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Communication During Palliative Care and End of Life: Perceptions of Experienced Pediatric Oncology Nurses

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COMMUNICATION DURING PALLIATIVE CARE AND END OF LIFE:
PERCEPTIONS OF EXPERIENCED PEDIATRIC ONCOLOGY NURSES

by

Kathleen Montgomery

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ABSTRACT
COMMUNICATION DURING PALLIATIVE CARE AND END OF LIFE:
PERCEPTIONS OF EXPERIENCED PEDIATRIC ONCOLOGY NURSES

by

Kathleen Montgomery

The University of Wisconsin-Milwaukee, 2013
Under the Supervision of Professor Kathleen Sawin

Advances in cancer and supportive therapy have led to improved outcomes for children with cancer. Despite progress, children still die from complications of cancer therapy or their disease. Communication during palliative care and end of life is essential to successful navigation through the end of life continuum. Nurse communication during palliative care and end of life is a phenomenon with limited research, and it is unclear how the level of nursing experience influences the perspectives of nurses communicating during end of life. The purpose of this dissertation study was to describe the commonalities of nurses' experiences of communicating palliative care and end of life perspectives when caring for dying pediatric oncology patients, and perceptions of barriers and facilitators to effective communication. This study was part of a larger multi-site qualitative study. The framework that guided this study is based on empirical phenomenology as a research philosophy and approach, and on group-as-a-whole theory. This study represented focus group data gathered from 27 pediatric oncology nurses who had greater than five years of experience or who were advanced practice nurses not involved in the direct evaluation of other nurses. The overall finding was characterized as the "Essence of Experience", which reflected how the concept of experience transcended

the core themes and provided nurses the know-how to optimize nurse PC/EOL communication. Five core themes with corresponding themes and subthemes surfaced from rich focus group discussions and supported the overall finding. The core themes included (a) evolution of PC/EOL, (b) skill of knowing, (c) expanded essence of caring, (d) experienced nurse as committed advocate, and (e) valuing individual response to grief. Enhancing nurse communication skills during palliative care and end of life requires opportunities to gain experience coupled with clinical strategies, such as standardized curricula, simulation, competency-based orientation programs, mentorship and peer support. Future research is needed to better understand outcomes associated with strategies aimed at improving nurse communication skills during palliative care and end of life in pediatric oncology.

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I dedicate this work to my family, friends, and colleagues.
To my husband, thank you for your patience, love, and continued support throughout this
journey.

To my family, I am grateful for all the support you have provided me over the years.
I would like to thank my Major Professor, Dr. Sawin. I am honored to have received her
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Chapter 1

End-of-life care research is a compelling priority for pediatric oncology because of our inherent valuing of children, families, and health care providers. Preventing or diminishing suffering in a dying child may well have acute and lasting effects for the bereaved survivors, including family members and the child's health care team (Hinds, Pritchard, & Harper, 2004).

Childhood Cancer in the US

Each year, thousands of parents lose their children to conditions such as prematurity, congenital anomalies, accidental injuries, cancer, heart disease, and other illnesses (Field & Behrman, 2003). Despite advances in cancer therapy and improvements in overall survival rates over the past several decades, children still die from cancer. In fact, cancer is the second most common cause of death among children older than one year in the US (Heron, 2011). In 2009, the incidence of cancer in children 20 years of age and younger was 17 per 100,000, and the mortality rate was 2.5 (Howlander et al., 2011). Given the prevalence of childhood cancer and mortality attributable to cancer, there is a need to continue developing curative therapies while enhancing services that reduce suffering of dying children and their family members (Hare, 2005). The death of a child goes against the natural order of the life course, making it difficult for children, parents, family members, and health care professionals (HCPs) to understand and accept.

Significance

Models of care for children dying a cancer-related death include traditional hospital care, hospice within a hospital setting, home hospice, home with no hospice, or a combination of services (Field & Behrman, 2003; Hinds, Pritchard, & Harper, 2004; Sumner, 2010). How models are implemented for specific patients is dependent on a

number of factors, including the ability of the health care team to predict the dying trajectory, patient and family preferences, availability of end of life (EOL) services, and family and community resources (Bell, Skiles, Pradhan, & Champion, 2010; Field & Behrman, 2003; Hinds, Pritchard, & Harper, 2004). Still, there is limited information to guide models of care during EOL, including cost analyses, impact of models of care on patient, parent, and HCP outcomes (Field & Behrman, 2003; Hinds, Pritchard, & Harper, 2004).

EOL research in pediatrics requires attention due to current gaps in the literature related to variation in care provided to children and families during EOL, lack of access to standardized palliative care (PC) and EOL services, and the unclear impact of PC and EOL care on outcomes. More specifically, the role of communication and its impact on the PC and EOL care continuum are unclear. Due to their continued presence with children and families throughout the EOL trajectory, pediatric oncology nurses may shed light on communication patterns including facilitators and barriers of effective communication.

Many entities, including the National Institute of Nursing Research (NINR), Oncology Nursing Society (ONS), National Hospice and Palliative Care Organization (NHPCO), and Institute of Medicine (IOM), have included PC and EOL care into their strategic plans over the course of the last decade. In the NINR 2011 Strategic Plan, three specific priority areas regarding PC and EOL were identified: (a) improve understanding of the complexity underlying PC and EOL care, (b) determine the impact of HCPs' training in PC and EOL on health outcomes, and (c) develop new communication strategies among HCPs, patients, and families to enhance decision-making regarding care

options. From a broader perspective, the NHPCO outlined objectives with a focus on promoting an interdisciplinary care coordination model across the EOL care continuum.

Integration of Palliative Care, Hospice, and End of Life Services in the US

Despite availability of PC and EOL services, many children with life-limiting conditions do not receive such services (Meier, 2009). This reality conflicts with the American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care (2000) statement which supports the integration of PC teams early in the plan of care. Children who are at risk of cancer-related death need PC and EOL services that facilitate care planning and help the HCP team gather and integrate input from children and adolescents. However, according to Johnston et al. (2008), only 58% of participating Children's Oncology Group institutions (n=187) had PC teams. In comparison to other services, 90% had a pain service, 60% had a hospice service, and 39% had a bereavement program. In order to ensure access and delivery of PC/EOL services, the following barriers that may hinder access to PC/EOL services must be addressed: limited availability of trained HCPs and services, and the philosophy of curative-focused care delivery that dominates the US health care system (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009). Other barriers to early integration of PC in children with life-limiting conditions include the following: complex ethical, legal, and policy issues affecting children; inability of community-based hospice providers to offer PC to children; fragmented care for children with complex chronic conditions; and difficulty in symptom assessment and management in children at EOL (Friebert, Greffe, & Wheeler, 2011; Himmelstein, Hilden, Boldt, & Weissman, 2004).

In a systematic review by Linton and Feudtner (2007), mechanisms underlying differences and disparities in pediatric PC included broad contextual influences, patient-clinician relationships, and patient-specific characteristics. Contextual influences included access to care, poverty, family structure, and social class. Patient-provider relationship influences included provider bias, quality of information exchange, and trust. Patient-specific characteristics included perceptions of control, religion and spirituality, and medical conditions.

Several factors may contribute to the low utilization of PC and EOL care services due to a variety of health insurance coverage mechanisms in pediatrics. The IOM (2003) identified factors, such as insurance coverage limitations in state Medicaid programs and some private insurance plans, and low levels of reimbursement to HCPs, hospitals, and PC/EOL programs impact use of PC/EOL services. Policy strategies to support utilization of PC/EOL services in pediatrics include (a) financial incentives to HCPs to train in and provide PC and EOL care through loan forgiveness and competitive wages, (b) financial incentives to health care institutions that provide PC/EOL services and support penalties for those that do not, and (c) reimbursement by insurers to HCPs for time spent informing and counseling children and parents regarding their diagnosis, prognosis, options for care, and EOL decision-making (Field & Behrman, 2003; Meier, 2009).

PC/EOL services have shown to impact patterns and outcomes of care. Detection of symptoms not identified by the primary HCP team, recommendations to changes in medications to enhance symptom management, increased allied health consultations, support for EOL discussions earlier in the trajectory, and improved timeliness of documentation of those discussions are examples of outcomes associated with PC/EOL

services (Wolfe et al., 2008; Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009). Research suggests that integrating PC earlier in the EOL trajectory may offer an opportunity to positively impact symptom control and subsequent distress, quality of life, and facilitation of patient- and family-centered care that is consistent with the child's prognosis (Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009). Furthermore, Wolfe et al. (2008) found that an increased utilization of PC team services that meet the needs of children with cancer and their families significantly improved EOL care with parents reporting better preparedness for the EOL trajectory, decreased child suffering, and improvements in advanced care planning.

Conceptual Definitions

The difficulties of addressing a topic as broad as EOL are complicated by the dynamic and evolving work in health care (Bookbinder, Rutledge, Donaldson, & Pravikoff, 2001). These difficulties can be categorized as conceptual, clinical, and methodological. The ambiguous nature of EOL, including its definition, related concepts, and context in which it occurs, creates both clinical and methodological challenges. According to the National Institutes of Health (2004), there is currently no clear definition of EOL. However, evidence supports the following components: (a) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate, and (b) the symptoms or impairments resulting from the underlying irreversible disease that require formal (paid, professional) or informal (unpaid) care and can lead to death.

Moreover, despite major progress within the domain of PC, society continues to use PC, hospice care, and EOL care interchangeably. Each concept may be clinically

relevant, but the purpose, outcomes, and appropriate context for each type of care may be drastically different. There is a critical need for clarity around each of these three concepts in order to provide the appropriate care for a person and their family. EOL and EOL care may not be brand new concepts; however, they are gaining momentum and popularity in the clinical, academic, and research environments.

Palliative Care

Historically PC has evolved into its own concept that is distinct from other types of care provided to individuals with life-limiting and life-threatening conditions. Until the early 1990s, the term PC was used in the US to describe the care of dying individuals who were mainly adult cancer patients (Magno, 1990). Changes in the number of individuals living with chronic conditions, coupled with our technological abilities, have resulted in the evolution of how our society terms and utilizes PC. The World Health Organization (WHO) defines PC in children as “the active total care of the child's body, mind and spirit,” ... providing “support to the family...and “begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease” (World Health Organization, 2012).

The concept of PC in the US has evolved to address the needs of a wide range of patient populations. Specifically PC is appropriate for individuals and families who may not be termed ‘dying’ but for whom alleviation of suffering and improvement of quality of life may be relevant goals (Meghani, 2004). Pediatric PC may include curative treatment, disease modifying therapy, or compassionate care (Vern-Gross, 2011). Based on this conceptual change, PC can be integrated earlier in the disease course and is no

longer restricted to the EOL trajectory. This conceptual evolution helps to distinguish hospice care from palliative care.

Hospice

Hospice is defined as a program of care that provides, arranges, coordinates, and advises on a variety of medical and supportive services for dying patients and those close to them (Field & Behrman, 2003). However, hospice services specifically available to pediatric patients are limited. Kane et al. (2000) estimates that less than 1% of all dying children in the US receive hospice care. Mission statements for many hospice centers often imply the goal of helping terminally ill children and their families to prepare for and achieve a good death (Hendrickson & McCorkle, 2008; Kring, 2006).

Although there may be agreement across mission statements, consensus on a definition for good death is lacking. A dimensional analysis of the concept of a good death in a child with cancer by Hendrickson and McCorkle (2008) identified seven core dimensions: (a) age-appropriate participation, (b) personal style, (c) quality of life, (d) preparation for death, (e) aspects of care, (f) legacy, and (g) impact on survivors. Furthermore, the three most common perspectives of a good death included the dying child, the child's family, and HCPs. The authors suggest that in order to support a good death, attention is needed to identify services and interventions that are most effective and appropriate for children who die a cancer-related death and for those involved in their care at EOL.

End of Life

EOL care is health care provided when all curative options have been exhausted and care is focused on preparing for an anticipated death (Field & Behrman, 2003). Goals

of EOL care may include symptom prevention and management, and assisting the dying child and family members in finding comfort and meaning (Nuss, Hinds, & LaFond, 2005). EOL is a type of PC that is focused on symptom control, comfort, and psychosocial and spiritual support in the period of time leading to an anticipated death (Okun, 2008). Table 1 identifies components of care for pediatric PC and EOL care.

Communication

Communication is a complex two-way process that is dependent on human interaction to send, receive, and interpret verbal and nonverbal messages; and is socially constructed within societal and cultural norms (Long, 2011). In the health care setting, communication may be more complex reflecting a multi-way process involving the patient, parent, family, and various members of the care team. Communication is complex and is an essential component that transcends PC, hospice care, and EOL care. Verbal and nonverbal communication processes influence the quality of HCP relationships with patients and families (Zoppi & Epstein, 2002). Effective communication primarily consists of providing accurate and concise information in a timely, sensitive, and straightforward manner that is understandable to the patient and family (Dahlin, 2010). Furthermore, effective communication provides the foundation of a trusting relationship among the child, family, and health care provider (Levetown, Meyer, & Gray, 2011).

Improvements in science and health care have gradually changed the nature of dying. Due to advances in medical technology, adults and children are living longer with chronic diseases. With an increase in awareness about the experience of death as it coincides with chronic conditions, there is a subsequent change in public attitudes and

interest in the medical decision-making process. As the population ages, more members of the general population are receiving EOL care or encountering situations involving EOL care of family and friends. Each individual's response to EOL experiences varies from one person to the next, especially for children, who may not have previous experiences within their own family to reference.

During EOL, children and their families commonly face a broad array of simple and complex decisions and tasks. These choices are grouped on an equally broad spectrum and may be practical, psychosocial, spiritual, legal, or medical in nature. HCPs are obligated to navigate and support children and their families through the EOL process and provide individualized care. Communication is the cornerstone of care provided at EOL that allows nurses to assess the wishes of the child and family, provide information related to the plan of care, and evaluate the effectiveness of interventions.

Nurse Communication at End of Life

Communication has been found to be a critical part of the nurse-patient relationship; both the relationship and communication are fostered through the foundation of trust and personal attitudes and values brought in by the nurse (Lowey, 2008; Sobo, 2004). Specifically, Lowey (2008) found that a strong nurse-patient relationship, such as trust, continuity, and understanding were essential components of effective communication. Furthermore, effective communication is critical for patients and parents to make informed decision about their care and advanced care planning during PC and EOL (Dahlin, 2010). Nurses are often one of the first HCPs to identify issues in patients with life-limiting illnesses, including advanced care planning, goals of care, conflict

between the patient and family, and use of life-sustaining treatments (Dahlin, 2010).

Furthermore, according to Foster et al. (2010),

Nurses are in a unique position to provide accurate and complete information to families, inform interdisciplinary health care team members of the wishes of the ill child and the family, ensure that clinical decisions reflect the values and goals of the child and his or her family, and support all members of the health care team (p. 212).

Communication among HCPs, patients, and their families related to EOL is an important component in providing quality care (Lowey, 2008). HCPs are responsible for maintaining open communication with the family throughout the EOL trajectory (Vern-Gross, 2011). Broad positive outcomes that have been associated with effective HCP-patient and HCP-family communication include improved patient experience, improved quality of HCP-patient interaction, and effective and collaborative decision-making (Hinds, Oakes, Hicks, & Anghelescu, 2005; Wolfe et al., 2008; Zoppi & Epstein, 2002). Despite limited literature describing outcomes associated with effective communication in pediatrics, studies have been conducted in the adult population. In a randomized controlled trial evaluating the impact of a formal advance care planning intervention through a trained nurse or allied health facilitator with elderly patients, those who had received the intervention were significantly more likely to have had their EOL wishes known and respected (Detering, Hancock, Reade, & Silvester, 2010). Furthermore, the study reported significant increases in patient and family satisfaction scores, satisfaction related to the quality of death reported by the family's perspective, and presence of family members for advanced care planning discussions; while fewer symptoms of post-traumatic stress, depression, and anxiety were reported among bereaved family members (Detering, Hancock, Reade, & Silvester, 2010). Similarly, Heyland et al. (2009) found

seriously ill adults reported significantly higher levels of satisfaction with EOL care when they engaged in honest discussions about their prognosis with physicians. These studies demonstrate how communication within the EOL context can impact important outcomes for the patient, family, and health care institution.

Literature from the adult population can be useful in guiding research designs in pediatrics, which has only briefly examined the features that characterize effective communication among the nurse, patient, and the family at EOL, as it relates to caring for children with life-threatening malignancies (Lowey, 2008; Sobo, 2004; Vern-Gross, 2011). As a result, our understanding of communication and how it fits conceptually into pediatric EOL models is unclear. Generating knowledge about how best to communicate with children dying a cancer-related death is important, because providing information and addressing their concerns may decrease tension in families and enhance the cooperation of the child, reduce anxiety, and norm discussions surrounding EOL (Beale, Baile, & Aaron, 2005). Many nurses feel uncomfortable communicating with dying patients, which may stem from lack of training, lack of confidence to incorporate communication into their practice, and lack of mentoring in effective communication (Dahlin, 2010). Although many education programs are successful in impacting clinician behaviors, skill-focused training often is not directed toward fostering a strong, compassionate and caring relationship between clinicians and patients and families (Zoppi & Epstein, 2002).

Overview of the Study

Caring for children during PC and at EOL is an experience that has received little research attention. Due to a lack of quantitative and qualitative research, the nursing

discipline has limited evidence to ground our understanding of the experience of nurses caring for children during PC/EOL. Steinhauer and Barroso (2009) stated the gaps in PC quantitative research best when they wrote,

When reading the latest research finding published in palliative care literature or medicine's core clinical journals, one encounters a frequent refrain, 'More research is needed to understand why providers...' or 'More research is needed to understand how patients...' Every investigator has the experience of completing the clinical trial or observational study that yielded statistically significant results yet contains major gaps in understanding why the intervention was or was not successful, what mechanisms influenced positive uptake, or why unexplained variation persists. Qualitative methods provide the tools for answering these questions (p. 725).

The original study was developed by Hendricks-Ferguson (2007) in response to a research priority put forth by the Oncology Nursing Society (ONS) in their 2005-2009 Research Agenda. The agenda focused on the implementation of family-focused psychosocial research to support family function during the demands of illness, including communication about their feelings about their child's illness. Supporting the agenda is the central belief that oncology nurses have a responsibility to ensure family involvement during EOL care. The purpose of the study was to describe nurses' experiences of communicating about PC and EOL care with children with cancer, their families, and HCPs (Hendricks-Ferguson, 2007).

Research Questions

The specific aims and research questions were determined as part of an original study and include:

Aim 1: Describe the commonalities of nurses' individual experiences of communicating PC/EOL perspectives when caring for a dying child.

Aim 2: Describe nurses' perceptions of factors that facilitate and impede PC/EOL communication with dying children, their families, and HCPs.

Framework

The framework that guided the study is based on empirical phenomenology as a research philosophy and approach, and on group-as-a-whole theory (Giorgi, 1997; Kooken, Haase, & Russell, 2007; Munhall, 2007; Stubblefield & Murray, 2002). When patients, families, nurses, or other HCPs enter into a PC/EOL relationship, each member of the relationship must understand one another's situation in the world (Hendricks-Ferguson, 2007). Empirical phenomenology is a method that may be used to create this understanding. Empirical phenomenology stems from the assumption that a scientific explanation must be grounded in the meaning structure of the individuals studied (Aspers, 2009). This approach suits the study of nurse communication during PC/EOL, because it allows the researcher to create the understanding of the interactions between children, families, and nurses within the PC/EOL relationship.

Sample

The original study collected data from a total of twelve focus groups evenly distributed across three sites. The three sites selected for recruitment of pediatric oncology nurse participants as part of the original study included: Riley Hospital for Children in Indianapolis, Indiana, St. Louis Children's Hospital in St. Louis, Missouri, and Children's Hospital of Wisconsin in Milwaukee, Wisconsin. Each focus group had five to seven participants. Groups of participants were assigned based on their length of experience caring for children dying a cancer-related death and their current nursing role. The dissertation, *Communication during Palliative Care and End of Life: Perceptions of*

Experienced Pediatric Oncology Nurses represents data collected from nurses with greater than 5 years of experience or advanced practice nurses who did not have supervisor responsibilities.

Design

The study design used focus groups as the primary data collection approach. The use of focus groups in phenomenological methods is somewhat unique, and is not completely consistent with the philosophical underpinnings of phenomenology (Webb, 2002). The philosophical approach to phenomenology relates consciousness to the individual level. However, Agazarian (1989) describes group-as-a-whole theory as one that values the group consciousness through group experiences. Furthermore, Hendricks-Ferguson (2007) identified that groups are increasingly recognized as useful in phenomenological studies within specific contexts. The rationale for using focus groups as a technique for data collection in the dissertation was supported through the initial planning process. Through discussions with staff, the principal investigator of the study discovered that nurses' experiences of communicating about PC/EOL were similar and that the group narratives were both rich and spontaneously focused on experiences with specific patients, families, and HCP who were commonly known among the nurses (Hendricks-Ferguson, 2007). The conclusion drawn from those preliminary discussions was that the nurses themselves felt strongly that their lived experiences would best be obtained from groups of those who have worked together to provide PC/EOL (Hendricks-Ferguson, 2007).

Orientation to the Dissertation

The following chapters in the dissertation, *Communication during Palliative Care and End of Life: Perceptions of Experienced Pediatric Oncology Nurses* will outline literature related to the phenomena of child and parent experiences during EOL and nurse communication, findings of a qualitative empirical phenomenological study describing perspectives of experienced nurses providing care during PC/EOL, and discuss implications for practice, research, and policy. A total of three manuscripts are included as part of the final dissertation. Chapter 2 is a manuscript describing the state of the science of the child and parent experience at EOL. This information in Chapter 2 on EOL provides the context of care children with cancer and their families receive from HCPs during the vulnerable period of EOL care. Specifically, how care is enhanced or impeded by HCPs is discussed. The perspectives of children and parents, coupled with those of nurses and other HCPs are particularly useful in identifying gaps related to communication and other aspects of EOL care.

Chapter 3 is the second manuscript, which adds a complimentary perspective to those of children and parents by outlining findings of a literature review related nurse communication during PC/EOL. The literature was grouped into themes and synthesized. Through the synthesis a number of implications for nursing practice and future research were identified. Based on the gaps, the importance of exploring the phenomenon of communication from a quantitative and qualitative lens is explored. Given communication is not a well-understood concept of EOL models; recommendations are presented for future research, including the priority for qualitative designs to further understand nurse communication as a phenomenon in pediatric oncology during PC/EOL.

Chapter 4 is the third manuscript, which consists of the study findings. The qualitative methodologically is described and corresponding analytic procedures are presented. The analysis resulted in five core themes that are accompanied by themes, subthemes and exemplar quotes. There is a brief discussion of the findings, implications for nursing practice, and future research.

Chapter 5 is a traditional chapter that synthesizes implications for practice; future research and policy based on the study findings. The findings of this dissertation study provide insight into the perspectives of experienced pediatric oncology nurses communicating and providing care during PC/EOL. Their stories highlight a variety of issues and areas that need to be addressed in the clinical setting and through future research. Providing quality care and meeting the needs of nurses and other HCPs during and after EOL are examples of areas that require attention by clinical administration and leadership. In addition, gaps in the educational training of nurses and HCPS and access to PC/EOL services for children with cancer have policy implications at a national level.

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Chapter 2

State of the Science: Experiences of Pediatric Oncology Patients and their Parents at End of Life

Abstract

Advances in cancer and supportive therapy have led to improved outcomes with children with cancer. Despite progress in overall survival, children still die from complications of cancer therapy or their disease. Pediatric palliative and end of life care are clinical and research priorities. The child and parent experience provides valuable information to guide how health care professionals can improve the transition to end of life and the care provided to children and families during the vulnerable period of end of life. The purpose of this state of the science synthesis is to describe the experience of pediatric oncology patients and their parents during end of life, and identify gaps to be addressed with future research. The analysis of the evidence revealed five themes: symptom prevalence and symptom management, parent and child perspectives of care, patterns of care, decision-making, and parent and child outcomes of care. Guidelines for quality end of life care are needed. More research is needed to address methodological gaps and include the child's experience.

Key Words: Cancer, Pediatric Oncology, Experience, Child, Parent

Seventeen out of 100,000 children ages 0-19 are diagnosed with cancer annually in the US (Howlander et al., 2011). Advancements in cancer and supportive therapy for children have led to improved outcomes. In 1960, the 5-year relative survival rate for childhood cancer was less than 30%, and as of 2008 has increased to 83% (Howlander et al., 2011). Despite advances in pediatric oncology treatments and technology, a low percentage of children treated for cancer die from their disease (Kurashima, Latorre Mdo, Teixeira, & De Camargo, 2005).

The symptomatology trajectory for children and adolescents battling cancer varies. It has been reported that many children who die a cancer-related death may die while experiencing two to eight difficult symptoms, such as pain (Hinds, Pritchard, & Harper, 2004). The prevention of suffering, including symptom management, in children dying of cancer is a central value for clinicians in pediatric oncology (Hinds et al., 2005).

Pediatric oncology nurses play a central role in the development and provision of the child's plan of care. The discipline of nursing transcends multiple settings, providing continuity across wellness and illness trajectories. End of life (EOL) is a vulnerable time for children, adolescents and their families. Pediatric oncology nurses, along with interdisciplinary partners, may influence EOL outcomes, such as the assessment of symptoms and associated distress, symptom management, decision-making processes with the child and family, and quality transitions across settings (Nuss, Hinds, & LaFond, 2005).

Palliative care (PC) and EOL are concepts that have continued to gain relevancy in the community, health care, and research settings. The World Health Organization (WHO) defines PC in children as “the active total care of the child's body, mind and

spirit,” ... providing “support to the family...and “begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease” (WHO, 2012). Despite clear agreement from an international organization on the definition of PC, structures and services that support such a comprehensive definition have been slow to develop. Progress has been made in the US where PC has evolved to address the needs of a wide range of patient who may not be termed ‘dying’, but for whom alleviation of suffering and improvement of quality of life may be relevant goals (Meghani, 2004).

In contrast to PC, EOL lacks a consistent definition in the literature. The National Institutes of Health (NIH) identified through evidence the following components of EOL: (a) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (b) the symptoms or impairments resulting from the underlying irreversible disease require formal or informal care and can lead to death (NIH, 2004). Generally, EOL is considered the supportive care provided to individuals and families at the terminal phase of life. As part of the growing emphasis to enhance understanding of EOL, the National Institute of Nursing Research (NINR) identified EOL for pediatric patients with cancer as a research priority with a focus on the impact of health care professionals' communication with the child and family, and health outcomes associated with health care professionals trained in providing care at EOL (NINR, 2011). The purpose of this synthesis of literature is to describe how pediatric oncology patients and their parents experience EOL care, and identify gaps to be addressed with future research.

Methods

In order to conduct a review, a literature search was completed. Multiple databases were searched including CINAHL, PubMed, and PsycInfo. An additional manual reference search was conducted from the initial articles retrieved. Key words included “symptom management”, “end of life”, “end of life care”, “palliative care”, “terminal care”, “death”, “dying”, “hospice*”, “child*”, “pediatric*”, “parent*”, “neoplasm”, “cancer”, “tumor*”. Exclusion criteria were used to refine the initial search and excluded publications prior to 2000, with the exception of seminal work, and publications that were not peer-reviewed. Following a manual review of references, additional articles that met search criteria were included in the sample. Studies in the English language that addressed child/parent experience at EOL were chosen for further analyses. Studies of palliative care that focused on children and parent experiences at EOL included but general studies of PC were not included. A total of 43 articles were included in the final sample. A summary of the literature search can be found in Figure 1. The literature was analyzed by common themes, and those themes were used to organize and discuss the findings. An evidence table was developed to summarize the results (See Table 2). The evidence-leveling system by Melnyk and Fineout-Overholt (2005) was used to rate the evidence for this literature review. The system includes seven levels of evidence, which were used to provide a consistent and comprehensive list of evidence (Melnyk & Fineout-Overholt, 2005).

