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EFFECTS OF SPIRITUAL CARE EDUCATION ON PEDIATRIC NURSES' KNOWLEDGE, ATTITUDES, AND COMPETENCE

by

Cheryl L. Petersen, RN, BSN

A Dissertation submitted to the Faculty of the Graduate School,
Marquette University,
in Partial Fulfillment of the Requirements for
the Degree of Doctor of Philosophy.

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ABSTRACT

EFFECTS OF SPIRITUAL CARE EDUCATION ON PEDIATRIC NURSES' KNOWLEDGE, ATTITUDES, AND COMPETENCE

Cheryl L. Petersen, RN, BSN

Marquette University, 2015

Holistic nursing care embraces the physical, psychological, and spiritual needs of the patient and family, thereby providing support and reducing suffering. Nurses' spiritual care can improve the well-being and quality of life of children with cancer by assisting them to find meaning in their lives. At the end of life, spiritual care assists children in coping with their diagnosis, suffering, and losses. There are distinct deficiencies in education that lead nurses to feel unprepared to provide spiritual care to children. This study employed a prospective, longitudinal design to evaluate the potential effects of an online spiritual care educational program on pediatric oncology nurses' attitudes towards and knowledge of spirituality/spiritual care and their competence to provide spiritual care to children with cancer at the end of life. Narayanasamy's Actioning Spirituality and Spiritual Care Education and Training in Nursing (ASSET) model framed this design, for this model offers distinct strategies to guide spiritual care education.

Participants included 112 pediatric nurses who provide care to children with cancer. Online multimedia content was supplemented with an asynchronous discussion forum. One-way repeated-measures analysis of variance compared scores on nurses' attitudes towards and knowledge of spirituality/spiritual care at baseline, immediately after completion of the program, and three-months later. Analyses indicated a very large effect over time. One-way repeated measures analysis of variance compared scores of nurses' spiritual care competence at baseline, immediately after a participant's completion of the program, and three-months after a participant's completion of the program. There was a very large effect over time on nurses' level of spiritual care competence. Linear regression found a positive relationship between the total change score in nurses' attitudes towards and knowledge of spirituality/spiritual care and the total change score in nurses' level of spiritual care competence.

Online spiritual care educational initiatives may exert a meaningful effect on pediatric oncology nurses' knowledge, attitudes, and competence to provide spiritual care. The ASSET model provides a useful framework for conceptualizing and investigating the effects of spiritual care educational initiatives. Results from this study address a gap in knowledge to advance nursing education and serve as a foundation for further investigation.

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CHAPTER ONE
Introduction

Despite major advances in diagnosis and treatment over the last 30 years, cancer remains one of the leading causes of death in children (Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006). Although the 5-year relative survival rate is now over 80%, approximately 1,250 children under the age of 15 years are expected to die of this disease in 2015 (American Cancer Society, 2015). Comprehensive nursing care of children at the end of life should embrace the physical, psychological, and spiritual needs of children and their families, with focus placed on providing support, reducing suffering, and enhancing quality of life (Campion, 2011). Nurses have provided spiritual care for patients and their families from the time of the discipline's origins in the religious orders, where nursing was an extension of God's work (Ross, 1995). The focus on holistic care advocated at St. Christopher's Hospice, the world's first hospice facility established in London in 1967, has tremendously influenced contemporary end of life care, with the provision of spiritual care considered a vital aspect of nursing care (Campion, 2011). More recently, Watson's Human Caring Science emphasized the importance of holistic nursing care of a patient's mind, body, and spirit in reducing suffering (Tomey & Alligood, 2002).

Creation of an overarching definition of spirituality is extraordinarily challenging due to the unique spiritual needs, values, and beliefs of each individual (Hickey et al., 2008). Spirituality has been defined as a dynamic, individualized process that involves relationships with other individuals, as well as God or a supreme being; spirituality depicts an individual's personal beliefs, principles, and transcendent experiences that extend beyond oneself and encompass a search for meaning and purpose in life and death

(Emblem, 1992; Meravigilia, 1999). An important aspect of spirituality for some individuals is religion, a structured expression of specific beliefs, doctrines, practices, and rituals held by a community of people to connect to a higher power (McEvoy, 2000). Religion, often considered to be a category under the construct of spirituality, may thereby serve as a means for expression and enrichment of spirituality (Elkins & Cavendish 2004; Emblem, 1992).

Spirituality is highly personal and universal to all children, regardless of age or stage of development (Kenny, 1999b). Children are defined as individuals who are 18 years of age and younger. Minimal studies have investigated the spirituality or spiritual care of children, and this is especially true regarding children who are dying from cancer. This vulnerable population constitutes the group of children who likely need spiritual support the most: It is known that spirituality may improve the psychological well-being and quality of life of children with cancer by assisting them to find meaning in their lives and struggles (Hart & Schneider, 1997). At the end of life, spirituality becomes especially important as children and their families struggle to make sense out of the diagnosis, suffering, and losses, allowing them to look beyond the physical world for answers (Purow, Alisanski, & Putnam, & Ruderman, 2011). For children who face a terminal diagnosis of cancer, spirituality can provide assistance in coping with feelings of loss and fear as death approaches, as well as grief related to future losses, concerns about being forgotten, or worries about loved ones who will be left behind (Hufton, 2006; McSherry, Kehoe, Carroll, Kang, & Rourke, 2007). In addressing their spiritual distress, children may express concern regarding the afterlife, a desire to finish unfinished business, sadness over separation from peers, fears about death, and questions about their beliefs (Foster,

Bell, & Gilmer, 2012). It is important to study the tenets of spiritual care for this population of children in order to come to better understand the optimal ways of supporting them through the intense losses, fears, and tragedies.

Spiritual care is defined as interactions to promote the spirituality of patients and their families and encourage the expression of their spiritual needs through purposeful monitoring and compassionate response, with the goal of assisting them to find peace and quality of life in the days that remain (Burkhart & Hogan, 2008). When focusing on children with cancer who are at the end of life, a particularly vulnerable population, there are several attributes of spiritual care that allow a child to find peace: assessing spiritual needs; aiding the child to find hope; assisting the child to express feelings and concerns; guiding the child in strengthening relationships; helping the child to be remembered; and assisting the child to find meaning and purpose (Petersen, 2013). For children with cancer facing a terminal diagnosis, spiritual care interventions such as assisting a child to engage in prayer may assist a child in managing sadness and despair. In one study of children with advanced cancer, 78% of the children reported that they completed activities to feel close to God; 59% of children prayed for a normal life again, and 31% prayed for family, friends, or other children who have died. For those children who identified that they prayed, 82% indicated that prayer helped them to feel better or less sad (Kamper, van Cleve, & Savedra, 2010). By providing the child and family access to spiritual care resources such as pastoral care staff, clergy, or prayer, nurses' also provide spiritual care that may minimize the vulnerability of children with cancer to sadness and heartache. Attention must be given, however, to the developmental level of the child, allowing

spiritual care interventions to be specifically tailored to the individual child's specific spiritual needs.

In addition to providing psychological support and a sense of connection for children with cancer at the end of life, spiritual care must also address parents' spiritual needs, thereby reducing their psychological distress and providing a way for them to find understanding, guidance, comfort, and support in the face of a tragic loss (Meyer, Ritholz, Burns, & Truog, 2006). Parents whose children are at the end of life often want nurses to assist them to maintain a spiritual connection with their child, help them to pray and conduct religious rituals, and aid their children to form connections with other individuals or God (Meert, Thurston, & Briller, 2005).

The spiritual needs of parents of ill children often center on dealing with feelings of fear, coping with their children's pain, and finding meaning in their children's suffering (Feudtner, Haney, & Dimmers, 2003). Robinson, Thiel, Backus, & Meyer (2006) reported that 73% of parents whose child died in the intensive care unit indicated that spiritual resources were their most vital support during the death of their child and sustained them throughout the tragedy and the days that followed. Parents of children who have died in the intensive care unit reported that spirituality had a positive influence on their ability to cope and provided the sense of a guiding presence throughout their experience (Schneider & Mannell, 2006). In addition to providing spiritual resources, practice of faith and discussions of beliefs also offer comfort to parents of children who have died (Meyer et al., 2006).

Prior studies with adult cancer patients have shown a significant relationship between spirituality and positive coping, as well as decreased levels of stress, depression,

and anxiety (Brady, Erdman, & Fitchett, 1999; Carmody, Reed, & Kristeller, 2008; Whitford, Olver, & Peterson, 2008). Spiritual care in adults with cancer has been shown to improve quality of life, enhance patient satisfaction with health care, increase the use of hospice, decrease the use of aggressive medical interventions at the end of life, and diminish medical costs (Balboni et al., 2010; Balboni et al., 2011; Williams, Meltzer, Arora, Chung, & Curlin, 2011). While several studies have identified the association between spiritual well-being in adults with cancer and decreased levels of stress and anxiety and increased levels of hope, minimal research has explored the impact of spiritual well-being for children at the end of life and their families (Kaczorowski, 1989; Knapp et al., 2011; Kurtz, Wyatt, & Kurtz, 1995; Mickley, Soeken, &Belcher, 1992; Yates, Chelmer, James, Follansbee, & McKegney, 1981). Additional research investigating the effects of spiritual care in pediatric populations and their families is sorely needed to evaluate if spiritual care assists children with cancer to better cope with the challenges encountered at the end of life and continue to live full lives, even as death approaches.

Statement of the Problem

Experts concur that a comprehensive focus on the health of an individual's mind, body, and spirit is paramount in the provision of comprehensive patient care at the end of life (Puchalski et al., 2009). Professional organizations and accrediting bodies have indicated that spirituality must be addressed in the provision of quality nursing care (American Nurses Associations, 2010; International Council of Nurses, 2006; Joint Commission on Accreditation of Healthcare Organizations, 2004). However, spiritual care has infrequently been addressed in nursing education and research (Hufton, 2006; Mitchell, Bennett, & Manfrin-Ledet, 2006). In a survey of students and faculty at 12

Midwestern nursing schools, Meyer (2003) found that less than 6.4% of nursing classroom discussions and less than 8.3% of clinical discussions include the topic of spirituality or spiritual care of patients. Smith and Gordon (2009) suggested that there are distinct barriers that lead health care professionals to feel unprepared to address patients' and families' spiritual needs in clinical practice. These barriers include a lack of knowledge about the effect of spiritual care on patient outcomes, a failure to recognize patients' spiritual needs, and a lack of understanding of the best ways to provide spiritual care (Sulmasy, 2006). Nurses and other health care professionals receive minimal training about how to provide spiritual care specifically to children with cancer and their families (Purow et al., 2011). Gaps in nurses' knowledge and perceived competence to provide spiritual care may prevent many children with cancer and their families from receiving adequate spiritual care at the end of life (Knapp et al., 2011). Previous studies have not addressed whether an educational program specific to the provision of spiritual care will assist pediatric oncology nurses to feel competent to provide spiritual care to children with cancer at the end of life and their families.

Purpose and Specific Aims of the Study

The purpose of this study is to determine the potential impact of an online spiritual care educational program on pediatric nurses' perceived spiritual care competence (as measured by the Spiritual Care Competence Scale) and their attitudes towards/knowledge of spirituality and spiritual care (as measured by the Spirituality and Spiritual Care Rating Scale). The relationship between nurses' attitudes towards/knowledge of spirituality and spiritual care and their perceived spiritual care competence will also be evaluated (McSherry, Draper, & Kendrick, 2002; van Leeuwen, Tiesinga, Middel, Post, &

Jochemsen, 2009). This project made an original contribution to the science of end of life care, for it is the first study that examined the potential effects of a theory-driven educational program on nurses' attitudes, knowledge, and competence to provide spiritual care for children with cancer at the end of life and their families. The program was delivered online and was completed at the learner's own pace. In order to determine the impact of this spiritual care educational program, the following specific aims were addressed:

1. Evaluate the potential effect of the online spiritual care educational program on nurses' perceived spiritual care competence, as measured by the Spiritual Care Competence Scale (SCCS) (van Leeuwen, Tiesinga, Middel, Post, & Jochemsen,, 2009).

2. Evaluate the potential effect of the online spiritual care educational program on nurses' attitudes towards and knowledge of spirituality/spiritual care, as measured by the Spirituality and Spiritual Care Rating Scale (SSCRS) (McSherry et al., 2002).

3. Investigate if the amount of change in nurses' attitudes towards and knowledge of spirituality/spiritual care, as measured by the SSCRS, predicts the amount of change in nurses' perceived spiritual care competence, as measured by the SCCS

Significance to Nursing

It is through first educating pediatric nurses about how to effectively provide spiritual care to children with cancer at the end of life and their families that future work may be done investigating the effects of spiritual care on outcomes for children and their families. By quantitatively evaluating the potential effects of a theory-driven spiritual care

educational program for pediatric nurses, this study serves as a foundation for future research efforts investigating the outcomes of spiritual care on patient care outcomes including quality of life, parent satisfaction with care, utilization of hospice services, use of aggressive medical interventions at end of life, and medical costs. While the relationship of nurses' spiritual care to these important patient outcomes has been investigated in the adult population, research has not addressed these relationships in the care of children with cancer at the end of life and their families (Balboni et al., 2010; Balboni et al., 2011; Williams et al., 2011).

Significance to Vulnerable Populations

In today's world, vulnerability consists of a convergence of multiple factors and extends through race, ethnicity, class, and gender. During times of illness, vulnerability also includes patient and family exposure to harm, as well as the patient's diminished or absent capacity for self-protection. The risk of harm increases for individuals and families who have few economic, social, psychological, and spiritual resources to draw upon in times of difficulty (Aday, 1994). Vulnerable individuals may be at risk for poor physical, psychological, social, or spiritual health due to community or individual characteristics, as well as life circumstances that increase the probability of poor health-related outcomes (Aday, 1994). This vulnerability to harm during times of illness may lead to a reliance on other individuals, including nurses, to offer protection in ways that are not always necessary for healthy individuals (Sellman, 2005). Children with cancer who are at the end of life are an extraordinarily vulnerable population. The extent of their exposure to potential harm is great and their capacity for self-protection is either absent or

substantially decreased by nature of their age and disease status (Dixon-Woods, James, Kippen, & Liamputtong, 2008).

Parents caring for a child with cancer who is at the end of life are vulnerable to a multitude of potential negative health outcomes due to effects of stress on the hypothalamic-pituitary-adrenal axis, neuroendocrine function, and the immune system (Dickson-Swift, Findlay, Young, Cox, & Heney, 2001). Studies have indicated a statistically significant increased risk of mortality due to unnatural and natural causes in bereaved mothers even twenty years after a child's death, and this risk is greatest during the first three years after the child's death. Bereaved fathers have been found to have a slightly increased risk of mortality from unnatural causes in the first three years after their child's death (Li, Precht, Mortenson, & Olsen, 2003). The death of a child also results in a markedly increased risk of suicide for both bereaved mothers and fathers, especially when the child died in early childhood; this risk is greatest during the first month after the child's death (Qin & Mortensen, 2003). In a large evaluation of data from Denmark registries (n=314,807), researchers found that parents who faced the death of a child were at higher risk of hospitalization due to mental illness including affective disorders, schizophrenia, and substance abuse. The highest risk of hospitalization for a psychiatric disorder for bereaved mothers was during the first year after the child's death, but a significant elevation of relative risk was found during the first five years after the child's death. Bereaved fathers experienced a decline in the relative risk of hospitalization due to an affective disorder over time; only a risk of hospitalization for substance abuse stayed significantly elevated after five years (Li et al., 2005).

The death of a child is likely one of the most profound losses a parent may experience, a tragedy that may have long-term effects on those left behind (Rogers, 2008). Parents of children who have died may experience significant grief and vulnerability to harm for an extended period of time after a child's death (Thompson et al., 2011). The findings from the literature underscore the importance of nursing care for children with cancer at the end of life and their families to provide support, enhance coping, and address spiritual distress (Alam, D'Agostino, Barrera, Schneiderman, & Nicholas, 2012; Dell'Orfano, 2002; Fletcher, Schneider, & Harry, 2010; Foster, Lafond, Reggian, & Hinds, 2010; Meert, Thurston, & Briller, 2005; Meyer et al., 2006; Robert et al., 2012; Robinson et al., 2006; Schneider & Mannell, 2006; Wheeler, 2001; Woodgate et al, 2003; Yeh, Lee, & Chen, 2000; Zeller, Catandella, Cairney, & Bannister, 2010).

The ethical principle of justice mandates that all individuals receive consistent and equivalent care; data suggest that spiritual care is not provided to all patients, thereby supporting the need for spiritual care educational programs to assist nurses to overcome barriers to providing spiritual care (Cerra & Fitzpatrick, 2008; Feudtner et al., 2003; Sulmasy, 2006). The proposed research addresses the vulnerability of children with cancer at the end of life and their families through evaluation of a spiritual care educational program that has been specifically designed with the assistance of multidisciplinary experts, children, and their families. The goal of this program was to assist pediatric nurses to address the spiritual needs of children with cancer at the end of life and their families, with the aim of reducing suffering and guiding them to find peace.

Conclusion

It is a distinct responsibility of nurses to provide patients with care that reduces their vulnerability to harm and suffering (Sellman, 2005). In addressing the spiritual needs of young patients and their families, nurses' provide one dimension of comprehensive end of life care that may allow for protection from harm. There is a definitive need for research to determine spiritual care needs of children with cancer and their families and ways to best meet these needs. This study will evaluate the potential effects of a spiritual care educational program on nurses' perceived attitudes towards and knowledge of spirituality/spiritual care and nurses' perceived competence to provide spiritual care to children with cancer who are at the end of life. In addition, this study will be the first investigation to incorporate both the Spiritual Care Competence Scale (SCCS) and the Spirituality and Spiritual Care Rating Scale (SSCRS) to evaluate the relationship between nurses' perceived attitudes towards and knowledge of spirituality/spiritual care with their perceived spiritual care competence (McSherry et al., 2002; van Leeuwen, et al., 2009). The results will lay the foundation for future research to evaluate the effects of spiritual care on outcomes for children with cancer at end of life and their families.

Comprehensive spiritual care education for nurses is necessary to improve the delivery and outcomes of nursing care at the end of life (Cocknell & McSherry, 2012). It is vital for nurses to continue to pursue educational opportunities once in practice to ensure the highest level of nursing practice that is congruent with current evidence Through the provision of spiritual care, nurses enable vulnerable patients and their families to attain important goals of end of life care: a relationship of trust with the health care team and, optimally, a peaceful death for the child (Petersen, 2013).

CHAPTER TWO
Background

This chapter reviews the literature that is relevant to the development of the educational program and the conduct of this study. First, the chapter includes a discussion of the concepts of palliative and end of life care. Next, a comprehensive integrative review is included regarding the effects of spiritual care education for practicing nurses, with critical analysis of the quality of the existing research. Additional content in this chapter reviews the existing body of literature regarding spiritual care of children with cancer at the end of life and their families. A concept analysis was completed to delineate the critical attributes, antecedents (preceding phenomena), and consequences of nurses' spiritual care of the child with cancer at the end of life, and the subsequent manuscript is presented in Appendix A (Petersen, 2013). Next, a scoping review highlights the role of spiritual care in minimizing vulnerability for parents whose children have been diagnosed with cancer or who face the end of life. In addition, the literature addressing the value of spiritual care for siblings whose brother or sister died was reviewed. These comprehensive literature reviews provided the theoretical basis for development of the spiritual care educational program and form the foundation for conduct of this study.

In addition, this chapter includes a review of the state of the science of online nursing education and strategies to enhance online learning; this literature guided design of the online spiritual care educational program that is evaluated in this study. Lastly, this chapter includes a discussion of the conceptual framework and the philosophical perspective that form a foundation for this study. Assumptions based on the primary investigator's ontological perspective of the construct of spirituality, spiritual care, and

spiritual care education will be reviewed. The gaps in theory and practice that became evident through review of the existing body of literature will be addressed. By addressing deficits in nurses' knowledge and competence, this study aims to change nursing practice to improve the care of terminally ill children and their families.

Palliative and End of Life Care

Since the emergence of reports such as the National Consensus Project for Quality Palliative Care (2013), there continues to be a growing recognition of the benefits of palliative and end of life care. As modern technology expands our ability to support life, the importance of balancing medical technology with humanistic, holistic care that addresses patients' physical, psychological, social, and spiritual needs has become increasingly clear (Petersen, 2014). Palliative care is a philosophy, as well as a system for delivering patient care that prioritizes quality of life for the patient and the family, optimal level of function, assistance with the decision-making process, and opportunities for individual growth throughout the illness experience (National Consensus Project for Quality Palliative Care, 2013). This care is provided at any time point in the disease trajectory; optimally, palliative care should be initiated when an individual is diagnosed with a life-threatening or life-altering disease to allow for relationships to be established over time. Care is provided by an interdisciplinary team made up of occupational therapists, child life specialists, physical therapists, psychologists, social workers, physicians, nurses, and chaplains (Zahradnik, 2013).

