

Copyright by

Kathleen A. Kobler

2017

Health Care Professionals' Awareness of a Child's Impending Death

BY

KATHLEEN A. KOBLER

B.S., Northern Illinois University, 1984

M.S., University of Illinois at Chicago, 2008

THESIS

Submitted as partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Nursing Sciences
in the Graduate College of the
University of Illinois at Chicago, 2017

Chicago, Illinois

Defense Committee:

Catherine Vincent, Chair and Advisor

Colleen Corte

Agatha Gallo

Cynthia Bell, Wayne State University

Karen Kavanaugh, Children's Hospital of Wisconsin

To the countless children and their families who taught me well that moments matter, and how
love endures the most difficult of transitions

~

To dear colleagues, who inspired this project by their dedication in caring for those who hurt

~

To my family, for faithfully providing water in the desert and joy in the journey

~

To Margaret Mary Kobler, my sister-in-law who I never got to meet in person, and
to our three babies, whose leaving too soon informed all that resulted in the following pages

You remain in my heart, always

ACKNOWLEDGEMENTS

I am beyond thankful for the wise and incredible nurse researchers who kindly agreed to serve on my dissertation committee. To Dr. Catherine Vincent, my advisor and committee chair, whose expert teaching, helpful direction, and steadfast support are a gift, indeed. It was during your theory course that the idea for this dissertation research came to mind! Thank-you, for all the ways you've inspired me to move past my doubts and complete this work. To Dr. Colleen Corte, whose teaching in my very first graduate course sparked a respect for conceptual models and theory development. Thank-you, for believing in me from the very beginning, and for the helpful perspective you've brought to this work. To Dr. Agatha Gallo, who probably unbeknown to her until now, gave me the courage to pursue this research when I listened to her guest lecture in Dr. Vincent's PhD theory course. Thank-you for your insightful and sound advice which has strengthened this project tremendously. To Dr. Cynthia Bell, whose thoughtful work with adolescents at end of life has impacted my daily clinical practice. Thank-you for challenging me to stretch my thinking as the theoretical model was emerging, and for offering the brilliant recommendation to consider Eisenhardt's approach for case study research. And to Dr. Karen Kavanaugh, who gently planted the idea on my heart years ago about pursuing graduate studies. I'm forever grateful for all that I've learned from you, for your expert guidance during this research, and for all the ways you've supported and encouraged me over the years.

In addition, I wish to thank Dr. Patricia Hershberger for her expert instruction and feedback when I created the first dissertation paper draft in her literature review course. My sincere gratitude also to my colleague Diane Boyle, whose collaboration early in my graduate studies informed and fueled my interest in decision makers' awareness in pediatric settings.

ACKNOWLEDGEMENTS (continued)

I would like to acknowledge the health care professionals who so graciously shared their time and thoughts with me, making this research possible. I hope your words and experiences are reflected within the pages of this dissertation with the respect and gratitude well deserved. Thank-you, for all the ways you model compassionate care for children and families on a daily basis.

I would also like to sincerely acknowledge the many babies, children, and their families who allowed me to bear witness to their journeys, and deepened my faith along the way. I hope the legacy they have left behind shines through this work.

I'm not even sure how to fully convey my gratitude to my husband, Jim, and to our six children, Megan, Kaitlyn, Erin, Jimmy, Kara, and Jake. Thank-you for joyfully and patiently living out loud around me as I was writing away at the far end of the dining room table. I will always treasure the ways you've extended grace and love without measure. And I would be remiss to not thank Ms. Penelope, our rabbit, who faithfully warmed my feet and kept me company while I wrote in the wee morning hours.

Lastly, with sincere respect and gratitude to those whose benevolence made it possible for me to pursue graduate studies and complete this dissertation research through these awards: UIC College of Nursing Alumni Association Board Scholarship, W. E. Van Doren Scholarship, Dean Joan L. Shaver Scholarship, Kathryn Venolia Memorial Scholarship Fund, Marguerite A. Dixon Award Fund, David & Teryl Schawk Nursing Scholarship, Seth and Denise Rosen Memorial Research Award, and the Jonas Foundation Nurse Scholar Award.

KAK

TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
I. DECISION MAKERS' AWARENESS OF A CHILD'S IMPENDING DEATH: AN INTEGRATIVE LITERATURE REVIEW	1
A. Methods	3
B. Results	5
1. Sample Characteristics	5
2. Contributing Factors to Initial Awareness	7
3. Timing of Decision Makers' Awareness	7
4. Dimensions Specific to Parental Awareness	8
5. Dimensions Specific to Health Care Professional Awareness	9
6. Lack of Congruence in Decision Makers' Awareness	9
7. Outcome of Decision Makers' Awareness	10
C. Discussion.....	11
1. Clinical Implications.....	12
2. Limitations.....	13
3. Recommendations for Future Research.....	14
D. Conclusion.....	15
E. References.....	16
II. HEALTH CARE PROFESSIONALS' AWARENESS OF A CHILD'S IMPENDING DEATH.....	33
A. Background	33
1. Reaching Awareness that the Child Will Not Survive	34
2. Discordance in Timing between Parents' and Professionals' Awareness	35
3. Existing Conceptual Framework for End-of-Life Care	36
B. Purpose	37
C. Methods	37
1. Case Definition	38
2. Case Selection (Infant/Child)	38
3. Participant Recruitment (Health Care Professional)	40
4. Data Collection	41
5. Data Analysis.....	43
D. Results	44

1. Relational Dimension	46
a. What was.....	46
b. What is.	48
c. What should be.....	49
3. Internal Dimension	51
a. What was.....	51
b. What is.	52
c. What should be.....	53
4. The Delicate Dance of Figuring it Out	54
5. Outcome of Health Care Professionals' Awareness.....	55
a. Professional responsibility.	55
b. Staying connected.	56
c. Grounded uncertainty.....	57
d. Holding in.	59
6. Theoretical Model of Health Care Professionals' Awareness	61
E. Discussion	62
1. Practice and Research Implications	66
2. Limitations	69
F. Conclusion	70
G. References	71
APPENDIX A.....	87
APPENDIX B	96
APPENDIX C	98
VITA.....	100

LIST OF TABLES

<u>TABLE</u>		<u>PAGE</u>
I.	Empirical Studies Included: Parent and Health Care Professional (HCP) Awareness of a Child's Impending Death.....	24
II.	Interview Guide.....	81
III.	Overview of Chosen Cases.....	82

LIST OF FIGURES

<u>FIGURE</u>	<u>PAGE</u>
1. Theoretical Model of Health Care Professionals' Awareness of a Child's Impending Death.....	84
2. Health Care Professionals' Awareness of a Child's Impending Death: Theoretical Model with Added Outcome.....	85
3. Theoretical Model of Health Care Professionals' Awareness through Full Transition to a Child's Dying.....	86

LIST OF ABBREVIATIONS

HCP	Health Care Professional
HIPPA	Health Insurance Portability and Accountability Act
IRB	Institutional Review Board
NIH	National Institute of Health
NICU	Neonatal Intensive Care Unit
PICU	Pediatric Intensive Care Unit
PSHU	Pediatric Surgical Heart Unit

SUMMARY

The purpose of this dissertation research was to explore the phenomenon of death awareness in neonatal and pediatric settings. Throughout the trajectory of care for children with serious illness, multiple moments of decision making arise, especially as the child transitions to end of life. The quality of the child's end-of-life care depends upon parents and health care professionals recognizing the child's condition as terminal, and collaborating to determine goals of care that will honor the child's living, and dying.

The first paper is an integrative review of the literature, with specific aims to learn how decision makers for a child with serious illness become aware of a child's impending death, and how such awareness impacts end-of-life decision making. Findings of this integrative review are presented, along with recommendations for clinical practice and further research.

The second paper includes results of a qualitative research study exploring death awareness from the perspective of health care professionals caring for children at end of life. The aims of this research were to explore the processes of how health care professionals arrive at an awareness that a child with serious illness will die, and how such awareness of a child's impending death impacts end-of-life decision making. The researcher used a case study approach, which resulted in an emerging theoretical model to describe health care professionals' awareness of a child's impending death.

The appendices include approval letters for the qualitative research from Institutional Review Boards of the University of Illinois at Chicago and Advocate Health Care, the Certificate of Confidentiality obtained from the National Institute of Health for this research, and the researcher's curriculum vitae.

I. DECISION MAKERS' AWARENESS OF A CHILD'S IMPENDING DEATH: AN INTEGRATIVE LITERATURE REVIEW

Neonatal and pediatric deaths continue to significantly impact families and health care teams. In 2014 alone, there were over 41,800 deaths of children ages newborn to 19 years, with an infant mortality rate of 5.82% per 1,000 live births (Kochanek, Murphy, Xu, & Tejada-Vera, 2016). Children age 14 and under are most likely to have their dying unfold in hospital settings, although this trend is slowly shifting to death at home for children with complex medical conditions; 74% of neonatal deaths occur in the hospital setting (Feudtner, Zhong, Faerber, Dai, & Feinstein, 2015).

As care transitions to end of life for children with serious illness, multiple moments of decision making arise for the child. For this paper, decision makers are defined as parents, guardians, or health care professionals responsible for making decisions for an infant or child with a life-limiting condition. Health care professionals strive to understand parents' preferences for shifting goals of care (Hill et al., 2014), but children may continue to receive aggressive medical interventions up until the moment of death, often leading to ethical dilemmas for their families and team (Armentrout, 2007; Wolfe et al., 2000). A wealth of literature highlights parents' experiences with end-of-life decision making for their infant (Brosig, Pierucci, Kupst, & Leuthner, 2007; Eden & Callister, 2010; McHaffie, Lyon, & Hume, 2001; Moro et al., 2011; Wocial, 2000), and for their child (Hinds et al., 2001; Madrigal et al., 2012; Meert, Thurston, & Sarnaik, 2000; Xafis, Wilkinson, & Sullivan, 2015).

Determining end-of-life care is not a onetime event, but rather a process—an extension of the relationships between child, parents, and health care team members (Papadatou, 2009) as all involved grapple with understanding the child's deteriorating condition. In clinical settings,

health care professionals carefully balance their desire to secure plans for the child's end-of-life care with the parents' readiness to enter into such discussions. Interwoven through all aspects of a child's care is the complex dynamic of parents wanting to be a "good parent" (Feudtner, Walter, et al., 2015; Hinds et al., 2009; McGraw et al., 2012), which also impacts the context of end-of-life decision making. Health care professionals strive to reach decisions in a manner that is respectful of each individual parent's need to fulfill core duties for their child (Feudtner, Zhong, et al., 2015).

Parents express their willingness to participate in decision making for their child (Gillam & Sullivan, 2011; Moro et al., 2011), with many preferring to share responsibility for end-of-life decisions with the child's team (Brosing et al., 2007; Caeymaex et al., 2011; McHaffie et al., 2001). Parents appreciate receiving honest, complete information from trusted team members (Eden & Callister, 2010; Gilmer, Foster, Bell, Mulder, & Carter, 2012; Meert et al., 2000; Meyer, Ritholz, Burns, & Truog, 2006). Parents also value an end-of-life planning process that allows them to maintain a hopeful attitude (Feudtner et al., 2010; Kamihara, Nyborn, Olcese, Nickerson, & Mack, 2015; Mack et al., 2007) and offers opportunities to stay connected with their child in relationship (Butler, Hall, Willetts, & Copnell, 2016; Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden, 2010; Meyer et al., 2006).

While physicians and nurses feel morally obligated to speak with parents regarding a child's poor prognosis or failing treatment, communication is complicated when parental expectations differ from those of the health care team (De Graves & Aranda, 2005; Epstein, 2010). Parents often simultaneously hold dual goals for a miracle while wishing for their child's comfort and relief of suffering (Feudtner et al., 2010). When gaps exist between parents and team members' goals and expectations, communication and trust may erode, paradoxically

resulting in escalating medical interventions at end of life as parents ask for everything to be done (Gillis, 2008; Surkan, Dickman, Steineck, Onelöv, & Kricbergs, 2006).

While evidence exists regarding pediatric end-of-life care once parents and health care professionals convey a mutual understanding that death is imminent, there is little exploration to date regarding the processes, timing, and impact of how a child's involved decision makers arrive at this awareness. Glaser and Strauss (1965) outlined the concept of death awareness for adults with terminal conditions, Ruland and Moore's (1998) middle-range nursing theory of peaceful death pertains to adult patients at end of life, and Fortney and Steward (2014) offer an emerging framework outlining the process of a peaceful neonatal death. None of these models address the processes of arriving at an awareness that a patient or loved one will die. The purpose of this integrative literature review is to evaluate existing neonatal and pediatric end-of-life research to enlighten how decision makers arrive at an awareness of a child's impending death, and how such awareness impacts end-of-life decision making.

Methods

An extensive search of the literature was conducted in several electronic databases (i.e., PubMed, CINAHL, PsycINFO, and ISI Web of Science), and was informed by search strategies for planning and managing a search of electronic databases as outlined by Cooper (1998). The search was limited to empirical studies published in English over the last 35 years; the chosen time frame captures the emergence of pediatric hospice and palliative care delivery. Initial key search terms of *awareness*, *perception*, *dying*, and *end of life* were individually linked with the words *neonate*, *infant*, *child*, and *pediatric*, along with *parent*, *nurse*, *physician*, and *health care professional*. This initial search yielded four pediatric-focused studies with specific empirical evidence of parent or health care professionals' awareness of a child's dying. Consultation with a

medical reference librarian resulted in identification of one additional study for consideration. Ancestral searching of these five qualitative studies led to an exploration of theoretical writings by Glaser and Strauss regarding awareness of death (1965) and timing of death awareness (1968) to further inform about the phenomenon and possible search strategies.

Due to the limited evidence focusing specifically on parent and health care professional's awareness of a child's impending death, the literature search was then expanded by adding these keywords: *death, decision-making, transition, prognostic awareness* and *congruence* in individual combinations with of *neonate, infant, child* and *pediatric*, along with *parent, nurse, physician, and health care professional*. This expanded search was also limited to studies published in English. Inclusion criteria were studies that described either parent or health care professionals' experiences during the early phases of end-of-life care. Exclusion criteria were studies about a child's perceptions at end of life, care at the immediate time of neonatal or pediatric death, or perinatal decision making prior to birth.

A total of 204 empirical studies met the inclusion criteria and abstracts were reviewed. Studies were included for further consideration if the abstract included at least one reported finding regarding communication about a terminal condition, awareness of impending death, understanding of prognosis, or decision making during a child's transition to end-of-life care. Based upon these search inclusion criteria, 42 additional studies were assessed in their entirety. After review, a total of 24 studies met the criteria for inclusion based upon findings related to the early phases of end-of-life decision making. Analysis of findings was completed using the guidelines for qualitative research synthesis by Pope, Mays and Popay (2007) and coding and synthesis strategies by Sandelowski and Barroso (2007). Analysis began by examining the demographics of the 24 included studies, including country of origin, study design, and research

method. Key phrases pertaining to parent or health care professional awareness, as defined by a cognitive or emotional acknowledgement of the child's impending death, were extracted from each manuscript for coding purposes. The first round of coding was completed to arrange the findings in the chronological order of reaching awareness, beginning with early cues or precursors to awareness, the process of becoming aware, and actions taken upon reaching awareness. Codes were then established regarding outcome of impending death awareness for both parents and health care professionals. The extracted key phrases were also coded based upon the context in which awareness occurred, such as when caring for the child's physical needs or through conversations with others, and by the attributes of awareness as described by both parents and health care professionals. Constant comparison of parent and health care professional awareness was completed within each study and across all cases to evaluate commonalities and differences in the findings (Ayres, Kavanaugh, & Knafl, 2003). Synthesis of codes to themes, where possible, was completed to represent all integrative review findings.

Results

Sample Characteristics

The 24 research studies included in this integrative review (see Table I) were conducted in the following countries: Australia (2), Brazil (1), Canada (2), The Netherlands (2), Northern Ireland (1), Scotland (1), Sweden (4), Switzerland (1), United Kingdom (2), and United States (8). A range of serious illnesses were represented, with 12 studies about children with cancer, and 12 studies of children with other life-threatening conditions. Some of the studies were set in a variety of intensive care settings, including three in neonatal intensive care (NICU), three in pediatric intensive care (PICU), and two in both NICU and PICU settings.

A total of 976 parents who experienced the death of their infant or child participated in the chosen studies. The sample also included 130 physicians, 118 nurses, 6 social workers, and 1 respiratory therapist who cared for the children throughout their disease trajectory. A total of 121 children's medical records were analyzed to inform decision-making processes at end of life.

The majority of the chosen studies were qualitative in design (15), along with five quantitative studies, and two of mixed-method design. Most of the qualitative study researchers used semi-structured interviews to enlighten decision makers' experiences; two of the qualitative research teams used case study or content analysis methods. In all five of the quantitative studies, questionnaires were the primary form of data collection. Researchers of the two mixed-method studies used questionnaires, interviews, and medical record review. Questionnaire development for all of the chosen quantitative and mixed method studies was informed by face-to-face interviews with parents, literature review, clinical practice, and focus groups; all questionnaires were subjected to face validity review, and many were tested via pilot studies.

Only two of the included studies were based on a theoretical framework, as the majority were a qualitative design. Of the two studies that did include a theoretical or conceptual framework, Jordan, Price, and Prior (2015) incorporated constructs from passage/transition theory, while Wocial (2000) offered a conceptual model on navigating uncharted territory.

Researchers in four studies explored parent-health care professional mutual understanding of a child's terminal prognosis (De Clercq, Elger, & Wangmo, 2016; de Vos et al., 2015; Rosenberg et al., 2013; Wolfe et al., 2000), while the remainder focused separately on parent or health care professionals' experiences. All sample studies were conducted retrospectively after the child's death.

Of the 24 studies, only one study's aim was specific to exploring the timing of parents' awareness of their child's impending death (Valdimarsdóttir et al., 2007). In the other studies, decision makers' awareness emerged as secondary or incidental findings within the context of pediatric end-of-life research. An interpretive synthesis of findings from these remaining studies, with a specific focus on data regarding the early stages of end-of-life decision making, offers insight into beginning awareness that a child will not survive.

Contributing Factors to Initial Awareness

Parents' initial understanding of their child's declining medical status resulted from a variety of experiences. For some parents, beginning awareness was sparked by timely information about the child's deterioration and poor prognosis as conveyed by trusted health care professionals (Lannen et al., 2010; Valdimarsdóttir et al., 2007; Wocial, 2000). Other parents sensed their child was deteriorating and suffering (Hunt, Valdimarsdóttir, Mucci, Kreicbergs, & Steinbeck, 2006; McHaffie et al., 2001) or enduring futile medical interventions (Valdimarsdóttir et al., 2007), which set the stage for parental awareness of the impending death. Parents of neonates reported a readiness to enter into end-of-life decision making only after holding their child in an intensive care setting (Wocial, 2000). There was no explicit description of contributing factors for health care professionals' beginning awareness, other than when physicians identified the child was no longer responding to medical treatments (Poles & Bousso, 2011) or nurses felt the infant or child was showing signs of suffering (Davies et al., 1996; Lewis, 2017).

Timing of Decision Makers' Awareness

Reaching an awareness of the child's impending death was often a gradual process for both parents and health care professionals (De Graves & Aranda, 2002; De Graves & Aranda,

2005; Docherty, Miles, & Brandon, 2007; Jordan, Price, & Prior, 2015). Awareness of a child's terminal condition was described by decision makers with a variety of metaphors that provide insight to additional dimensions of time for this phenomenon, including parents' descriptions of: living in limbo (Jordan et al., 2015), marching towards death (Price, Jordan, Prior, & Parkes, 2012), and navigating uncharted territory (Steele, 2002).