Findings and Discussion

The majority of the final sample included studies rated at level 6 (evidence from a single descriptive or qualitative study). Two studies were rated at level 4 (evidence from

well-designed case-control and cohort studies). From this sample, the majority of research conducted has used descriptive designs. .

The analysis of the evidence revealed five themes: (a) symptom prevalence and symptom management, (b) parent and child perspectives of care, (c) patterns of care, (d) decision-making, and (e) parent and child outcomes of care. Results of the analysis are reported by theme followed by a critique of the quality of the literature. A complete summary of the evidence listed by theme and publication year can be found in Table 2.

Results of Thematic Analysis

Symptom prevalence and symptom management.

Of the 10 studies that described symptoms experienced at EOL in children dying a cancer-related death, the most frequently cited symptoms included pain, changes in breathing or dyspnea, changes in motor function, difficulty swallowing, fatigue, changes in appearance, nausea/vomiting, and anxiety (Collins et al., 2000; Heath et al., 2010; Hendricks-Ferguson, 2008; Hongo et al., 2003; Jalmsell, Kreicbergs, Onelöv, Steineck, & Henter, 2006; Pritchard et al., 2008; Pritchard et al., 2010; Theunissen et al., 2007; Wolfe et al., 2000; Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009). Preventing and managing symptoms and assisting the dying child or their family in finding comfort and meaning during EOL are important goals of EOL care (Nuss, Hinds, & LaFond, 2005). The prevalence of symptoms experienced at EOL does not necessarily provide the HCP with information regarding the level of distress a particular symptom or set of symptoms cause the child or parent. It has been shown that the presence or type of symptoms reported by parents in the last week of their child's life does not necessarily predict the level of parental concern (Hendricks-Ferguson, 2008; Pritchard et al., 2010). This

suggests that the number of symptoms experienced by children who die a cancer-related death should motivate clinicians to query parents about the child's current symptoms of most concern and prioritize these symptoms for interventions (Pritchard et al., 2010). Furthermore, unrelieved child or parental distress has been found to be a contributing factor for parents reporting symptoms of most concern, parental distress, and the overall rating of care at EOL (Kars et al., 2011; Mack et al., 2005; Pritchard et al., 2008; Pritchard et al., 2010).

Few studies indicate that children experience distressing symptoms at the EOL despite access to HCPs experienced with EOL care, advanced technology, and availability of numerous agents to alleviate symptoms (Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006). Future research is needed to better understand the symptoms experienced in children with cancer at EOL and symptom management strategies. Findings of studies suggest that symptom clusters are present in dying children and adolescents, but the exact composition, nature of the clusters, and which symptoms are most distressing to dying children and their families are unknown (Hinds, Pritchard, & Harper, 2004; Mack et al., 2005). Strategies shown to be supportive to parents while the child is experiencing distressing symptoms include pharmacologic and non-pharmacologic interventions, nurse presence with the child and family, providing competent EOL care, and providing anticipatory guidance (Hendricks-Ferguson, 2008; Pritchard et al., 2008; Pritchard et al., 2010). Open communication and access to their child's provider throughout EOL may contribute to parental satisfaction with their dying child's symptom experience (Hendricks-Ferguson, 2008; Pritchard et al., 2010; Wolfe et al., 2000; Zhukovsky et al., 2009).

Seven studies evaluated pain management strategies used during EOL through retrospective medical record review or case studies. All but one study (Hendricks-Ferguson, 2008) described the management of pain as a single symptom, and most reflected the use of pharmacologic agents independently of other adjuvant therapies (Anghelescu, Faughnan, Baker, Yang, & Kane, 2010; Hooke, Hellsten, Stutzer, & Forte, 2002; Orsey, Belasco, Ellenberg, Schmitz, & Feudtner, 2009). Opioid therapy is the most studied pain intervention at EOL. Studies have shown more than 50% of children who die a cancer-related death receive some degree of opioid therapy during EOL (Bell, Skiles, Pradhan, & Champion, 2010; Orsey, Belasco, Ellenberg, Schmitz, & Feudtner, 2009).

Additional studies evaluated the use of continuous and intermittent opioid interventions for pain in pediatric oncology patients (Anghelescu et al., 2010; Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006; Schiessel, Gravou, Zernikow, Sittl, & Griessinger, 2008). Anghelescu et al. (2012), Hooke et al. (2007) and Conway et al. (2009) used continuous propofol and ketamine (analgesics) respectively to manage pain at EOL in individual patients. Such case studies may provide insight to the direction of future pharmacologic pain interventions. Hendricks-Ferguson et al. (2008) and Hongo et al. (2003) evaluated the use of multimodal approaches to pain management during EOL including pharmacologic therapies (opioids, analgesics, chemotherapy, and radiation therapy) as well as non-pharmacologic therapies (physical presence, comfort activities, and physical closeness). However, the literature lacks recommendations for a bundle of activities aimed at managing a specific symptom (e.g. pain) or cluster of symptoms. Further research is needed to address limitations of intervention research related to

symptoms during EOL, including small sample sizes, retrospective descriptive designs, and lack of valid and reliable tools to measure symptoms at EOL in pediatrics.

There is a need to expand the knowledge base regarding interventions aimed at managing all types of symptoms experienced at EOL, not just limiting the knowledge to the study of pain. For example, knowledge of symptom differences related to the child's age and developmental responses is limited, resulting in an absence of evidence to guide appropriate symptom interventions. Furthermore, it is equally important to understand the child and parent perspectives of symptom management interventions. Following the implementation of interventions to address symptoms during EOL, HCPs must evaluate the effectiveness of those strategies. Only three studies reviewed specifically discussed outcomes of pain management (Angelescu et al., 2010; Hooke et al., 2002; Schiessel et al., 2008). Hooke et al. (2002) identified strategies for determining outcomes including partnering with the patient and family. In terms of evaluating intervention effectiveness, there was variation across the four studies. Schiessel et al. (2008) defined daily dose changes, daily patient-controlled analgesia boluses, and pain scores as outcomes for pharmacologic interventions. Angelescu et al. (2010) and Hooke et al. (2002) identified patient pain scores as key outcome indicators for evaluating pain interventions.

Parent and child perspectives of care.

The parental perspective of EOL care was a key theme supported by seven studies (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Heath et al., 2009; Hendricks-Ferguson, 2007; Kars, Gryphonck, & van Delden, 2011; Kars et al., 2011; Mack et al., 2005; Zelcer, Cataudella, Cairney, & Bannister, 2010). Five studies consisted of a qualitative design using phenomenological, grounded theory, or content analysis methods

(Contro et al., 2002; Hendricks-Ferguson, 2007; Kars et al., 2011; Kars et al., 2011; Zelcer et al., 2010), one used a quantitative descriptive design (Mack et al., 2005), and one used a mixed methods approach (Heath et al., 2009). Two studies evaluated factors that supported parental ratings of quality EOL care (Heath et al., 2009; Mack et al., 2005). High ratings of care were found to be associated with receiving anticipatory guidance regarding the EOL trajectory, feeling prepared, HCPs communicating with child and parents in a sensitive manner, and communicating directly with the child during EOL (Heath et al., 2009; Mack et al., 2005). These findings are consistent with Contro et al. (2002) who found unsatisfactory ratings when interactions with HCPs related to treatment or prognosis were seen by parents as confusing, inadequate, or uncaring. Low ratings of care were associated with parental perceptions of receiving conflicting information and inadequate management of symptoms (Heath et al., 2009). Studies by Heath et al. (2009) and Mack et al. (2005) did not clarify which HCPs the parents assessed, nor the potential outcomes associated with high or low ratings of care.

In a study by McCarthy et al. (2010), time since death and parental perception of the oncologist's care has been shown to moderately predict parental grief symptoms. Furthermore, the child's quality of life during the last month, preparedness for the death, and economic hardship moderately predicted grief and depression outcomes. Research is needed to better understand predictors of parent perceptions of quality EOL care and associated outcomes in order to create interventions targeted at improving the overall EOL experience for the child and parents.

Three qualitative studies exploring parental perspectives during EOL provide the beginning groundwork for developing conceptual frameworks that include the child and

parent (Kars et al., 2011; Kars et al., 2011; Zelcer et al., 2010). Kars et al. (2011) described emotions related to the transition from treatment to EOL and preliminary outcomes associated with a timely transition. A timely completion of the parental transition from preservation to letting go may be important to the child's well-being during EOL (Kars, Grypdonck, & van Delden, 2011). An important component of the parental transition is communication. Hendricks-Ferguson (2007), found the majority of parents reported EOL options were shared spontaneously and late in the child's dying trajectory, despite preference to have EOL discussions early or when cancer-directed therapy had failed. To date, a well-studied and accepted theoretical or conceptual framework describing the EOL experience for a child and/or parent is lacking.

In a second study by Kars et al. (2011), parents identified four stages that occur during EOL: (a) becoming aware of the inevitable death, (b) making the child's life enjoyable, (c) managing the change for the worse, and (d) being with the dying child. Presence with their child during suffering has been described as an essential component of parenting during EOL (Kars et al., 2011). Furthermore, Zelcer et al. (2010) described themes representing the parent experience, such as the dying trajectory, parental struggles, and dying at home. Parents identified loss of communication with their child as a significant point in the child's dying trajectory (Zelcer et al., 2010). More research is needed to further develop a framework that addresses parental transitions during EOL. Nurses have the opportunity assess and meet the needs of children and their parents during all phases of EOL, whether they are physiological, emotional, or psychosocial in nature. "Nurses can help parents to face the reality of their child's situation and redefine their role accordingly, such as by providing information and alternative perceptions that

fit the child's changed needs while preserving the parent-child relationship" (Kars, Grypdonck, & van Delden, 2011, E260).

Patterns of care.

A total of 11 studies evaluated patterns of care at EOL (Arland, Hendricks-Ferguson, Pearson, Foreman, & Madden, 2013; Bell, Skiles, Pradhan, & Champion, 2010; Bradshaw, Hinds, Lensing, Gattuso, & Razzouk, 2005b; Dussel et al., 2009; Klopfenstein, Hutchison, Clark, Young, & Ruymann, 2001; Kurashima, Latorre Mdo, Teixeira, & De Camargo, 2005; Shah, Diggins, Stiller, Murphy, Passmore, & Murphy, 2011a; Tzuh Tang et al., 2011; Ullrich et al., 2010; Wolfe et al., 2008). The majority of children who die a cancer-related death die in a hospital setting, with smaller portions of children dying in an intensive care unit (ICU) or home setting (Bell et al., 2010; Bradshaw et al., 2005b; Klopfenstein et al., 2001; Kurashima et al., 2005; Shah et al., 2011a; Tzuh Tang et al., 2011; Ullrich et al., 2010; Yanai et al., 2012). Location of death for children with cancer has been shown to be correlated with the following factors: age, diagnosis (hematologic vs. solid tumor), cause of death, length of last hospital admission, discussion with HCP regarding EOL, and presence of a do-not-resuscitate (DNR) order (Bell et al., 2010; Bradshaw et al., 2005b; Dussel et al., 2009; Klopfenstein et al., 2001; Shah et al., 2011a; Wolfe et al., 2008; Yanai et al., 2012). Children with hematologic malignancy and those with treatment-related complications are more likely to die in the hospital (Shah, Diggins, Stiller, Murphy, Passmore, & Murphy, 2011b). The child's diagnosis and type of malignancy influences the type of symptoms experience at EOL, which may contribute to the location of death. Children who died in an acute care or ICU hospital setting often died of treatment-related complications rather than disease

progression, or died while undergoing hematopoietic stem cell (HPC) transplantation.

Pediatric oncology patients that undergo HPC transplantation are significantly more likely to die from treatment-related complications and often have less time to prepare for EOL (Bradshaw, Hinds, Lensing, Gattuso, & Razzouk, 2005a; Ullrich et al., 2010).

Conversely, children with cancer that have not had HPC transplantation are more likely to die of disease progression and thus have more opportunity to prepare for EOL (Bradshaw et al., 2005b; Ullrich et al., 2010).

Patterns of care during EOL may be influenced by HCP communication through EOL discussions with the child and family. In a study by Bell et al. (2010), only 68% of 107 patients and their parents had an initial EOL discussion with their oncologist, and 50% of those discussions occurred in the last 30 days of life. Similarly, Hendricks-Ferguson (2007) found 43% of 28 parents believed EOL discussions should be initiated earlier in the disease trajectory before treatments have failed. When initial discussions about PC or EOL begin in the last 7-30 days of life, there is minimal time for EOL preparation. Delays in conversations may be due to parent variables including inadequate knowledge of communication strategies, difficulty dealing with emotions, and a desire to protect the child from the pain of separation; or HCP variables including variability in the knowledge of disease trajectory (Bell, Skiles, Pradhan, & Champion, 2010). When EOL discussions occurred more often and earlier (> 30 days from the child's death) parents reported feeling more prepared during the child's last month of life (Wolfe et al., 2008). The timing of EOL discussions is an important factor for HCPs to consider. Often the child's diagnosis or disease status will provide information to guide timing of conversations with the child and parent. Whenever possible, EOL conversations should

be initiated early in the trajectory. Early EOL discussions are essential to identify what components of EOL care are most important to the child and family, and to allow sufficient time to enact plans that support the child's and parents' wishes. However, there may be situations where early EOL discussions may not be feasible due to unexpected clinical changes or respect for a parent's wish to not openly communicate with the child about EOL. Therefore, HCPs should consider the child's expected disease trajectory soon after diagnosis to provide guidance on timing of initial EOL discussions. Children who have good disease prognosis and their parents may not require EOL discussions early after diagnosis, compared to those with a poor prognosis. Interventions aimed at supporting dialogue between HCPs, children, and parents may influence overall patterns of care.

Decision-Making.

A total of six studies explored aspects related to EOL decisions and the decision-making process through qualitative, quantitative, or mixed methods designs (Edwards et al., 2008; Hinds et al., 2005; Hinds et al., 2009; Maurer et al., 2010; Pousset et al., 2009; Tomlinson et al., 2011). Four studies used parent-report (Edwards et al., 2008; Hinds et al., 2009; Maurer et al., 2010; Tomlinson et al., 2011), and 2 studies explored the child's perspective (Hinds et al., 2005; Pousset et al., 2009). Authors who described parent perspectives often involved decisions of choosing cancer-directed therapy, DNR, or terminal care. Common decision factors across EOL choices included medical facts, doing the best thing for to the child, and the opinions of others (Hinds et al., 2009; Maurer et al., 2010). However, the factors influencing decisions to continue cancer-directed therapy or EOL care differed. Maurer et al. (2010) found quality of life and the

child's wishes were the most frequently reported factors for parents who chose terminal care, compared to the need to continue cancer-directed therapy as the most reported factor for parents that chose additional cancer therapy.

As a standard of care, EOL decisions should involve both parents, HCPs, and when appropriate the child. However, a standardized approach for when and how to include the child in EOL decision-making is lacking. Agreement among all involved in the decision-making process is essential in setting and determining a plan to meet EOL goals. Edwards et al. (2008) found that when both parents focused on decreasing the suffering experienced by the child during EOL, they were slightly more likely to report retrospectively that the child suffered less. This suggests that creating opportunities for parents to work through EOL goals together may lead to improvements in the overall EOL experience of the child (Edwards et al., 2008).

In parents with conflicting EOL goals for their child, preliminary qualitative studies have found their definition of what it means to be a good parent to their child was constant across EOL trajectories (Maurer et al., 2010). The concept of a good parent was described in studies by Maurer et al. (2010) and Hinds et al. (2009) with common themes including doing right by making informed and unselfish decisions in the best interests of the child, providing support and presence at the child's side, teaching the child to make good decisions, advocating for the child to HCPs, and promoting the child's health. HCPs can play a role in fostering parents' ability to fulfill the role of being a good parent. Hinds et al. (2009) found four clinician behaviors that support the feeling of being a good parent: (a) HCPs telling parents they are "good parents", (b) not forgetting the child and

family once the child has died, (c) providing more material items and support options, and (d) providing coordinated EOL care.

Children and adolescents consider different factors compared to their parents when making care-related decisions. In a study examining the child's perspective in decision-making at EOL, Hinds et al. (2005) found adolescents were able to negotiate complex decision processes, during which they considered more than one factor at a time and were able to integrate all factors into a final decision. Furthermore, factors most frequently identified by adolescents as important to their EOL decision included caring about others, avoiding adverse events, and wanting no more therapy (Hinds et al., 2005; Jankovic et al., 2008). The inclusion of the child perspective in prospective research describing EOL decisions should continue to be explored in future research.

Child and parent outcomes of care.

Only 2 studies in the sample specifically evaluated outcomes associated with EOL care (Kreicbergs et al., 2005; McCarthy et al., 2010). In a study by McCarthy et al. (2010), 41% of parents (n = 58) who had a child die a cancer-related death met diagnostic criteria for grief-related separation distress and 22% had clinically significant depressive symptoms. Furthermore, parental perceptions of the child's quality of life during the last month of life, preparedness for the death, and economic hardship were found to predict grief and depression outcomes (McCarthy et al., 2010). In regards to symptom management at EOL, Kreicsberg et al. (2005) found 57% of parents (n = 449) who had a child with unrelieved pain at EOL were still affected by that experience 4-9 years after the child's death. These findings suggest that interventions aimed at supporting the child and parent during EOL may moderately impact short- and long-term outcomes. More

research is needed to increase our understanding of the impact of the EOL experience on the parent and other family members, on individual and family health, and associated health care costs.

Critique of the Literature

A number of methodological issues were identified in the synthesis of literature on child and parent experience during EOL. Limitations include small sample sizes, sub-optimal representation across genders and ethnicities, single-site, retrospective designs, and use of parent-report and medical records as data sources without the collection of concurrent data from the child. Furthermore over 30% of the studies were conducted outside the US, where there may be variability in health care delivery systems and EOL services and thus different parent or child experiences of EOL care. The EOL experience for children and their parents is an emerging phenomenon with a predominance of descriptive or observational studies. The resulting level of evidence associated with the majority of studies limits the strength of recommendations related to future research and clinical practice.

Gaps and Implications for Future Research

In the report *Approaching Death: Improving Care at the EOL*, the IOM (1998) made several recommendations aimed at addressing the current shortcomings in EOL care, including the need to define and implement priorities at a national level for strengthening the knowledge base for EOL care. In order to address gaps in the EOL knowledge foundations there must be research related to effective pediatric palliative care programming and other interventions aimed at improving the quality of care, regulation and reimbursement of EOL services, development of validated instruments that address

the complexity of EOL, and development of informatics tools that will facilitate the integration and analysis of data from EOL studies (AAP, 2000; NINR, 2011).

What is clear from the state of the science related to the child and parent experience during EOL in pediatric oncology is that there is an initial understanding of (a) the types of symptoms children experience when dying a cancer-related death, (b) the types of interventions used to manage those symptoms and improve care delivery during EOL, (c) the patterns of care children receive, (d) the types of decisions that need to be discussed general to pediatrics and EOL and specific to children with cancer, and (e) preliminary outcomes of bereaved parents following the death of a child.

A thorough understanding of the child's perspective related to each theme and how the pediatric oncology nurse may impact the child and parent experience is unknown. In response to limited valid and reliable instruments to measure concepts within each theme, there is an opportunity to leverage both quantitative and qualitative methods to seek knowledge of the child and parent experience during the transition from curative-focused therapy to PC and EOL. Furthermore, exploring the experiences of nurses and other HCPs during PC and EOL may enhance the knowledge foundation related to the experiences of children and parents from a different perspective.

Another area for investigation includes the development and testing of a conceptual framework. The majority of studies lacked a theoretical underpinning, an omission that may provide challenges as the state of the science progresses. Kane, Hellsten, and Coldsmith (2004) proposed that "Pediatric EOL care research also include testing and refining theories that account for the association of social and spiritual relationships and the relief of suffering... in order to develop interventions designed to

minimize suffering and improve the quality of life for children dying from serious illnesses and their families” (p. 181). An established conceptual framework will equip researchers to describe the core concepts of EOL care and how they interact with one another to achieve a particular outcome.

There is a clear need to develop and test instruments that prospectively measure symptoms, quality of life, communication, and decision-making in the pediatric oncology population. Despite the availability of reliable tools to measure quality of life in pediatric oncology patients, there is an absence of tools that adequately measure quality of life within the context of EOL (Hinds, Burghen, Haase, & Phillips, 2006).

Limitations related to sample characteristics across studies were identified as a critical gap in this review. Specifically, studies did not reflect optimal representations across ethnicities and race. It is important that future studies allow opportunities for participants representing both genders and a variety of race and ethnicities, which may be accomplished through multi-site or cooperative research. Moreover, there is limited research on EOL specific to pediatric oncology. Replication studies are needed to enhance the reliability and generalizability of findings to other pediatric oncology settings. In addition to replicating descriptive designs, there is a clear need for intervention research to support areas identified in the literature, including symptom management, patterns of care, and decision-making. Areas of focus include assessment, interventions, and outcomes of individual symptoms and symptom clusters. Development and implementation of a bundle of activities aimed at managing symptoms may provide consistency and applicability of symptom management strategies to the clinical setting. Intervention research will allow investigators to advance the state of the science related to

the child and parent experience during PC and EOL. Finally, it is unclear what role other factors might play in facilitating or limiting quality care related to each of the themes.

The great majority of available literature informing us about EOL for children and adolescents with cancer is based primarily upon medical record reviews and to a lesser extent, staff and parent observations (Hinds et al., 2007). Nurse researchers who have paved the path in pediatric PC/EOL research have identified several challenges to conducting this type of research (Table 3). Hinds et al. (2007) suggests the possible reasons for a lack of patient-reported outcomes in pediatric oncology at EOL, includes hesitation on behalf of the clinician to directly and formally solicit patient-reported preferences and outcomes because of concerns about offending the already emotionally burdened family. Researchers may experience concern about obtaining institutional review board approval due to the perceived potential emotional distress of interviewing children or parents, These perceptions may be a barrier to obtaining institutional review board approval for studies related to EOL in pediatrics. Further resistance from members of the health care team are based on the belief that interviews may cause parents additional stress resulting in the transition of their child to a different institution. Through intra- and interdisciplinary collaboration, nurse researchers may anticipate these barriers and develop research questions aimed at current limitations.

Implications for Nursing Practice

A clear understanding of EOL care has implications for clinical practice across a variety of disciplines. EOL care is complex; disciplines, assessments, interventions, and outcomes must be strategically aligned to provide quality and comprehensive holistic care. Standardized guidelines directing HCPs to provide quality EOL care are needed.

However, standardization must be balanced with individualization, as the patient and family values and preferences are core attributes for EOL care. Interdisciplinary HCPs need skills and tools to appropriately assess these values during EOL, in order to achieve patient and family goals and a peaceful death.

The profession of nursing is engaged in every level of symptom management, including the assessment, planning, delivery of interventions, and evaluation. Nurses provide a unique perspective to manage symptoms at EOL in pediatrics. The nature of the role allows for frequent interaction and relationship-building with the child and their parent. Frequently, nurses are critical in the communication between the patient, parents and the interdisciplinary care team. In order to support a child or adolescent and their family, there must be a trusting relationship between the child, parent, and care team (Pearson, 2010). Nurses support and preserve the parent-child relationship and facilitate the parental presence for the child during EOL (Kars et al., 2011). Nursing care given to any child should be holistic, encompassing not only the physical illness but also their mental, emotional, developmental, and spiritual needs (Pearson, 2010). Reflection on an individual's practice and previous clinical situations is essential for clinicians to enhance the care of future patients (Pritchard & Davies, 2002). Through reflection, nurses may identify questions that can be used to guide clinical interventions and research.

Communication is central to the child and parent experience and is a defining attribute of EOL care that supports the achievement of other core elements, such as provision of interdisciplinary care across the continuum, joint decision-making, and provision of anticipatory guidance. The need for improved interdisciplinary communication in complex health care settings continues to be supported. In addition to

communication, there is an increasing need to educate and reinforce to HCPs the core principles of therapeutic communication. Goal setting and identification of child and parent preferences would not be possible without communication. Parental ratings of quality of care increased when there were opportunities to address issues related to goals of care, potential outcomes related to changing and deteriorating clinical status of the child, and affirm there would be ongoing open and honest communication (Ullrich et al., 2010).

In order to identify appropriate interventions for children with cancer at EOL, HCPs must seek a partnership with the child and their family. Stillion and Papadatou (2002) suggest the following five major variables that HCPs should take into account whenever they seek to meet the needs of children who are terminally ill: (a) personality, (b) life experiences (especially those related with illness, death, and loss), (c) patterns of communication within the child's immediate surrounding, (d) the availability and quality of support, and (e) developmental level. Developmental level is critical not only in determining interventions, but also for gauging communication about EOL care and achieving a quality symptom assessment (subjective and objective). Furthermore, the interaction of these variables determines how children are likely to perceive, cope, and make sense of their illness and impending death (Stillion & Papadatou, 2002). Partnering with children, adolescents and their families allows the HCP to build trust and identify appropriate interventions for individual situations.

Along with communication, there is a general need for EOL education for HCPs. Although education in this area is improving, studies document the deficiencies in education about EOL care for physicians and nurses (Truog et al., 2008). EOL is

experienced in a variety of settings and environments, fueling a need to make education standard for health care professions. Methods that have been shown to improve the application of PC principles include education, training, and research (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009). Education that facilitates attitudinal and cultural changes among HCPs needs to be accompanied by support systems, so that an actual change in behavior occurs as a result of educational interventions (Pierce, 1999). Considerable work has been done in education about EOL care that can be adapted to multiple settings, including the development of training programs such as Education for Physicians on End of Life Care, End of Life Nursing Education Consortium (ELNEC), and curricula developed for internal medicine residency programs (Truog et al., 2008).

Conclusion

Based on a review of current literature related to EOL experience of children who die a cancer-related death and their family, several conclusions may be drawn. First, EOL is complex in nature with components that require assessment individually and collectively. Second, there is literature to support the presence of symptoms in children at EOL; however, there are few studies that have evaluated comprehensive symptom management interventions. Third, assessment of child and parent perception of care at EOL is critical in identifying phenomena that require future interdisciplinary research. Fourth, the decision-making process and communication influence the patterns of care at EOL. The EOL experience has been preliminarily shown to impact short- and long-term outcomes of parents; but more research is needed to evaluate and support the needs of other family members, including the dying child. The development and testing of

interventions may support the standardization of care delivered to children and their families at EOL.