Palliative care is the art and the science of preventing, managing, and relieving physical, psychosocial, emotional, and spiritual suffering through impeccable assessment and treatment, with focus placed on cure, palliation of suffering, and management of the

pain of bereavement (World Health Organization, 2013). Primary goals of palliative care are to enhance an individual's quality of life and maximize respect for cultural and spiritual values and beliefs (National Association of Orthopedic Nurses, 2005). The patient and family are typically viewed as one entity at the center of care (Himelstein et al., 2004).

The critical attributes of quality of life from the perspective of the individual are important to consider (Petersen, 2014). These attributes include an individual's subjective evaluation of the nature of their lives including satisfaction with the physical, psychological, social, and spiritual domains. The physical domain includes health and physical functioning, and the psychological domain is focused on emotional well-being. Relationships with others, a sense of belonging, and social roles are included in the social domain. The spiritual domain is centered on spiritual well-being, satisfaction with life, and a sense of fulfillment (Mandzuk & McMillan, 2005).

Effective communication is an important focus of palliative care in order to allow formation of a true partnership between the patient, family, and health care team so that the patient's values, beliefs, and wishes can be adequately identified and respected (Cozier & Hancock, 2012). In addition, hope is an essential aspect of palliative care, regardless of the patient's prognosis. Hope provides a way of coping with tragedy, thereby allowing a patient to look forward to realistic and sometimes redefined goals, even if the disease progresses (Bergstraesser, 2013). Words must be chosen carefully to instill hope, allowing a patient to look forward to future activities or events while still being realistic in acknowledging the typical trajectory of the illness (O'Shea & Bennett-Kanarek, 2013).

End of life care involves applying the concepts of palliative care to patients with advanced, chronic, or life-threatening illnesses who may have an estimated one to two years or less to live (Ferrell & Coyle, 2010). End of life care focuses on maintaining individuality and dignity in the provision of care; maximizing quality of life through effective symptom management; and minimizing physical, psychological, and spiritual suffering through interventions to assist a patient to achieve a peaceful death (Hendrickson & McCorkle, 2008). If the end of life experience is to be as peaceful and free from suffering as possible for a dying child, comprehensive control of physical symptoms is urgently required, as well as subsequent assessment and management of the psychological, social, and spiritual needs of the child and the family (Postovsky & Arush, 2004). The quality of end of life care has an immense effect not only on the child who is dying, but also on the family members, for the manner in which a child's end of life care experience is managed has a tremendous impact on the lives and the memories of their loved ones forever (Postovsky & Arush, 2004). The provision of spiritual care to address the spiritual needs of patients and their family members is considered a vital dimension of holistic end of life care (Ferrell & Coyle, 2010).

Spiritual Care of Children with Cancer at the End of Life

Spirituality is an important resource in times of distress and tragedy and a vital support throughout the illness or death of a loved one (Ross, 1995). While there has not been a great deal of research completed in the realm of spirituality in children, spirituality may exert an effect on coping with illness by assisting children in the search for answers, the quest for meaning, the building of strong relationships, and the escape from feelings of loss and fear (Fulton & Moore, 1995; Hufton, 2006). In providing care to children at the

end of life, palliative care clinicians often witness spiritual growth and the strength of the human spirit (Jones & Weisenfluh, 2003). However, dying children may also experience substantial spiritual suffering and distress at the end of life (Foster et al., 2012). Spiritual care, an essential aspect of end of life care of children, aims to assist children and their families to attain spiritual growth and overcome spiritual distress as the end of life approaches (Foster et al., 2010). The nursing process provides an organizing framework for the provision of spiritual care and includes the assessment and diagnosis of spiritual needs, planning and implementation of spiritual care interventions, and evaluation of the efficacy of these interventions (Greenstreet, 1999).

A concept analysis was conducted to further delineate the antecedents, attributes, and consequences of nurses' spiritual care for children with cancer at the end of life. Antecedents, or preceding phenomena, were identified and included a child's spiritual distress and existential questions at the end of life. Nurses' spiritual care for a child with cancer at the end of life included the following attributes: assessing spiritual needs; aiding the child to find hope; assisting the child to express feelings and concerns; guiding the child in strengthening relationships; helping the child to be remembered; and assisting the child to find meaning and purpose. The consequences or outcomes of spiritual care were identified as a relationship of trust with the health care team, enhanced end of life care, spiritual growth, and a peaceful death (Petersen, 2013). While these consequences are not always attained by children who are dying of cancer, they are the pre-eminent goals of nurses' spiritual care. This manuscript, entitled "Spiritual Care of the Child with Cancer: A Concept Analysis," is attached as Appendix A (Petersen, 2013).

Spiritual Care for Parents of Children with Cancer

In providing care to children with cancer at the end of life, nurses must also assess and address the spiritual needs of their parents (Hart & Schneider, 1995). Parents whose children are at the end of life often rely on spirituality and faith in a higher power as coping mechanisms to help them face immense stressors (Knapp et al., 2011). Spiritual care involves interactions to support the spirituality of patients and their families through purposeful monitoring and compassionate response to spiritual needs, with a goal of assisting patients and their families to find greater meaning, hope, and peace (Burkhart & Hogan, 2008). As death approaches for a child, spiritual care may assist parents to shift focus from the search for a cure to the hope for attainment of smaller, meaningful goals, such as the desire for a better relationship with a higher power, the accomplishment of certain events or activities, or a dignified, peaceful death for their child (Keene-Reder & Serwint, 2009; Robinson et al., 2006). Spiritual care to address parents' spiritual needs allows for the creation of an environment that may enable spiritual growth, even in the midst of an overwhelming tragedy (Woodgate et al., 2003). This comprehensive care allows children and families to treasure their final days and weeks together as a family.

A scoping review of the literature was completed to identify the effects of spirituality and spiritual care on the vulnerability of parents whose children have been either diagnosed with cancer or who faced the end of life. This review was completed to guide development of portions of the theory-driven spiritual care educational program that is evaluated in this study. A scoping review was completed due to the exploratory nature required and the scant amount of empirical research in this domain. This type of review is especially appropriate for areas with emerging evidence in which there is a lack of

quantitative research; the scoping review allows for the incorporation of a range of study designs in the published research and grey literature, addressing questions beyond intervention effectiveness to generate new knowledge (Grabovschi, Loignon, & Fortin, 2013; Levac, Colquhoun, & O'Brien, 2010). A scoping review also allows for a mapping of the primary concepts in a research area, key sources and types of evidence, and delineation of the depth and breadth of available knowledge (Arksey & O'Malley, 2005). The Arksey and O'Malley (2005) methodological framework guided the conduct of this scoping review. Requisite steps included identification of the research question; search for relevant literature; selection of articles based on specific inclusion and exclusion criteria; charting of data to allow thematic extraction; and summarization and report of the results to provide an overview of the breadth of the literature (Arksey & O'Malley, 2005). Synthesis provided a summary of themes regarding the effects of spirituality/spiritual care for parents whose children were diagnosed with cancer or whose children faced the end of life. The review identified the following themes regarding the benefits of spirituality/spiritual care: providing support, enhancing coping, instilling hope, finding meaning and purpose, and developing continuing bonds. Please see Table 1.

Providing Support

Two studies found that spiritual care provided requisite support for parents whose children were diagnosed with cancer (Dell'Orfano, 2002; Robert et al., 2012). In a qualitative study investigating the important aspects of end of life care from the perspective of parents whose children died, social support was one of four key themes delineated from focus group discussions. Comments from parents highlighted the inherent value of spiritual care from nurses, friends, and family members as an invaluable aspect of

social support that assisted them to cope with their child's death (Robert et al., 2012). Another study addressed the value of spiritual care in providing parents with support to face their child's illness. In interviews with 10 parents of children with neurologic compromise from cancer or physical injuries, 9 parents (90%) highlighted that nurses provided valuable spiritual care to their children and families. Spiritual care involved nurses' supportive acts of caring, compassion, and respect for patients' and families' individualized needs. Parents stressed that psychological support was received from relationships with family and friends, as well as from prayer; prayer offered a powerful source of comfort that was greatly appreciated by parents who faced their child's debilitating neurologic compromise (Dell'Orfano, 2002).

Enhancing Coping

In reviewing the literature, four studies found that spirituality or spiritual practices enhanced coping for parents whose children were diagnosed with cancer (Meert et al., 2005; Meyer et al., 2006; Robinson et al., 2006; Schneider & Mannell, 2006). One study (*n*=12)identified that spirituality served as a "beacon in the storm," paving the way for parents to restore their lives and find a meaningful future (Schneider & Mannell, 2006, p.3). In this phenomenologic study, researchers identified that spirituality was a key coping mechanism for each of the parents living with a child with cancer. Parents reported turning to their faith, beliefs, or spiritual advisors and clergy as sources of comfort throughout their child's illness in order to help them deal with the feeling of loss of control. An important aspect of spirituality noted by these parents was nature, which uplifted and comforted them during their child's cancer illness. Prayer was also described as an extremely powerful coping resource. These parents reported that spirituality had a

positive influence on their coping behaviors and helped their child to heal and find peace at the end of life. Prayer assisted them in coping with their child's illness by providing a concrete action that they could do to help their child (Schneider & Mannell, 2006). While some parents explained that they questioned their faith, they typically reported later returning to their beliefs as a source of comfort after the spiritual crisis was over (Schneider & Mannell, 2006). Similarly, a qualitative study of parents whose children died (*n*=56) in the pediatric intensive care unit found that parents acknowledged the spiritual distress they sometimes faced as their child was dying, and religious faith and prayer were central to their ability to eventually cope effectively with their child's death. Spiritual support from religious leaders and social/emotional support from religious communities also sustained them as their child was dying (Meyer et al., 2006).

Robinson et al. (2006) completed additional analysis of data from the Meyer et al. (2006) study and found that 41 of 56 parents (73%) included spiritual themes when asked about what helped them to get through their child's death. When asked to identify the advice that they would give to other parents facing a similar situation, they delineated the following resources: prayer, faith, access and support from clergy, and belief in the ongoing nature of their relationship with their child, even after death. Parents' spirituality provided emotional sustenance that assisted them during and after the loss of their child; they often described the tragedy first and foremost as a spiritual journey (Robinson et al., 2006).

Spiritual care to address the spiritual needs of parents whose children were at the end of life was found to provide great comfort to them, enhancing their ability to cope effectively. During interviews that occurred 2 years after a child's death (*n*=33), parents

were asked about their spiritual needs and how they were best met; they explained that healing words and compassionate actions from health care professionals offered great spiritual support and assisted these grieving parents to cope with the tragedy of their child's death. Effective spiritual care interventions that parents specifically identified included attentive listening, encouragement for parents to be involved in the child's care, availability of staff, and expression of emotions (Meert et al., 2005).

Instilling Hope

Two studies highlighted the importance of spirituality for fostering hope in parents whose children were diagnosed with cancer, even when their child's prognosis was grim (Fletcher et al., 2010; Zeller et al., 2010). In semi-structured focus group interviews that explored the end of life experience, parents of children with brain tumors (n=25) identified that spirituality, specifically personal sources of spiritual strength, provided hope for the future and strength in the face of adversity (Zeller et al., 2010). They reported that hope comforted them even as they faced their child's final days, allowing them the ability to function effectively as a caregiver despite the intense despair they felt. Their sense of hope did not cause them to be unrealistic about their child's future; while many parents continued to hope for a cure even at the end of their child's life, they were also able to realistically acknowledge the child's poor prognosis, while still hoping for a miracle (Zeller et al., 2010).

Similarly, a phenomenologic study of the lived experience of female caregivers of children with cancer (n=9) revealed that faith, positive thinking, hope, and religion assisted them in their ability to look towards the future. Spiritual faith in the afterlife served as a strong source of hope. Spiritual faith provided resilience that allowed them to

continue on towards a future that they realized might not include their beloved child (Fletcher et al., 2010).

Finding Meaning and Purpose

Parents often attempt to impose order on their experiences by attributing meaning and purpose to the death of their child (Meert et al., 2005). Spiritual care of parents whose children with cancer are at the end of life involves assisting them to find meaning and purpose in the life and death of their child, as well as renewed meaning in their own lives once their child has died. A child's death may disrupt parents' sense of identity and their relationships, as well as challenge their view of the world. Four studies highlighted this theme (Meert et al., 2005; Meyer et al., 2006; Wheeler, 2001; Yeh et al., 2000). In a grounded theory study, Taiwanese parents whose children were diagnosed with cancer (n=32) reported an increased reliance on spiritual practices in the search to find meaning from their experiences; spiritual beliefs often assisted these parents in the search for meaning in their child's short life, as well as the purpose of their child's death. The search for meaning regarding the death of their child was often the last step in the adaptation process that allowed them to move forward with their lives (Yeh et al., 2000).

Parents whose children with cancer were at the end of life reported in one-on-one interviews (n=33) that many of their spiritual needs centered around finding meaning in their child's life, death, and suffering (Meert et al., 2005). In fact, a majority of parents in another large study (n=176) responded that the death of their child resulted in a crisis of meaning in which they needed to find a purpose in their child's life and death, as well as a renewed purpose for their own lives in order to move forward and reinvest in living (Wheeler, 2001). Meaning was eventually found by most parents through relationships,

activities helping others, and experiences of personal spiritual growth; parents explained that these experiences allowed them to become better people (Wheeler, 2001). Similarly, in a study of 56 parents whose children died in three Boston hospitals, religious faith was identified as a priority in end of life care that was central to their ability to make meaning of the death of their child (Meyer et al., 2006).

Developing Continuing Bonds

The death of a child involves the loss of parents' hopes and dreams for their child and a reversal of the natural order of life (Alam et al., 2012). Three of the studies examined in this scoping review included this theme in findings (Alam et al., 2012; Fletcher et al., 2010; Meert et al., 2005). Parents whose children died of cancer reported that religious beliefs allowed them to maintain a continuing bond, a way to stay connected with their child even after the child's death. Continuing bonds allowed them to manage the pain of grief and bereavement (Alam et al., 2012). Similarly, in retrospective interviews as a part of an exploratory phenomenologic study, parents of children who died reported that remembering the child was a key factor that allowed them to continue on with their lives. By keeping the child's memory alive, the relationship between parent and child, although changed, continued on in a different form (Fletcher et al., 2010).

A child's death may alter parents' sense of identity, disrupt relationships, and challenge their view of the world. In a qualitative study that employed thematic analysis of videotaped interviews, 33 parents of children who died reported that memories made while the child was alive provided a vital connection after their child's death and served as a great source of comfort that extended beyond death for years to come (Meert et al., 2005).

Spiritual Care for Bereaved Siblings

According to Forward and Garlie (2003), bereaved siblings reported that they, too, search for new meaning from their loss and attempt to find ways to go on with their lives after the death of their brother or sister. The experience allowed some individuals to find personal growth that changed them in a positive way and strengthened them. Some children believed that spiritual beliefs provided comfort and a sense of a continuing bond with the child who died, offering the hope of being reunited in the afterlife or a belief that their brother or sister was in a better place (Forward & Garlie, 2003). Spirituality allowed siblings of children who have died to heal and to move on to live productive lives, while still maintaining a relationship with the deceased child (Davies, 1999).

Expression of feelings is an important aspect of healing for siblings of children who have died. Parents and other adult role models play a vital role in helping siblings face the death of their brother or sister, adapt to the loss, and move forward with their lives; loved ones should encourage the expression of feelings but must understand that some children may express their feelings better through other means of expression, such as writing or music. Siblings of a child who died may turn to a friend, aunt, or teacher to share feelings due to concern for their parents and the wish not to additionally burden them (Packman, Horsley, Davies, & Kramer, 2006).

Siblings report that interventions to continue the bonds with a child who has died are important to adaptation and coping after the death of their brother or sister (Forward & Garlie, 2003). It can be helpful for siblings to have a possession that belonged to the deceased child, a photo in their wallet, a special toy the child loved, or an item that belonged to their brother or sister. Creation of a memory book of favorite photos or a

journal allows family members to share thoughts, and happy memories may allow a family to commemorate a deceased child's memory (Packman et al., 2006). Bereaved siblings also report the importance of maintaining a connection with their deceased brother or sister by completing specific actions to continue the relationship, such as sharing conversations to keep happy memories alive or praying to their deceased brother or sister for help (Forward & Garlie, 2003; Davies, 1999).

Interventions to address the need for strong relationships with friends, family, or a higher power are important for siblings of children who have died. Play dates with friends, school, and normal daily activities are powerful tools to help siblings cope effectively and to find a much needed break from the grieving process (Davies, 1999). Attendance at a sibling bereavement group may help bereaved siblings realize that they are not alone in their grief, and interactions there may assist them to learn strategies to manage their feelings of loss. These support groups also provide a safe environment for them to share their feelings and concerns with others who have gone through a similar experience of loss (Packman et al., 2006).

Spiritual Care Education

In reviewing the literature, it is noted that spiritual care education for nurses is critical to providing quality spiritual care to children and their families and to meeting national end of life care guidelines, such as the National Consensus Conference Guidelines on Spiritual Care as a Dimension of Palliative Care (Balboni et al., 2013; Cerra &Fitzpatrick, 2008; Puchalski et al., 2009). Spiritual care educational programs may enhance nurses' knowledge and understanding of spiritual care and improve nurses' perceived competence to provide spiritual care (Lovanio & Wallace, 2007).

An integrative review was completed to evaluate the current state of the science regarding spiritual care education for nurses. Previous studies that investigated the effects of spiritual care educational programs on nurses' perceived spiritual care competence, nurses' attitudes towards and knowledge of spirituality/spiritual care, and patient care outcomes were reviewed.

The proliferation of nursing research in the past several decades has led to the need for a better process to synthesize knowledge related to a certain topic (Morin, 2012). The integrative review is a goal directed, systematic process that allows for the inclusion of diverse methodologies, with the potential to exert greater effect on the evidence base, informing research, practice, and policy initiatives (Whittemore & Knafl, 2005). The integrative review allows experimental and non-experimental findings to be synthesized to answer specific questions, identify gaps in the literature, and gain a more complete understanding of a phenomenon of interest. Critical analysis is followed by integration and knowledge generation, resulting in a reflection on the state of the science (Whittemore & Knafl, 2005). Whittemore and Knafl (2005) developed foundational guidelines for a systematic method of data analysis to protect against bias and improve the accuracy of resultant conclusions. The Whittemore and Knafl (2005) guidelines were employed in this integrative review. The Strength of Recommendation Taxonomy (SORT) guidelines, a comprehensive taxonomy to evaluate the quality, quantity, and consistency of the evidence in this integrative review (Ebell et al., 2004).

The purpose of this integrative review was to examine the evidence base regarding the effects of spiritual care educational programs on practicing nurses' attitudes, perspectives, level of knowledge, and spiritual care competence, as well as effects on

patients and nurses. An electronic search of the literature was completed, as well as an ancestral search strategy. The literature search was not limited by start date, and literature through the current date was included in order to capture changes in the understanding of the phenomenon over time. Inclusion criteria were English, peer-reviewed empirical research texts in the CINAHL, MEDLINE, and ERIC databases, which were deemed most likely to include relevant studies for this review. Exclusion criteria were case studies and research that did not involve focus on the effects of a spiritual care educational intervention on practicing nurses' attitudes, knowledge, or perceived spiritual care competence. Research studies focused on interdisciplinary education were included in this review if participants included nurses. Opinion essays were not included, for they would not provide solid evidence.

Searches were first completed in CINAHL using keywords and subject headings of spirituality/spiritual care and education, as well as spiritual care/baccalaureate/nursing. Dissertations were included in the CINAHL searches. Truncation was used to search for variations of word root endings. The CINAHL searches resulted in 149 articles for review. A MEDLINE search using the terms students, nursing, and spiritual care initially resulted in 141 articles. A third search was completed in ERIC using the keywords spiritual care and nurs*, resulting in 6 articles for further consideration. Next, all abstracts were reviewed, and articles that did not meet eligibility criteria were excluded from further analysis. An ancestral search was then employed by tracing hallmark citations from the reference lists of articles identified in the search. Critical analysis identified 15 articles that met all of the inclusion criteria, with 1 article from CINAHL, 6 articles from MEDLINE, 0 articles from ERIC, 1 dissertation, and 7 articles from the ancestral review.

Each article was then categorized in a matrix based upon the following criteria: design, sample/setting, independent and dependent variables, results, characteristics of the educational program, data collection instruments, statistical analyses, and study limitations. These categories were then synthesized to enhance visualization of patterns and interpretation of data.

In reviewing the quality, quantity, and consistency of the evidence according to the SORT guidelines, the strength of the recommendations from this body of evidence regarding was a rating of B on a scale of A-C, with A being the strongest recommendation and C being the weakest recommendation. While most studies in this integrative review found similar or coherent conclusions, there was limited quantity and quality of patient-oriented evidence regarding the direct benefits on the patients who receive spiritual care (Ebell et al., 2004). Only 1 study in this review focused on patient-oriented evidence and could be considered as level 2 evidence (Vlasblom, van der Steen, Knol, & Jochemsen, 2011); the remaining studies were level 3 evidence since they did not involve patient-related outcomes (Ebell et al., 2004). The dates of publication for research studies that were examined in this integrative review ranged from 2001-2013, and 73.3% of the 15 studies were published between 2008-2013 (*n*=11). Please see Tables 2-5 (renumber tables in back. The United States was the setting for 53.3% of the studies (*n*=8). Qualitative methods were employed for 20% of the studies (*n*=3), quantitative methods for 73.3% (*n*=11) of the studies, and mixed methods for 6.7% of the studies (*n*=1). For the qualitative studies, data analysis involved content analysis in 1 qualitative study (Baldacchino, 2011) and 1 mixed methods study (Ellman et al., 2012), Colazzi's phenomenologic method for 1 study (So & Shin, 2011), with no method of data analysis

noted in the final study (Shih, Gau, Mao, Chen, & Lo, 2001). The design was quasi-experimental pretest/posttest for 93.3% of quantitative studies (*n*=10), with 6.7% of quantitative studies (*n*=1) employing a randomized controlled trial.