Dimensions Specific to Parental Awareness

Parents' awareness of their child's impending death occurred within context of relationships with health care professionals, family members, and friends (Meyer, Burns, Griffith, & Truog, 2002; Wocial, 2000). Parents desired to maintain a close relationship with their child as they grappled with coming to terms of the prognosis (Kars et al., 2010).

Parents of children with cancer reported a fluctuating awareness, alternating between believing their child was stable and hoping for a cure (De Graves & Aranda, 2005), to considering that the child may die (Hinds et al., 1996). Other parents had difficulty reaching an awareness of the child's terminal condition; 50% of parents in one study reported being unable to process the difficult news (Lannen et al., 2010), while in another study, 26 to 45% of parents reached awareness a mere 24 hours before their child's death (Valdimarsdóttir et al., 2007). Parents also conveyed pushing the idea of their child's impending death out of mind (De Clercq et al., 2016; Kars et al., 2010), some achieved this change in focus by concentrating on alternative details of their child's immediate needs (Kars et al., 2010).

For parents of children with cancer, awareness involved reaching both an intellectual and emotional understanding that the child's disease was fatal (Hunt et al., 2006; Valdimarsdóttir et al., 2007). These parents described intellectual awareness as "knowing in the head" and emotional awareness as "knowing in the heart," with differing levels of knowing impacting

parents' decision-making processes (Hunt et al., 2006; Valdimarsdóttir et al., 2007). Reaching awareness for parents was accompanied by multiple feelings, including: uncertainty, anxiety, isolation, fragility, and distrust of the health care team (De Graves & Aranda, 2005; Jordan et al., 2015; Kars et al., 2010; Steele, 2002).

Dimensions Specific to Health Care Professional Awareness

Findings from the studies offered some insight into the phenomenon of awareness from a health care professionals' perspective. Nurses were often the first health care team members to come to an awareness of the child's impending death (Davies et al., 1996; Lewis, 2017; Mitchell & Dale, 2015). Nurses experienced feelings of grief and moral distress when their beliefs conflicted with the family's understanding (Davies et al., 1996), and also felt isolated and alone upon realizing they were ahead of the physicians' and parents' recognition of the child's deterioration (Lewis, 2017). Team members often experienced difficulty in reaching consensus about a child's terminal prognosis (Mitchell & Dale, 2015); little of the team's consensus-building discussions were documented in the child's medical record (De Graves & Aranda, 2002). Nurses and physicians felt a moral and professional obligation to explain a child's deteriorating condition in order to facilitate parental awareness of the child's impending death (De Clercq et al., 2012; De Graves & Aranda, 2005; Epstein, 2010).

Lack of Congruence in Decision Makers' Awareness

There was often discordance in decision makers' awareness of a child's impending death. Parents and health care professionals experienced differing perceptions of a child's declining condition, which led to disagreements and barriers in communication (Docherty et al., 2007; Epstein, 2010; Rosenberg et al., 2013; Wolfe et al., 2000). In one study, physicians' understanding of a terminal prognosis occurred six months prior to the parents' first recognition

that their child would die (Wolfe et al., 2000). By contrast, in other studies parental awareness preceded that of the health care professionals (Meyer et al., 2002; Mitchell & Dale, 2015), with parents considering or fully advocating for cessation of medical interventions before the option was offered by the health care team (de Vos et al., 2015; Meyer et al., 2002).

Health care professionals questioned or distrusted parents' ability to make decisions for their child's well-being if parents reached awareness ahead of the team (de Vos et al., 2015). Similarly, parents experienced strong feelings of distrust if health care professionals believed the child was dying when parents thought recovery was possible from what they believed to be an acute medical crisis (Steele, 2002). Even when all decision makers reached a joint awareness, focus on next steps significantly differed, further complicating the child's end-of-life care (Rosenberg et al., 2013).

Outcome of Decision Makers' Awareness

Interpretive analysis of chosen studies also provided insight into next steps in decision making once parents and health care professionals were aware the child would not survive. Upon reaching an awareness of the child's terminal condition, health care professionals recognized the importance of securing team consensus about the child's condition and feasible treatment options (Poles & Bousso, 2012; Valdimarsdóttir et al., 2007). Physicians were aware of delivering medical information in a way that would respect the family's hope for their child while also facilitating opportunities to discuss options for the child's end-of-life care (De Clercq & Elger, 2016; De Graves & Aranda, 2005; Epstein, 2010). Some physicians reported difficulty in communicating the child's terminal condition to the family (De Clercq et al., 2016). In another study, parents admitted to already considering extubation from ventilator support before the choice was offered by the pediatric intensive care physicians (Meyer, et al., 2002). Team

members' limited documentation in the medical record of their communication with families did include interpretations of how they believed the parent and child were understanding the situation (De Graves & Aranda, 2002).

Decision makers in the chosen studies showed glimpses of how reaching awareness caused them to shift in their beliefs or reach out to others. In one study, parents who became aware of their child's deterioration also focused on refining their hopes for their child (Kars et al., 2010). Nurses reported reaching out to team members as they experienced grief and moral distress about the child's impending death (Davies et al., 1996). Only one detrimental finding of parental awareness was noted in the sample: fathers with a shortened timeframe to reach awareness prior to their child's death experienced an increased risk for depression when compared with fathers who had a longer awareness timeframe (Valdimarsdóttir et al., 2007).

For many decision makers, the gradual awareness of a child's impending death eventually resulted in a mutual agreement to shift care from a curative to a palliative approach (De Graves & Aranda, 2005; Docherty et al., 2007; Hinds et al., 1996; Kars et al., 2010). Fathers who were aware of their child's terminal condition were three times more likely to advocate for their child to remain at home, rather than experience death in a hospital setting (Surkan et al., 2006). Parents reported valuing health care professionals who allowed them to make decisions for end-of-life care in a way that would allow them to have "no regrets" after the child's death (Kars et al., 2010).

Discussion

This integrative review of the literature provides insight into the essential first component of end-of-life care, as decision makers experienced a gradual awareness of a child's impending death and subsequently made decisions for next steps in care. The processes of exactly how

parent and health care professional reach awareness remains unclear, yet awareness of the impending death appears to occur within the context of relationship. Decision-makers' in the chosen studies were impacted through their connection with the child, including by witnessing the child's deteriorating physical condition or an increase in the child's level of suffering. Nurses were often the first members of a child's team to recognize the inevitability of death, most likely based upon their consistent, daily provision of the child's care. Parents relied on health care professionals to provide clear, honest medical updates; professionals paced the delivery of such information in a manner that respected parental hopes for their child.

Becoming aware of the child's impending death impacted parents and professionals on both cognitive and emotional levels, resulting in feelings of responsibility, hope, distress, and grief. Once reaching awareness of the child's terminal condition, each individual decision-maker had to choose when or how to share their awareness with others. Articulating awareness of a child's impending death resulted in the initiation of end-of-life care discussions, and in some cases resulted in an eventual shift to palliative care provision.

Clinical Implications

Health care teams have the privilege of journeying with children and families throughout the trajectory of a life-limiting condition. As the terminal phase approaches, attention should be focused on identifying individualized, supportive actions to facilitate all decision makers' awareness the child's impending death. Nurses are perfectly poised to simultaneously note changes in the child's status while assessing parents' awareness of the child's overall prognosis. Avenues should be created to foster timely, effective communication and decision making for parents and the healthcare team.

It is important to note that even when parents or health care professionals arrive at an awareness of the child's impending death, conflict may still occur regarding goals of care or treatment options. In such cases it is imperative for all involved to focus efforts on fostering ongoing communication and protecting trust by addressing all avenues of conflict. In addition, it is this author's clinical experience that even with extensive supportive communication and care, some parents are unable to articulate their awareness of the impending death until the child has actually died. Such situations call for the health care team to be patient and respectful of the parents' perceptions, while providing astute symptom management for the child and compassionate bereavement support for the entire family.

Pediatric palliative care teams provide expertise in end-of-life care provision, enhancing communication to foster effective shifts in care as a child's condition deteriorates (Feudtner, Zhong, et al., 2015; Kassam, Skiadaresis, Alexander, & Wolfe, 2015). The gradual nature of many decision-makers' awareness, as reflected in the findings of this literature review, provides insight to palliative teams in assessing and guiding discussions, especially when discrepancies exist between parent and professionals' awareness. Strategies should be identified to ensure that within the complex processes and communication challenges inherent in pediatric end-of-life care, focus can be maintained on maximizing the child's comfort and honoring the parent-child relationship.

Limitations

This integrative review was limited to research published in English, which could have resulted in a bias of findings, although studies were included from multiple countries. While an extensive search of the literature was completed using multiple databases, it is possible that evidence was inadvertently overlooked, as the phenomenon of death awareness has not yet been

extensively or directly studied in pediatric settings. Lastly, this integrative review of the literature includes only findings from neonatal/pediatric end-of-life research. It is possible that other attributes influence decision makers' awareness of a child's clinical condition earlier in the illness trajectory, and thus were not captured within the reviewed end-of-life research.

Recommendations for Future Research

The results of this integrative literature review point to the need to further understand the processes, timing, congruency, and impact of decision makers' awareness of a child's impending death in order for respectful, effective end-of-life care to unfold. Longitudinal studies would be helpful to determine the evolution of awareness for parents and health care professionals over time, with attention to evaluating changes in awareness as the child's dying draws near. It would also be important to explore a robust view of this phenomenon, including the nature of decision makers' awareness depending on the infant's or child's age, location of care (hospital vs. home), disease trajectory (acute vs. chronic), and presence of palliative care team support.

As parents and health care professionals choose to communicate their awareness of the child's impending death with others, the impact on parent-professional relationships should be explored, along with the subsequent impact on the child's care (continuing all therapies vs. de-escalation of aggressive medical intervention). It would also be valuable to evaluate when parents are unable to articulate their awareness of the child's terminal condition, opting instead to request escalation or continuation of intensive medical interventions until the moment of death. Understanding these processes may inform development of strategies to facilitate decision makers' identification, acknowledgement, and verbalization of their awareness in order to move forward with collaborative pediatric end-of-life care planning. Analysis of future research findings could also assist with identification of strategies to support teams who reach awareness

prior to the parents, or when discordance in views leads to health care professional moral and emotional distress.

Conclusion

Reaching awareness of a child's impending death is a complex process that unfolds differently for all decision makers involved in the child's care. Health care professionals and pediatric palliative care teams are responsible for guiding families through the tender work of planning for their child's end-of-life care in a manner that is respectful, supportive, and honors the child's living and dying.

References

- Armentrout, D. C. (2007). Holding a place: Parents' lives following removal of infant life support. *Newborn Infant Nursing Review*, 7(1), e4-e11. doi: 10.1053/j/nainr.2006.12.009
- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*, 13(6), 871-883. doi: 10.1177/1049732303013006008
- Brosig, C. L., Pierucci, R. L., Kupst, M. J., & Leuthner, S. R. (2007). Infant end-of-life care: The parents' perspective. *Journal of Perinatology*, 27, S10-S16. doi: 10.1038/sj.jp.7211755
- Butler, A. E., Hall, H., Willetts, G., & Copnell, B. (2016). Family experience and PICU death: A meta-synthesis. *Pediatrics*, 136(4), e961-972. doi: 10.1542/peds2015-1068
- Caeymaex, L., Speranza, M., Vasilescu, C., Danan, C., Bourrat, M. M., Garel, M., & Joussetme, C. (2011). Living with a crucial decision: A qualitative study of parental narratives three years after the loss of their newborn in the NICU. *PLoS One*, 6(12), 1-7. doi: 10.1371/journal.pone.0028633
- Cooper, H. (1998). *Synthesizing research: A guide for literature reviews* (3rd ed.). Thousand Oaks, CA: SAGE Publications.
- Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J.,...Stutzer, C. (1996). Caring for dying children: Nurses' experiences. *Pediatric Nursing*, 22(6), 500-507. doi: 10.1177/104345429200900213
- De Clercq, E., Elger, B. S., & Wangmo, T. (2016). Missing life stories: The narratives of palliative patients, parents and physicians in paediatric oncology. *European Journal of Cancer Care*, Feb8, 1-10. doi: 10.1111/ecc.12651

- De Graves, S. & Aranda, S. (2002). Exploring documentation of end-of-life care of children with cancer. *International Journal of Palliative Care Nursing*, 8(9), 435-443. doi: 10.12968/ijpn.2002.8.9.10688
- De Graves, S., & Aranda, S. (2005). When a child cannot be cured: Reflections of health care professionals. *European Journal of Cancer Care*, 14, 132-140. doi: 10.1111/j.1365-2354.2005.00520.x
- de Vos, M. A., Seeber, A. A., Gevers, S. K. M., Bos, A. P., Gevers, F., & Willems, D. L. (2015). Parents who wish no further treatment for their child. *Journal of Medical Ethics*, 41(2), 195-200. doi: 10.1136/medethics-2013-101395
- Docherty, S.L., Miles, M.S., Brandon, D. (2007). Searching for “The Dying Point:” Providers’ experiences with palliative care in pediatric acute care. *Pediatric Nursing*, 33(4), 335-341. doi: 10.1089/jjpm.2006.0236
- Eden, L. M., & Callister, L. C. (2010). Parental involvement in end-of-life care and decision making in the newborn intensive care unit: An integrative review. *The Journal of Perinatal Education* 19(1), 29-39. doi: 10.1624/105812410X481546
- Epstein, E. G. (2010). Moral obligations of nurses and physicians in neonatal end-of-life care. *Nursing Ethics*, 17(5), 577-589. doi: 10.1177/0969733010373009
- Feudtner, C., Carroll, K. W., Hexem, K. R., Silberman, J., Kang, T. I., & Kazak, A. E. (2010). Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making. *Archives in Pediatric and Adolescent Medicine*, 164(9), 831-839. doi: 10.1001/archpediatrics.2010.146

- Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J.,...Hinds, P. S. (2015). Good-Parent beliefs of parents of seriously ill children. *JAMA Pediatrics*, 169(1), 39-47. doi: 10.1001/jamapediatrics.2014.2341
- Feudtner, C., Zhong, W., Faerber, J., Dai, D., & Feinstein, J. (2015). Pediatric end-of-life and palliative care: Epidemiology and health service use. In Institute of Medicine Committee on Approaching Death: Addressing Key End-of-Life Issues. *Dying in America: Improving quality and honoring individual preferences near end of life* (pp. 533-572). Washington, DC: The National Academies Press.
- Fortney, C. A. & Steward, D. K. (2014). A new framework to evaluate the quality of a neonatal death. *Death Studies*, 38(5), 294-301. doi: 10.1080/07481187.2012.742475
- Gillis, J. (2008). 'We want everything done.' *Archives of Disease in Childhood*, 93(3), 192-193. doi: 10.1136/adc.2007.120568
- Gillam, L. & Sullivan, J. (2011). Ethics at the end of life: Who should make decisions about treatment limitations for young children with life-threatening or life-limiting conditions? *Journal of Paediatrics and Child Health*, 47, 504-508. doi: 10.1111/j.1440-1754.2001.02177.x
- Gilmer, M. J., Foster, T. L., Bell, C. J., Mulder, J., & Carter, B. S. (2012). Parental perceptions of care of children at end of life. *American Journal of Hospice and Palliative Care*, 30(1), 53-58. doi: 10.1177/1049909112440836
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. Chicago, IL: Aldine Publishing Company.
- Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. Chicago, IL: Aldine Publishing Company.

- Hill, D. L., Miller, V., Walter, J. K., Carroll, K. W., Morrison, W. E., Munson, D. A...& Feudtner, C. (2014). Regoaling: A conceptual model of how parents of children with serious illness change medical care goals. *BMC Palliative Care*, 13(1), 1-8. doi: 10.1186/1472-684X-13-9
- Hinds, P., Birenbaum, L. K., Clarke-Steffen, L., Quargnenti, A., Kreissman, S., Kazak, A.,...Willmas, J. (1996). Coming to terms: Parents' responses to a first cancer recurrence in their child. *Nursing Research*, 45(3), 148-153. doi: 10.1097/00006199-199605000-0005
- Hinds, P. S., Oakes, L., Furman, W., Quargnenti, A., Olson, M. S., Foppiano, P., & Srivastava, D. K. (2001). End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology. *Cancer Nursing*, 24(2), 122-134. doi: 10.1097/00002820-200104000-00007
- Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L.,...Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who made Phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27(35), 5979-5985. doi: 10.1200/JCO.2008.20.0204
- Hunt, H., Valdimarsdóttir, U., Mucci, L., Kreicbergs, U., & Steineck, G. (2006). When death appears best for the child with severe malignancy: A nationwide parental follow-up. *Palliative Medicine*, 20, 567-577. doi: 10.1177/0269216306069671
- Jordan, J., Price, J., & Prior, L. (2015). Disorder and disconnection: Parent experiences of liminality when caring for their dying child. *Society of Health & Illness*, 37(6), 839-855. doi: 10.1111/1467-9566.12235

- Kamihara, J., Nyborn, J. A., Olcese, M. E., Nickerson, T., & Mack, J. W. (2015). Parental hope for children with advanced cancer. *Pediatrics*, 135(5), 868-874. doi: 10.1542/prds.2014-2855
- Kars, M. C., Gryphonck, M. H. F., Beishuizen, A., Meijer-van den Bergh, E. M. M., & van Delden, J. J. M. (2010). Factors influencing parental readiness to let their child with cancer die. *Pediatric Blood Cancer*, 54, 1000-1008. doi: 10.1002/pbc.22532
- Kassam, A., Skiadaresis, J., Alexander, S., & Wolf, J. (2015). Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. *Pediatric Blood & Cancer*, 62(8), 1409-1413. doi: 10.1002/pbc.25530
- Kochanek, K. D., Murphy, S. L., Xu, J., & Tejada-Vera, B. (2016). Deaths: Final data for 2014. *National Vital Statistics Reports*, 65(4), 1-122. Retrieved from: https://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_04.pdf
- Lannen, P., Wolfe, J., Mack, J., Onelöv, E., Nyberg, U., & Kreicbergs, U. (2010). Absorbing information about a child's incurable cancer. *Oncology*, 78, 259-266. doi: 10.1159/000315732
- Lewis, S. L. (2017). Exploring NICU nurses' affective responses to end-of-life care. *Advances in Neonatal Care*, 17(2), 96-105. doi: 10.1097/ANC.0000000000000355
- Mack, J. W., Wolfe, J., Cook, E. F., Grier, H. E., Cleary, P. D., & Weeks, J. C. (2007). Hope and prognostic disclosure. *Journal of Clinical Oncology*, 25(10), 5636-5642. doi: 10.1200/JCO.2007.12.6110
- Madrigal, M., Carroll, K. W., Hexem, K. R., Faerber, J. A., Morrison, W. E., & Feudtner, C. (2012). Parental decision-making preferences in the pediatric intensive care unit. *Critical Care Medicine*, 40(10), 2876-2882. doi: ccm.0b13e31825b9151

