through and withdrawing. External factors that surfaced included peer support, unspoken professional 'codes of conduct,' expectations, and personal framework.

The interviews were transcribed and independently coded by two or three researchers before being coded by consensus. Analyses and interpretations were verified by additional pediatric nurses from a variety of settings.

The authors found that nurses had a variety of responses to terminally ill children. An overarching initiating concept was the stress of the realization that the child was going to die, particularly if the nurse had developed a relationship with the child. Nurses

expressed that they felt they ought to know how to care for dying patients and they should automatically know how to manage that distress.

Davies et al. (1996) reported that nurses experienced distress (grief and moral) with the death of patients. The nurses found that grief distress was often related to the need to demonstrate emotions of sadness and tears. Nurses who were able to express their emotions were better able to cope than those who felt their emotions contradicted the unspoken professional code of conduct. Some nurses managed their grief distress by engaging their families, friends and coworkers in conversations about their emotions while others withdrew from their patients and separated their professional and personal self. The workplace environment was a strong factor in nurses' ability to manage their grief. Some nurses found that being briefed on a patient's condition prior to arrival on their shift allowed them to prepare for the dynamics of the shift. Many nurses also found that debriefings after the shift allowed them to share their grief with their coworkers. Nurses who felt able to seek support were better able to manage their grief than those who felt unable to find or seek support.

Moral distress began when the nurse felt as though painful procedures were futile and unnecessary for the patient's comfortable death. When nurses felt unable to advocate and change what was felt to be inappropriate care they experienced increased moral distress.

The nurse's personal framework of education, religious background/beliefs, family situation, experience with personal losses, and previous nursing experience especially as it related to a similar chronic condition were natural buffers. Interestingly

the nurses explained that previous experience with adult deaths was considered very different than the pediatric deaths.

Those who managed their grief well found the experience of caring for someone at or near the end of life was an enriching experience. Those who were not able to manage their grief well moved to different clinical areas with a lower risk of patient death, or to a more task-oriented, fast paced role with limited capacity to develop relationships with patients, and those who stayed avoided developing relationships with their patients.

Limitations of this study include the lack of male nurses interviewed. Ethnicity of the nurses was not evaluated. The researchers evaluated nurses caring for chronically ill children which limited generality to nurses in patient care areas where death was more expected.

This study emphasized that grief for nursing staff could be pervasive in professional and personal lives; when appropriately managed and supported nurses derive satisfaction through providing end of life care. On the other hand, when poorly managed and unsupported nurses could withdraw both professionally and personally and grief could negatively affect their lives. Nurses should be evaluated on their level of comfort concerning bereaved families, as well as their own personal death anxiety to determine the best avenue of support.

In the previous studies nurses were positively and negatively affected by patient deaths. The nurses who had positive experiences had better coping skills and became more involved in their patient care and positively impacted families. The nurses who

were negatively impacted withdrew from patients and families which resulted in poorer patient care and fewer positive interactions with the family.

Spirituality was another concept that affected nurses' ability to cope with grief. Shinbara and Olson (2010) evaluated the importance of spirituality in nurses' self-reported grief and coping with grief. They explained that grieving was healthy and that spirituality was a healthy coping mechanism. Unfortunately, the newest grief studies did not focus on nurses' grief or spirituality, but rather on helping patients and families with their grief and spirituality. The purpose of this descriptive study was to assess the support that spirituality provided for grieving nurses, and the role spirituality played in coping with future grief. The design was a simple, descriptive, non-randomized survey of nurses.

The population was adult nurses, over age 18, who held nursing degrees, and currently practiced at a hospital. The sample of 68 nurses was obtained through the snowballing method beginning with 150 postcards and e-mails to individuals known to the researchers.

The measurement used for this study was the Need Assessment Questionnaire (NAQ) that was previously developed by one of the authors. It includes a Likert scale, a multiple answer section, and open-ended questions. The NAQ focused on how a nurse was affected by a patient loss, the grief support available, the grief support utilized, and the importance of spirituality in the nurse's coping.

A typical respondent was a white female in her mid-thirties with less than ten years nursing experience. The clinical areas included but were not limited to women's health, oncology, intensive care, and pediatrics. The authors found that the majority of nurses (70%) used personal faith as a grief coping mechanism and almost half (49%)

replied that they would use personal faith as a coping mechanism in the future. Other spiritual resources that were found to be beneficial included chaplains, education concerning spirituality, and pastoral care services.

This study was limited by its small, non-probability sample. The authors explained that the NAQ does not specify type of faith, religion or spirituality, nor does it delineate type of faith action used (e.g. prayer, counseling, services etc.). Validity and reliability of the NAQ were not discussed.

This study highlighted grief coping strategies used by nurses with a focus on spirituality. The authors found that spirituality was a highly utilized form of coping, and discussed how few researchers have studied strategies that help nurses cope with their own grief. This study lent support to furthering research concerning nurses' perceptions on death, dying and coping with personal grief.

Nurses were also impacted by professional loss which in turn affected their self-care. Keene, Hutton, Hall and Rushton (2010) performed a bereavement debriefing intervention at John Hopkins Children's Center to emotionally support health professionals who worked with dying children, and evaluated the intervention's effect on coping with grief. The format of the debriefing session was an open-ended, expert-guided session that was evaluated with a pre- and post- assessment.

The population was comprised of all health professionals at John Hopkins Children's Center involved in the care of a pediatric patient who died and who desired to attend a debriefing session. The sample included 676 health care professionals and involved 113 of 494 deaths from the years 2002-2005. Health care professionals included nurses, physicians, child life specialists, social workers, chaplains, nutritionists, clerical

associates, allied health therapists, the librarian, and foreign language interpreters. More than half of the attendees were nurses. Variables included participation in the bereavement program activities, impact of the debriefing on grief management and professional integrity, reason for requesting the debriefing session, distressing aspects of care, satisfying aspects of care, helpfulness of the debriefing session, and general comments concerning the debriefing session. The bereavement coordinator took minutes and captured the qualitative data by identifying themes that were discussed.

Quantitatively, 184 (27%) participants returned the pre- and post- evaluations.

The researchers found the main reasons for requesting a debriefing session were professional distress (85%) and a sudden or unexpected death (34%). Other reasons included multiple units involved in care, long term relationship with patient, multiple deaths in a short period of time, a critical incident, or team conflict. Reasons for refusing a debriefing session in 381 (77%) of the death cases included not knowing the patient and an expected death in which everything went well. The researchers found that a long relationship with the patient, a patient in pain, or an unexpected death caused the most emotional distress. The most satisfying aspects of care were good teamwork, end-of-life-care, and relationships with the family. Almost all the participants in the debriefings found the sessions helpful and meaningful, and over half the participants attended more than one debriefing. Participants scored higher in their ability to manage their grief and their professional integrity after the debriefing sessions.

Limitations to this study include bias of the bereavement coordinator who recorded the data from the sessions, a single hospital location, and low participant evaluation response. Those who attended the debriefings may have already felt as though

their grief management was inadequate skewing the results of the pre-evaluation survey, and no control group was used to rule out attendee bias. The authors were concerned about gender bias because the female nurses had a higher representation than male nurses; however, this confounding factor was not pursued. This original study demonstrated that the nursing population was affected by professional distress and relationships to pediatric patients who died unexpectedly. The authors also found that bereavement debriefing sessions helped health care professionals improve their grieving management and their professional integrity. The study supported the concept that patient deaths impact health care professionals who do not feel adequately prepared to manage their grief. The authors inferred that a health care provider's ability to provide appropriate end-of-life care was a highlight in the care of the dying. Further research concerning personal comfort in approaching dying patients and end-of-life care could lead to improved grief management and decreased professional distress in care of dying patients.

A nurse's personal attitude toward death and dying could influence the impact that a patient death has on a nurse's comfort level in approaching and interacting with families of dying children. F.K.Y. Wong, Lee, and Mok (2001) used a qualitative approach to determine nursing students' death and dying attitudes before the problem based (PBL) intervention, changes that resulted from PBL, and how different death and dying scenarios taught different skills. The participants were encouraged to be the catalyst of the learning environment and to use their resources – textbooks, co-workers, and themselves.

This study examined Chinese nursing students involved an applied psychology class. There were a total of 72 participants for the study. Participants were grouped and

given death and dying scenarios to analyze. They used personal experience, experts, and research evidence to determine appropriate assessments, interventions, and treatments for dying individuals and their families.

F. K. Y. Wong et al. (2001) identified three major themes in the student nurses' journals. The first theme expressed by the students was recognition of their own emotions concerning death and dying. Many of them were uncomfortable with their own mortality and therefore were uncomfortable with the reminder of their dying patients. The second theme was the desire to be better prepared to communicate and counsel dying patients and bereaved family members. The third theme identified was the adoption of a nursing, holistic, family centered approach to death and dying. The authors found that the nursing students moved from an avoidance attitude at the beginning of the intervention to a positive attitude of caring for the dying patients.

Strengths of this study included within-case and cross-case analysis, and comparison of the same participants before and after the intervention. Weaknesses include the inability to generalize to other nursing populations, Chinese cultural influences on the subject of death, and lack of demographics. This qualitative study provided evidence that nurses often feel underprepared and/or uncomfortable with death and dying and that a problem based learning approach can lead to improved attitudes toward caring for dying patients.

Nurses Impact Families

Nurses feel as if they ought to automatically know how to care for patients who are dying and their families; however, many find themselves lacking in knowledge and confidence to provide excellent care. Several studies showed the lasting negative impact

that bereavement could have on an individual and how professional nursing presence was reported to help during the initial bereavement period. The following studies describe how nurses impact families of dying patients.

Holman (1990), in a clinical expert opinion based on personal work experience and observations, expressed that as health care advances technologically there is an ability to focus on what can be done for the patient physically often to the detriment of a patient mentally, emotionally, and spiritually. Holman reviewed the anxiety that death could produce in the hospital setting and presented a pediatric death case study based on personal experiences.

Holman (1990) described an event of a chronic traumatically brain injured child who died. She explained that the medical and nursing staffs were unprepared to provide comforting care to an emotionally charged mother. She felt the hospital system needed to make staff morale, communication between disciplines, and death education a priority in order to positively impact staff and families involved in the care of dying patients.

The impact that nurses had on families of dying children could start at the notification to the family of the death of the child. Stewart (1999) performed a research review related to motor vehicle collision (MVC) deaths and associated survivor complicated grief or presence of post-traumatic stress disorder (PTSD). He reviewed and analyzed the Fatality Analysis Reporting System (FARS) from 1990 to 1996 in order to evaluate deaths based on four different criteria as they related to family response. The four categories of death were: suddenness of death (<6 hours from the collision), prematurity of death (persons <25 years of age), preventability (presence of alcohol or drugs), and violent/mutilating injuries. He followed with recommendations for death

notification designed to identify and handle potential complicated grief scenarios.

Variables in this research review included complicated grief related to traumatic death, post-traumatic stress disorder related to traumatic death, sudden death, premature death, preventable death, mutilating deaths, and family response to death notification.

Stewart (1999) found that how the family was notified as well as the circumstances surrounding the death affected the bereavement process. Incorrect or incomplete information during notification of death provided no emotional support, and chaotic environments decreased the ability to receive death notification well.

Although the suddenness of death was associated with the unexpected loss syndrome (ULS), including symptoms of shock, numbness, despair, avoidance, and social withdrawal, effects on bereavement were more closely related to the age of the person bereaved. When defining the categories of traumatic death, age was found to be the single most important factor in determining a premature death. Families grieving over a premature death had more anger, hostility, despair, guilt, rumination, depersonalization, and somatization than those grieving the expected loss of older individuals. Additionally, grieving parents were found to have higher levels of depression, anxiety, hostility, worry and negative emotions when compared to controls. The research demonstrated that a large percentage of bereaved siblings and parents (premature deaths) met the DSM III-R criteria for PTSD. Certain immediate reactions at the time of the notification were associated with later diagnosis of PTSD in the form of: dissociation, extreme anxiety/anger/fear, or disorganized reaction. Stewart (1999) also found that preventable deaths could lead to delayed mourning because of a lengthy legal process. Families often became more vengeful and angry during the drawn out trial for the accused.

Stewart (1999) used the FARS to evaluate location of death, length of survival time at the hospital (suddenness), ages of the deceased (prematurity), and presence of alcohol or drugs (preventable) in the motor vehicle collisions. He found that 75% of all MVC's between the years 1990-1996 had at least one of the three criteria for traumatic death.