Only 45% (*n*=5) of the studies with pretest-posttest design evaluated the effect of the intervention longitudinally (van Leeuwen, Tiesinga, Middel, and Post, 2008; Meredith, Murray, Wilson, Mitchell, & Hutch, 2012; Sandor et al., 2006; Wasner, Longaker, Fegg, & Borasio, 2005; Vlablom et al., 2011). Sample characteristics included nursing students from diploma, baccalaureate, and graduate programs; interdisciplinary studies included students from medicine, social work, pastoral care, nursing, and hospice volunteers; and additional studies included practicing nurses from acute care units, pediatrics, palliative care, and community agencies. One study offered participants a stipend for participation (Taylor, Mamier, Bahjri, & Anton, 2008). In the studies with interdisciplinary participants, 10.4-60.1% of participants were men. In the studies with solely nursing participants, 0-22.3% of participants were men. Data analysis for the quantitative studies most frequently employed paired samples t-tests (26.7%, n=*4*) (Lovanio & Wallace, 2007; Meredith et al., 2012; O'Shea, Wallace, Griffin, & Fitzpatrick, 2011; van Leeuwen et al., 2008); nonparametric tests (20%, n=3) (Costello, Atinaja-Faller, & Hedberg, 2012; Ellman et al., 2012; Wasner et al., 2005); repeated-measures ANOVA (13.3%, n=*2*) (Sandor et al., 2006; Taylor et al., 2008); and independent samples t-tests (13.3%, n=*2*) (Burkhart & Schmidt, 2012; Vlasblom et al., 2011). Of the quantitative studies, 100% found some statistically significant results (n=*11*).

Spiritual care educational programs ranged from 30 minutes (O'Shea et al., 2011) to 32 hours in duration (Baldacchino, 2011), with only 1 of the educational

programs focused solely on PowerPoint lecture (O'Shea et al., 2011). All other educational programs included multiple modalities for presentation of materials, including theory-based lectures, self-study, spiritual care practicum, online discussions, lectures, field trips, group discussions, case studies, journal reflections, or readings. Only one study completed a power analysis to ensure adequate statistical power to detect differences (Taylor et al., 2008), while three studies employed a control group (Burkhart & Schmidt, 2012; van Leeuwen et al., 2008; Vlasblom et al., 2011). Only 1 study utilized Bonferroni correction when completing several statistical analyses with a single data set (Wasner et al., 2005).

To compare research results in this integrative review, studies were organized according to assessed outcomes, including effects of spiritual care educational programs on nurses' level of knowledge, attitudes and perspectives toward spiritual care, and spiritual care competence, as well as effects on patients and the health care professionals, themselves.

Effect of Spiritual Care Education on Knowledge

Nurses' lack of knowledge and confidence in their ability to address patients' spiritual needs may inhibit the provision of spiritual care (Kellchear, 2000). Knowledge is defined as information, awareness, and skills obtained through experience or education (Merriam-Webster, n.d.). Seven studies evaluated the effects of spiritual care educational programs on nurses' level of knowledge (Table 1). Ellman et al. (2012) evaluated the use of a blended online course and interactive simulation to teach spiritual, cultural, and interprofessional aspects of palliative care to students from nursing, medicine, divinity, and social work in the United States. Free text responses to four online reflections were

evaluated in this mixed methods study; open-ended questions on post-course questionnaires focused on programmatic quality and attainment of learning objectives. Responses were evaluated with content analysis, as well as descriptive statistics. The program was rated highly by participants for educational quality and usefulness for future professional work; participants indicated that the program met its five learning objectives. Qualitative analyses addressed the high quality of the material and the importance of issues like spirituality that are traditionally beyond their discipline (Ellman et al., 2012). Limitations of this study included the reliance on student report and the lack of a reliable, valid tool to measure responses regarding knowledge gained from the intervention. Because the representation from social work was limited, responses from social work students were dropped from analyses. Higher learning outcomes, like acquired knowledge or behavioral changes, would enhance future research in this area. Limitations to qualitative processes were apparent, including the lack of use of criteria to enhance trustworthiness of the data and to minimize bias (i.e. data saturation, reflexivity, methods triangulation, participant review of findings, or support of themes with vivid quotations from participants) (Beck, 2009). Qualitative data analysis techniques were not discussed.

Three studies utilized quantitative designs, and all of these studies involved a quasi-experimental pretest/posttest design. An American study evaluated the effect of a mailed self-study program on nurses' and nursing students' ability to address spirituality with their patients (Taylor et al., 2008). Participants completed the Daily Spiritual Experience (DSE) scale to measure personal spiritual experience (Underwood & Teresi, 2002), the Spiritual Care Perspective Scale-Revised (SCPS-R) to measure attitudes toward spiritual caregiving (Taylor, Highfield, & Amenta, 1999), the Response Empathy Scale to

measure the ability to respond empathetically to a patient (Elliott et al., 1982), and Communicating for Spiritual Care Test to evaluate knowledge about how to communicate when providing spiritual care. Three of the instruments were reliable and valid instruments for measuring the desired constructs, with Cronbach's alpha values between .75-.92; however, the Communicating for Spiritual Care Test was designed by the principal investigator to test knowledge of the program content, and no psychometric testing was completed. Statistically significant increases in scores for each variable were seen for students and practicing nurses, including attitude towards spiritual care; ability to create an empathetic verbal response to a patient's spiritual pain; personal spiritual experience; and knowledge regarding communication in spiritual caregiving. Students' scores increased more than practicing nurses on the SCPS-R and the DSE. Findings suggested that spiritual care can be taught and that spiritual care education may be helpful to both students and nurses in varying contexts (Taylor et al., 2008). Limitations included the lack of longitudinal evaluation of the effects of the educational intervention, the risk of testing effect with repeated administration of the same scales, the lack of psychometric testing for the investigator-developed scale, and self-selection bias.

Meredith et al. (2012) investigated the effects of 4 workshops to improve palliative care staff members' knowledge and confidence in providing spiritual care to patients in Australia. Statistically significant changes were seen in knowledge of spirituality, spiritual care, personalized care, and confidence in providing care immediately after the workshop, as measured by the Spirituality and Spiritual Care Rating Scale (SSCRS) (Meredith et al., 2012). Improvements in scores were maintained 3 months later for knowledge of spiritual care and confidence in providing spiritual care, with confidence

continuing to grow from immediately post-workshop to 3 months later. Since numerous t-tests were completed to evaluate for statistical significance, the investigators explained that they employed a conservative level of significance (p=.01), but they did not make use of the Bonferroni correction. Limitations also included self-selection bias, limited generalizability, lack of a control group, and reliance on self-report, rather than behavioral measures of effect. The rate of attrition was high, for only 61% of participants returned the 3-month post-workshop questionnaire. Longer follow-up would be optimal to check retention of knowledge (Meredith et al., 2012).

Lovanio and Wallace (2007) conducted a pilot study with 8 nursing students who completed a 3-hour program on spirituality in nursing, integrated with a reflection journal and weekly clinical conference discussions. Completion of the intervention resulted in a statistically significant increase in scores on the Spirituality and Spiritual Care Rating Scale (SSCRS) (McSherry at al., 2002). The study results were limited by the small sample size, limited power, and homogeneous sample, and testing was done only immediately before and after completion of the program. The SSCRS has only an acceptable level of reliability documented in prior testing, with a Cronbach's alpha of .64 (McSherry et al., 2002).

Three qualitative studies evaluated the effects of a spiritual care educational intervention on nurses' level of knowledge. Baldacchino (2011) investigated the impact of a 28-hour study program with practicing nurses in Malta. Thematic analysis of responses to 5 open-ended questions identified two themes regarding the effects of the program: enhanced self-awareness of the nurse's role in spiritual care, including awareness of their own spirituality and increased knowledge about spirituality, spiritual

care, spiritual coping in illness, coping strategies, and ability to meet patients' spiritual needs (Baldacchino, 2011). More in-depth data may have been gathered by a focus group or face-to-face approach to collecting data. While the sample size was large for a qualitative study, the homogeneous characteristics of the participants (all were Christian) limited generalizability. Additional limitations included minimal description of the approach employed for data analysis, lack of use of triangulation, reflexivity, data saturation, or an audit trail, and no verification of findings with participants.

A phenomenologic study examined Korean nursing students' perceived gains in knowledge from a spiritual care practicum (So & Shin, 2011). Twelve nursing students in a Christian college diploma program participated in a 1-credit spiritual care practicum after completion of a spiritual nursing theory course. Interviews were conducted with each student upon completion of the practicum. Students identified difficulty grasping the abstract construct of spirituality, feelings of helplessness due to their lack of knowledge and ability to provide spiritual care to their patients, eventual improvement in coping skills, development of self-awareness, and spiritual growth. Limitations of this study included limited generalizability since all of the participants were Christian and the practicum focused solely on spiritual care of Christian patients. While researchers included vivid quotes to support themes, they did not include methods like triangulation and reflexivity during data collection and analysis to enhance trustworthiness and diminish bias. There were no details about an audit trail to enhance future replication of study findings.

A third qualitative study evaluated the clinical implications and knowledge gained from 18 weeks of classroom lectures, field trips, and discussions for 22 Master's level

nursing students in Taiwan (Shih et al., 2001). Methodological triangulation was employed in the development of course content, rather than in the conduct of the research, although the authors stated the design of the study was "methodological triangulation research design" (Shih et al., 2001, p. 333). As reported in narrative case studies and group discussions, the educational program resulted in enhanced knowledge for students in several realms: clarifying theoretical concepts of spiritual care, developing a culturally-specific care plan, and assisting in the actual delivery of spiritual care (Shih et al., 2001). The concepts of data saturation and reflexivity were not discussed by the authors, although vivid quotations from participants enhanced the discussion regarding areas of personal growth and knowledge gained from the program. The method employed for data analysis was not discussed, and a majority of the article focused on development of the educational program, rather than the research.

Effect of Spiritual Care Education on Attitudes and Perspectives

In addition to level of knowledge, nurses' attitudes and perspectives towards spiritual care are important elements of their ability to provide spiritual care (McSherry, 2006). Attitudes are the way a person perceives something that may affect behavior, while perspectives are a way of looking at or thinking about something relative to its importance (Merriam-Webster, n.d.). Nurses' attitudes about their own spirituality have been shown to serve as strong predictors of the quality of spiritual care that will be provided to patients (Meyer, 2003).

Two empirical studies and one Doctor of Nursing Practice capstone project evaluated the effects of spiritual care educational programs on nurses' attitudes and perspectives. (Table 3). O'Shea et al. (2011) evaluated the effect of a spiritual care

educational program on nurses' perspectives about providing spiritual care to patients and their families. Participants completed the Self-Perceptions of Spirituality Scale (Reed, 1987) and the Nurses' Perspectives Toward Providing Spiritual Care-Revised (Taylor et al., 1994), two reliable and valid instruments with previously documented Cronbach's alpha of .82 and .90, respectively. Nurses were found to have a more positive perspective towards providing spiritual care to patients and their families immediately after completing the educational program. Several statistically significant correlations were found: the more spiritual the nurses viewed themselves, the more positive their perspectives were towards providing spiritual care to their patients and families; nurses' comfort with providing spiritual care showed a strong positive correlation with personal spirituality (O'Shea, 2011). Weaknesses of this study include a small convenience sample and the limited nature of the educational intervention, which involved only a 30-minute PowerPoint presentation. In addition, posttest responses were obtained immediately after completion of the educational program; longitudinal analysis would allow for a better evaluation of sustained effects. A greater understanding of the effect of enhanced perspectives on the actual provision of spiritual care is also important in future research studies. Finally, while the previously reported psychometrics for both instruments used in this study were excellent, reliability and validity of the instruments in this patient population were not provided.

An interdisciplinary course integrated spiritual and religious concerns of patients and providers into already existing curricular courses in the School of Nursing and the School of Medicine at the University of Texas (Sandor et al., 2006). Content was presented through expert lectures, group discussions, readings, case studies, and personal

reflection. Junior nursing students and first-year medical students completed the Spiritual Experience Index-Revised (SEI-R) and the Spiritual Importance Scale (SI) at baseline and 1-year after completion of the course content. Details of instrument psychometrics were included from the literature and in this sample, with acceptable-excellent Cronbach's alpha results of .70-.97 for the SEI-R and .72-.74 for the SI (Burkhart, Schmidt, & Hogan, 2011; Ellison, 1983). A statistically significant increase in students' perceived importance of spirituality in practice was noted over time after completion of the program, with females and nursing students considering spirituality to have greater importance. Unexpectedly, students regressed to a more dogmatic or underdeveloped spiritual level over time, with medical students declining more dramatically than nursing students. Course evaluation comments were mixed: some students indicated that course content was "out of context", "unscientific" and "not relevant," while other students indicated enthusiasm about integration of spiritual care into clinical practice (Sandor et al., 2006, p. 40). Limitations of the study were not addressed by the authors but included the use of a convenience sample, lack of a control group, focus on perceptions rather than more objective behavioral measures or patient outcomes, and the lack of effect size/power analysis to justify sample size.

In her capstone project, Reade (2013) completed secondary analysis of a data set to determine the effects of a 6-hour course for bone marrow transplant nurses in the United States. Participants completed the Spiritual Perspectives Scale (SPS), a reliable and valid instrument to measure spiritual perspectives and how an individual incorporates spirituality into life, and the Nurse Spirituality Questionnaire (NSQ) (Reed, 1986). A statistically significant, small to moderate effect was noted in change score on the SPS,

with a large effect noted in change scores in the NSQ after completion of the spiritual care educational program. There was no significant correlation between spiritual perspectives and spiritual care at pretest or at posttest. While psychometrics were excellent for the SPS (Cronbach's alpha=.95 in this study), the source for initial psychometrics for the NSQ was not identified, and the Cronbach's alpha in this study population was only .65. Power analysis was not included to justify sample size; however, effect sizes were provided to quantify the strength of change in the outcome (Reade, 2013).

Effect of Spiritual Care Education on Spiritual Care Competence

Spiritual care competence involves a complex set of skills and knowledge that allows a nurse to successfully provide spiritual care within the context of the nursing process. Spiritual care competence is comprised of three core domains, including awareness and use of self to ease spiritual suffering, integration of spiritual dimensions into the nursing process, and assurance of quality and expertise in providing spiritual care (van Leeuwen & Cusvellar, 2004). Educational programs to address spiritual care may also impact nurses' perceived competence to provide spiritual care (Lovanio & Wallace, 2007). Three quantitative studies evaluated the effect of a spiritual care educational intervention on nurses' perceived spiritual care competence (Table 5).

Van Leeuwen et al., (2008) employed a pretest/posttest crossover design to test the effect of a 6-week educational program for Christian nursing students in the Netherlands on perceived competence to provide spiritual care. Educational lecture sessions were combined with reflection. Participants completed the Spiritual Care Competence Scale (SCCS), a reliable and valid tool that has been tested with nursing students, at baseline, 6 weeks after baseline, 14 weeks after baseline, and 20 weeks after baseline. The SCCS is a

reliable and valid instrument to measure nurses' perceived competence in providing spiritual care and has shown strong construct validity; reliability was evidenced by Cronbach's alpha coefficients from .56-.82.for the six sub-scales. The attitudes toward patient spirituality subscale (Cronbach's alpha of .56) showed good homogeneity, with average inter-item correlations of .25 or more, so it was retained for use in the study (van Leeuwen, Tiesinga, Middel, Post, & Jochemsen, 2007). Statistically significant differences in scores of three subscales (professionalization and improving spiritual care, referral to professionals, and attitude towards the patient's spirituality) were noted between groups, as well as over time for the whole cohort of students on all subscales of the SCCS. The researchers raised the question of whether students' perceptions of competence are a valid estimation of their ability to provide spiritual care. In addition, IRB approval was not obtained from the university in the Netherlands since the "research method was not burdensome or risky" (van Leeuwen et al., 2008, p. 2776). The researchers identified a mild risk of emotional reaction from participants, and lecturers for the program monitored the students and provided emotional support, as necessary. Since students attended the same college of nursing, there was a risk of contamination with this design.

In their evaluation of the effects of a 2-hour simulation lab session highlighting a spiritual care case study for maternal-child health nursing students, Costello et al. (2012) found a statistically significant improvement in students' perceived spiritual care competence immediately after completion of the simulation. Spiritual care competence was measured by the Spiritual Care Competence Scale (SCCS) (van Leeuwen et al, 2007). The simulation resulted in statistically significant improvement in students' attitudes

towards spirituality, ability to assess spiritual needs and refer patients to spiritual resources, and communication skills. Students verbally reported that they would be more apt to discuss spirituality in future interactions with patients (Costello et al., 2012). The study could have been strengthened by inclusion of a control group, testing at a future time point to detect if effects are maintained over time, and evaluation of the relationship between spiritual care education, quality of spiritual care, and patient care outcomes.

Burkhart and Schmidt (2012) investigated the effects of a blended spiritual care and reflective educational program on senior undergraduate nursing students' ability to provide spiritual care, their spiritual well-being, and their reflective practices. The students from two cohorts were divided into control and intervention groups, with the intervention group attending 1 full-day and 1 half-day retreat and a web-based discussion board to share experiences. Participants completed the Spiritual Care Inventory, the Spiritual Care in Practice Survey, and the Spiritual Well-Being Scale, with Cronbach's alphas for the tools in this sample ranging from .80-.95 (Burkhart & Schmidt, 2012; Burkhart, Schmidt, & Hogan, 2011; Ellison, 1983). In the intervention group, statistically significant differences were found in scores of students' perceived ability to provide spiritual care, especially in complex family situations. Additional analyses demonstrated change in intervention group participants' personal spiritual practices, with an increase in faith rituals and reflective meaning-making activities; these practices offered support in stressful times. Researchers employed independent sample t-tests to evaluate statistical significance since pretest survey scores of the intervention and control groups did not demonstrate statistically significant differences in means or variances. This study included potential self-selection bias, for those individuals who identified interest in

participating in the study could be more sensitive to the intervention. The intervention was limited to faith-based schools, and the study lacked longitudinal follow-up of effects. Response rates were low (25%-31%). While inclusion of a control group typically minimizes the effects of confounding variables, there was a great risk of contamination in this study since participants were randomly assigned to control and intervention groups in each cohort. Power analysis was not completed to support sample size.

Effects of Spiritual Care Education on Patients and Health Care Professionals

Two quantitative studies evaluated the effects of spiritual care education on patients or the professionals providing care (Table 5). Vlasblom et al., (2011) investigated the effects of a 16-hour educational program. There were 49 nurses from four units in the hospital who received the intervention, and a fifth unit served as a control group. Patients from each unit provided feedback regarding spiritual care received during their hospitalization. The questionnaire consisted of content from Dutch-language measuring instruments, and no information regarding reliability or validity of the instrument was reported. Patients from the control and intervention units completed a questionnaire that was adapted from the Spiritual Care in the Last Stage of Life instrument; questions relating specifically to the end of life were removed from the instrument; however, the researchers assumed "questions which are relevant at the end of life are also relevant for spirituality at other times" (Jochemsen, Klaasse-Carpentier, Casveller, van der Scheur, & Bouwar, 2008; Vlasblom et al., 2011, p. 793). The study found several statistically significant results: more reports were filed about spiritual needs of patients after the training; non-reporting of spiritual needs no longer occurred; and patients experienced more support from nurses to meet their spiritual needs. A statistically significant increase

was seen in the number of nurses who reported that they searched the chart or asked patients about spiritual needs or interest in consulting a chaplain. Serious concerns about the rigor of this study exist due to the assumptions made by the researchers and the risk of contamination, since the intervention and control groups were at the same hospital. No documentation was provided for reliability and validity of the instruments in measuring the desired concepts in this population. In addition, only 63% of nurses who completed the first questionnaire also completed the follow-up questionnaire 6-weeks after the program was completed (Vlasblom et al., 2011).

Another study evaluated the effects of a 3-hour training for interdisciplinary palliative care professionals on palliative care medical professionals' spirituality, religiosity, and level of self-transcendence (Wasner et al., 2005). There was a statistically significant increase in scores on the Self-Transcendence Scale immediately after the training, but this effect did not remain 3-months later (Reed, 1991). Functional Assessment of Chronic Illness Therapy-Spiritual Well-being scale scores (FACIT-Sp), which measured important aspects of spirituality like meaning in life, peacefulness, and sense of comfort from one's spiritual beliefs, showed statistically significant increases immediately after completion of the program (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). These results were not sustained at the 3-month posttest time point after Bonferroni correction. Scores did not change significantly over time for religiosity, which involves overall religiousness and strength received from one's religion. Weaknesses in the study included the lack of report of reliability and validity testing of the instruments in this study sample, use of a convenience sample, as well as too small a number of

participants to allow for group analyses. Additional limitations included lack of power analysis to justify sample size, no inclusion of effect size, and potential self-report bias.