- McGraw, S. A., Truog, R. D., Solomon, M. Z., Cohen-Bearak, A., Sellers, D. E., Meyer, E. C. (2012). "I was able to still be her mom"—Parenting at end of life in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, 13(6), e350-e356. doi: 10.1097/PCC.0b013e31825b5607
- McHaffie, H. E., Lyon, A. J., & Hume, R. (2001). Deciding on treatment limitation for neonates: The parents' perspective. *European Journal of Pediatrics*, 160, 339-344. doi: 10.1007/pl00008444
- Meert, K. L., Thurston, C. S. & Sarnaik, A. P. (2000). End-of-life decision-making and satisfaction with care: Parental perspectives. *Pediatric Critical Care Medicine*, 1(2), 179-185. doi: 10.1097/00130478-200010000-00017
- Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 30(1), 226-231. doi: 10.1097/00003246-200201000-00032
- Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics*, 117(3), 649-657. doi: 10.1542/peds.2005-0144
- Mitchell, S., & Dale, J. (2015). Advance care planning in palliative care: A qualitative investigation into the perspective of Paediatric Intensive Care Unit staff. *Palliative Medicine*, 29(4), 371-379. doi: 10.1177/0269216315573000
- Moro, T. T., Kavanaugh, K., Savage, T. A., Reyes, M. R., Kimura, R. E., & Bhat, R. (2011). Parent decision making for life support for extremely premature infants: From the prenatal through end-of-life period. *Journal of Perinatal and Neonatal Nursing*, 25(1), 53-60. doi: 10.1097/jpn.0b013e31820377e5

- Papadatou, D. (2009). *In the face of death: Professionals who care for the dying and the bereaved*. New York: Springer Publishing Company.
- Pope, C., Mays, N., & Popay, J. (2007). *Synthesizing qualitative and quantitative health evidence: A guide to methods*. New York, New York: Open University Press.
- Poles, K. & Bousso, R. S. (2011). Dignified death: Concept development involving nurses and doctors in Pediatric Intensive Care Units. *Nursing Ethics*, 18(5), 694-709. doi: 10.1177/0969733011408043
- Price, J., Jordan, J., Prior, L., & Parkes, J. (2012). Comparing the needs of families of children dying from malignant and non-malignant disease: An in depth-qualitative study. *BMJ Supportive & Palliative Care*, 2, 127-132. doi: 10.1136/bmjspcare-2011-000104
- Rosenberg, A. R., Dussel, V., Kang, T., Geyer, J. R. Gerhardt, C. A., Feudtner, C., & Wolfe, J. (2013). Psychological distress in parents of children with advanced cancer. *JAMA Pediatrics*, 167(6), 537-543. doi: 10.1200/JCO.2014.55.4659
- Ruland, C. M. & Moore, S. M. (1998). Theory construction based on standards of care: A proposed theory of the peaceful end of life. *Nursing Outlook*, 46(4), 169-175. doi: 10.1016/S0029-6554(98)90069-0
- Sandelowski, M., & Barroso, J. (2007). *Handbook for synthesizing qualitative research*. New York: Springer Publishing Company.
- Steele, R. G. (2002). Experiences of families in which a child has a prolonged terminal illness: modifying factors. *International Journal of Palliative Nursing*, 8(9), 418-434. doi: 10.12968/ijpn.2002.8.9.10687

- Surkan, P. J., Dickman, P. W., Steineck, G., Onelöv, E., Kricbergs, U. (2006). Home care of a child dying of a malignancy and parental awareness of a child's impending death. *Palliative Medicine*, 20, 161-169. doi: 10.1191/0269216306pm11390a
- Valdimarsdóttir, U., Kreicbergs, U., Hauksdóttir, A., Hunt, H., Onelöv, E., Henter, J., & Steineck, G. (2007). Parents' intellectual and emotional awareness of their child's impending death to cancer: A population-based long-term follow-up study. *Lancet Oncology*, 8, 706-714. doi: 10.1016/S1470-2045(07)70209-7
- Wocial, L. D. (2000). Life support decisions involving imperiled infants. *Journal of Perinatal and Neonatal Nursing*, 14(2), 73-86. doi: 10.1097/00005237-2000090000-00008
- Wolfe, J., Klar, N., Grier, H.E., Duncan, J., Salem-Schatz, S., Emanuel, E.J., & Weeks, J. C. (2000). Understanding of prognosis among parents of children who died of cancer: Impact on treatment goals and integration of palliative care. *JAMA*, 284(19), 2469-2475. doi: 10.1001/jama.284.19.2469
- Xafis, V., Wilkinson, D., & Sullivan, J. (2015). What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback. *BMC Palliative Care*, 14(19), 2-11. doi: 10.1186/s12904-015-0024-0

Table I. Empirical Studies Included: Parent or Health Care Professional (HCP) Awareness of a Child's Impending Death

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
Davies et al. (1996) Canada	To understand nurses' experiences caring for children dying after prolonged illness	Qualitative, Grounded theory	N = 25 nurses at a tertiary care pediatric hospital in Western Canada	Individual semi-structured, interviews	<ul style="list-style-type: none"> • Nurses reported being first team members to recognize inevitability of child's death • Nurses experienced moral distress and grief distress when following medical orders that conflicted with their belief that children should experience peaceful death
De Clercq, Elger, & Wangmo (2016) Switzerland	To provide insight on lived experiences of pediatric palliative care patients, their parents, and physicians through illness narratives	Qualitative, Narrative analysis	N = 10 (n = 5 parents, n = 5 physicians)	Face-to-face interviews	<ul style="list-style-type: none"> • Parents preferred to only briefly discuss possibility of their child's impending death • Physicians aware at the time of interview that condition of the child was "impossible to heal" • Physicians felt responsibility to be guardian of family's hopes • Physicians reported difficulty in communicating message of child's impending death to family
De Graves & Aranda (2002) Australia	To explore how the shift from cure to palliation for children with cancer is documented in the medical record	Qualitative, Analysis of medical record documents	N = 18 records of children who died of progressive cancer in 1999	In-depth content analysis from medical records	<ul style="list-style-type: none"> • Documentation in medical records reflected gradual awareness by families and health care professionals (HCPs) of a child's approaching death • Medical record documentation often with missing dimensions/silence regarding family/HCPs conversations and interactions about end-of-life decision making

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
De Graves & Aranda (2005) <i>Australia</i>	To explore challenges HCPs face caring for child with cancer no longer responding to curative therapy	Qualitative, Exploratory design	N = 14 HCPs (n = 5 nurses, n = 6 physicians/hematology oncology (hem/onc) consultants, and n = 3 hem/onc Social Workers)	RN participatory group discussions; 6 consultants & 3 hem/onc SWs had single, in-depth interviews	<ul style="list-style-type: none"> • Shift of care from cure to palliative not discrete/one-time event but process as awareness and acceptance grows • “Fluctuating awareness” congruent with clinical path of cancer; Shifts in awareness influenced by families’ hope for cure amidst uncertainty of treatment outcomes • HCP goal to gradually raise family’s awareness when active treatment failing
de Vos et al., (2015) <i>The Netherlands</i>	To discuss who can best protect a child’s interests at end-of-life	Qualitative, Case study	N = 2 Parents of 3 yr old with brain damage from auto-immune encephalitis	Review of audio recordings from parent-HCP meetings, chart review	<ul style="list-style-type: none"> • Parents’ awareness of child’s impending death preceded HCP awareness • HCP advocated for continued medical interventions, parents requested cessation • HCP questioned parents’ ability to advocate for child’s best interests
Docherty, Miles, & Brandon (2007) <i>United States</i>	To describe experiences and of HCPs in giving care to children who have undergone intensive therapies for life-threatening illnesses	Qualitative, Descriptive design	N = 17 (n = 9 nurses, n = 4 doctors, n = 3 social workers, n = 1 respiratory therapist in NICUs, PICUs, bone marrow transplant units)	Semi-structured and open-ended interviews	<ul style="list-style-type: none"> • Finding true dying point often not unanimously agreed upon by parents & HCP • “Discordant perceptions” of need to shift from curative care to palliative care. • Stressful for HCPs to switch from curative to palliative care • Shift to palliative care occurred over time as awareness and acceptance developed
Epstein (2010) <i>United States</i>	To explore obligations of nurses and physicians	Qualitative, Hermeneutic approach	N = 32 (n = 21 nurses, and	Semi-structured interviews	<p>Obligations included talking with parents to:</p> <ul style="list-style-type: none"> • Explain clinical situation

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
	providing end-of-life care in the NICU		n = 11 physicians representing all 21 neonates)		<ul style="list-style-type: none"> • Ensure parents understood what was happening clinically • Show clinical evidence of a poor prognosis <p>HCPs communication with parents was complicated when parents' expectations differed from the reality of child's situation</p>
Hinds et al. (1996) United States	To explore the process experienced by parents dealing with first recurrence of cancer in their child	Qualitative, Grounded theory	N = 33 guardians (n = 27 mothers, n = 1 grandmother n = 5 fathers)	Interviews, observations, and medical record content analysis	<ul style="list-style-type: none"> • Coming to terms with child's cancer recurrence involved alternating cognitive shifting between knowledge of cure and death • 7 out of 33 guardians in study experienced guarded recognition of child's prognosis; these parents anticipated eventual limitation of curative interventions
Hunt, Valdimarsdottir, Mucci, Kreicbergs, Steineck (2006) Sweden	To identify sources of stress among parents with thoughts that death could be best for their child with severe malignancy	Quantitative, Survey design	N = 449 parents who lost a child to cancer between 1992 to 1997	Mail-in questionnaire	<p>Parents experienced:</p> <ul style="list-style-type: none"> • Intellectual awareness time: period from parent cognitive awareness that the child's disease is fatal to the actual time of their child's death • Emotional awareness time: period from parent recognition/sense or feeling that child's disease is fatal to the actual time of their child's death <p>A child's unrelieved pain plus parent's emotional awareness time was associated with parents thinking death would be best for the child</p>

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
Jordan, Price, & Prior (2015) <i>Northern Ireland</i>	To understand parents' experience when caring for child with life-threatening illness	Qualitative, Interpretive approach	N = 25 parents of children who had died	Semi-structured interviews	<ul style="list-style-type: none"> • Parents reported gradual awareness of child's life-threatening or life-limiting condition • Parents described uncertainty of child's living/dying as "living in limbo" • Parents report feeling isolated and fragile during uncertain time of child's dying
Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden (2010) <i>The Netherlands</i>	To identify from a parental perspective factors that influence the parents' end-of-life decision making	Qualitative, Grounded theory	N = 44 parents of n = 23 children with incurable cancer	Face-to-face, semi-structured interviews	<ul style="list-style-type: none"> • Parents reported actively working to sustain an intrinsic belief that child's condition was not fatal • Parents reported fragmentation of thought/feelings regarding the approaching death by focusing instead on alternative details of the child's needs • Parents reported feeling fearful/anxious when anticipating their child's dying • Parents had strong desire to maintain a peaceful relationship with their child
Lannen, Wolfe, Mack, Onelöv, Nyberg, & Kreicbergs (2010) <i>Sweden</i>	To assess parents' ability to absorb information that their child's cancer was incurable	Quantitative, Survey design	N = 449 parents who lost a child to cancer 4 to 9 years earlier	Mail-in questionnaire	<ul style="list-style-type: none"> • 60% of parents in the study reported an ability to absorb the information that their child's cancer was incurable • Parents reported they could absorb information when content delivered in appropriate, respectful manner • Parents informed about child's terminal condition were more likely to have "expressed their farewells" in a way that was most important to them

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
Lewis (2017) <i>United States</i>	To explore through lived and told stories NICU nurses experiences of caring for dying infants and their families	Qualitative, Narrative analysis	N = 36 NICU nurses who are members of National Association of Neonatal Nurses	Online survey with space for written narrative responses	<ul style="list-style-type: none"> • Nurses reported being aware that child would die before the physicians and parents reached a similar awareness • Nurses who reached an awareness the child will die experienced feelings of isolation and aloneness • Nurses who reached awareness before physicians and parents reported watching the child “suffer in discomfort and pain”
McHaffie, Lyon, & Hume (2001) <i>Scotland</i>	To explore parents’ perceptions of treatment withdrawal or withholding of medical treatment	Qualitative	N = 108 parents of neonates who died in a NICU	Face-to-face, semi-structured interviews	<p>Four factors helped parents reach an understanding about child’s terminal condition and make the decision to shift care goals to end-of-life:</p> <ul style="list-style-type: none"> • Visible deterioration • Prospect of suffering • Clear information regarding poor condition • Information regarding bleak prognosis <p>Parents reported tolerating uncertainty about their child’s condition and asked HCPs to do everything possible to help their child</p>
Meyer, Burns, Griffith, & Truog (2002) <i>United States</i>	To identify priorities for quality end-of-life care from the parents’ perspective	Quantitative, Survey design	N = 56 parents whose children died in three PICUs in Boston, MA	Questionnaire	<ul style="list-style-type: none"> • 45% of parents reported considering the possibility of withdrawing medical interventions before discussion occurred with any staff member • 90% of physicians discussed withdrawal of life support, almost half of parents had previously considered such a decision • Parents made decisions for child’s end-of-life care in the context of a social network (includes family, friends, and HCPs)

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
Mitchell & Dale (2015) <i>United Kingdom</i>	To explore experiences of HCPs regarding challenges of advance care planning for children with life-limiting illness in PICU settings	Qualitative	N = 14 HCPs (n = 8 physician consultants, and n = 6 nurses)	Individual semi-structured interviews	<ul style="list-style-type: none"> • HCPs delay in recognition of child's end-of-life trajectory was a barrier to advanced care planning, and gaining team consensus was a significant barrier to advance care planning • Nursing staff most frequently identified child's deteriorating condition before other team members • Some parents also identified child condition as transitioning to end-of-life
Poles & Bousso (2011) <i>Brazil</i>	To develop the concept of dignified death for children in PICU settings	Qualitative, Hybrid model concept analysis	N = 16 HCPs (n = 9 nurses, n = 7 physicians)	Interviews with open ended questions about what is a dignified death in PICU	<ul style="list-style-type: none"> • HCPs' "acceptance of irreversibility of illness" determined to be antecedent of a good death in PICU settings • Acceptance that a child will die most often made by experienced clinicians • Recommendation that consensus should be reached among all involved clinicians to facilitate a shift from curative to focus on relieving suffering • HCPs recognition of "natural evolution of illness" resulted in no further care escalation
Price, Jordan, Prior, & Parkes (2012) <i>United Kingdom</i>	To examine the experiences of bereaved parents concerning care provided to children who died from	Qualitative	N = 25 parents representing 16 children (n = 6 died of cancer, and n = 10 died of non-malignant condition)	Semi-structured interviews	<ul style="list-style-type: none"> • Parents of children with cancer noted becoming increasingly aware of an "inevitable march towards death" • Parents of children with non-malignant conditions reported death was rarely anticipated, as child had previously beat the odds

Author(s) (Year) Country	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
	cancer compared to those who died from non-malignant condition				<ul style="list-style-type: none"> • Parents of children with cancer reported child's end-of-life care as well-resourced and meeting the child's needs • Parents of children with non-malignant conditions reported child's end-of-life care as under-resourced and inadequate for child's needs
Rosenberg et al. (2013) United States	To describe parent-provider concordance regarding prognosis and goals of care for children with advanced cancer	Mixed methods, Survey design and document review	N = 131 (n = 77 parents, n = 47 physicians, n = 7 nurse practitioners; for n = 104 children with recurrent or refractory cancer)	Questionnaire and medical record content analysis	<ul style="list-style-type: none"> • Poor level of agreement between parent and HCP regarding a child's prognosis and goals of care • Parents were more likely than HCP to report a cure as likely • Perceptions of prognosis and goals of care varied by child's type of cancer
Steele (2002) Canada	To enhance understanding families' experiences of a child with neurodegenerative life-threatening illness (NLTI)	Qualitative, Grounded theory	N = 29 family members of children with neuro-degenerative life-threatening illnesses (NLTI)	Observations and face-to-face interviews	<ul style="list-style-type: none"> • Parents in study moved through "process of navigating uncharted territory" when caring for their child with NLTI • Parents reported distrust of HCPs who advised during acute illness that the child's death was near, when parents still believed their child had good quality of life
Surkan, Dickman, Steineck, Onelöv, &	To assess the relationship between place end-of-life care	Quantitative, Survey design	N = 449 parents of children who died due to malignancy	Mail in questionnaire	<ul style="list-style-type: none"> • The odds of children dying at home was almost three times higher for parents who reported understanding child's illness was

Author(s) (Year) <i>Country</i>	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
Krieberg (2006) <i>Sweden</i>	in relation to parental awareness of the child's impending death		between 1992 and 1997		incurable, compared to those who never received such information <ul style="list-style-type: none"> Fathers' awareness of child's impending death more strongly related to child dying at home than the mothers' awareness
Valdimarsdóttir, Krieberg, Hauksdóttir, Hunt, Onelöv, Henter, & Steineck (2007) <i>Sweden</i>	To study care-related determinants of when parents gain awareness of their child's impending death to cancer, and whether the duration of this awareness affects the parents' long-term morbidity	Quantitative, Survey design	N = 449 parents whose child died of malignancy between 1992 and 1997	Mail in questionnaire, completion of State-Trait Anxiety Inventory and Center for Epidemiology Studies Depression Scale	<ul style="list-style-type: none"> Parents distinguished between two forms of awareness: "knowing in the head" (reasoning) or "knowing in the heart" (intuition/feeling) 26% of parents reported short intellectual awareness time (< 24 hours before child's death) 45% of parents reported short emotional awareness time (< 24 hours before child's death) Risk increased for short intellectual and emotional awareness time if parents did not have information about child's terminal condition Compared with fathers who had longer emotional awareness time, fathers with short emotional awareness time had increased risk of depression and absence from employment. This difference not noted for mothers
Wocial (2000) <i>United States</i>	To explore parents' experiences in the NICU when	Qualitative, Descriptive	N = 20 parents of n = 23 infants who received	Face-to-face or phone interviews using open-	<ul style="list-style-type: none"> Parents reported that holding their critically ill child helped move their end-of-life decision making forward

Author(s) (Year) <i>Country</i>	Purpose	Study Design	Sample	Method or Measures	Results Specific to Awareness
	faced withholding and/or withdrawing treatment		treatment in a single NICU	ended questions	<ul style="list-style-type: none"> • Clear, timely, accurate information about infant's deteriorating condition helped parents "grasp their situation" • Parents had confidence in information about their child's medical status when information received from trusted HCPs • A trusting relationship with HCPs helped parents to engage in end-of-life decision making
Wolfe, Klar, Grier, Duncan, Salem-Schatz, Emmanuel, Weeks (2000) <i>United States</i>	To evaluate parental understanding of prognosis in children who die of cancer.	Mixed methods, Survey design, Interview, Document review	n = 103 parents, n = 42 pediatric oncologists, and n = 103 medical records of children whose parents are participants in study	In-person or telephone structured interview with parents; Physician questionnaire; Retrospective chart review with content analysis	<ul style="list-style-type: none"> • Parents recognized their child had no chance for cure a mean of 106(150) days(Standard deviation-SD) days before the child's death • Physician recognition occurred earlier with a mean of 206(330) days(SD) before the child's death • Earlier recognition of no realistic chance for cure by both parents and HCPs is associated with stronger emphasis on shifting treatment to lessen suffering and greater integration of palliative care

II. HEALTH CARE PROFESSIONALS' AWARENESS OF A CHILD'S IMPENDING DEATH

As a child's trajectory of serious illness unfolds, parents and health care professionals engage in multiple rounds of decision making, especially as end of life approaches. Authors of the Institute of Medicine's 2015 report, *Dying in America*, call for identification of best practice in end-of-life care and decision-making processes for neonates and children (Feudtner, Zhong, Aerber, Dai, & Feinstein, 2015). A wealth of evidence exists about the experiences of children, parents, and team members during end-of-life care and the moments surrounding the child's death (Bell, Skiles, Pradhan, & Champion, 2010; Bluebond-Langner, Belasco, & Wander, 2010; Butler, Hall, Willetts, & Copnell, 2016; Davies et al., 1996; Eden & Callister, 2010; Hinds et al., 2012; Kavanaugh, Moro, & Savage, 2010; McGraw et al., 2012). Little is known about the very beginning of this process as health care professionals become aware that a child will not survive. In this paper, the author shares research findings of health care professionals' experiences as they reach awareness of a child's impending death, and how such awareness impacts end-of-life decision making.

