See page 190 for details about a podcast interview with the author of this article.

Conceptual Framework for the Study of Parental End-of-Life Decision Making in Pediatric Blood and Marrow Transplantation

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Purpose/Objectives: To describe a conceptual framework that will facilitate research and practice concerning parental end-of-life decision making in pediatric blood and marrow transplantation (BMT).

Data Sources: A review of relevant literature from Ovid®, CINAHL®, EBSCO, MEDLINE®, PsycINFO, and various sociology and theology databases was combined with experiential knowledge.

Data Synthesis: The method of concept and theory synthesis and derivation as described by Walker and Avant was used in the development of this framework.

Conclusions: Use of the proposed conceptual framework is expected to provide the organization necessary for thinking, observation, and interpretation of parental end-of-life decision making in pediatric BMT.

Implications for Nursing: The ability to describe the process of parental end-of-life decision making in pediatric BMT will help nurses to provide appropriate counseling, education, and support for these children and their families at the end of life. In addition, the process will help nurses to promote the well-being of the children's families after end of life.

Blood and marrow transplantation (BMT) is an aggressive medical treatment associated with high morbidity and mortality. Survival rates for BMT vary from 25%–50%, depending on the underlying diagnosis and type of transplantation performed (Barrera, Boyd-Pringle, Sumbler, & Saunders, 2000; Drew, Goodenough, Maurice, Foreman, & Willis, 2005; Kolb, Gidwani, & Grupp, 2006). Despite the statistics, BMT often represents the most viable treatment option for children with certain types of life-threatening cancers, bone marrow failure, metabolic disorders, or immunodeficiency syndromes. Many children receiving BMT have endured lengthy, aggressive treatment only to suffer disease relapse or experience failure of more conventional treatment. Throughout an often prolonged course of disease, parents of children receiving BMT are forced to make numerous treatment decisions with the intent and hope of saving their child's life (Stevens & Pletsch, 2002). When curative efforts fail, parents suddenly are faced with decisions that focus on end-of-life treatment and care for their dying child.

Authors who have addressed parental end-of-life decision making for children have focused on parental priorities for end-of-life care, the meaning of end-of-life decision making for parents, the challenge of decision making involving palliative treatment with potentially toxic medications as opposed to supportive care alone, and the degree and type of control parents express throughout the decision-making process (Hinds et al., 2000, 2001; Meyer, Burns, Griffith, & Truog, 2002; Pyke-Grimm, Degner, Small, & Mueller, 1999; Sharman, Meert, & Sarnaik, 2005; Tomlinson et al., 2006). For this article, parental end-of-life decision making is defined as a parent's decision to not resuscitate or withdraw life-sustaining therapy to allow the terminally ill child to die a natural death.

Parents have consistently reported that end-of-life decisions are the most difficult they have faced on behalf of a seriously ill child (Hinds et al., 1997; Hinds, Schum, Baker, & Wolfe, 2005) and, in retrospect, they express regret, doubt, and second guessing over the decision (Drew et al., 2005; Meyer et al., 2002). BMT is recognized as a particularly aggressive treatment that is delivered in an environment of semi-isolation. Children who die following BMT usually do so in the hospital after a prolonged stay, punctuated by numerous treatments and procedures (Hinds, Schum, et al., 2005). The transition from aggressive curative care to palliative care often is abrupt (Meyer et al., 2002). The parental decision to forego or withdraw life support for a dying child following BMT is the ultimate final decision and may occur from hours or even minutes to several days or longer prior to the child's death (Drew et al., 2005).

Process of Framework Development

Review of Relevant Literature

Extensive experiential knowledge in the area of pediatric BMT nursing was used as a foundation for the review of extant literature as the initial step in the process of framework development. Databases accessed in the literature review included Ovid®, CINAHL®, EBSCO, MEDLINE®, PsycINFO, and various sociology and theology databases. Key words used in the search were *pediatric cancer*, *parental grief*, *pediatric bone marrow transplantation*, *end-of-life decision making*, *parental decision making*, *culture and end-of-life decision making*, *transcendence*, *acceptance*, *equanimity*, *hope*, and *transitioning*.