Research Questions

The purpose of this study was to determine the potential impact of an online spiritual care educational program on pediatric nurses' perceived competence to provide spiritual care to children with cancer at the end of life and their families, as well as the program's potential effects on nurses' attitudes and knowledge about spiritual care. The relationship between nurses' knowledge and attitudes towards spiritual care, as assessed by the Spirituality and Spiritual Care Rating Scale (SSCRS), and their perceived spiritual care competence, as assessed by the Spiritual Care Competence Scale (SCCS), were also evaluated (McSherry et al., 2002; van Leeuwen et al, 2009). Specific research questions that addressed the study purpose follow:

Q1: What was the effect of the spiritual care educational program on nurses' perceived spiritual care competence?

Q2: What was the effect of the spiritual care educational program on nurses' attitudes towards and knowledge of spirituality/spiritual care?

Q3: Did the change in nurses' attitudes towards and knowledge of spirituality/spiritual care predict the amount of change in nurses' perceptions of spiritual care competence after completion of the spiritual care educational program?

Conceptual Framework

Serving as a facilitative frame of reference, a conceptual framework organizes related events or processes that are important to the discipline of nursing, thereby guiding the development and testing of the hypothesis and ensuring the outcomes are in the

context of science (Fawcett, 2005; Mock, St. Ours, & McCorkle, & Wald, 2007). The conceptual framework provides assumptions and principles upon which a study is built. The conceptual framework for this study is the Actioning Spirituality and Spiritual Care Education and Training in Nursing (ASSET) model (Figure 1). This model has been shown to guide changes in nurses' knowledge, attitudes, and competence in providing spiritual care to patients, thereby offering a strategy to guide spiritual care education (Narayanasamy, 1999).

The ASSET model has three main components that are integrated into the online spiritual care educational program evaluated in this study: structure, process, and outcomes. ***Structure*** includes self-awareness through reflection on one's personal beliefs and spirituality, as well as the spiritual dimensions of nursing that allow for integration of spiritual care knowledge and skills into nursing practice. Requisite skills to implement spiritual care include communicating, trust building, providing hope, and acting as a catalyst to assist patients and families in meeting their spiritual needs. Specific to this study, structure consisted of content in the spiritual care educational program focused on transfer of theory-driven knowledge regarding spiritual care of children with cancer at the end of life and their families. Study participants completed three online modules developed from extensive review of the literature and consultation with interdisciplinary experts, children, and their families. Participants also completed a reflection of their personal beliefs and sources of meaning, purpose, hope, and strength.

Process highlights the experiential learning that occurs from self-study of spirituality and values clarification, the importance of a broad perspective of spirituality, and application of the nursing process to the provision of spiritual care. Process in this

study involved completion of the theory-driven, online spiritual care educational program entitled "Nurses' Care of the Spirit for Children with Cancer at the End of Life and their Families." In this program, the nursing process guided the process of providing spiritual care. ***Outcome***s in this study included nurses' knowledge and attitudes towards spiritual care and competence to provide spiritual care (Narayanasamy, 1999). Perceived spiritual care competence was measured by the Spiritual Care Competence Scale (SCCS), and nurses' attitudes towards and knowledge of spirituality/spiritual care was measured by the Spirituality and Spiritual Care Rating Scale (SSCRS) (McSherry et al., 2002; van Leeuwen et al., 2009).

Philosophical Underpinnings

Positivism is one paradigm to guide the conduct of nursing research. A paradigm offers principles that define a view of the nature of the world, an individual's place in the world, and the relationships of its inherent parts (Guba & Lincoln, 1995). In positivism, a greater knowledge of the workings of the world is attainable through research. Since nursing is advanced through knowledge of the natural and human sciences, nursing research is a natural fit with this philosophy (Wainwright, 1997). Developed out of the work of 19th century philosophers Mill, Newton, and Locke, the positivist paradigm emphasizes the rational and the scientific.

In regards to ontology, which involves the nature of reality and the world's objective state, emphasis is placed on the belief that an objective reality can be studied and known; the world is not merely a construction of the human mind (Polit & Beck, 2012). Reality exists and is driven by natural laws that transcend time and context (Guba, 1995).

A scientific approach is employed to test hypotheses about the phenomena of interest and the relationships among them (Polit & Beck, 2012).

Epistemology involves the "study of knowledge, including the origin, nature, methods, and limitations of knowledge development," as well as human beings' perceptions of the world (George, 2010, p. 665; Reed & Scherer, 2012). Knowledge is objective and unaffected by those being researched in the positivist paradigm, and this neutrality can be attained through the use of control (Polit & Beck, 2012). Control minimizes bias and maximizes validity and precision through imposed conditions and procedures throughout the conduct of the scientific process (Polit & Beck, 2012). When threats to validity are recognized, strategies are employed to reduce or eliminate these threats (Guba & Lincoln, 1995). Potential confounding variables are controlled to prevent undue influence upon the outcome (Guba & Lincoln, 1995).

Methodology involves the manner in which knowledge is collected regarding what can be known. In nursing research, methodology is typically dictated by the research question (Guba & Lincoln, 1995). Selection of methods may also be based on the existence of valid and reliable measures to evaluate the desired outcome variables (Reed & Scherer, 2012). Within the positivist paradigm, quantitative research is employed to subject hypotheses to empirical testing for verification (Guba & Lincoln, 1995). Quantitative research involves systematic testing of predictions in the real world and gathering of empirical evidence to attain a better understanding of the phenomena that are under investigation (Polit & Beck, 2012). This research was based on the positivist philosophy, and quantitative research was employed to achieve a better understanding of the underlying relationships between phenomena (Polit & Beck, 2012)

Statement of Assumptions

In nursing research, assumptions support a specific approach to the conduct of research. Assumptions, insights believed to be true, can be based on the support of previous research, accepted knowledge, philosophical arguments, or personal beliefs and values (Powers & Knapp, 2006). Based on the primary investigator's ontologic perspective of the phenomena of spirituality, spiritual care, and spiritual care education, several assumptions underlie this study:

1. Spirituality is a universal concept that is important to all children and their family members, regardless of age, race, developmental stage, or religion.
2. In the provision of holistic nursing care, it is important to address the spiritual needs of children with cancer who are at the end of life, as well as the spiritual needs of their families; the child and family are seen as one entity requiring nursing care.
3. Nurses, as members of the interdisciplinary team, play a key role in the provision of spiritual care to children and their families.
4. Spiritual care impacts children with cancer at the end of life and their families by providing support, enhancing coping, instilling hope, and aiding them to find meaning and purpose in their experiences.
5. Nurses' spiritual care can enhance end of life care by guiding children and their families to strengthen their relationships with the health care team, experience spiritual growth, and find peace in the midst of tragedy.
6. Education has the potential to affect attitudes, knowledge, and competence to provide spiritual care.

7. Nurses' perceptions of their abilities to provide spiritual care are consistent with their actual abilities to provide spiritual care to children with cancer at the end of life and their families.

Gaps in the Literature

While spirituality is implicit in holistic models of nursing care, gaps in knowledge and practice prevent many children with cancer at the end of life and their families from receiving adequate spiritual care (Hufton 2006, Knapp *et al.* 2011). There are few articles in the literature focused specifically on nurses' spiritual care of children; research in this area is overwhelmingly sparse. The majority of the literature on spirituality at the end of life does not involve children, but instead focuses on older adults (Hufton, 2006). Experts have expressed concern that discussion of spiritual views of death and dying may be purposefully avoided with children (Fulton & Moore, 1995).

In considering the limitations of the spiritual care education research included in this review, most investigators did not address the numerous potential confounding variables that existed, including the variation in nature, duration, content, and format of the spiritual care educational programs that were being compared; variation in participants' initial attitudes towards spirituality prior to completion of the spiritual care educational program; and the motivation of the participants (for example, interest in a stipend versus interest in knowledge to advance practice) (Meredith et al., 2012). Additional limitations were noted with regards to the rigor of both the qualitative and quantitative studies that were reviewed. It is important to increase the rigor of future studies and shift to longitudinal evaluations that measure retention of the effects of spiritual care education over time. It is also vital for researchers to better examine the

effects of spiritual care education on nurses' actual provision of spiritual care in the clinical environment, with reliable and valid measures of effects on patient and family outcomes. In addition, researchers must consider multi-site collaborations that will enable the use of randomized controlled trials with control groups to minimize potential bias and maximize control of confounding variables (Meredith et al., 2012; Taylor et al., 2008). Challenges abound, however, in accomplishing these goals due to limited access to adequate numbers of patients and the inherent difficulties encountered in studies with this extraordinarily vulnerable population.

Comprehensive spiritual care education, guided by theory and input from children with cancer who are at the end of life, is required to teach pediatric nurses how to best provide support, enhance coping, instill hope, and assist in the quest to find meaning. Spiritual care education must also inform nurses how to best integrate the important attributes of spiritual care into daily nursing care for children with cancer who are dying: assess the child's spiritual care needs; aid the child to find hope; assist the child to express feelings and concerns; guide the child in strengthening relationships; help the child to be remembered; and assist the child to find meaning and purpose (Petersen, 2013). Spiritual care education is critical if barriers to providing quality spiritual care are to be overcome and national end of life care guidelines are to be met (Balboni et al., 2013; Cerra &Fitzpatrick, 2008; Puchalski et al., 2009).

This research addresses several of the delineated gaps in the literature: the design is longitudinal in nature to test for retention of effects of the educational program over time; the spiritual care educational intervention is driven by theory, previous research, and the testimony of children with cancer and their families. Finally, this study will evaluate

the relationship between nurses' attitudes towards and knowledge of spirituality/spiritual care and their perceived competence to provide spiritual care.

Summary

Spiritual care is a key aspect of comprehensive nursing care for children and their families, from the beginning to the end of life, across all dimensions of the illness trajectory. Spiritual care education for nurses is imminently required if the spiritual domain is to be adequately addressed at the end of life. It is through first educating pediatric nurses about how to provide spiritual care to children with cancer at the end of life and their families that future work may be done investigating the effects of spiritual care on important patient care outcomes including quality of life, patient satisfaction, use of hospice services, initiation of aggressive medical interventions at the end of life, and medical costs. By assessing and meeting the spiritual needs of children and their families, nurses minimize their spiritual suffering and ensure that potential coping strategies are not lost (O'Shea et al., 2011).

Ferrell and Coyle (2010), international experts in end of life and palliative care, provide a meaningful definition of spiritual care that highlights its inherent value to patients who are at the end of life and their families:

> Spiritual care means finding a way to make a connection, discovering any needs or desires that might improve quality of life, and then advocating and making arrangements for the fulfillment of those needs and desires. The job of a spiritual caregiver is always to be open, listen, observe, and when in doubt, ask questions…. We can never be certain what is inside someone else's heart. To ask is always best. (p.669)

CHAPTER THREE
Research Design and Methods

This chapter includes a comprehensive description of the rationale for decisions made regarding design of the study and development of the educational program, with a review of preliminary work that was completed. The rationale for decisions made regarding choice of setting, data analytic techniques, selection of sample participants, and data collection methods is provided. Discussion also highlights procedures to enhance methodological rigor and protect human rights throughout conduct of the study.

Preliminary Work: Design of the Spiritual Care Educational Program

It is important to integrate principles of effective teaching into spiritual care education. Teaching involves the creation of a critical learning environment in which an instructor arouses curiosity, challenges students to rethink assumptions, and embeds skills and information in assignments that students will hopefully find fascinating (Bain, 2004). Skillful curricular design enables the sharing of knowledge to be done in a way that is meaningful and retained over the long duration. Nursing curricula must include content related to the specific concepts that are taught, relevant nursing theory and research, and direct application to practice (Billings & Halstead, 2012).

Online course delivery provides a creative, innovative means of curriculum delivery, allowing for a cost-effective presentation of quality content to a diverse group of students (Billings & Halstead, 2012). Three factors have been consistently found to result in positive outcomes from online courses: instructor involvement, media usage, and effective interactions between participants. It is an educator's use of educational practices, such as discussions among students and respect for diverse ways of learning, that

determine satisfaction with the online learning experience and the attainment of intended outcomes. Health care educators must also determine what students need to know in order to succeed in a challenging health care environment and design a learning experience that will facilitate acquisition of those required competencies (Billings & Halstead, 2012). In contrast, educators must also consider that a lack of quality student support services result in decreased student learning, diminished student satisfaction, and increased attrition in an online learning environment (Billings & Halstead, 2012; Harrington, Laster, Stennet, & Carnwell, 2001).

There are multiple components that are consistently found in successful online course offerings. **Readings** are an important component of online curricula, since knowledge is dynamic and constantly changing. The instructor builds upon readings during subsequent lectures and discussions. In developing the online spiritual care educational program, literature from diverse fields, such as pastoral care, medicine, nursing, and social work, was integrated into the design. A list of ancillary resources and websites was also included to provide additional information for students who were interested in learning more about the topic.

Technology plays a crucial role in the delivery of an online curriculum, for the novelty of new types of media often results in increased learner attention. Media should address specific learning outcomes. It is important to use multimedia materials with consideration of strengths and weaknesses of the chosen materials to evaluate for impact and effectiveness (Smaldino, 2010). Individual feedback from participants allows the instructor to obtain feedback and evaluate the impact and effectiveness of the chosen media (Billings & Halstead, 2012).

Since it is also important to apply knowledge from other professions to nurses' professional practice, innovative use of multimedia also allows for connections to be made with interdisciplinary experts from around the world, thereby erasing time and place boundaries (American Association of College of Nursing, 2008; Billings & Halstead, 2012). **Videos,** including interviews with interdisciplinary experts from websites like YouTube, can provide content, stimulate discussion, create a sense of community, and offer opportunities for reflective learning. **Case studies** provide for authentic learning experiences that bring real world experiences into the academic environment to better equip students to navigate the environment beyond the classroom. The use of case studies also allows students to make connections between theory and practice, illustrating course content in real-life situations. Critical thinking is stimulated and knowledge is better retained. Case studies also enable students to practice problem solving in a safe environment. Discussion of case studies often revitalizes a class and maximizes collaboration and communication through peer interaction, sharing of prior experience, and validation of thinking (Billings & Halstead, 2012).

In the online learning environment, **film clips** enrich a learning experience; their use should directly relate to curricular objectives, emphasize key points, and provide visual memory cues for students. **Photos** allow for the creation of an environment infused with culturally based learning opportunities. **Lectures** are important to share important content, development in the field, and definitions of critical concepts. Lectures may be enhanced with web and computer-based materials, interactive activities, and multimedia presentations to keep learners' attention and interest (Billings & Halstead, 2012).

In online environments, a **discussion board** explores concepts from multiple points of view and promotes reflection and critical analysis. Instructors provide discussion questions that are based on Bloom's taxonomy, encouraging progressively more sophisticated critical thinking and allowing students to synthesize knowledge (Billings & Halstead, 2012). A discussion board allows students to demonstrate comprehension of course content in a multitude of ways: giving examples, analyzing common themes and underlying assumptions, synthesizing information into new applications, exploring common themes and underlying assumptions from fellow students' postings, and asking complex questions that are based on course materials and discussions (Garrison, Anderson, & Archer, 2001; Leppa, 2004). Online threaded dialogue is a primary source of evaluating a learner's critical thinking. Instructors must provide feedback in an encouraging way by listening, encouraging, valuing, respecting, and effectively communicating (Lerret & Frenn, 2011). A discussion board serves as an effective teaching tool by maximizing a sense of community among course participants, encouraging the learners to share different views, allowing independent learning, and providing time for reflection (Billings & Halstead, 2012; Mahoney et al., 2005).

Lastly, **reflection exercises** enhance problem solving, creativity, and curiosity in an online learning environment by creating opportunities for learners to develop critical thinking and reasoning skills. The process of reflection allows the learner to connect knowledge gained from the course to problem solving in the real world, therefore linking theory to practice. Questions are crucial to help learners modify mental models: when questions are asked, learners index thoughts into memory. Reflection exercises are important components of online learning curricula since they teach students to understand,

apply, analyze, synthesize, and evaluate while simultaneously enhancing the ability to examine one's own thinking critically, allowing a learner to recognize and solve moral dilemmas (Billings & Halstead, 2012).

The online spiritual educational program integrated readings and lectures with videos, case studies, interviews with experts and children with cancer, a blog written by a young woman with cancer, and reflection exercises to provide a multimedia environment for learning. In our current world of dramatic social change, there is a great focus on convenience and efficiency, interdisciplinary collaboration, and enhancement of the process of education. Online education allows an educator to cater to differing needs of student learners due to the inherent flexibility in the delivery of content, the ability to facilitate interdisciplinary collaboration from content experts around the world, and the potential to erase all boundaries, thereby eliciting a larger potential audience (Billings & Halstead, 2012).

Development of the Spiritual Care Educational Program

Studies have demonstrated the efficacy of online administration of spiritual care educational programs (Burkhart & Schmidt, 2012; Ellman et al., 2012). As a result of the strengths identified in the literature and the ability to ensure that the spiritual care educational intervention was identical for all participants, the spiritual care educational program was offered in an online environment. Participants completed a 3-hour self-study program, combined with asynchronous interactions in an online discussion forum to maximize flexibility while facilitating learning. The primary investigator (PI) developed the theory-driven online spiritual care educational program with the assistance of numerous mentors and experts: Dr. Margaret Callahan (dissertation chair and end of life

expert), Dr. Richard Fehring (spirituality expert), Dr. Kathryn Schroeter (nurse ethicist), and Dr. Heidi Schweizer (Marquette University Director of E-learning). Educational content was based on extensive review of the nursing, medical, and theological literature; content from the interdisciplinary National Consensus Conference Report, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care"; relevant theory including Fowler's Stages of Faith and Erickson's Theory of Psychosocial Development; interviews with experts in the field of spiritual care; and videotaped or audiotaped interviews with parents and children with cancer (Erickson, 1959; Fowler, 1981; Puchalski et al., 2009). Content of the spiritual care educational program is delineated in Appendix D.

In developing the online spiritual care educational program, multimedia components were included to maximize participants' interest, for the novelty of new types of media often results in increased learner attention (Billings & Halstead, 2012). Media was chosen to address specific learning outcomes (Billings & Halstead, 2012). The program integrated numerous strategies to reach a diverse group of learners: visual-spatial (case study videos), bodily-kinesthetic learning (written reflections), verbal linguistic (voiceover PowerPoint lectures), musical (YouTube music video written and sung by an adolescent with terminal osteosarcoma), logical-mathematical (discussion board questions that encouraged critical thinking), interpersonal (discussion board), intrapersonal (reflection exercises), and existential (a blog written by a young woman in her life in the six months before her death) strategies were employed (Billings & Halstead, 2012).

Key principles of online course design guided course development: (1) build upon a foundation of desired learner outcomes; (2) define learning outcomes, objectives, and competencies; (3) organize content into short modules; (4) include an overview,

objectives, learning activities, readings, and assignments in each module; and (5) provide students with the chance to apply course principles in context (Billings & Halstead, 2012). Specifically, the educational program focused on the following learning objectives: learners would be able to describe the attributes of spiritual care of the child with cancer at the end of life; contrast ways to provide spiritual care to children at various developmental levels; summarize the goals of spiritual care and the implications for the provision of nursing care; discuss the key factors for integration of spiritual care into the nursing process; and apply the National Consensus Conference findings to nursing practice.

Content areas in the educational program included a definition of spirituality; attributes of spiritual care for a child with cancer at the end of life; goals and benefits of spiritual care for children and their families; Fowler's Stages of Faith and Erikson's Theory of Psychosocial Development as guiding frameworks; the importance of therapeutic communication; spiritual assessment tools for care of children and their families; implications for nursing practice; and use of the nursing process to guide the provision of spiritual care (Erikson, 1959; Fowler, 1981). Key concepts from the National Consensus Conference, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care," were imbedded into the program's lecture content (Puchalski et al., 2009). The relationship of content to the conceptual framework and the National Consensus Conference Report is highlighted in Table 6.

Research Design

The choice of research methodology and subsequent design was based on the purpose of this study, the research questions, and the availability of reliable and valid instruments to measure the phenomena of interest (Guba & Lincoln, 1995; Reed &

Shearer, 2012). This study employed a prospective, longitudinal design to allow for evaluation of the immediate and sustained effects of the spiritual care educational program on nurses' attitudes towards and knowledge of spirituality/spiritual care, as well as the effect on nurses' perceived spiritual care competence. Spiritual care competence was measured by the Spiritual Care Competence Scale (SCCS) (van Leeuwen et al., 2009). Nurses' attitudes towards and knowledge of spirituality/spiritual care were measured by the Spirituality and Spiritual Care Rating Scale (SSCRS) (McSherry et al., 2002). Data was collected at baseline (time point 1), upon completion of the spiritual care educational program (time point 2), and three-months after completion of the spiritual care educational program (time point 3). This study design allowed the concepts of interest to be examined for continuity or change within individuals from one data collection point to another (Taplin, 2005).