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Chapter 3

Nurse Communication During Palliative Care and End of Life

Abstract

Through communication, nurses play a critical role promoting quality care during the transition from curative-focused, or cancer-directed therapy to palliative care and end of life. Facilitators, barriers, and outcomes of nurse communication are areas of limited study. The purpose of this review is to synthesize the literature on nurse communication during palliative care and end of life for children with cancer and their families, identify gaps in the literature, and discuss the relevance of this synthesis for nursing practice. An analysis of the literature yielded five themes: (a) importance of communication, (b) facilitators of communication, (c) barriers of communication, (d) outcomes of communication, and (e) interventions supporting communication. There is an increasing need to teach and reinforce the core principles of therapeutic communication to nurses and health care professionals. Gaps in the current literature suggest future directions in the development of a theoretical framework; development of data collection instruments that accurately capture nurse communication; development of studies aimed at understanding the influence of experience on communication patterns; and creation of communication-directed interventions aimed at impacting outcomes for children, families, and nurses.

Key Words: Communication, Nurse, Cancer, Pediatric Oncology

In the United States (US), 17 out of 100,000 children ages 0-19 are diagnosed with cancer annually (Howlander et al., 2011). Over the past few decades, advances in technology, use of multimodal therapy, and improvements in supportive care have impacted cancer-related morbidity and mortality. In 1960, the 5-year relative survival rate for childhood cancer was less than 30%, and as of 2008 it has increased to 83% (Howlander et al., 2011). Despite advancements in therapy and supportive care, children still die from cancer. Of the children diagnosed with cancer between 2001 and 2005, the incidence of death was 2.5 per 100,000 children (American Cancer Society, 2009).

The loss of a child is often viewed as unnatural, or going against the normal order of life events. Parents and other family members often experience intense emotions during the child's death. Parents and health care professionals (HCPs) similarly struggle to understand, why? The end of life (EOL) trajectory may have a quick onset and last only moments, or may be delayed, lasting months. Due to their role, nurses have the opportunity to provide care across a variety of settings, and to positively influence patient care through effective communication (Malloy et al., 2006). This paper focuses on the critical role nurses play in communication, which fosters the maintenance of quality care during the transition from curative-focused, or cancer-directed therapy to EOL (Thompson, McClement, & Daeninck, 2006).

Communication is a two-way process of sending and receiving verbal and nonverbal messages (Long, 2011). In the health care setting, communication may be more complex reflecting a multi-way process involving the patient, parent, family, and various members of the care team. Communication related to palliative care (PC) or EOL lacks a consistent definition in the literature. To address this lack of consistency, the EOL

definition proposed by Masera et al. (1999) was expanded to include a PC component. PC/EOL communication is defined for this synthesis as sensitive discussions about the process of transition from curative-focused therapy to PC/EOL, the options for treatment of symptoms, and the process of dying which includes the disclosure of feelings about death, dying, and the plan of care (Masera et al., 1999; Montgomery, Hendricks-Ferguson, & Sawin, 2013). PC/EOL communication does not occur in isolation, but rather is dependent on the interpretation of the individual receiving the message. Communication is socially constructed within cultural norms, and is influenced by a number of variables including, age, race, religion or spiritual beliefs, and personal experiences (Long, 2011). The act of communication may consist of verbal and non-verbal patterns, and includes the person(s) communicating, the content being communicated, and the level of understanding following the communication (Foster, Lafond, Reggio, & Hinds, 2010).

The purpose of this review is to synthesize the literature on nurse communication during PC/EOL care for children with cancer and their families, identify gaps in the literature, and discuss the relevance of this synthesis for nursing practice and the implications of the gaps for future research. A systematic review of current research is critical to advancing the science of PC/EOL and nurse communication. Through the synthesis of study conclusions, and identification of strengths and weakness of study designs and analyses, scientists can provide direction for future research.

Methods

In order to conduct a review, a literature search was completed. Multiple databases were searched including: CINAHL, PubMed, and MEDLINE. An additional manual reference search was conducted from the initial articles retrieved. Key words

included “end of life”, “end of life care”, “palliative care”, “terminal care”, “child*”, “pediatric*”, “neoplasm”, “nurs*”, “communication”, and “decision-making”. Studies in the English language that met one or more of the following inclusion criteria were chosen for further analyses: (a) communication between nurses, HCPs, and patients/parents during PC/EOL, (b) nurse experience during PC/EOL, and (c) interventions aimed at supporting nurse communication during PC/EOL. Exclusion criteria were used to further refine the initial search and included publications prior to 2001, with the exception of seminal work, and publications that were not peer-reviewed. Abstracts were reviewed for relevance. Due to the limited number of studies describing nurse communication at EOL in pediatric oncology (n = 2), the population parameters were broadened. Articles that exclusively included nurses or included nurses within a broader sample of other HCPs were included. Articles were also included if they focused on one of five populations: pediatric oncology, pediatric critical care, pediatrics, adult oncology, or pediatrics and adult mixed. The pediatric critical care, pediatrics, and pediatric and adult mixed populations were limited to articles that included care of oncology patients. A total of 17 articles were included in the final sample. A summary of the literature search can be found in Figure 2. The evidence-leveling system by Melnyk and Fineout-Overholt (2005) was used to rate the evidence for this literature review.

Findings and Discussion

An analysis of the literature yielded five themes: (a) importance of communication, (b) facilitators of communication, (c) barriers of communication, (d) outcomes of communication, and (e) interventions supporting communication. In the absence of a theoretical or conceptual framework related to nurse communication during

PC/EOL care, results of the analysis will be reported by theme with nurses as the subjects. The findings from this review will be presented by theme and followed by discussion from other relevant literature. All articles included in the final sample were rated at level 6 (evidence from a single descriptive or qualitative study). A summary of the evidence for nurse communication during PC/EOL listed alphabetically by population can be found in Table 4.

Critique of the Literature

The final sample had a high degree of variability across designs and geographical location. The final sample included quantitative (n = 13), qualitative (n = 2), and mixed methods (n = 2) designs. Four studies (Emold, Schneider, Meller, & Yagil, 2011; Papadatou, Martinson, & Chung, 2001; Turner, Payne, & O'Brien, 2011; Wilkinson, Gambles, & Roberts, 2002) were conducted outside the US, including representations from Israel, England, Hong Kong, and Greece.

Sample sizes had a high degree of variability, ranging from 15 (Zhukovsky et al., 2009) to 714 (Beckstrand, Rawle, Callister, & Mandelco, 2010). Eight studies exclusively studied nurses, while others included physicians and other HCPs in their samples. The majority of studies that utilized a quantitative or mixed methods design relied heavily on new surveys to collect data. Only three studies used previously established data collection instruments: the Caring for the Terminally Ill Patients Nurse Survey (CTIPNS) (Boyd, Merkh, Rutledge, & Randall, 2011), the Adult Dispositional Hope Scale (Feudtner, 2007), and the Maslach Burnout Inventory and Working Environment Scale (Emold et al., 2011). Of the validated instruments, most did not directly measure items related to nurse communication.

Three studies descriptively evaluated an intervention aimed at supporting PC/EOL communication (Meyer et al., 2009; Turner et al., 2011; Wilkinson et al., 2002). The intervention ranged from a 1-day course to a 3-day workshop. Only one study evaluated the intervention against a control group; however, the control group included a mix of HCPs that had either no exposure to the intervention or had previously participated in the intervention (Turner et al., 2011). Limited information was available on the content and integrity of the interventions. Finally, quantitative studies reported minimal statistics, often including p-values without explicitly including relevant statistical findings. This limitation makes it difficult to discern the degree of correlation or variance for a particular phenomenon of interest.

Many of the limitations identified in this sample suggest a need for methodological improvements, including the following: (a) inclusion of a theoretical framework grounded by qualitative research to guide the study design, (b) larger sample sizes for quantitative and mixed method designs, (c) intentionality of studying the pediatric oncology nurse, (d) more diverse samples from nurse populations to account for cultural considerations, (e) prospective designs, (f) longitudinal designs, and eventually (g) intervention research. Therefore, current nurse communication literature reflects the two broad types of study designs, qualitative and quantitative; retrospective data collection involving interviews or surveys with nurses and other HCPs; and the use of non-established data collection instruments. These findings are consistent with conclusions drawn from Nuss, Hinds, & LaFond (2005), suggesting research designs have been slow to evolve over time.

Summary of Evidence

Importance of communication.

Nurses play a vital role in communicating with children and families throughout the illness trajectory. Communication is essential as it becomes clear a child will die from their disease or therapy-related complications. In a study by Lee and Dupree (2008), pediatric critical care nurses identified the importance of communication and emotional support when caring for children and families at EOL. Additionally, acute and critical care pediatric nurses who care for oncology patients have reported managing pain, maintaining the child's quality of life, and improving communication as important goals at EOL (Tubbs-Cooley et al., 2011). The importance of communication between children, families, nurses, and HCPs during PC/EOL is juxtaposed against the reality that adult oncology nurses report difficulties and only moderate confidence in their communication skills (Boyd et al., 2011; Emold et al., 2011). Difficulties and moderate confidence may be reflective of the high degree of variability in how nurses define PC/EOL communication and age of the patient population. Some nurses may believe PC/EOL communication relates specifically to prognostication, while others may perceive PC/EOL communication more broadly, encompassing an inquiry of the child and parents about their understanding of the child's disease trajectory. Nurse-reported confidence levels in their PC/EOL communication skills may be associated with their perceived role and responsibility for engaging in sensitive discussions. Additionally, confidence levels may be influenced by the general age of the population. Nurses may report different levels of confidence or difficulty in the context of communicating with children compared to adults.

Furthermore, a quarter of adult oncology nurses in a study by White and Coyne (2011) did not feel adequately prepared to effectively care for dying patients. Those nurses also ranked communication with patients and families about dying as the second most important nursing competency during PC/EOL.

Literature relevant to the importance of communication during PC/EOL suggests there may be ambiguity among nurses regarding their role in communication with patients, families, and other HCPs specific to PC/EOL and prognostication (Helft, Chamness, Terry, & Uhrich, 2011). The lack of clarity may be related to inconsistencies in expectations of nurses in their level of engagement in PC/EOL discussions within and across hospital settings, especially as it relates to conveying information about the child's disease status. In a study by Helft et al. (2011), a majority of adult oncology nurses agreed that nurses have the responsibility to prepared patients for EOL and that answering questions related to prognosis-related information was within their nursing scope of practice. However, in the same study a majority of nurses disagreed they should provide estimated life expectancy (Helft, Chamness, Terry, & Uhrich, 2011). Burns et al. (2001) suggested that pediatric nurses do not take primary responsibility for discussions related to PC/EOL decision-making, but rather see their role as caring for the child and family at EOL and supporting decisions made by the child, parents, and HCPs (Burns, Mitchell, Griffith, & Truog, 2001). Parents may view nurses more as an extension of the family, providing a more active and supportive role than other family members during PC/EOL (Meyer et al., 2009). Therefore, nurse communication during PC/EOL may affect the family's ability to cope with the dying process.

Facilitators of communication.

Facilitators of PC/EOL communication for nurses and HCPs are described from two perspectives: nursing and structural. From a nursing perspective, a number of characteristics were identified as facilitators of PC/EOL communication. There is limited literature that indicates nurses with greater years of experience and greater PC/EOL education and training reported increased comfort, increased competency, and feeling better prepared for PC/EOL communication (Boyd et al., 2011; Feudtner, 2007; Helft et al., 2011; Malloy, Virani, Kelly, & Munevar, 2010). However, unknown is particularly how experience influences competency in PC/EOL communication and what the needs are for nurses of varying experience levels.

From a structural perspective, Zhukovsky et al. (2009) found PC consultation improved documentation of PC/EOL communication with patients and families, as well as lead to recommendations for family conferences to facilitate communication. Family conferences were identified as important in facilitating EOL decision-making and parent-and clinician-clinician communication (Michelson et al., 2011).

The American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care (2000) support the integration of PC teams early in the plan of care. In two studies evaluating the impact of PC consultation on patterns and outcomes of care, PC consultation was shown to detect symptoms not identified by the primary HCP team, provide recommendations to medications to enhance symptom management, increase the number of allied health consultations, support EOL discussions earlier in the trajectory, and improve the timeliness of documentation of those discussions (Wolfe et al., 2008; Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009). Authors who have evaluated the

integration of PC earlier in the EOL trajectory have described a positive impact on symptom control and subsequent distress, quality of life, and facilitation of patient- and family-centered care that is consistent with the child's disease prognosis (Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009). Furthermore, Wolfe et al. (2008) found an increased focus and utilization of PC team significantly improved EOL care with parents reporting better preparedness for the EOL trajectory, decreased child suffering, and improvements in advanced care planning.

Barriers of communication.

Barriers to effective PC/EOL communication can be broadly described as patient- or family-related, nurse- or HCP-related, and system-related. From a patient and family perspective, commonly cited barriers included those who spoke languages other than English or came from different cultural backgrounds (Beckstrand, Rawle, Callister, & Mandelco, 2010; Davies et al., 2008; Helft et al., 2011; Malloy et al., 2010; Papadatou et al., 2001). Additionally, Durall et al. (2012), Davies et al. (2008), and Papadatou et al. (2001) found unrealistic parent expectations, misunderstanding of patient's prognosis, and lack of readiness as barriers to PC/EOL communication.

From a nurse and HCP perspective, physician and nurse discomfort were cited as barriers to PC/EOL communication (Durall, Zurakowski, & Wolfe, 2012; Helft et al., 2011; Malloy et al., 2010). Issues related to HCPs' ability to predict the EOL trajectory were also reported among nurses and physicians as barriers to engaging in PC/EOL communication (Davies et al., 2008; Durall et al., 2012; Papadatou et al., 2001).

From a system perspective, barriers included time and staffing constraints, and inadequate education related to PC/EOL and communication (Davies et al., 2008; Helft et

al., 2011). Examples of barriers to effective communication during family conferences identified by Michelson et al. (2011) are presence of multiple multidisciplinary services present resulting in conflicting information, balance of messages of hope and realism, use of interpreters for non-English speaking families, schedule conflicts for physicians, and lack of nursing presence due to other patient care responsibilities. A theme identified in the review relates to the adequacy of the number of staff providing direct care in key areas including nursing, physicians, interdisciplinary team members, and ancillary support services. The number of staff may be a misleading measure of adequacy because of the variability in how roles are utilized for direct care across settings, and the experience level and expertise of the staff. More information is needed to understand the factors including experience that support or hinder the presence of HCPs for timely discussions related to the child's plan of care during PC/EOL.

A critical obstacle encountered by pediatric critical care nurses was described as discontinuity of care of the dying child due to lack of communication between the interdisciplinary team (Beckstrand, Rawle, Callister, & Mandelco, 2010). The need for strategies to promote nurse involvement in interdisciplinary communication with children and families is essential (Boyd, Merkh, Rutledge, & Randall, 2011). Thompson (2006) found the following HCP behaviors to be helpful in facilitating quality transitions to EOL care: asking questions to assess information needs and identify misunderstandings, providing information about PC/EOL care, and delivering timely information in a sensitive way. These behaviors align with the needs identified by parents of children who died. Michelson et al. (2011) described the importance of family conferences to HCPs in EOL care and decision-making in pediatric intensive care units. HCPs valued family

conferences as an avenue for supporting HCP communication with the family and other HCPs, as well as an opportunity to support the child and family at EOL (Michelson et al., 2011). These preliminary studies may provide the groundwork for the development of a theoretical framework that addresses how nurse and HCP behaviors, including communication, impact the child and family transition from curative-focused treatment to EOL.

Relevant literature has outlined that HCPs often lack experience and training in communicating about the transition to PC/EOL, DNR or altered code status, and symptom management (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Pritchard & Davies, 2002; Sahler, Frager, Levetown, Cohn, & Lipson, 2000). Commonly cited difficulties in communication with patients and families included the variability within EOL trajectory and the dying process as a barrier to providing quality PC (White & Coyne, 2011). HCPs encounter issues related to predicting the EOL trajectory, which results in the potential for conflicting communication about what will happen next. In addition to predicting the EOL trajectory and impending death of the child, pediatric oncologists have identified limited training in PC/EOL communication and poor access to role models as barriers to PC/EOL communication (Burns, Mitchell, Griffith, & Truog, 2001; Hilden et al., 2001; Sahler, Frager, Levetown, Cohn, & Lipson, 2000; Wolfe et al., 2008).

Outcomes of communication.

Limited literature has addressed outcomes of effective and non-effective communication. Authors of three studies discussed potential outcomes of effective PC/EOL communication. Malloy et al. (2010) found through narratives that adult and

pediatric nurses were generally more satisfied in their role when they felt they were able to effectively communicate during PC/EOL. More specifically, Lee and Dupree (2008) reported pediatric critical care nurses' beliefs that PC/EOL communication was essential for effective decision-making, acceptance of family choices, and emotional closure for nurses specifically. Furthermore, Meyer et al., 2009 reported increased confidence and decreased anxiety among adult nurses related to having difficult conversations regarding PC/EOL. These studies initially explore qualitatively and quantitatively outcome variables that may be associated with effective PC/EOL communication. However, more research is needed to adequately support the identification of nurse-related outcomes.

Interventions supporting communication.

Studies by Wilkinson et al. (2002), Meyer et al. (2009), and Turner et al. (2010) included designs that preliminarily evaluated educational interventions aimed at supporting PC/EOL communication in nurses and other HCPs. Wilkinson et al. (2002) had one previous study supporting the intervention (Wilkinson, Roberts, & Aldridge, 1998). No additional evidence was provided for interventions used by Meyer et al. (2009) and Turner et al. (2010). Nurses and HCPs reported an improvement of communication skills and increased preparation to engage in difficult conversations following 1-day courses provided by Meyer et al. (2009) and Wilkinson et al. (2002). Turner et al. (2010) did not find any differences in self-rating of communication skills between HCPs who had taken the course and those that did not. However, nurses rated their communication skills significantly higher than physicians, and nurses felt more strongly that communication is essential to the role and training should be mandatory rather than optional. These findings suggest that it would be beneficial to further explore the unique

needs of nurses and other HCPs related to intervention development, implementation, and outcomes.

Gaps

In addition to the methodological gaps discussed earlier, a thorough understanding of the pediatric oncology nurse's perspective related to communication is unknown. The current literature includes samples of nurses from different hospital settings (e.g., pediatric oncology, critical care, and acute care), as well as additional HCPs. However, there is a gap in understanding how roles within professions and level of experience impact outcomes. Some studies did explore differences between disciplines within samples, suggesting that nurses may need to be studied separately from other HCPs. Variation in sample characteristics across studies hinders the ability to draw conclusions about the specific population of pediatric oncology nurses. As a result, findings from this review may be limited in their ability to represent nurse communication in pediatric oncology.

The question remains of how to improve nurse communication with children and families during PC/EOL. A variety of approaches addressing current gaps are required to provide an answer. Qualitative studies are necessary to further understand the experiences of pediatric oncology nurses communicating during PC/EOL. In light of limited valid and reliable instruments to measure communication and outcomes of effective communication, there is an opportunity to use qualitative approaches to seek an understanding of the nurse's experience communicating with children and parents during PC/EOL. There is a need to support the development a conceptual or theoretical

framework and uncovering aspects of communication not currently captured in quantitative research.

In addition to using qualitative findings to ground quantitative work, there may be some benefit to further exploring how nurse characteristics (e.g. years of experience, PC/EOL education and training) impact facilitators and barriers of communication. The studies included samples of nurses or HCPs with varying levels of experience within their professions and with EOL care. Specific evaluation of experienced nurses allows researchers to understand how EOL experiences impact communication and care pattern, differences between novice and experienced nurses, and how to leverage strategies to foster growth in novice staff. Furthermore, there is a need to explore the unique variables influencing communication among nurses specifically, before comparisons may be made to other HCPs. Finally, efforts should be continued in the development of interventions supporting nursing communication that are grounded in evidence, meet the needs of practicing nurses, and have specific outcome variables identified.

Implications for Nursing Practice

There is an increasing need to educate and reinforce to nurses and HCPs the core principles of effective communication. Communication with children and families is an important component of PC/EOL care, and allows HCPs to provide quality care across the continuum, engage in decision-making, and provide anticipatory guidance.

Communication enables goal setting during PC and EOL that incorporates child and family wishes. HCPs should strive to engage children and adolescents, when appropriate, in PC/EOL discussions. However, communication must take into account the development level of the child and be done in a sensitive manner to ensure the child's

voice is heard. Michelson et al. (2011) identified three essential components of family conferences: preconference planning, communication during conferences, and post-conference processing. A number of associated challenges exist for each component, including providing skillful communication, coordinating communication among a number of multidisciplinary team members, and logistic difficulties ensuring that people with the most appropriate expertise are involved in the family conference (Michelson et al., 2011).

In addition to providing PC/EOL communication education offerings for HCPs and implementing strategies to promote involvement of the child and family in PC/EOL discussions, there is an opportunity for leaders in pediatric health care to provide clarity regarding the roles and responsibilities by discipline for engaging in PC/EOL discussions. Health care system-based policies may provide critical guidance for nurses, physicians, and allied health professionals in how to appropriately participate in PC/EOL discussions consistent with each discipline's scope of practice.

Future Research

Based on the limitations identified from the current state of the science, several lines of investigation are suggested. First is the critical need to develop and test a theoretical framework to ground future study designs. The presence of a framework may allow researchers to better understand how communication supports or hinders components of care including symptom management, decision-making, anticipatory guidance, and psychosocial support. Second, valid and reliable instruments need to be developed to measure nurse communication in pediatrics, communication patterns including facilitators and barriers, and child-, family-, and nurse-outcomes associated

with effective communication. The limited number of studies in the past decade that focus on the phenomenon of nurse communication during PC/EOL in pediatrics drives a need to further understand the role of nurse communication in providing quality PC/EOL care. Third it is imperative to develop studies that enhance our understanding of how the nurses' level of experience and expertise impacts communication patterns between children, families, and other HCPs during PC/EOL. Fourth, there is a need to address ambiguity related to expectations through the development of guidelines outlining roles and responsibilities by discipline for engaging in PC/EOL discussions that is consistent with each discipline's scope of practice.

Overall, research is needed to expand the knowledge base of nurse communication in pediatric oncology during PC/EOL, as well as strategies to bring the current science to the bedside for nursing practice. A summary of methodological approaches and study designs that can be useful to advance the state of the science by contributing to our understanding of nurse communication in the context of PC and EOL can be found in Table 5. Areas of focus include exploration of nurses' experience communicating with children, families, and other HCPs during EOL; assessment of nurse comfort with communication during PC/EOL and communication skills; interventions to support effective nurse communication with children, families, and other HCPs; and outcomes of effective nurse and HCP communication. Within these areas it is critical to evaluate how level of overall nursing experience and experience caring for children during PC/EOL influences findings. The development and implementation of a bundle of strategies aimed at fostering effective nurse communication may provide the opportunity

for health care settings to use the approaches that best match the needs of their nursing staff.

Conclusion

Based on a review of current literature related to nurse communication during PC/EOL several conclusions may be drawn. First, PC/EOL are complex processes that often consist of an unpredictable trajectory, resulting in difficulties for nurses and HCPs to engage in timely and appropriate communication with children and families. Second, the current state of science reflects an inadequate number of studies describing PC/EOL communication of pediatric oncology nurses; therefore, findings from similar populations may need to be integrated into this PC/EOL literature to provide direction for future research. Third, nurses value effective communication with children and families during PC/EOL, but often experience internal barriers across the health care system. Gaps in the current literature suggest future directions in the development of a theoretical framework; development of data collection instruments that accurately capture nurse communication; development of studies aimed at understanding the influence of experience on communication patterns; and creation of communication-directed interventions aimed at impacting outcomes for children, families, and nurses.

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Chapter 4

Communication during Palliative Care and End of Life: Perceptions of Experienced Pediatric Oncology Nurses

Abstract

Background: Communication between patients, families, and health care providers is a central component of end of life care. Nurse communication during palliative care and end of life is a phenomenon with limited research. It is unclear how the level of nursing experience influences perspectives of nurses communicating during end of life.

Objective: The purpose of this study was to describe the commonalities of nurses' experiences communicating during palliative care and end of life, and perceptions of barriers and facilitators to effective communication.

Methods: This study was part of a larger multi-site study that used a qualitative, empirical phenomenology design, and represents focus group data gathered from pediatric oncology nurses with greater than 5 years of experience or who were advanced practice nurses not involved in the direct evaluation of other nurses.

Results: Five core themes with corresponding themes and subthemes were identified. The core themes included (a) evolution of palliative care and end of life, (b) skill of knowing, (c) expanded essence of caring, (d) experienced nurse as committed advocate, and (e) valuing individual response to grief.

Conclusions: Findings reflect how the concept of experience transcended the 5 core themes, and captured how experience provided nurses the know-how to fulfill the roles of communication, caring, and advocacy for children and families.

Implications for Practice: Enhancing nurse communication skills during end of life requires opportunities to gain experience coupled with clinical strategies, such as standardized curricula, simulation, competency-based orientation programs, mentorship and peer support.

Key Words: Communication, Nurse, Cancer, End of Life, Palliative Care

Despite advances in cancer-directed therapy and supportive care, children still die from cancer. Communication is a central component of palliative care (PC) and end of life (EOL) care for these children their families. PC/EOL communication is described as sensitive discussions about the process of transition from curative-focused therapy to PC/EOL, the options for treatment of symptoms, and the process of dying which includes the disclosure of feelings about death, dying, and the plan of care (Masera et al., 1999; Montgomery, Hendricks-Ferguson, & Sawin, 2013). Communication facilitates the implementation of other core components of PC/EOL, such as the provision of interdisciplinary care across the continuum, decision-making, and provision of anticipatory guidance. Emphasizing the need for good communication, a number of organizations have made recommendations and commitments to address gaps in Pediatric PC and EOL care and research (American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003; National Institute of Nursing Research, 2011). While understanding communication during PC/EOL in all nurses is important, exploring the experienced nurse's perceptions on communication at these vulnerable times might be especially useful in improving care through fostering the nurses' knowledge and enhancing the skills of nurses with less years of experience.

A synthesis of the literature found nurses PC/EOL communication skills were influenced by various factors including opportunities to care for children at EOL, formal PC/EOL training, and communication challenges between disciplines and across the continuum of care (Montgomery, Hendricks-Ferguson, & Sawin, 2013). However, the gaps identified in the literature need to be addressed to fully understand and improve

communication between HCPs, children, and families in complex health care settings.(Davies et al., 2008; Durall et al., 2012; Helft et al., 2011; Malloy et al., 2010; Papadatou et al., 2001). One of these gaps is a lack of clarity on the impact of nurse experience on PC/EOL communication.

There have been few studies that examined years of experience in adult oncology as a contributing factor in PC/EOL care delivery. Authors have reported that oncology nurses who had more experience caring for adult patients at EOL had more positive attitudes about death and caring for dying patients (Dunn, Otten, & Stephens, 2005; Lange et al., 2008). These findings may be influenced by the age of the patient, in that nurses who care for adult patients may have different attitudes about death and the care of dying patients if asked similar questions within the context of pediatrics. Another factor that may impact the findings is the increase in opportunities to gain PC/EOL experience over time. Attitudes about death and the care of patients may be different for nurses who care for children and adolescents. Experienced nurses are able to reflect on and learn from previous PC/EOL experiences. Reflection on experience can provide nurses with a systematic approach to develop a PC/EOL knowledge foundation, identify care patterns, implement appropriate care-related interventions, develop professional maturity, and build expert practice (Morrison & Symes, 2011; Sherwood & Horton-Deutsch, 2013). Identifying characteristics of expert practice in nursing and understanding the skills necessary to care for patients at their most vulnerable times is essential to determine strategies to build and maintain competency (Morrison & Symes, 2011). Studies using qualitative methods have uncovered elements of expert practice in nursing and identified

theoretical knowledge as only one of many elements supporting expertise (Morrison & Symes, 2011).