Stewart (1999) determined that about 55% of MVC death notifications occurred in hospitals and the other 45% occur at the scene. He expressed that although the content of death notification cannot be changed, the process should be used as secondary prevention. Recommendations of death notification included (1) correct identification of deceased and family, (2) utilization of a death notification team, (3) correct information concerning crash, injuries sustained, and procedures performed in clear, simple language, (4) use of direct language of death, (5) supportive response, (6) preparation for dissociative reactions, (7) provision of the opportunity to view the body, and (8) provision of follow up care.

This study was limited in that it was not an original research study, the literature reviewed were not all pediatric specific, and the recommendations for death notification were based on clinical experience, not formal research. Additionally, the perspectives of the death notification team, and the perceptions of the family being notified were not evaluated. This study highlighted the effect of traumatic bereavement on families and the current lack of research related to perceptions of communicating with bereaved families.

Stewart, Lord and Mercer's (2001) original research was a quasi-experimental design that surveyed death notifiers about death notification before and after a Mother's Against Drunk Driving (MADD) death notification seminar. The survey was sent to 636

persons who had attended the MADD death notification seminar with a return rate of 39%. The sample included 245 death notifiers including law enforcement officers, health care providers, emergency medical technicians, victim advocates, coroners, and clergy. The respondents included 136 males and 108 females, with ages ranging from 22 to 79 years with a mean age of 46.4. Variables included death notification education, need for death notification education, and beneficial aspects of the seminar.

The researchers found that approximately 40% of those surveyed did not have death notification training in either classroom or on the job. Through open-ended questions, the researchers found that the majority of attendees felt the need for a specific process for death notification and found death notification challenging. Fewer responders needed more information on how to handle their own emotional response or how to provide further resources to families in death notification. Important aspects of the seminar were learning how to notify a family member of a death, contacting family members, and following death protocols.

Strengths of this study were a large sample size including both male and female respondents, and improved death notification communication. Limitations of this study included a non-random sample, and self-assessment knowledge after the seminar was completed.

In addition to improving communication between disciplines, communication needs to be improved between health care providers and families, and training needs to be increased concerning appropriate treatment of dying children. Russell and Alexander (2005) presented a secondary research analysis of appropriate care and treatment of dying children, their families, and the health care team in the pediatric intensive care unit

(PICU). In this study, the authors explained the patient needs included pain management, freedom to talk about death, involvement in the end of life decision, as well as validation of emotions and encouragement to reminisce about life. Families of dying children were described as vulnerable. The authors explained that these parents needed honest, correct, and timely information concerning the care and treatment of their child. Russell and Alexander emphasized that communication with families was extremely important. Families needed preparation for the transition time between removal of life support and death, and the ability to visit freely and perform religious and cultural rituals of death and dying. The authors also explained that families occasionally became irrational, demonstrating anger near the time of death. They found that families who received appropriate bereavement intervention and counseling through nursing or counseling staff in the hospital needed external counseling less frequently. The investigators also explained that the PICU team suffered during the death and dying of a patient most often when there was internal conflict with the treatment plan. The authors suggested debriefings and a family-like team environment would help ease the stress of bereavement.

Strengths by Russell and Alexander's (2005) work included a focus on family and staff who cared for critically ill and dying children, personal expertise of the authors, and relatively recent primary research references. Limitations included that this was not an original research study and the population of focus was in India.

Nurses and End of Life Care

Several studies explored nursing needs assessment in relation to care of dying patients, and death and dying interventions. In their original research study, Tse et al.

(2006), surveyed nurses and physicians at the Department of Medicine and Geriatrics, Caritas Medical Centre in Hong Kong (DMG) concerning their perspectives on caring and supporting family members of dying patients. Previous studies identified that families view quality end-of-life care through the emotional support given and that bereaved families feel that doctors and nurses could have provided more support; however, the health care professionals did not feel prepared to assist families of dying patients.

The method was a self-administered questionnaire developed by specialists in palliative care, clinical psychology, medical social work, nursing, and quality improvement. Questions were open-ended and focused on frequent family members' concerns and difficult family situations, as well as staff familiarity with death protocols, attitudes toward grief, and bereavement training needs. The questionnaire was piloted to three nurses and wording was adjusted accordingly. Open-ended questions were analyzed by a medical doctor and social worker who had worked with many dying patients. The quantitative results were found using the Pearson chi-squared test with a 0.05 level of significance and p-value <0.003.

Nurses reported that families frequently asked medical questions and some family members had unrealistic expectations of recovery in dying patients. Difficult family situations for staff included lack of family acceptance of death and family members becoming emotionally upset. Tse et al. (2006) found no correlation between a nurse's confidence in managing a family member's grief and a nurse's willingness to actively take a role in helping a family member manage grief. Most nurses felt comfortable with the actual death protocol, although that too was not correlated with willingness to actively

help a family member manage grief. The authors concluded that there was a need to increase training concerning bereavement care.

The strength of this study was the nursing perspective concerning families of dying patients. Weaknesses of this study included an adult patient population, a sample from a population in a single hospital in a Chinese culture, and lack of demographic data to determine if the results could be generalized to the rest of the nursing population.

In general, nurses felt they needed more education concerning end-of-life care. Rushton et al. (2009) addressed how the program Being With Dying (BWD) affected health care professionals care of dying patients as well as their self-care in an attempt to respond to perceived end-of-life care needs of nurses. BWD was a program designed to improve mindfulness and receptive attention to dying patients through stability of mind and contemplation. The BWD program focused on the soft side of care, the psychosocial, emotional, spiritual, and ethical side of end-of-life care. The research design utilized an online anonymous survey sent to a selection of previous BWD program participants with active e-mail addresses, and a voice-recorded telephone interview with pre-designed questions. The sample included 95 online survey participants, and 20 telephone interviewees. The population was limited to those who had attended the BWD workshop between the years 1996-2006. The variables measured in this study included demographics, the workshop's influence on individuals, skills learned, barriers to using skills, and the workshop's effect on personal or professional behaviors.

The survey was developed by the research team. No test-retest reliability was performed. Questions included in the quantitative portion of the survey were straightforward; the qualitative portion of the telephone interview was open-ended and

evaluated using a two level open coding model with the goal to clarify themes. Specific questions were not described. The authors found that attendees realized presence or ‘being there’ was an important part of the healing process. Physicians in particular found it reassuring and relaxing that they did not have to “fix” anything, but rather that they could simply be present. Presence included truly listening and personal internal balance. Respondents also found that they were more compassionate and better able to recognize grief in patients, families, coworkers and themselves. They realized how important it was to take care of themselves so that they could continue to provide compassionate care.

Strengths of the study included the workshop’s effect on end-of-life care and changed personal and professional behaviors leading to improved self-care which inevitably leads to improved patient care. This study was relevant to the current study as it demonstrated that education was an effective next step after identifying current level of comfort in approaching bereaved families. Limitations of this study included delayed recall as some of the participants in the research had attended the workshop years prior to the survey. Ethnicity was not assessed decreasing the ability to generalize to a specific ethnicity. A high percentage of women (nearly 75%) decreased the ability to generalize across genders. Participants agreeing to perform the survey may have had a more positive experience than those refusing to participate.

Nurses and Death Anxiety

Studies on nurses and end-of-life care also evaluated the concept of death anxiety and how it affects nurses and their care of dying patients. Payne, Dean, and Kalus (1998) compared the level of death anxiety in hospice nurses to that of emergency nurses. The design was a cross-sectional correlational study using the Death Attitude Profile-Revised

Questionnaire (DAP-R) and a researcher designed semi-structured interview. The populations studied were United Kingdom emergency nurses from a district general hospital and a local hospice. Both groups experienced an average of 150 deaths per year. Sixty nurses were contacted to participate in the study, and 20 emergency nurses and 23 hospice nurses did participate. Participant's ages ranged from 25-52, with the average ages for emergency and hospice nurses of 33 and 37 respectively. Emergency nurses had an average of four years experience, while the hospice nurses had an average of three years experience. Gender, religious, and ethnic data were not obtained.

The nurses' attitudes toward death were measured by the DAP-R, a 32-item scale that assesses five specific attitudes toward death (Wong, P. T. P., Reker, & Gesser, 1994). The five specific attitudes assessed were (1) fear of death, (2) death avoidance, (3) natural acceptance – understanding that death is a natural progression neither to be desired nor avoided, (4) approach acceptance – belief that death is the passage into an afterlife, and (5) escape acceptance – that death provides an escape from the pain and disappointment of this life. During the semi-structured interview the researchers asked six questions concerning (a) patient care that had gone well, (b) patient care that was difficult to handle, (c) taking thoughts of the patient home, (d) talking to someone at home, (e) talking to someone at work, and (f) feeling supported. Interviews were audio-taped and a content analysis was developed to analyze the interviews.

Payne et al. (1998) found that indeed the hospice nurses had a much lower death anxiety when compared to Emergency nurses. Emergency nurses scored significantly higher on death avoidance and fear of death subscales. Additionally, emergency nurses reported that they did not see death as a release. During the semi-structured interviews

the emergency nurses had a difficult time remembering dying patients whose care had gone well. Most of the emergency nurses who remembered care that had gone well remembered the interactions with family, while only two remembered the patient and that was because it was a recent case. On the other hand, 20 of the hospice nurses described how care had gone well for a specific patient and the relationship that had developed over time. When considering difficult to cope with patient deaths, the emergency nurses remembered those who reminded them of someone close to them, those to whom the event was particularly traumatic, or those for whom the end result was unknown due to the patient being placed in the ICU. The hospice nurses found difficult to manage symptoms, relatives, and occasionally the physical result of the illness caused difficult patient care. Most of the emergency nurses (90%) stated they thought about their difficult days at home, 85% had someone at home with whom to talk, and 80% felt as though they had someone at work with whom they were able to talk. Slightly fewer hospice nurses (83%) thought about difficult days at home, and fewer (78%) felt they had someone at home with whom to talk; however, every single one of the hospice nurses felt they had someone at work with whom to talk.

Limitations to the study include small sample size, cross-sectional design, lack of assessment of the nurses' internal reasons for choosing emergency versus hospice nursing, and self-report which evaluated perception of coping versus actual behaviors. Additionally, gender, ethnicity and religious aspects of death anxiety were not explored.

Death anxiety and comfort level with care for dying patients could affect quality of care and interactions with dying patients. Demmer (1998) surveyed nurses who worked in New York City at residential AIDs facilities, in order to evaluate the nurses'

death anxiety, the presence/use of coping resources, and the nurses' comfort in caring for dying patients. The design was a correlational study evaluating demographics, death anxiety, coping resources, and comfort level with dying individuals. The author defended the need for further research on death anxiety explaining that high death anxiety leads to less quality of care, apprehension in communication, and less comfort for dying patients.

The study population included 437 nurses and support staff in New York City who worked in an adult, AIDs residential facility. The sample obtained included 197 respondents from seven facilities. Demographics of the sample included an average age of 40 years, primarily female (87%), married (48%), African-American (52%), heterosexual (91%), holding a non-baccalaureate/associates nursing degree (55%), with the remaining levels of education evenly distributed in registered nurses, licensed practical nurses, and certified nursing assistants.

Measurements used in this study included the Death Anxiety Scale, and the Coping Resources Inventory – a 60-item scale that evaluates resources that help coping with stress which includes five subscales: the Cognitive Coping subscale that evaluates positive versus negative outlook on life, the Emotional Coping subscale which measure a person's identification and expression of emotion, the Social Coping subscale which evaluates presence and utilization of social networks, the Spiritual Coping subscale that evaluates a person's act of living within a clear set of philosophical values, and the Physical Coping subscale. Additionally, the author used the Comfort with Dying Patients Scale, a scale that evaluates nurses' comfort in working with patients with a poor life prognosis.

Demmer (1998) utilized a convenience sample of 28 to pilot the questionnaire. However, the results of this pilot group or a description of any changes to the questionnaire were absent from the article. The author also did not discuss the reliability or validity of the questionnaires.

The author found that married individuals had a higher mean anxiety than singles, African-American individuals reported fewer physical coping resources, and those with advanced degrees demonstrated the presence of more coping resources than those with lesser degrees. However, the authors did not find a significant correlation between death anxiety and coping resources, or comfort with dying patients.

Although the specific population of nurses caring for AIDs patients was not the population of study in the current research concerning pediatric nurses comfort level in approaching families of dying children, some of the reasons for particular stressors in working with AIDs patients included the death and dying of young patients. This study lent support that death anxiety and comfort level in working with dying patients need to be assessed separately and cannot necessarily be assumed by the assessment of just one of the variables.