Research Methods

Setting

Participants for this study were recruited by email from international membership in the Association of Pediatric Hematology/Oncology Nurses (APHON). The spiritual care educational program, two content quizzes, the demographics survey, and instruments were administered by the Marquette University online course management system D2L, which is password-protected.

Selection of Sample Participants

Pediatric nurses who identified that they provide care to children with cancer were eligible to voluntarily participate in this study. Nurse participants were employed full-time, part-time, or in a casual position on the patient units or clinics where children with

cancer receive care. Eligible participants were required to have access to the Internet outside of the hospital to allow for access to the online course management system that administered the educational program. Individuals who did not provide nursing care for children with cancer, who could not read and speak English, or who did not have Internet access were excluded from participation in this study. Potential participants were contacted about voluntary participation in the study through email notification to members of the Association of Pediatric Hematology/Oncology Nurses organization, or they were informed verbally by the PI's attendance at APHON local chapter meetings in Milwaukee, WI; Madison, WI; and Indianapolis, IN. A priori power analysis utilizing G*Power 3 and a review of sample calculation tables estimated 60-80 nurses as an adequate sample size for the study (Faul, Erdfelder, Laang, & Buchner, 2010). The sample size was based on a function of power (.80) with a moderate effect size (.25) of the intervention on the outcome variables, an assumption of a .5 correlation between repetitive measures, and an alpha level of .05. While most previous studies evaluating the effects of a spiritual care educational intervention did not include a power analysis, one study employed a moderate effect size (.25) to calculate sample size in the testing of a spiritual care educational program; statistically significant differences were found in attitudes, ability to respond to spiritual pain, and knowledge of communication skills important in the provision of spiritual care (Taylor et al., 2008). A sample size of 200 was recruited to allow for a 40% attrition rate from baseline (time point 1) to the first posttest completed immediately after the participant completed the educational program (time point 2), as well as a 40% attrition rate from time point 2 and a posttest completed 3-months after the spiritual care educational program was completed (time point 3). Initial attrition rates were also

examined. Previous longitudinal studies of the retained effects from spiritual care educational programs evaluated the retention of knowledge at time points of six-weeks to six-months after participants' completion of the educational programs, and these previous studies experienced rates of attrition up to 39% (Meredith et al., 2012; van Leeuwen et al., 2008; Wasner et al., 2005).

Study Variables and Instruments

Participants completed two Likert-based self-report scales, the Spiritual Care Competence Scale (SCCS) and the Spirituality and Spiritual Care Rating Scale (SSCRS) at three time points: baseline before a participant completed the spiritual care educational program (time point one), immediately after the participant completed the spiritual care educational program (time point two), and three months after completion of the spiritual care educational program (time point three). Demographic data was collected at baseline (time point one). The SCCS quantitatively measured nurses' perceived spiritual care competence and the SSCRS quantitatively measured nurses' attitudes towards and knowledge of spirituality/spiritual care. The surveys demonstrated adequate reliability and validity in previous research, with results included in the subsequent sections reviewing the specific instruments

Instruments

(1) The Spiritual Care Competence Scale (SCCS): The SCCS, a 27-item, five-point Likert-based instrument, is a reliable and valid instrument to measure nurses' perceived competence in providing spiritual care (van Leeuwen et al, 2009). The instrument has six subscales: Assessment and Implementation of Spiritual Care, Professionalization and Improving the Quality of Spiritual Care, Personal Support and

Patient Counseling, Referral to Professionals, Attitude Towards Patient Spirituality, and Communication. The items in each subscale are summed and averaged to obtain a subscale mean. There are no items that require reverse-scoring. A higher score is indicative of a higher level of perceived spiritual care competence. The scale has shown strong construct validity. Excellent overall reliability of this instrument has been documented, with a Cronbach's alpha coefficient of .9 (Costello et al., 2012). Internal consistency has been evidenced by the following Cronbach's alpha coefficients for the six subscales: 0.82 (Assessment of Spiritual Care), 0.82 (Professionalization and Improving the Quality of Spiritual Care), 0.81 (Personal Support), 0.79 (Referrals to Professionals), 0.56 (Attitudes Towards Patient Spirituality), and 0.71 (Communication). The six subscales show good homogeneity, with average inter-item correlations of .25 or more, with good test-retest reliability (van Leeuwen et al., 2009). In evaluating internal validity, while there is no universally agreed upon minimum standard for reliability, many researchers indicate that reliabilities of .6 or .7 or higher are adequate or good (Dekovic, Janssens, & Gerris, 1991; Holden, Fekken, & Cotton, 1991; Warner, 2012). The optimal level of mean inter-item correlation is in the range of .2 to .5 for a broad, higher order construct (Clark & Watson, 1995). All six subscales, including the Attitudes Towards Patient Spirituality subscale with a Cronbach's alpha coefficient of .56, were retained in the instrument since the inter-item correlation of the Attitudes Towards Patient Spirituality subscale (.25) evidences a homogeneous instrument measuring the broad construct of spirituality (van Leeuwen et al., 2009). Exploratory factor analysis found that the six dimensions explained 53% of total variance.

(2) The Spirituality and Spiritual Care Rating Scale (SSCRS): The SSCRS is a 17-item instrument that uses a five-point Likert-based scale to explore nurses' attitudes towards and knowledge of spirituality and spiritual care. The SSCRS has four factor-based subscales: Spirituality, Spiritual Care, Religiosity, and Personalized Care. The items in each subscale are summed and averaged to obtain a subscale mean. Items 4, 5, 13, and 16 require reverse-scoring. An overall score is obtained by summing the instrument items. A higher score is indicative of a higher level of knowledge and a more positive attitude towards spirituality and spiritual care. This tool exhibited an acceptable level of internal consistency reliability, with documented Cronbach's alpha coefficients of 0.64-.71 for the overall instrument (McSherry et al., 2002; Wallace & O'Shea, 2007). Exploratory factor analysis resulted in significant loadings for all items on 1 of 4 factors, with 48% of variance explained by a 4-factor structure: Spirituality, Spiritual Care, Religiosity, and Personalized Care (McSherry et al., 2002). Reliability coefficients for the subscales have been reported: Spirituality (existential aspects of life and meaning in life) .77; Spiritual Care (listening, spending time, and respect) .69; Religiosity (type of faith and worship) .71; and Personalized Care (personal values, morals, and relationships) .65 (Wallace & O'Shea, 2007). Principle Components Analysis established the psychometric quality and construct validity of the instrument in measuring nurses' attitudes towards and knowledge of spirituality and spiritual care (McSherry et al., 2002).

Data Collection Methods

The online spiritual care educational program, quizzes, and surveys were administered to study participants via the Marquette University online course management system. The SCCS and SSCRS surveys took approximately five to ten minutes each to

complete. Before beginning the online spiritual care educational program, participants completed the demographics survey, the SCCS, and the SSCRS through the course management system (time point one). Upon completion of each of the first two modules of the online program, participants took an online quiz to test their knowledge of course content. The quizzes included five multiple-choice items that were randomly chosen from a pool of potential items. Participants received immediate feedback of their performance. If the participant did not obtain a score of 80%, they took the quiz again with five new, randomly chosen items. Upon completion of the online spiritual care educational program (time point two), participants completed the SCCS, the SSCRS, and a program evaluation form online. Items on the SCCS and the SSCRS were scrambled to alter their order, thus preventing participants from becoming test savvy. Three months after completion of the spiritual care educational program (time point three), participants completed the SCCS and the SSCRS to test for retention of effects of the spiritual care educational program. Once again, the items were scrambled to alter their order. Participants received a $50 gift card upon completion of the surveys at time point three. The online course management system tracked participant progress in the course, indicated completion, and recorded scores and quizzes. Survey data were transferred from the online course management system to a file in the Statistical Package for the Social Sciences, version 21.0 (SPSS, Inc.).

Research Procedure

The time points for data collection (baseline, upon completion of the program, and three months after completion of the program) were chosen to allow for evaluation of immediate and sustained effects of the online spiritual care educational program. The

rationale for this timeline came from a study in which Meredith et al. (2012) found that participants in a spiritual care educational training program showed maintained improvement in scores on knowledge of ways to provide spiritual care three months after completion of the program, with increased scores in confidence related to providing spiritual care to patients. Researchers reflected that this was likely due to the participants' subsequent experience integrating theory into clinical practice. The three-month post-completion time point was therefore included in this study to test for retention or increase in spiritual care knowledge and perceived spiritual care competence once nurses returned to the practice environment armed with new, theory-driven knowledge.

Methodological Rigor

Methodological rigor was addressed through consideration of threats to internal and external validity, utilization of strategies to minimize the chance for bias, and choice of research design. Study validity involves the degree to which appropriate inferences can be made about the relationships between variables. There are four types of validity that affect the rigor of quantitative research design: internal validity, statistical conclusion validity, construct validity, and external validity (Polit & Beck, 2012). Since this is a quasi-experimental design, several potential threats to internal validity are acknowledged and details are provided, when appropriate, to delineate how these threats were addressed through control; the quality of the evidence is strengthened when biases are ruled out or controlled (Polit & Beck, 2012).

Internal Validity

Internal validity**,** the extent that an inference is attributable to the independent variable**,** was addressed in several ways through integration of strategies to address

potential threats. **Temporal sequencing** was not a serious concern in this study since the researcher developed the intervention, and the intervention was administered before evaluation of the outcome variables. The threat of **history**, in which external events take place during administration of the intervention and affect the outcome variable, was considered; no other national training in spiritual care was being completed to the PI's awareness during conduct of the study. **Self-selection** is one of the most challenging threats to the internal validity of studies that do not employ an experimental design; self-selection may result in a biased sample when used with nonprobability sampling, for inherent characteristics of the nurses who agree to participate in this study may differ from those individuals who decide not to participate (Warner, 2012). A homogenous sample of pediatric nurses who provide care to children with cancer at the end of life minimized variability on potential confounding variables in this sample. While the use of a homogeneous sample may limit external validity, it may also enhance interpretability of relationships between independent and dependent variables (Polit & Beck, 2012).

Another potential bias to internal validity in nursing research is maturation. **Maturation** involves changes occurring within participants over the course of a study due to the passage of time, rather than as a direct result of the independent variable. A one-group, pretest-posttest longitudinal design is susceptible to maturation (Polit & Beck, 2012). The risk was minimized in this study since the posttests were completed over a short period of time. In a single-group quasi-experimental study, another risk to internal validity is **mortality** due to attrition, which may result in different types of individuals remaining in a study than those individuals leaving a study. Mortality may result in the erroneous appearance that a change in the outcome variable resulted from the intervention,

instead of as a result of characteristics of the participants who remained in the study. The risk of attrition is greater when the length of time between data collection points is long. As the rate of attrition is higher, the likelihood of bias is higher (Polit & Beck, 2012). The risk of attrition was addressed in this study by careful consideration of previous rates of attrition documented in other studies of spiritual care educational programs when determining sample size goals, as well as by keeping the length of time between data collection points short (one month and three months). The risk of attrition was also addressed by offering a stipend ($50) in appreciation for the time required for study participation only after completion of surveys at all three test points. Participants provided their email addresses on the informed consent form; to improve retention of participants, an email reminder to complete the final SCCS and SSCRS scales was sent to all participants through the online course management system (Polit & Beck, 2012).

Testing, the effect of taking a pretest on an individual's performance on a posttest, may threaten internal validity, for the act of collecting data from individuals may change these individuals. The items on the SCCRS and SCCS were scrambled at each time point to minimize the chance that participants become test savvy due to repeated use of the instruments. The final threat to internal validity that was considered in this study was **instrumentation**. The threat of instrumentation, in which measuring tools may provide more accurate measures with data collector's experience, was minimized in this study through consistent online administration of the instruments to all participants through the online course management system (Polit & Beck, 2012).

Statistical Conclusion Validity

In addition to internal validity, statistical conclusion validity was maximized in planning this study. Statistical conclusion validity, the validity of the inference that a relationship exists between variables, was addressed through the use of a sufficiently large sample size to ensure the study has adequate power to detect true relationships among variables (Polit & Beck, 2012). A power analysis using G*Power was completed to plan sample size to ensure sufficient power to analyze each of the research questions (Faul et al., 2010). Statistical conclusion validity was also addressed through a strong operationalization of the independent variable due with the educational program's basis both in theory and from consultation with interdisciplinary experts, children with cancer and their families. Statistical conclusion validity was also addressed through **intervention fidelity**. Online administration of the course allowed for optimal intervention fidelity, the extent to which an intervention follows its plan, with equivalent application from one participant to the next. The spiritual care educational program was identical for all participants, since conditions of administration were standardized, thereby minimizing potential contamination of the intervention and variability from one participant to the next. Intervention fidelity was also enhanced in this study through steps to maximize **treatment adherence**, in which participants completed the entire intervention. Participants took online quizzes after completion of the first two program modules before proceeding to the next program module (Polit & Beck, 2012).

Construct Validity

A third type of validity that was considered in planning this study was construct validity. Construct validity, which involves adequate representation of the underlying

construct under examination, was addressed through the careful development of the theory-driven spiritual care educational intervention. The educational program was constructed after extensive review of the literature on the following topics: spiritual care for children with cancer and their siblings; spiritual care for parents whose children with cancer are at the end of life; and online nursing education. Experts in nursing, medicine, online education, and pastoral care were consulted throughout development of the spiritual care educational program. In addition, measurements of the dependent variables had strong correspondence with the outcome constructs, thereby enhancing construct validity (Polit & Beck, 2012).

External Validity

Consideration was also given to **external validity** in development of this study. External validity, or the degree to which study results are maintained over variations in people, conditions, and settings, was a critical consideration for research that serves as a basis for evidence-based practice (Warner, 2012). By including nurses from all over the country and the world in this study, inferences about the relevance of findings to other settings was strengthened (Polit & Beck, 2012). In addition, the three-hour online spiritual care educational program and study were designed to allow for ease of replication: Three-hours of training, administered consistently in an online environment, is a reasonable amount for administrators to devote resources to, in order to advance the quality of care for children with cancer at the end of life and their families.

Self-Report Bias

The use of self-report instruments involves a risk of bias, for participants may respond in socially acceptable ways (Polit & Beck, 2012). While the self-assessment

method is common in nursing studies, nurses' perception of their ability to provide spiritual care may not be equivalent to their actual ability to provide spiritual care to children with cancer at the end of life (van Leeuwen et al., 2008). In addressing these potential sources of bias and the resultant threats to validity, this study provides valuable information to fill a gap in the literature and advance the science of holistic nursing care for children with cancer at the end of life and their families. The use of a repeated-measures design allowed for a more powerful test for changes in the dependent measures over time, as delineated in the following section detailing statistical procedures and the associated rationale for decisions made (Warner, 2012).

Statistical Procedures and Rationale

Statistical analyses for this study, which addressed the specific aims, included one-way repeated measures analysis of variance (ANOVA) with post hoc analysis and regression analysis. All analyses were conducted with the Statistical Package for the Social Sciences, version 21.0 (SPSS, Inc.). Probability levels of $p < .05$ were used in all analyses to determine statistical significance, except as noted when Bonferroni correction was employed with RM-ANOVA to reduce the risk of Type I error. Prior to analysis, the data were cleaned. Descriptive statistics were completed to describe the sample population and evaluate the assumptions required for parametric tests. Preliminary data screening was completed to ensure that distributions of differences in the dependent variables were approximately normally distributed and that there were no outliers (Pallant, 2010). Descriptive analyses provided a demographic summary, including the following participant characteristics: age, gender, race, number of years of experience as a nurse, extent of experience caring for children with cancer, educational preparation, and previous

spiritual care and palliative care education.

The online administration of the study instruments offered participants a warning if any survey items did not have a response before the participants submitted the survey at any of the three data collection time points. Pairwise deletion was employed to deal with missing data.

Specific Aim 1

One-way repeated measures ANOVA design allows subjects to be measured on three or more occasions on the same continuous scale (Pallant, 2010). One-way repeated measures ANOVA was employed to evaluate the effect of the online spiritual care educational program (independent variable) on nurses' perceived competence to provide spiritual care to children with cancer at the end of life and their families (dependent variable). Pre-test and post-test scores on the SCCS were compared at three time points: baseline, baseline to completion of the educational program, and baseline to three months after completion of the educational program. Instrument items were scrambled at the various time points.

An assumption for use of this parametric test is approximate normality in the distribution. With sample sizes that are large enough (30 or more), however, the violation of this assumption does not cause a major problem (Pallant, 2010). An additional assumption was that the dependent variable must be measured at the interval or ratio level; in this study, the dependent variables were measured with Likert-based scales (the SCCS and the SSCRS) that evaluated data at the interval level (Pallant, 2010). Homogeneity of variance is an assumption that samples were obtained from populations that had equal variances, with a similar variability in scores. Levene's test for equality of variance was

completed within the analysis of variance analysis to test for homogeneity of variance, and the goal was to find the test to be not significant (a significance level greater than .05), which indicated that the variances were equal across time points and that the assumption of homogeneity of variance was not violated; analysis of variance is reasonably robust to a violation of this assumption (Pallant, 2010). Sphericity was also evaluated with Mauchly's Test of Sphericity. This assumption was violated. Mulivariate statistics do not require sphericity, so it was safest to inspect the multivariate statistics (Pallant, 2010).

Lastly, when the same individuals are tested under several different conditions, their scores are often correlated across conditions. By employing one-way repeated measures ANOVA, the violation of the assumption of independence of observations was addressed and managed (Shin, 2009). Since the same subjects were tested in each group, the advantage of employing repeated-measures ANOVA was that this analytic technique further partitioned the error term, reducing its size. The variability related to individual differences between subjects was removed, resulting in a smaller error term, as well as the potential for an increase in the value of the F statistic and a resultant increase in power to detect significant differences between means (Warner, 2012).

The significant F test indicated that the null hypothesis was rejected and that there were significant difference in the mean score of the dependent variable across the three groups, but it did not specify where the difference was found. To identify specifically where a statistically significant difference was and to make more precise conclusions, post-hoc (a posteriori) comparisons must be completed (Abdi & Williams, 2010; Pallant, 2010). Post-hoc comparisons were run with this analysis, with Bonferroni correction made, with the ultimate goal of ensuring that unexpected results were reliable and to

deconstruct the differences (Abdi & Williams, 2010; Hulley, Cumings, Browner, Grady, & Newman, 2013; Pallant, 2010). Post-hoc comparisons were more appropriate than planned comparisons, in which only certain differences in scores are evaluated, since there were no clear conceptual grounds for comparing specific groups in this study (Pallant, 2010).

Specific Aim 2

One-way repeated measures ANOVA was used to evaluate the effect of the online spiritual care education program (independent variable) on nurses' attitudes towards and knowledge of spirituality/spiritual care (dependent variable), as measured by the SSCRS. Scores were compared at three time points in order to test retention of knowledge and avoid carryover effects: baseline, baseline to completion of the educational program, and baseline to three months after completion of the online spiritual care educational program. Instrument items were scrambled at the various time points to minimize testing effects. Assumptions for a parametric test were evaluated, identical to the process identified with specific aim 1. Since the sample size was 30 or more, the analysis was robust enough to proceed with a parametric analysis (Pallant, 2010). Sphericity was also evaluated with Mauchly's Test of Sphericity. This assumption was not violated in this analysis.

When the same individuals are tested under several different conditions, their scores are often correlated across conditions. By employing one-way repeated measures ANOVA, the violation of the assumption of independence of observations was addressed and managed (Shin, 2009). Since the same subjects were tested in each group, the advantage of employing repeated-measures ANOVA to achieve this specific aim was that this analytic technique further partitions the error term, reducing its size. Once again, as

seen with specific aim 1, the variability related to individual differences between subjects was removed, resulting in a smaller error term, as well as the potential for an increase in the value of the F statistic and a resultant increase in power to detect significant differences between means (Warner, 2012). While a significant F test indicated that the null hypothesis was rejected and that there was a significant difference in the mean score of the dependent variable across the three groups, it did not specify where the difference was. To identify where the statistically significant differences were, post-hoc tests were completed, with Bonferroni correction made to protect against Type I error (Hulley et al., 2013; Pallant, 2010). Post-hoc comparisons were more appropriate than planned comparisons, in which only certain differences in scores are evaluated, since there were no clear conceptual grounds for comparing specific groups in this study (Pallant, 2010).

Specific Aim 3

A bivariate linear regression was performed to evaluate if the amount of change over time in nurses' perceived spiritual care competence (as measured by the SCCS) could be predicted from the amount of change over time in nurses' perceived knowledge and attitudes towards spirituality/spiritual care (as measured by the SSCRS). Change scores were calculated to show the difference in scores from time point two (immediately after a participant's completion of the spiritual care educational program) to time point one (baseline). Preliminary data screening indicated that scores on both variables were normally distributed. A scatterplot showed a reasonably linear relationship between variables, with a bivariate normal distribution. There were three bivariate outliers noted on the scatterplot, and the analysis was run with and without the outliers, showing congruent results. Results are reported from the analysis with outliers removed.