Background

Health care professionals seek to care for children with serious illness in a manner that meets each child's individual needs, while also respecting parents' expectations and desire to fulfill core responsibilities for their child (Feudtner, Walter, et al., 2015; Hinds et al., 2009; McGraw et al., 2012). Parents value the opportunity to collaborate and share in decision making with the child's health care team (Brosig, Pierucci, Kupst, & Leuthner, 2007; Caeymaex et al., 2011; Gillam & Sullivan, 2011; McHaffie, Lyon, & Hume, 2001; Moro et al., 2011) while receiving honest information about the child's condition from trusted team members (Eden &

Callister, 2010; Gilmer, Foster, Bell, Mulder, & Carter 2012; Meert, Thurston, & Sarniak, 2000; Meyer, Ritholz, Burns, & Truog, 2006;). Parents also appreciate when health care professionals facilitate end-of-life decision making in a manner that allows them to maintain hope (Feudtner et al., 2010; Kamihara, Nyborn, Olcese, Nickerson, & Mack, 2015; Mack et al., 2007) and to stay connected in relationship with their child (Butler et al., 2016; Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden, 2010; Meyer et al., 2006).

Health care professionals report feeling a moral and professional obligation to inform parents about their child's deteriorating medical status or unsuccessful treatment measures, and report difficulty in sharing the news when cure is no longer possible (De Clercq, Elger, & Wangmo, 2016; Docherty, Miles, & Brandon, 2007; Lewis, 2017; Mitchell & Dale, 2015). Communication is further complicated when parental expectations about the child's condition are significantly different than the team's (De Graves & Aranda, 2005; Epstein, 2010), as parents often hold simultaneous goals of hope for a cure and hope for relief from suffering (Feudtner et al., 2010). When a disconnect exists between health care professional and parent understanding, communication and trust can erode as parents ask for everything to be done, often resulting in the escalation of medical interventions at end of life (Gillis, 2008; Surkan, Dickman, Steineck, Onelöv, & Kreicbergs, 2006).

Reaching Awareness that the Child Will Not Survive

Parents report a gradual awareness of their child's impending death, facilitated through health care professionals sharing information about the child's condition in a truthful, direct manner (Lannen et al., 2010; Valdimarsdóttir et al., 2007; Wocial, 2000). Other parents became aware that death was inevitable as they perceived their child was suffering (Hunt, Valdimarsdóttir, Mucci, Kreicbergs, & Steinbeck, 2006; McHaffie et al., 2001) or enduring futile

medical treatments (Valdimarsdóttir et al., 2007). Parents of children with cancer describe experiencing both an intellectual, “knowing in the head,” and emotional understanding, “knowing in the heart,” that their child’s disease was fatal (Hunt et al., 2006; Valdimarsdóttir et al., 2007). Researchers provide insight to health care professional’s awareness, reflected when physicians realize that a child is no longer responding to therapies (Poles & Bousson, 2011), or when nurses believe a child is experiencing increased levels of suffering (Davies et al., 1996; Lewis, 2017).

Discordance in Timing between Parents’ and Professionals’ Awareness

End-of-life care planning requires that all of the child’s decision makers have reached some level of awareness of the child’s critical or deteriorating condition and are willing to enter into conversations about the issues at hand. Differences in timing between parental and health care professional awareness has a significant impact on attempts at end-of-life decision making.

Nurses are often the first team members to recognize the inevitability of the child’s death, which leads to feelings of grief, moral distress, and isolation when others have not yet reached the same awareness (Davies et al., 1996, Lewis, 2017; Mitchell & Dale, 2015). Physicians also reach an early awareness; in one study, physicians’ understanding of children’s terminal prognosis occurred six months prior to the parents’ first recognition that their child would die (Wolfe, et al., 2000). Alternatively, parents’ awareness of a child’s impending death can precede that of the health care team, with some parents advocating for cessation of medical interventions before the option is offered by the child’s care team (de Vos et al., 2015). In one study, parents of children in pediatric intensive care settings considered the possibility of withdrawing interventions for their child well before such choices were introduced by the team (Meyer, Burns, Griffith, & Truog, 2002).

Health care professionals question or distrust parents' ability to make decisions for their child's well-being when parents convey reaching an awareness of a terminal prognosis ahead of the team (de Vos et al., 2015). Similarly, parents experience strong feelings of distrust when health care professionals believe a child is dying and the parents feel recovery is possible from what they perceive as an acute medical crisis (Steele, 2002). Even when decision makers reach a joint awareness that a child will not survive, focus on next steps may significantly differ, further complicating decision making and the child's care (Rosenberg et al., 2013; Tomlinson et al., 2011). These discrepancies highlight the need to explore the processes, timing, and impact of decision makers' awareness so that respectful end-of-life care can be implemented.

Existing Conceptual Framework for End-of-Life Care

At present, no theory or conceptual framework effectively captures the experiences of decision makers becoming aware of impending death in neonatal and pediatric settings. Several end-of-life care theories provide insight into aspects of death awareness from an adult patient perspective. During their study of adults with terminal conditions, Glaser and Strauss (1968) described the dying trajectory as a passage occurring over time, inherent with cultural rules and expectations for the patient, family, and health care professionals. From the same adult-focused data, Glaser and Strauss (1965) developed their theory of death awareness that includes four types of death awareness: closed awareness, suspected awareness, mutual pretense awareness, and open awareness, all of which have ramifications on how adults make decisions at end of life.

Other researchers have created frameworks that guide the provision of care as death approaches. Ruland and Moore's (1998) middle-range nursing theory of peaceful death pertains to adult patients at end of life, while Fortney and Steward (2014) offer an emerging framework

outlining the process of a peaceful neonatal death; neither model addresses the initial processes of arriving at an understanding that a patient or beloved infant will die.

In Papadatou's model of health care professional grief (2009), clinicians vacillate between experiencing their own grief and avoiding such feelings when a patient dies. Papadatou (2009) notes professionals must be aware of their own feelings, while simultaneously being present, to ensure an appropriate death experience for the patient and family. Darlington, Korones, and Norton (2017) describe an emerging framework for parental coping when their child is facing death that includes a similar regulation of emotions, as parents avoid strong feelings in order to cope with their child's daily needs. While each model speaks to parent or health care professional feelings or thoughts, neither describe the process or impact of realizing the child's death is inevitable.

Purpose

The purpose of this research was to examine the early phases of neonatal and pediatric end-of-life decision making from the perspective of health care professionals. To achieve this purpose, two aims were established: (1) explore the processes of how health care professionals arrive at an awareness that a child with a serious illness will die and (2) explore how health care professionals' awareness of a child's impending death impacts end-of-life decision making.

Methods

A qualitative design was used to elicit the experiences of health care professionals caring for infants and children during the time of significant disease progression. Eisenhardt's (1989) case study approach was chosen, providing an organized process for conducting case study research and synthesizing previous grounded theory (Glaser & Strauss, 1965; Glaser & Strauss, 1968) with case study approaches (Yin, 2014). It was anticipated that concepts and propositions

emerging from a case study approach could result in theory development for the phenomenon of interest (Eisenhardt, 1989).

Eisenhardt's (1989) case study approach includes nine distinct steps: defining a research question, selecting cases theoretically, crafting protocols for multiple data collection methods, entering the field to conduct data collection, analyzing data, shaping hypothesis, enfolding literature, and reaching closure of the study. These steps allow for an emergent design that accommodates potential shifts in case selection as data collection and initial data analysis overlap (Creswell, 2014; Eisenhardt, 1989; Yin, 2014). Each step of Eisenhardt's approach (1989) was incorporated into this research, as described further in this methods section.

Case Definition

For this study, the case was considered to be a hospitalized infant or child with serious illness experiencing a significant decline in clinical status/disease progression, and members of the child's health care team. Interdisciplinary team members actively caring for the child were invited to take part in the research. Data analysis began upon completion of interviews from the first case, and also informed subsequent case selection (Eisenhardt, 1989). Per Eisenhardt (1989), optimal case study research sample size entails 4-10 cases; four cases (infants/children) were chosen for this research with 2-5 health care professionals participating in each case, yielding a large volume of rich data. As noted by Patton (2015), it was not possible to fully define the depth and breadth of case until after all data analysis was completed.

Case Selection (Infant/Child)

The research was conducted at a 400+ bed teaching children's hospital with two campuses separated by 30 miles located in a mix of urban and suburban settings. Case identification and participant recruitment began after receiving Institutional Review Board (IRB)

approval and a Certificate of Confidentiality from the National Institute of Health (NIH).

Eligible cases were identified by the researcher in collaboration with hospital's pediatric palliative care team, as this team is consulted to care for children with life-limiting conditions. Eligible cases were assessed and chosen by the researcher from patients receiving care in the neonatal intensive care (NICU), pediatric intensive care (PICU), pediatric surgical heart (PSHU), and pediatric inpatient units.

Case inclusion criteria were neonatal or pediatric patients (as defined by ≥ 1 day old to 17 years of age) who were clinically transitioning to end-of-life (as defined by multi-system organ failure, or declining medical status, or minimal response to curative medical interventions, or designation of a terminal prognosis by an attending physician). As all attempts were made to capture real-time experiences of participants (health care professionals), the following situations were excluded for case selection: diagnosis of brain death moving rapidly to organ donation or extubation/death, extreme prematurity where living/dying occurred within 24 to 48hrs, and prenatal diagnosis of a terminal fetal condition. Exclusion criteria for cases also included teens 18 years of age or older who could legally make their own medical decisions, and cases where the child was expected to recover back to his/her baseline health status.

The researcher used purposeful theoretical sampling, selecting cases to aid in extending the emergent theory; cases were chosen that represented opposite ranges of the phenomenon of interest (Eisenhardt, 1989), specifically in relation to types of disease progression. As data collection and analysis occurred simultaneously, the researcher considered selection of critical, unusual, revelatory, or extreme cases to further inform the constructs, relationships, and overall phenomenon of interest (Eisenhardt & Graebner, 2007; Yin, 2014).

A total of four cases were selected for this research. The decision was made to halt pursuing additional case selection when the researcher identified no new aspects of the phenomenon emerging during data analysis (Eisenhardt, 1989).

Participant Recruitment (Health Care Professional)

Health care professionals were considered potential participants upon evidence of active involvement in the chosen case (child's) care, as determined through observation of interactions on the child's hospital unit, electronic medical review with evidence of the health care professional's documentation in the child's chart, and/or confirmation by the pediatric palliative care team as a child's key caregiver. The researcher's goal was to approach potential participants within days of the health care team realizing the child would not survive, in hope of capturing as close to real-time data on this phenomenon as possible.

Recruitment of eligible health care professionals occurred via a hand-delivered or emailed study invitation letter extending the invitation to participate in a face-to-face or phone interview. Interested study participants contacted the researcher to confirm participation. All confirmations were received within 24 hours of the initial invitation; all interviews took place within one week of confirming interest in participation. The researcher maintained a record of recruitment attempts and was mindful of "passive refusal" characteristics conveyed by potential participants (Kavanaugh & Campbell, 2014). The researcher's goal was to minimize participant burden by creating a recruitment and interview process that was respectful of participants' work flow and patient care responsibilities (Kavanaugh & Campbell, 2014).

In all, 19 health care professionals were invited to participate in the research; only two provided no response to the original invitation. Out of the 17 who expressed an interest, two did

not participate in the study; one decline came after a death in the potential participant's family, and the second potential participant eventually decided not to choose a date for the interview.

Data Collection

Eisenhardt (1989) calls for incorporation of data from multiple sources to foster a synergistic view of the evidence. The use of multiple data sources also strengthens the developing theory through triangulation of evidence, enhancing the possibility of generating novel theory out of exposure to contrasting data across all cases (Eisenhardt, 1989), while lessening the potential of researcher bias (Eisenhardt, 1989; Yin, 2014). Data collection methods for this research included observation, electronic medical record review, and in-person, semi-structured interviews with health care professionals.

The researcher observed staff interactions around the chosen case's (infant/child's) bedside to learn about team-child interactions. These observations occurred during the day shift within the week prior to participant recruitment. Field notes were maintained during observations and for the duration of the study, recording interactions, emerging thoughts, decisions, and personal reflections (Eisenhardt, 1989; Kavanaugh, Moro, Savage, & Mehendale, 2006).

Medical record review was conducted by searching the identified case's (infant/child's) electronic medical record (EMR) for documentation by interdisciplinary team members regarding goals of care, decision making, or communication with the child or parents. The researcher used an IRB approved medical record review template to gather relevant decision-making data from the EMR.

Interviews with health care professionals involved in the child's care occurred only after written informed consent was obtained, and were held either by phone or at a private location in the children's hospital, away from the child's unit of care. Interviews lasted between 30 to 60

minutes, and were digitally recorded. The researcher transcribed each interview into a Word document and checked each transcript in entirety for accuracy. The recorded interviews were erased upon completion of transcription.

A semi-structured interviewing approach was used, accommodating shifts in questioning or adding probes to follow hunches, while also balancing the potential sensitive nature of the topic through introductions such as, “Could I ask you...” (Charmaz, 2014). Probes incorporating subjects own word choice were used whenever possible. All interview questions were crafted to honor the sacredness of the work at hand (Lincoln, 1995). The final interview questions allowed for assessment of participant discomfort or other interview issues, while also conveying respect (Kavanaugh, Moro, Savage, & Mehendale, 2006). Please see Table II to review the semi-structured interview guide.

The interviews allowed each participant the opportunity for insightful self-reflection and processing of their experiences (Kavanaugh & Campbell, 2014). Participants were assessed throughout the interview for signs of emotional distress, and were informed that they may discontinue the interview at any time. When signs of distress were noted, the researcher provided immediate, empathic support and with some participants, the mutual decision was made to either pause or stop the interview completely. The researcher provided a safe space for all participants to transition back to their work day, at times sitting quietly with the participant until he/she conveyed a readiness to leave the interview site or to end the phone conversation.

Data analysis began upon completion of the first interview, as recommended by Eisenhardt (1989), informing subsequent case selection and modification of data collection based upon emerging themes. Data collection for each case ceased when the child was discharged home (three cases/10 interviews) or died at the hospital (one case/5 interviews).

Data Analysis

As per Eisenhardt's (1989) case study approach, data analysis began simultaneously with data collection. The researcher maintained an audit trail of all activities in a reflexive manner, recording personal thoughts, decisions, and perceptions that arose during data analysis (Creswell, 2014; Miles, Huberman, & Saldaña, 2014). Data from observation field notes, EMR documentation notes, and transcribed interviews were coded using a code book developed and refined by the researcher. The starting list of codes was created based on study aims and the interview questions; refinement of codes occurred during the coding and analysis processes (Charmaz, 2014; Saldaña, 2016).

The first round of coding was completed by hand on paper versions of transcribed interviews. The researcher then waited at least 48 hours before re-coding electronic versions of the transcribed interviews using ATLAS.ti8 qualitative analysis software. Initial codes were verified and memos written if changes were made to ensure intracoder reliability (Creswell, 2014). A record of code definitions was also maintained in ATLAS.ti8 to minimize potential code drift throughout all data analysis activities (Creswell, 2014).

First cycle coding methods included: attribute, concept, emotion, in vivo, process, simultaneous, and value coding; second cycle coding included waves of focused and axial coding, along with simultaneous maintenance of analytic memos, with an eventual transition to final theoretical coding (Saldaña, 2016). During first and second cycle coding, the researcher reviewed compilations of individual codes using a matrices format (Miles et al., 2014) to evaluate for similarities and differences of the codes within each case and across cases.

Per Sandelowski (2011), each case is a "unique configuration of elements" that are interwoven in such a way to make the case all it is, and therefore the case should be evaluated as

a whole. Data analysis within each case afforded identification of unique case patterns and was followed by analysis across all four cases to identify across-case patterns or differences (Ayres, Kavanaugh, & Knafl, 2003). During this time, the researcher created initial sketches to conceptually depict the process of health care professionals' awareness of a child's impending death. The researcher also spent time free writing to answer the question, "What would the participants in each case want me to know?" (Ayres, Kavanaugh, & Knafl, 2003). Attributes and key findings of each case are summarized in Table III.

After constant immersion in the data, a beginning theoretical model of health care professionals' awareness emerged. The researcher subsequently went back to the original transcripts to re-look for key statements that exemplified the new awareness model's concepts, relationships, and outcomes. New matrices were created to look within and across all cases from a thematic and emerging theoretical model perspective (Miles et al., 2014). Lastly, the theoretical model was printed out and each case was mapped onto the model using participants' own words, again comparing within case and across all cases to ensure conceptual accuracy.

During the final stages of case study research as outlined by Eisenhardt (1989), the emerging concepts and relationships were compared and reconciled with both supporting and conflicting literature (Eisenhardt, 1989).

Results

A total of 15 health care professionals from multiple disciplines participated including physicians (6), nurses (6), social worker (1), chaplain (1), and child life specialist (1). The participants had the following distribution of years working in their chosen profession: 1-4 years (5), 5-15 years (7), 16 years or more (3).

Health care professionals experienced a multi-faceted, fluid process of becoming aware of a child's impending death informed by two main dimensions: (1) Relational - through interactions with the child, the parents, and other health care team members, and (2) Internal - through reflection on personal thoughts, feelings, perceptions, and biases (See Figure 1). Health care professionals reported reaching a timely initial cognitive awareness of the child's terminal condition, in part based on their experiences with past patients who had similar diagnoses. As one participant shared, "But I knew it from a previous, with a similar case that actually this case is worse in prognosis than the previous case of the other girl who had passed away." For physicians and nurses, this initial cognitive awareness was also based on their knowledge of the child's medical condition and recent diagnostic testing results.

I'm feeling like this is a non-starter. Like his, this is not something that's medically, um, possible. There are limits to what our tech, you know, what we as medical professionals can accomplish. We can't accomplish a good outcome for this child in any sense.

The social worker, chaplain, and child life specialist participants looked to physicians' descriptions of the child's medical condition to inform their initial cognitive awareness that the child would not survive.

I think it was just told to me that, ah, by (oncologist's name) that um, she was another, very similar to (name of another patient). So another patient who had a very similar diagnosis. So I pretty much from the beginning knew that it was probably terminal.

Health care professionals' initial understanding was quickly followed by a deeper focus on awareness of all that was collectively unfolding for the child, the parents, their colleagues, and themselves. Health care professionals simultaneously considered the child's situation with information from the past (what was) and present-day (what is) with an anticipation of the future

(what should be), as they pondered possible care options and impact of the terminal condition on all involved. This time-oriented attention to past, present, and future was also informed by relational and internal dimensions, as health care professionals continued to receive information from others while also processing their own internal thoughts and feelings.

Woven throughout this process of awareness was a “delicate dance of figuring it out” (participant’s own words) pertaining to the issues at hand for the child’s care. Themes emerged during data analysis that exemplified the outcome of health care professionals’ awareness as they considered all that encompassed the child’s end-of-life care, including: (1) sense of responsibility, (2) staying connected, (3) grounded uncertainty, and (4) holding in.

The use of Eisenhardt’s case study approach (1989) for this research resulted in an emerging theoretical model of health care professional’s awareness of a child’s impending death, as depicted in Figure 1. Results are presented here describing the model components, with specific findings to illustrate each.

Relational Dimension

Health care professionals discussed multiple ways of receiving information from a relational perspective that impacted their current awareness. This relational dimension was characterized by interactions with the child, parents, and other team members and could be divided into the three intertwining time-oriented focuses of past (what was), present (what is), and future (what should be).