Deffner and Bell (2005) assessed nurses' death anxiety and comfort level in communicating with patients and families about death. Deffner and Bell explained that the purpose of the study was to discover if a nurse's personal death anxiety and/or if education concerning emotionally charged communication correlated with comfort level in communicating with patients and families about death. In the review of literature, the authors found that nurses felt that death was uncomfortable and communication with patients and families difficult. When professionals were uncomfortable they avoided

communicating with patients and families which led to poorer outcomes. Additionally, nurses felt as though they should know how to handle death and dying despite their discomfort. The method was a correlational study using a survey. Items on the survey included the Templer (1970) Death Anxiety Scale (DAS) and one Likert-style question concerning comfort level in communicating about death, and demographics. The authors found an inverse correlation between death anxiety and the following: age, education, years of nursing experience, emotionally charged communication education, and current nursing employment. The authors suggested that the exposure of nurses to their own death anxiety level could increase awareness and sensitivity to dying patients and their families. The authors hypothesized that emotionally charged communication education would be related to lower death anxiety and increased comfort in speaking with dying patients and their families. Strengths of this study included a large sample size (n=190) and validity of the DAS. Weaknesses of the study included cross-sectional style, convenience sample, and no specific definition of emotionally charged communication education.

Bené and Foxall (1991) described how death anxiety has been linked to depression, burnout, and other somatic complaints among nurses. They speculated that job stress was an additional cause of increased death anxiety. However, job stress was also a variable of concern. Nurses in general had been found to have some of the highest levels of job stress. The authors explain that hospice nurses have been found to have lower levels of death anxiety, but findings have been inconclusive as to whether hospice nurses have more or less job stress than other nursing areas. As a result Bené and Foxall

compared hospice nurses to medical surgical nurses in the variables of death anxiety and job stress.

Populations of interest in Bené and Foxall's (1991) study included hospice and medical-surgical nurses; the study was not specified as to pediatric or adult nurses. The sample included 30 hospice nurse respondents and 40 medical-surgical nurse respondents. The respondents were primarily female, living with a significant other, and had either a BSN degree or nursing diploma. Hospice nurses were more likely to have received death education (90%), have more years of work experience, and hold positions other than staff nurse than the medical surgical nurses.

The measurements Bené and Foxall (1991) used were the Templer/McMordie Scale (TMS) which is the Death Anxiety Scale with a 7-point Likert scale, the Nursing Stress Scale (NSS) – a 44-item, 4-point Likert scale that measured stressors in eight different areas specific to nursing, as well as demographic information. Demographics included age, gender, marital status, income, nursing specialty, death education, nursing experience, and current job position.

Bené and Foxall (1991) demonstrated that hospice nurses report more job stress related to death and dying while medical surgical nurses reported more job stress related to staffing, patient aggression, communication on unit, and floating to other units. In the combined job stress severity scale, the authors found that medical surgical nurses scored significantly higher on emotional demands, patient aggression, death and dying, and floating to other units with a significant correlation between medical surgical nurses' job stress and death anxiety. On the other hand the findings showed no correlation between job stress or any of the subscales with personal death anxiety among hospice nurses. This

study represented a preliminary look into additional factors that may influence death anxiety. Causation could not be inferred, and the stressors and anxiety may have been coincidental. However, this research did consider job stress as a contributing factor to death anxiety.

Limitations to Bené and Foxall's (1991) study included a small sample size and the inability to determine causality of job stress and death anxiety due to the cross-sectional design. Other limitations to consider would be the overall evaluation of job stress in hospice nursing versus nursing in specific medical surgical units. There were some questions on the NSS that did not seem as strongly applicable to hospice nurses (e.g. floating to other units). Additionally, the authors did not evaluate or adjust for other factors related to level of death anxiety (e.g. age, years of nursing experience.)

Murphy (1986) explained in her literature review that avoidance of death and dying was a major coping mechanism in the health care profession which led to decreased and impersonal care. Murphy evaluated the effectiveness of a death awareness workshop in decreasing death anxiety among nurses. This study was a quasi-experimental design using a control group and an intervention group who attended a two-day death awareness workshop. Utilizing the Death Anxiety Scale, both the intervention group and the control group filled out the scale prior to the conference, immediately after the conference, and one month after the conference.

The population was composed of nurses from New Jersey. The sample included 150 registrants at the state's nurses association conference, and 150 nurses selected to match gender and nursing responsibility from ten area hospitals who did not attend the

conference. The intervention group consisted primarily of staff nurses and nurse educators.

Measurements used in this study included demographics, Templer's Death Anxiety Scale – 15 true/false questions, and the Crowne-Marlow Social Desirability Scale. The author administered the Crowne-Marlow Social Desirability Scale to the intervention group with their first post-test Death Anxiety Scale in order to discourage participants from changing their answers to be more socially acceptable.

The researcher found that the death awareness workshop had the desired effect of significantly decreasing the death anxiety of the participants immediately and one month after the workshop. Murphy (1986) found that the nurses between the ages of 31-40 and those who had worked as a nurse between 7-12 years had the most significant decreases in death anxiety. No correlation was found between death anxiety and other demographics (marital status, nursing education, loss of significant other, religious preference, or nursing area of responsibility). The control group showed no significant change in death anxiety.

The study was a carefully prepared, quasi-experiment with a large sample (n=101) and appropriate measures to maintain quality of data. The author stated that she was unable to determine if death anxiety was affected more by life experience or by nursing experience as there was no clear differentiation. Additionally, those who chose to go to the state conference with a death awareness workshop may have been more concerned about death anxiety and more sensitive to addressing their own death anxiety. This study emphasized the importance of death anxiety awareness education with the goal of

decreasing death anxiety in order to counteract the negative effects of death anxiety in the health care profession.

Attitudes Toward Death and Dying and Appropriate Care

In addition to death anxiety, a nurse's attitude toward death and dying could also affect care of the dying patient and interactions with the family. Brockopp, King, and Hamilton (1991) correlated nurses' interaction with dying patients with death anxiety, fear of death and dying, and a sense of personal control. The authors hypothesized that the hospice nurses who chose to work with dying patients would have positive attitudes toward dying, less death anxiety, and a greater personal sense of control than nurses who chose to work with patients whose goal was to get well.

The design of this descriptive study included a population of interest, nurses in palliative care, and two contrasting, comparison, nursing populations, orthopedics and psychiatric. The convenience sample, recruited from six Canadian acute care hospitals, included 32 palliative nurses, 44 psychiatric nurses, and 29 orthopedic nurses. The orthopedic and psychiatric nurses experienced an average of five deaths per year.

Attitudes toward death and dying were assessed using the tool 'Understanding the Dying Person and His Family' (Winget, Yeaworth, & Kapp, 1978). The Fear of Death and Dying questionnaire assessed the fear of death and dying, and the Sphere of Control Scale assessed the nurses' sense of personal control. The self-report surveys were distributed manually and collected by drop box or through the mail.

The researchers found that palliative care nurses had better attitudes toward death and dying, as well as lower death anxiety. However, no difference was found between

palliative care nurses and non-palliative care nurses concerning sense of personal control or fear of the death and dying of others.

Limitations of this study included a non-random sample, self-report questionnaires, cross-sectional style, as well as a lack of demographic data, and reasons for going into a particular field of nursing. Additionally, the authors recognized from the beginning that nurses' attitudes toward death may have influenced their choice to go into palliative care versus the field of palliative care affecting nurses' attitudes toward death.

Brockopp et al. (1991) laid a foundation of baseline assessments of nurses' attitudes toward death and dying, death anxiety, and the effect of their personal sense of control on death anxiety. This study was valuable in developing the premise that personal death anxiety affects the care of dying patients and strengthened the need for further research of death anxiety in other populations of nursing.

Braun, Gordon, and Usiely (2010) hypothesized that a nurse's personal attitude toward death would affect how the nurse cared for dying patients. The authors surveyed 147 Israeli oncology nurses at an oncology nurse conference. The majority of the sample was Jewish, married, full-time, oncology staff nurses with academic degrees. Over 50% described themselves as secular. Half of those surveyed had taken a specific course in death and dying. All the nurses surveyed had been exposed to death and dying in their work. Forty-four percent reported being exposed to six or more deaths per month.

The Frommett Attitude Toward Care of Dying Patients (FATCOD), a 30-item scale was used to measure nurses' attitudes toward providing care for dying patients and their families. The DAP-R (Wong, P. T. P. et al., 1994) was used to assess nurses attitudes toward death. Additionally, the demographics of age, gender, education,

religiosity, professional experience, and exposure to dying patients were obtained to clarify confounding variables.

Braun et al. (2010) found that religious nurses had higher approach acceptance. They also found that older nurses and nurses who cared for a greater number of dying patients (>6 deaths per month) had lower death avoidance scores. Nurses with higher levels of fear of death, death avoidance and approach acceptance demonstrated less positive attitudes in caring for dying patients. The correlation between the variables of fear of death and death avoidance and the variable of a caring attitude toward dying patients was reflected in previous research. However, the variable of approach acceptance was previously shown to correlate with a more positive attitude. The authors postulated that the difference in this research finding might be related to the Jewish versus the Christian culture. The authors explained that the DAP-R scale was written and researched in a Christian culture where the afterlife is viewed as a positive place, whereas Jewish culture focused on the here and now with limited regard to the afterlife.

The authors found that personal attitudes toward death only explained about 22% of the variances in the sample. Limitations in the study included the cross-sectional design, low response rate despite being the highest response rate in the current literature, possible skewed sample, and the use of a scale in a primarily Jewish culture that was designed for a Christian culture.

Braun et al. (2010) stressed that training and support education should address attitudes toward death and dying to improve self-awareness concerning fear of death and caring for dying patients. This research strengthened the concept of assessing death anxiety as a tool to determine comfort level in working with dying patients and their

families. It demonstrated that fear of death was associated with less positive attitudes in caring for dying patients.

Valente and Saunders (2010) surveyed psychiatric nurses about their perceptions concerning providing end-of-life care. The purpose of the study was to discover what kind of expertise the nurses had in end-of-life care, if they were interested in end-of-life care, and what type of education the nurses felt they needed to provide better end-of-life care.

The study was a descriptive, cross-sectional design utilizing the Psychiatric Nurses' Role in End-of-Life Care (PNREOL) survey that was designed by the researchers. The researchers had the PNREOL reviewed by a panel of psychiatric and end-of-life care judges for content validity. They also had a group of nursing students and a group of psychiatric nurses test-retest to verify reliability of ($r=0.90$); Cronbach alpha ($\alpha=0.85$). The sample was a convenience sample ($n=190$) of attendees at the American Psychiatric Nurses Association 2006 annual conference. Variables measured included demographics, current and potential end-of life interest, skills, knowledge, as well as ways of improving personal knowledge, and knowledge of others concerning end-of-life care. Variables were measured either by self-report or by a 4-point Likert scale (little, some, moderate, very/excellent).

Valente and Saunders (2010) found that psychiatric nurses' skills concerning end-of-life care included therapeutic communication, expertise concerning and ability to handle mental health struggles (anxiety, depression, and suicidal ideation), screening assessments of mood disorders and mental health, and grief work. However, the nurses also identified that they had limited exposure/experience in working with dying patients

and felt that they needed more education on the following topics in end-of-life care: communication, legal and cultural issues, patient education, death and dying, mental status, pain management, palliative care, and grief. The nurses also expressed the need to have end of life assessment tools and knowledge of appropriate end-of-life care interventions.

A limitation of this study was the single field of nursing represented. Students and male nurses were underrepresented in the results. Another limitation was the non-random sample and the inability of participants to express that they had no interest in end-of-life care (had to answer little, some, moderate, very/excellent.) The nurses were surveyed on what they could potentially bring to end-of-life care, not what they have brought to the end-of-life care of patients.

Even with the expert knowledge of major components in end-of-life care (therapeutic communication, assessment of mood disorders/mental illness, and grief work) nurses still felt limited in the skills needed for end-of-life care as well as the need for continuing education in treatments and interventions for the dying patient. Further research is needed to directly evaluate perceptions of nurses who actually work with dying patients.

Death Anxiety Studies

Lehto and Stein (2009) performed a systematic review of the concept of death anxiety using Rodgers (2000) concept analysis method in order to provide a theoretical definition of death anxiety. The process of concept analysis was formulated into five steps: 1. Identify concepts and related terms, 2. Determine setting and sample, 3. Collect data, 4. Analyze data, 5. Develop implications/hypotheses for future development. The

authors reviewed eight foundational books concerning death anxiety and 89 health science/nursing journal articles published after 1980 in English. The variables assessed were attributes of death anxiety, factors associated with death anxiety, measurement of death anxiety, and consequences of death anxiety.