Partial correlations were completed to explore the relationship between change scores in nurses' level of knowledge and attitudes towards spirituality/spiritual care (as measured by the SSCRS) and change scores in nurses' level of spiritual care competence (as measured by the SCCS) while controlling for (1) overall years of experience as a nurse; or (2) years of experience in pediatric oncology. Preliminary analyses were completed to ensure there were no violations of the assumptions of normality, linearity, and homoscedasticity.

Human Subjects Protection

Institutional Review Board (IRB) approval was obtained from Marquette University prior to initiation of the study, study recruitment, or data collection. The primary investigator, who completed Collaborative Institutional Training Initiative (CITI) training, introduced the study to all potential participants either in person at APHON monthly meetings or by email recruitment of national members. Prior to data collection, the primary investigator obtained written, informed consent from participants after screening for eligibility and explanation of the details of the study. Participants were informed that participation was voluntary and that they could withdraw from the study at any time. The investigational nature and purpose of the study were discussed, as well as the potential risks and benefits of participation. This study involved minimal risk to participants; the researcher was aware of the potential risk for participants' spiritual distress due to the subject content, and a hospice chaplain was available for future discussion or consult after participation in the online spiritual care educational program, if necessary.

The primary investigator explained the participant's right to confidentiality and anonymity. Strict confidentiality and anonymity were maintained through the use of the university's password protected online course management system to administer the spiritual care educational program, quizzes, surveys, and course evaluation. Participants provided an email address for contact from Dr. Heidi Schweizer, who assigned each participant a generic username and password to access the online course management system. Each participant was sent this generic username by email, and the username remained unknown to the investigator throughout the study. The participant received individual email reminders, sent anonymously through the online course management system, to complete surveys at the required time points.

The de-identified subject data was entered into a secure, encrypted computer for analysis using SPSS version 21.0. Only the principal investigator had access to the de-identified data. Upon completion of all surveys and quizzes, participants received a $50 Amazon gift card via email to show appreciation for their time. The principal investigator monitored adherence to the protocol throughout conduct of the study.

Summary

This chapter provides a detailed synopsis of the preliminary work completed in anticipation of this research, as well as the research design and methodology that were employed to investigate three research questions. The following methods were specifically described: the setting, the process for selection of participants, study variables, instruments, data collection methods, research procedures, methodological rigor, statistical procedures, and human subjects protection.

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Appendix A: Manuscript

Petersen, C. L. (2013). Spiritual care of the child with cancer at the end of life: A concept analysis. *Journal of Advanced Nursing, 70*(6), 1243-1253. doi: 10.1111/jan.12257

Abstract

Aim. The aim of this paper is to report an analysis of the concept of spiritual care of a child with cancer at the end of life.

Background. Spirituality is a vital dimension of a child's experience at the end of life, providing comfort, support, and a sense of connection. Spiritual care is paramount to address the substantial spiritual distress that may develop.

Design. Rodgers' method of evolutionary concept analysis guided the review process.

Data sources. The literature search was not limited by start date, and literature through the end of 2012 was included. English, peer-reviewed texts in the databases CINAHL, ATLA, and PubMed were included.

Methods. Critical analysis of the literature identified surrogate terms, related concepts, attributes, antecedents, and consequences.

Results. The analysis identified six attributes: assessing spiritual needs; assisting the child to express feelings; guiding the child in strengthening relationships; helping the child to be remembered; assisting the child to find meaning; and aiding the child to find hope. Antecedents include existential questions and spiritual distress. Consequences include a peaceful death, spiritual growth, a relationship of trust, and enhanced end of life care.

Conclusion. Spiritual care is a vital aspect of holistic nursing care; however, gaps in knowledge and practice prevent children from receiving adequate spiritual care at the end of life. Nurses would benefit from increased awareness, skills, and knowledge about spiritual care. Research is needed to identify interventions that exert the greatest effect on patient care outcomes.

Keywords: spiritual care, child, cancer, dying, concept analysis, nurses/midwives/nursing

Summary Statement.

Why is this research or review needed?

- Nurses have not been sufficiently educated about how to provide spiritual care to pediatric patients.
- Nurses would benefit from increased awareness, skills, and knowledge about spiritual care for children with cancer at the end of life.

What are the key findings?

- This analysis illustrates the importance of assessing a dying child's spiritual needs and assisting the child with cancer to express feelings, strengthen relationships, be remembered, and find meaning and hope.
- In addition to offering support, spiritual care at the end of life allows a dying child to live fully, even as death approaches, and to find spiritual growth and peace.

How should the findings be used to influence policy/practice/research/education?

- The attributes identified in this concept analysis should provide the foundation for a guideline regarding the provision of spiritual care as a vital component of the comprehensive care of the child with cancer at the end of life.
- Nursing educators should address care of a child's spirit in discussions of end of life care.
- Additional research in this domain should identify the spiritual care interventions that exert the greatest effect on patient care outcomes for children with cancer at the end of life.

INTRODUCTION

When children are nearing the end of life, spiritual care becomes paramount, for it addresses the substantial spiritual distress that may develop (Knapp *et al.* 2011). Despite major advances that have been made in treatment over the last thirty years, childhood cancer remains one of the leading causes of death in children (Jalmsell *et al.* 2006). Approximately 1,340 children under the age of 14 years will die of their disease in 2012 (American Cancer Society 2012). Spirituality is a vital dimension of a child's experience at the end of life, providing comfort and support, as well as a sense of connection with a higher power, and loved ones (Purow *et al.* 2011). Spiritual care to address patients' spiritual needs is an important aspect of comprehensive end of life nursing care. By serving as a source of comfort and support in the cancer journey, spiritual care is a vital dimension of nursing care of a child with cancer. This support becomes especially important when a child is dying, for the child often struggles to make sense out of the diagnosis, suffering, and losses by looking beyond the physical world for answers (Purow et al., 2011). By integrating spiritual aspects into patient care, nurses enhance patients' quality of life and positively influence the course of the illness trajectory (World Health Organization, 2007). The aim of this study is to provide foundational knowledge about the attributes of spiritual care of children at end of life, advance the science of end of life care, and increase nurses' ability to provide spiritual care to children with cancer at the end of life.

Background

Previous studies have shown that spiritual care is associated with important patient outcomes, including improved quality of life, enhanced satisfaction with hospital care,

increased use of hospice, decreased use of aggressive medical interventions at the end of life, and diminished medical costs (Balboni *et al.,* 2010, Balboni *et al.,* 2011, Williams *et al.,* 2011). However, most spiritual care literature does not include children, and there is minimal literature that discusses how to provide spiritual care to dying children (Jones & Weisenfluh 2003, Knapp *et al.,* 2011). Longitudinal studies that investigate children's spiritual needs as cancer progresses are needed, as well as the effect of hospitalization on the need for spiritual care (Bull & Gillies 2007). Research to identify if spiritual care education is effective in improving patient care outcomes is also lacking (Ross 1995). To address these practices and research gaps, the components of spiritual care for children need to be explicitly defined.

Rodger's method of concept analysis was employed because the most important outcomes of this method include the identification of a strong conceptual foundation for future knowledge development and a basis for consistent communication and understanding (Rodgers 2000). Foundational work regarding the concept of spiritual care of the child with cancer at the end of life has not been completed in nursing. Definitions of spiritual care are often generalized and diverse, leading to inconsistency in communication and descriptions of the concept (Clarke 2009). Following the steps of Rodger's evolutionary method of concept analysis, a significant concept was chosen, the context was identified and included the interdisciplinary perspectives of nursing, medicine, and theology, and data was collected using a systematic database search and an ancestral search for hallmark articles. The concept's antecedents, attributes, and consequences were discovered as themes emerged from analysis of descriptors of the phenomenon presented in the articles reviewed for the study. A model was developed to

identify connections between the concept's antecedents, attributes, and consequences and an exemplar case was presented. Implications for practice and directions for future research were identified (Rodgers 2000). The ultimate goal of this concept analysis is to make explicit the attributes, antecedents, and consequences of spiritual care of children with cancer at the end of life so that practitioners can operationalize the concept in their practice and educators can embed learning about spiritual care in foundational nursing education. Knowledge gained from this concept analysis will advance the conceptual understanding of a topic that has not received adequate attention in the literature, serve as a vital foundation for further knowledge development for nursing practice, and contribute to scientific inquiry in the realm of pediatric end of life care.

This concept analysis focuses on the individual child with cancer at the end of life since spiritual care must meet a single child's specific needs, values, and beliefs. This focus is due to the great variability in the cognitive function, cultural values, and religious beliefs from one child to another. While the spiritual needs of the child with cancer at the end of life are inseparable and intertwined with the spiritual needs of the child's parents, this concept analysis addresses the spiritual care of the child as a unique individual since previous research and literature have already addressed the spiritual needs of parents of dying children (Anderson & Steen 1995).

Data Sources

An electronic examination of the pediatric literature was completed. The literature search was not limited by start date, and literature through the end of 2012 was included. English, peer-reviewed texts in the databases CINAHL, ATLA, and PubMed were included. A search was first completed in CINAHL using keywords and subject headings

of spiritual care, spiritual, and end of life/death or dying/palliative care, with the search limited to children eighteen years of age and younger. Truncation was used to search for variations of word root endings. This search resulted in 51 articles for review. Since the Christian theological tradition has exerted a historical influence on the description of spirituality and caring and has, therefore, impacted spiritual care in nursing, the American Theological Library Association (ATLA) database was also examined. Keywords included spiritual and end of life/palliative/dying and child, resulting in 58 articles. A PubMed search using the keywords spiritual care, child, and cancer resulted in 36 articles. All searches were limited to the English language, children, and to peer-reviewed journal subsets. Next, all abstracts' subheadings and headings were examined, and articles that did not involve spiritual care of children were excluded from further analysis. An ancestral search was employed by tracing citations identified in the reference lists of articles identified through the search. Hallmark articles on spiritual care were then examined. The final sample consisted of 51 journal articles from the disciplines of nursing (28), medicine (18), and theology (5). Content was quite similar between the disciplines of nursing and medicine, while content from the theology journal articles focused on the religious aspects of spirituality.

Data collection included review of each article to identify the attributes of spiritual care. These attributes were transcribed onto data collection sheets that were organized into the categories of data required for the concept analysis: attributes, antecedents, consequences, surrogate terms, and related concepts (Rodgers 2000). Surrogate terms are means of expressing the concept in other words in the literature and serve as additional manifestations of the concept. These terms included spirituality and spiritual needs of

children. Related concepts are additional concepts that involve a relationship or connection to the concept of interest (Rodgers 2000). A related concept was religion. While spirituality and religion are interwoven, they have different definitions, although both involve a focus on what is held sacred to the individual (Elkins & Cavendish 2004). Spirituality includes religion, a structured expression of specific beliefs, doctrines, and rituals held by a community of people to connect to a higher power or God (Mueller 2010). Religion serves as a means for expression and enrichment of spirituality for some individuals (Elkins & Cavendish 2004).

RESULTS

Attributes

In concept analysis, the process of data analysis involves organizing similar aspects from the literature search into a cohesive, comprehensive description of the relevant topic (Rodgers 2000). After collection of data was complete, the literature was analyzed for dominant attributes to address the multiple facets of the concept, as well as associated antecedents, consequences, and implications for practice. These attributes of spiritual care for the child with cancer at the end of life include assessing spiritual needs, assisting the child to express feelings and concerns, guiding the child in strengthening relationships, helping the child to be remembered, assisting the child to find meaning and purpose in life and suffering, and aiding the child to find hope. Reference sources for each attribute are presented in Table 1.

Assessing the child's spiritual needs

A spiritual assessment should be conducted by nurses in the care of all seriously ill children so that appropriate interventions can be initiated and supportive beliefs and

practices can be identified (Knapp *et al.* 2011). Spiritual assessment involves identification of a child's beliefs, sources of strength or fears, and important relationships through therapeutic communication and listening (Elkins & Cavendish 2004). Several approaches for the spiritual assessment of patients and their family members have been developed for nurses and other health care professionals. Adult assessment mnemonics include the SPIRIT, the HOPE, and the FICA (Maugens 1996, Puchalski 1999, Anandarajah & Hight 2001). The SPIRIT mnemonic guides a nurse to assess the patient's spiritual belief system, personal spirituality, integration with a spiritual community, ritualized practices and restrictions, implications for medical care, and terminal events planning (Maugens 1996). The HOPE mnemonic addresses sources of hope, organized religion, personal spirituality and spiritual practices, and effects on medical care (Anandarajah & Hight 2001). Assessment using the FICA mnemonic addresses faith, importance of faith in the individual's life, community support, and how to best address spiritual issues in care (Puchalski 1999). For the pediatric population, the BELIEF mnemonic was developed to guide pediatric nurses in their discussions with children about religious and spiritual beliefs and to serve as a guiding framework for open-ended dialogue. The components addressed in the BELIEF tool include belief system, ethics and values, lifestyle, involvement in a spiritual community, education, and the effect of religious beliefs on potential, future events (McEvoy 2000).

Assessment of spiritual needs is vital in the provision of spiritual care to a child, but this assessment can be challenging. In completing an assessment of a dying child's spiritual needs, the child's developmental stage should be considered. The concepts from any assessment tool must be worded in a developmentally appropriate way that is

understood by the child. Assessment tools should not be used in ways that limit the extent of inquiry about a child's spiritual needs since these tools may not adequately investigate dimensions of spirituality that are important to individuals of all religions or cultures (Purow *et al.* 2011). In addition, spiritual needs may not be communicated verbally, so the nurse must carefully assess the child's behavior: children may exhibit nightmares, resistance of care, and regression (Hart & Schneider 1997).

Assisting the child to express feelings and concerns

In addition to assessing the child's spiritual needs, the nurse should also assist a dying child to express feelings and concerns, a distinct challenge due to the broad range of developmental levels seen in children. Dying children face many impending losses: the loss of function, independence, access to friends or activities, and future. As a result, they describe their lives as full of heartache and sadness (Woodgate *et al.* 2003). The most common feelings and concerns expressed by dying children are regarding self-identity, meaning in life and suffering, unfinished business, anger with God, questions regarding who will care for them and where they will go after they die, when they will see their loved ones again, and whether they will run and play after death (Jones & Weisenfluh 2003, Foster *et al.* 2012). They have great apprehension about death and worry about those they will leave behind (Berde & Wolfe 2003).

In assisting a dying child to express these feelings and concerns, nurses must have excellent communication and listening skills (Steen & Anderson 2002). Therapeutic communication allows a dying child the opportunity to express feelings, beliefs, and fears, as well as the chance to share their story. In a study of hospitalized children and their families, empathetic listening and conversations about the spiritual journey were identified

as the most effective spiritual interventions in addressing spiritual needs (Feudtner *et al.* 2003). In addition to therapeutic communication, play therapy, music therapy, humor, storytelling, journal writing, prayer, guided imagery, and creative arts therapy also facilitate the expression of feelings, losses, and concerns, allowing a dying child to manage and share intense emotions (Elkins & Cavendish 2004, Hufton 2006). Bibliotherapy, or story telling about an individual's life through a journal or scrapbook, can also be an effective tool to gain insight, encourage reflection, and enhance communication (Fulton & Moore 1995).

Guiding the child in strengthening relationships

Another important attribute in a nurse's provision of spiritual care is guiding the child who is dying to strengthen relationships with family, friends, and God or a higher power (if this is in agreement with the family's and child's belief system and is a source of support). All individuals, regardless of whether they are religious or not, have the need for connection with the world around them (Narayanasamy 1999). Relationships with family and friends provide protection, care, and comfort to the child with cancer at the end of life, often allowing the heavy burdens to be somewhat lightened (Monterosso & Kristjanson 2008). These relationships serve as a source of love, compassion, distraction, and support. Dying children are more likely to attain peace at the end of life if they have attained joy from their relationships with others (Jones & Weisenfluh 2003, Meert *et al.* 2005). The nurse can encourage the dying child to mobilize and maintain relationships to ensure that the child has maximum support for the challenging days ahead. Relationships can be supported through the sharing of cards, letters, visits, humor, and reminiscing (Elkins & Cavendish 2004). A sense of belonging to something that transcends the child

may provide great comfort. In one study of children with advanced cancer, 78% of the children reported that they did something to be close to God (Kamper *et al.* 2010). Spiritual resources, including relationships with pastoral care staff and clergy, may provide additional spiritual support for a child with cancer at the end of life (Hart & Schneider 1997).

Helping the child to be remembered

Spiritual care of a child with cancer at the end of life also involves helping the child to be remembered (Jones & Weisenfluh 2003). In providing spiritual care to address this need, the nurse may assist a dying child to create a legacy. A legacy involves the identification of the dying child's accomplishments and the difference that the child made to others, allowing the child to find meaning in the impending loss (Foster *et al.* 2009). A legacy may include a special gift, video, or letter to loved ones, the sharing of special mementos or the giving away of personal items, meaningful conversations, and special outings together with loved ones (Foster *et al.* 2012). Memories, images, interactions, and shared gifts enable a connection to continue after the child's life has ended and allow the child to be remembered. By assisting loved ones to acquire mementos and memories from the dying child's last days, nurses give a special gift, for these items often hold great meaning and comfort to the individuals left behind (Meert *et al.* 2005).

Dying children often hope to leave a legacy in another way: by affecting the lives of others through their words and actions. Bereaved family members have frequently reported that their child inspired them to live differently due to their attitudes, priorities, and wisdom (Foster *et al.* 2009). This may be a result of actions that a dying child took to help others, such as raising money in the fight against cancer, seeking participation in

research to help others who face a similar journey, or even befriending a newly diagnosed child with cancer.

Assisting the child to find meaning and purpose

Assisting a dying child with cancer to find meaning and purpose from life and suffering is another important attribute of spiritual care. Therapeutic listening and dialogue can guide the dying child to find meaning from discussions about accomplishments, valued relationships, and attained goals (Champagne 2008). The use of stories about the child's life may help to identify meaning and purpose from previous experiences (Bone 2010). Belief in God may assist some individuals to come to understand their illness and the potential meaning or purpose of suffering, as well as to attain an understanding that God may have a purpose for the experiences, even if they cannot discern it (Purow *et al.* 2011). Strengthening the bonds of faith through prayer and religious rituals may assist some children in coping at the end of life. In addition, altruistic acts, such as consent for autopsy, fundraising for cancer research, and participation in research to advance science, allow some dying children to bring goodness from their experiences (Meert *et al.* 2005). The identification of meaning in the midst of tragedy allows the child with cancer at the end of life to keep the spirit energized and find ways to cope through even the most difficult of times (Woodgate & Degner 2003).

Aiding the child to find hope

The last attribute of spiritual care is aiding the child with cancer at the end of life to find hope. Hope is defined as a concept that is innate to human nature, for it involves looking forward to a positive, future-oriented outcome with the confidence that it will happen (Foster *et al.* 2010). In the care of a child at the end of life, hope serves as a

coping strategy to offer support through the end of life journey. In aiding the child to find hope, the nurse helps the child to find a balance between hope and grief and to identify new sources of joy once the possibility of the child's cure from cancer is gone (Jones & Weisenfluh 2003; Foster *et al.* 2010). The focus can be shifted from the search for a cure to the attainment of smaller, more attainable goals as the disease progresses, such as looking forward to future events or activities (Keene-Reder & Serwint 2009). Hope for a cure may also be transformed into hope for a dignified, peaceful death, a better relationship with God, or the anticipation of the afterlife (Robinson 2006).

Definition

Spiritual care of the child with cancer at the end of life involves assessing the child's spiritual needs, assisting the child to express feelings and concerns, guiding the child in strengthening relationships, helping the child to be remembered, assisting the child to find meaning and purpose, and aiding the child to find hope. A diagrammatic representation of the concept, indicating interrelatedness of the six attributes as parts of the whole of spiritual care, as well as antecedents and consequences of the provision of spiritual care, is displayed in Figure 1.

Antecedents and Consequences

In addition to the six attributes of the concept of spiritual care for a child with cancer at the end of life, two antecedents, or preceding phenomena, were identified in the analysis. While the provision of spiritual care is a nursing process, the antecedents and consequences are patient-centered phenomenon. Existential questions regarding the meaning of life, death, and suffering, as well as questions regarding God or a higher power, are antecedents to spiritual care (Hufton 2006; Swinton 2010). Spiritual distress is

a common antecedent to spiritual care that involves a disruption in the life principle that integrates an individual's entire being. This distress occurs as a result of a challenge to the belief system that serves as a source of hope and strength (North American Nursing Diagnosis Association, 1999). Signs of spiritual distress in children may include tearfulness, nightmares, social withdrawal, regressive behavior, and resistance of care (Fulton & Moore 1995).