Nurse communication during PC/EOL, as a phenomenon, is not well described in the literature. Due to a lack of research, the nursing discipline has limited evidence to ground its understanding of the experience of nurses communicating during PC/EOL. Furthermore, evaluating experienced nurse (e.g. those with 5 or more years of experience in PC/EOL) perceptions of communication has not been addressed. The purpose of this study was (a) to describe the commonalities of nurses' individual experiences of communicating PC/EOL perspectives when caring for a dying child and (b) to describe nurses' perceptions of factors that facilitate and impede PC/EOL communication with dying children, their families, and HCPs.

Methods

This study was part of a larger multi-site study that used a qualitative, empirical phenomenology design (Hendricks-Ferguson, 2007). A qualitative approach provided a valuable and often underused method for strengthening the knowledge base in PC through capturing the experiences of patients, families, and HCPs (Steinhauser & Barroso, 2009). The framework that guided this study is based on empirical phenomenology as a research philosophy and approach, and on group-as-a-whole theory (Giorgi, 1997; Kooken, Haase, & Russell, 2007; Munhall, 2007; Stubblefield & Murray, 2002). When patients, families, nurses, or other HCPs enter into a PC/EOL relationship, each member of the relationship must understand one another's situation in the world (Hendricks-Ferguson, 2007). This understanding can be created through empirical phenomenology, which stems from the assumption that a scientific explanation must be grounded in the

worldview of the individual subjects (Aspers, 2009). Semi-structured interviews consisting of open-ended questions were used in focus group settings to explore experienced nurses' perspectives communicating during PC/EOL.

Setting and Sample

The overall study consisted of 12 focus groups with pediatric oncology nurse participants across three large children's hospitals in the Midwestern US (Hendricks-Ferguson, 2007). This study represents data gathered from a sample of registered nurses with (a) greater than 5 years of experience or who were advanced practice nurses not involved in the direct evaluation of other nurses working in a pediatric oncology clinical setting; (b) English speaking and (c) willing to share their experiences in a group setting. Approval was obtained for the overall study by the institutional review board at each of the 3 sites.

Procedures

The procedure was standardized for all focus groups at each site and described in detail elsewhere (Hendricks-Ferguson et al., 2013). In order to create a supportive environment, moderators and field note recorders were not associated with the hospitals where the focus group was conducted. Moderators used a discussion guide with data-generating questions addressing communication experiences with children and other HCPs during EOL care (Appendix A). All participants completed a Demographic Questionnaire, which included items related to gender, age, race, marital status, education status, nursing experience, current position, and completion of any PC/EOL related education or training (Appendix B).

Data Analysis

Focus group interviews were transcribed verbatim from audiotape by a professional transcriptionist. Colaizzi's eight-step approach was used in the analysis of focus group data (Colaizzi, 1978). The eight-stage iterative process began with the focus group moderator and recorder reviewing the transcripts and field notes for accuracy. The primary authors repeatedly read transcripts, extracted significant statements, revised significant statements into restatements, and developed formulated meaning statements. Regular meetings were held where investigators validated formulated meaning statements and identified themes based on commonalities across statements. Consensus on core themes, themes, and subthemes were obtained. Full descriptions of core themes were created in narrative form. Finally, essential elements of the experience were validated both by the research team and other colleagues. Colaizzi's approach combined with focus group methodology has been shown to be appropriate in obtaining perspectives of communication in other populations (Hicks, Bartholomew, Ward-Smith, & Hutto, 2003; Kooken et al., 2007). Descriptive statistics were used to summarize sample characteristics.

Findings

Study participants were recruited from 3 hematology/oncology services across 3 different sites, and consisted of 24 pediatric registered nurses and 3 nurse practitioners. All 27 participants for this study were female. Their ages ranged from 27 to 54 years, with a mean age of 42 years. All participants were Caucasian and were primarily single (n=15) or married (n=11). Basic nursing educational preparation included: diploma/associate degree (n = 4), bachelor's degree (n = 20), master's degree (n = 3). The majority of participants had not attended an educational program focused on PC/EOL for

children (n = 21) or completed certification requirements for the national End of Life Nursing Education Consortium (ELNEC) program (n = 24).

Experienced Nurse Perspectives

A total of 1,299 formulated meaning statements resulted from 2,175 significant statements extracted from the focus group data. The participants shared perspectives about communicating with children with cancer, their families, and other HCPs during PC/EOL. The overall finding was characterized as the “Essence of Experience”, which reflected how the concept of experience transcended the 5 core themes and provided nurses the know-how to optimize nurse PC/EOL communication. Table 6 includes a list of core themes, themes, subthemes, and selected exemplar quotes. Five core themes with corresponding themes and subthemes surfaced from rich focus group discussions and supported the overall finding. The core themes included (a) evolution of PC/EOL, (b) skill of knowing, (c) expanded essence of caring, (d) experienced nurse as committed advocate, and (e) valuing individual response to grief.

Core theme I: Evolution of PC/EOL.

This core theme captured the participants’ beliefs that PC/EOL concepts have evolved and changed over time. Participants’ descriptions yielded two themes: evidence of the evolution and continued challenges. Evidence of the evolution included descriptions capturing a noticeable shift from reactive to proactive communication and care planning. This shift was partly influenced by the development and implementation of PC teams in two of the hospitals included in the sample. Nurses’ perceived members of the PC team as facilitators of EOL communication earlier in the trajectory. Additionally, nurses described specific examples of the trusting interrelationship between

the child, family, PC team and health care team. Furthermore, when nurses were engaged in the discussions they felt part of the child's bigger care team.

Despite a perceived positive evolution of PC/EOL, nurses clearly described continued challenges. In contrast to the positive feelings described by nurses when they were engaged as part of the child's care team, nurses reflected on layers of perceived disrespect felt when PC teams in particular did not actively seek out the nurse's assessment of the child. Additionally, nurses described not being included in crucial PC/EOL conversations. When PC/EOL discussions occurred without the presence of a nurse, participants described interactions where children and families had repeated or clarifying conversations with the nurse. This interaction resulted in a subtheme of brewing the stew. This subtheme was defined as an escalating situation where the nurse, because she was not included in the team PC/EOL discussion, unintentionally contributed to a child's or parent's confusion about the plan of care or created unnecessary emotional distress due to miscommunication. As a group, the nurses shared common experiences that reflect both positive and challenging aspects of the PC/EOL evolution.

Core theme II: Skill of knowing.

The skill of knowing described the experienced nurses' ability to assess and intervene based on knowledge of patterns of communication specific to parents and children's PC/EOL experiences. Nurses' descriptions were represented in a number of themes that reflected their skill in determining readiness to engage in PC/EOL discussions, assessing understanding following interactions, and providing support during and after sensitive conversations. Participants across sites reflected on experiences where parents' readiness was restricted by their desire to limit direct conversations with their

child about EOL in an act of protection. Parents protecting children from the truth related to their EOL trajectory resulted in a range of feelings for nurses, including acceptance, understanding, and frustration. In contrast, nurses also experienced children protecting parents, describing how adolescents and young adults did not want to share their understanding of the dying trajectory to prevent their parents from having an emotional response. “Opportunity Knocks” reflected a prime communication opportunity nurses seized when parents approached them unexpectedly with questions that initiated EOL discussions. In addition to readiness these experienced nurses reflected on the importance of communicating support to parents who were seeking validation of their actions and to children and parents who are vacillating in their acceptance of EOL.

Nurses described their own struggles to overcome complex obstacles including cultural variations, difficulty in predicting the EOL trajectory, and the perception of limited self-efficacy. Despite overall experience level, nurses described situations where they were at a loss for words and lacked comfort in how to communicate with the child or family. This loss was often accompanied by the nurse’s own fears and insecurities about saying the right thing to children and families during the vulnerable period of EOL. This finding is consistent with Bergdahl et al. (2007) who found expert nurses in the home care setting felt limited because of a lack of EOL experience. Furthermore, nurses from this study described the limited number of opportunities to care for children at EOL in the hospital setting, resulting in challenges to increase self-efficacy. However, when nurses were able to gain experience engaging in PC/EOL discussions, they described an increase in overall comfort.

Core theme III: Expanded essence of caring.

The expanded essence of caring described the experienced nurse's ability to build intimate moments that went beyond typical care, and foster physical and emotional connectedness between children and families during complex EOL circumstances. When compared with the novice nurse, the experienced nurses' expanded the interventions provided, recognizing what parents did not know about EOL or when they did not know how to ask for what they needed (Ferguson et al., 2013). This "Expanded Essence of Caring" was grounded in a strong trusting relationship with the child and parents, as well as cumulative EOL experiences.

Nurses collectively described how their actions fostered physical and emotional connectedness near death. Specifically, nurses shared intimate moments in which they could sense death was near and coached parents and family members to physically hold their child during the last moments of life. The experienced nurses' commitment to foster this connectedness created lasting memories and provided precious experiences to enhance care for future children.

This theme included an important and sometimes overlooked aspect of communication; balancing messages of hope and realism. Nurses specifically described communicating with children and families about hope, paying close attention to the balance and fear of providing false hope in the face of a known EOL trajectory. Furthermore, experienced nurses articulated that hope can and often does change for children and families throughout EOL. This finding also is supported in a study of nurses communication with adults and their families during transition from curative focused therapy to EOL in the critical care setting (McClement & Degner, 1995)

Core theme IV: Experienced nurse as committed advocate.

The experienced nurses believed it was their responsibility to be an advocate for the child and family during PC/EOL. The focus group data represents nurses' actions that went above and beyond to fulfill child and family preferences during the vulnerable period of PC/EOL. The nurses' actions embodied use of their expert communication knowledge to provide anticipatory guidance, approach problems with creative solutions, recognize that advanced care planning is needed before a crisis exists, and respecting religious convictions impacting EOL care. Nurses described experiences in which they communicated with parents about details associated with escalation of care (e.g. transfer to the Intensive Care Unit), and allowed time for parents to pause and process that information during a chaotic time when the patient was unstable. In one particular situation, the nurse's commitment to advocate and have a conversation during a brief and critical period in the patient's trajectory, allowed the parents to speak up and state their wish to not have their child transferred to the Intensive Care Unit.

Nurses described their belief that the child's nurse must prepare the family, resulting in an appreciation of the parents knowing what to expect throughout the trajectory and at the moment of death. Specifically the experienced nurse was able to anticipate the symptoms that the child may experience during EOL and act as a creative problem solver to match care with the child's needs. Nurses reflected on experiences where the family's religious convictions impacted care. Specifically nurses encountered situations with parents who were resistant to advanced care planning or do not resuscitate (DNR) discussions and medication to manage a child's pain. The reasons behind the resistance were unique to each family, but in one instance the family believed they should

not interfere with God's plan by taking action. Nurses also described balancing spiritual needs with the child's needs while being respectful of religious convictions.

Core theme V: Valuing individual response to grief

“Valuing Individual Response to Grief” captured nurses’ descriptions of the types of support and communication experienced nurses needed following the death of a child or adolescent. It also more broadly captured the culture of grief in which the nurses live and the desire for leaders and peers to value each individual’s response to grief. Nurses described the culture of grief they experienced as part of caring for children at EOL. Specifically, nurses perceived that there is limited time to grieve following the death of a child, with hospital staff requesting to fill the patient’s room as soon as it can be emptied and clean. The pressure to maintain day-to-day unit operations in a clinical environment may be insensitive to nurses’ desire to have protected time to grieve and allow for the management of physical environment triggers of grief, such as opening the doors to the room of a patient who recently died.

Experienced nurses from all sites recognized that support interventions must be comprehensive, consistently offered, and individualized. Specifically, nurses identified the need to increase opportunities to “Leverage Peer Support”, or using peers to their maximum advantage to support nurses following the death of a child. This subtheme was supported by the perception that their peers are the only people who truly understand what it means to provide EOL care to a dying child. Additionally, they indicated that the type of support must match the energy associated with the complexity of care provided to children and families during PC/EOL, such as allowing for time to grieve and avoiding activities that exhibit insensitivity. Through their descriptions, experienced nurses

highlighted the gaps in support for novice and experienced nurses and the role of peer mentorship. Support interventions that are grounded in a one-size-fits-all framework may be helpful for novice nurses but are not adequate for experienced nurses.

Discussion

This study used empirical phenomenology and group-as-a-whole theory to describe experienced pediatric oncology nurses' experiences communicating during PC/EOL. A major strength of this study was its innovative design, outlined by the use of focus groups with homogenous samples across multiple sites. To counter the likelihood of producing less diverse data with groups of participants with similar backgrounds, additional sites with different geographic locations were included to increase the possibility of illuminating experiences that rise above local hospital setting influences. A focus group environment allowed nurses to share stories and find commonalities across experiences caring for children during PC/EOL, and provided investigators an approach to support data saturation through interactions and other focus-group dynamics.

Nurses described the "Evolution of PC/EOL" and the visible shift among colleagues to be proactive in engaging PC and communicating with children and families about EOL earlier in the trajectory. Of the 3 data collection sites, 2 had PC teams as an available service within the hospital setting. Nurses who had experience working with PC teams reflected most often on their positive role in coordinating and managing care across the continuum. In some situations, PC teams were integrated close to EOL; while in others the service was engaged with the team early in a child's diagnosis.

The nurse navigates the complexity of PC/EOL communication through his or her "Skill of Knowing" in how to engage children and parents in discussions, assess the level

of understanding, and provide support. This is consistent with Morrison & Symes (2011) who found expert nurses had a skilled know-how in their ability to mobilize resources and adapt to situations through collecting a wider range of cues to support clinical decisions. When nurses were able to effectively communicate, satisfaction with their role increased (Malloy et al., 2010). Despite the experienced nurses' unique communication skill set, they still encountered intrinsic barriers, including their own fears and insecurities about saying the right thing during EOL. This contrasts findings by Enskar (2012), who found experienced pediatric oncology nurses perceived an expert nurse to be a nurse who has confidence in his or her knowledge related to the general care patients, and in his or her ability to apply that knowledge consistently in practice.

In this study, nurses also experienced a rollercoaster of emotions when communicating with children during PC/EOL. Nurses encountered challenges managing their own emotions when parents chose to limit the flow of information related to disease status and trajectory to their child or when children refrained from communicating EOL concerns in order to protect their parents. From nurses' perspectives, they practiced restraint to fulfill their desire to honestly and openly communicate with a child they believed knew what was occurring. The nurses' respect for parent wishes superseded their own values and beliefs. As a group, experienced nurses were able to draw from multiple EOL experiences to understand that withholding information from children may result in some circumstances for the nurse to take action and advocate for open communication, while in other situations to be respectful of parent wishes and take no action.

Nurses had an “Expanded Essence of Caring” towards children and families at EOL. This essence transcended the nurses’ communication patterns and provision of physical and emotional care. In a study exploring expert nurses’ experiences providing palliative home care, skill and knowledge was regarded as an important facilitator in creating and maintaining caring relationships with patients and families (Bergdahl et al., 2007). The expanded essence further suggested that nurses develop pattern recognition across EOL experiences, allowing the nurse to critically evaluate and respond to individual situations.

The nurses also told stories of how they anticipated and overcame obstacles to act as a “Committed Advocate”. Creative problem solving allowed the nurses to match the child’s care with his or her preferences. A nurse’s level of perceptiveness, or his or her ability to be open, accessible, and understanding in the relationship with the patient, has been shown to increase with EOL experience (Bergdahl et al., 2007). This perceptiveness allows the nurse to evaluate the appropriateness of advocacy depending on the child or family’s individual needs or circumstance. Matching the right care or interventions with the cultural beliefs was challenging for nurse participants in this study. Nurses have been shown previously to rank communicating with patients and families from different cultures as the most difficult (Malloy et al., 2010).

Nurses described the need for individualized support as “Valuing Individual Response to Grief” when it comes to supporting nurses following the death of a child. Nurses shared that support strategies for novice nurses are different than those valued by experienced nurses. The need for time and availability for reflection and debriefing as valued strategies for being able to transform knowledge into clinical practice and

minimize burnout is consistent with previous research (Enskar, 2012). The experience of caring for children during PC/EOL coupled with meaningful reflection allow nurses to develop a skill set in their approach to PC/EOL communication, advocacy for care management, and ability to facilitate connectedness between the child and family.

Implications for Nursing Practice

Findings from this study provided insight on how to advance several of the National Cancer Institute's recommendations to achieve optimal verbal and nonverbal communication with children and their families at EOL. In their summary on pediatric supportive care, the National Cancer Institute (2013) highlighted that care for children and families at EOL is complex, and communication focused on advanced care planning with children and families should occur early in the trajectory and be caring, sensitive and individualized to the specific concerns. When communication is insufficient or ineffective among HCPs there may be suboptimal care provided to children and families. Examples of such care include inadequate symptom management, decreased quality of life, medication errors, and misunderstandings regarding child and family preferences for advance care (Michelson & Steinhorn, 2007). Furthermore, miscommunication regarding advance care planning may lead to aggressive therapies that are unwanted by the child or family (Michelson & Steinhorn, 2007).

Specialized knowledge and skills in communication are required to address the challenges of providing PC and EOL care in complex health care settings (Hubble, Trowbridge, Hubbard, Ahsens, & Ward-Smith, 2008; Malloy et al., 2006). Based on a literature review, Zoppi and Esptein (2002) characterized communication as a concept that is both learned and innate; a blend of learnable skills, and inherent qualities to the

individual. Zoppi and Esptein (2002) further suggested that communication interventions target multiple levels, including the patient, HCP, and health care system.

Nurses in this study reported fairly low levels of attendance for PC and EOL education activities and programs, including ELNEC and ELNEC-PPC, suggesting clinical settings should increase education and training opportunities for nurses of all levels of experience, including those with greater than 5 years. Enhancing communication skills during PC/EOL in pediatric oncology nurses requires a variety of clinical strategies, which may include standardized PC/EOL curricula, simulation, competency-based orientation programs, mentorship, peer support, and reflection. Instructional techniques that may be useful for teaching effective communication during PC/EOL focus on understanding what the patient is saying from a developmental perspective and the interpersonal skill of relationship building (Sahler, Frager, Levetown, Cohn, & Lipson, 2000). Development and implementation of training strategies are most effective when the learner is ready to enhance their knowledge and skills. A study by Turner et al. (2010) found nurses valued more than physicians, mandatory EOL training for oncology professionals, communication as a central component to health care professionals providing care at EOL, and training across experience levels. This highlights the importance of clinical settings to lay the foundation preparing health care professionals from various disciplines for EOL focused education and training.

Limitations and Conclusion

This study has a number of limitations that should be acknowledged. First, due to the study's qualitative design and small sample, findings are not generalizable to the larger pediatric oncology nurse population. Second, the study may be influenced by

selection bias. Nurses who chose not to participate may be systematically different than those that do participate. However, the consistency across three sites supports the findings and may suggest bias may not be a limitation. The findings also represented a specific point in time in each institution's trajectory developing PC and EOL care. Participants had little education with a focus on PC/EOL when data were collected, but as this is an evolving situation, some participants might have changed their knowledge or behavior since that time. Third, findings reflected experiences of nurses at Midwestern institutions and the perceived culture towards PC/EOL at those institutions, and therefore the results are not representative of clinical oncology settings across the US. Fourth, the sample consisted of only Non-Hispanic, White and female participants, and there is a degree of uncertainty whether the addition of participants from other ethnicities and gender would alter study findings. Fifth, the impact of the participant's role in the practice setting (advanced practice nurse or registered nurse) could not be assessed. It is unknown how the scope of practice and responsibilities associated with each particular role influenced the findings of this study.

In conclusion, findings of this study provided insight into the perspectives of experienced pediatric oncology nurses communicating during PC/EOL. The overall finding was characterized as the "Essence of Experience", and reflected how the concept of experience transcended the 5 core themes and provided nurses the know-how to optimize nurse PC/EOL communication. Their stories highlighted a variety of issues and areas that need to be addressed in the clinical setting and through future research. Providing the child and family quality care and meeting the needs of nurses and other HCPs during and after EOL are broad examples of areas that require attention by clinical

administration and leadership. In addition, gaps in nurse's educational training and access to PC/EOL services for children with cancer have policy implications at a national level.

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Chapter 5

In its summary on pediatric supportive care, the National Cancer Institute (2013) highlighted that care for children and families at end of life (EOL) is complex and recommending the following: (a) communicating with children and families in a sensitive and caring way and within the context of the child's development level, (b) integrating symptom assessment and management strategies during EOL, (c) identifying and addressing emotional and spiritual needs of the child and family, and (d) engaging parents in early discussions about advanced care planning. Enhancing the quality of interdisciplinary care at EOL has reached the national platform as an important health care goal (Field & Behrman, 2003; Michelson & Steinhorn, 2007).

As discussed previously, communication is a central component of the care provided to children and families throughout the EOL trajectory. Communication provides the foundation for assessing patient and family needs, assessing HCPs' effectiveness in meeting those needs, and taking responsibility of for updating health care team members about the patient's and family's progress (Michelson & Steinhorn, 2007; Papadatou et al., 2001). Effective communication is particularly important when a child with life-limiting illness is at risk of dying, and allows for the medical, psychosocial and spiritual needs of the child and family to be identified and addressed in the plan of care (Hubble et al., 2008).

Early discussions about palliative care (PC) and EOL align with recommendations from the American Academy of Pediatrics and the Institute of Medicine (American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003; Michelson & Steinhorn, 2007). When communication is

insufficient or ineffective among HCPs, there may be suboptimal care provided to children and families. Examples of such care include inadequate symptom management, decreased quality of life, medication errors, and misunderstandings regarding child and family preferences for advance care (Michelson & Steinhorn, 2007). Furthermore, miscommunication regarding advance care planning may lead to aggressive therapies that are unwanted by the child or family (Michelson & Steinhorn, 2007).

The timing of EOL discussions is an important factor for HCPs to consider. Often the child's diagnosis or disease status will provide information to guide timing of conversations with the child and parent. Early EOL discussions are essential to identify what components of EOL care are most important to the child and family, and to allow sufficient time to enact plans that support the child's and parents' wishes. However, there may be situations where early EOL discussions may not be feasible due to unexpected clinical changes or respect for a parent's wish to not openly communicate with the child about EOL. Therefore, HCPs should consider the child's expected disease trajectory soon after diagnosis to provide guidance on timing of initial EOL discussions. Children who have good disease prognosis and their parents may not require EOL discussions early after diagnosis, compared to those with a poor prognosis. Interventions aimed at supporting dialogue between HCPs, children, and parents may influence overall patterns of care.

The findings of this study provided insight into the perspectives of experienced pediatric oncology nurses communicating during PC/EOL. Their stories highlighted a variety of issues and areas that need to be addressed in the clinical setting and through future research. How to provide the child and family quality care and meeting the needs

of nurses and other HCPs during and after EOL are broad examples of areas that require attention by clinical administration and leadership. In addition, gaps in nurses' educational training and access to PC/EOL services for children with cancer have policy implications at a national level.

Clinical Practice

As part of the health care team caring for a child with cancer, nurses support the planning, implementation, and evaluation of the plan of care. The discipline of nursing provides continuity of care across the health-illness continuum, including the EOL trajectory, which may be an extremely vulnerable time for children and their families. The findings of this study described a wide range of clinical practice issues experienced pediatric oncology nurses encountered, starting at the patient level and reaching to the level of hospital administration and leadership. This section describes implications for clinical practice and benefits for improving the care and support of children dying from cancer and the nurses who care for them, including developmental considerations, PC programs, education and training, nursing experience, and support strategies for nurses.

Developmental Considerations

Developmental considerations relate to the clinical care provided to children during PC and EOL including the type and breadth of EOL-specific communication. Clinically, HCPs should consider the child's development level when providing physical care and psychosocial support to the child and family. It is important to assess children's abilities to conceptualize death and the possibility of their own death. The elementary school-age child begins to understand their own mortality and may benefit from HCP interventions to support their continued understanding of their situation, allowing the

child some control and participation in medical decision-making as appropriate (Michelson & Steinhorn, 2007).

In this study, experienced nurses shared stories how they perceived children to be mature despite their young age in their ability to understand their disease prognosis and EOL trajectory. Nurses found tailoring their language and allowing opportunities for children to engage in discussions about death to be useful tools in communicating with young children. Nurses and HCPs should first assess parents' comfort with communicating about EOL prior to engaging in direct conversations with any child under the age of 18.

Due to their age and developmental level, adolescents pose unique challenges when determining the plan of care at EOL. Ethical and legal issues arise based on the fact that adolescents are less than 18 years of age and lack the legal authority to make decisions related to their own health care. This issue is compromised with an adolescent who appears developmentally appropriate to make such decisions based on the health care team's assessment. Even when full decisional authority is not appropriate, there is strong support to elicit and incorporate young adolescents' treatment preferences (Freyer, 2004; Hinds et al., 2005).

In this study, nurses experienced a roller coaster of emotions when communicating with adolescents during EOL. Nurses encountered challenges managing their own emotions when parents chose to limit the flow of information related to disease status and trajectory to their teenage child. From the nurses' perspective, they practiced restraint to fulfill their desire to honestly and openly communicate with an adolescent they believed knew what was occurring. The nurses' respect for parental wishes

superseded their own values and beliefs. As a group, experienced nurses were able to draw from multiple EOL experiences to understand that withholding information from adolescents may result in some circumstances for the nurse to take action and advocate for open communication, while in other situations to be respectful of parental wishes and take no action. The unique challenges raised in the adolescent age group is an area pediatric oncology HCPs should be prepared to identify and manage, in order to realize the physical comfort and personal fulfillment that may constitute the overarching goals of successful EOL care (Freyer, 2004).

Palliative Care Programs

At the time of this study 2 of the 3 data collection sites had PC teams as an available service within the hospital setting. Nurses who had experience working with PC teams reflected most often on their positive role in coordinating and managing care across the continuum. In some situations, PC teams were integrated close to EOL, while in others the service was engaged with the team early in a child's diagnosis. The nurses described how PC team members modeled effective EOL communication with children and families. Furthermore, nurses shared how PC teams facilitated trusting relationships between the child, family, health care team, and other PC team members. There were few instances where experienced nurses perceived PC teams more negatively. The negative emotions stemmed from the nurse's perception that PC team members were taking over the care of the child and ignored the existing relationship between nurse and family. Overall, PC teams were described as key members of the larger interdisciplinary team in facilitating EOL communication, managing symptoms at EOL, and implementing interventions that honored child and family wishes.

Early integration of PC teams in the plan of care has been supported by a number of organizations, including the American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care (2000). Literature suggests that integration of PC earlier in the EOL trajectory may offer an opportunity to positively impact symptom control and subsequent distress, quality of life, decision-making and facilitation of patient- and family-centered care that is consistent with the child's disease prognosis (Voyles, 2013; Zhukovsky et al., 2009). Furthermore, Wolfe et al. (2008) found the use of PC team services significantly improves EOL care with parents reporting better preparedness for the EOL trajectory, decreased child suffering, and improvements in advanced care planning.

From a symptom management perspective, PC teams and consultation have been one aspect of care evaluated in the literature. For instance, studies have shown that PC consultation can detect symptoms not identified by the primary HCP team, provide recommendations for medications to enhance symptom management, increase the number of allied health consultations, support EOL discussions earlier in the trajectory, and improve the timeliness of documentation of those discussions (Wolfe et al., 2008; Zhukovsky, et al., 2009). The use of PC teams is a first step in the management of multiple symptoms across a continuum; however, more research is needed to understand the full range of benefits PC teams can offer children, families, and HCPs.