Lehto and Stein (2009) described six attributes of death anxiety: emotion, cognition, experiential, developmental, sociocultural, and motivation. The emotional attribute of death anxiety was found to be the original unconscious expression of hardwired fear of non-existence which eventually developed into a conscious fear of non-existence. Cognitively death was in opposition to our core structures (e.g. our bodies heal and function to survive.) Religious beliefs of positive existence after death were a buffer to death anxiety because belief in an afterlife was a way of still existing and was in line with core structures. However, the level of religiosity buffering death anxiety was dependent on age, gender and devoutness. Death anxiety began as an unconscious experience because the presence of death anxiety was denied and avoided. A culturally derived death anxiety buffer was self-esteem. Self-esteem was found to be developed through a sense of belonging to a society. The sense of belonging then created a buffer to death anxiety. Developmental stage also affected the level of death anxiety experienced. Death anxiety was heightened in the identity crisis period of Erickson's stages of development crises. Those who experienced neglect and separation anxiety – mistrust vs. trust – may have had increased death anxiety. As a person progressed developmentally into a middle aged person who was satisfied and had meaning and purpose, death anxiety decreased, and eventually stabilized in old age. Death anxiety in the young was often practical death anxiety (who will care for my family) whereas death anxiety in the elderly

was related to physical and psychological problems. Our society and culture also shaped death anxiety by its acceptance or avoidance of elderly or ill people. In Western cultures the elderly and ill were hidden which could have led to increased death anxiety as death became an uncommon phenomenon because it was not publicly experienced. Denial of death was the prevalent death attitude in the United States. However, cross-cultural studies found that females still had higher death anxiety. Death anxiety could also be considered a source of motivation. Think of Charles Dickens' character Ebenezer Scrooge and how his death anxiety motivated him to be a better neighbor. Death was the ultimate motivator, to conquer and overcome, fulfilling the underlying desire to be immortal. We became motivated to survive; as a result we adhered to group norms, striving to align with others.

The scales used to measure death anxiety included the Death Anxiety Scale, the Collett-Lester Fear of Death Self Scale –which measures the fear of death at a conscious level, Spika's death perspective scale, the Death Anxiety Questionnaire – designed for populations facing life threatening illness, the Multidimensional Fear of Death Scale, Implicit Association Test – death valence, death anxiety, and denial, and the Children's Apperception Test. As a clarifier Lehto and Stein (2009) explained that fear of death and death anxiety are both emotionally and physiologically different, and were processed in different areas of the brain.

Antecedents to death anxiety included awareness of death salience – the knowledge of death's inevitability, stressful environment (e.g. war, divorce transitions), diagnosis of a life threatening illness (e.g. new onset, symptomatic), and experiencing others' death and dying. However, persons with good interpersonal interactions and who

had a terminal diagnosis had lower death anxiety scores. Experiences with death and dying only increased death anxiety when there was grief related to the bereavement. In nursing Lehto and Stein (2009) found that more experienced nurses often had a higher death anxiety and that critical care nurses had a higher death anxiety than hospice nurses. An interesting finding in palliative care education of volunteers demonstrated that the education did not lower death anxiety but caused the volunteers to feel more prepared for a death situation.

Lehto and Stein (2009) found that cultural consequences of death anxiety in the United States led to consumerism. The theory of consumerism as a consequence of higher death anxiety was the concept of whoever has the most toys when he dies wins. Additionally, Lehto and Stein found that a cultural buffer against death anxiety came from feeling a part of a society. The reasoning behind this finding was the thought of belonging and the ability to leave a legacy. The authors found that death anxiety could increase commitment in a romantic relationship for females or a withdrawal of emotion in males. Death anxiety was found to motivate new learning, growth, acceptance, meaning in life, and pursuit of authentic existence.

Research Questions

This study seeks to answer the following research questions. What factors (demographics, pediatric nursing experience, frequency of interacting with families of dying children, bereavement and emotionally charged communication education, death anxiety, and/or choosing to interact with families) affect the comfort level of pediatric nurses in approaching families and their choice to interact with families of dying children? Is bereavement education related to comfort level?

Definition of Terms

Variable Definitions:

1. Nurses – Registered Nurses and Licensed Practical Nurses who participate in patient care and family interactions.
2. Families – Persons that have a close relationship with a patient (legal, emotional, or physical).
3. Patients – Persons experiencing a loss, spending time within a hospital setting who have interactions with nursing staff.
4. Approach/Intervention for dying Patients and the Families – communication of intent to support, assist, or provide resources to families and or patients in regards to a loss
5. Barriers/Conflicts approaching families of dying children – An internal struggle of emotions that inhibit staff from therapeutically approaching and engaging bereaved patients or families in order to provide compassionate care.
6. Families feel “cared for” – when a family of a deceased patient senses support by words, actions or resources from staff.
7. The grieving process – procession through the 5 stages of grief (denial, anger, bargaining, depression, acceptance) (Godin, 2000) and/or accepting resources for effective management methods for chronic sorrow (Eakes, Burke, & Hainsworth, 1998)
8. Staff comfort level in approaching families of dying children – confidence in initiating bereavement care and addressing patient and family grief (Tse et al., 2006)

9. Death Anxiety – Unconscious and generalized fear related to death (Braun et al., 2010)
10. Grief – the mainly emotional reaction to bereavement, incorporating diverse psychological and physical reactions (Stroebe, Schut, & Stroebe, 2007)
11. Bereavement – the situation of having recently lost a significant person through death (Stroebe et al., 2007)
12. Complicated grief – deviation from the normal (in cultural and societal terms) grief experience in either time course, intensity, or both, entailing a chronic and more intense emotional experience or an inhibited response, which either lacks the usual symptoms or in which onset of symptoms is delayed or interferes with tasks of recognizing reality, emotionally reacting to the separation, and experiencing the full range of emotions associated with grief (Stroebe et al., 2007).

CHAPTER 3

METHODS

Design

This early feasibility study used a quantitative descriptive design. Data were obtained through a survey that assessed pediatric nurses' demographics, level of nursing education, nursing specialty, bereavement education and education concerning emotionally charged communication, personal death anxiety, frequency and comfort level of approaching families of dying children as well as their choice to interact with those families.

The participating hospital's e-mail system was used as the recruitment method. A third party hospital employee deployed an approved e-mail query (Appendix C) that explained the purpose of the survey, the participant's role, and provided information on informed consent and an external link to the survey (Appendix D). The survey was distributed to all inpatient pediatric nurses. The questionnaire was available online through Survey Monkey. In addition, reminder research flyers (Appendix E) were provided to each pediatric unit to encourage staff to complete the survey; however, only the pediatric Emergency department received a paper copy of the flyer. The survey was available for 8 weeks. Follow up reminder e-mails (Appendix F) were sent at three and six weeks from the start of the survey. Based on the design of this study once a

participant submitted the survey there was no ability to withdraw the response from the study.

Sample and Setting

The target population was pediatric nurses who worked within a children's hospital system and had the potential to interact with families of children who were dying or had died. Additionally, the researcher requested information concerning the number and causes of pediatric deaths stratified by each nursing specialty unit (Appendix G) in order to demonstrate the suitability of the chosen convenience sample. Inclusion criteria of participants included employment within a pediatric hospital setting on a pediatric unit, licensed as a registered nurse, and the capability to respond in English to a questionnaire written in English. Exclusion criteria included persons less than 18 years old and adults unable to provide consent. Other vulnerable populations were not identified in this survey and therefore might not have been excluded.

The sampling method was a non-probability, stratified, convenience sample. The convenience sample was nurses from within a regional children's hospital that was stratified into nursing specialties based on self-report (e.g. critical care, emergency, medical surgical, neonatal, etc.)

Instruments

The instruments used in the current research study were a demographic tool, the Death Anxiety Scale (DAS) (Templer, 1970), and bereavement related questions (Appendix D). Permission to use the DAS was obtained (Appendix H). Pediatric nurses were asked the following demographic questions: age, gender, ethnicity, religious

association, level of nursing education, years of pediatric experience, and years of total nursing experience.

Deffner and Bell (2005) used the Death Anxiety Scale (DAS) and an additional question about nurses' comfort level in communication with bereaved families to determine if results from the DAS had a relationship with comfort level of communication. The results of the study showed a positive correlation between the four positive questions, and a negative correlation between seven of the negative questions. The final four negative questions did not correlate with comfort level in communicating with bereaved families.

The Death Anxiety Scale was comprised of 15 true/false questions. There were four positive questions (e.g. I am very much afraid to die) and eleven negative questions (e.g. I am not at all afraid to die). Positive questions answered with a "true" response scored a point and negative questions answered with a "false" response scored a point. Vice versa responses were given zero points. Scores range from 0-15 points. The higher the score the more anxious the participant was about death.

Validity for the DAS was initially addressed in the original article presenting the instrument. Templer (1970) spelled out each step to determine validity and reliability through (1) the rationale for selection of the items and evaluation of seven judges to determine face validity, (2) item analyses to remove non-discriminating questions, developing internal consistency, (3) test-retest reliability with "a coefficient of 0.76 (Kuder-Richardson Formula 20)" (p. 168), and (4) using heterogeneous samples to determine reliability across sample groups. Since the development of the DAS in 1970, Templer et al. (2006) explained that the scale has been "translated into a number of

different languages, including Afrikaans, Arabic, Chinese, Dutch, Farsi, French, German, Hindi, Hmong, Italian, Japanese, Korean, Portuguese, Russian, Spanish and Swedish” (p. 210). The benefit of using the DAS in this study is to further strengthen the correlation of death anxiety and comfort in approaching bereaved families (building on previous studies) and provide a stepping stone to appropriate education to increase nurses’ comfort in approaching families of dying children.

In addition to the questions in the DAS this research study included bereavement questions concerning comfort level in approaching bereaved families: choosing to interact with families of dying children, previous bereavement training, education on emotionally charged communication, and frequency of approaching families of dying children. Face validity, criterion validity, and construct validity of the additional bereavement questions were established by expert review.

Independent/Dependent Variables

The independent variables included age, gender, ethnicity, religious association, level of nursing education, nursing specialty, years of nursing experience, bereavement education, emotionally charged communication education, frequency of interaction, and DAS score. The dependent variables were DAS mean score, comfort level in approaching and choice to interact with families of dying children.

Procedure

Approval of the research was sought and granted by both the Grand Valley State University’s Human Research and Review Committee (HRRC) (Appendix I) and from the internal review board (IRB) of the participating hospital. Part of obtaining approval from the participating hospital’s IRB included finding support within the clinical

bereavement structure of the hospital. Support for the research was provided by the hospital's bereavement coordinator, bereavement committee, and the manager of Pastoral Care Bereavement Services.

After IRB approval was obtained and internal leadership support was given, the first step of recruitment was to provide the survey to the participants. The e-mail query (Appendix C) was provided to a third party within the hospital system who deployed the initial e-mail and two follow up e-mails (Appendix F) at week three and six. As the survey was short and the nursing profession as a whole was concerned about promoting the nursing knowledge base, no monetary compensation was provided. The risks to participants and methods to reduce those risks can be viewed in Appendix J.

CHAPTER 4

RESULTS AND DATA ANALYSIS

The plan of this study was to evaluate whether pediatric nurses' comfort level in approaching families of dying children was related to personal demographics, bereavement education, emotionally charged communication education, or personal death anxiety. Demographics included in this study were age, gender, ethnicity, religion, level of nursing education, nursing specialty, and nursing experience. Experience questions assessed years of total nursing experience and years of pediatric nursing experience as well as nursing specialty. Education questions focused on highest level of nursing education received, and hours of bereavement and emotionally charged communication education. This study was designed to provide a baseline assessment of pediatric nurses' comfort level in approaching bereaved families to evaluate for factors that would influence bereavement care and serve as a foundation for evaluation of future bereavement education interventions.

The population chosen was a convenience population of English-speaking pediatric registered nurses at a metropolitan children's hospital. Four hundred and twenty-five participants were sent a query through the hospital system's work e-mail with an explanation of the study and a link to an anonymous online survey. Participants were

given the opportunity to respond to any and/or all of the survey questions with the option to provide personal comments.