Similarly, the consequences are assessed in terms of patient-centered outcomes. The consequences of spiritual care include a peaceful death, spiritual growth, a relationship of trust, and enhanced end of life care. Spiritual care may assist a dying individual to achieve peace at the end of life by offering support and affirmation that important accomplishments and loving relationships in life have been attained (Campion 2011). Spiritual growth is another possible consequence, for skilled spiritual care of a dying child allows for maturation and development through improved relationships with others or God, identification of new meaning to life and suffering, interest in helping others, identification of new goals, and redefined hope (Foster *et al.* 2010). A relationship of trust through improved communication between the health care team, the child, and the child's loved ones is another consequence of spiritual care (Purow *et al.* 2011). The open communication that occurs allows nurses to better address the child's overall needs, values, and goals, resulting in enhanced end of life care (Kamper 2010). The consequences identified in this concept analysis are the ultimate goals of spiritual care. Unfortunately, they may not always be realized, for some children face continued spiritual suffering due to the inability to come to terms with the tragedy at hand and the overwhelming losses encountered (Foster *et al.* 2012).

Exemplar

Rodgers (2000) stated that an exemplar provides a practical exhibition of a concept in its appropriate context to enhance the clarity and application of the concept. The following exemplar was constructed from the experiences of the author in her work with children with cancer at the end of life:

Anna was an eighteen-year-old girl who was first diagnosed with Ewing's sarcoma at the age of twelve. While her spirit remained hopeful during much of her journey, she also faced times of understandable distress as the disease progressed. In providing spiritual care, her nurses' assessed Anna's spiritual needs repeatedly during visits to clinic, and sources of support were identified. Her relationships with her family members were strong, but Anna struggled with some of her friendships that faded as the disease progressed. Her nurse practitioner encouraged Anna to express her feelings, and she decided to write a blog on the internet to communicate her innermost concerns and frustration. The pastor from her church frequently offered spiritual support, and in providing spiritual care, one of Anna's primary nurses assisted her to identify her hopes for the future, including a last trip to visit a friend and beliefs about the afterlife. At one appointment, Anna highlighted her interest in leaving a legacy so she could find meaning from this difficult journey and be remembered. Clinic nurses who provided spiritual care to Anna told her of a unique opportunity to raise money for childhood cancer research by shaving the heads of employees at the hospital, aiding her to find meaning and a sense of purpose in her battle against cancer. A local news show interviewed Anna, and she eloquently described her experiences and struggles in the fight against cancer.

News spread rapidly about Anna and her heartfelt discussions about cancer. One nurse who knew that it was important to Anna to be remembered spoke with the dean of a local university, with Anna's permission. As a result, Anna was invited to share her touching blogs with students of an interdisciplinary palliative care course. She was thrilled to know that her words would help to prepare health care professionals to provide better care to children who are dying. As her death became imminent, Anna left special gifts for her family members and purchased spa services for her mom. She planned her funeral, a party at a local restaurant in which attendees were asked to "celebrate life". After a difficult six-year battle, Anna died, after spending the last months of her life at home, surrounded by family and friends.

DISCUSSION

The attributes of spiritual care of the child with cancer do not exist in isolation or as independent parts of a whole; instead, they are extensively related and interconnected. For example, the assessment of spiritual needs involves therapeutic communication in which the child expresses feelings, beliefs, sources of strength and hope, and concerns (Elkins & Cavendish 2004). Creation of a legacy includes, for some children, meaningful conversations with loved ones to express innermost feelings of love, sadness, and apprehension. The conversations that occur in the creation of a legacy may lead some children to find meaning and purpose in life and death (Champagne 2008, Foster *et al.* 2009). In addition, actions completed by the child with the hope of being remembered, such as fundraising to raise money for the fight against cancer, participating in research, and befriending other children who have recently been diagnosed with cancer often assist

the child in the search to find meaning in the experience of having terminal cancer (Meert *et al.* 2005).

The results of this concept analysis have theoretical implications. The concept of spiritual care of the child with cancer at the end of life comprehensively reflects Watson's Human Caring Science, a nursing theory that places emphasis on the integration of the mind, body, and spirit of an individual and assumes that the practice of caring is central to nursing. In this theory, the practice of human caring involves human care transactions in which the nurse and patient come together in a given moment, leading to a deep connection at the spiritual level and allowing new opportunities for healing (Watson 1996). Attributes of the concept of spiritual care of the child with cancer at the end of life are reflected in several of Watson's carative factors, which are aspects of the human care process that assist the nurse to cherish and value the individual patient. The attribute of aiding the child to define hope is reflected in the carative factor of instillation of faith-hope when the nurse assists a patient in identifying beliefs that are meaningful. Next, by assisting the child to express feelings and concerns, the nurse and child develop rapport and a helping-trust relationship, a hallmark aspect of Watson's theory. As a result of this relationship, the nurse is better able to guide the child in strengthening relationships. Watson addressed the importance of the systematic use of a scientific problem-solving method for decision-making to organize patient care, and the attribute of assessing the child's spiritual needs before designing developmentally appropriate interventions reflects this factor. Finally, the carative factor of assisting the patient to gratify human needs is addressed in helping the child to be remembered and to find meaning and purpose in life and suffering (Watson 1996).

Limitations

While there are important theoretical implications from this concept analysis, there are also several limitations. Spirituality in children includes the development of faith and beliefs about living and dying, which parallels children's cognitive development. While this analysis lays a foundation to build upon for further knowledge development, it does not address the specific modifications needed to address the child's developmental level in the provision of spiritual care to ensure that spiritual care interventions are developmentally-appropriate and meet the needs of the individual child. Fowler's Stages of Faith and Piaget's theory of cognitive development provide excellent frameworks to understand the spirituality of children and to characterize developmentally appropriate spiritual care interventions (Fowler 1981, Piaget 1983). Further investigation into the effect of a child's developmental level on the provision of spiritual care is needed to identify the most useful spiritual care interventions for children of various developmental levels. In addition, this analysis did not examine the effect of specific cultural and religious beliefs on the spiritual care of a child with cancer at the end of life.

CONCLUSION

Spiritual care of the child with cancer at the end of life is a process concept that forms a mid-range descriptive theory highlighting the important nursing processes, antecedents, and consequences involved in spiritual care of this patient population. While the value of spiritual care for the child with cancer at the end of life is widely acknowledged, there are many challenges that lie ahead in further operationalizing the process of providing this care. Nurses report that they do not provide spiritual care to their patients due to the inability to recognize patients' spiritual needs, a failure to acknowledge

that it is their duty to address them, and a lack of knowledge of how to offer spiritual care (Sulmasy 2006). A lack of training also plays a part in nurses' inability to provide spiritual care to children (Purow *et al.* 2011). Future research must address the effects of spiritual care education programs on pediatric oncology nurses' spiritual care competence and on patient outcomes, such as referrals to pastoral care staff and satisfaction with spiritual care. While researchers acknowledge the need for spiritual care education programs to assist nurses to overcome barriers to providing quality spiritual care, it is unknown how to design these programs to best affect patient care outcomes (Feudtner *et al.* 2003, Cerra & Fitzpatrick 2008). Research is also required to develop a spiritual assessment tool to guide them in completing a developmentally appropriate spiritual assessment; however, a reliable, validated spiritual assessment tool for children that is general enough to identify their spiritual needs in the clinical environment has not yet been developed (Rubin *et al.* 2009).

This concept analysis provides new insight into the concept of spiritual care of the child with cancer at the end of life by synthesizing evidence from the nursing, medical, and theological literature. The six attributes of spiritual care of children provides a framework of explicit strategies for nurses to implement in providing spiritual care. The antecedents and consequences identify attributes of the child that can be assessed to determine the need for spiritual care and the outcomes of the nursing care process of spiritual care. As a result, current nursing knowledge is expanded by identifying actionable processes for providing spiritual care, bringing an abstract idea to practical applicability. Watson's Human Caring Science may guide further research into the realm of spiritual care of children with cancer at the end of life. By completing research to

address children's spiritual distress and existential questions about life, death, or God through the provision of spiritual care, nurses may be better able to assist them to face the difficult end of life journey with the tools required to experience spiritual growth and peace.

CONFLICTS OF INTEREST

No conflict of interest has been declared by the author.

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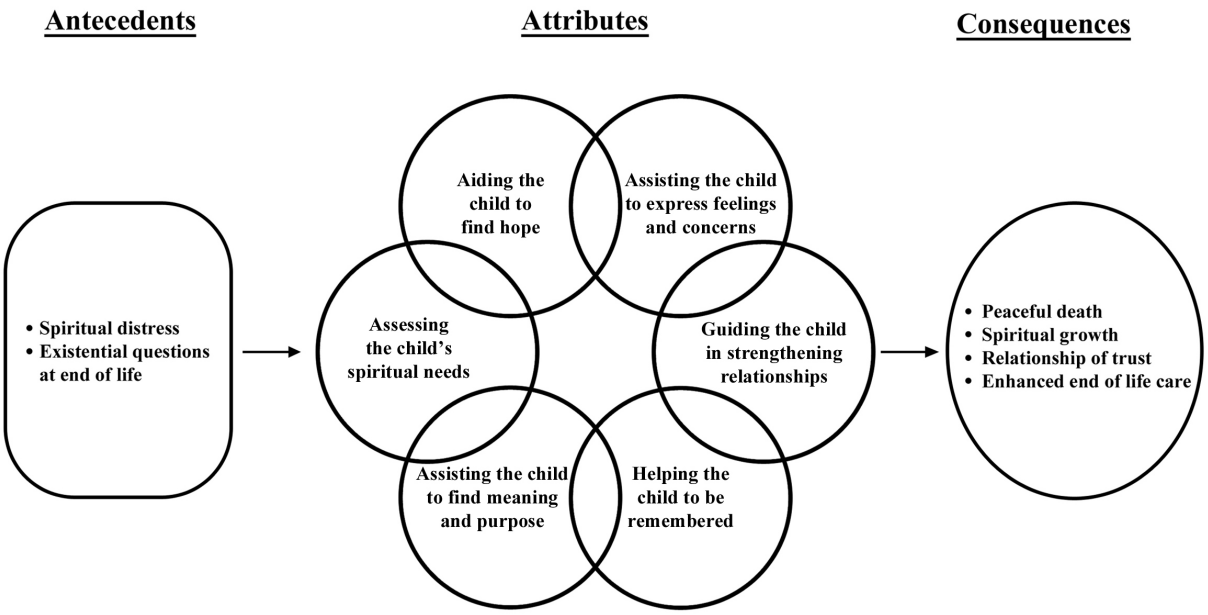
Table 1

Attributes of Spiritual Care of the Child with Cancer.

Attributes	Reference Sources
Assessing the child's spiritual needs	Pediatric sources: Anderson & Steen (1995), Hart & Schneider (1997), Puchalski (1999), McEvoy (2000), Anandarajah & Hight (2001), Larimore (2001), Davies et al. (2002), Steen &Anderson (2002), McEvoy (2003), Elkins & Cavendish (2004), McGheehin-Heilferty (2004), Smith & McSherry (2004), Hufton (2006), Grossoehme (2008), Mueller (2010), Knapp et al. (2011), Purow et al. (2011) General sources: Maugans (1996), Kenny (1999b), Puchalski (2001), Fosarelli (2008)
Assisting the child to express feelings and concerns	Pediatric sources: Fulton & Moore (1995), Hart & Schneider (1997), Kane & Primomo (2001), Davies et al. (2002), Steen & Anderson (2002), Berde & Wolfe (2003), Feudtner (2003), Jones & Weisenfluh (2003), Woodgate et al. (2003), Elkins & Cavendish (2004), Smith & McSherry (2004), Hufton (2006), Bull & Gillies (2007), Foster et al. (2010), Mueller (2010), Foster et al. (2012) General sources: Puchalski (2001), Campion (2011)
Guiding the child in strengthening relationships	Pediatric sources: Fulton & Moore (1995), Hart & Schneider (1997), Kane & Primomo (2001), Davies et al. (2002), Dell-Orfono (2002), Feudtner et al. (2003), Jones & Weisenfluh (2003), Woodgate et al. (2003), Elkins & Cavendish (2004), McGheehin-Heilferty (2004), Smith & McSherry (2004),

	Meert et al. (2005), Sulmasy (2006), Bull & Gillies (2007), Monterosso & Kristjanson (2008), Kamper et al. (2010), Swinton & Pattison (2010), Campion (2011), Purow et al. (2011) General sources: Kenny (1999a), Narayanasamy (1999), Puchalski (2001), Fischer (2006), Agrimson & Taft (2008)
Helping the child to be remembered	Pediatric sources: Armstrong-Dailey & Zarbock (2001), Jones & Weisenfluh (2003), McGheehin-Heilferty (2004), Meert et al.(2005), Hufton (2006), Foster et al (2009), Foster et al. (2012) General sources: Puchalski (2001)
Assisting the child to find meaning and purpose	Pediatric sources: Hart & Schneider (1997), Kane & Primomo (2001), Puchalski (2001), Davies et al. (2002), Steen & Anderson (2002), Woodgate et al. (2003), Elkins & Cavendish (2004), McGheehin-Heilferty (2004), Meert et al. (2005), Hufton (2006), Robinson et al. (2006), Sulmasy (2006), Champagne (2008), Foster et al. (2009), Bone (2010), Ratcliff (2010), Purow et al. (2011), Foster et al. (2012) General sources: Kenny (1999a), Meraviglia (1999), Narayanasamy (1999), Agrimson & Taft (2008), Clark (2009), Puchalski (2009), Campion (2011)
Aiding the child to find hope	Pediatric sources: Davies et al. (2002), Steen & Anderson (2002), Jones & Weisenfluh (2003), Robinson (2006), Schneider & Mannell (2006), Keene-Reder & Serwint (2009), Foster et al. (2010)

Figure 1. Spiritual Care of a Child with Cancer at the End of Life



Appendix B

Study Forms and Instruments

Participant Characteristics

Please circle the correct answer or indicate the correct response:

Gender: male female

Age: _____

Race/ethnicity: White Black Asian Hispanic Other

Number of years of experience as a nurse:_____

Number of years of experience caring for children with cancer:_____

Have you received education in the past regarding spiritual care, end of life, or palliative care of children? (Yes/No) _____

If so, what education did you receive? (i.e. ELNEC course or type of conference)

_____

Educational preparation: ADN RN/BSN Graduate Degree

Prefer not to answer

Spiritual Care Competence Scale

Please circle one answer that best reflects the extent to which you agree or disagree with each statement.

Attitude towards patient spirituality

1) I show unprejudiced respect for a patient's spiritual/religious beliefs regardless of his or her spiritual/religious background.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

2) I am open to a patient's spiritual/religious beliefs, even if they differ from my own.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

3) I do not try to impose my own spiritual/religious beliefs on a patient.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

4) I am aware of my personal limitations when dealing with a patient's spiritual/religious beliefs.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

Communication

5) I can listen actively to a patient's 'life story' in relation to his or her illness/handicap.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

6) I have an accepting attitude in my dealings with a patient (I am concerned, sympathetic, inspire trust and confidence, empathetic, genuine, sensitive, sincere and personal).

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

Assessment and implementation of spiritual care

7) I can report orally and/or in writing on a patient's spiritual needs.

Strongly disagree Disagree Uncertain Agree Strongly agree

8) I can tailor care to a patient's spiritual needs/problems in consultation with the patient.

Strongly disagree Disagree Uncertain Agree Strongly agree

9) I can tailor care to a patient's spiritual needs/problems through multidisciplinary consultation.

Strongly disagree Disagree Uncertain Agree Strongly agree

10) I can record the nursing component of a patient's spiritual care in the nursing plan.

Strongly disagree Disagree Uncertain Agree Strongly agree

11) I can report in writing on a patient's spiritual functioning.

Strongly disagree Disagree Uncertain Agree Strongly agree

12) I can report orally on a patient's spiritual functioning.

Strongly disagree Disagree Uncertain Agree Strongly agree

Referral

13) I can effectively assign care for a patient's spiritual needs to another care provider/care worker/care discipline.

Strongly disagree Disagree Uncertain Agree Strongly agree

14) At the request of a patient with spiritual needs, I can in a timely and effective manner refer him or her to another care worker (e.g. a chaplain/the patient's own priest/clergy).

Strongly disagree Disagree Uncertain Agree Strongly agree

15) I know when I should consult a spiritual advisor concerning a patient's spiritual care.

Strongly disagree Disagree Uncertain Agree Strongly agree

Personal support and patient counselling

16) I can provide a patient with spiritual care.

Strongly disagree Disagree Uncertain Agree Strongly agree

17) I can evaluate the spiritual care that I have provided in consultation with the patient and in the multi-disciplinary team.

Strongly disagree Disagree Uncertain Agree Strongly agree

18) I can give a patient information about spiritual facilities within the care institution (including spiritual care, religious services).

Strongly disagree Disagree Uncertain Agree Strongly agree

19) I can help a patient continue his or her daily spiritual practices (including providing opportunities for rituals, prayer, meditation, reading the Bible/Koran, listening to music).

Strongly disagree Disagree Uncertain Agree Strongly agree

20) I can attend to a patient's spirituality during daily care (e.g. physical care).

Strongly disagree Disagree Uncertain Agree Strongly agree

21) I can refer members of a patient's family to a spiritual advisor/pastor if they ask me or if they express spiritual needs.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

Professionalization and improving the quality of spiritual care

22) Within the department, I can contribute to quality assurance in the area of spiritual care.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

23) Within the department, I can contribute to professional development in the area of spiritual care.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

24) Within the department, I can identify problems relating to spiritual care in peer discussions.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

25) I can coach other care workers in the area of spiritual care delivery to patients.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

26) I can make policy recommendations on aspects of spiritual care to the management of the hospital unit.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

27) I can implement a spiritual-care improvement project in the hospital unit.

Strongly disagree *Disagree* *Uncertain* *Agree* *Strongly agree*

Spirituality and Spiritual Care Rating Scale

Please circle one answer that best reflects the extent to which you agree or disagree with each statement.

1) I believe nurses can provide spiritual care by arranging a visit by the hospital chaplain or the patient's own religious leader, if requested.
Strongly disagree Disagree Uncertain Agree Strongly agree

2) I believe nurses can provide spiritual care by showing kindness, concern and cheerfulness when giving care.

Strongly disagree Disagree Uncertain Agree Strongly agree

3) I believe spirituality is concerned with a need to forgive and a need to be forgiven.

Strongly disagree Disagree Uncertain Agree Strongly agree

4) I believe spirituality involves only going to church/place of worship.

Strongly disagree Disagree Uncertain Agree Strongly agree

5) I believe spirituality is not concerned with a belief and faith in God or a Supreme Being.

Strongly disagree Disagree Uncertain Agree Strongly agree

6) I believe spirituality is about finding meaning in the good and bad events of life.

Strongly disagree Disagree Uncertain Agree Strongly agree

7) I believe nurses can provide spiritual care by spending time with a patient and giving support and reassurance especially in times of need.

Strongly disagree Disagree Uncertain Agree Strongly agree

8) I believe nurses can provide spiritual care by enabling a patient to find meaning and purpose in their illness.

Strongly disagree Disagree Uncertain Agree Strongly agree

9) I believe spirituality is about having a sense of hope in life.

Strongly disagree Disagree Uncertain Agree Strongly agree

10) I believe spirituality has to do with the way one conducts one's life here and now.

Strongly disagree Disagree Uncertain Agree Strongly agree

11) I believe nurses can provide spiritual care by listening to and allowing patients time to discuss and explore their fears, anxieties and troubles.

Strongly disagree Disagree Uncertain Agree Strongly agree

12) I believe spirituality is a unifying force which enables one to be at peace with oneself and the world.

Strongly disagree Disagree Uncertain Agree Strongly agree

13) I believe spirituality does not include areas such as art, creativity and self expression.

Strongly disagree Disagree Uncertain Agree Strongly agree

14) I believe nurses can provide spiritual care by having respect for privacy, dignity and religious and cultural beliefs of a patient.

Strongly disagree Disagree Uncertain Agree Strongly agree

15) I believe spirituality involves personal friendships and relationships.

Strongly disagree Disagree Uncertain Agree Strongly agree

16) I believe spirituality does not apply to Atheists or Agnostics.

Strongly disagree Disagree Uncertain Agree Strongly agree

17) I believe spirituality includes peoples' morals.

Strongly disagree Disagree Uncertain Agree Strongly agree

Appendix C

Institutional Review Board

Marquette University
Research Information Sheet
Protocol Number: HR-2858
Exempt Status Granted 9/19/2014

MARQUETTE UNIVERSITY
AGREEMENT OF CONSENT FOR RESEARCH PARTICIPANTS
Effects of Spiritual Care Education on Pediatric Nurses' Knowledge, Attitudes, and Competence
Cheryl L. Petersen, PhDc, MSN, RN, CPHON
College of Nursing

You have been invited to participate in this research study. Before you agree to participate, it is important that you read and understand the following information. Participation is completely voluntary. Please ask questions about anything you do not understand before deciding whether or not to participate.

PURPOSE: The purpose of this research study is to identify the effects of an online spiritual care educational program on pediatric nurses' knowledge, attitudes, and spiritual care competence. You will be one of approximately 82 participants in this research study.

PROCEDURES: The Marquette University computer system in which the educational program and short surveys are accessed is password protected, and you will be contacted by email by a faculty member from Marquette University other than the primary investigator of this study to provide you with an username and password to access the educational program and the surveys. If you participate in this study, you agree to complete the educational program and surveys within 30 days of providing consent to participate in this study. You also agree to complete two surveys at one final time point that is three months after you complete the educational program.