Literature about parental decision making for very ill children reflects diverse theoretical perspectives but agrees that parents rely on something in addition to facts and data about their child's physical condition to make decisions about end-of-life treatment (Hinds, Drew, et al., 2005; Hinds et al., 2001; Hinds, Schum, et al., 2005; Kirschbaum, 1996; Meyer et al., 2002; Provoost et al., 2006; Sharman et al., 2005; Tomlinson et al., 2006). Parents have indicated a reliance on past experiences, personal observations of their child's pain and suffering, an overwhelming desire to do what is best for the child, and a perception of the child's desire to live as important considerations in limiting or withdrawing life support (Meyer et al., 2002; Sharman et al., 2005). Religious and spiritual beliefs, support from family members, and information provided by healthcare providers also play a role in parental end-of-life decision making (Hinds et al., 2000, 2001; Meert, Thurston, & Sarnaik, 2000; Meyer et al., 2002).

Numerous studies have sought to elicit parental opinions about factors that either facilitate or inhibit end-of-life decision making for a critically ill child (Hinds, Drew, et al., 2005; Hinds et al., 1997, 2000, 2001; London & Lundstedt, 2006; Meert et al., 2000; Tomlinson et al., 2006). Parents have reported that being able to get information regarding the status of their child's disease, recommendations from healthcare professionals, knowing that all curative options have been tried, and feeling supported by healthcare providers are factors that facilitate decision making (Hinds et al., 1997, 2000, 2001; Meert et al., 2000). The degree and type of control that parents experience relative to decision making may have consequences for parental psychological adjustment to the process (Stewart, Pyke-Grimm, & Kelly, 2005). Parents and children with cancer also have indicated a strong desire to benefit others as a factor in their decision making (Hinds, Drew et al., 2005). An important theme in all the literature is that parents felt positive about their participation in research studies and expressed appreciation for the opportunity to talk about their experience.

Most studies focused on parents whose child had cancer and was cared for in a pediatric intensive care unit (PICU). Limited research exists in parental decision making for end-of-life treatment outside the area of pediatric oncology and the PICU setting. Not all children with terminal disease die in the PICU (Tomlinson et al., 2006). Children dying from BMT complications may stay on the transplantation unit, where families are comfortable with the surroundings and familiar with the staff. In addition, not all children receiving BMT have cancer as a primary diagnosis. Whether parents of children dying outside of the PICU setting or children with a disease other than cancer dying from BMT complications describe different factors that influence or are important in making end-of-life treatment decisions is not known.

Literature that addresses specific concepts important to parental end-of-life decision making is limited. The preponderance of relevant literature focuses on adult patients who are dying and their caregivers (Badger, 2005; Baggs et al., 2007; Braun, Beyth, Ford, & McCullough, 2008; Christ & Blacker, 2005; Clayton, Butow, & Tattersall, 2005; Gorman, Ahern, Wiseman, & Skrobik, 2005).

Purpose

This article aims to propose and describe a conceptual framework for understanding parental end-of-life decision making in pediatric BMT. Pediatric BMT nursing defines a conceptual area of study that is not linked solely to pediatric cancer. The proposed framework is significant to nursing, patient care, and knowledge development because pediatric BMT nursing is a field of specialty practice that warrants research attention. The framework may be modified or refined based on future research and practice experience.

Development Strategies

Despite differences in opinion on appropriate strategies that should be implemented in theory development, authors agree on the need for a philosophical foundation to the chosen approach (Chinn & Kramer, 2004; Fawcett, 1989; Meleis, 2007; Walker & Avant, 2005). According to Crotty (2005), describing a philosophical stance is an "attempt to explain how it provides a context for the process and grounds its logic and criteria" (p. 7). Theoretical perspective is a way that individuals view the world and, as a result, make sense of it.

Individual theoretical perspective flows from epistemology. Crotty (2005) described epistemology as the "theory of knowledge embedded in the theoretical perspective and thereby in the methodology" (p. 3). Specifically, epistemology provides a philosophical foundation for deciding what kinds of knowledge are probable and how one can ensure that knowledge is legitimate as well as adequate (Crotty, 2005). Neomodernism has been described as evolving from postmodernism, with a focus on deconstruction to encourage an interest in meaning's reconstruction. Neomodernism has been stimulated, in part, by the freedom that is encouraged by postmodern thought

(P.G. Reed, personal communication, September 7, 2006). With respect to nursing, neomodernism is a belief that nursing philosophy and practice are domains unto themselves that interface with nursing science to form nursing knowledge. Neomodernism posits that practice and science partner to create new knowledge. Human beings are the focus of nursing care and stimulate scientific inquiry that by its nature must embrace new methodologies and research strategies. The neomodern view recognizes the uniqueness of each individual, while acknowledging that certain underlying universal principles exist. Differences are valued and an ongoing critique is essential. Neomodernism recognizes a return of metaphysics to nursing, balanced by an awareness of history, context, and free will that inform knowledge production (P.G. Reed, personal communication, September 7, 2006).