Education and Training

Specialized knowledge and skills are required to address the challenges of providing PC and EOL care in complex health care settings (Hubble et al., 2008; Malloy et al., 2006). Experienced nurses in this study expressed gaps in their educational

preparation to communicate effectively in EOL situations involving children. These gaps occurred early in the nurses' careers as they completed undergraduate programs and moved into their clinical settings. Implementing strategies in a purposeful way may help nurse leaders support the PC and EOL knowledge base of novice and experienced pediatric oncology nurses. Educational strategies have several components such as the content, learner, facilitator, method of delivery, and timing. Instructional techniques that may be useful for teaching effective communication during EOL should target how HCPs approach difficult topics through communication, listening to the patient, and relationship building (Sahler, Frager, Levetown, Cohn, & Lipson, 2000).

PC and EOL communication should involve the child, family, and health care team. It is critical to evaluate educational needs and deficits within and across the disciplines of nursing, medicine, and allied health. Facilitators of education should be well versed in literature related to PC/EOL and communication in pediatrics, and be able to draw on previous experiences in order to engage learners. The mode of learning is heavily dependent on the assessment of the learner, knowledge or skill to be gained, resources to facilitate learning, and the desired outcome of learning. Different modes that have been shown to be effective to facilitate learning include competency evaluation, standardized curricula, and simulation. The specific mode of learning may be standardized or tailored to the nurse. Examples of tailored interventions that have been shown to specifically support novice pediatric oncology nurses include opportunities to: develop technical nursing skills, connect with experienced nurses through sharing of experiences, and discuss the concept of coping to try different interventions to support more positive behaviors (Hinds et al., 1994). Lastly, the timing of learning is critical to

achieve optimal outcomes. Learning may occur as part of the orientation to the specialty population for nurses, when the nurse is actively providing care at EOL, or following the EOL experience.

PC/EOL education and training programs also exist within the context of a health care setting and may be influenced by the availability of resources. Funding and nurse staffing may support or impede nurse leaders' abilities to implement strategies to engage nurses, broaden their knowledge foundation, and enhance care provided to children and families during PC/EOL. Multi-modal learning may be effective in developing and enhancing communication skills during PC/EOL in pediatric oncology nurses.

Competency.

The concept of an EOL competency for nurses is novel and may be most useful for evaluating novice nurses or those new to pediatric oncology. Despite limited literature supporting the use of competency evaluation for experience nurses, there may be an indication to use competency as a tool for identifying preceptors, coaches, and mentors for PC and EOL. Literature has shown increased retention rates following the implementation of a competency-based orientation program for new graduate nurses entering specialty care settings (Fey & Miltner, 2000). The competency model from which a nurse fellowship program was created consisted of three tiers of competencies, including core, specialty, and patient care management (Fey & Miltner, 2000). The program not only valued a competency-based approach to orientation, but also emphasized the importance of having strong preceptors to guide and evaluate new graduate performance. As an essential component, communication transcends core, specialty, and care management competencies. The competency-based approach may

allow novice nurses to understand the importance and role communication plays across the illness trajectory, and not just specific to EOL, as well as standardize the principles experienced nurses teach as preceptors.

Standardized curricula.

The Initiative for Pediatric Palliative Care (IPPC) was designed to support hospital settings that serve pediatric populations by bringing together essential content and resources to train HCPs in PC and EOL care (Browning, 2005). The following principles guide the curriculum: maximize family involvement, involve and inform children of care decisions, improve symptom management, provide emotional and spiritual support, and facilitate the continuity of care across settings (Browning, 2005). IPPC modules are delivered through small group seminars with an emphasis on multidisciplinary participants. A unique component of the educational program is the incorporation of family experiences to compliment traditional lectures and discussion (Browning, 2005).

The End of Life Nursing Education Consortium (ELNEC) was originally developed and made available to nursing and other disciplines in 2000. In 2001 after an initial evaluation of the consortium, the ELNEC-Pediatric Palliative Care (PPC) curriculum was developed to better meet the needs of nurses caring for neonates, children and adolescents at EOL. The ELNEC-PPC was created as a 2-day, train-the-trainer program, with the intent that those who participated in the program would play an instrumental role in spreading the information to their respective settings (Jacobs et al., 2009). The ELNEC-PPC curriculum consists of ten modules including (a) Nursing Care in Pediatric Palliative Care, (b) Special Considerations in Pediatric Palliative Care, (c)

Communication, (d) Ethical/Legal Issues, (e) Cultural Considerations, (f) Pain Management, (g) Symptom Management, (h) Care at the Time of Death, (i) Loss/Grief/Bereavement, and (j) Models of Excellence in Pediatric Palliative Care (Malloy et al., 2010).

A program evaluation found the ELNEC-PPC curriculum to be an essential step towards the standardization of evidence-based nursing care delivered during EOL. In a study by Jacobs et al. (2009), participants found the ELNEC-PPC curriculum to have a high degree of flexibility, allowing it to be implemented in a variety of settings, which provided a strong knowledge base and self-confidence when participants were called upon to train others in their health care setting. Nurses in this study reported fairly low levels of attendance for PC and EOL education activities and programs, including ELNEC and ELNEC-PPC, suggesting clinical settings should increase education and training opportunities for nurses of all levels of experience, including those with greater than 5 years. Barriers that have been reported to implementing EOL care concepts through education or training include funding, time, and personal responsibilities (Jacobs et al., 2009; Coyne et al., 2007). The challenge with any core curriculum in a didactic learning environment is the application of key concepts to the clinical setting. Standardized curricula lay the foundation for skill development, but additional strategies are required to develop, enhance, and hardwire skills. Simulation and role play are modes of learning that can offer an opportunity for nurses to apply core knowledge concepts related to communication and other aspects of EOL care in a simulated setting.

Simulation.

Simulation allows learners to apply core knowledge gained through standardized curricula in a mock clinical setting. In a systematic review of medium- and high-fidelity simulation, Cant and Cooper (2010) found the use of simulation showed measurable improvements in knowledge, clinical skills, critical thinking skills, and confidence. Additionally, simulation was shown to be a more effective learning tool when compared to traditional lecture (Cant & Cooper, 2010). Simulation can be used to help translate a number of clinical concepts, including communication, to specific situations in the clinical environment. Zavertrnik, Huff, and Munro (2010) found simulation to be an effective method to enhance nurse communication skills. Moreover, it provided a non-threatening environment for nursing students to practice communication skills and for facilitators to adequately evaluate students' skill level (Zavertrnik, Huff, & Munro, 2010). Within the EOL setting, the concept and skill of communication can be improved via simulation. Smith-Stoner (2009) stated, "Simulators provide an effective bridge between the unknown of caring for a dying person and developing the skills necessary to facilitate a meaningful death experience for patients and their families" (p. 115). Furthermore, "The impact of tending to a patient who dies during the simulation and interacting with a standardized actor as a family member provides opportunities to overcome fears and develop clinical skills" (Smith-Stoner, 2009).

In this dissertation study, experienced pediatric oncology nurses described several sensitive EOL situations that would be excellent simulation scenarios in a controlled learning environment. One example was a discussion between a nurse and the mother of an adolescent regarding use of pain medication to relieve pain. The nurse perceived the

conversation as difficult because of a conflict between the use of pain medications and the mother's religious convictions. The nurse felt emotional distress because the adolescent was experiencing pain, and was uncertain about how to proceed with further discussions around symptom management, while being respectful of religious beliefs. Uncertainty about when and how a nurse should respond to a conflict between the medical needs of the child and a family's religious convictions is expected among nurses with varying levels of experienced levels who have limited EOL experience. Simulation can offer tailored scenarios, which enhance communication skills and increase comfort with difficult situations for nurses with various amount of experience. An example of an EOL communication scenario is outlined in Table 7.

Outcomes of education and training.

There are a variety of outcomes demonstrated through research and posited by researchers related to the implementation of formal educational programs focused on care at EOL. These type of educational programs aim to foster receptive attitudes in nurses by providing knowledge in EOL care and coping skills, supporting appropriate EOL competency, and exposing them to various EOL scenarios that mimic those they would see in their clinical settings (Lange et al., 2008). Nurse-specific outcomes may be general to their role caring for children and families at EOL such as overall job satisfaction, attitudes related to PC and EOL, and self-reported satisfaction with communication skills. Outcomes may also be specific to an educational strategy and include pre- and post-measures reflecting knowledge or skill retention. Measures related to knowledge or comfort level with skills at EOL are most reflective of literature evaluating EOL educational programs. Child- and family-specific outcomes include satisfaction with care

at EOL, self-reported satisfaction with communication from and to health care professionals, and the parent-report of a peaceful death. From an organizational perspective, there are a number of potential outcomes of interest, such as nurse retention, nurse and patient/family satisfaction scores. Organizational level outcomes related to EOL education and communication have been initially conceptualized but not well studied in pediatrics.

Experience Level

Education alone may not adequately support clinical competence of nurses at the bedside. In order to foster clinical knowledge and skills related to providing care at EOL, attention must be paid to the experience level of the nurses and their attitudes about caring for dying children. There have been few studies that examined years of experience in adult oncology as a contributing factor in PC/EOL care delivery. Authors have reported that oncology nurses who had more experience caring for adult patients at EOL had more positive attitudes about death and caring for dying patients (Dunn, Otten, & Stephens, 2005; Lange et al., 2008). These findings may be influenced by the age of the patient, in that nurses who care for adult patients may have different attitudes about death and the care of dying patients if asked similar questions within the context of pediatrics. Another factor that may impact the findings is the increase in opportunities to gain PC/EOL experience over time. Attitudes about death and the care of patients may be different for nurses who care for children and adolescents. Experienced nurses are able to reflect on and learn from previous PC/EOL experiences. Reflection on experience can provide nurses with a systematic approach to develop a PC/EOL knowledge foundation, identify care patterns, implement appropriate care-related interventions, develop

professional maturity, and build expert practice (Morrison & Symes, 2011; Sherwood & Horton-Deutsch, 2013). Identifying characteristics of expert practice in nursing and understanding the skills necessary to care for patients at their most vulnerable times is essential to determine strategies to build and maintain competency (Morrison & Symes, 2011). Studies using qualitative methods have uncovered elements of expert practice in nursing and identified theoretical knowledge as only one of many elements supporting expertise (Morrison & Symes, 2011).

In this study the overall finding *Essence of Experience*, described experienced nurses' perspectives communication during PC and EOL. The nurses had a unique ability to reflect on previous EOL experiences and translate those experiences into meaningful actions to children dying a cancer-related death and their families. The experience of caring for children at EOL coupled with meaningful reflection allow nurses to develop a skill set in their approach to EOL communication, advocacy for care management, and ability to facilitate connectedness between the child and family. Despite their level of experience, pediatric oncology nurses still struggled with insecurities around PC and EOL communication. These struggles coincided with beliefs that opportunities to care for children at EOL in the hospital setting are limited. Depending on the child and family preference, location of death may occur in home or hospice settings, decreasing opportunities for inpatient nurses to gain experience.

Nurses also recalled periods in where their self-efficacy was limited, such as starting as a new pediatric oncology nurse. Novice nurses are more at risk to struggle with the transition from student to professional. Stressors that have been found in pediatric oncology nurses in the first 3-6 months of hire included recognition of

inadequate knowledge base and impatience with identified deficits, avoidance of making patient care related errors and associated guilt with mistakes, achieving strong time management skills, perceptions of being a new nurse, and transition to working off-shifts and the associated physical and emotional effects (Hinds, Quargnenti, Hickey, & Mangum, 1994). These stressors and their associated reactions and consequences are dependent on the experience level of the nurse, suggesting that novice nurses may have a different set of needs in comparison to more experienced nurses, requiring a unique set of tailored interventions aimed at supporting the novice nurse (Hinds et al., 1994).

In summary EOL experiences increase the nurse's level of expertise. Experienced nurses are expected to develop communication and mentor nurses of all experience levels, including novice nurses. Novice nurses have little EOL experience and limited opportunities for acquiring these advanced communication skills (Hendricks-Ferguson et al., 2013). Despite the increase in number of opportunities for EOL experiences among experienced nurses, there is need for ongoing competency development to address the communication needs of nurses with mixed experience levels. Nurses with moderate levels of experience require increased opportunities, through patient care or simulation, to develop and enhance communication and EOL skills. Nurses with greater than 5 years of experience have the responsibility to grow their own competency and mentor other nurses related to effective communication and EOL care.

Support Strategies

Nurses must care for themselves in addition to the children and families they care for during PC/EOL. A number of strategies have been used clinically to provide support for nurses and other HCPs, such as providing access to counseling, organizing regular

and timely debriefing sessions, providing mentorship to those with less experience, and encouraging a supportive and compassionate working environment (Michelson & Steinhorn, 2007). Although not a primary focus, this study provided experienced nurses an opportunity to share their perspectives related to support measures implemented in their institutions.

Coaching and mentorship.

Unlike standardized curricula and simulation, mentorship and peer support provide ongoing opportunities to discuss EOL situations, the associated stressors, and enhance communication skills during EOL. Mentorship and peer support are vital strategies for the novice nurse throughout the first few years caring for a specialty population. This study illustrates how experienced nurses value coaching and mentorship as well, but often lack a structure to formally leverage peers in their settings.

The literature reflects an increasing focus on mentorship programs for novice nurses. In a qualitative study by Davies et al. (1996), intervening strategies that were found to promote coping behaviors and decreased withdrawal and overall distress included peer support, supportive work environment, realistic and appropriate codes of conduct for professional nurse behavior, and resources aimed to support nurses over the EOL continuum. MacKay and Bellamy-Stack (2010) developed and evaluated a mentorship initiative aimed to help new pediatric oncology nurses in completing specialized tasks and with their coping to various stressors experienced in the inpatient setting. They found that a resource nurse role had a positive impact on the self-reported work-related stress levels experienced by inpatient nurses caring for pediatric oncology patients (MacKay & Bellamy-Stack, 2010).

Reflection.

Reflection is an important and often overlooked component of learning. Through reflection novice and experienced pediatric oncology nurses may identify their own strengths and areas of struggle as these relate to caring for children and families at EOL. Furthermore, reflection allows nurses an opportunity to individually assess the impact of their caring behaviors during EOL, expanding their skill of knowing how to address needs of children and families. In addition to providing clinical and emotional support to novice nurses, Linder (2009) found self-reflection to be an important intervention that warrants attention in the development and implementation of orientation and continuing education programs. As an ongoing strategy, reflection aligns well with mentorship and peer support, and may be used to debrief the transition to PC or EOL among groups of nurses. Sahler et al. (2000) describes how structured training in the act of listening supports three purposes: reconciling HCPs with their own personal issues about death and loss, improving their listening skills, and enhancing the consistency in which they cope with their emotions when providing care at EOL.

Debriefings.

Debriefing is a support activity in which staff are invited to participate in a facilitated session to share stories, express concerns, and filter emotions related to difficult child or family situation. Debriefings may be implemented as a standard support measure for HCPs following the death of a child, or used only in situations HCPs perceive as particularly difficult. In either case, the focus of debriefings is usually open allowing for participants to take the discussion where they feel it is needed most.

Facilitators are charged with creating a respectful environment that encourages participants to share feelings.

The data indicated that nurses did not find debriefings in their individual practice settings to be particularly beneficial in supporting their coping needs following the death of a child. However, experienced nurses did share the perceived benefits of debriefings for novice nurses, as an activity to model positive coping behaviors. Kent et al. (2012) found nurses' early experiences with patient death to have a lasting impact on personal and professional lives. Formal debriefings may be more valuable for novice nurses learning to cope with death and dying in pediatrics. Experienced nurses in this study described timely support from peers following the death of a child more positive than formal debriefing sessions. Despite a lack in perceived benefits related to debriefings, experienced nurses did share a common sense of duty to mentor and provide perspective to novice nurses as they foster coping skills during a critical point in their early nursing career.

Leadership Practices.

Nursing leaders may encounter challenges balancing interventions to provide emotional, social, and spiritual support to nurses of varying experience levels. A major finding from this study is the concept that one size does not fit all nurses when it comes to support strategies. As discussed previously, there may be a line defining what strategies are most valuable to novice staff compared to experienced staff. As part of retention action plans, leaders may place more emphasis on supporting novice nurses and potentially overlook the needs of experienced staff.

These findings clearly show experienced nurses need support. Experienced nurses discussed how their clinical settings did not allow adequate time to grieve immediately following the death of a child. Nurses perceived that the hospital's needs to fill the room with a new patient and achieve high levels of staffing productivity trumped the grieving needs of nurses. These seemingly routine actions by operational leadership to maintain efficiency in a given day have lasting effects on experienced nurses. Experienced nurses shared the difficulties of immediately taking a new patient assignment and caring for a patient in the same room after a child died. Nursing leaders can advocate for their nurses by filtering staffing and room requests, and allowing protected time for nurses to grieve immediately following the death of a child.

Future Research

The National Institute of Nursing Research (NINR) and Institute of Medicine (IOM) identified EOL care as a research priority. Specifically they recommended a focus on the impact of HCPs' communication with the child and family, as well as the health outcomes associated with HCPs trained in providing care at EOL (NINR, 2011; IOM 1998). The state of the science review of nurse communication during PC and EOL outlined: (a) communication is an important component of care that supports the child and parent experience during PC and EOL, (b) nurses and other HCPs experience facilitators and barriers to PC and EOL communication, (c) preliminary interventions aimed at supporting PC/EOL communication have been studied, and (d) the potential impact effective communication may have on the nurse (Montgomery, Hendricks-Ferguson, & Sawin, 2013).

This study addressed an important aspect of PC/EOL care, communication. A number of communication issues should be addressed in future research including the development of an overall model for communication during EOL and understanding the influence of communication patterns on symptom management and quality of life, utilization of PC and EOL services, decision-making and advanced care planning, provision of culturally appropriate care, and parental ratings of quality of care (Hare, 2005; Heath et al., 2009; Hinds, Pritchard, & Harper, 2004; Hinds, Burghen, & Pritchard, 2007; Nuss, Hinds, & LaFond, 2005; Thompson, McClement, & Daeninck, 2006). In addition, other gaps identified in the literature such as larger and more diverse samples, inclusion of the child in research, prospective designs, longitudinal designs, and intervention research still need to be addressed (Nuss, Hinds, & LaFond, 2005; Montgomery et al., 2013; Pritchard & Davies, 2002). Although this study did not directly target these issues, it did address the recommendation to better understand the impact of nurse experience on communication in PC/EOL, specifically those who had worked in pediatric oncology for 5 years or more.

Advancing the State of the Science

A variety of methodological approaches and study designs can be used to move the state of the science forward by contributing to our understanding of nurse communication in the context of PC and EOL. Regardless of the approach, pediatric PC/EOL researchers would benefit from collaborations across institutions to promote adequate sample sizes and achieve diversity across patient and nurse populations. Research cooperatives provide a useful platform for conducting multi-site research. Table 5 describes (a) research methods, (b) their general indication for use, (c) suggested

PC/EOL topics that may benefit from the method, and (d) gaps that the method can address. The aims of the qualitative and the quantitative methods are different; qualitative approaches seek understanding, interpretation, and meaning, while quantitative methods seek causal explanation, prediction, and control (Munhall, 2007). Both approaches can support researchers to advance the state of the science.

Qualitative methods may be useful when data is limited and there is a need for more in depth understanding of particular phenomena. Examples of such phenomena include people who are experiencing a rare disease like a pediatric cancer, and currently encounter care trajectories like EOL that few experience (Akard et al., 2013). In the absence of a strong knowledge foundation for the phenomenon of nurse communication during PC/EOL, there is good reason to support approaches that seek to understand what it means to communicate with children and families during PC/EOL before an attempt is made to measure it. Qualitative research may provide a valuable and often underused approach for strengthening the knowledge base in PC through capturing the experiences of patients, families, and HCPs (Steinhauser & Barroso, 2009). Furthermore, qualitative research is the rigorous attempt to produce findings by describing and interpreting patterns, and is a good fit for naturalistic inquiry and for studying complex and natural phenomena (Chenail, 2011). Qualitative study designs rely on purposive sampling with the goal of obtaining information representative of underlying but previously unobserved concepts, theories, or principles (Steinhauser & Barroso, 2009). Qualitative approaches may provide a good fit with the current needs of the phenomenon of nurse communication during PC/EOL.

The use of descriptive designs and surveys to describe factors associated with PC/EOL care or communication dominates the research foundation. Descriptive study designs have been helpful in identifying frequency of facilitators and barriers to care or communication, but have shown to have high variability across sample characteristics and instruments. Limited availability of valid and reliable tools is one reason for the wide variation, leading each team of researchers to determine its own factors to describe. Examples of topics with such variation include impact of PC/EOL training on nurse or HCP knowledge and comfort to communicate effectively during EOL, barriers and facilitators to communication, access to PC or hospice service, and job satisfaction. In order to address gaps in descriptive designs, the focus should shift to the development of instruments and PC/EOL models.

Experimental and quasi-experimental designs are the priority for researchers to evaluate potential PC/EOL communication interventions. Descriptive qualitative or quantitative studies have identified important needs, barriers, and potential useful communication strategies. However, there have been no interventions to enhance nurse communication based on this data. This gap is somewhat expected due to the relatively small research base for the phenomenon. However, there may be novel approaches to intervention development outside of the quantitative realm. Qualitative methodologies can be useful to advance the state of the science of pediatric PC and EOL in a variety of ways, including the development of intervention research (Akard et al., 2013). Akard et al. (2013) used qualitative findings to develop a legacy-making intervention for pediatric oncology patients. The authors found qualitative findings provided preliminary data in support of an intervention's efficacy, contributed to further refinement of an intervention,

informed researchers on the feasibility of participant retention, and suggested outcomes (Akard et al., 2013). Furthermore, qualitative methods may provide valuable insight to the experience of a particular intervention. A similar approach may provide researchers a targeted and non-traditional path toward intervention development for nurse communication.

PC/EOL researchers should prioritize the impact of PC/EOL care on bereaved family member outcomes. There is limited literature in pediatrics that describes the health-related effects (e.g. depression and anxiety) of bereaved family members in pediatrics. Furthermore, very few researchers have evaluated the connections between family satisfaction with EOL and health care utilization and costs of care for family members after the death of a patient. Future research must consider phenomena that occur after death when developing a comprehensive model in order to advance the state of the science and develop policy to enhance the quality of PC/EOL care.

Policy

Issues associated with quality communication in pediatric PC and EOL care are multidimensional, requiring approaches targeted at local and national levels. Communication is a central tenet of PC and EOL care; thus it is necessary to outline policy implications that impact PC and EOL care broadly. Gaps in PC and EOL care can be addressed through increasing access to PC and EOL services for pediatric patients, enhancing educational and training standards for HCPs, improving the overall quality of care delivered through the EOL trajectory, and increasing funding to research with a PC or EOL focus. These approaches can be strengthened through policy development.

Access to Services

In contrast to care for adults, hospice and PC services for pediatric patients remain limited. Hospice and PC programs and practices have become established in the adult medical care communities. In response to practices for adults, there is a new emphasis on identifying and overcoming barriers to EOL care in children (Fowler et al., 2006).

However, as discussed previously, access to PC and hospice services is inconsistent for pediatric patients, and for children with cancer there is no guarantee they will receive such services. Access to hospice or PC through local hospice services is most available to pediatric oncologists for referrals. However, there is limited access to PC teams and inpatient hospice units within the hospital settings for pediatric patients (Fowler et al., 2006; Hilden et al., 2001)

Despite a push from the American Academy of Pediatrics to integrate PC earlier in the care for children with life-limiting illnesses, Fowler et al. (2006) found that some pediatric oncology patients are referred late in the disease trajectory. Barriers for obtaining hospice referrals include restriction to services for pediatric patients and for patients who benefit from continued therapy for purposes of palliation (e.g. chemotherapy). Limitations on hospice requirements for pediatrics are partly due to the structure of Medicare. The Medicare model was used to create most hospice benefits and was designed for adult cancer patients who were not expected to live longer than 6 months. Additionally, some hospices do not offer supportive therapies during the hospice care period, including blood transfusions and nutrition support (Fowler et al., 2006). Supportive and palliative disease-specific therapies are critical to a child's quality of life during EOL. It is important to consistently provide access to PC services to children with

life-limiting illnesses in response to the need to provide a consistent HCP that can support and evaluate the child and family as a cohesive unit (Voyles, 2013).

Policy strategies may enhance utilization of PC and EOL services. Examples of strategies include providing (a) financial incentives to HCPs to train in and provide PC and EOL care through loan forgiveness and competitive wages, (b) financial incentives to health care institutions that provide PC/EOL services and support penalties for those that do not, and (c) reimbursement by insurers to HCPs for time spent informing and counseling children and parents regarding their diagnosis, prognosis, options for care, and EOL decision-making (Field & Behrman, 2003; Meier, 2009).

Over the past few years, Massachusetts implemented an exclusively state-funded, community-based pediatric PC program, with the aim to increase access to effective communication through PC services in the response to the previously restrictive eligibility criteria (Bona, Bates, & Wolfe, 2011). Massachusetts was the first state to take on such an endeavor, adopting a new law that would open up funding to support PC services for children with life-limiting conditions. As part of the overall program, the state revised eligibility criteria for the PC program, making it less restrictive, expanded the availability of types of services included in the program, and made initial steps to collect data related to enrollment, service utilization, cost, family satisfaction, and HCP satisfaction (Bona et al., 2011). Despite specific information related to data collection methods, the state program has seen high variability in costs due to changes in PC and hospice enrollment, positive family satisfaction ratings, and constructive HCP feedback identifying facilitators and challenges of program implementation (Bona et al., 2011). Massachusetts provides an initial model, with strategies that have shown to be successful

and others that need modification, to support planning and implementation at the national level.

In addition to enhancing access to PC services for pediatric patients and HCPs, the structure and care elements of those services can be influenced by policy. Formal PC services provide a vehicle to address current and future standards published by professional and accreditation organizations. An example of a standard put forth by the National Consensus Project for Quality Palliative Care (2013) include the documentation of a comprehensive care plan that acknowledges the patient's priorities in goals of care. It is the responsibility of the local health care setting to implement processes to establish compliance with the standard. Health care administrators can support implementation of key processes through the allocation of personnel and resources. Health care administrators are incentivized to improve their organization's reliability with a standard when entities include those standards in the criteria for national rankings. The reputation of the health care organization is critical to the financial well being of that particular institution, and can be influenced by compliance with professional and accreditation standards. Linking PC/EOL standards to national rankings, in addition to outcomes of quality care may be a useful strategy to improve PC/EOL delivery to all patients at EOL.

Education and Training Requirements

Broad approaches to improving communication in PC/EOL services include child, family, and HCP education, training, and research (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009). From a child and family perspective, interventions aimed at enhancing decision-making in children should identify the child's values, goals, hopes, and fears that may influence communication and the decision-making process at EOL in a way

modeled after the advanced care planning process in adults (Barfield et al., 2010).

Education regarding effective strategies that optimize documentation of EOL discussions is needed. From a HCP perspective, in order to apply what is known about PC/EOL communication to improve clinical practice, trained multidisciplinary champions are helpful to increase awareness and role model best practices (Grant et al., 2009). Examples of programs that support application of effective communication and PC principles include End of Life Nursing Education Consortium, Education for Physicians on End of Life Care Curriculum, Center to Advance Palliative Care, and Advocating for Clinical Excellence: Transdisciplinary Palliative Care Education. These national educational and training programs provide an established structure for delivering education and disseminating best practices to clinicians.