DURATION: The study, including completion of the spiritual care educational program and the surveys, will involve approximately three hours of your time. If you agree to participate, you will complete the following activities online:

- An online spiritual care educational program.
- A short, online survey about your background. This survey will be completed before you begin the spiritual care educational program.
- A short, online survey about your ability to provide spiritual care to children with cancer at the end of life and their families. This survey will be completed at three time points: before completing the spiritual care educational program, immediately after completing the program, and 3 months after completing the program.
- A short, online survey about your attitudes towards and knowledge of spirituality and spiritual care. This survey will be completed at three time

points: before completing the spiritual care educational program, immediately after completing the program, and 3 months after completing the program.

There are no right or wrong answers to the questions on these forms. Please answer all of the questions. Completing these surveys is strictly your choice. No one will know how you answered the surveys, for you will answer these surveys in an online system in which you are assigned a username and password. The researchers will not have access to the list that links your name or email to your username.

RISKS: The content of the educational program could make you sad or upset from remembering past experiences caring for children who were at the end of life. If that happens, you may request to be referred to a chaplain who has offered to be available to talk with participants in this study.

Someone could find out that you are in the study and learn something about you that you did not want others to know. The computer system in which this program and surveys are accessed is password protected, and you will use a username that is assigned to you at the start of the study.

BENEFITS: By participating in this study, you may be better prepared to address the spiritual needs of children with cancer at the end of life and their families through the nursing care that you provide.

CONFIDENTIALITY: We will do our best to protect your privacy. All information you reveal in this study will be kept confidential. All of your data will be connected to a computer system username, rather than using your own name or information that could identify you as an individual. The researchers will not have access to the link between your name and the computer username. When we share the results of the study in medical journals or at presentations, we will not include any information that identifies you. We will do our best to make sure that no one outside of the study will know you are a part of the study.

The spreadsheet linking your name and your computer system username will be destroyed 12 months after the completion of the study. The de-identified data set, with no link to your identity, will be kept indefinitely. Your research records may be inspected by the Marquette University Institutional Review Board or its designees and (as allowable by law) state and federal agencies.

COMPENSATION: You will be paid for being in this study. You will receive a $50 gift card from Amazon sent to you by email. You must complete all surveys at the three

time points to receive the gift card, but if you skip over any questions that you do not wish to answer, you will still be paid for your participation.

VOLUNTARY NATURE OF PARTICIPATION: Participating in this study is completely voluntary, and you may withdraw from the study and stop participating at any time. Please contact Dr. Heidi Schweizer at heidi.schweizer@marquette.edu if you would like to withdraw from this study. Your data will then be removed from the dataset.

CONTACT INFORMATION: If you have any questions about this research project or the online educational program, you can contact Cheryl Petersen at cheryl.petersen@marquette.edu. If you have questions or concerns about your rights as a research participant, you can contact Marquette University's Office of Research Compliance at (414) 288-7570 or orc@mu.edu.

I HAVE HAD THE OPPORTUNITY TO READ THIS CONSENT FORM, ASK QUESTIONS ABOUT THE RESEARCH PROJECT AND AM PREPARED TO PARTICIPATE IN THIS PROJECT.

_____
(Printed Name of Participant)

_____ _____
(Signature of Participant) Date

_____
(Email address of Participant)

_____
(Printed Name of Individual Obtaining Consent)

_____ _____
(Signature of Individual Obtaining Consent) Date

Appendix D

"Nurses' Care of the Spirit for Children with Cancer at the End of Life and Their Families"
Content: Spiritual Care Educational Program

Course Introduction

- "Relating to Patients on a Humanistic or Human Level": YouTube interview with Dr. Traci Balboni, MD, MPS, Harvard Medical School/Dana Farber Cancer Institute, a radiation oncologist and international expert in spiritual care.

Module 1

Learning Outcomes

- Describe the attributes of nurses' spiritual care for children with cancer at the end of life.
- Contrast the spiritual care of children at various developmental levels.
- Summarize the goals of spiritual care and the implications for the provision of nursing care.

Introduction

Content

- "Spiritual Care of Children with Cancer at the End of Life and Their Families": voiceover PowerPoint highlighting findings from the literature
- *Reading:*
  Davies, D., Brenner, P., Orloff, S., Summer, L., & Worden, W. (2002). *Addressing spirituality in pediatric hospice and palliative care,18(1), 59-67.*
- *Supplemental Readings:*
  Hart, D., & Schneider, D. (1997). Spiritual care for children with cancer. *Seminars in Oncology Nursing, 13(4), 263-270.*

  Hufton, E. (2006). Parting gifts: the spiritual needs of children. *Journal of Child Health Care, 10(3), 240-250.*

  Purow, B., Alisanski, S., Putman, G., & Ruderman, M. (2011). Spirituality and pediatric cancer . *Southern Medical Journal, 104 (4), 299-302.*

Module 2

Learning Outcomes:

- Discuss the key factors for integration of spiritual care into the nursing process.
- Apply the Consensus Conference guidelines to your own nursing practice.

Introduction

Content

- "Advancing the Delivery of Spiritual Care for Children with Cancer and Their Families": voiceover PowerPoint highlighting the report of the Consensus

Conference, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care" (Puchalski et al., 2009)

- "Lessons Learned": an interview with an 11-year old boy with progressive glioblastoma multiforme about the importance of spirituality and spiritual care
- "Tales of Hope from a Hospice Chaplain": Hospice Chaplain John D'Allesio, shares enlightening stories of the benefits of spiritual care for children at the end of life
- "Keeping the Spirit Strong"
- Discussion prompt for the discussion board:
  "Share your thoughts regarding how this educational program may impact or change your practice. What additional guidance do you need to provide adequate spiritual care to children and their families?"

Module 3

Learning Outcomes:

- Apply knowledge of spiritual care interventions to the care of children with cancer at the end of life and their families.

Introduction

Content

- "My Last Days: Meet Zac Sobiech: a documentary that highlights an adolescent's quest to express his feelings through his music and to be remembered by family and friends at the end of his life.
- Supplemental Resources
  Foster, T.L., Bell, C.J., & Gilmer, M.M. (2012). Symptom management of spiritual suffering in pediatric palliative care. *Journal of Hospice and Palliative Nursing, 14*(2), 109-115.
- Discussion prompt for the discussion board:
- What lessons did Zach Sobiech ("My Last Days" documentary) or Tyler Doherty ("Letters to Go" movie trailer) teach us that could be applied to the spiritual care of other children dying of cancer and their families?
- Personal Reflection Exercise:
  "Please share details about your openness to spiritual beliefs that are different than your own. Consider an example or a potential future encounter in your practice. How do you show respect for patients' and families' spiritual beliefs that are different than your own beliefs? What steps do you take to ensure that you do not impose your beliefs on others?"

Table 1. Effect of Spiritual Care on the Vulnerability of Parents whose Children Have Cancer or Whose Children are at the End of Life.

Author	Study Design	Sample	Setting	Data Collection	Theme	Findings
Alam, D'Agostino, Barren, Schneiderma, and Nicholas, 2012	Qualitative: Content analysis	31 parents of children who died who were treated in hematology/oncology department	Ontario	Interviews	• Developing continuing bonds	• Religious beliefs allowed parents to maintain a bond with child after death • Building child's legacy important to parents
Dell'Orfano, 2002	EBP project: Thematic analysis	10 parents of children with brain injuries due to MVA, cancer	United States	Interviews	• Providing support	• Spiritual care provided by nurses, friends and family provided comfort and support
Fletcher, Schneider, and Harry, 2010	Qualitative: Phenomenology	12 caregivers of children with cancer	Ontario	Interviews	• Instilling hope • Developing continuing bonds	• Spiritual belief in afterlife provided hope • Keeping the memory of the child alive was a key factor for parents to successfully move forward in life
Meert, Thurston, and Briller, 2005	Qualitative: Thematic analysis	33 parents whose children died in PICU	United States	Interviews	• Finding meaning and purpose • Enhancing coping	• Spiritual care: assisted parents to find meaning and purpose in child's death and assisted them to cope
Meyer, Ritholz, Burns, and Truog, 2006	Qualitative: Thematic analysis	56 parents whose children died in PICU	United States	Open-ended questionnaire	• Enhancing coping • Finding meaning and purpose	• Faith was central to parents' ability to cope and make meaning of child's death; faith, sustained and comforted parents
Robert et al., 2012	Qualitative: Thematic analysis	14 parents whose children died and received oncology services	United States	Focus groups	• Providing support	• Spiritual care was an important aspect of social support
Robison, Thiel, Backus, and Meyer, 2006	Qualitative: Thematic analysis	56 parents whose children died in PICU	United States	Self-report questionnaires	• Enhancing coping • Developing continuing bonds	• Parents relied on spirituality to provide emotional sustenance • Parents identified spiritual recourses that helped them get through child's death, including belief in transcendent nature of relationship with child
Schneider and Mannell, 2006	Qualitative: Phenomenology	12 parents of children with cancer	Ontario	Semi-structured interview; field notes	• Enhancing coping	• Spirituality: important resource with positive influence on coping behaviors
Wheeler, 2001	Qualitative: Descriptive study	176 bereaved parents	United States	Open-ended questionnaire	• Finding meaning and purpose	• Bereavement involves spiritual crisis of meaning from child's life and death
Yeh, Lee, and Chin, 2000	Qualitative: Grounded theory	12 parents of children with cancer	Taiwan	Interviews Reflexive journals Review of charts Observation Focus groups	• Enhancing coping • Finding meaning and purpose	• Spirituality assisted parents in search for meaning of life and child's illness • Most frequently employed coping mechanism: increasing spiritual practices and searching for meaning
Zeller, Cataudella, Cairney, and Bannister, 2010	Qualitative: Thematic analysis	25 parents whose children died of brain tumors	United Kingdom	Focus groups	• Instilling hope	• Sources of spiritual strength provided hope and strength

Table 2. Effects of Spiritual Care Education on Nurses' Knowledge

Study	Sample / Setting	Design	Intervention	Results
Baldacchino, 2011	103 acute care unit nurses, Malta	Qualitative thematic analysis	28 hours of teaching sessions, group work, and 4-hour group seminar	• Enhanced awareness of spirituality and nurses' role in spiritual care • Increased knowledge about spirituality, spiritual care, and ability to meet patients' spiritual needs
Ellman, 2012	309 students (nursing, medicine, social work, divinity), United States	Mixed-methods	30-minute online case study, 90-minute interdiscipinary workshop to teach spiritual and cultural aspects of palliative care	• High ratings on educational quality and usefulness for future professional work • Enhanced recognition of important issues beyond students' own disciplines
Lovanio & Wallace, 2007	8 nursing students, United States	Quasi-experimental pretest/posttest, pilot (baseline, immediately after program)	3-hour presentation, self-reflection journal, clinical conferences for 10 weeks	• Increased knowledge of and attitudes towards spirituality and spiritual care after the program
Meredith, Murray, Wilson, & Mitchell, 2012	113 palliative care professionals (medicine, nursing, chaplaincy, psychology counselors), Australia	Quasi-experimental pretest/posttest (baseline, immediately after program, 3 months later)	Spirituality in Palliative Care workshop (time frame not identified)	• Increased knowledge of spirituality and spiritual care • Increased confidence in providing spiritual care after workshop; confidence continued to grow over next 3 months
Shih, Gaw, Mao, Chen, & Lo, 2001	22 graduate nursing students, Taiwan	Qualitative: methods triangulation	18 weeks of classroom lectures, field trips, discussions	• Self-reports of knowledge gained about theoretical concepts of spirituality and spiritual care, spiritual care planning, and ways to provide spiritual care
So & Shin, 2011	12 Christian nursing students, Korea	Qualitative: phenomenology	1-credit spiritual care practicum	• Improved coping skills regarding providing spiritual care, self-knowledge, and personal spiritual growth
Taylor, Mamier, Bahjri, Anton, & Peterson, 2008	201 nursing students, United States	Quasi-experimental pretest/posttest (baseline, immediately after program)	10-hour self-study course; workbook and DVD	• Increased knowledge about communication in provision of spiritual care and ability to create empathetic response to spiritual suffering

Table 3. Effects of Spiritual Care Education on Nurses' Attitudes and Perspectives

Study	Sample / Setting	Design	Intervention	Results
O'Shea, Wallace, Griffen, & Fitzpatrick, 2011	41 pediatric nurses, United States	Quasi-experimental pretest/posttest (baseline, immediately after program)	30-minute lecture	• More positive perspective toward providing spiritual care to patients after program • Nurses' comfort with providing spiritual care showed strong linear correlation with personal spirituality
Reade, 2013	43 bone marrow transplant nurses, United States	Quasi-experimental pretest/posttest (baseline, 1 month after program completed)	6-hour course	• Increased frequency of spiritual care provided to patients • Program assisted participants to reflect, resulting in increased value of spirituality • Slight enhancement of personal spiritual perspectives
Sandor, Sierpina, Vanderpool, & Owen, 2006	416 students (junior nursing students, first year medical students), United States	Quasi-experimental pretest/posttest (baseline, 1 year later)	Course included readings, reflection, small group case discussions, large group session	• Increase in perceived importance of spirituality in practice after program • Medical and nursing students showed equivalent spiritual support scores • Declining scores in dogmatism after program

Table 4. Effects of Spiritual Care Education on Nurses' Spiritual Care Competence

Study	Sample / Setting	Design	Intervention	Results
van Leenwen, Tiesinga, Middel, Post & Jochemsen, 2008	97 Christian nursing students, Netherlands	Quasi-experimental pretest/posttest crossover design (baseline, 6 weeks, 14 weeks, 20 weeks)	27 hours of content in 6-week course: lectures, reflection, vignette analysis	• Increased scores regarding spiritual care competence in planning, delivery of spiritual care, referral to spiritual care staff, professionalization, and quality assurance
Costello, Atinaja-Faller, & Hedberg, 2012	52 students in a maternal-child health course, United States	Quasi-experimental pretest/posttest crossover design (baseline, immediately after program)	2-hour simulation case study	• Increased scores in ability to assess spiritual needs and refer to pastoral care • Increased communication skills • Improved attitudes toward spirituality
Burkhart & Schmidt, 2012	59 nursing students, United States	Randomized controlled trial	$1^{1/2}$ day retreat, lecture, reflection, online discussion board	• No differences in spiritual well-being, religious well-being, or existential well-being • Increase in provision of spiritual care by intervention group participants • Positive changes in on-going assessments of patients spiritual needs

Table 5. Effects of Spiritual Care Education on Patients and Professionals

Study	Sample / Setting	Design	Intervention	Results
Vlasblom, van der Steen, Knol, & Joehensen, 2011	49 community nurses, nonacademic hospital, Netherlands	Quasi-experimental pretest/posttest (baseline, 6 weeks)	4 sessions (4 hours each) plus reflections and literature review	• More reports filed about patients' spiritual needs • More referrals to chaplaincy • Increased patient report of support from nurses
Wasner, Longaker, Figg, & Borasio, 2005	48 palliative care professionals (nurses, physicians, pastoral care, volunteers, social workers), Germany	Quasi-experimental pretest/posttest (baseline, 6 months)	$3^{1/2}$ day training based on Tibetan Buddhist tradition with nondenominational approach	• Increased scores on FACIT-Sp immediately after training • Increased self-transcendence scores immediately after training • Improvement in attitudes toward work and satisfaction with work

Table 6. Crosswalk: Relationships between spiritual care educational program content, the conceptual framework, and the Consensus Conference Guidelines: Improving the Quality of Spiritual Care as a Dimension of Palliative Care.

Actioning Spirituality and Spiritual Care Education and Training in Nursing (ASSET) Model	**Consensus Conference Recommendations for Improving Spiritual Care**						
	Spiritual Care Model	**Spiritual Assessment**	**Spiritual Treatment / Care Plan**	**Interprofessional Considerations**	**Training and Certification**	**Personal and Professional Development**	**Quality Improvement**
Structure: includes self-awareness, reflection on one's personal beliefs, and integration of new knowledge into nursing practice		• Spiritual Care of Children with Cancer at the End of Life and their Families	• Relating to Patients on a Humanistic or Spiritual Level	• Relating to Patients on a Humanistic or Spiritual Level • Tales of Hope from a Hospice Chaplain		• Reflection Exercise • Discussion Questions	
Process: the experiential learning that occurs from the study of spirituality, as well as the application of the nursing process to the provision of nursing care	• Advancing the Delivery of Spiritual Care	• Spiritual Care of Children with Cancer at the End of Life and their Families • Advancing the Delivery of Spiritual Care • Addressing Spirituality in Pediatric Hospice and Palliative Care	• Spiritual Care of Children with Cancer at the End of Life and their Families • My Last Days: Meet Zac Sobiech • Symptom Management of Spiritual Suffering in Pediatric Palliative Care • Lessons Learned • Keeping the Spirit Strong		• Advancing the Delivery of Spiritual Care	• Relating to Patients on a Humanistic or Spiritual Level	• Advancing the Delivery of Spiritual Care
Outcome: the results of educational initiatives, including increased levels of knowledge and competence, as well as improved quality of care						• Perceived spiritual care competence • Perceived attitudes towards and knowledge of spirituality and spiritual care	

(Narayanasamy, 1999; Puchalski et al., 2009)

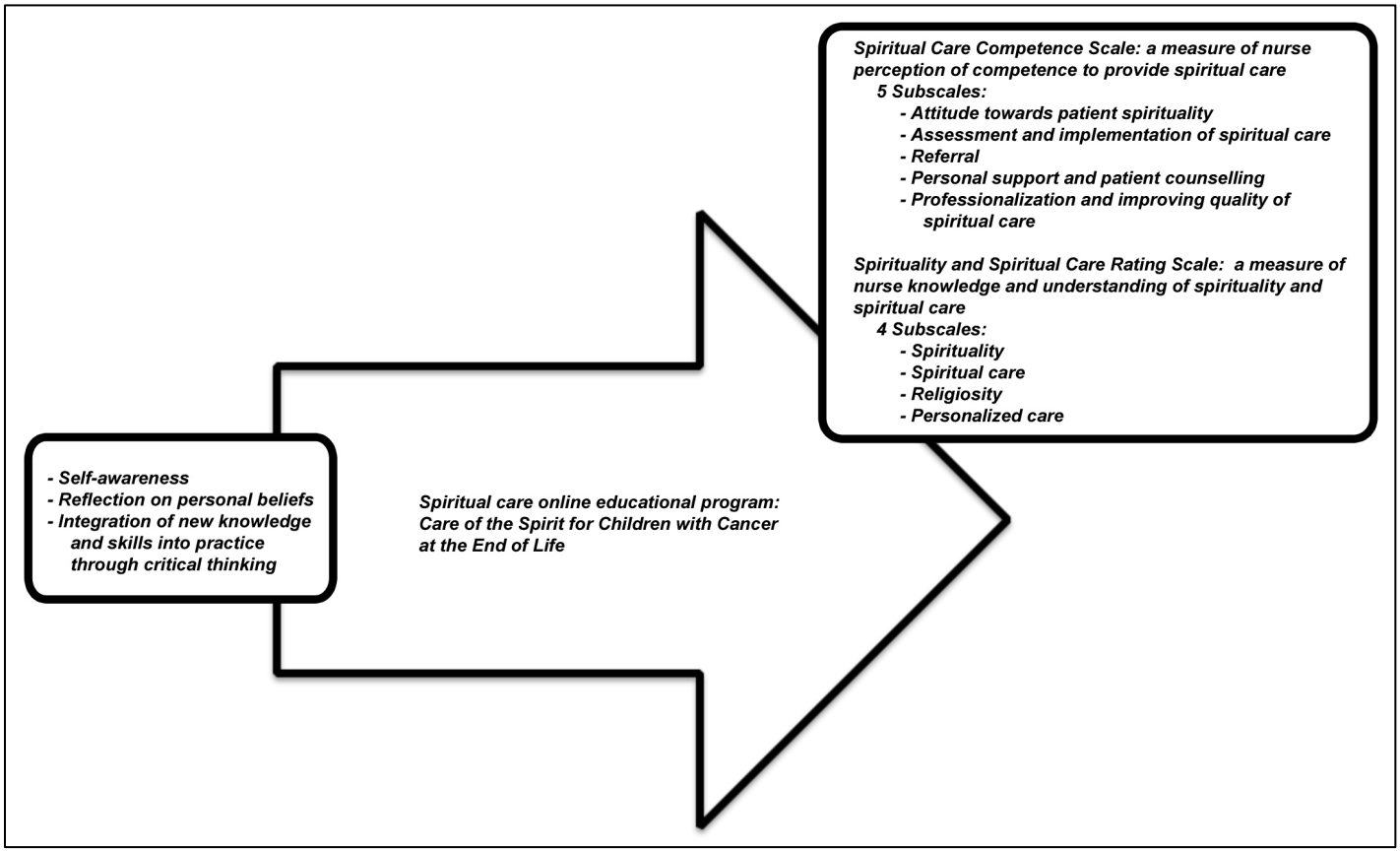



Figure 1. Conceptual Framework: Actioning Spirituality and Spiritual Care Education and Training in Nursing Model. Adapted from Narayanasamy, 1999.