The framework development method described in this article also is consistent with the idea that an individual's environment is comprised of something more than physical surroundings. Whitehead (1978), recognized for his formulation and refinement of process philosophy, suggested that every real-life object could be thought of as a series of events and processes. In *Process and Reality: An Essay in Cosmology*, Whitehead (1978) proposed that process, as opposed to substance, should be considered the preeminent metaphysical component of the world. The nature of all things may be viewed as an ongoing, self-constructing process.

For Whitehead (1978), environment is defined as the totality of the individual's physical surroundings plus person-to-person interaction. As a result, environment is a process that is ongoing, evolving, and ever changing. Change is the critical component of the process and is not always predictable or reversible. Human reaction to any given situation is dynamic, fluid, and likely unpredictable (Lowe, 1990). According to Whitehead (1978), people exist in flux, constantly changing as an ongoing process of reality. Incorporation of Whitehead's (1978) ideas clearly supports research focusing on an individual's beliefs, perceptions, and attitudes as integral to the ongoing development of knowledge in nursing. Research efforts aimed at the understanding of process as it evolves will lead to deeper appreciation of connectedness in everyday human experience, particularly as it may help generate theoretical explanations for the spiritual or other nonempirical experiences of parents facing end-of-life treatment decisions.

A conceptual framework or model refers to a set of "global ideas about the individuals, groups, situations, and events of interest to a science" (Fawcett, 1989, p. 88). The ideas or phenomena may be articulated as concepts and can be either concrete or abstract. The concepts described in the proposed framework are highly abstract and, therefore, do not lend themselves to empirical testing. The relationships between the concepts are assumptions that describe how they may be integrated into a meaningful configuration. Fawcett (1989) described conceptual models as evolving from the researcher's intuitive insights that are framed within the structure of a related discipline. The benefit of the conceptual model comes from the organization that it provides for thinking. The path to model development "requires imagination, knowledge of the subject matter, and logical thinking" (Fawcett, 1989, p. 89).

Walker and Avant (2005) suggest three approaches to conceptual model or theory building. Synthesis refers to information that is based in observation and used to develop a new concept. The researcher's ability to extract or pull together a concept from a body of data or personal experiential knowledge is the basis for synthesis in concept development. Derivation relates to the ideas of metaphor and analogy and allows a concept to be redefined, transposed, or otherwise adapted from one field of study to another. Analysis is a process that assists in the dissection of a concept from its whole into component parts so that the meaning can be better understood. The purpose of analysis is to refine or clarify the meaning of the identified concept (Walker & Avant, 2005). The processes of synthesis, derivation, and analysis presented were incorporated with experiential knowledge, epistemology, and philosophical perspective with a review of extant literature to identify, describe, and suggest the concepts and relationships that are presented.

Description of Framework

In the pediatric BMT setting, parental end-of-life decision making is a journey with many twists and turns. The process culminates with the parental end-of-life decision to not resuscitate or to withdraw life-sustaining therapy for their dying child. The parental ability to move from an initial hope for the child's cure through a process of transitioning to the end-of-life decision is predicated on a parent's awareness of the potential for the child's terminality. The process also is significantly influenced by the parent's personal spiritual perspective, a parental sense of knowing, the cultural background of the parents, information sharing that occurs at numerous points along the decision-making path, and parental biobehavioral responses. Concepts described as potentially important to the process of parental end-of-life decision making include hope, spiritual perspective, sense of knowing, parental cultural background, information sharing, parental biobehavioral responses, and transitioning (Badger, 2005; Davies, Reimer, & Martens, 1990; Goldberg, 1998; Herth, 1993; Hinds et al., 1997, 2001; Kylma & Vehvilaninen-Julkunen, 1997; London & Lundstedt, 2006; Meyer et al., 2002; Sharman et al., 2005; Tejada-Reyes, 2002; Tomlinson et al., 2006; Truog, Meyer, & Burns, 2006; Waldrop, Kramer, Skretny, Milch, & Finn, 2005) (see Figure 1).