What was. For this relational dimension category, health care professionals called to mind past conversations, interactions, or experiences with others that informed their understanding of the issues at hand. Many aspects of the “what was” relational focus were common to across all cases in the research, including: report of previous interactions and

working relationship with the child and family, mention of the child's previous physical status, including signs/symptoms at the time of initial diagnosis, and description of how the child's body reacted to previous treatments or interventions. As one participant explained,

So I had a strong suspicion when I saw her the morning after she came in when her pain was to the degree that it was, because, and that she had swelling that leg, and um (pause), she didn't really have a reason to have that. And it was very similar to how she presented initially just on the other side...

Participants in each case also recalled how parents preferred to receive medical information during past hospitalizations, and were mindful of how parents made previous decisions for their child's care. Some participants reflected on early communication with the family and moments of perceived conflict, and used such past interactions to inform their belief about how the family was currently processing the child's situation.

Um, a kicker in the whole thing though, is that the parents did not want to tell her the prognosis of the tumor. She knew that she had a tumor, but she didn't know what kind it was, how severe it was, how long she had to live. So that was a big ethical concern initially, and again with this admission.

Other participants recalled their relationship with previous patients who had the same diagnosis, and drew upon that past experience to inform the child's current situation.

At least the previous case of this (name of tumor) that I had that died recently, hers was resected almost entirely, and the margins were still positive, and then it regrew. Hers (current child) was not even resectable at all, so I feel like she's already starting with like a disadvantage.

What is. All participants shared a robust awareness of the child's current condition as informed by engagement with others, comprising this category of "what is" in the relational dimension. Across all cases, health care professionals shared vivid descriptions of the following: what the child recently said/did or how the child acted in their presence, including descriptions of child's current physical, cognitive, and emotional state, the child's current treatments and interventions, and recent conversations with the parents, including examples of how the parents were now making choices for the child's care or conveying an understanding of their child's condition. One participant described her perception of the child's current status with these words:

I see the progression of the disease. He is unable to move any of his limbs...you know, just over the last week the change in...his face. And he used to be able to smile or grimace, and move his tongue and now he's not doing those things...His eyes still, you know, he's still able to follow you with his eyes.

Another health care professional offered this description of changes perceived in the child's behavior. "She's kind of changed in her openness to talk about how she's feeling. She doesn't, she seems withdrawn, doesn't really say too much. She seems angry at times...It is hard to communicate as effectively as it was in the past."

Physician and nurse participants provided description of delivering news of disease progression and sharing medical-related updates with the family. Several participants described personal life experiences that were simultaneously unfolding and impacting their care of the child, including death in the family or a new pregnancy.

Yes, and it's not to say I wouldn't have chosen this had I know the plan as it stands currently, but, um, (*pause*) the fact that, you know. Now I just really adore him, so and I really love the family too. But I don't, I don't know, um, things have transpired in my

own life, so, this might not have been the best time for me to care for a patient like this under the current plan.

Another participant described how the experience of her sister's death impacts her current care, stating,

And I did in a lot of situations share about my own loss. Only if theirs is, you know definitely a loss, or it's going to be a loss soon. Um, just because I think then I'm someone who's not just a professional, I also have some personal, you know, I share it very briefly, I don't expand upon it unless they ask me. I did share it with him [the father], you know. It's always hard to see that kind of pain, you know, obviously I have a lot of empathy for that.

What should be. This relational dimension focus on "what should be" encompasses all of the ways participants described their expectations for next steps in care as related to others (the child, the parents, or team members). Several relational "what should be" expectations were common across all cases: the child's comfort should be maximized at end-of-life (physical, emotional, spiritual), the child should receive the highest level of care for the remainder of his/her life (respected and treated with dignity), and a clear plan should be established for care (including communication between family and team). Three participants offered these reflections:

(1) "I think just what's best for (child's name), which how is he gonna feel more comfortable, and not burdened by us?" (2) "I just pray that she finds, that she comes to some kind of, I don't know if acceptance is the word, or some kind of place where at least she can, yeah, know that she's leaving something positive." and (3)

I guess I just hope that he goes peacefully and that somehow in his little brain he knows, like, that he was cared for with love his whole life. And you know, when his parents aren't there, you know his parents love him so much. And that he found like love in his nurses.

For the cases involving older children, participants focused on future care that would allow the child to know diagnosis/prognosis and have the autonomy and opportunity to express feelings and make decisions about living out his/her remaining time.

I would be worried or afraid that anyone could pass away without having that space to, um (pause) process what that means for her and to be honest about that. I feel like her parents want her to have that space, so I also try to trust that they'll make that happen.

Participants also expected future care that would allow the child and parents to have opportunities for memory-making or legacy building.

For some of the cases, participants hoped for no further re-hospitalizations, believing the child should receive all future care at home with the support of a hospice team. Participants also shared statements of "what should be" from a decision-making perspective, as reflected in their expectation that parents should "get on the same page," or the child should "declare" themselves physically so decisions about de-escalating care would be clear. As one participant noted:

I guess more specifically, I hope that, you know it's hard to say that you hope that someone declines, but I hope that he at least, you know, pronounces himself (physically) in some way makes it obvious that, you know, his time is coming, or that it's not.

Because like I said he's been kind of in the gray area so much. Um. Other than that, I mean, I just, I would just like him to be comfortable. I just think that most of his, most of the things that we're doing for him right now like can't possibly be comfortable.

Participants also expressed thoughtful expectations about “what should be” including: the child experiencing the love of family and health care team, the parents and siblings feeling supported in their grief, and providing to support team members involved in the child’s care.

Internal Dimension

Health care professionals offered glimpses into the internal processes that informed their awareness that the child would not survive. This internal dimension was characterized by the participants’ own thoughts, feelings, biases, and preferences and could also be divided into the same three overlapping time-oriented focuses of past (what was), present (what is), and future (what should be).

What was. For this internal dimension category, participants remembered their past thought processes or feelings that were now being called to mind as a part of their current awareness. Common across all cases were reflections of participants’ internal knowledge about neonatal/pediatric medical conditions and progression. Some participants also remembered their own feelings caring for other children who had died, or feelings that arose with the death of their own family member. One participant described how her grandmother’s recent death impacted her thoughts while caring for a child whose parents were choosing to not share the terminal diagnosis.

Part of this (small sigh)...so we lost my grandma in November. We, I kind of had to be like the rational one for my family, like, “You guys should, this is, this is what dying looks like.” And still them not being able to process well, and them then not telling my grandma until like two days before, then she said, “Am I dying, Oh no!” Like I wouldn’t want that experience for myself....If you have an opportunity to be able to have some

control over what happens, or what you say or do, or how you want things, I want people to be able to have that.

Other health care professionals shared feelings about their earlier involvement in the child's care, including concern upon hearing of the initial diagnosis.

What is. The internal dimension of "what is" was reflected multiple times throughout all interviews with participants. Across each case, health care professionals shared their present feelings about the child's situation and also what it felt like to be participating in the child's care, which included feeling sad, grateful, privileged, alone, weary, conflicted, and overwhelmed. Many spoke to valuing their current relationship with the child, as exemplified by this participant's reflection:

And also feeling my own pain of, um, (child's name) is going to die. And she shouldn't, this lovely, vibrant child shouldn't die. That just shouldn't happen. And my own pain of, I hate that she is going through this. Um, and I'm gonna miss her. And I'm gonna miss seeing her family.

Throughout all cases, participants also expressed feeling supported by either their colleagues or their own personal family members as they cared for the child.

But it's kind of like, I see it's the same kind of experience that it would be of being at war. Like I said it's a stupid analogy, because I don't view this as a war. But those of you, your comrades who are on the front line with you, like nobody else can really understand it the way you all understand each other.

Some participants shared their personal faith beliefs about God and heaven that they related to the child's impending death.

So I know that the progression of this, without too much like umm, complications, would be that he would be extubated, be surrounded by love, and he would die. So those, that part doesn't worry me so much. And my own personal belief is that God is taking care of him. So that is another thing, he may have angels surrounding him the whole time, I don't, we don't even know. I'm going to go with that [tearfully].

Other participants described perceiving their own personal limitations or feeling burdened while caring for the child and family. Several participants spoke of learning important life lessons by knowing the family and participating in the child's care, such as this participant who shared:

I wish, it is just very hard sometimes to rationalize why these things happen, especially to kids, babies. But I also think that there is a greater purpose and a reason he was born, and reason that he, you know, was with us. And you have to, you know I told his mom, "I take, I take a lot away from that. I take a lot away from what (child's name) has taught me about just keeping the little things precious."

What should be. In the internal dimension of "what should be" participants reflected on their beliefs, thoughts, and feelings about the future. With each case, participants vocalized their expectations about how they might be personally involved in the child's future care. Some participants wondered how it would feel if they decided to reach out to the family when the child is discharged home. Other participants discussed their conflicting thoughts on whether or not they wished to be present when the child dies.

I'm very torn about um (pause) even taking care of him, too. Because it is hard you know. A full day of like looking at him all day like that. But at the same time I want, I want to take care of him, because I feel like I care a lot about him and I want you know, him to have that...So it is making me more and more attached to him which makes it

harder...Somedays I pray that it is not on a day I'm working, but at the same time I want to be there. Yeah.

Several participants shared that the child's situation made them think about what they might choose if their own child was at end of life in the future. "It made me sad. I have a three year old, and like I was telling my co-worker like, I would tell my daughter, 'you're gonna go to heaven,' and we would want to talk about it." Many of the participants expressed their anticipation of how they might work through their own feelings of grief or find support for themselves after the child's death.

The Delicate Dance of Figuring it Out

In addition to being informed by relational interactions with others and their own internal reflections, health care professionals described a specific issue or aspect of the child's care that was foremost on their mind and required, from their perspective, some form of decision making or action. In many of the cases, participants likened participation in decision-making for the child to be that of a delicate or intricate dance. As such, participants' exact words were chosen to describe the component of health care professionals' awareness that is focused on identifying and addressing key problems or issues currently impacting the child and family. One participant used the dance metaphor to describe the multiple layers of support available in the interdisciplinary team with these words:

I've noticed...there's sometimes a dance of figuring out on the, on the provider team or care team kind of, who's going to do what part. Un, it's not a bad or good thing, I'm just recognizing like I'm thinking about that the art therapist is involved with her, that child life is involved with her, I'm involved with her...and so knowing, kind of, where is the conversation about, um, death happening? Or where is the conversation we are trying to

have about what (child's name) wants or what space she needs happening? Are we all trying to have the same conversation? You know, that kind of dance. How do we do that in a way that um, meets the need of (child's name) and her family?

For participants in Case 1, the “figuring it out” was determining how to help the parents reach an agreement on when the child should be extubated from ventilator support. In Case 2, participants were working on “figuring out” how to minimize suffering and limit aggressive medical interventions if the child's condition deteriorated further. The “figuring it out” in Case 3 was focused on determining how to best support the child in processing the recent news of disease progression. Participants in Case 4 were focused on “figuring out” how to help the parents disclose to the child the true diagnosis and terminal prognosis, as this information was being withheld, per parents' request.

Outcome of Health Care Professionals' Awareness

Four main themes were identified, each of which can be characterized as an immediate outcome of becoming aware that a child will die. While two have roots in the relational dimension (professional responsibility and staying connected), the other two reflect the internal dimension (grounded uncertainty and holding in).

Professional Responsibility. Awareness of the child's impending death resulted in participants perceiving a professional responsibility for current and future aspects of the child's care. Participants in all cases described feeling responsible for optimizing the child's physical, emotional, and spiritual comfort, while also minimizing suffering. All health care professionals also expressed a perceived responsibility for guiding or participating in ongoing decision-making for the child's care.

Physicians described feeling responsible for offering timely information on the child's clinical status and choices for feasible medical interventions.

You kind of know with certain families like, you want to be the one to give them that news, too, you know. So it's sad that you have to say it but at the same time you don't really want anyone else to tell them that either, because you like to think that you know how the family would like to hear that news and the best way to communicate with them. And so at the same time it is kind of like a privilege to end up being the one, you know. I'm going to do that for you because I kind of know what you, how much you want to know at each stage and I know you better and wouldn't want somebody else to do it.

Many of the nurses, along with the social worker, chaplain, and child life specialist reported feeling responsible for helping the child to process his/her feelings, and felt it their duty to provide a protective environment for the parents and child to accomplish what was most important. As one participant offered, "I wish I could go into her mind and help, you know, like pull apart all those feelings and see like, are there other things we could do to make her feel not so, you know, trapped."

Staying connected. Understanding that a child is transitioning to an end-of-life situation resulted in participants feeling committed to staying connected in relationship with the child, the parents, and colleagues/team members. One health care professional, anticipated how she might stay in contact with the child after discharge home stating,

I don't know what is the HIPAA about visiting and stuff, if she decides to be in a hospice setting or whatever. But I'm not done with her! She might not be getting any more chemo, I don't know. But I still want to be involved. And for her to know that I have her back for sure.

All participants described relying heavily on face-to-face interactions with other team members to inform their thinking and make determinations for how to best guide and support the child and family. Most health care professionals shared that they preferred interaction with others over reading the medical record in order to feel informed on the child's current condition. Per one participant, "I think the documentation is secondary. The in-person conversations I feel are really paramount to make sure that everything is clear and that I'm not interpreting something that someone has written in a way that they didn't intend."

Participants described how they are currently connected to the child and family, and anticipated how those encounters might change if child goes home for end-of-life care. Some health care professionals even identified becoming aware during the research interview of potential strategies for connecting in relationship with the child and family. One participant realized, "...I'm not going to be here [tomorrow], so maybe I'll write her a little card....have somebody give it to her."

Grounded uncertainty. Health care professionals shared current and future aspects of the child's care that they perceived as uncertain. One participant described the child's current situation as liminal in nature: "Now I feel like we're stuck in the limbo of things. I feel, like I'm probably more negative than the other people I've talked with." Another shared the experience of daily caring for the child while considering the uncertainty of when death would arrive by stating,

So when she comes in I don't look at her and think, you know, "Oh what's it going to be and who knows when?" But I just try to think about what's the best today that we can do, because that's all you can do.

Across all cases, these uncertainties were expressed as participants wondered about the child's understanding of his/her condition, the child's level of comfort, or what decisions the parents might make for the child's care. As one participant wondered about the child with severe neurological deficits,

Like I said he doesn't have a whole lot of like awareness of what is going on, and it is hard to tell what his level of consciousness is, so it could just be me projecting my own, you know, my own feelings on what he looks like. And maybe that doesn't mean anything. Does he smile? Does he frown? It is hard to know if any of those things he's actually doing on purpose or not.

Uncertainties were also expressed as participants made assumptions or best guesses as to what the parents or child might be thinking, feeling, or deciding, based on the present situation. One participant described her thoughts about the child who had not yet been told of the terminal diagnosis with these words:

I feel like if she knew she would be able to console her parents, too. And I don't think she's being allowed to do that because she doesn't know. Like, her parents are the ones, you know, holding the weight of all of this. Whereas, I feel like if she also knew she could, kind of, help them cope too. I don't know. I feel like she's old enough that she would understand. But what I don't know is why they're sheltering her from that so much.

All participants were asked about their hopes and fears for the child. Responses were consistently grounded in an understanding of the child's current situation with anticipation about a still uncertain future state, including: hope for a peaceful death, worry that the child felt alone,

or concern the parents will decide to continue full medical interventions. This participant's words reflect concern about the level of future treatment:

I worry that he would get worse and his parents would change their minds about, you know, maybe in an acute situation or something like that they would change their minds and they wouldn't be ready, and then he would end up getting CPR and intubated and all that stuff. And that would obviously prolong, you know, prolong things for him. I definitely would not want that to happen. Hopefully that won't be the case, but it is hard to tell.

Uncertainties about next steps in the child's care were often grounded in an expressed belief about the family's ability to eventually make a decision or come to consensus and express their wishes for the child's end-of-life care.

But, I don't have any worries like the family, they're not gonna, this is normal feet-dragging or whatever, this is just coping and grief and letting things soak in. I don't really have, she [child's mother] knows what is good, she knows what she feels is good for (child's name) and she will get there.

Another participant reflected on her own feelings within the context of the parents' experience, expressing belief in the eventual outcome. "But at the same time I know, you know, it's ah, you know, what I'm feeling is a spit into the ocean of what his family's feeling. You know, we'll get through." Participants also reflected on potential resources, including the expertise of other colleagues, who could guide the family and team through identified areas of uncertainty.

Holding in. Health care professionals provided glimpses into their internal thoughts and feelings, yet as often reflected in the silence that occurred during the interviews, participants

were also holding much in mind that went unspoken. When asked, participants stated there were aspects about the child's care that they were holding in mind, but not always sharing with others. "...maybe I haven't really said out loud, but I feel like everyone feels the same, just about like, you know, I hear the mom planning like some sort of fundraiser, something for like (name of month), and I'm thinking like, "I don't know if that's, if she's still going to be there." Another participant described holding close the idea that the other children the team is caring for may die too:

I think, you know, (sigh) taking care of her and then moving on to taking care of the next patient and sometimes you're like, I'm thinking, this you know, "maybe we're just a year or two away from this same thing happening." Or caring for another patient and saying, "I'm so happy that this family is not going to have to go through this." You know, just with, kind of what's expected to happen.

Other participants expressed feeling frustrated with the current pace of decision-making, or being aware of their own emotions while also wishing to be present for the parents. This health care professional shared:

I certainly have my own personal sorrow about his predicament. And I think what I hold (pause) is how I can best communicate that to the family. Um. So that they understand that I appreciate their son and what he means to them. But by the same time hold true what I know is medically appropriate for him and in his medical best interest.

Some participants shared how they put aside feelings of guilt, inadequacy, grief, sadness, and the reality of the child's eventual death in order to be fully present to the child and family in the moment.

When she was first diagnosed, right off the bat the doctors said, “This is not a good prognosis.” She’s you know basically they said at that point, “She’s not gonna do well.” Um (pause) but then you know, she started moving forward in treatment and she’s so delightful and the family’s so delightful, and I just kind of chose to forget a little that (pause) she’s going to die. And even though it was in the back of my mind all along, you know, maybe to engage with her and her family I needed to put it in the back of my mind, um, so that I could continue to do my work with them, you know.

Participants also described how they are mindful to hold in check their own biases and personal preferences for the child’s care, especially in cases where their ideas might conflict with the wishes of the child or parents.

Yeah, I mean I think that my only bias is the hope that she would be at home, with people she loves and surrounded by things that are comfortable to her, if or when she does die. If I take a step from my own bias, I hope that it looks like what she wants it to look like. Um, cause maybe that’s not what she wants it to look like.

Theoretical Model of Health Care Professionals’ Awareness

Figure 1 depicts the emerging theoretical model of health care professionals’ awareness, beginning with initial cognitive awareness of the child’s terminal condition, incorporating the fluid motion of the “delicate dance” within the relational/internal and time-oriented dimensions, and including the thematic outcome of health care professionals’ awareness. This theoretical model captures the research findings that emerged from data collected as health care professionals were in the very act of “figuring out” next steps in the child’s end-of-life care.

Based upon this researcher’s 32 years of clinical experience and knowledge of existing neonatal/pediatric end-of-life research, it is anticipated that the initial cycle of a health care

professionals' awareness does indeed inform decision-making with the family and leads to concrete interventions or actions for all involved. Figure 2 depicts the addition of such outcome to the awareness model, the majority of which had not yet occurred for the cases in this research.