Studies have shown that many pediatric oncologists lack formal training in EOL communication and care (Fowler et al., 2006; Hilden et al., 2001). Fowler et al. (2006) found that despite a lack of formal training, oncologists felt comfortable dealing with EOL issues, like managing pain and psychosocial issues. In contrast, Hilden et al. (2001) reported an increase in formal training and experience was significantly associated with increased comfort level in oncologists. In response to these gaps, policy can guide plans to develop and implement PC and EOL training standards. Minimum standards for education or training and practice are necessary to engage oncologists and other HCPs, develop communication and care competency, and maintain skills over time. Oncology professional organizations (medicine and nursing) should be responsible for developing such standards, while practice settings (e.g. hospitals, home care agencies, etc.) and educational institutions should be responsible for implementing the standards. Incentives

for adhering to PC and EOL training standards may include financial reimbursement for PC and EOL services, preference for PC- and EOL-related funding, and higher quality marks for a particular practice setting or educational institution.

Barriers that further hinder access to PC/EOL services include limited availability of trained HCPs and services, and the philosophy of curative-focused care delivery that dominates the US health care system (Grant et al., 2009). In response to potential barriers, health care institutions need to engage in activities that may influence and evolve their culture of care delivery. Examples of activities may include presentations in hospital and non-hospital settings, journal clubs, ethics rounds, morbidity and mortality case reviews, and establishment of intentional partnership with community stakeholders.

Funding for Research

A challenge for providing support and implementation of innovative policies that improve access and quality of PC and EOL communication and services is the lack of evidence for the specialty (Grant et al., 2009). Research focused on evaluating PC and EOL programs is a priority. Without critical evidence guiding specific components of PC and EOL programs and the outcomes associated with individual components and the overall program, the advancement of care for children with life-limiting conditions will remain stagnant. Research that is needed to expand the body of evidence includes: decision-making approaches about treatment and EOL care options, communication on sensitive topics, support for parents and family members, models of care delivery, and symptom management (Grant et al., 2009).

There is a clear need for quality indicators across hospital settings in order to nationally benchmark PC and EOL communication and care. Current literature reflects a

high degree of variability in the type of interventions and patterns of care during EOL. Hinds, Pritchard and Harper (2004) write that, “Methods for conducting a cost-effective analysis of EOL care need to be developed and then used as part of the overall assessment of innovative care programs, thus allowing both the effectiveness and the cost of EOL treatments to be documented”. In order to achieve such work, the desired outcome of quality EOL care (e.g. effective communication, good death, peaceful death, family satisfaction) must be defined and operationalized with valid and reliable measures to describe the aspects of EOL that lead to improved patient and family outcomes.

Conclusion

Communication during PC and EOL intimately involves the patient, family, and health care professionals, and is essential to successful navigation through the EOL continuum. Health care professionals are obligated to navigate children and their families through the EOL process and facilitate care at EOL. This study enhances our understanding of experienced pediatric oncology nurses’ perspectives communicating and caring for children and families during PC/EOL, including facilitators and challenges to communicating throughout the EOL trajectory. Improving communication skills at EOL in pediatric oncology nurses requires a variety of clinical strategies, which may include standardized EOL curricula, simulation, competency-based orientation programs, mentorship and peer support, and reflection. More research is needed on PC/EOL educational interventions and the outcomes associated with strategies aimed at improving nurse communication skills at EOL in pediatric oncology.

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Figure 1

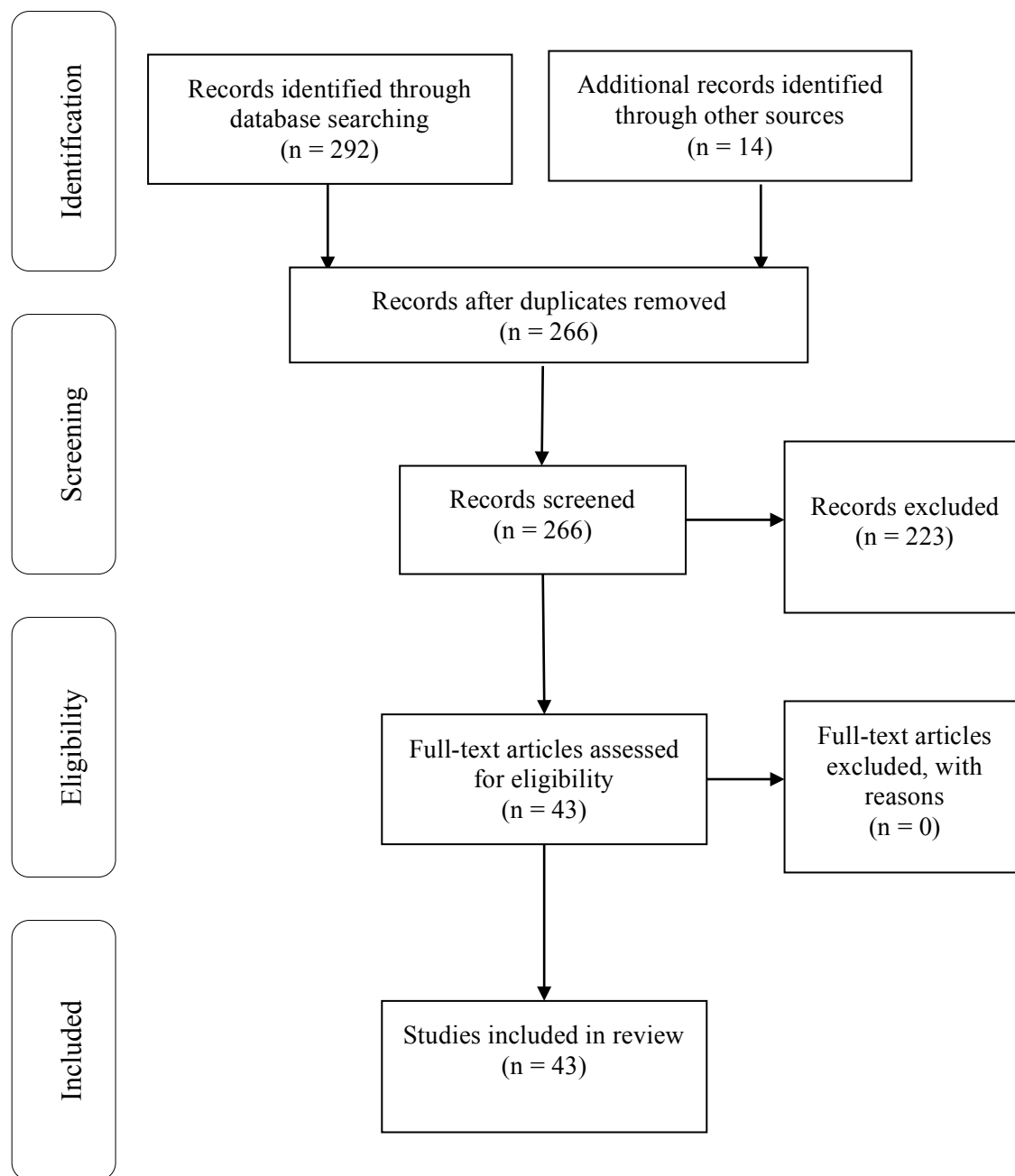
Summary of Literature Search for Child and Parent Experiences during End of Life

Figure 2

Summary of Literature Search for Nurse Communication during Palliative Care and End of Life

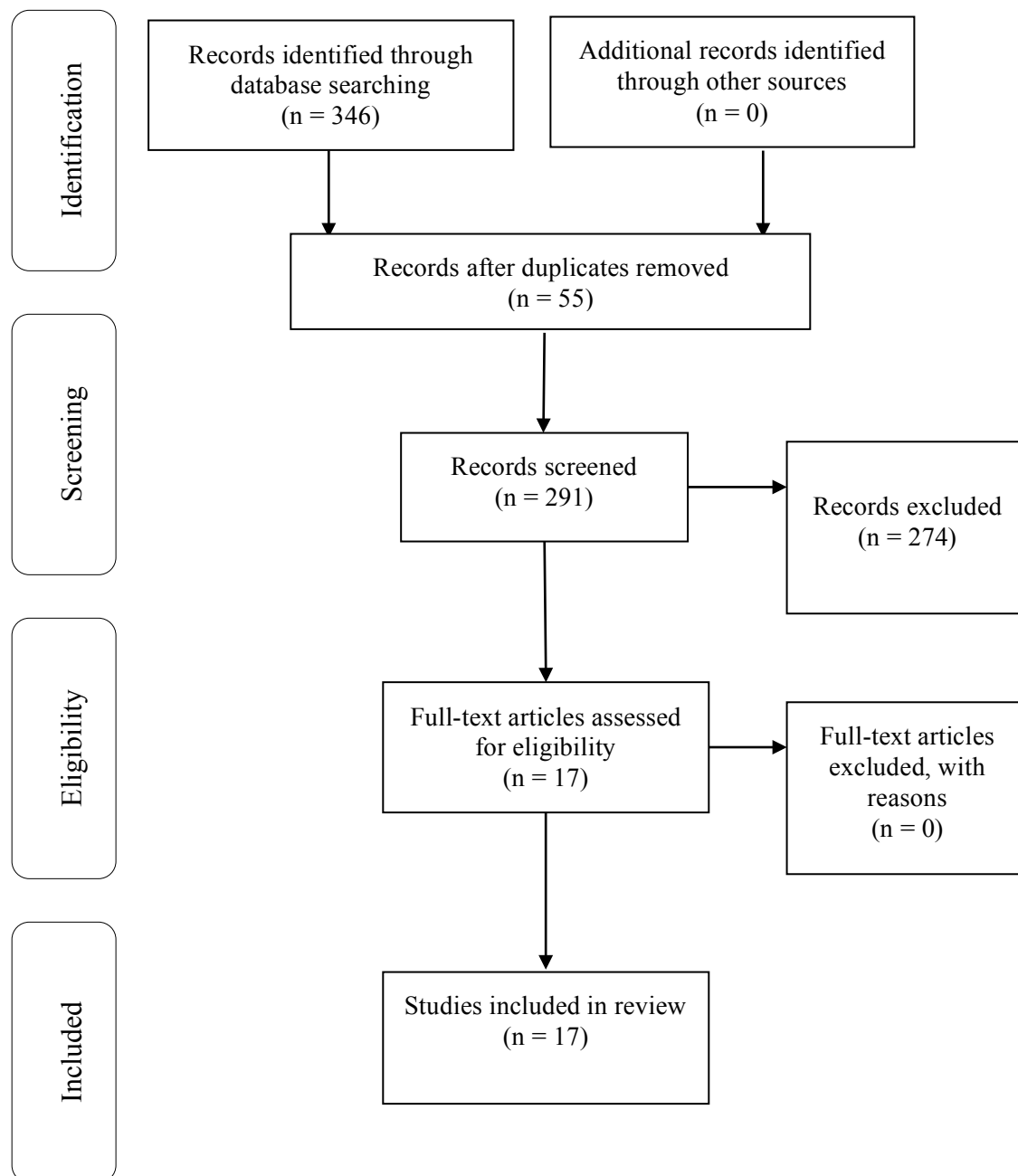


Table 1

Components of Pediatric Palliative Care and End of Life

Type of Care	Components	Outcomes
Pediatric Palliative Care	<ul style="list-style-type: none"> • Information and support with decision-making • Detailed symptom assessment and monitoring • Helping children and families with practical needs • Spiritual and psychosocial support for children and families • Planning the site of ongoing and future care • Ensuring smooth transitions across the continuum of care 	<ul style="list-style-type: none"> • Detection of symptoms • Symptom management • Number of allied health consultations • Timing and Frequency of documentation related to PC/EOL and advance care planning
End of Life	<ul style="list-style-type: none"> • All of the components of palliative care • Advance care planning • Information about the dying process • Support through the dying process • Help anticipating the nature and site of death • Planning for arrangements after death 	<ul style="list-style-type: none"> • All of the outcomes of palliative care • Parental ratings of care • Parental grief and depression • Decision-making • Clinician-patient interaction

Note. Reproduced with permission from Himmelstein et al. (2004). Pediatric palliative care. *New England Journal of Medicine*, 350, 1754. Copyright Massachusetts Medical Society.

Table 2

Summary of Evidence for Patient and Parent Experiences during End of Life

Author (Year)	Sample	Limitations	Conclusions
<i>Symptom Prevalence and Symptom Management</i>			
Angelescu et al. 2012 QT	3 pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Retrospective chart review 	<ul style="list-style-type: none"> • Propofol sedation was found to alleviate anxiety and agitation even when pain could not be adequately controlled. • Opioids dose was reduced in 1 patient and had no or minimal change in 2 patients. • Patients received propofol between 2-8 d
Angelescu et al. 2010 QT	10 pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Retrospective chart review 	<ul style="list-style-type: none"> • Length of epidural use (4-57d) and peripheral nerve block use (3-81d) • 12 of 13 (93%) pain blocks (93%) improved pain control reflected in change in mean pain score.
Heath et al. 2010 QT	100 parents of 96 pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Australia • Single-site • Retrospective design 	<ul style="list-style-type: none"> • Patients who received cancer-directed therapy during EOL significantly suffered from more symptoms than those who did not receive therapy. • Severity of symptoms did not differ from those who received cancer-directed therapy than those who did not. • Symptoms most frequently reported: pain, fatigue, and poor appetite. • 84% of parents reported their child a lot or great deal of suffering from at least 1 symptom (43% from 3 or more). • Most commonly treated symptoms: pain (95%), constipation (74%), nausea/vomiting (70%).
Pritchard et al. 2010 MX	52 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Secondary data analysis • Did not ask parents regarding symptoms of no concerns • Small sample size • Retrospective design 	<ul style="list-style-type: none"> • Symptoms of most concern: change in behavior (23.62%) change in breathing (16.01%), pain (16.01%), difficulty swallowing (2.34%), weakness/fatigue (5.47%), and vomiting (4.5%). • Factors influencing level of most concern include: unrelieved parental or child distress (39.85%), new or unexpected symptom (39.45%), and behavioral and emotional change (10.35%). • Factors influencing no concerns: symptoms present for at least 1 week (33.94%), symptoms that cause no distress (12.84%), symptoms that were well managed (8.26%).
Zhukovsky et al. 2009	15 pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Retrospective chart 	<ul style="list-style-type: none"> • Median number of documented symptoms at point of consultation was 5 per child (range = 2-10).

Author (Year)	Sample	Limitations	Conclusions
QT		review	<ul style="list-style-type: none"> • PC consultation universally resulted in detection of symptoms not identified by the primary HCP team (median = 3 new symptoms per patient). • Documented communication about EOL care issues with parents was uncommon and rarely involved children. • PC consultation resulted in recommendations for medication changes in 14 out of 15 children; allied health consultation in 8; counseling in 11; patient care conference in 3; family conference in 6.
Orsey et al. 2009 QT	1,466 pediatric oncology patients	<ul style="list-style-type: none"> • Retrospective chart review 	<ul style="list-style-type: none"> • 56% of sample were prescribed opioids daily and 44% received less than daily opioids in last week of life • Patient-level characteristics that increased likelihood of receiving daily opioids: age, broad category of cancer diagnosis, and length of hospital stay • Hospital-level characteristics accounted for variation in daily opioid prescription during last week of life.
Conway et al. 2009 QT	2 pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site 	<ul style="list-style-type: none"> • Decrease in rate of opioid dosage increased with pain plan. • Decrease in opioid related side effects with pain plan.
Hendricks-Ferguson 2008 QL	28 patients of pediatric oncology patients	<ul style="list-style-type: none"> • Single-site • Retrospective design 	<ul style="list-style-type: none"> • Symptoms of greatest concern on day of death: changes in breathing (57%), loss of motor function (32%), changes in energy level (29%). • Symptoms of greatest concern during last week of life: loss of motor function (36%), changes in energy level (36%), changes in breathing (32%) • Symptom relief strategies: physical comfort activities (54%), medications (50%), preventive actions for physical symptoms (39%), physical closeness (39%); physical presence (39%).
Pritchard et al. 2008 MX	65 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Retrospective design 	<ul style="list-style-type: none"> • Most frequently reported symptoms at EOL included: changes in behavior (53.8%), changes in appearance (28.8%), pain (67%), weakness/fatigue (21.2%), and breathing changes (28.8%). • Most helpful interventions by HCPs: pain and anxiety medications (31.3%), being present with the child/family (10.0%), providing competent care (12.5%), and giving anticipatory guidance (6.3%).

Author (Year)	Sample	Limitations	Conclusions
Schiessl et al. 2008 QT	8 pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Germany • Small sample size • Single-site • Retrospective design 	<ul style="list-style-type: none"> • Daily opioid IV dose increased by 30% during the last week of life. • Pain scores did not change significantly during PCA therapy despite escalating doses of opioids.
Hooke et al. 2007 QT	9 pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site 	<ul style="list-style-type: none"> • Propofol administered IV improved quality of life at EOL.
Theunissen et al. 2007 QT	59 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Netherlands • Small sample size • Single-site • Retrospective design 	<ul style="list-style-type: none"> • Mean number of symptoms during EOL was 6.3 (SD 2.7). • Most frequently reported physical symptoms: pain (75%), poor appetite (75%), fatigue (72%), lack of mobility (66%), vomiting (53%). • Most frequently reported psychological symptoms: sadness (65%), difficulty talking about feelings (41%), fear to be alone (37%), loss of perspective (36%). • No statistical difference in number of symptoms between tumor types.
Jalmsell et al. 2006 QT	449 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Sweden • Retrospective design 	<ul style="list-style-type: none"> • Most frequently reported symptoms with high or moderate impact on child: fatigue (86%), reduced mobility (76%), pain (73%), poor appetite (71%). • No statistical difference in most reported symptoms between tumor types.
Hongo et al. 2003 QT	28 pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Hong Kong and Greece • Small convenience sample • Retrospective chart review 	<ul style="list-style-type: none"> • Signs and symptoms most experienced at EOL: poor appetite (100%), dyspnea (82.1%), pain (75%), fatigue (71.4%), nausea/vomiting (57.1%), anxiety 53.6%).
Collins et al. 2000 QT	160 pediatric oncology patients	<ul style="list-style-type: none"> • Instrument only validated for this study 	<ul style="list-style-type: none"> • Pain was the most prevalent symptom for inpatient group (84.5%) and was rated moderate to severe by 86.8% and highly distressing by 52.8% of patients. • Inpatients experienced significantly greater number of symptoms compared to outpatients (mean=12.7; 6.5). • Patients who had recently received chemotherapy significantly experienced more symptoms (mean=11.6).
Wolfe et al.	103 parents	<ul style="list-style-type: none"> • Small sample size 	<ul style="list-style-type: none"> • Most frequently reported symptoms:

Author (Year)	Sample	Limitations	Conclusions
2000 QT	of pediatric oncology patients	<ul style="list-style-type: none"> • Single-site • Retrospective design 	<ul style="list-style-type: none"> • fatigue, pain, dyspnea, poor appetite. • 89% of parents reported their child a lot or great deal of suffering from at least 1 symptom (51% with 3 or more). • Most frequently treated symptoms: pain (76%), dyspnea (65%) – successful treatment in <30% of children. • Lack of involvement of an oncologist was associated with significantly more suffering from pain (OR = 2.6; CI 1.0-6.7).
<i>Parent and Child Perspectives of Care</i>			
Kars et al. 2011 QL	44 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Netherlands • Small sample size 	<ul style="list-style-type: none"> • Feelings of loss play a prominent role during EOL. • Dealing with loss is reflected as an internal struggle between preservation and letting go. • Preservation is characterized as parents trying to maintain the child's status quo. • Letting go means parents give up their resistance to loss in order for their child's well-being. • Timely completion of parent transition positively influences the child's well-being.
Kars et al. 2011 QL	42 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Netherlands • Did not collect concurrent data 	<ul style="list-style-type: none"> • 4 EOL stages were identified: <ul style="list-style-type: none"> ○ Becoming aware of the inevitable death. ○ Making the child's life enjoyable. ○ Managing the change for the worse. ○ Being with the dying child. • Nurses may play a role in helping parents during EOL.
Zelcer et al. 2010 QL	25 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Canada • Limited to children with brain tumors • Small sample size • Single-site 	<ul style="list-style-type: none"> • 3 Themes described the EOL experience: <ul style="list-style-type: none"> ○ Dying trajectory. ○ Parental struggles. ○ Dying at home. • Neurologic symptoms are most experienced during EOL. • Loss of communication was a significant turning point in the dying trajectory. • Maintaining normalcy and spiritual strength were reported coping mechanisms.
Heath et al. 2009 MX	96 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Single-site • Small sample size • Retrospective design 	<ul style="list-style-type: none"> • Parents were most satisfied when they received care from the primary care team (oncologists, RNs, etc.). • Majority of parents recalled discussions about transition to PC and home. • 21% recalled formal discussions about life-sustaining treatments.

Author (Year)	Sample	Limitations	Conclusions
			<ul style="list-style-type: none"> • 70% felt they rarely received conflicting information from HCPs. • High ratings of care were significantly associated with parental perceptions that HCPs gave bad news in a sensitive manner; gave clear information about what to expect at EOL; provided feeling of pre-preparedness for medical problems at EOL; communicated directly with the child. • Low ratings were significantly associated with parental perceptions of receiving conflicting information.
Hendricks-Ferguson 2007 QL	28 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Single-site • Small sample size • Retrospective design 	<ul style="list-style-type: none"> • EOL options presented to parents ranged from 2d-9m before death, majority received EOL information <2 months before death. • 96% of parents reported EOL options being shared spontaneously late in the dying trajectory • Parents' memories of HCP communication regarding EOL: <ul style="list-style-type: none"> ○ Positive memories (17%) ○ Negative memories (50%) ○ Discussion of EOL during therapy (17%) ○ No memory of EOL discussions (14%) • Parents' preferences for timing of EOL support: <ul style="list-style-type: none"> ○ Early introduction (43%) ○ When treatments have failed (39%) ○ No recommendation (18%)
Mack et al. 2005 QT	142 parents of pediatric oncology patients 144 pediatric oncology patients	<ul style="list-style-type: none"> • Sample not representative of adolescent and young adult populations • Lack of information on reliability and validity for surveys • Lack of control for multiple site variation 	<ul style="list-style-type: none"> • Physicians' ratings of care were significantly inversely correlated with parent's report of child's experience of pain (OR = 0.15) and >10 hospital days at end of life (OR = 0.24). • Higher parent ratings of physician care were significantly associated with receiving anticipatory guidance for end of life (OR = 19.90), communicating with care/sensitivity (OR = 7.67), communicating with child (OR = 11.18), and preparing parent for child's death (OR = 4.84).
Contro et al. 2002 QL	68 family members of pediatric patients	<ul style="list-style-type: none"> • Small sample size • Single site • Lack of valid and reliable instruments 	<ul style="list-style-type: none"> • Unsatisfactory interactions with HCPs were identified as: confusing, inadequate, or uncaring communications regarding treatment or prognosis.

Author (Year)	Sample	Limitations	Conclusions
Arland et al. 2013 QT	133 pediatric oncology patients Cohort 1: 22 patients (No EOL care program) Cohort 2: 93 patients (EOL care program)	<ul style="list-style-type: none"> • Single site • Retrospective chart review • Limited to children with brain tumors • Limited information on the fidelity of the EOL care program 	<ul style="list-style-type: none"> • Cohort 1 experienced higher number of admissions, poor symptom control • Cohort 2 experienced less complications • No impact of the EOL care program on death occurring in a hospital setting.
Yanai et al. 2012 QT	18 pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Japan • Small sample size • Single-site • Retrospective chart review 	<ul style="list-style-type: none"> • All patients who died in the ICU (n = 6) received aggressive treatments. • Preferred location of death: home (n = 4), hospital (n = 2), no preference (n=1), not assessed (n = 11). • Place of death was significantly associated with preference of family (home v. hospital v. none) • Patients with hematological disease all died in a hospital setting, with a majority dying in the ICU.
Tzuh Tang et al. 2011 QT	1,208 pediatric oncology patients	<ul style="list-style-type: none"> • Study location – Taiwan • Retrospective chart review 	<ul style="list-style-type: none"> • 78.8% died in acute care hospital setting. • 52.5% received chemotherapy in last month of life; 14.3% visited the ER more than once; 32.5% were admitted to the hospital more than once; 60.2% had a LOS greater than 14 days; 57.0% received care in the ICU in the last month of life; 48.2% were mechanically ventilated; 24.0% received CPR in the last month of life; only 7.2% of patients received hospice care.
Shah et al. 2011 QT	1,864 pediatric oncology patients	<ul style="list-style-type: none"> • Study location – England • Retrospective chart review 	<ul style="list-style-type: none"> • 47% died in the hospital, 45% died at home. • No associations between location of death and gender or participation in clinical trials. • Children with leukemia or lymphoma were more likely to die in the hospital compared to solid tumors. • 70% of Asian and Black children died in the hospital; 42% of Caucasian children in the hospital.
Bell et al. 2010 QT	107 pediatric oncology	<ul style="list-style-type: none"> • Single-site • Only recorded MD initiated EOL 	<ul style="list-style-type: none"> • 58 adolescents died in a hospital; 16 died at home (missing data for 29). • Half of hospital deaths occurred in the ICU

Author (Year)	Sample	Limitations	Conclusions
	patients	discussions (not APN RN, etc.) <ul style="list-style-type: none"> • Small sample size • Retrospective chart review 	and of those, most deaths were significantly attributed to treatment-related complications. <ul style="list-style-type: none"> • Aggressive life-sustaining measures occurred in 12% of adolescents • 68% had initial EOL discussions with their oncologist; 50% occurred in the last 30 days of life.
Ullrich et al. 2010 QT	141 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Retrospective chart review 	<ul style="list-style-type: none"> • The HPCT group significantly spent more days in the hospital in the last month of life, were more likely to be intubated in the last 24 hours of life, to die in the ICU, and less likely to have a planned location of death or have hospice involved compared to the non-HPCT group. • The most experienced symptoms at EOL for both groups included: pain, anorexia, fatigue, nausea/vomiting, dyspnea, and fever or infection.
Dussel et al. 2009 QT	140 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Retrospective chart review 	<ul style="list-style-type: none"> • 62% of parents were able to plan their child's location of death. • Planning was significantly less likely among children with hematological cancers compared to other diagnoses. • Dying from disease progression v. treatment toxicity was significantly associated with likelihood of planning location of death. • Parents who had experienced a previous loss were significantly more likely to plan location of death. • Parents who reported they strongly agreed that physicians communicated about EOL options were significantly more likely to plan location of death. • 97% of parents who planned their child's location of death reported the child died in that location. • Parents who planned location of death felt significantly more prepared for medical circumstances around the time of death and being very comfortable compared to parents who did not.
Wolfe et al. 2008 QT	119 pediatric oncology patients Baseline cohort: 102 pediatric	<ul style="list-style-type: none"> • Single-site • Small sample size • Lacked RCT design for interventions • Retrospective design • Selection bias 	<ul style="list-style-type: none"> • Hospice discussions significantly occurred more often (76% v 54%) and earlier (52 days v 28 days before death) compared to baseline cohort. • DNR orders were documented earlier (18d v 12d). • Deaths in ICUs decreased significantly. • Parents significantly reported less child

Author (Year)	Sample	Limitations	Conclusions
	oncology patients		suffering from pain and dyspnea. <ul style="list-style-type: none"> Parents felt significantly more prepared during the child's last month of life.
Bradshaw et al. 2005 QT	145 pediatric oncology patients	<ul style="list-style-type: none"> Single site Small sample size Retrospective design 	<ul style="list-style-type: none"> 45.5% of deaths occurred in the hospital; 30.3% occurred in the home. Patients whose deaths were attributed to cardiopulmonary or cardiovascular events (73.5%) or infection (77.8%) were twice as likely to die in the hospital than those with progressive disease (36.8%). BMT patients and leukemia patients were more likely to die from complications. Patients with brain tumors were more likely to die at home. DNR order was present in 48.3% of cases, and completed a median of 11 d before death (range, 0-409 d). 73.9% of BMT patients had a documented DNR in their records.
Kurashima et al. 2005 QT	71 pediatric oncology patients	<ul style="list-style-type: none"> Study location – Brazil Single site Small sample size Retrospective design 	<ul style="list-style-type: none"> 59% of patients died at home. Male gender and public insurance were significantly associated with dying at home (gender: OR = 3.8; public insurance: OR = 4.9) No associations between location of death and race, family composition, educational background of patient or father, or religion. Mothers or children with a home care provider who had higher levels of education were likely to have a child who died at home.
Klopfenstein et al. 2001 QT	95 pediatric oncology patients	<ul style="list-style-type: none"> Small sample size Retrospective chart review 	<ul style="list-style-type: none"> 10% of sample died with full ICU support. 35% of total sample received hospice support. The following factors had significant correlation with disease-related death: referral to hospice, diagnosis, inpatient setting, and support being withdrawn.