A paucity of literature involving parental end-of-life decision making addresses the concept of hope. Authors

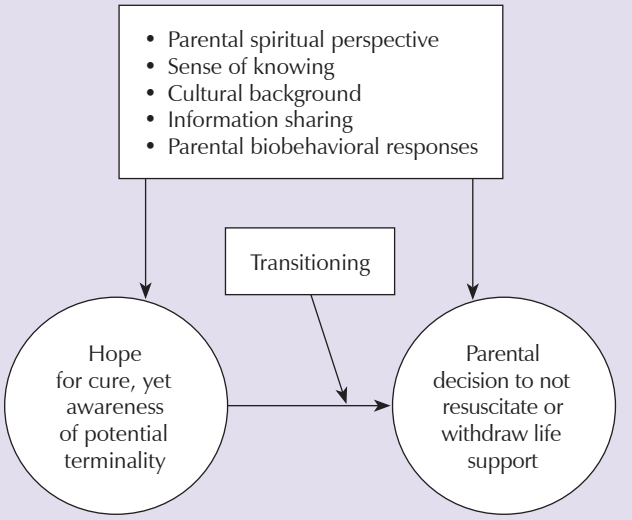

Figure 1. Proposed Process of Parental End-of-Life Decision Making in Pediatric Blood and Marrow Transplantation

have described hope primarily in terms of hope for the future (i.e., a good outcome), identifying a strong link with parental spirituality and connectedness between parent and child (Meyer et al., 2002; Sharman et al., 2005; Tomlinson et al., 2006; Truog et al., 2006). Parents start the treatment process with a hope for cure that is tempered by an awareness, however slight, of the potential for their child's terminality (Hinds et al., 1996). However, hope for cure is tested as parents recognize their child's terminality. Future research is expected to demonstrate that hope for a desired outcome is transformed during the process of parental transitioning and that the experience of hope becomes a means to provide comfort to parents during this time, thus facilitating end-of-life decision making.

In literature on parental end-of-life decision making, parents are described as receiving comfort from God and family, having a sense of connectedness to their child, and having personal religious or spiritual beliefs (Hinds et al., 2000; Kirschbaum, 1996; London & Lundstedt, 2006; Meyer et al., 2002; Sharman et al., 2005). The connectedness between parent and child often is felt as a spiritual connection and is identified by parents as a strong support mechanism for end-of-life decision making (Tomlinson et al., 2006). Parents do not verbalize a search for meaning in the death of the child, choosing instead to focus on the child's quality of life as the primary parental spiritual driver (Meyer et al., 2002; Sharman et al., 2005).

Spiritual perspective contemplates influences on parental beliefs (including beliefs regarding death), values, and behavior that may or may not have a basis in observable reality (Goldberg, 1998; Heyse-Moore, 1996; Kruse, 2004; Kruse, Ruder, & Martin, 2007; Tanyi, 2002; Teixeira, 2008; Wayman & Gaydos, 2005). Although the beliefs may be grounded in religion, parents' ability to verbalize a strong religious foundation for their spiritual perspective on life is not necessarily a primary prerequisite. Parental spiritual perspective is expected to play a key role in most parents' ability to engage in decision making, from hope for cure to recognition of the child's terminality, as a result of transitioning to the end-of-life decision.

Sense of knowing has roots in the concepts of discernment, connectedness, and perception. Discernment has been described as the presumption that the parent is able to separate the child's best interests from their own and amounts to a benefit-burden analysis as the basis for decision making (Carnevale, 2007). Connectedness between parent and child is described in pediatric literature as a critical construct that assists parents in decision making (London & Lundstedt, 2006; Meyer et al., 2002; Sharman et al., 2005; Tomlinson et al., 2006). The emphasis is on parents deciding what is best for their child and doing whatever is necessary to limit the child's suffering, thus improving the child's quality of life. Kirschbaum (1996) described the way the child looks or behaves as another important component in parental decision making that may inform the parent's sense of knowing.