Likewise, based upon this researcher's years of clinical experience and existing neonatal/pediatric end-of-life evidence, the initial cycle of health care professionals' awareness is most likely followed by multiple cycles, as each new issue or need arises for the child and family. These multiple cycles of the "delicate dance of figuring it out" eventually end upon arrival at the moment of the child's actual dying. It is in these tender moments when all involved are pointedly aware that uncertainties have ceased, and focus turns instead to tending to the child's dying body and honoring the relationship between child, family, and team. Many participants in this study expressed their hope for the child to experience a peaceful death surrounded by the love of family and the team. Figure 3 illustrates the trajectory of health care professionals' awareness in its entirety, and is overlaid upon phases of transition, which will be described further in the Discussion section of this paper.

Discussion

Health care professionals' awareness of a child's impending death is a fluid, ongoing, and complex process informed through relationship with others and internal reflection. As per Eisenhardt's (1989) case study approach, synthesized findings are compared with existing evidence confirming and/or conflicting with the findings. This emerging theory of health care professionals' awareness appears to be unique, but also has components that resonate with portions of other existing theories, conceptual framework, or research findings.

The timing of data collection for this study was such that the health care professionals were still involved in the early phases of becoming aware of a child's impending death, resulting

in many participants sharing what was still unknown about the situation at hand. The overall flow of awareness cycles unfolds amidst this uncertainty, while occurring in tandem with the child's changing needs as death approaches. As a whole, the cycles of awareness depict a significant transition for the child and all involved.

Arnold van Gennep, an anthropologist who studied how humans across all cultures experience significant transitions in their lives, reported his findings in the sentinel work, *Rites of Passage* (1960). Per van Gennep, times of significant transition begin as all involved separate from the known, enter into a period of liminality (described as a period of waiting), and ultimately arrive at a new place of reintegration within their community. van Gennep's work highlights how throughout this journey, rites or rituals are developed by those experiencing the transition, creating structure, order, and meaning amidst uncertainty.

The emerging theory of health care professionals' awareness can be overlaid into van Gennep's rites of passage model (1960). The passage in the awareness model (depicted in Figure 3) begins when health care professionals separate from the reality that the child can be cured, then enter into repeated cycles of awareness and the delicate dance of figuring out what is needed for the child's end-of-life care, and eventually reconnect in community with all who are with the child during the actual death. This researcher offers for consideration that the cycles of awareness and acts of decision-making inherent in neonatal/pediatric end-of-life care are in and of themselves rites of passage, thus reflective of van Gennep's work.

Neonatologist and palliative physician Dr. Brian Carter's recent writings on liminality in pediatric palliative care (2017) further informs the findings from this study. Carter (2017) describes children and families as being "betwixt and between" their past life and the current ramifications of a serious illness, and also presents strategies for palliative care teams to be

present in such spaces of liminal uncertainty. Across all cases of this research, participants conveyed their experiences of becoming aware of all that encompasses a child's needs amidst uncertainty, exemplifying what it means, per Carter (2017) to be "betwixt and between." Additionally, Jordan, Price, and Prior (2015) report their findings of parental experiences of living in liminality when caring for a child with serious illness, strengthening the idea that the concept of liminality is a fitting component in the trajectory of pediatric end-of-life care.

This research is the first to focus solely on exploring death awareness from the perspective of neonatal and pediatric health care professionals. The findings here hint to congruence with Glaser and Strauss' work on death awareness (1965) and timing of such awareness (1968). As noted in their adult patient-focused studies, health care professionals were holding much in mind about their patient's overall well-being and understanding of the prognosis, while simultaneously attending to pressing health care needs (Glaser & Strauss, 1965), which is similar to the experiences of participants in this research. However, the neonatal and pediatric health care professionals reported only an open awareness approach to the child's impending death, as all were engaged in honest conversations with parents about the child's terminal condition. There was no evidence of participants' engaging with parents in a closed awareness, suspected awareness, or mutual pretense awareness as described previously by Glaser and Strauss (1965) in their adult end-of-life research.

Health care professionals in this research shared feelings of grief at the thought of the child's impending death. Some participants reported conflicting feelings of wishing to care for the child at the time of death and at the same time, preferring the death not happen on their watch. These honest feelings fully reflect Dr. Danai Papadatou's dual process of health care

professionals' grief (2009), as a clinician vacillates between the desire to stay connected and also self-protect from the intensity of all that encompasses a child's end-of-life care.

The relational aspect of how health care professionals were informed in this research, especially participants' reflections on their preference to receive updates from other team members rather than reading the medical record, resonates with findings from previous studies. Beringer and Heckford (2012) and de Graves and Aranda (2002), in their retrospective chart review research, noted that medical records for children with serious illness often lacked details about conversations with families and decision-making progress at end-of-life. Participants in this research conveyed a strong preference for using an oral tradition approach to convey or receive pertinent information, rather than relying on documentation in the child's medical record.

Nurses' shared experiences in this study resonated with findings of researchers who explored neonatal and pediatric end-of-life care from a nursing perspective. Nurses in this research conveyed strong, often conflicting emotions when providing end-of-life care, along with a keen focus on wishing to minimize the child's level of suffering, all of which were noted previously by Bloomer, O'Conner, Copnell, and Endacott (2015), Davies et al. (1996), Stayer and Lockhart (2016). Health care professionals in this research also reported ways in which they were personally and professionally impacted by caring for the child. Their descriptions resonate with Beaune, Muskat, and Anthony's findings (2017) of clinicians who experienced personal growth and new or altered life perspectives when caring for children at end-of-life.

Although with each health care professional in this research focused on different issues, all conveyed overarching concern for the child's well-being from a physical, spiritual, and emotional perspective. Across all cases, participants were united in their goals to minimize suffering and provide a peaceful death, and were also mindful of the relationship between parent

and child. Their expressed expectations for the child's dying resonate with components of Ruland and Moore's (1998) proposed theory peaceful death for adults, including a desire to control pain, provide comfort, and have loved ones present at the time of death.

In evaluating the theoretical model of health care professionals' awareness that emerged from this study, the researcher also reviewed theories and writings on sense-making and transition. While components of these concepts resonate with the new awareness model, the cycles of awareness as reflected in this data appear to be a unique and separate phenomenon. Additionally, the researcher re-reviewed evidence describing parents' experiences with end-of-life decision making for their child, and did not find existing theoretical models or conceptual framework that fully matched the emerging theoretical model of health care professionals' awareness that emerged from this research.

Practice and Research Implications

In clinical settings a child's end-of-life trajectory unfolds at varying paces, significantly impacting all involved. Health care professionals in this research simultaneously processed information on multiple levels, resulting in a myriad of reactions and emotions to the child's situation; their responses provide insight to ways the theory of health care professionals' awareness can be used in clinical settings.

Perhaps most striking to the researcher was the depth of emotion participants conveyed at such an early point in the end-of-life care trajectory. As the researcher coded for emotions, it was noted that participants most often openly emoted strong feelings when considering the actual moments of the child's death, describing physical changes seen in child that made deterioration very real, or wondering what the child was thinking about or feeling.

Health care professionals in this study reported feeling best supported by colleagues who are “in the trenches” with them, yet also described moments of isolation or uncertainty about the support structure they might access. Of note, this research was conducted at a children’s hospital with multiple avenues for staff support already engrained in the culture of care and often provided at the time of a child’s death. These include opportunities for resiliency training, regular staff debriefings, designated self-care space, ethics rounding, and continual access to interdisciplinary team members responsible for staff support. Health care professionals’ report of emotional impact indicates the importance of reaching out and supporting neonatal and pediatric team members during the early phases of death awareness and throughout the end-of-life care trajectory.

The interview questions, as noted in the interview guide (Table II), provided an avenue for participant processing and problem solving. Several participants came upon realizations about the child’s case during the interview they had not considered prior, or discovered new ways to support the child or family. All participants reported the interview experience to be a beneficial time of processing, using words that included: helpful, therapeutic, cathartic, and reflective. Participants’ report of the interview experience provide insight that perhaps some of the main questions from the research interview might be in fact a helpful assessment tool to learn more about health care professionals’ awareness. Such questions could include:

- *What is your understanding of the child’s situation?*
- *Based on your understanding, what do you expect to happen next?*
- *What do you hope for?*
- *What worries you the most?*
- *What is most important to you right now?*

- *What gives you strength or supports you at this time?*

These same questions are used by palliative care clinicians to assess parental perceptions (Waldman & Wolfe, 2013; Duncan & Kobler, 2016; Limbo, Kavanaugh, & Kobler, 2017) and can be easily adapted to assist health care professionals in processing their emerging awareness and perceived priorities for the child's care.

The researcher has recently found the awareness model's internal and relational dimensions to be a helpful framework when helping health care professionals' to process their level of awareness. The researcher has incorporated simple assessment questions such as, *"What about this case is reminding you of past experiences?"* or *"What aspects of the child's care are assumed to be true and what are verified as true right now?"* This approach was quite effective in helping team members to articulate what was foremost on their mind, while calling out assumptions and identifying the true issues to be addressed in the moment. As such, perhaps a very practical outcome of the awareness model will be to create assessment questions for the internal and relational dimensions of the awareness model that would help team members more fully evaluate their thoughts, and identify presumptions, biases, and feelings. Answers to such questions can help to refine clinicians' focus on gaps in their awareness of the child's situation and further facilitate end-of-life decision making.

Future research is needed to enlighten and deepen the emerging theoretical model of health care professionals' awareness, including longitudinal studies to explore experiences across the entire trajectory of a child's end-of-life care. Enhancing understanding of these processes can inform development of strategies to facilitate health care professionals' identification, acknowledgement, and verbalization of pediatric end-of-life awareness in order to move forward with effective care planning. Study design that includes respectful and ethical ways to explore

death awareness from the child and parental perspective would be beneficial, with the goal of identifying similarities and differences in early end-of life decision-making processes.

In addition, research to explore the impact of early awareness of a child's impending death can provide further insight to health care professionals' needs as they process the reality that a child in their care will not survive. Analysis of further research data can also identify measurable strategies to support team members, especially nurses, who reach awareness prior to the parents, or when discordance in views leads to health care professional moral and emotional distress. It is anticipated that subsequent research would include measurement of resources or tools created to guide health care professionals' emerging awareness and articulation of such awareness to all involved in the child's care.

Limitations

This research was completed at one teaching children's hospital in the Midwest, with findings reflecting health care professionals' experience at a mixed suburban/urban location. While the researcher attempted an a priori approach, there remains the potential for preconception regarding possible theoretical constructs and propositions, based upon the researcher's 32 years of clinical experience caring for infants and children at end of life. As there are most likely aspects of their experience that participants chose to keep private, it is possible that there are additional key factors influencing health care professionals' awareness that were not shared during the research interviews. The case study approach can produce large amounts of empirical evidence that could result in "overly complex" theory generation (Eisenhardt, 1989); care was taken to analyze the rich, thick data in a manner congruent with the aims of this study.

Conclusion

From the beginning moments of awareness that a child will not survive, health care professionals hold much in their minds and hearts as they strive to meet the child's needs and guide parents in the early phases of decision making. Health care professionals' awareness is a fluid, ongoing process informed by relationship with others and internal reflection. Providing health care professionals with avenues to process and share their ongoing awareness of a child's impending death is an essential component to ensuring quality care that honors all aspects of the child's living and dying.

References

- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*, 13(6), 871-883. doi: 10.1177/1049732303013006008
- Beaune, L., Muskat, B., Anthony, S. J. (2017). The emergence of personal growth amongst healthcare professionals who care for dying children. *Palliative and Supportive Care*, 22, 1-10. doi: 10.1017/S1478951517000396
- Bell, C. J., Skiles, J. L., Pradhan, K. R., & Champion, V. L. (2010). End-of-life experiences in adolescents dying with cancer. *Journal of Supportive Care in Cancer*, 18(7), 827-835. doi: 10.1007/s00520-009-0716-1
- Beringer, A. J., & Heckford, E. J. (2002). Was there a plan? End-of-life care for children with life-limiting conditions: A review of multi-service healthcare records. *Child: Care, Health and Development*, 40(2), 176-183. doi: 10.1111/cch.12020
- Bloomer, M. J., O'Connor, M., Copnell, B., & Endacott, R. (2016). Nursing care for families of dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and sources of discomfort. A mixed methods study. *Australian Critical Care*, 28, 87-92. doi: 10.1016/j.aucc.2015.01.002
- Brosig, C. L., Pierucci, R. L., Kupst, M. J., & Leuthner, S. R. (2007). Infant end-of-life care: The parents' perspective. *Journal of Perinatology*, 27, S10-S16. doi: 10.1038/sj.jp.7211755
- Bluebond-Langner, M., Belasco, J. B., & Wander, M. D. (2010). "I want to live, until I don't want to live anymore": Involving children with life-threatening and life-shortening illnesses in decision making about care and treatment. (2010). *Nursing Clinics in North America*, 45, 329-343. doi: 10.1016/j.cnur.2010.03.004

- Butler, A. E., Hall, H., Willetts, G., & Copnell, B. (2016). Family experience and PICU death: A meta-synthesis. *Pediatrics*, 136(4), e961-972. doi: 10.1542/peds2015-1068
- Caeymaex, L., Speranza, M., Vasilescu, C., Danan, C., Bourrat, M. M., Garel, M., & Joussetme, C. (2011). Living with a crucial decision: A qualitative study of parental narratives three years after the loss of their newborn in the NICU. *PLoS One*, 6(12), 1-7. doi: 10.1371/journal.pone.0028633
- Carter, B. S. (2017). Liminality in pediatric palliative care. *American Journal of Hospice and Palliative Care*, 34(4), 297-300. doi: 10.1177/1049909116629758
- Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Los Angeles: SAGE Publications, Inc.
- Darlington, A. E., Korones, D. N., & Norton, S. A. (2017). Parental coping in the context of having a child who is facing death: A theoretical framework. *Palliative and Supportive Care*, 13, 1-10. doi: 10.1017/S1478951517000463
- Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J.,...Stutzer, C. (1996). Caring for dying children: Nurses' experiences. *Pediatric Nursing*, 22(6), 500-507. doi: 10.1177/104345429200900213
- De Clercq, E., Elger, B. S., & Wangmo, T. (2016). Missing life stories: The narratives of palliative patients, parents and physicians in paediatric oncology. *European Journal of Cancer Care*, 8, 1-10. doi: 10.1111/ecc.12651
- De Graves, S. & Aranda, S. (2002). Exploring documentation of end-of-life care of children with cancer. *International Journal of Palliative Care Nursing*, 8(9), 435-443. doi: 10.12968/ijpn.2002.8.9.10688

- De Graves, S., & Aranda, S. (2005). When a child cannot be cured: Reflections of health care professionals. *European Journal of Cancer Care*, 14, 132-140. doi: 10.1111/j.1365-2354.2005.00520.x
- de Vos, M. A., Seeber, A. A., Gevers, S. K. M., Bos, A. P., Gevers, F., & Willems, D. L. (2015). Parents who wish no further treatment for their child. *Journal of Medical Ethics*, 41(2), 195-200. doi: 10.1136/medethics-2013-101395
- Docherty, S.L., Miles, M.S., Brandon, D. (2007). Searching for “The Dying Point:” Providers’ experiences with palliative care in pediatric acute care. *Pediatric Nursing*, 33(4), 335-341. doi: 10.1089/jjpm.2006.0236
- Duncan, J., & Kobler, K. (2016). Communication in pediatrics. In Dahlin, C., Coyne, P. J., & Ferrell, B. R. (Eds.), *Textbook in advanced practice palliative nursing* (pp. 597-608). New York, New York: Oxford University Press.
- Eden, L. M., & Callister, L. C. (2010). Parental involvement in end-of-life care and decision making in the newborn intensive care unit: An integrative review. *The Journal of Perinatal Education* 19(1), 29-39. doi: 10.1624/105812410X481546
- Eisenhardt, K. M. (1989). Building theories from case study research. *Academy of Management. The Academy of Management Review*, 14(4), 532-550.
doi: 10.4135/9781412986274.n1
- Eisenhardt, K. M., & Graebner, M. E. (2007). Theory building from cases: opportunities and challenges. *Academy of Management Journal*, 50(1), 25-32. doi: 10.5465/amj.2007.24160888
- Epstein, E. G. (2010). Moral obligations of nurses and physicians in neonatal end-of-life care. *Nursing Ethics*, 17(5), 577-589. doi: 10.1177/0969733010373009

- Feudtner, C., Carroll, K. W., Hexem, K. R., Silberman, J., Kang, T. I., & Kazak, A. E. (2010). Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making. *Archives in Pediatric and Adolescent Medicine*, 164(9), 831-839. doi: 10.1001/archpediatrics.2010.146
- Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J.,...Hinds, P. S. (2015). Good-Parent beliefs of parents of seriously ill children. *JAMA Pediatrics*, 169(1), 39-47. doi: 10.1001/jamapediatrics.2014.2341
- Feudtner, C., Zhong, W., Faerber, J., Dai, D., & Feinstein, J. (2015). Pediatric end-of-life and palliative care: Epidemiology and health service use. In Institute of Medicine Committee on Approaching Death: Addressing Key End-of-Life Issues. *Dying in America: Improving quality and honoring individual preferences near end of life* (pp. 533-572). Washington, DC: The National Academies Press.
- Fortney, C. A., & Steward, D. K. (2014). A new framework to evaluate the quality of a neonatal death. *Death Studies*, 38(5), 294-301. doi: 10.1080/07481187.2012.742475
- Gillam, L. & Sullivan, J. (2011). Ethics at the end of life: Who should make decisions about treatment limitations for young children with life-threatening or life-limiting conditions? *Journal of Paedtrics and Child Health*, 47, 504-508. doi: 10.1111/j.1440-1754.2001.02177.x
- Gillis, J. (2008). 'We want everything done.' *Archives of Disease in Childhood*, 93(3), 192-193. doi: 10.1136/adc.2007.120568
- Gilmer, M. J., Foster, T. L., Bell, C. J., Mulder, J., & Carter, B. S. (2013). Parental perceptions of care of children at end of life. *American Journal of Hospice and Palliative Care*, 30(1), 53-58. doi: 10.1177/1049909112440836

- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. Chicago, IL: Aldine Publishing Company.
- Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. Chicago, IL: Aldine Publishing Company.
- Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Baker, J. N.,...Furman, W. L. (2012). Parent-clinician communication intervention during end-of-life decision making for children with incurable cancer. *Journal of Palliative Medicine*, 15(8), 916-922. doi: 10.1089/jpm.2012.0006
- Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L.,...Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who made Phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27(35), 5979-5985. doi: 10.1200/JCO.2008.20.0204
- Hunt, H., Valdimarsdóttir, U., Mucci, L., Kreicbergs, U., & Steineck, G. (2006). When death appears best for the child with severe malignancy: A nationwide parental follow-up. *Palliative Medicine*, 20, 567-577. doi: 10.1177/0269216306069671
- Jordan, J., Price, J., & Prior, L. (2015). Disorder and disconnection: Parent experiences of liminality when caring for their dying child. *Society of Health & Illness*, 37(6), 839-855. doi: 10.1111/1467-9566.12235
- Kamihara, J., Nyborn, J. A., Olcese, M. E., Nickerson, T., & Mack, J. W. (2015). Parental hope for children with advanced cancer. *Pediatrics*, 135(5), 868-874. doi 10.1542/prds.2014-2855
- Kars, M. C., Grypdonck, M. H. F., Beishuizen, A., Meijer-van den Bergh, E. M. M., & van Delden, J. J. M. (2010). Factors influencing parental readiness to let their child with cancer die. *Pediatric Blood & Cancer*, 54, 1000-1008. doi: 10.1002/pbc.22532