Decision-Making

Tomlinson et al. 2011 QT	26 parents of pediatric oncology patients	<ul style="list-style-type: none"> Study location – Canada Single-site Small sample size Asked parents about potential scenario of choosing between chemotherapy or supportive care alone. 	<ul style="list-style-type: none"> Variable correlation among parents in the importance of factors in contributing to cancer-directed therapy v. supportive care. Greatest agreement between couple was observed for: physical health (ICC = 0.4, p = 0.022), pain (ICC = 0.46, p = 0.068), nausea (ICC = 0.61, p = 0.017), fatigue (ICC = 0.50, p = 0.047). Other family members' quality of life was the strongest correlating factor to influence parents' decision for chemotherapy or
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Author (Year)	Sample	Limitations	Conclusions
			supportive care alone ($r = 0.68$, $p = 0.11$).
Maurer et al. 2010 QL	62 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Single-site • Small sample size 	<ul style="list-style-type: none"> • 31 parents chose Phase I therapy; 27 chose DNR or terminal care • Phase I parents: felt compelled to continue cancer-directed therapy • DNR/Terminal care parents: desired increased QOL and patient wishes • Common decision factors: medical facts, doing right, opinion of others • Common themes of good parent: doing right, providing support and presence, and sacrifice for the child.
Hinds et al. 2009 QL	62 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Single-site • Lacked equal distribution of parents across treatment decisions 	<ul style="list-style-type: none"> • Aspects of the definition of being a good parent included: making informed, unselfish decisions in the child's best interest; remaining on the child's side; showing the child they are cherished; teaching the child to make good decisions; advocating for the child with HCP staff; and promoting the child's health • Clinician strategies represent 3 categories: strategies that parents benefit from and what continued, strategies parents want increased; and strategies parents want initiated • 4 clinician behaviors that support being a good parent: HCPs telling parents they are "good parents", not forgetting the child and family once the child has died, providing more material items and support options, and coordinated care at EOL.
Edwards et al. 2008 QT	38 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Retrospective design • Single-site • Small sample size 	<ul style="list-style-type: none"> • Majority of mothers and fathers reported less suffering as the primary goal for their child at EOL. • When parents disagreed on the primary goal of lessening suffering, both parents were more likely to report that the child suffered significantly from cancer-directed treatment.
Pousset et al. 2009 MX	38 pediatric oncology patients	<ul style="list-style-type: none"> • Small sample size • Study location – Belgium • Single-site • Retrospective self-report 	<ul style="list-style-type: none"> • In terminal situations it was more acceptable for adolescents to request for non-treatment decisions (90%) alleviation of symptoms (84%), and euthanasia (64%) compared to adolescents without a cancer diagnosis. • In non-terminal situations, all three types of decisions were significantly less acceptable.
Hinds et al.	20 pediatric	<ul style="list-style-type: none"> • Small sample size 	<ul style="list-style-type: none"> • 90% of children accurately recalled all of

Author (Year)	Sample	Limitations	Conclusions
2005 QL	oncology patients 19 parents of pediatric oncology patients	<ul style="list-style-type: none"> Self-report 	<p>their treatment options and identified their own death as a consequence of their decision.</p> <ul style="list-style-type: none"> Factors most frequently identified included: (patients) caring about others (95%), avoiding adverse events (70%), wanting no more therapy (65%), (parents) child's preferences (94.7%), trusting staff and being supported by them (84.2%), deciding as a good parent would do (84.2%).
<i>Parent and Child Outcomes of Care</i>			
McCarthy et al. 2010 QT	58 parents of pediatric oncology patients	<ul style="list-style-type: none"> Retrospective design Small sample size Single-site Cross-sectional design 	<ul style="list-style-type: none"> 41% of parents met diagnostic criteria for grief-related separation distress. 22% had clinically significant depressive symptoms. Time since death and parental perception of oncologist's care significantly predicted parental grief symptoms ($r=-0.35$) but not depressive symptoms ($r=-0.19$). Perceptions of the child's quality of life during the last month ($r=0.43$; $r=0.37$), preparedness for the death ($r=0.33$; $r=0.34$), and perception of oncologist care ($r=0.62$; $r=0.29$) significantly predicted grief and depression outcomes respectively. Total variance for depression was 20.6% ($F=3.96$); with perceptions of child's QOL and preparedness making significant and unique contributions.
Kreicsberg et al. 2005 QT	449 parents pediatric oncology patients	<ul style="list-style-type: none"> Study location – Sweden Retrospective design Lack of information on reliability and validity for questionnaire 	<ul style="list-style-type: none"> 2 most frequent stressors experienced by parents were: pain not relieved (45%) and negligent care of child (46%). 57% of parents who had a child with pain not relieved were still affected by it 4-9 years after the child's death. Lack of staff not present at time of death results in an increased probability of parents reporting that their child had a difficult moment of death ($RR=1.4$, [1.0-1.8]).

Note. QT = quantitative design; QL = qualitative design; MX = mixed methods design.

Table 3

Barriers to Conducting End of Life Research in Pediatrics

Challenges to End of Life Research

- A negative risk/benefit ration as perceived by the institutional review board
 - Parent refusal rates limiting generalizability of findings
 - Timing of research to involve the child while the child is still able to participate
 - Few measures developed and tested in dying children or adolescents
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Note. Reprinted from Seminars in Oncology Nursing, Vol. 21, S. Nuss, P. Hinds, & D. LaFond, Collaborative clinical research on end-of-life care in pediatric oncology, pp. 125-134. Copyright 2005, with permission from Elsevier.

Table 4

Summary of Evidence for Nurse Communication during Palliative Care and End of Life

Author (Year)	Sample	Limitations	Conclusions
<i>Pediatric Oncology</i>			
Papadatou et al. (2001) MX	63 pediatric oncology and critical care nurses	<ul style="list-style-type: none"> • Small sample size • Differences in sample characteristics between Greek and Chinese nurses • Study location – Greece and China • Cross-sectional design 	<ul style="list-style-type: none"> • Nurses experience difficulties in communicating with the child and parent at EOL. • Hong Kong nurses significantly reported greater communication difficulties compared to Greek nurses ($\chi^2=20,431$; $df=1$) • Difficulties were related to interactions with demanding parents, grieving parents, and communicating about the child's prognosis. • Importance of comprehensive, culturally appropriate education with courses in communication skills and interpersonal relations.
Zhukovsky et al. (2009) QT	15 pediatric oncology patients	<ul style="list-style-type: none"> • Retrospective chart review • Small sample size • Single institution study with limited generalizability • Cross-sectional design • Data collection included documented EOL discussions only and may underestimate the total number of actual discussions • PC consultation intervention may be impacted by institution's standard of care 	<ul style="list-style-type: none"> • 3 topics with the most documentation at initial assessment for Primary team and PC team included: (1) prognosis (73%; 60%); (2) resuscitation status (40%; 27%), and (3) DNR decision (40%; 27%). • 4 topics with least amount of documentation included: (1) location of death (7%; 7%); (2) well-being of other siblings (0%; 27%); (3) bereavement care (0%; 0%); and (4) involvement of child (13%; 20%). • PC consultation lead to recommendations for family and patient cares conferences.
<i>Pediatric Critical Care including Oncology</i>			

Beckstrand et al. (2010) QT	474 pediatric critical care nurses	<ul style="list-style-type: none"> • Sample did not account for differences between PICU and NICU nurses • Cross-sectional design 	<ul style="list-style-type: none"> • Language barriers (POM score=17.73) and discontinuity of EOL care for the child due to lack of communication between the interdisciplinary team (POM score=13.49) were commonly cited barriers to providing effective EOL care (POM represents an obstacle's perceived magnitude).
Durall et al. (2012) QT	266 pediatric nurses and physicians	<ul style="list-style-type: none"> • Selection bias • Instrument only evaluated to face-validity and pilot tested • Cross-sectional design 	<ul style="list-style-type: none"> • Most cited barriers to EOL discussions may be related to inadequate communication and included: (1) unrealistic parent expectations (43.5%); (2) difference between clinician and patient/parent understanding of prognosis (39.4%); (3) lack of parent readiness to have discussions (37.8%); (4) clinician concern about taking away hope (28.6%); (5) clinician uncertainty about prognosis (27.0%); (6) and clinicians not knowing the right time to address the issue (25.5%). • Nurses identified lack of importance to clinicians and ethical considerations as barriers significantly more often than physicians. • 71% of clinicians believed that EOL discussions occurred too late in the patient's trajectory.
Lee & Dupree (2008) QL	29 pediatric ICU nurses, physicians, and psychosoci al support personnel	<ul style="list-style-type: none"> • Small sample size • Single institution study with limited generalizability • Sample included a variety of HCPs with varying roles in the care of children at EOL • Cross-sectional design 	<ul style="list-style-type: none"> • 5 major themes included: (1) importance of communication, (2) accommodating others, (3) ambiguity about the use of technology, (4) sadness, and (5) emotional support. • Communication was identified as essential for effective decision-making, acceptance of choices, and emotional closure for nurses. • Communication at EOL was identified as an area requiring improvement and future research.

Meyer et al. (2009) MX	106 critical care pediatric nurses, physicians, and psychosocial personnel	<ul style="list-style-type: none"> • Small sample size • Single institution study with limited generalizability • Sample included a variety of HCPs with varying roles in the care of children at EOL • Selection bias • Intervention study did not include a comparison group • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • 93-98% of participants reported that the 1-day interdisciplinary learning workshop improved their sense of preparation to have difficult conversations, improved communication skills and confidence, and decreased anxiety about difficult conversations. • 4 themes included: (1) identifying one's existing competence, (2) integrating new communication skills and relational capacities, (3) appreciating interdisciplinary collaboration, and (4) valuing learning itself.
Michelson et al. (2011) QL	48 pediatric ICU nurses, physicians, social workers, child life specialists, chaplains, and case managers	<ul style="list-style-type: none"> • Small sample size • Single institution study with limited generalizability • Sample included a variety of HCPs with varying roles in the care of children at EOL • Cross-sectional design 	<ul style="list-style-type: none"> • 4 major topics included: (1) Purpose of family conferences, (2) structure of conferences, (3) challenges to conducting effective conferences, and (4) suggestions for improving conferences. • Family conferences were identified as important in facilitating EOL decision-making and parent-clinician/clinician-clinician communication in a PICU setting. • Challenges to effective communication at family conferences include presence of multiple specialties, balancing messages of hope and realism, and language barriers.
<i>General Pediatrics including Oncology</i>			
Davies et al. (2008) QT	240 pediatric nurses, physicians, and other personnel	<ul style="list-style-type: none"> • Single institution study with limited generalizability • Sample included a variety of HCPs with varying roles in the care of children during PC • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • Most frequently cited barriers to PC included: (1) uncertain prognosis (55%); (2) family's readiness to accept incurable condition (51%); (3) language barriers (47%); and (4) time constraints (47%). • Nurses reported unavailability of ethics committee interfered with optimal care more often than physicians. • Additional barriers stemmed from problems with communication and inadequate education. • Need for more education and mentorship opportunities in PC/EOL to address deficits in knowledge and experience including communication skills.

Feudtner et al. (2007) QT	410 pediatric nurses including critical care, acute care, and emergency	<ul style="list-style-type: none"> • Single institution study with limited generalizability • Lack of valid and reliable instruments (exception HOPE scale) and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • Greater experience in nursing practice and increased hours of PC/EOL education were significantly associated with: (1) increased comfort working with dying children and families ($\beta=0.15$; $\beta=0.34$); (2) decreased levels of difficulty talking about death and dying ($\beta=-0.18$; $\beta=-0.21$); and (3) increased levels of PC competency ($\beta=0.88$; $\beta=1.49$).
Tubbs-Cooley et al. (2011) QT	410 pediatric nurses including critical care, acute care, and emergency department	<ul style="list-style-type: none"> • Part of the sample had limited experience caring for children and their families during PC/EOL • Single institution study with limited generalizability • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • Cluster analysis identified the top 5 goals for PC: (1) Managing pain, (2) maintaining quality of life, (3) improving communication, (4) alleviating psychosocial stress for the patient, and (5) alleviating psychosocial stress for the family. • Cluster analysis identified the top 5 problems with PC: (1) lack of opportunity to debrief after the patient's death, (2) uncertainty about goals of care, (3) team's reluctance to discuss hospice with family, (4) difficulty eliciting DNR status from family, and (5) poor communication between team and family. • Approaches to improve PC/EOL care should occur at a system- and individual-level.
<i>Adult Oncology</i>			
Boyd et al. (2011) QT	31 oncology nurses	<ul style="list-style-type: none"> • Small sample size • Single institution study with limited generalizability • Lack of valid and reliable instruments and use of self-report 	<ul style="list-style-type: none"> • Nurses reported moderate skills (2.3-2.5 on a scale of 1-5) related to caring or patients at EOL and discussing hospice care. • PC index was significantly associated with: (1) nurse experience (0.40); (2) hospice training (0.45); (3) nurse comfort with communication of prognosis (-0.46); and (4) the belief that nurses should be trained in terminal care (0.43).
Emold et al. (2011) QT	39 oncology nurses	<ul style="list-style-type: none"> • Small sample size • Single institution study with limited generalizability • Study location – Israel 	<ul style="list-style-type: none"> • 2 areas with the highest reported self-confidence rating (>85%): (1) assessing patient anxiety and depression; and (2) initiating discussions about patient concerns. • Area with the lowest reported self-confidence rating (<50%) included challenging a patient who denies their illness (30.8%). • Areas with moderate self-reported confidence ratings (50-85%) included: (1) helping a patient with uncertainty (51.3%); (2) exploring a patient's intense feelings (38.5%); and (3) discussing bad news with patients (35.9%).

Helft et al. (2011) QT	394 oncology nurses	<ul style="list-style-type: none"> • Sample reflected nurses who may have more education than nurses represented at a single institution • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • Most cited barriers to prognosis-related communication include: (1) physician discomfort with giving bad news (72%); (2) fear of taking away patients' hope (67%); (3) lack of time (60%); (4) nurse discomfort with giving bad news (46%); (5) nurse uncertainty about role in prognosis-related communication (43%) and (6) cultural (43%). • Nurses reported often not be included in prognosis-related communication between the physician and patient. • Nurses with increased age, experience as a nurse and with patients with cancer, and education related to prognosis-related education were associated with the sense of being well prepared.
Turner et al. (2010) QT	109 oncology nurses, physicians, and allied health staff	<ul style="list-style-type: none"> • Sample included a variety of HCPs with varying roles in the care of adults at EOL • Single institution study with limited generalizability • Study location – England • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • The majority of the sample (51.4%) rated their communication skills as excellent or very good, and the remaining (45.9%) rated their skills as good following a standardized training course. • There were no significant differences between staff who completed the course and those that did not. • Nurses rated their skills significantly higher than physicians. • 6 attitudes regarding communication skills training were significantly different between nurses and physicians, with more disagreement from physicians: (1) mandatory training for cancer and PC professionals; (2) good communication is essential to the job; (3) experienced staff should not need additional training; (4) skills do not need to be taught; (5) professionals should have training in separate groups; and (6) support from manager when dealing with stressful situations.
White et al. (2011) QT	714 oncology nurses	<ul style="list-style-type: none"> • Sample reflected nurses who may have more education than nurses represented at a single institution • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • 3 highest ranked competencies included: (1) symptom management (26%); (2) communication with patients/families about dying (21%); and (3) the meaning of PC (19%). • 25% of nurses did not feel adequately prepared to effectively care for dying patients.

Wilkinson et al. (2002) QT	308 oncology nurses	<ul style="list-style-type: none"> • Single institution study with limited generalizability • Study location – England • Lack of valid and reliable instruments and use of self-report • Cross-sectional design • Intervention did not compare a control group • Did not specifically address communication related to PC/EOL 	<ul style="list-style-type: none"> • Nurses' communication skills related to emotionally difficult issues including, (1) patient's diagnosis/condition, (2) understanding of present illness, and (3) psychosocial assessment significantly improved following communication training.
<i>General Pediatrics and Adults</i>			
Malloy et al. (2010) QT	333 nurses	<ul style="list-style-type: none"> • Sample included a variety of HCPs with varying roles in the care of children at EOL • Selection bias – all nurses attended PC training • Lack of valid and reliable instruments and use of self-report • Cross-sectional design 	<ul style="list-style-type: none"> • 5 highest ranked (1-10 with 10 being most difficult) difficult conversations included: (1) communicating with patients/families from different cultures (4.07); (2) talking to patients after receiving bad news (3.71); (3) talking about PC issues (3.67); (4) talking about spiritual issues (3.61); and (5) advance care planning (3.10). • Nurses with <10 years of experience had greater difficulty with: (1) talking with family about seriously ill patients (mean=4.3); (2) discussing advance care planning (mean=3.5); (3) talking about PC issues (mean=5.3); and (4) talking about hospice with patients/families (mean=3.6). • Narratives reflected nurse satisfaction when they felt they were able to effectively communicate.
<i>Note.</i> QT = quantitative design; QL = qualitative design; MX = mixed methods design.			

Table 5

Research Methods for Advancing the State of Science in Nurse Communication during Palliative Care and End of Life

Method	Indications	Topics	Current Gaps
Qualitative	Development of conceptual or theoretical models Instrument development Enhance understanding of the experience Intervention development	PC model EOL model Communication model Effective communication instrument	Limited models to address PC, EOL, and communication Absence of instruments to measure effective communication, quality of life, and decision-making
Quantitative – Survey and Descriptive	Describe opinions or frequencies related to a specific topic	Barriers and facilitators of communication and care Job satisfaction Knowledge Comfort Symptom clusters Patterns of care Access to services Communication problems	Small sample sizes Samples with mixed HCP roles Limited access to valid and reliable tools
Quantitative – Experimental or Quasi-Experimental	Test hypotheses of associations between variables	Interventions related to: Communication Symptom management Advance care plan discussions PC/EOL education or training programs	Limited models to guide intervention development

Table 6

List of Core Themes, Themes, Subthemes, and Exemplar Quotes describing the “Essence of Experience”

Theme	Subtheme	Exemplar Quotes
Core Theme I: Evolution of PC/EOL		
Evidence of the Evolution	It’s the PC difference	“The palliative doctor afterwards came in and talked to [the patient] and sat on the bed, and talked to her about the discussion [the parents and health care team] had, what was going on, what they thought was going to happen and what her wishes were.” “Now palliative’s more involved and we get more to talking about the issues.”
	Shift from reactive to proactive communication and care planning	“We’ve gone a long way from when I first started...when we first started it was you either were going to wait until just before the patient’s going to crash before we talk to the family about really where we’re at...and how do you feel about it when you actually have time to think about it versus when you’re in crisis.”
	When nurses are incorporated they feel part of a bigger team	“When you make yourself available, it’s a good experience and you’re part of the team.”
	Trusted relationship between HC team, PC, and family	“So palliative I think has been really, it’s kind of like that constant, like the watch over, the helper.”
Continued Challenges	Medical Motto	“That’s the medical motto...you want to help people, you want to make them better...but still at times it’s...what did I do wrong? What could I have done? What do I do? Why didn’t I save them?”
	Layers of perceived disrespect when PC does not incorporate the nurse	“And sometimes it just seems like [the PC team] kind of come in and take over. And it’s like, well, now, wait a minute...I’ve known this guy for eight months, you’ve met him for 10 minutes...can we sit and talk so that we’re all part of the group.”
	Nurses are left in the dark / On the outside looking in	“If you’re busy sometimes there’s a lot of parent communication that nurses always aren’t privy to...it seems like you’re kind of left out of the process. And if you don’t make a point to make yourself available, sometimes you’re literally wiped out.”
	Brewing the stew	“The physicians will just sideline the families and talk to them and not involve the nurses...and I think that kind of makes it harder for the families...because they have to rehash that whole conversation.”
Core Theme II: Skill of Knowing		
Readiness to Engage in PC/EOL discussions	Parents protecting children	“I think that has always been a little difficult...when parents don’t want to tell their children but you know that child knows what is going on. I have just found that this is how people cope...and I just need to support them in the only way they know how to do it.”
	Children protecting parents	“And [adolescent patient] asks just the right questions, dancing around the issue because her mom is always present...I can just read in her eyes, ‘My mom isn’t saying it and I’m not going to say it because mom’s gonna cry.’”
	Opportunity knocks – Nurse assesses parental	“You can’t predict when they’re going to be ready for that conversation. It just sort of happens. I mean, opportunity

	cues to engage in discussions	knocks.”
	Maturity in youth	“[Young patient] talked about how she wouldn’t have anymore pain...she was not looking forward to death, but she saw the positives of her death...she was a very insightful little girl”
Supporting the child/family during PC/EOL Discussions	Parents seeking validation for EOL decisions	“I see parents...they just want that okay that it’s okay what they have been doing and it’s okay to let go.”
	Being okay with choices of the child and parents	“That parent saying [they needed to do everything for their child]...it helped me to not be uncomfortable with that family, with how hard they were pushing...this family has to live on past the child’s death with all the decisions made. Whatever decisions they make it’s okay.”
	The burden of too many options	“I’m [parent of child] okay with my son dying, but when they just bring in more and more and more choices of something that could be done, then I feel like I have to do everything that I could have for my son.”
	Children and parents vacillate in their acceptance of EOL	“[The young adult] went from not being a DNR to being a DNR and then later in the afternoon, he went back to not being a DNR.”
Experience Does Not Equate Comfort	Offers for gaining experience are limited	“[EOL care] can be very sporadic because so many people want to die at home that you can go for very long periods of time not really discussing or going over what to see and expect with somebody. I think it takes practice.”
	At a loss for words	“After all the time that I’ve been a nurse, you’d think, oh, I practiced this a long time, but no, I feel very much at a loss.”
	Nurse has own fears and insecurities	“I’ll be there and I’ll support you but I think I’m afraid to say the words...because I’m afraid of it and I’m afraid of how [the parents will] react. It’s getting over me to help them, and that’s a very hard thing.”
Next Layer of Unresolved Challenges	Access to resources	“We don’t really talk about [EOL with families]. We don’t really have the resources for it.”
	Documentation of advanced care planning discussions	“We had to call [the physician] after [the patient] was deteriorating because we had no clarification about what his status was. We had to call and she said, ‘No, I talked to [the parents]. He is a DNR.’ But there was clearly not one written.”
	EOL trajectory is unpredictable	“It’s out of my control; this disease has decided to take this turn. Now what’s my job?” “It is frustrating to me that you have these patients and they are very obviously dying, but nobody knows how long it is going to take somebody to die...and parents want to know when it’s going to [happen].”
Core Theme III: Expanded Essence of Caring during EOL		
Building Intimate Moments and Fostering Connectedness	Facilitating and physical connectedness	“I said, ‘Do [the parents of the child] want to hold him?’ The look on [the mother’s] face was like, ‘yeah’, and I said, ‘Let’s get her in bed.’ I helped her get in bed with him and put her arms around him...I went to walk away and mom grabbed my hand and did not let me go...we held him and he died within minutes of her getting in bed with him.”
	Treasuring intimate moments	“[The child’s] his mother asked if I would tell him it was okay to die. That was probably the hardest thing I have had to do as a nurse. I gave [the child] permission that his Mom said it was okay and that she would be okay and his brother would be okay.”

	Commitment to honor the child	“[Child’s mother] had said before she left, ‘I know that he is gone but there is a part of me that just needs to know that [the nurses] will be with them. You won’t leave him alone until the very last minute.’ I had a hard time when they came and took him down the hall it was like I can’t let him go because I am supposed to stay. I am supposed to continue to take care of him, and it is hard to just let them walk down the hall with the body.”
Balancing Messages of Hope and Realism	Giving false hope	“There is a difference between allowing people to maintain their hope and then giving them false information.”
	Hope always changes	“There’s always that hope question, that’s always the hardest thing. The definition of hope always changes. I remember one mom said, ‘I still have hope’, and I said ‘I have hope, too’.”
Core Theme IV: Experienced Nurse as Committed Advocate		
Parents are Appreciative of Knowing	Nurse anticipates symptoms patient will experience during EOL	“[The patient] had started pain meds and [the nurse] said [to the parents], ‘I just want you guys to know, I don’t know how much longer he’ll get to talk to you, so whatever you need to say or do, do it tonight. Every day before you go to bed, realize that this could be the last day you talk to him.’ I think [the parents] were appreciative of knowing.”
	Nurse’s responsibility to prepare family	“My responsibility if there is something to say or to prepare the family that this is going to happen.”
Creative Problem Solver	Achieving small battles for the patient	“I thought I achieved a small battle for her...confronting her staff doctor about [the need to increase her pain medications].”
Advocate for Communication before a Crisis	Timing of PC/EOL discussions	“I think we did that and did a good job with it, so it kind of makes a difference I think if you know it’s coming, if you can plan for it.”
	Helping parents process escalation of interventions	“I said to the mother, ‘You know they have a different approach in Intensive Care than we have here. Their approach is about maintaining his airway and they will do things that we wouldn’t do there. Are you prepared to have them intubate and then perhaps have to make that decision to take him off the ventilator?’ I was by [the patient’s] bedside but I was looking at them. All of a sudden [the] dad said, ‘Stop.’ They were huddled together in a big hug and Dad said, ‘Stop, stop. We are not going to do any more.’”
Religious Convictions can Impact EOL Care	Nurse is respectful of the family’s religious convictions	“I just looked at [the child’s parent] and I said, ‘God is not bound by your DNR. If God wants to heal him, He will. If he doesn’t, it doesn’t matter whether you sign the DNR or not. That doesn’t tie God’s hands behind His back.’ And there was of a sudden [it was] like the first time she ever thought about that as a possibility.”
	Balancing spiritual needs with the child’s medical needs	“It’s like convincing [the parents] that you’re not giving up hope on your Higher Power to help you...that it’s all right to give pain medicine, but to make them feel that they weren’t denouncing their religion or their faith by doing these things to make their child comfortable.”
Core Theme V: Valuing Individual Response to Grief		
Culture of Grief is Experienced Differently	No chance to grieve	“What really hurt my feelings working up on the floor is that somebody dies and within hours their room is filled again. It is like, can’t we let that room stay vacant for just a little while until we all get through the first hours of grief...it hurts my heart to think that we are not even allowed to grieve.”
	Major grief is for the parents	“I lay awake for weeks after, grieving for the parents. I am a parent but I haven’t lost a child to death.”