Data collection began at the end of June, 2011, and completed the first week of August, 2011. Results from the survey were obtained from the online survey service, SurveyMonkey. There were a total of 180 (42%) returned surveys. Eight subjects were removed because they answered no further questions of the survey after the participation agreement. An additional seven participants were removed as they did not answer one or more questions of the DAS, leaving a total of 165 participants or 39% of the population. The DAS was scored and entered into the PASW raw data file by the primary investigator. The quantitative data frequencies, correlations, and descriptives were performed with the statistical software PASW 17. Correlations of comfort level in approaching families of dying children were evaluated using the bivariate statistic Spearman's Rho. The mean DAS scores within variables were compared using a one-way ANOVA with the DAS calculated score. The qualitative answers provided by willing participants were analyzed for themes, coded and grouped by the primary investigator.

Quantitative Findings

Demographics

As all questions in the survey were optional not all participants in the final analysis answered all demographic questions. However, the missing answers had no apparent bearing on the final analysis.

Gender. The gender of the sample was predominantly female. With only five responders there was, male there were insufficient raw data to analyze the relationship between gender and DAS scores.

Age. Age was answered in ordinal generational groups (e.g. 18-24, 25-34) ranges were grouped based on an assumed generation of ten years. As the protocol required participants to be over 18, the youngest age category was shortened to 18 to 24 years. The final category included 65+ years, however, no participants were in this age range. After the initial frequencies were completed, the age category of 18 to 24 years had few participants (n=3) and therefore was combined with the next age category of 25 to 34 years. All other age categories had sufficient response. See Table 1.

Table 1

Demographic: Age

Age	n	%
18-34	90	54.5
35-44	33	20.0
45-54	27	16.4
55-64	11	6.7
Did not respond	4	2.4
Total	165	100.0

Ethnicity. Eight categories of ethnicity were provided on the survey. Most of the participants were Caucasian non-Hispanic (96%). Each of the following categories contained a single response: Asian, Hispanic, Multiracial and Other. Since there was minimal diversity among the subjects, only descriptive frequencies were performed.

Religion. Participants were asked to place themselves into their religious affiliation. Options and percentages included Agnostic (3%), Atheist (1%), Buddhist

(0%), Catholic (19%), Hindu (0%), Muslim (0%), Protestant (53%), and Other (17%) with the ability to clarify what was meant by other. Those who clarified their religious association as Lutheran, Christian Reformed, Christian, and Baptist were categorized under Protestant, those who clarified their religious association as “none” or “searching” were placed under the agnostic category, and those who did not clarify what other meant remained in the other category. Because the purpose of the question was to assess the effect of religion on death anxiety and comfort level, religious categories were combined to either religious association or non-religious association. In the religious associated categories Catholic and Protestant were combined. The non-religious category contained the agnostic and atheist participants.

Experience and Education

Level of nursing education. All participants were asked to identify the highest level of education. Options included nursing focused achievements (i.e. Diploma, ADN, BSN, MSN, and doctoral). The majority of nurses (~70%) held a Bachelor of Science in Nursing. Associate degree nurses made up 20% of the respondents. Nine percent of respondents held a diploma, and less than 2% of respondents held masters degrees.

Nursing specialty. Nurses were asked to identify their nursing specialty. Options to choose from included critical care, emergency, neonatal, medical/surgical, hematology/oncology, surgery, and other. The surgical specialty had a small response (n=7) and was combined with the medical/surgical specialty. Additional unlisted specialties included cardiology, gastrointestinal, and nephrology. These specialties comprise the other category. See Table 2.

Table 2

Experience: Nursing Specialty

Nursing Specialty	n	%
Neonatal	48	29.1
Medical/Surgical	43	26.0
Critical Care	33	20.0
Emergency	24	14.5
Hematology/oncology	13	7.9
Other	4	2.4
Total	163	99.9

Years of nursing experience. Participants were asked their years of nursing experience and to differentiate between years of pediatric nursing experience and total nursing experience. Unfortunately, the placement of the question concerning total nursing experience was directly after the question concerning years of pediatric experience. As a result, many participants did not respond to this question (58% responded), or responded in a way that reflected that the question concerning total years of nursing experience was confusing. Therefore, only the years of pediatric experience were used in the final analysis. See Table 3

Table 3

Experience: Pediatric Nursing Experience

Years of Pediatric Nursing Experience	N	%
0-1	16	9.7
2-3	22	13.3
4-5	29	17.6
6-8	23	13.9
9-11	16	9.7
12-19	17	10.3
20+	31	18.8
Did not respond	11	6.4
Total	165	99.7

Bereavement and emotionally charged communication education. The question was posed to determine how many hours of bereavement education and how many hours of emotionally charged communication education the nurse had received. This was done in order to assess whether a specific form of emotionally charged communication education was more significant than the other. The majority of nurses (57%) had four hours or less of bereavement education. Almost half (47%) had four hours or less of emotionally charged communication education. More nurses had received emotionally charged communication education than bereavement education. Fewer

nurses had more than 20+ hours of bereavement (7.3%) or emotionally charged communication education (9.1%). See Table 4.

Table 4

Education: Bereavement and Emotionally Charged Communication

Hours of Education	Bereavement Education		Emotionally charged communication education	
	N	%	n	%
0-4	94	57.0	79	47.9
5-9	31	18.8	39	23.6
10-19	18	10.9	22	13.3
20+	12	7.3	15	9.1
Did not Respond	10	6.0	10	6.0
Total	165	100	165	99.9

Comfort level in approaching families of dying children. Congruent with the purpose of the study, nurses' comfort level was evaluated to determine if a relationship between demographics, experience, education, personal death anxiety, or choice to interact with families of dying children existed. Spearman Rho (r_s) correlation analysis was used to determine a relationship.

There were weak ($p < .05$) positive correlations found between comfort level and years of pediatric experience ($r_s = .170$) and hours of emotionally charged communication education ($r_s = .170$). Stronger ($p < .01$) positive correlations were found between comfort level and frequency of interactions ($r_s = .362$), hours of bereavement education ($r_s = .210$),

and choice to interact with families of dying children ($r_s=.480$). There was a negative correlation between comfort level and DAS ($r_s=-.147$); however, this did not reach a level of significance. See Table 5.

Table 5

Comfort Level Correlation Matrix

	Comfort	PedsExp	Frequent	BrvtEd	CommEd	DAS	Interact	Age
Comfort	1.000
	165	-	-	-	-	-	-	-
PedsExp	.170*	1.000
	.031	.	-	-	-	-	-	-
	161	161
Frequent	.362^	.294^	1.000
	.000	.000	.	-	-	-	-	-
	165	161	165
BrvtEd	.210^	.293^	.246^	1.000
	.007	.000	.002	.	-	-	-	-
	165	160	164	164
CommEd	.170*	.308^	.130	.431^	1.000	.	.	.
	.031	.000	.098	.000	.	-	-	-
	163	159	163	162	163	.	.	.
DAS	-.147	-.039	.083	.037	-.004	1.000	.	.
	.060	.627	.290	.635	.957	.	-	-
	165	161	165	164	163	165	.	.
Interact	.480^	.236^	.451^	.215^	.181*	.043	1.000	.
	.000	.003	.000	.006	.021	.585	.	-
	165	161	165	164	163	165	165	.
Age	.074	.389^	.152	-.002	.071	-.090	.164*	1.000
	.346	.000	.052	.983	.369	.253	.035	.
	164	161	164	163	162	164	164	164

Note.

^ Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed).

Comfort = Comfort level in approaching families of dying children

PedsExp = Pediatric nursing experience

Frequent = Frequency in approaching families of dying children

BrvtEd = Bereavement education

CommEd = Emotionally charged communication education

DAS = Death Anxiety Scale mean score

Interact = Choice to interact with families of dying children

Correlations between comfort level and gender, ethnicity, and religion were not performed due to a lack of variation in the sample. Additionally, the total years of nursing experience variable was eliminated due to low content validity in that only 58% of the participants answered the question, and that several of the nurses answered the question in a way that implied that the question was confusing.

Choosing to interact with families of dying children. As stated earlier, there was no predicted relationship for choosing to interact with families as it was an exploratory construct. Four percent of nurses would avoid interacting with families of dying children, 49% of the sample would choose to interact with families of dying children, and 47% were neutral. A Spearman Rho (r_s) correlation analysis was used and found a significant positive relationship ($p < .01$) between choosing to interact with families and the following: age ($r_s = .276$), pediatric nursing experience ($r_s = .236$), bereavement education ($r_s = .215$), emotionally charged communication education ($r_s = .581$), and frequency of approaching families of dying children ($r_s = .451$). There was no significant correlation between choice to interact with families and DAS score.

Death Anxiety Scale comparison of means. In order to further evaluate the differences of death anxiety within variables a one-way within subjects ANOVA was performed comparing DAS scores and the following variables: selected demographics, comfort level, and choice to interact with families of dying children.

Differences in DAS mean scores were compared by the five Likert-type scale of comfort level conditions. However, there was no significant difference of DAS score in the five comfort level conditions [$F(5, 160) = 1.688, p = .155$].

The DAS mean scores were compared by the following four age groups: 18-34, 34-44, 45-54, and 55-64. A significant difference in DAS scores ($p < .05$) was found by age [$F(4, 159) = 3.98, p = .04$]. The only significant difference found was in the 55-64 age group. Post hoc comparisons using a Scheffe test indicated that the mean score for the 55-64 age group ($M=3.09, SD=1.758$) was significantly lower than the 18-34 ($M=5.88, SD=2.435$), 34-44 ($M=6.27, SD=2.516$), and 45-54 ($M=5.78, SD=2.242$) groups. These results suggested that DAS levels may be influenced by the age of the participant. It is interesting to note that the 35-44 age group had the highest DAS mean scores ($M=6.27, SD=2.516$).

The DAS mean scores of nurses were compared by five specialties: critical care, medical/surgical, emergency, hematology/oncology, neonatal. There was a significant difference in DAS score ($p < .05$) among nursing specialties [$F(5, 159) = 2.451, p = .036$]. When comparing the mean DAS scores of nurses within the pediatric specialties using the least significant difference (LSD) nurses in the critical care and medical/surgical specialties were found to have significantly higher scores than nurses in the emergency and hematology/oncology specialties. See Table 6.

Table 6

Nursing Specialty DAS Score Means

Specialties	DAS Score (M)	SD
Hematology/Oncology	7.00	2.309
Emergency	6.71	2.458
Neonatal	5.73	2.410
Medical/Surgical	5.47	2.576
Critical Care	5.18	2.038

These results implied that critical care nurses and medical/surgical nurses tended to have lower death anxiety than nurses in either the emergency or hematology/oncology specialty. The results did not suggest that neonatal nurses' death anxiety mean scores were significantly different than any other pediatric nursing specialty.

The DAS mean scores were compared between nurses in the following six pediatric nursing experience groups: 0-5 years, 6-8 years, 9-11 years, 12-19 years, and 20+ years. There was no significant difference of DAS score in the six pediatric nursing experience groups [$F(5, 155) = 1.624, p = .157$]. Although the DAS mean scores were not significantly different by experience, it is of note that the mean DAS scores in the other experience groups were higher than those with 20+ years of experience. These results suggested that nurses with the greatest amount of experience tended to have lower death anxiety than nurses of lesser years of experience.

No significant difference of DAS score means was found within the variables of religion, frequency of approaching families of dying children, or level of nursing

education. One-way ANOVAs were not performed on the variables of gender and ethnicity due to lack of diversity in the sample and the total nursing experience variable was not calculated due to poor response.

Qualitative Findings

Finally, several questions provided a space for qualitative comments from participants concerning frequency of exposure to families of dying children, comfort level in interacting with those families, and personal choice of whether or not to interact with those families. Themes that emerged from these comments included a) increased frequency of exposure to families and dying children would increase comfort level in approaching families, b) certain experiences – both personal and professional – helped increase comfort level, c) a strong desire to help and support families, d) difficulty in knowing what to say, and e) relationships with the family influenced additional interactions. Additionally, two nurses felt that the death of the child might be perceived by the family as the health care professional's fault.

Several nurses mentioned that for them caring for dying children was not a frequent occurrence. One nurse mentioned that she felt her comfort level would increase if she were exposed to more families of dying children. Another nurse mentioned that although she does not want to become desensitized to the situation her comfort level increases with each dying child for which she provides care. Another explained that she did not have much experience with families of dying children; however, she did have experience with adult hematology/oncology patient deaths which she felt prepared her for working with pediatric deaths even though she admitted that the two situations were very different.