- Kavanaugh, K. L., & Campbell, M. L. (2014). Conducting end-of-life research: Strategies for success. *Nursing Science Quarterly*, 27(1), 14-19. doi: 10.1177/0894318413509711
- Kavanaugh, K., Moro, T., & Savage, T. (2010). How nurses assist parents during decision-making regarding life support decisions for extremely premature infants. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 39, 147-158. doi: 10.1111/j.1552-6909.2010.01105.x
- Kavanaugh, K., Moro, T. T., Savage, T., & Mehendale, R. (2006). Enacting a theory of caring to recruit and retain vulnerable participants for sensitive research. *Research in Nursing & Health*, 29, 244-252. doi: 10.1002/nur.20134
- Lannen, P., Wolfe, J., Mack, J., Onelöv, E., Nyberg, U., & Kreicbergs, U. (2010). Absorbing information about a child's incurable cancer. *Oncology*, 78, 259-266. doi: 10.1159/000315732
- Lewis, S. L. (2017). Exploring NICU nurses' affective responses to end-of-life care. *Advances in Neonatal Care*, 17(2), 96-105. doi: 10.1097/ANC.0000000000000355
- Limbo, R., Kavanaugh, K., Kobler, K. (2017). Honoring relationship and hope. In Kobler, K., & Limbo, R. (Eds.). *Conversations in perinatal, neonatal, and pediatric palliative care*. Pittsburgh, PA: Hospice and Palliative Nurses Association.
- Lincoln, Y. S. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry*, 1(3), 275- 289. doi: 10.1177/107780049500100301
- Mack, J. W., Wolfe, J., Cook, E. F., Grier, H. E., Cleary, P. D., & Weeks, J. C. (2007). Hope and prognostic disclosure. *Journal of Clinical Oncology*, 25(10), 5636-5642. doi: 10.1200/JCO.2007.12.6110

- McGraw, S. A., Truog, R. D., Solomon, M. Z., Cohen-Bearak, A., Sellers, D. E., Meyer, E. C. (2012). "I was able to still be her mom" - Parenting at end of life in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, 13(6), e350-e356. doi: 10.1097/PCC.0b013e31825b5607
- McHaffie, H. E., Lyon, A. J., & Hume, R. (2001). Deciding on treatment limitation for neonates: The parents' perspective. *European Journal of Pediatrics*, 160, 339-344. doi: 10.1007/pl00008444
- Meert, K. L., Thurston, C. S. & Sarnaik, A. P. (2000). End-of-life decision-making and satisfaction with care: Parental perspectives. *Pediatric Critical Care Medicine*, 1(2), 179-185. doi: 10.1097/00130478-200010000-00017
- Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 30(1), 226-231. doi: 10.1097/00003246-200201000-00032
- Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics*, 117(3), 649-657. doi: 10.1542/peds.2005-0144
- Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. (3rd ed.). Los Angeles, CA: SAGE Publications, Inc.
- Mitchell, S., & Dale, J. (2015). Advance care planning in palliative care: A qualitative investigation into the perspective of Paediatric Intensive Care Unit staff. *Palliative Medicine*, 29(4), 371-379. doi: 10.1177/0269216315573000
- Moro, T. T., Kavanaugh, K., Savage, T. A., Reyes, M. R., Kimura, R. E., & Bhat, R. (2011). Parent decision making for life support for extremely premature infants: From the

- prenatal through end-of-life period. *Journal of Perinatal and Neonatal Nursing*, 25(1), 53-60. doi: 10.1097/jpn.0b013e31820377e5
- Papadatou, D. (2009). *In the face of death: Professionals who care for the dying and the bereaved*. New York: Springer Publishing Company.
- Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). Thousand Oaks, CA: SAGE Publications, Inc.
- Poles, K. & Bousso, R. S. (2011). Dignified death: Concept development involving nurses and doctors in Pediatric Intensive Care Units. *Nursing Ethics*, 18(5), 694-709. doi: 10.1177/0969733011408043
- Rosenberg, A. R., Dussel, V., Kang, T., Geyer, J. R. Gerhardt, C. A., Feudtner, C., & Wolfe, J. (2013). Psychological distress in parents of children with advanced cancer. *JAMA Pediatrics*, 167(6), 537-543. doi: 10.1200/JCO.2014.55.4659
- Ruland, C. M. & Moore, S. M. (1998). Theory construction based on standards of care: A proposed theory of the peaceful end of life. *Nursing Outlook*, 46(4), 169-175. doi: 10.1016/s0029-6554(98)90069-0
- Saldaña, J. (2016). *The coding manual for qualitative researchers*. (3rd ed.). Los Angeles, CA: SAGE Publication, Inc.
- Sandelowski, M. (2011). “Casing” the research study case study. *Research in Nursing Health*, 34, 153-159. doi: 10.1002/nur.20421
- Stayer, D. & Lockhart, J. S. (2016). Living with dying in the Pediatric Intensive Care Unit: A nursing perspective. *American Journal of Critical Care*, 25(4), 350-356. doi: 10.4037/ajcc2016251

- Steele, R. G. (2002). Experiences of families in which a child has a prolonged terminal illness: modifying factors. *International Journal of Palliative Nursing*, 8(9), 418-434. doi: 10.12968/ijpn.2002.8.9.10687
- Surkan, P. J., Dickman, P. W., Steineck, G., Onelöv, E., Kreicbergs, U. (2006). Home care of a child dying of a malignancy and parental awareness of a child's impending death. *Palliative Medicine*, 20, 161-169. doi: 10.1191/0269216306pm11390a
- Tomlinson, D., Hendershot, E., Bartels, U., Maloney, A., Armstrong, C., Wrathall, G., & Sung, L. (2011). Concordance between couples reporting their child's quality of life and their decision making in pediatric oncology palliative care. *Journal of Pediatric Oncology Nursing*, 28(6), 319-325. doi: 10.1016/j.ejca.2011.04.038
- Valdimarsdóttir, U., Kreicbergs, U., Hauksdóttir, A., Hunt, H., Onelöv, E., Henter, J., & Steineck, G. (2007). Parents' intellectual and emotional awareness of their child's impending death to cancer: A population-based long-term follow-up study. *Lancet Oncology*, 8, 706-714. doi: 10.1016/S1470-2045(07)70209-7
- van Gennep, A. (1960). *The rites of passage*. Chicago, IL: The University of Chicago Press.
- Wocial, L. D. (2000). Life support decisions involving imperiled infants. *Journal of Perinatal and Neonatal Nursing*, 14(2), 73-86. doi: 10.1097/00005237-20000900000-00008
- Waldman, E. & Wolfe, J. (2013). Palliative care for children with cancer. *Nature Reviews Clinical Oncology*, 10, 100-107. doi: 10.1038/nrclinonc.2012.238
- Wolfe, J., Klar, N., Grier, H.E., Duncan, J., Salem-Schatz, S., Emanuel, E.J., & Weeks, J. C. (2000). Understanding of prognosis among parents of children who died of cancer: Impact on treatment goals and integration of palliative care. *JAMA*, 284(19), 2469-2475. doi: 10.1001/jama.284.19.2469

Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.). Los Angeles: SAGE Publications, Inc.

TABLE II

Interview Guide

Background Questions

1. What is your professional discipline?
2. How many years you have worked in your profession?
3. Tell me about your role in caring for *Insert name of child (identified case)*.

Awareness Questions

4. How do you believe the child is doing at this time?
5. How did you come to your current understanding of the child's condition?
6. Help me to understand if and how you decide to share your thoughts about the child's condition with others?
7. Are there things you wish to express to others about the child, but do not have the opportunity to do so?
8. How do you interact with the child's parents?
9. What do you believe is the parents' understanding of their child's current condition?

Goals of Care/Decision-Making Questions

10. What do you expect to happen next for the child?
11. As you consider the child's current condition, what is your hope?
12. What is your greatest concern?
13. What goal for the child/child's care is most important to you at this time?
14. What is most helpful to you as you care for the child at this time?
15. When you think about the child's health care needs at this time, what documentation in the electronic medical record is most helpful to you?
16. How do you act upon decision-making information documented in the electronic medical record?
17. Holding in mind your understanding of the child's current condition, what health care decision, if any, do you believe should be made at this time?

Concluding Statements

18. What else would be important for me to know about your experience that I have not asked?
-or- What questions do you have for me?
19. What was it like for you to talk with me today?

TABLE III*Overview of Chosen Cases*

Attributes and Key Findings	Case 1	Case 2	Case 3	Case 4
Nature of the Child's Condition	Neonate with degenerative neuro-muscular disorder	Teen with life-long severe neurological deficits and respiratory insufficiency	Teen with metastatic cancer and significant disease treatment while receiving treatment	Teen with inoperable tumor experiencing a significant exacerbation of symptoms
Participants' Profession/# who participated in interviews	Nurse (3) Physician (2)	Physician (2)	Nurse (2) Physician (1) Social Worker (1) Chaplain (1)	Nurse (1) Physician (1) Child Life Specialist (1)
Time from completion of interviews to the child's death	2 weeks	Home on hospice, still alive	2 months	3 months
Nature of Case	Definitive terminal diagnosis with signs of significant disease progression at the time of interviews	Multiple past hospitalizations, current admission for respiratory failure. Child stabilized as interviews occurred, decision made to enroll in home hospice care	Receiving multiple treatments for cancer with recent diagnosis of significant disease progression. Family and team grappling with this news at the time of interviews	Receiving palliative treatments for inoperable condition. Presented in emergency room for significant symptom exacerbation at the time of interviews
Delicate Dance of Figuring it Out	Focus on determining when parents would choose a date for extubation from ventilator support	Focus on how to minimize suffering and not add treatments should the child's condition significantly change	Focus on how support the child and family process news of disease progression/determine next steps for care	Focus on helping parents tell their child news of the diagnosis and prognosis (parents withholding information, per their preference)

Attributes and Key Findings	Case 1	Case 2	Case 3	Case 4
Participant Hopes for the Child/Case	For the child to experience love, comfort, and a high level of care; For a decision-making partnership with parents	For a concrete end-of-life plan of care; for the child's comfort and minimization of suffering	For the child's comfort, peace of mind and spirit; For the child to have autonomy in making decisions for care; For the child to come to terms with death	For the child to know the diagnosis and prognosis; For the child to have autonomy in making decisions for care
Participants' Fears about Case	Family feels pressured to make a decision; Child's comfort and risk for infection	Parents would not really continue hospice care at home; The child would be re-hospitalized with next signs of physical deterioration	Child may not be fully honest/sharing her true feelings; Worried about type of death the child would experience	Fear that without knowing the diagnosis or prognosis, the child would not be able to live out/experience what he/she would determine to be most important
Expectations of what would be next for the child's situation	The child would continue to experience physical deterioration; Parents would choose a date for extubation	The child would go home on hospice care but parents will choose to readmit to the hospital upon signs of deterioration and re-escalate care	The child would have time before disease progression to engage in activities or opportunities important to her; Anticipate seeing signs of disease progression soon	The parents would continue to withhold information from the child; the child will continue to be readmitted for physical changes and receive additional treatment
Impact of the Case	Participants reported child has impacted them personally, including "light in the darkness," and "new focus in life"	Participants reported feeling a professional duty to care for the child amidst feeling burdened by weight of such care	Participants reported feeling close to child and family, feeling privileged to care for child, and an enhanced personal faith	Two participants reported reflecting on what they would want for their own child; the other participant expressed gratitude to participate in child's care

Figure 1. Theoretical Model of Health Care Professionals' Awareness of a Child's Impending Death

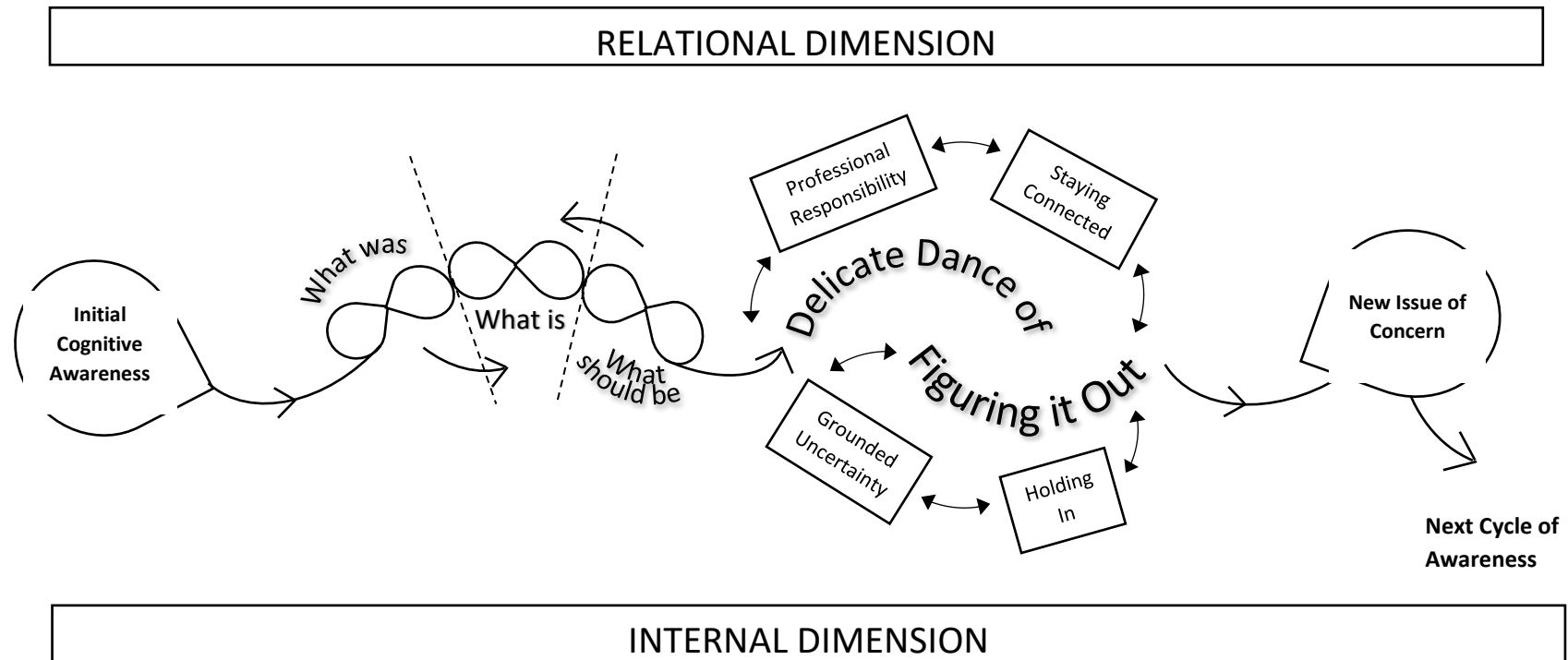


Figure 2. Health Care Professionals' Awareness of Impending Death: Theoretical Model with Added Outcome (shaded box)
(as informed by clinical experience and existing neonatal/pediatric end-of-life research)

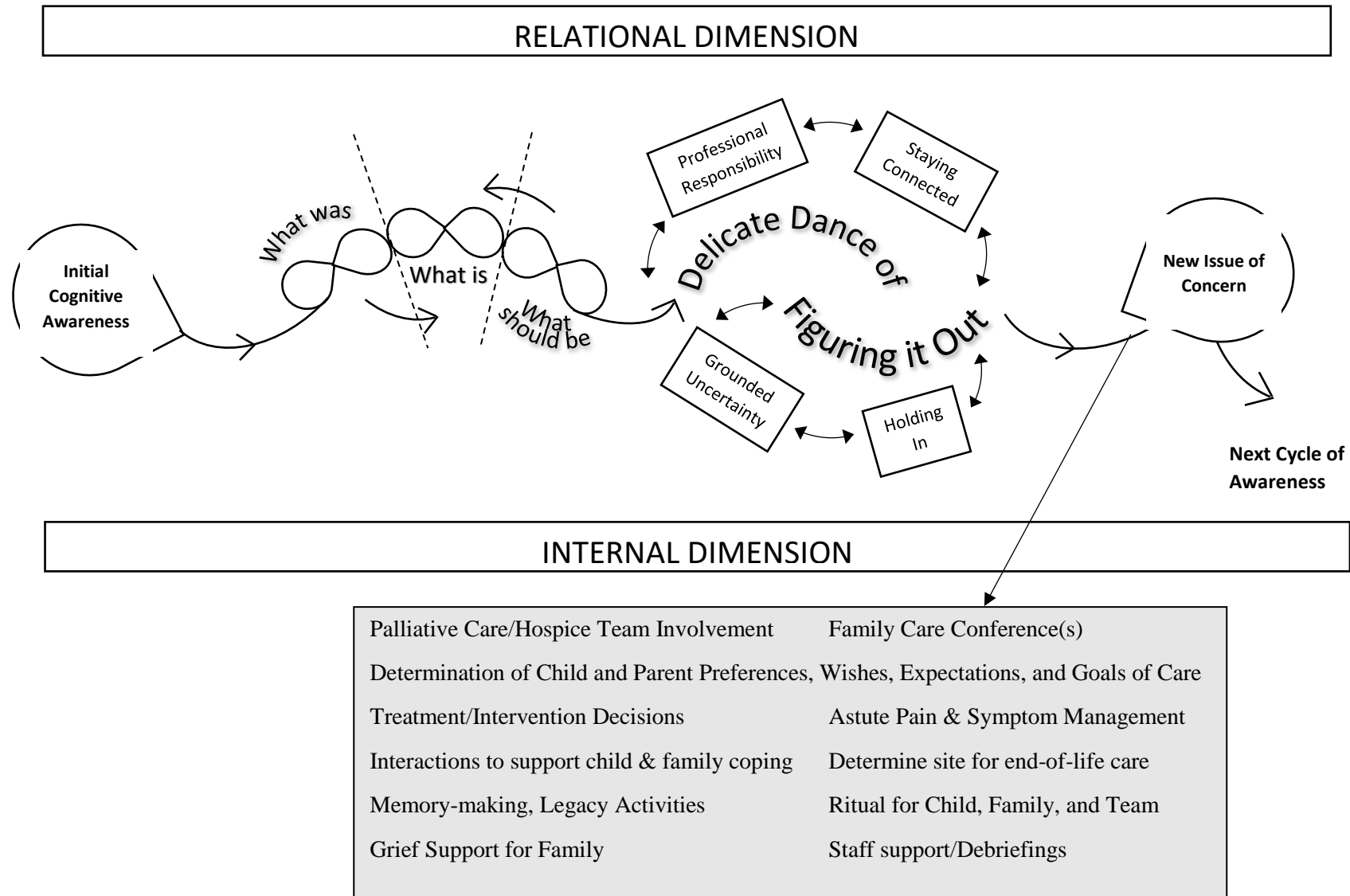
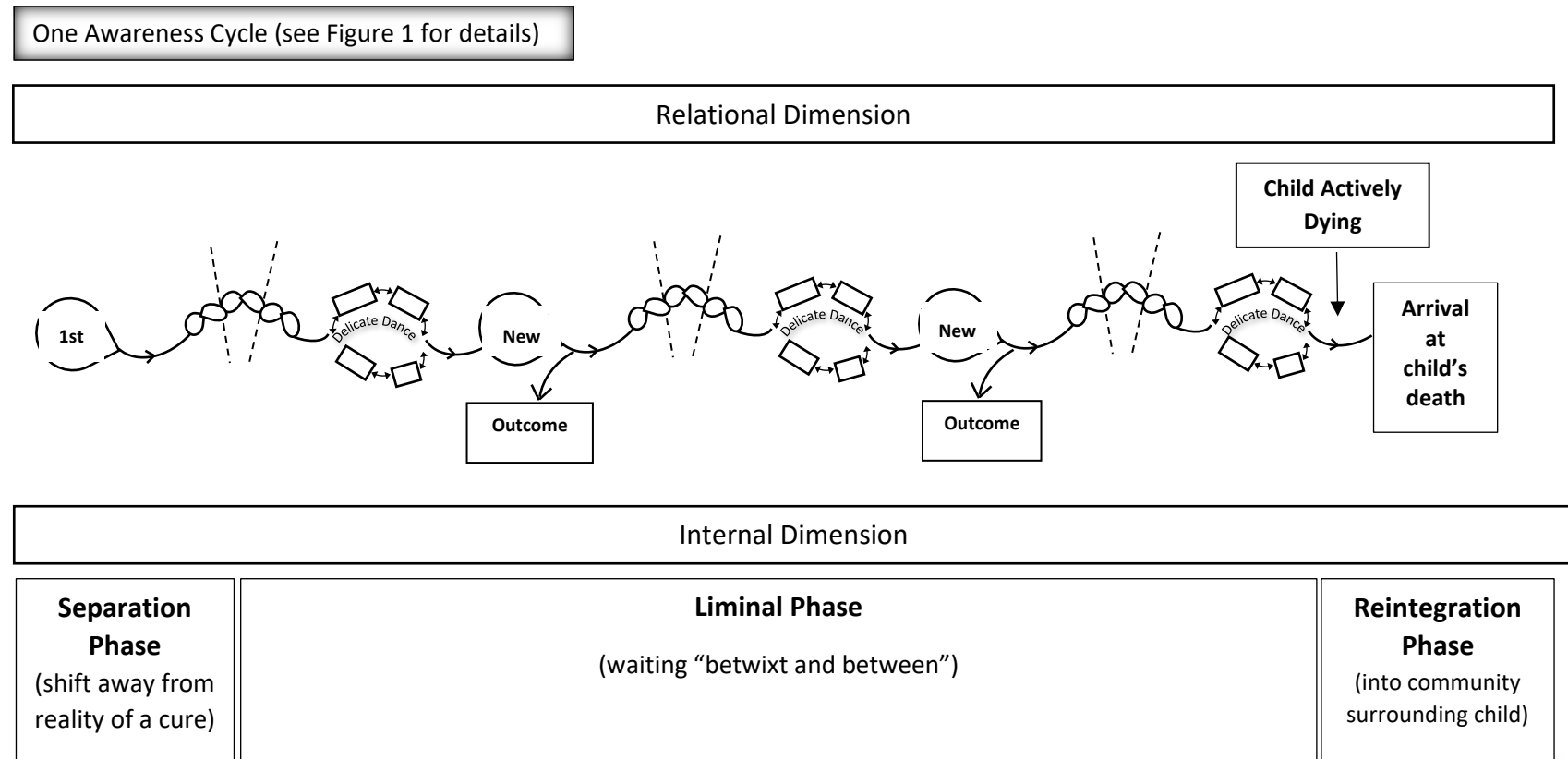