Sense of knowing generally is described by parents in situations in which their child is unable or too young to clearly articulate a preference in end-of-life treatment. The concept suggests a wordless link between parent and child possibly cued by the child's physical condition as end-of-life approaches. Therefore, sense of knowing may be relevant particularly with younger children (i.e., younger than age 10) whose cognitive development may preclude their ability to engage in abstract, existential thought processes regarding their own end-of-life decision making (Dickey, 2007).

The influence of culture on parents may be found in the family roles of parents, the structure and dynamics of the family, family communication patterns, and general decision making practices (Andrews & Boyle, 2003). Cultural as well as religious beliefs are believed to influence whether parents will consent to medical treatment that is recommended for their child (Linnard-Palmer & Kools, 2005); however, the literature reviewed indicates that cultural views of death do not influence parental end-of-life decision making. Culture may impact parents in ways they do not understand; therefore, parents are not likely to act contrary to their inherent belief system, particularly during the process of end-of-life decision making.

Sharing of information occurs throughout the entire process of parental end-of-life decision making. Parents are known to rely heavily on facts and data regarding their child's condition when confronted with situations requiring decision making (Hinds et al., 1997, 2000, 2001; London & Lundstedt, 2006; Meert et al., 2000; Meyer et al., 2002; Sharman et al., 2005; Tomlinson et al., 2006). Without adequate information, parents have greater difficulty arriving at the point of transitioning that is a necessary precursor to end-of-life decision making. Mack, Wolfe, Grier,

Cleary, and Weeks (2006) noted that "parents have the capacity to hope for a cure while simultaneously preparing for the possibility of death, but they need information to do so" (p. 5269). Meyer et al. (2002) found that parents who described feeling well informed about their child's condition, treatment options, chance for survival, and the pros and cons of continuing treatment reported a greater sense of confidence in end-of-life decision making.

Biobehavioral parental responses (e.g., fear, anger, helplessness, guilt, fatigue) are either embedded or inherent in the end-of-life decision-making process (Davies et al., 1998; Drew et al., 2005; Oppenheim, Valteau-Couanet, Vasselon, & Hartmann, 2002; Steele & Davies, 2006; Stevens & Pletsch, 2002). The potential influence of parental responses on the overall process of end-of-life decision making should not be underestimated. Drew et al. (2005) described the impact of pediatric BMT on parents' psychological functioning, particularly when the child dies in the hospital setting. The fear that parents describe of simply having their child undergo BMT was significantly exacerbated by the physical isolation of the inpatient BMT setting. Parental fear coupled with the isolation of the BMT setting may create an obstacle to parental emotional expressivity, thus impacting parents' ability to engage fully in the end-of-life decision-making process.

Guilt is tied closely to parental fear (Drew et al., 2005). Parents may be afraid to express their true feelings for fear of seeming to be unhopeful. Feelings of guilt also emerge when the natural parental role of child protector is put to issue in the BMT setting, as parents frequently must decide on treatments and interventions that cause pain and discomfort to their child (Davies et al., 1998).

The inability to change the child's circumstance and contribute to a cure may lead to great parental distress, often expressed as anger (Oppenheim et al., 2002). In addition to fear of the child's death and having to face the child's suffering, parents described feeling angry that they had no choice about BMT and that the environmental constraints of being on the BMT unit are significant (Oppenheim et al., 2002; Stevens & Pletsch, 2002). The physical and social isolation parents experience within the BMT unit environment coupled with anger, fear, feelings of helplessness, and guilt create a difficult situation for all involved in the end-of-life decision-making process.

In the pediatric BMT setting, the impact of fatigue on parents may include mental and physical exhaustion manifested as physical weariness, slowed speed of information processing, impaired cognitive functioning, and depression (Steele & Davies, 2006). Parents are known to employ a method of going into slow motion as a strategy for dealing with the effects of fatigue. Slow motion as a cognitive strategy is a form of attentional impairment that diminishes the ability of parents to learn new things or to process new information (Steele & Davies, 2006). Hinds et al. (2001) noted that end-of-life decision making, once the sole domain of the physician, now includes patients, their families, and other members of the healthcare team. Although slow motion may be a protective mechanism for parents, the end result often is an impaired ability to acquire new information, which may affect parents' ability to fully participate in end-of-life decision-making process for their terminally ill child (Steele & Davies, 2006).