In addition to frequency of exposure several nurses described a single personal or professional experience that influenced their choice to interact with families and their comfort level in approaching families. For example, one nurse mentioned that she has cared for only one dying patient and that through her care she was able to help the patient have a peaceful death and support the parents. She felt she was able to help and that she would respond the same way in similar situations. Several nurses explained how the personal loss of siblings, family members, or close friends who were adolescents has influenced their care of families with dying children. Another nurse mentioned that although the death of one of her friends to cancer was a beautiful experience, another was horrific. She felt that, “with experience, one learns that difficult discussions can lead to a better outcome.”

Another theme that surfaced through the comments was that there is a strong desire to help and support the family. Nurses made comments such as, “I hope I am supportive,” “I do whatever I can,” and, “it is important to support the emotional side of death.” Additional suggestions of support included listening to the family, following the family’s lead, giving the family time to themselves, and being present. One nurse explained that, “Being able to support (by listening, presence) can make a profound difference.”

Many nurses felt that they had trouble knowing what to say. With statements such as, “The challenge lies in what to say, and what not to say,” and, “I do not feel well-trained in what to say,” and “I fear that I will say the wrong thing...and make it worse”, nurses expressed their discomfort in approaching and interacting with families of dying

children. One nurse summed up the difficulty by saying that it was important to know that, “There are no words that can change the situation.”

Lesser themes that were represented were the importance of a relationship with the family and a feeling of responsibility for the death. For example, one nurse explained that she did not choose to approach families of dying children for which she had not cared. Another explained that caring for families and dying children can be “fulfilling and satisfying,” if you, “get to know them [the family].” Two nurses mentioned that they felt the family might perceive that it was the hospital’s fault that the child died, which made them both uncomfortable in talking and approaching the families after the child had died. Both nurses mentioned that they knew it was not the hospital’s fault and that the care had been performed just as it should; however, they felt the family may not see it that way.

Other statements were related to death anxiety. One nurse explained that she was comfortable discussing death and dying, but was uncomfortable with the actual death. One mentioned that she only feared death because she did not want to leave her family behind. Another explained that she would have answered the DAS differently if it had been asked about her children. One nurse explained how he personally struggled with the unexpected death of a patient. Finally, one nurse explained that bereavement education only helps with coping, and not with one’s comfort level with the family.

Chapter 5

DISCUSSION AND IMPLICATIONS

Demographics

Gender

The sample's gender distribution is reflective of the nursing population in general. According to the most recent U. S. Department of Health and Human Services nursing report of 2004 (USHHS: HRSA, 2006) almost 6% of the nursing population were male. The males were approximately 3% of the respondents in this study. According to Lehto and Stein (2009) females, cross-culturally, had higher death anxiety. As a result of low male response, and previous studies showing gender differences in death anxiety, this study cannot be generalized to male nurses.

Ethnicity

According to ethnicity percentages reported by the U.S. Census Bureau (2010) for the city and county of the population the sample loosely reflected an expected nursing population, with the exception of African Americans (0%) and Hispanics (0.6%). Where the sample contained 96% Caucasian, the city and county had 64% and 80% respectively. Similarly for the Asian ethnicity, the sample had 0.6%, the city 2% and the county 1%. Although ethnic and racial minority nurses composed 12.2% of the nursing population, the distribution of minority nurses was lower than the general population distribution of

those ethnicities (USHHS: HRSA; 2006). This would make sense as to why a sample of nurses would have a smaller representation of minorities than the general population.

Religion

Religious association was deemed to be an important demographic question because what a person believes about the after-life could affect the level of death anxiety. This sample demonstrated a higher percentage (70%) of religious individuals than the general county population of 52% religious association (City-data.com, 2010). It was assumed that those who believed in an after-life would have a religious association and would have a lower death anxiety based on Braun et al.'s (2010) study. However, the question in the survey was not clear as to a belief in the afterlife or devoutness.

Experience and Education

Level of nursing education. This variable was an exploratory question to assess if the level of nursing education was correlated with comfort level in approaching bereaved families. Logically, it would follow that the more opportunity for education the more likely the topic of death and dying would be addressed at a greater depth. However, the level of education had no bearing on personal death anxiety or comfort level in approaching families of dying children.

Nursing specialty. Depending on their specialty nurses may have different experiences related to death and dying. A neonatal nurse may experience more patient deaths in a year compared to a medical/surgical nurse who may not experience any deaths in a year. Nurses in other specialties who care for patients with chronic illnesses, such as oncology, may have had a longer time to develop a relationship with a family than those in the emergency specialty. This question was exploratory to evaluate if different

specialties had differing levels of death anxiety and comfort level in approaching families of dying children.

Bereavement and emotionally charged communication education. It was hypothesized by Deffner and Bell (2005) that nurses who had training in emotionally charged communication would be more comfortable communicating with bereaved individuals. Instead they found that individuals with emotionally charged communication education were more comfortable communicating with bereaved individuals. As a replication study the question was posed on how many hours of bereavement education and how many hours of emotionally charged communication education the nurse had received in order to assess whether a specific form of emotionally charged communication education was correlated with comfort level. The results demonstrated a positive correlation between the comfort level approaching families of dying children and increased hours of both bereavement education and emotionally charged communication education. These results demonstrate that in order to help pediatric nurses become more comfortable in approaching families of dying children the amount of bereavement and emotionally charged communication education should be increased.

Pediatric nursing experience. In previous research older and more experienced nurses reported that they were more comfortable speaking with bereaved families (Deffner & Bell, 2005). However, the researchers were unable to determine if both experience and age increased comfort level or if older nurses tended to have more experience with dying patients than younger nurses. Therefore participants were asked their years of nursing experience in order to continue to evaluate the potentially confounding factor of nursing experience versus age. In this study participants were

asked how comfortable they were in approaching and interacting with families of dying children. Age was not found to be significantly correlated with comfort level in approaching families, but more pediatric nursing experience was correlated with an increased comfort level. And although age and experience were both found to have a correlation with either increased interaction with families of dying children, only four percent of participants claimed to avoid interacting with families of dying children, while 47% were neutral and 49% would choose to interact with families. These findings indicate that even when nurses are not comfortable approaching families of dying children, they are willing to interact with the families. This result is similar to Tse et al.'s (2006).

As a further exploration of years of nursing experience, participants were asked to differentiate between years of pediatric nursing experience and total nursing experience. Unfortunately, the placement of the question concerning total nursing experience was placed directly after the question concerning years of pediatric experience. As a result, many participants did not respond to this question (58% responded), or responded in a way that reflected that the question concerning total years of nursing experience was confusing. Therefore, only the years of pediatric experience were used in the final analysis.

Comfort Level in Approaching Families of Dying Children

The results of this study suggested that comfort level in approaching families of dying children was positively related to pediatric nursing experience, frequency of interactions, bereavement and emotionally charged communication education, and choosing to interact with families of dying children. The results did not demonstrate that

comfort level in approaching bereaved families was significantly correlated to the DAS score.

This finding can help explain that it was more likely that the relationship between comfort level and bereavement and emotionally charged communication education was not just a result of getting older. As education is directional, in that it cannot be reversed, it could be inferred that as a nurse has more bereavement or emotionally charged communication education he or she would have an increased level of comfort in approaching families of dying children.

Although frequency of interactions is also directional, the impact of feeling more comfortable in approaching families of dying children might have increased the frequency of interactions or vice versa. However, the qualitative portion of the survey seemed to indicate that nurses who had more frequent exposures to death and dying became more comfortable with approaching families of dying children.

Choosing to Interact with Families of Dying Children

Results also indicated that most nurses either choose to interact or are willing to interact with families of dying children, and that interaction choice was positively affected by age, frequency of interactions with families of dying children, pediatric nursing experience, bereavement and emotionally charged communication education. Of note death anxiety scores had no significant correlation with a nurse's choice to interact. Choosing to interact with dying patients despite discomfort or feeling unprepared was also demonstrated in Tse et al's (2006) study of nurses in Hong Kong.

Death Anxiety

Death Anxiety Scale (DAS) mean scores were lower in the oldest nurses. The most advanced age category (55-64 years) had significantly lower mean scores than any other age category. Results suggested that the older the pediatric nurse is the more likely she is to have lower death anxiety. However, the DAS mean scores did not correlate with age progression. Rather, the DAS mean scores were the highest in the 35-44 year category, although this did not reach a statistical significant difference. Murphy (1986) found similar results in her study concerning the effectiveness of a death awareness workshop. Potential explanations of this result were that this generation was a “sandwich generation” of care. For example, nurses in this age category may have had school age children for whom they feel responsible. One nurse commented that she was only anxious about death because she did not want to leave her husband and children behind. This age category may also have ill parents or grandparents for whom they are providing care. The event of 9/11/2001, the terrorist attack on the twin towers that pushed the country into a security alert, occurred during the time these nurses had just graduated from college and entered into a visibly shaken nation. Cohen et al. (2006) found that American adults’ seasonal pattern of anxiety changed after 9/11/2001. The authors found that anxiety levels were higher than in years prior to 2001, and spiked in autumn as opposed to winter. Cohen et al. also explained that in the year of the anthrax scare in 2003, anxiety levels were the highest measured. Additionally, many chronic illnesses are diagnosed during this generation of life in the United States. Family and friends might have died from a heart attack, complications of diabetes, or cancer, while other family and friends and the nurses themselves might have been diagnosed with chronic diseases such as

fibromyalgia, hypertension, or cancer. The diagnosis of these chronic illness or the closeness of death might have caused these nurses to have been more anxious about death.

The results suggested that critical care nurses and medical surgical nurses had the lowest death anxiety of the specialties surveyed. Both critical care nurses and medical/surgical nurses had lower DAS mean scores than either nurses in emergency or hematology/oncology care. The sample was normally distributed over the nursing specialties and each specialty demonstrated a normal distribution of age, thereby eliminating sample size and age as confounding factors. It was expected that nurses in the emergency specialty would demonstrate a higher death anxiety due to the standard of care of stabilizing and transferring to definitive care quickly, thus limiting the development of a relationship with families of dying children. Payne et al. (1998) found that emergency nurses had higher death anxiety than hospice nurses. Payne et al.'s results demonstrated that emergency nurses did not remember care that went well for dying patients, and the emergency nurses did not see death as a release. The frequency of exposure to families of dying children was also decreased because the patient and family are not cared for long term in the emergency department surveyed. The high death anxiety in the hematology/oncology specialty was surprising because nurses in this specialty had the capability of developing long term relationships with patients and their families along with frequent exposure to families of dying children. However, with the development of new cancer treatments, and more expertise in the field of pediatric oncology, perhaps hematology/oncology nurses are actually exposed to fewer deaths than those in the critical care and medical/surgical specialties. The neonatal specialty had no

significant difference of DAS mean scores when compared to the other pediatric nursing specialties. This finding was paradoxical because the neonatal unit had the highest frequency of deaths than any other unit (Appendix G) and at this particular hospital it was known to the researcher that many of the neonatal nurses were trained in the Resolve Through Sharing Bereavement Program. However, the neonatal nursing staff was quite large and not every nurse has frequent exposure to patient deaths.

Nurses who described themselves as very comfortable in approaching families of dying children were found to have no significant differences in DAS mean scores. This finding might have been undermined by a small sample size, or falsely represented by a sampling error. The difference between this study and that of Deffner and Bell (2005) was that in this study the correlation between comfort level and total DAS score was measured, while Deffner and Bell cited the correlation of comfort level with each individual measure of the DAS.

Qualitative Results

Qualitatively nurses expressed that they wanted to help and support families, but felt ill prepared and under-experienced in approaching families of dying children. They felt that if they were exposed more frequently to families of dying children they would feel more comfortable. Ratner (2010) validated this feeling by describing how she became more comfortable with caring for dying patients the more she was witnessed death. Braun et al. (2010) found that as care of dying patients increased in frequency personal death anxiety decreased.

Having had good personal and professional experiences with death and dying increased the nurses' comfort in working with families of dying children. However,

several expressed that not knowing what to say or not to say and having had a feeling of responsibility for the death caused discomfort in working with the families. Some nurses explained that they were comfortable being present with the family and that it was helpful to provide a listening ear. Rushton et al. (2009) explained that healing presence included listening and being with the dying patient.

Alternative Explanations

In previous studies, age was demonstrated to correlate strongly with DAS scores and comfort level in approaching bereaved families (Braun et al., 2010; Deffner & Bell, 2005). However, the results from this study did not demonstrate that finding. As noted previously Deffner and Bell (2005) used the individual questions of the DAS instead of a total score and therefore cannot be directly compared.

Potentially the reason age was not correlated with comfort level was that although DAS and age had a negative relationship, the high DAS mean score of the middle categories may have disrupted the statistical analysis. The higher death anxiety of nurses with 9-19 years of pediatric nursing experience and the nurses aged 35-44 years might be a phenomenon of this particular research site, or it might be a phenomenon of this generation.