	Common response to death	“It’s hard...to walk back in those rooms. Especially if it’s a patient whose been in that room for months. I’ve always had a hard time going back in that room and just pretending like nothing ever happened in this room. It’s hard.”
Experienced Nurses Need Support Too	Support needs to be comprehensive, consistent, and individualized	“A big part of it is just needing someone to talk to, needing someone to listen. That’s the biggest part. Someone who understands.”
	Experienced EOL nurses provide perspective	“[An experienced hospice nurse] had a saying for me when I first started, ‘You’re so lucky that [the patient] chose you to be there [for their death]’. I’m lucky? I don’t feel lucky. But then I used that so many times afterwards...I always write notes to the nurses that lose their patients...you’re lucky to be there. But you don’t feel lucky at the time.”
	Levering peer support	“I look to my co-workers more for support than anything.”
	We aren’t going to cure every child	“That’s our role as an oncology nurse. We’re not going to cure everyone...we’re there to help them through this process.”
Supporting Novice Nurses	It’s hard to watch new nurses struggle	“I think it’s maturity in our own comfort levels [about death]. And there’s no way to harness that for the new nurse. It’s something that you actually have to experience.” “I think most of [the novice nurses] really don’t know how to deal with [death]. I think a lot of them are scared.”
	Duty to mentor	“As a new nurse it would have been helpful for somebody to come and tell me these things. The people I learn from are people I work with. We weren’t taught that in nursing school.”

Table 7

Sample Palliative Care and End of Life Communication Scenario to Use with Pediatric Oncology Nurses

Scenario Information	Prompting Questions	Teaching Points
<p>Background: You are assigned to Elise, a 16-year-old female patient with osteosarcoma. She was diagnosed at 13 and previously received chemotherapy. She was in remission for 12 months when she relapsed with osteosarcoma. Her disease has spread to other areas of her body including her lungs. Despite additional curative-focused therapy, her disease did not respond. The team recommended that she and her family transition to EOL care.</p> <p>Current Shift: You enter Elise's room to complete your morning safety checks and assessment. Her father is at the bedside. During your assessment, Elise describes a new onset of pain in her hip and back.</p>	<p>What additional information would you like to obtain from Elise?</p> <p>What additional history would you like to know?</p> <p>How would you proceed with a conversation with Elise and/or her father about her pain management?</p> <p>Would you like to engage additional members of the care team?</p>	<p>Assess presence of documented religious beliefs and anticipate how they may impact care.</p> <p>Complete a thorough pain assessment and compare to previous pain episodes.</p> <p>Use open-ended questions to assess openness and desire for pain management.</p> <p>Provide options for pain management strategies.</p> <p>If you experience difficulties early, pause and engage additional team members.</p>
<p>From your initial conversation with Elise and her father, you learn they joined a new church after learning of Elise's poor prognosis. Elise's father is adamant that Elise should not receive pain medication, because God will heal her.</p> <p>You notice Elise has been fairly quiet during this discussion.</p>	<p>What concerns do you have regarding this new information?</p> <p>What feelings emerge with the conflict of wanting to help a patient in pain and feel you can't intervene?</p> <p>Would you engage Elise further in the discussion? If yes, how?</p> <p>Would you engage other members of the care team? If yes, who and how?</p> <p>How would you respond if the Resident did not think it was necessary to have a team discussion?</p>	<p>May feel a conflict between your own beliefs and feelings you cannot intervene.</p> <p>Discuss with the father if you can engage Elise separately about the topic.</p> <p>Depending on the care team, access the medical resident first or advanced practice provider to outline your concerns.</p>

The medical resident, advanced practice provider, and social worker agree with you that a care conference is warranted.	How would you present your assessment and concerns in a care conference setting?	Provide clear assessment, including objective and subjective information, of Elise's pain.
You are asked to present your assessment and concerns in the care conference.	What information from the care team would you like to have prior to the care conference?	It is essential to understand other members of the care team and their insight into the situation.
	How will you assess responses from Elise and her father?	Look for verbal and non-verbal cues.

Appendix A: Discussion Guide with Data Generating Questions

Upon arrival to the focus group meeting, one of the facilitators will invite each participant to a private room to review the purpose of the study and the consent form. Allow time for each participant to read the consent privately, receive answers to questions, and sign both copies of the consent. Thank the participant for agreeing to be a part of this study. Then invite the participant to complete the demographic data form.

After collecting all signed consents and demographic forms, direct the participants to the scheduled meeting room and begin the session. Take time to have participants informally introduce themselves to one another, orient them to restroom locations, and offer refreshments.

Begin the discussion by saying, “We appreciate the time you have taken to participate in this study and to prepare ahead of time for our meeting. Now we will review the rules for our discussion.

Guidelines for Moderators

1. Remind participants of the purpose of the study and answer any questions by the participants.
2. Participants should be encouraged to share their opinions, experiences, and related comments about PC/EOL communication during the session. Encourage self-disclosure, both positive and negative perceptions.
3. Tell participants of your confidence in their caring and professionalism to hold all discussion as confidential and not be discussed outside of the group.
4. Remind participants of the purpose of audio-taping of sessions and note-taking by the recorder to document non-verbal communication during the session.
5. Remind participants that the focus group will end after they feel they have shared everything they want to, but will last no longer than 2 hours.
6. Inform the participants that the moderator will schedule a 15 min. break during the session.
7. Remind participants that refreshments will be served during the session.

“For the next two hours, we will discuss several broad topics related to communicating about palliative and end-of-life care with children with cancer, their families, and health care providers. As you share your experiences, it is important to keep in mind the comprehensive definitions of the terms used in this study. Palliative care refers to the active and total care to improve quality of life for a patient whose disease is not responsive to curative treatment, combining active and compassionate therapies intended to comfort, soothe, and relieve people with a life-threatening condition. Also for this study end-of-life care refers to the terminal phase of care when health care professionals continue palliative care in light of the imminence of death, implementing emotional and spiritual support for the child with cancer, family, and caregivers while simultaneously enhancing comfort measures during the final phase of life.

Please describe your experiences with as much detail as you can. We will take a break about half-way through the session.

The session will be audio-taped. Since we will use your first names, we want to again assure you that we will be careful to remove all names and other identifying information from transcriptions of the audiotapes. We are confident of your caring and professionalism to keep all information discussed here as confidential. So that everyone can feel comfortable with sharing his or her experiences, we ask that you not discuss anything shared by another participant outside of this session. Before we begin, are there any other questions?"

Allow enough time for participants to ask and have questions answered.

Focus Group Discussion Guide

“Now, let’s begin.” Turn on tape-recorder.

(Data Generating Questions for Study Aim 1 Research Question 1.1 regarding patients)

We are going to focus our first on patients. Please tell us about your experiences of communicating with children with cancer about palliative and end-of-life care.

You may use the following prompt questions if participants have difficulty beginning the discussion and to encourage full descriptions:

- We are most interested in specific stories you can share. What can you share about an experience with a specific patient?
- Please, can you tell me more about that?

(Data-generating questions for Study Aim 2, research questions 2.1 and 2.4 regarding patients. Note: Ask these questions only after a full description of experiences of communicating with children with cancer have been fully explored.)

- What do you think especially helped you in communicating with children with cancer about palliative and end-of-life care?
- What literature has been available to you as an institutional resource for communicating about palliative and end-of-life care to children with cancer?
- What personnel at your institution have you used as a resource for communicating about palliative and end-of-life care to children with cancer?
- What barriers prevent you from communicating effectively about palliative and end-of-life care to children with cancer?
- What did you perceive as priority concerns for nurses in communicating to children with cancer about palliative and end-of-life care?

After this sequence of discussion is completed, check in with participants if they need a break.

(For Aim 1, Research questions 1.2 and 1.3, and Study Aim 2, Research Questions 2.2, 2.3, 2.5, and 2.6, repeat the above sequence of data-generating questions, substituting families of children with cancer and HCP.)

If you haven't taken a break before, take one at this time.

For our last topic, please tell us your personal experiences of communicating with other health care providers of children with cancer about palliative and end-of-life care.

You may use the following prompt questions if participants have difficulty beginning the discussion and to encourage full descriptions:

- What do you think especially helped you in communicating with other health care providers of children with cancer about palliative and end-of-life care?
- What literature has been available to you as an institutional resource for communicating about palliative and end-of-life care to health care providers?
- What personnel at your institution have you used as a resource for communicating about palliative and end-of-life care to health care providers?
- What barriers prevented you from communicating effectively about palliative and end-of-life care to health care providers?
- What did you perceive as priority concerns for nurses in communicating with other health care providers of children with cancer about palliative and end-of-life care?

End the session on time. Thank the nurses for their participation and remind them to not repeat or discuss any information shared by other participants.

(Hendricks-Ferguson, 2007; Oncology Nursing Society Grant)

Appendix B: Demographic Form

Gender: Male Female **Age:** _____

Race: Caucasian, African-American, Asian
 Hispanic, Other (Please describe)

Marital Status: Single Married Divorced
 Separated

Highest Degree: Diploma ASN BSN
 MSN Nurse Practitioner _____ Other (describe)

Years of Employment in Nursing: _____

Years of Experiences in Adult and/or Pediatric Nursing:

adult acute care adult chronic care adult oncology unit
 adult ICU adult hospice adult home care

pediatric acute care pediatric chronic care (other than cancer)
 pediatric ICU pediatric home care pediatric hospice
 school nurse _____ Other (describe)

Years of Experience in Pediatric Oncology Nursing:

Less than 1 year 1-5 years 5-10 years
 10-20years >20 years

Current Position:

Staff nurse Charge nurse Unit Educator
 Nurse Practitioner Unit Manager _____ Other (explain)

Completion of Educational Program (e.g., local or national nursing conference) focused on Palliative/End-of-Life Care for child (indicate number of programs):

during 2005 during 2001-2004 during 1995-2000
 never attended

Completion of Education Program (i.e., by current employer) focused on Palliative/End-of-Life Care for Child (indicate number of programs):

during 2005 during 2001-2004 during 1995-2000
 never attended not offered by current employer

Completion of a Death and Dying Course for College Credit Focused on Adults:

Yes No

Completion of a Death and Dying Course for College Credit Focused on Children:

Yes No

Completion of Certification for the National ELNEC Program:

Yes NO

(Hendricks-Ferguson, 2007; Oncology Nursing Society Grant)

Appendix C: Exemplar Consent Form from One Site

**CHILDREN'S HOSPITAL OF WISCONSIN
HUMAN RESEARCH REVIEW BOARD
STATEMENT OF VOLUNTEER CONSENT FOR RESEARCH STUDY**

TITLE OF STUDY:**End-Of-Life Communication Experiences of Pediatric Oncology Nurses****PRINCIPAL INVESTIGATOR: Dr. Kathleen Sawin****PHONE NUMBER:** (414) 266-3615**FULL STREET ADDRESS:** Children's Hospital of Wisconsin, 6000 W. Wisconsin Avenue**E-MAIL ADDRESS:** KSawin@chw.org **FAX NUMBER:** 414 266-2720**CO-INVESTIGATORS:** Dr. Claretta Dupree (414) 266-6494
Wendy Morris (414) 266-2848**NAME OF SUBJECT:** _____ **MEDICAL RECORD NUMBER:** N/A

WE INVITE YOU TO TAKE PART IN THIS RESEARCH STUDY. TAKING PART IN THIS RESEARCH STUDY IS YOUR CHOICE. YOU DO NOT NEED TO PARTICIPATE. YOU MAY LEAVE THIS RESEARCH STUDY AT ANY TIME. IF YOU LEAVE THIS RESEARCH STUDY, YOU WILL NOT BE PENALIZED. YOU WILL NOT BENEFIT FROM BEING IN THIS RESEARCH STUDY. THIS FORM WILL HELP YOU UNDERSTAND WHAT WE PROPOSE TO DO. THIS FORM TELLS YOU WHAT WILL HAPPEN IN THE RESEARCH STUDY. THIS FORM ALSO TELLS YOU ABOUT THE RISKS, DISCOMFORTS AND OTHER INFORMATION ABOUT THE RESEARCH STUDY.

A. WHAT IS THE PROBLEM?

You are invited to participate in a research study of the experiences of Pediatric Oncology Nurses in communication about palliative and end-of-life care (physical and emotional comfort for the dying patient) (PC/EOL). This information will be used to identify healthcare barriers to communication and to assist in development of interventions aimed at helping the nurse support parents as they develop their perspectives on palliative/end-of-life care for their child/adolescent.

B. WHAT IS THE PURPOSE OF THIS RESEARCH STUDY?

The purpose of this study is to describe the nurses' experience of communicating about palliative care and end-of-life perspectives with pediatric oncology patients and their families. Approximately 60-84 nurses in three children's hospitals will participate in the focus groups. Twenty to 28 of these nurses will be from Children's Hospital of Wisconsin.

C. WHAT IS INVOLVED IN THE RESEARCH STUDY?

If you agree to be in the study, you will do the following things:

- Two weeks prior to the focus group meeting, a discussion guide, including a series of open-ended questions will be provided to you. These questions will be used during the focus group meeting and are provided beforehand, so you can think about them ahead of time if you want to. We would like you to give as full and rich descriptions as you can in your answers.
- Upon arriving at the focus group location, you will be given the consent form to review in a private area and we will answer any questions about the study you may have at that time.
- If you still wish to participate, we will ask you to sign two consent forms, you will keep one copy and we will keep one copy for our files.
- Upon receiving your consent, we will you will be given a general orientation to the site (e.g., location of bathrooms, etc.).
- Your participation in the focus group will last up to two hours.
- The focus group interviews will be audiotaped and transcribed
- You will be given a description of the reason you have been invited to participate and the goals of the research project.
- Light snack and drinks will also be provided.

D. WHAT ARE THE RISKS OF THE RESEARCH STUDY?

While participating in the study, the risks are:

- You may find the discussions distressing or experience psychological or emotional discomfort. For example, you may experience sadness or become teary eyed during discussions about end-of-life care of patients.
 - You may stop participation in the discussion at any time and/or choose not to answer a question.
 - Psychological discomfort will be managed by use of referral to the Employee Assistance Program (EAP). The EAP offers free and confidential services to help you with stressful personal and work problems. All conversations with EAP counselors are confidential and personal files are not a part of the participants' employee record.
- Confidentiality risk. There is a possibility of others knowing information you have shared.
 - The researcher will use no names or identifying information as part of the reports, published, or otherwise of the study.
 - A pediatric nurse researcher from outside CHW will facilitate the focus group.
 - Because the focus groups include employees discussing content involving employment status, confidentiality issues are important, to protect each participant's future employment status. The focus group facilitator will begin the focus group by reminding participants about the importance of keeping the information discussed in the focus group

confidential. The focus group facilitator will then ask each participant to verbally agree not to repeat anything discussed during the focus group meeting.

E. WHAT IF PROBLEMS OCCUR DURING THE STUDY OR WITH TREATMENT?

If you feel you have been injured as a result of this research study, you should immediately contact Dr. Kathleen Sawin, Dr. Claretta Dupree or Ms. Wendy Morris. You may also call the Chairperson of the hospital's committee that reviewed this research study at 414-266-2986.

If you experience emotional distress related to the interview questions about the death of a child, there are staff in the critical incident stress debriefing (CISD) team that will be available to you in addition to the Employee Assistance Program (EAP) staff. Contact information for both resources will be attached to your copy of the consent form. In addition, staff at the focus group will be available to contact either resource for you if you wish.

By signing this form, you do not waive your legal right to seek other compensation for study related injuries.

F. WHAT ARE THE POSSIBLE BENEFITS?

The information which is obtained may be useful scientifically and possibly helpful to others. The benefit to you, which may be expected from participating in this study, is the opportunity to discuss your experience and feelings regarding the recent death of a child, but this is not guaranteed.

G. WHAT ARE THE FINANCIAL RISKS?

There is no financial cost to participating in this study.

H. WILL YOU BE PAID FOR TAKING PART IN THE RESEARCH STUDY?

If you are paid hourly, you will receive compensation for the time (up to 2 hours) you spend participating in a focus group at your regular hourly rate. If you are salaried you may use work time for the focus group participation. Participants will receive payment in the respective amount of their CHW base rate on the next scheduled pay period.

I. DO YOU HAVE TO PARTICIPATE IN THIS RESEARCH STUDY?

You do not have to participate in this study. You are free to withdraw at any time. Your decision to withdraw will not affect your employment status. However, if you decide to stop participating in the study, we encourage you to talk to the researcher first.

J. WHAT IF YOU HAVE MORE QUESTIONS?

For questions about the study or a research-related injury, contact the researcher Dr. Kathleen Sawin at 266-3615, Dr. Claretta Dupree at 266-6494 or Ms. Wendy Morris at 266-2848. Also, the research study has been reviewed and approved by the Human

Research Review Board, whose purpose is to see that the rights and welfare of research participants are adequately protected, and that risks are balanced by potential benefits. A member of this committee is available to speak to you if you have any questions or complaints at 414-266-2986.

You will get a copy of this form. You may also request a copy of the protocol (full study plan).

K. WILL INFORMATION BE CONFIDENTIAL?

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Also, scientific data from this study may be presented at meetings and published so that it may be useful to others, as long as it is not identifiable with you.

Audiotape recordings will be typed into written form without any identifying information by a professional typist. After the study is analyzed and findings are published, the audiotapes will be destroyed. Only Dr. Kathleen Sawin, Dr. Claretta Dupree, Ms. Wendy Morris and their research assistant will have access to the tape recordings.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as: the transcription service and the research team, and the Human Research Review Board at Children's Hospital of Wisconsin (414-266-2986).

L. PERMISSION TO PROCEED

The proposed research study and consent has been explained to you by:

**Name of Principal or Co-Investigator,
 Asst.**

**Signature of Principal or Research
 or Co-Investigator**

When you sign this form, you agree that you have read the above description of this research. You also agree that your questions have been answered, and that you want to take part in this research.

 Signature of Subject or Authorized Representative

 Date

Appendix D: Exemplar of Data Table from 216 Pages of Analysis

Original Statement (SS) ♥	Restatements (RS) ♥	Formulated Meaning (FM) ♥	Preliminary Notes/Themes ♥
and I said to the mother, and this is probably not within my bounds to do, but I did it. I said to the mother, “You know they have a different approach in Intensive Care than we have here.	Acknowledged the nurse had a conversation with the mother that she felt was likely not within her boundaries to do so.	♥1.48 Nurse knowingly engaged in a conversation outside her scope with a family by discussing the differences in approaches between ICU-level care and the care delivered on the oncology unit.	IIID2c
Are you prepared to have them intubate and then perhaps have to make that decision to take him off the ventilator?”	Indicated the nurse asked the patient’s mother if she was prepared to have her child intubated and possibly have to make a difficult decision to take her child off the ventilator in the future.	♥1.49 Nurse is willing to take a risk and help the parents think through the cascade of decisions that will be made if the child is transferred to the ICU, which ultimately allows the parents breathing room to huddle, think, and stop the interventions.	IIID1c
And he started to talk that language and his mother is an ICU nurse so she knew that language and I think she began to think about that.	Acknowledged the ICU physician started to talk in medical language and the patient’s mother who was an ICU nurse and understood the language began to think more about what was being said.	♥1.53 Nurse recognized the mother [ICU RN] was able to understand the medical language of the ICU physicians.	VIK
He is laying there, so I didn’t know him that well but I kind of just talked to him a little bit, as we are trying to package him up and send him to ICU.	Acknowledge the patient was laying in bed and the nurses did not know him well so she talk to him a little bit while they were preparing to transfer.	♥1.56 Despite not knowing the patient well, the nurse talked to the child as she was preparing for ICU transfer.	IIID2c
They were huddled together in a big hug and Dad said, “Stop, stop. We are not going to do any more.”	Indicated the parents were huddled together in a big hug and the father said to Stop and that they did not want to do any more treatment.	♥1.58 Nurse recalled the parents huddled together when the father abruptly told the HC to stop what they were doing because they did not want any more tx.	Unknown
Then my comfort was for that mother who had made that decision at that moment, which was the right decision, but it didn’t have to go that way.	Belief the parents made the right decision in the moment for not more tx, but that the decision did not have to be made in a rushed situation.	♥1.59 Nurse empathized with the mother who had to make a difficult decision during a difficult and chaotic situation.	IIF
And that is really physician-driven and I think it’s a universal problem in our workplace.	Belief rushed decision-making is a universal problem at the hospital and a physician-driven problem.	♥1.61 Nurse thinks rushed EOL decision-making may be physician-drive universal problem in some hospital settings.	IB2c
There is a difference between allowing people to maintain their hope and then giving them false information.	Belief there is a difference between supporting parents to maintain hope and providing false information.	♥1.62 Nurse values the importance of physicians balancing messages of hope and reality to patients/families during PC/EOL.	IVA

Appendix E: Exemplar of Data Analysis Outline

ESSENCE OF EXPERIENCE

♥3.43a Belief the experience nurse has a whole skill of knowing, that the novice nurse may not, in managing patients and promoting connectedness with their family during EOL.

I. EVOLUTION OF PC/EOL

A. Evidence of the Evolution / Days Before PC

♦3.04a Openness to PC/EOL has improved as new physicians have joined the team leading to less frustration among nurses.

♥3.00 Nurse recalled a physician presenting 2 paths (1 invasive, 1 non-invasive/supportive) to urgently support a deteriorating patient.

1. Shift from reactive to proactive communication & care planning

♣1.30 EOL discussions in the past often occurred when death was imminent.

♣1.31 In the past, teams struggled to have EOL discussions with patients and families.

♣1.32 Feeling that there was a crisis point prior to the patient's death despite communication along the trajectory.

♣3.01 Nurse acknowledges an evolution of EOL communication towards a more proactive approach earlier in the trajectory rather than waiting until just before the patient decompensated to have a frank discussion with the family.

♣3.05a Nurse believes that the physician and team plan proactively during PC/EOL unless there is an unexpected change in the patient's status.

♣3.05b Nurse believes that PC is essential to the evolution of EOL care, because it facilitates the HCP and family to be realistic and proactive rather than reactive in creating a plan for when the patient's status changes quickly.

♣3.05c Belief PC/EOL discussions are occurring more proactively now rather than waiting for a crisis.

♥1.71 Nurse appreciated a physician who laid out a game plan with all the tx options to the family of a newly diagnosed patient.

♥1.72 Nurse appreciated a physician who spoke to a family about how tx can lead the child down 2 different routes: remission or PC/EOL; regardless of the route they travel, remission or PC/EOL the nurse appreciated the physician conveying a sense of commitment to the care of the child.

♥1.74 Nurse appreciated the physician initiating PC discussions with a newly diagnosed family and not waiting until the patient deteriorates later in the disease trajectory.

a. Positive: Shift to have DNAR discussions earlier in the trajectory

♦3.02 Belief addressing DNR status with the family during EOL has improved over the past couple years.

2. Implementation of PC Teams

♣1.85 The team advocates having PC involved early in the diagnosis for children with poor prognoses.

a. It's the PC difference

♣1.17 Mutual commitment by nurse and NP to care for patient during all care including EOL trajectory

♣1.56a The PC NP and Physician were helpful in facilitating EOL decision-making discussions (DNR) with an indecisive patient.

♣2.80 Nurse valued how the PC physician assessed the child's wishes and prepared patient for the EOL discussion (current status and expected outcome).

♣2.89 PC instrumental managing the patient's symptoms at EOL and keeping her comfortable.

♣3.04 PC engages patients, families, and the care team in honest conversations and assess individual feelings about the reality of the patient's EOL trajectory.

♣3.10 Belief that PC is the one point of consistency across the EOL trajectory regardless of the patient's physical setting.

b. PC teams are responsive to child's and nurse's needs

♣1.3 PC team has grown and is responsive when the nurse calls.

♣2.00 When death is imminent the primary team usually takes a backseat and EOL care management is shifted to the PC team to make the QOL decisions with the patient and family.

♣2.89 PC instrumental managing the patient's symptoms at EOL and keeping her comfortable.

♣3.11 PC has facilitated bringing patients back to the inpatient unit from the ICU when death is imminent at the request of the family.

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Publications

Montgomery, K., Belongia, M., Mulberry, M., Phillips, S., & Schulta, C. (2013). Perceptions of enteral nutrition and total parental nutrition in pediatric oncology and bone marrow transplant patients and parents. *Journal of Pediatric Oncology Nursing*, 30, 90-98. doi: 10.1177/1043454212471726.

Presentations

Montgomery, K. (2013, September). *State of the Science: Nurse Communication During Palliative Care and End of Life in Pediatric Oncology*. Podium presentation at the Association of Pediatric Oncology Nurses Association National Conference, Louisville, KY.

Montgomery, K., Belongia, M., Mulberry, M., Phillips, S., & Schulta, C. (2012, October). *Perceptions of Enteral and Parenteral Nutrition in Health Care Professionals*. Poster session presented at the Association of Pediatric Oncology Nurses Association National Conference, Pittsburgh, PA.

Sawin, K., Hendricks-Ferguson V., Dupree, C., Haase, J. & Montgomery, K. (2011, June). *Novice Pediatric Oncology Nurses Experience in End-Of-Life Communication*. Presented at the 10th International Family Nursing Conference, Kyoto, Japan.

Montgomery, K. & Malin, S. (2010, April). *Feasibility of a Guided Imagery Intervention for Newly Diagnosed Pediatric Oncology Patients*. Poster session presented at the Midwest Nursing Research Society Conference, Kansas City, MO.

Hendricks-Ferguson, V., Haase, J., Dupree, C., Sawin, K., & Montgomery, K. (2009, February). *An Innovative Approach to Colaizzi's Method of Empirical Phenomenology*. Poster session presented at the Advances in Qualitative Methods Conference, Vancouver, Canada.

Montgomery, K. (2008, April). *Posttraumatic Stress Disorder and Childhood Cancer Survivors: An Evidence-Based Synthesis*. Poster session presented at the Society of Pediatric Nurses National Conference, Denver, CO.

Research Grants

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Guided Imagery in Pediatric Oncology, Dream Makerz Foundation and the Audrey and Jack Miller Family Charitable Foundation, January, 2009.

Complementary and Alternative Therapies Family Workshops, Jack Miller Foundation, April, 2010.

Awards

Milwaukee Forty under 40 Award, Milwaukee Business Journal, 2012

Rising Star Alumni Award, University of Wisconsin-Milwaukee College of Nursing, 2011

Outstanding Graduate Student Award, Society of Pediatric Nurses-Greater Wisconsin Chapter, 2009

Chancellor's Award, University of Wisconsin-Milwaukee College of Nursing, 2008-2012

Professional Memberships

Association of Pediatric Hematology/Oncology Nurses

Rocky Mountain Chapter of the Association of Pediatric Hematology/Oncology Nurses

Western Institute of Nursing Research

Children's Oncology Group