The parental biobehavioral responses identified may exist alone or in combination throughout the entire end-of-life decision-making process. The degree to which the responses influence end-of-life decision making in pediatric BMT has not been described fully. As a result, separating the parental biobehavioral response from any conceptual framework developed to study end-of-life decision making in the pediatric BMT setting is impractical.

Davies et al. (1990) described transition as a change that necessitates abandonment of a set of assumptions, coupled with the development of a new set of assumptions that helps people to cope with alterations in their life. Badger (2005) viewed transition as a change in medical treatment for the patient from a curative focus to comfort care. Waldrop et al. (2005) noted that transition is a process for caregivers of patients with terminal illness involving movement from one stage of caregiving to another as patients' medical condition changes.

Parents agree to accept BMT for their child with a sense of hope that the treatment will provide a cure for the underlying disease but also with an awareness (not necessarily articulated) that no other options exist if their child is to survive (Stevens & Pletsch, 2002). At the point of transitioning, parental hope for cure may wane as a deepening awareness and recognition of the child's terminality begins to take hold. The parental focus in decision making changes with a greater emphasis placed on the child's comfort as the end-of-life approaches. Transitioning is believed to be a necessary occurrence for parents to make the end-of-life decision as described in this article.

Conclusion

According to Meert et al. (2000), end-of-life decision making for parents is a "unique and often devastating experience" (p.183). An improved and more informed ability to reliably and validly describe parental end-of-life decision making in pediatric BMT will help nurses provide appropriate counseling, education, and support to children and their families during the process leading to the end of life. In addition, the process will help nurses promote the well-being of the children's families after end of life. Studies of these issues will help nurses become better prepared to identify breakdowns in the decision-making process and develop interventions to assist parents in moving through the process, and, therefore, help parents to participate more fully in decision making.

The proposed framework offers a conceptualization of key components that may be used in either qualitative or quantitative studies of parental end-of-life decision

making in pediatric BMT. The framework will be helpful in guiding the initial focus and questions in qualitative studies of parental end-of-life decision making in pediatric BMT but does not preclude new approaches for additional research. The concepts as presented may be adapted or modified for examining relationships and testing hypotheses in quantitative research designs. Therefore, the next step is to examine the proposed framework systematically in research as well as practice to determine what is valid and useful and what areas may need refinement or modification.

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References

Andrews, M.M., & Boyle, J.S. (2003). *Transcultural concepts in nursing care* (4th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.

Badger, J.M. (2005). Factors that enable or complicate end-of-life transitions in critical care. *American Journal of Critical Care, 14,* 513–521.

Baggs, J.G., Norton, S.A., Schmitt, M.H., Dombeck, M.T., Sellers, C.R., & Quinn, J.R. (2007). Intensive care unit cultures and end-of-life decision making. *Journal of Critical Care, 22,* 159–168. doi: 10.1016/j.jcrc.2006.09.008

Barrera, M., Boyd-Pringle, L.A., Sumbler, K., & Saunders, F. (2000). Quality of life and behavioral adjustment after pediatric bone marrow transplantation. *Bone Marrow Transplantation, 26,* 427–435.

Braun, U.K., Beyth, R.J., Ford, M.E., & McCullough, L.B. (2008). Voices of African American, Caucasian, and Hispanic surrogates in the burdens of end-of-life decision making. *Journal of General Internal Medicine, 23,* 267–274. doi: 10.1007/s11606-007-0487-7

Carnevale, F.A. (2007). The birth of tragedy in pediatrics: A phronetic conception of bioethics. *Nursing Ethics, 14,* 571–582.

Chinn, P.L., & Kramer, M.K. (2004). *Integrated knowledge development in nursing* (6th ed.). St. Louis, MO: Mosby.

Christ, G., & Blacker, S. (2005). Enhancing our understanding of the impact of transition to end-of-life caregiving. *Journal of Palliative Medicine, 8,* 622. doi: 10.1089/jpm.2005.8.622

Clayton, J.M., Butow, P.N., & Tattersall, M.H. (2005). The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. *Cancer, 103,* 1957–1964.

Crotty, M. (2005). *The foundations of social research.* London, UK: Sage.