Impact of Study

This study added to the body of nursing knowledge concerning the specialty of pediatrics and bereavement research. It provided baseline data by use of a validated tool to assess death anxiety, and it assessed baseline data of comfort level in approaching families of dying children. By finding a difference of DAS scores in a comparison of nursing specialties, this study provided support for developing educational programs and

interventions in different specialties. It validated the academic and professional opinion that bereavement education can help prepare nurses to work with families of dying children. It also validated the appropriateness of educating nurses on death and dying through exposure to death and dying experiences to increase comfort level in working with families of dying children.

Strengths

Strengths of this study include a large sample size (n=165) which allowed for normal distributions across age, pediatric nursing experience, bereavement and emotionally charged communication education, DAS scores, and nursing specialties. The sample obtained reflected the community population's ethnicity and religion distribution and reflected the nursing population's gender and nursing education distribution. Additionally, the sample was obtained from a pediatric hospital with an average of 104 deaths over the last 3 years (Appendix G), allowing for a pediatric focused nursing population with the potential to experience pediatric death.

The data were electronically collected decreasing the risk of entry error. The survey was short which decreased participant drop out. Evaluation comments indicated that the survey was clear, concise, and easy to fill out.

Weaknesses and Limitations

A weakness of the research was that the sample was from a convenience population from one facility. There were no baseline studies of death anxiety or comfort level in approaching families of dying children from this nursing population prior to the hospital's development of a bereavement committee and annual bereavement conferences. The primary investigator was a novice researcher. Use of an electronic

survey might have limited the participation of nurses in the older age categories. Another weakness included the cross-sectional design of the study, which eliminated the ability to establish cause and effect.

A limitation of the research included a non-diversified sample. Although the sample reflected the nursing community and the community at large the results could not be generalized to male, religiously diverse, or ethnically diverse nursing populations. Another limitation included the complete absence of assessing cultural and language barriers between nurses and families of dying children.

Professional Implications

Results of this study indicated that comfort level in approaching families of dying children could be improved through bereavement education and emotionally charged communication education, and evaluated with the DAS. Results suggested that bereavement education, more specifically education that provided exposure to death and dying and experiences of a good death, could improve comfort level in approaching bereaved families. Nurses described that knowing what to say and what form of communication was best received by families would lead to better outcomes. This study also implied that the DAS total score was not a good measurement tool of comfort level in approaching bereaved families, although further studies would need to be performed to determine what tool would work best for assessing comfort level in approaching families of dying children.

Organization and Practice Change Recommendations

Recommendations for administrators of pediatric hospitals concerned about improving the nurses' comfort level in approaching bereaved families would include

focusing on bereavement education, emotionally charged communication education, and end-of-life education. Considerations for education might include regularly providing a small, non-obtrusive bereavement education pearl of information, or discussing a good death and dying experience during daily report or in a weekly update. They should focus education efforts on effective communication that would lead to good outcomes. Further education could include sending nurses to bereavement conferences, providing a course on death and dying, or coordinating a death and dying simulation.

Nursing Education Changes

Implications for changes in nursing education would be to improve the nursing accreditation requirement of end-of-life care to include therapeutic end-of-life communication and interventions, and have a greater emphasis on appropriate communication and interventions for dying patients as well as families. Communication with patients and families during death and dying was difficult, but knowing that the communication was therapeutic helped one nurse rise above that difficulty. Expanding textbook practical knowledge on therapeutic communication and appropriate interventions during death and dying of all patients – elderly, pediatric, expected deaths versus unexpected deaths – would provide a lasting resource for nursing students. Schools of nursing should consider requiring a death and dying course as part of the nursing curriculum. They might also consider a simulation experience or an experience with a palliative care nurse in order to allow nursing students to have a good experience with death and dying as part of the clinical practicum.

Further Research

Suggestions for further research on this topic would include replication studies, bereavement education interventions, assessment using a different death anxiety or death attitude instrument, and an assessment of the effect of cultural and language barriers. Replication studies in pediatric hospitals throughout the United States could provide a more ethnically and religiously diverse population. Other studies did not mention cultural diversity as a further research topic; however, the results of the studies cannot be generalized to all populations. The study should also be replicated in small rural hospitals because of different rates of exposure to death and dying.

Bereavement education interventions more specifically would focus on exposure, experience and communication concerning death and dying. Several authors found that nurses wanted experience and education concerning death and dying (Mallory & Allen, 2006; Tse et al., 2006; Wong, F. K. Y. et al., 2001). Simulation which has been used to teach nursing tasks (e.g. intravenous therapy, catheterizations, code responsibilities) is beginning to be used as a safer way to simulate death and dying. Simulation of death and dying could fulfill the need of increased exposure to death and dying to increase comfort level in approaching families of dying children. Mallory and Allen encouraged death and dying courses for improved education. Studies on interventions that used death and dying courses would provide evidence of the value of education in death and dying. Utilizing a different death anxiety tool may provide a correlation with comfort level in approaching families of dying children. Adding questions or a focus on cultural diversity and language barriers would also be an area of expanding the research. The results indicated that bereavement education could improve comfort level. Yet, Katz and Ferrell (1999)

reported that nursing education concerning death and dying is limited to nearly non-existent.

Methodology changes would include changing the wording and formatting of some of the survey questions, adding clarifying questions, and potentially using a different instrument to assess death anxiety. Differentiating exact age, years of experience, and hours of education could be accomplished by asking for an entered number. The differentiation would have allowed for stronger results, although, the results might not have changed. The question concerning total nursing experience was apparently confusing. It would be important to consider rewording/moving the question (e.g. place the question before asking about pediatric nursing experience or ask for pediatric nursing experience and additional other nursing experience). Because of the qualitative comments concerning the polarity of the DAS true/false comments, future researchers should consider using the Likert scale version of the DAS. The final question to consider changing would be the question of choosing to interact with families of dying children. Due to the overwhelming response of being either neutral or choosing to interact with families of dying children it would be good to use a 10-point scale to rate how willing the participant would be to choose a patient assignment with a dying child, or to interact with families of dying children above the standard assessments.

Results and Conceptual Framework

The results, as related to the Bereavement Caring Model (see Figure 2), demonstrated that barriers and conflicts that influenced a nurse's comfort level when approaching families of dying children included death anxiety, age, years of experience, bereavement and emotionally charged communication, and nursing specialty. Nurses also

identified frequency of exposure to death and dying as a barrier to feeling comfortable approaching families of dying children. A nurse's relationship with the patient and family also influenced his or her comfort level in interacting with families of dying children. Several nurses inferred that surrounding circumstances affected their comfort level of approaching and interacting with families of dying children. Circumstances that surrounded the death/cause of dying was a barrier that was not specifically addressed in the current study; however, it would be beneficial to study how much the circumstances surrounding the death affected nurses comfort level and interaction with families of dying children.

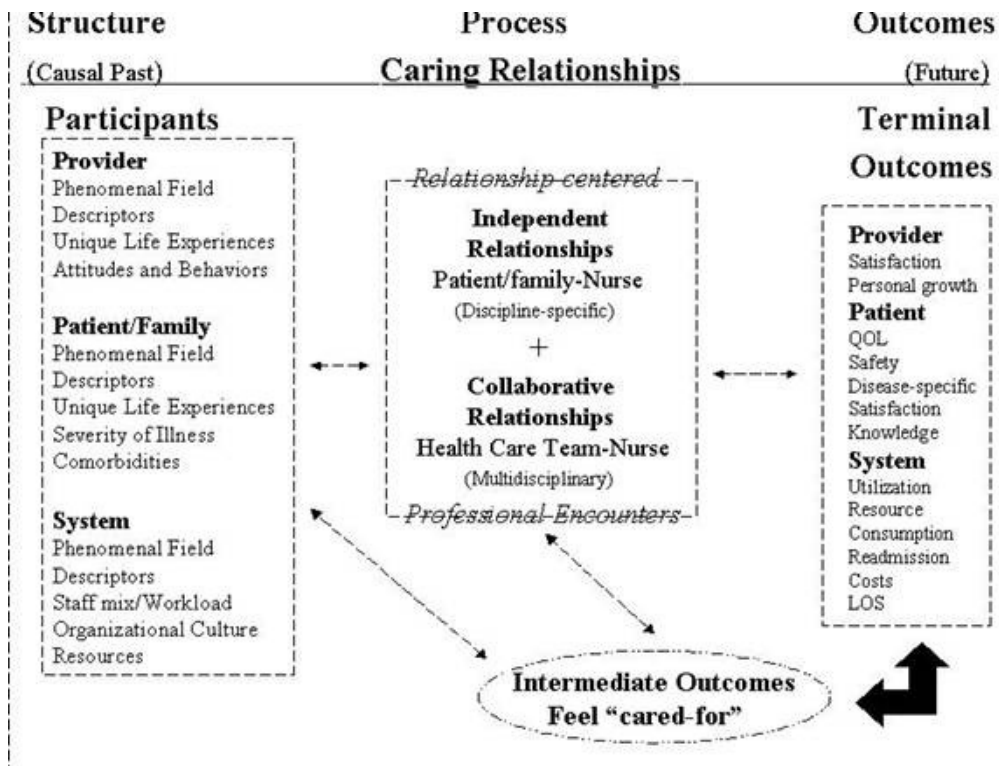
Summary

In summary, pediatric nurses tended to be neutral in their comfort level in approaching bereaved families, and yet almost all were willing to interact with these families. Bereavement and emotionally charged communication education, as well as experience in pediatric nursing, death and dying, and life in general tended to increase one's comfort level in approaching families of dying children. Nurses felt that more frequent exposure to families of dying children and knowing what to say would help the nurses be more comfortable in approaching families of dying children. Further research in bereavement education interventions would benefit the nursing body of knowledge and pediatric nursing as a whole.

Appendix A

The Quality Caring Model

The Quality Caring Model (Duffy & Hoskins, 2003)



Depicts Duffy's (2003) middle range nursing theory of caring as the nurse's role in patient care. Duffy describes her philosophy that the positive outcomes of nursing stem from a caring relationship. The figure demonstrates that pre-existing life situations of provider, patient, and system have the measureable outcome of feeling cared for through caring relationships. This figure is from "The quality-caring model©: Blending dual paradigms" by J. R. Duffy and L. M. Hoskins, 2003, *Advances in Nursing Science*, 26(1), p. 81. Used with permission from Dr. J. R. Duffy (personal communication, October 30, 2011).

Appendix B

Permission to Use the Quality Caring Model

E-mail to Dr. Joanne Duffy:

Dr. Duffy,

My name is Elizabeth Cook and I am a graduate student at GVSU. I am writing on behalf of my thesis. I am asking permission to use an adapted version of your Quality Caring Model as part of the theoretical basis of my thesis. I blended Dr. Watson's Theory of Human Caring and the Quality Caring Model in order to evaluate interactions with nurses that lead to interventions and better patient outcomes. The study looked at Pediatric nurses' comfort level in approaching families of dying children. I attached the adaptation. Your response would be much appreciated.

Elizabeth Cook (Personal Communication, E. J. Cook, October 29, 2011).

Response from Dr. Joanne Duffy:

Sure Elizabeth, you may use this, but you should know that the QCM has been revised since 2003 and is presented in chapter 10 of the book, *Quality Caring in Nursing: Applying theory to Clinical Practice, Education, and Leadership*, Springer Publishing, 2009. Since the QCM was influenced by Watson's theory, I am not sure you need both of them in your study. But that is up to you and your faculty to decide.

Good luck,

Joanne (Personal Communication, J. R. Duffy, October 30, 2011).

Appendix C

Recruitment E-mail Query

Caring for families and children at the end of life is one of the most difficult things we do as pediatric nurses. It is important to understand this experience and consider ways to help nurses feel more capable and prepared to encourage families of dying children. I am asking you to help me explore this experience. As a master's student at Kirkhof College of Nursing, I have prepared an online survey to gather more information about this. Attached is an information form that you should save or print that describes the study I am asking you to participate in. It includes contact information for me, the human subjects committee chairs at Spectrum, and Grand Valley State University should you have any questions or concerns about the study.

This is the link to the survey: <http://www.surveymonkey.com/s/HBFSMYQ>. Please be assured that your responses are confidential. I will be presenting preliminary findings at the HDVCH Bereavement Committee in the early fall of 2011.

Thank you very much in advance for your participation.