Davies, B., Deveau, E., deVeber, B., Howell, D., Martinson, I., Papadatou, D., . . . Stevens, M. (1998). Experiences of mothers in five countries whose child died of cancer. *Cancer Nursing, 21,* 301–311.

Davies, B., Reimer, J.C., & Martens, N. (1990). Families in supportive care—Part I. The transition of fading away: The nature of transition. *Journal of Palliative Care, 6*(3), 12–20.

Dickey, S.B. (2007). Helping children and adolescents become competent to participate in healthcare decisions. *Pennsylvania Nurse, 62,* 16–17.

Drew, D., Goodenough, B., Maurice, L., Foreman, T., & Willis, L. (2005). Parental grieving after a child dies from cancer. *International Journal of Palliative Nursing, 11,* 266–273.

Fawcett, J. (1989). *Analysis and evaluation of conceptual models of nursing* (2nd ed.). Philadelphia, PA: F.A. Davis.

Goldberg, B. (1998). Connection: An exploration of spirituality in nursing care. *Journal of Advanced Nursing, 27,* 836–842.

Gorman, T.E., Ahern, S.P., Wiseman, J., & Skrobik, Y. (2005). Residents' end-of-life decision making with adult hospitalized patients: A review of the literature. *Academic Medicine, 80,* 622–633.

Herth, K. (1993). Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing, 18,* 538–548.

Heyse-Moore, L.H. (1996). On spiritual pain in the dying. *Mortality, 1,* 297–315.

Hinds, P.S., Birenbaum, L.K., Clarke-Steffen, L., Quargnenti, A., Kreissman, S., Kazak, A., . . . Wilimas, J. (1996). Coming to terms. *Nursing Research, 45,* 148–153.

Hinds, P.S., Drew, D., Oakes, L.L., Fouladi, M., Spunt, S.L., Church, C., . . . Furman, W.L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology, 23,* 9146–9154.

Hinds, P.S., Oakes, L., Furman, W., Foppiano, P., Olson, M.S., Quargnenti, A., . . . Strong, C. (1997). Decision making by parents and healthcare professionals when considering continued care for pediatric patients with cancer. *Oncology Nursing Forum, 24,* 1523–1528.

Hinds, P.S., Oakes, L., Furman, W., Quargnenti, A., Olson, M.S., Foppiano, P., & Srivastava, D.K. (2001). End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology. *Cancer Nursing, 24,* 122–136.

Hinds, P.S., Oakes, L., Quargnenti, A., Furman, W., Bowman, L., Gilger, E., . . . Drew, D. (2000). An international feasibility study of parental decision making in pediatric oncology. *Oncology Nursing Forum, 27,* 1233–1243.

Hinds, P.S., Schum, L., Baker, J.N., & Wolfe, J. (2005). Key factors affecting dying children and their families. *Journal of Palliative Medicine, 8*(1, Suppl.), S70–S78. doi: 10.1089/jpm.2005.8.s-70

Kirschbaum, M.S. (1996). Life support decisions for children: What do parents value? *Advances in Nursing Science, 19,* 51–71.

Kolb, E.A., Gidwani, P., & Grupp, S.A. (2006). Hematopoietic stem cell transplantation. Retrieved from http://www.emedicine.com/ped/topic2593.htm

Kruse, B.G. (2004). The meaning of letting go.. *Journal of Hospice and Palliative Nursing, 6,* 215–222.

Kruse, B.G., Ruder, S., & Martin, L. (2007). Spirituality and coping at the end of life. *Journal of Hospice and Palliative Nursing, 9,* 296–304.

Kylma, J., & Vehvilainen-Julkunen, K. (1997). Hope in nursing research. *Journal of Advanced Nursing, 25,* 364–371.

Linnard-Palmer, L., & Kools, S. (2005). Parents' refusal of medical treatment for cultural or religious beliefs. *Journal of Pediatric Oncology Nursing, 22,* 48–57. doi: 10.1177/1043454204270263

London, M.R., & Lundstedt, J. (2006). Families speak about inpatient end-of-life care. *Journal of Nursing Care Quality, 22,* 152–158.

Lowe, V. (1990). *Alfred North Whitehead: The man and his work: 1910–1947* (Vol. 2). Baltimore, MD: Johns Hopkins University Press.

Mack, J.W., Wolfe, J., Grier, H.E., Cleary, P.D., & Weeks, J.C. (2006). Communication about prognosis between parents and physicians of children with cancer: Parent preferences and the impact of prognostic information. *Journal of Clinical Oncology, 24,* 5265–5270. doi: 10.1200/JCO.2006.06.5326

Meert, K.L., Thurston, C.S., & Sarnaik, A.P. (2000). End-of-life decision making and satisfaction with care: Parental perspectives. *Pediatric Critical Care Medicine, 1,* 179–185.

Meleis, A.I. (2007). *Theoretical nursing: Development and progress* (4th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.

Meyer, E.C., Burns, J.P., Griffith, J.L., & Truog, R.D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine, 30,* 226–231.

Oppenheim, D., Valteau-Couanet, D., Vasselon, S., & Hartmann, O. (2002). How do parents perceive high-dose chemotherapy and autologous stem cell transplantation for their children? *Bone Marrow Transplantation, 30,* 35–39. doi: 10.1038/sj.bmt.1703587

Provoost, V., Cools, F., Deconinck, P., Ramet, J., Deschepper, R., Bilsen, J., . . . Deliens, L. (2006). Consultation of parents in actual end-of-life decision-making in neonates and infants. *European Journal of Pediatrics, 165,* 859–866 doi: 10.1007/s00431-006-0190-4.

Pyke-Grimm, K.A., Degner, L., Small, A., & Mueller, B. (1999). Preferences for participation in treatment decision making and information needs of parents of children with cancer: A pilot study. *Journal of Pediatric Oncology Nursing, 16,* 13–24.

Sharman, M., Meert, K.L., & Sarnaik, A.P. (2005). What influences parents' decisions to limit or withdraw life support? *Pediatric Critical Care Medicine, 6,* 513–518.

Steele, R., & Davies, B. (2006). Impact on parents when a child has a progressive, life-threatening illness. *International Journal of Palliative Nursing, 12,* 576–585.

Stevens, P.E., & Pletsch, P.K. (2002). Ethical issues of informed consent. *Cancer Nursing, 25,* 81–87.

Stewart, J.L., Pyke-Grimm, K.A., & Kelly, K.P. (2005). Parental treatment decision making in pediatric oncology. *Seminars in Oncology Nursing, 21,* 89–97.

Tanyi, R.A. (2002). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing, 39,* 500–509.

Teixeira, M.E. (2008). Self-transcendence: A concept analysis for nursing praxis. *Holistic Nursing Practice, 22,* 25–31.

Tejada-Reyes, I. (2002). Making death a meaningful transition. *Clinical Journal of Oncology Nursing, 6,* 173–174.

Tomlinson, D., Capra, M., Gammon, J., Volpe, J., Barrera, M., Hinds, P.S., . . . Sung, L. (2006). Parental decision making in pediatric cancer end-of-life care. *European Journal of Oncology Nursing, 10,* 198–206. doi: 10.1016/j.ejon.2005.11.003

Truog, R.D., Meyer, E.C., & Burns, J.P. (2006). Toward interventions to improve end-of-life care in the pediatric intensive care unit. *Critical Care Medicine, 34*(11, Suppl.), S373–S379. doi: 10.1097/01.CCM.0000237043.70264.87

Waldrop, D.P., Kramer, B.J., Skretny, J.A., Milch, R.A., & Finn, W. (2005). Final transitions. *Journal of Palliative Medicine, 8,* 623–638. doi: 10.1089/jpm.2005.8.623

Walker, L.O., & Avant, K.C. (2005). *Strategies for theory construction in nursing* (4th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.

Wayman, L.M., & Gaydos, H.L.B. (2005). Self-transcending through suffering. *Journal of Hospice and Palliative Nursing, 7,* 263–270.

Whitehead, A.N. (1978). *Process and reality: An essay in cosmology* (D.R. Griffin & D.W. Sherburne, Eds.). New York, NY: Free Press.

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Rishel is a doctoral candidate in the College of Nursing at the University of Arizona and a patient care manager in the Adult/Pediatric Bone Marrow Transplant and Adult Hematology/Oncology Inpatient Unit at the University Medical Center in Tucson. Her special interest is parental decision making in pediatric oncology.

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