Elizabeth Cook, RN, BSN, MSN-candidate

Appendix D

Survey Questions

1. Participation Agreement:

You are invited to participate in the research study, Pediatric Nurses' Death Anxiety and Level of Comfort in approaching Families of Dying Children. This is a graduate student research project that is self-funded. To be eligible to participate in this research study you must be a registered nurse working in a pediatric unit with bedside care experience. Individuals under 18, those who are unable to consent, and those unable to complete a survey in English will be excluded.

You do not have to participate in this study if you do not want to. There are no penalties or consequences of any kind if you decide that you do not want to participate. You may choose not to answer any questions on the survey, for any reason and at any time.

If you agree to be part of this voluntary research study, you will be asked to complete the following anonymous online survey. You may experience anxiety, stress, or discomfort in recalling personal bereavement or encounters with traumatically bereaved families. The researcher is not affiliated with possible promotions or clinical evaluations. You do not have to answer every question on the survey to submit your other answers. The survey is short, and can be completed at any location with internet access. You may choose not to participate in the research until you submit your survey, after submission there is no way to differentiate your response from another participant. No compensation will be provided. The researcher anticipates 100 responses to this survey.

Although there is no direct benefit from participating in this study, you may benefit by being able to share your personal anxieties and/or comfort in approaching bereaved families. You may feel benefits from participating in nursing research, and influencing future nursing knowledge concerning pediatric bereavement and working with bereaved families. Your privacy will be protected by not associating any identifying factors with the survey. Any comments written in the survey may be quoted in published material, however any identifiable factors will be removed or changed to protect privacy. Data from this study will be analyzed, summarized, and processed over the next three years. At the end of the three years the original data set will be destroyed.

This research has been approved by Grand Valley State University's Human Research Review Committee (HRRC) and Spectrum Health's Institutional Review Board (IRB). You should also know that Grand Valley State University's HRRC and Spectrum Health's IRB may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The HRRC is a group of people who review research studies to make sure they are safe for participants. Take as long as you like before you make a decision. We will be happy to answer any questions you have about the study.

If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator: Elizabeth Cook by phone 616-970-4576 or by e-mail uhee@mail.gvsu.edu. You may contact the GVSU HRRC by telephone at 616-331-3197 or by e-mail at hrrc@gvsu.edu or the Spectrum Health IRB by telephone 616-486-2031 or by e-mail at irb@spectrum-health.org if:

- You have any questions concerning your rights as a research participant.
- Your questions concerns, or complaints are not being answered by the investigator.
- You cannot reach the investigator.
- You want to talk to someone besides the investigator.
- You want to get information or provide input.

By clicking the acceptance button below I am stating that I have read this form and decided to participate in the project described above. Its general purposes, the particulars of involvement, and possible hazards and inconveniences have been explained to my satisfaction

I accept (NOTE: There is only one response. The participant must accept in order to continue with the rest of the survey. This is the only required answer in the survey.)

2. Demographics

- a. Gender:
 - i. Female
 - ii. Male
- b. Age
 - i. 18-24
 - ii. 25-34
 - iii. 35-44

- iv. 45-54
 - v. 55-64
 - vi. 65+
 - c. Ethnicity
 - i. African American
 - ii. Asian
 - iii. Caucasian non-Hispanic
 - iv. Multiracial
 - v. Native American
 - vi. Pacific Islander
 - vii. Other
 - d. Religious Background Preference
 - i. Agnostic
 - ii. Atheist
 - iii. Buddhist
 - iv. Catholic
 - v. Hindu
 - vi. Jewish
 - vii. Muslim
 - viii. Protestant
 - ix. Other
 - e. Other (Please Specify)
- 3. Level of Nursing Education (Choose highest level achieved.)
 - a. Diploma
 - b. A.D.N.
 - c. BSN
 - d. MSN
 - e. DNP/PhD
- 4. Years of Nursing Experience
 - a. Pediatrics
 - i. 0-1 Years
 - ii. 2-3 Years
 - iii. 3-4 Years
 - iv. 5-8 Years
 - v. 8-10 Years
 - vi. 10-12 Years
 - vii. 12-15 Years
 - viii. 15-18 Years
 - ix. 18-20 Years
 - x. 20+ Years

- b. All Nursing Areas
 - i. 0-1 Years
 - ii. 2-3 Years
 - iii. 3-4 Years
 - iv. 5-8 Years
 - v. 8-10 Years
 - vi. 10-12 Years
 - vii. 12-15 Years
 - viii. 15-18 Years
 - ix. 18-20 Years
 - x. 20+ Years
- 5. Pediatric Nursing Specialty
 - a. Critical Care
 - b. Emergency
 - c. Med/Surg
 - d. Neonatal
 - e. Heme/Oncology
 - f. Surgery
 - g. Other specialty not listed: _____
- 6. Hours of professional training received (classes, in services, conferences etc.)
 - a. Bereavement
 - i. 0-4 Hours
 - ii. 5-9 Hours
 - iii. 10-14 Hours
 - iv. 15-19 Hours
 - v. 20+ Hours
 - b. Emotionally Charged Communication (e.g. Crucial Conversations etc.)
 - i. 0-4 Hours
 - ii. 5-9 Hours
 - iii. 10-14 Hours
 - iv. 15-19 Hours
 - v. 20+ Hours
- 7. Frequency of approaching Families of Dying Children
 - a. Never
 - b. Rarely
 - c. Occasionally
 - d. Frequently
 - e. All the time
 - f. Comments: _____
- 8. Death Anxiety Scale

Please read the following carefully to select the most appropriate True/False answer.

- a. I am very much afraid to die.
 - i. True
 - ii. False
- b. The thought of death seldom enters my mind.
 - i. True
 - ii. False
- c. It doesn't make me nervous when others talk about death.
 - i. True
 - ii. False
- d. I dread the thought of having to have an operation.
 - i. True
 - ii. False
- e. I am not at all afraid to die.
 - i. True
 - ii. False
- f. I am not particularly afraid of having cancer.
 - i. True
 - ii. False
- g. The thought of death never bothers me.
 - i. True
 - ii. False
- h. I am often distressed by how time flies so very rapidly.
 - i. True
 - ii. False
- i. I fear a painful death
 - i. True
 - ii. False
- j. The subject of life after death troubles me very much.
 - i. True
 - ii. False
- k. I am really scared of having a heart attack.
 - i. True
 - ii. False
- l. I often think about how short life really is.
 - i. True
 - ii. False
- m. I shudder when I hear people talking about a World War III.
 - i. True

- ii. False
 - n. The sight of a dead body is horrifying to me.
 - i. True
 - ii. False
 - o. I feel that the future holds nothing for me to fear.
 - i. True
 - ii. False
- 9. Please choose the answer that best describes your experience in approaching families of dying children.
 - a. Comfort Level in Approaching Families of Dying Children
 - i. Very Uncomfortable
 - ii. Uncomfortable
 - iii. Neutral
 - iv. Comfortable
 - v. Very Comfortable
 - b. Level of Interaction with Families of Dying Children
 - i. Avoid Interaction with Families
 - ii. Neutral
 - iii. Choose Interaction with Families
 - c. Additional comments concerning comfort level in approaching families of dying children:

10. Evaluation

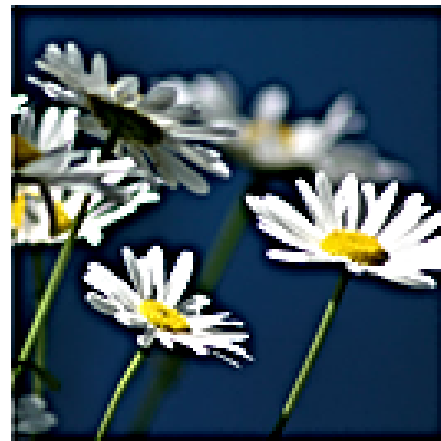
Comments concerning the process and clarity of the survey are appreciated:

Appendix E

Research Flyer



**Pediatric Nurses' Death Anxiety and Level of Comfort
in Approaching Families of Dying Children**



You are invited to participate in the research study, Pediatric Nurses' Death Anxiety and Level of Comfort in approaching Traumatically Bereaved Families.

This is a graduate student research project that is self-funded. If you agree to be part of this voluntary research study, you will be asked to participate in one anonymous online survey.

Bereavement Research

Elizabeth Cook
Primary Researcher
Phone: 616-970-4576
E-mail: uhcc@gvsu.edu

Data Collection Starts: June, 2011

Data Collection Ends: August, 2011

616-331-3917;
hrc@gvsu.edu
Spectrum HRRC:
616-486-2031;
irb@spectrum-health.org



Appendix F

Reminder E-mail

Two weeks ago [or four weeks ago] you received an invitation to participate in a study about helping families who have lost a child through death. If you have already responded, I am very grateful for your participation. If you have not responded, I would appreciate you taking a few minutes to do so now. I have attached the information to the study to this email--please save or print the information so you have the contact information you might need if you have concerns about the study. Here is the link to the survey: <http://www.surveymonkey.com/s/HBFSMYQ>

Thank you very much in advance for your participation.

Elizabeth Cook, RN, BSN, MSN-candidate

Appendix G

Death Stratification

Nursing Unit	2008	2009	2010	2011 (Jan-Jun)
	Deaths	Deaths	Deaths	Deaths
	Ages 0-18	Ages 0-18	Ages 0-18	Ages 0-18
Labor and Delivery	9	12	8	3
Women's Health	1	0	0	0
LRND	28	15	23	16
Medical/ Surgical	5	1	4	0
NICU	38	26	30	33
PICU	34	31	27	12
ED	8	6	7	11
Total	123	91	99	75

Appendix H

Permission to Use the Death Anxiety Scale

Dear

Please excuse this impersonal form letter that I send to the many people who write or call me about my Death Anxiety Scale and/or Death Depression Scale. Feel free to use one or both of them in any way. Since they are not on the commercial market there is no charge.

Enclosed find a DAS form that I have used since 1970, articles pertaining to DAS construction, validation, items, scoring and norm-like information, and other important material. One point is scored for each item answered in the keyed high death anxiety direction so that a DAS score could be as low as 0 or as high as 15. A Likert format for the DAS is described by McMordie in Psychological Reports, 1979, 44, 975-980. Enclosed find the true-false and Likert form of the Death Depression Scale and a couple of articles pertaining to the DDS.

The book, Death Anxiety, by Richard Lonetto and Donald I. Templer (Hemisphere Publishing Corporation, Washington, 1986) reviews the correlates of death anxiety (age, sex, other demographic variables, parental resemblance, religion, personality, public health, psychopathology, occupation, behavior, death of significant others), factor analyses, death imagery, intervention, the measurement of death anxiety, and Templer's two-factor theory of death anxiety.

Feel free to contact me for additional information or advice, including help in preparation of a manuscript for a journal article if your findings are sufficiently interesting.

Sincerely,

Donald I. Templer

Donald I. Templer, Ph.D.
Professor of Psychology

Appendix I

GVSU HRRC Approval

Please note that Grand Valley State University Human Research Review Committee has published the following Board Document on IRBNet:

Project Title: [238336-1] Pediatric Nurses' Death Anxiety and Level of Comfort in Approaching Families of Dying Children
Principal Investigator: Elizabeth Cook, BSN

Submission Type: New Project
Date Submitted: May 16, 2011

Document Type: Exempt Approval Letter
Document Description: Exempt Approval Letter
Publish Date: June 3, 2011

Should you have any questions you may contact Seth Galligan at galligse@gvsu.edu.

Thank you,
The IRBNet Support Team

www.irbnet.org

Appendix J

Risk to Participants and Methods to Reduce Risk

RISKS	REDUCING RISKS
<p>Participants may potentially experience anxiety, stress, or discomfort in recalling personal bereavement as well as events or encounters with traumatically bereaved families.</p>	<p>Anonymous, voluntary submission of survey. Clear disclosure of the contents of the survey prior to taking the survey. Ability to stop the survey at anytime. Knowledge that research on this subject will lead to better understanding of appropriate care for traumatically bereaved families. Therapeutic expression of fears/anxiety. Because the participants are staff of Spectrum Health the ENCOMPASS program is also available to provide guidance for any mental health concerns.</p>
<p>Perceived influence of survey results on performance evaluations.</p>	<p>Assurance that the survey is completely anonymous, that the researcher/evaluator by a person who is not affiliated with promotion or clinical evaluations. External link to the survey not attached to name, e-mail, or place of work. Ability to not complete every answer on the survey (e.g. unit of practice.)</p>
<p>Loss of time</p>	<p>Survey is short. The survey is voluntary. The survey is online and can be completed at any location with internet access. Loss of time will be limited and will not be compensated.</p>

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