Figure 3. Theoretical Model of Health Care Professionals' Awareness through Full Transition to a Child's Dying
(as informed by Carter, 2017; van Gennep, 1960)



APPENDIX A

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response to Modifications)

April 5, 2016

Kathleen Kobler, MS

Women, Child, & Family Health Science
938 Twisted Oak Lane
Buffalo Grove, IL 60089
Phone: (847) 723-7911 / Fax: (847) 723-2261

RE: **Protocol # 2016-0208**
“Health Caregivers' Awareness of a Child's Impending Death”

Dear Ms. Kobler:

Your Initial Review application (Response to Modifications) was reviewed and approved by the Expedited review process on March 25, 2016. You may now begin your research.

Please note the following information about your approved research protocol:

Please remember to submit a copy of IRB/Privacy Board approval from Advocate Children's Hospital, including HIPAA determinations and/or waivers, prior to accessing/analyzing identifiable information and/or recruiting/enrolling subjects at that site. Approvals must be accompanied by an Amendment form when submitted to the UIC IRB.

Please note that the UIC IRB does not release recruitment/consent documents until the Certificate of Confidentiality protecting data is obtained. The approved Certificate must be accompanied by an Amendment form when submitted to the UIC IRB, and the stamped and approved documents will be released at that time.

Please note that Appendix D2 is not necessary if the data will be permanently de-identified before this research is closed via a Final Report.

Protocol Approval Period: March 25, 2016 - March 25, 2017

Approved Subject Enrollment #: 32

APPENDIX A (continued)

Additional Determinations for Research Involving Minors: The Board determined that this research satisfies 45CFR46.404, research not involving greater than minimal risk.

Performance Site: UIC

Sponsor: None

Research Protocol:

- a) Health Caregivers' Awareness of a Child's Impending Death; Version 2; 03/21/2016

Recruitment Materials:

- a) Research Invitation Letter; Version 2; 03/21/2016
- b) Electronic Medical Record Data Collection Template; Version 2; 03/21/2016
- c) Eligibility Checklist; Version 2; 03/21/2016

Informed Consents:

- a) Health Caregivers' Awareness of a Child's Impending Death; Version 2; 03/21/2016
- b) A waiver of documentation (verbal consent/no written signature obtained) and an alteration of consent have been granted for provider eligibility screening purposes only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal risk; data for potential provider subjects who are ineligible or decline will be destroyed)

Assent(s):

- a) A waiver of child assent and parent permission has been granted for the review of patient subject records at Advocate Children's Hospital for identification purposes only under 45 CFR 46.116(d)

Parental Permission(s):

- a) A waiver of child assent and parent permission has been granted for the review of patient subject records at Advocate Children's Hospital for identification purposes only under 45 CFR 46.116(d)

HIPAA Authorization:

- a) UIC IRB must rely on the Advocate Children's Hospital Privacy Board for the grant of a waiver of HIPAA authorization for access to records as Advocate medical records are not under the jurisdiction of the UIC IRB/Privacy Board

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis),

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

APPENDIX A (continued)

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
02/22/2016	Initial Review	Expedited	03/03/2016	Modifications Required
03/21/2016	Response To Modifications	Expedited	03/25/2016	Approved

Please remember to:

→ Use your **research protocol number** (2016-0208) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:

"UIC Investigator Responsibilities, Protection of Human Research Subjects"

(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello

Assistant Director, IRB # 2

Office for the Protection of Research Subjects

cc: Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
Catherine Vincent (faculty advisor), Women, Child, & Family Health Science, M/C 802

APPENDIX A (continued)

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Amendment to Research Protocol and Consent Documents – Expedited Review UIC Amendment # 1

September 14, 2016

Kathleen Kobler, MS
Women, Child, & Family Health Science
938 Twisted Oak Lane
Buffalo Grove, IL 60089
Phone: (847) 723-7911 / Fax: (847) 723-2261

RE: **Protocol # 2016-0208
“Health Caregivers' Awareness of a Child's Impending Death”**

Dear Ms. Kobler:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and consent forms under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Please note that stamped and approved .pdfs of all recruitment and consent documents will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain these emailed documents for your files for auditing purposes.

Please note that the UIC IRB is releasing recruitment/consent documents with this amendment as the Certificate of Confidentiality protecting data has been obtained.

Amendment Approval Date: September 14, 2016

Amendment:

Summary: UIC Amendment #1, dated 24 August 2016, submitted 25 August 2016, approved by advisor 26 August 2016, and approved by department and accepted by OPRS/IRB 29 August 2016, is an investigator-initiated amendment regarding the following:

(1) submission of a revised data extraction instrument adding the child patient's age and medical diagnosis; revising recruitment procedures to follow-up with potential subjects within 5-7 days after the initial recruitment effort, either in person or via telephone, due to the time constraints presented by the research (Electronic Medical Record Data Collection Template, v3, 8/16/2016; Protocol, v2, 3/21/2016 on cover, v3, 8/16/2016 in footer);

(2) submitting a copy of the Certificate of Confidentiality to the investigator at UIC (4/27/2016 - 3/25/2017);

(3) submitting a copy of Advocate Health Care IRB approval, as all subjects will be staff and patient records at the Advocate site (8/12/2016 - 8/11/2017); and

(4) submitting revised recruitment and consent documents as per the Advocate IRB (recruitment letter, v2, 3/21/2016; consent/authorization document, AHCIRB 6411, no other footer).

Approved Subject Enrollment #: 32

Performance Sites: UIC, Advocate Health Care

Sponsor: None

Research Protocol:

a) Health Caregivers' Awareness of a Child's Impending Death; Version 3; 08/16/2016

Recruiting Materials:

a) Eligibility Checklist; Version 2; 03/21/2016

b) recruitment letter; Version 2; 03/21/2016

c) Electronic Medical Record Data Collection Template; Version 3; 08/16/2016

Informed Consents:

a) Health Caregivers' Awareness of a Child's Impending Death (AHCIRB 6411)

b) A waiver of documentation (verbal consent/no written signature obtained) and an alteration of consent have been granted for provider eligibility screening purposes only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal risk; data for potential provider subjects who are ineligible or decline will be destroyed)

Assent:

a) A waiver of child assent and parent permission has been granted for the review of patient subject records at Advocate Children's Hospital for identification purposes only under 45 CFR 46.116(d)

Parental Permission:

a) A waiver of child assent and parent permission has been granted for the review of patient subject records at Advocate Children's Hospital for identification purposes only under 45 CFR 46.116(d)

HIPAA Authorization:

a) UIC IRB must rely on the Advocate Children's Hospital Privacy Board for the grant of a waiver of HIPAA authorization for access to records as Advocate medical records are not under the jurisdiction of the UIC IRB/Privacy Board

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
08/29/2016	Amendment	Expedited	09/14/2016	Approved

Please be sure to:

→ **Use only the IRB-approved and stamped consent documents and HIPAA Authorization forms when enrolling subjects.**

→ Use your research protocol number (2016-0208) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 996-2014.

Sincerely,

Sandra Costello

Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Please note that stamped and approved .pdfs of all recruitment and consent documents listed below will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain these emailed documents for your files for auditing purposes.

Enclosures:

- 1. Informed Consent Document:**
 - a) Health Caregivers' Awareness of a Child's Impending Death (AHCIRB 6411)
- 2. Recruiting Materials:**
 - a) Eligibility Checklist; Version 2; 03/21/2016
 - b) recruitment letter; Version 2; 03/21/2016
 - c) Electronic Medical Record Data Collection Template; Version 3; 08/16/2016

cc: Catherine Vincent (faculty advisor), Women, Child, & Family Health Science, M/C 802
Barbara McFarlin, Women, Child, & Family Health Science, M/C 802

APPENDIX A (continued)
UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

**Approval Notice
Continuing Review**

March 1, 2017

Kathleen Kobler, MS

Women, Child, & Family Health Science
938 Twisted Oak Lane
Buffalo Grove, IL 60089
Phone: (847) 723-7911 / Fax: (847) 723-2261

RE: Protocol # 2016-0208
“Health Caregivers' Awareness of a Child's Impending Death”

Dear Ms. Kobler:

Your Continuing Review was reviewed and approved by the Expedited review process on February 27, 2017. You may now continue your research.

Please submit the next NIH Certificate of Confidentiality extension/amendment as part of a new UIC IRB upon receipt.

Please note that *Karen Kavanaugh's* research training expired on **02/19/2017** and she must complete a minimum of two hours of continuing education in order to participate in the conduct of the research. **Please be reminded that she may not participate in any research-related activities until this CE requirement has been full-filled.** You may refer her to the OPRS website, where continuing education offerings are available: <http://research.uic.edu/compliance/irb/education-training>

Please note the following information about your approved research protocol:

Protocol Approval Period: March 25, 2017 - March 25, 2018

Approved Subject Enrollment #: 32 (11 Subjects enrolled to date)

Additional Determinations for Research Involving Minors: The Board determined that this research satisfies 45CFR46.404, research not involving greater than minimal risk. Therefore, in accordance with 45CFR46.408, the IRB determined that only one parent's/legal guardian's permission/signature is needed. Wards of the State may not be enrolled unless the IRB grants specific approval and assures inclusion of

additional protections in the research required under 45CFR46.409. If you wish to enroll Wards of the State contact OPRS and refer to the tip sheet.

Performance Sites: UIC, Advocate Health Care

Sponsor: None

Research Protocol(s):

- b) Health Caregivers' Awareness of a Child's Impending Death; Version 3; 08/16/2016

Recruitment Material(s):

- d) Eligibility Checklist; Version 2; 03/21/2016
- e) recruitment letter; Version 2; 03/21/2016
- f) Electronic Medical Record Data Collection Template; Version 3; 08/16/2016

Informed Consent(s):

- c) Health Caregivers' Awareness of a Child's Impending Death (AHCIRB 6411)
- d) A waiver of documentation (verbal consent/no written signature obtained) and an alteration of consent have been granted for provider eligibility screening purposes only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal risk; data for potential provider subjects who are ineligible or decline will be destroyed)

Assent(s):

- b) A waiver of child assent and parent permission has been granted for the review of patient subject records at Advocate Children's Hospital for identification purposes only under 45 CFR 46.116(d)

Parental Permission(s):

- b) A waiver of child assent and parent permission has been granted for the review of patient subject records at Advocate Children's Hospital for identification purposes only under 45 CFR 46.116(d)

HIPAA Authorization(s):

- b) UIC IRB must rely on the Advocate Children's Hospital Privacy Board for the grant of a waiver of HIPAA authorization for access to records as Advocate medical records are not under the jurisdiction of the UIC IRB/Privacy Board

Your research continues to meet the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)., (6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
--------------	-----------------	----------------	-------------	---------------

02/10/2017	Continuing Review	Expedited	02/27/2017	Approved
------------	-------------------	-----------	------------	----------

Please remember to:

→ Use your **research protocol number** (2016-0208) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance document,

"UIC Investigator Responsibilities, Protection of Human Research Subjects"
(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-2939. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Jewell Hamilton, MSW

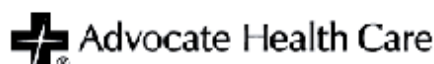
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

E
nclosure(s):

Please note that stamped and approved .pdfs of all recruitment and consent documents will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain the emailed documents for your files for auditing purposes.

cc: Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
Catherine Vincent, Faculty Sponsor, Women, Child, & Family Health Science, M/C 802

APPENDIX B



Institutional Review Board
3075 Highland Parkway, 4th Fl.
Downers Grove, IL 60515
IRBMail@AdvocateHealth.com

APPROVAL

August 12, 2016

Kathleen Kobler, MS, APN, PCNS-BC, CHPPN, FPCN
Advocate Children's Hospital – Park Ridge and Oak Lawn
kathie.kobler@advocatehealth.com

Dear Ms. Kobler:

On 08/12/16 the IRB reviewed the following protocol:

Type of Review:	Initial – Expedited		
IRB ID:	6411	Approval period:	08/12/16 – 08/11/17
Title:	Health Caregivers' Awareness of a Child's Impending Death		
Investigator:	Kathleen Kobler, MS, APN, PCNS-BC, CHPPN, FPCN		
Funding:	Not Applicable		
Document reviewed:	HRP-211 dated 06/06/16; Revised HRP-211 (not dated, but received 08/11/16); HRP-226 dated 06/07/16; UIC IRB Initial Review Approval Letter dated 04/05/16; Determination of Authorization of Principal Investigator (PI) dated 06/15/16; Cover Letter dated 06/06/16; IRB Fee Waiver Request dated 06/06/16; Protocol (Final Version received 08/10/16); Appendix A – Eligibility Checklist (Version 2.0 dated 03/21/16); Appendix B – Electronic Medical Record (EMR) Data Collection Template (Version 3.0 dated 08/10/16); Appendix C – Research Invitation Letter (Version 2.0 dated 03/21/16); Consent; Appendix E – Interview Guide (Version 2.0 dated 03/21/16); Department of Health & Human Services Letter regarding the Certificate of Confidentiality dated 04/27/16		

The study was approved under Expedited criteria 5, 6, and 7b.

5: Research involving materials (data, documents, records, or specimens) that have been collected for any purpose, or will be collected solely for non-research purposes.

6: Collection of data from voice, video, digital, or image recordings made for research purposes.

7b: Research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The AHC IRB is organized under the authority of, and in accordance with, regulations of the United States Department of Health and Human Services, Food and Drug Administration (Title 21 Code of Federal Regulations [CFR] Part 56 [Institutional Review Board], and Title 45 CFR Part 46 [Protection of Human Subjects]).

APPENDIX B (continued)



Advocate Health Care

Institutional Review Board
3075 Highland Parkway, 4th Fl.
Downers Grove, IL 60515
IRBMail@AdvocateHealth.com

APPROVAL

August 11, 2017

Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN
Advocate Children's Hospital
Kathie.kobler@advocatehealth.com; kkoble2@uic.edu

Dear Ms. Kobler:

On 08/11/17 the IRB reviewed the following protocol:

Type of Review:	Continuing - Expedited	IRB:	IRB00001341
IRB ID:	6411	Approval period:	08/12/17 – 08/11/18
Title:	Health Caregivers' Awareness of a Child's Impending Death		
Investigator:	Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN		
Funding:	Not Applicable		
Documents Reviewed:	HRP-212 dated 08/09/17; UIC IRB approval letter dated 03/01/17		

The IRB approved the protocol for the period stated above.

Within 25 business days of study close or 6 weeks before the expiration date of 08/11/18, whichever is earlier, you are to submit a completed "FORM: Continuing Review (HRP-212)" and required attachments to request continuing approval or closure. If continuing review approval is not granted before the expiration date, approval of this protocol expires on that date and all study activities must cease.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

Joal Hill, JD, MPH, PhD
Chairman, Advocate Institutional Review Board

The AHC IRB is organized under the authority of, and in accordance with, regulations of the United States Department of Health and Human Services, Food and Drug Administration (Title 21 Code of Federal Regulations [CFR] Part 56 [Institutional Review Board], and Title 45 CFR Part 46 [Protection of Human Subjects]).

APPENDIX C



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Eunice Kennedy Shriver National
Institute of Child Health and
Human Development
National Institutes of Health
Building 31A, Rm 2A03
9000 Rockville Pike
Bethesda, MD 20892

4/27/2016

University of Illinois at Chicago
Dr. Catherine Vincent
1737 W. Polk Street, Suite 310
Chicago, IL 60612

Dear Dr. Vincent,

Enclosed is the Confidentiality Certificate, protecting the identity of research subjects in your single-site/single-process project entitled "Health Caregivers' Awareness of a Child's Impending Death".

Please note that the Certificate expires on 03/25/2017. Please be sure that the consent form given to research participants accurately states the intended uses of personally identifiable information and the confidentiality protections, including the protection provided by the Certificate of Confidentiality with its limits and exceptions.

If you determine that the research project will not be completed by the expiration date, 03/25/2017, you must submit a written request for an extension of the Certificate three (3) months prior to the expiration date. If you make any changes to the protocol for this study, you should contact me regarding modification of this Certificate. Any requests for modifications of this Certificate must include the reason for the request, documentation of the most recent IRB approval, and the expected date for completion of the research project.

Please advise me of any situation in which the certificate is employed to resist disclosure of information in legal proceedings. Should attorneys for the project wish to discuss the use of the certificate, they may contact the Office of the NIH Legal Advisor, National Institutes of Health, at (301) 496-6343.

Correspondence should be sent to:

Steven Hirschfeld MD PhD CAPT USPHS
Eunice Kennedy Shriver National Institute of Child
Health and Human Development
National Institutes of Health
Building 31A, Rm 2A03
9000 Rockville Pike
Bethesda, MD 20892

Sincerely,

Approved Date: 04/27/2016

Steven Hirschfeld MD PhD CAPT USPHS
Associate Director for Clinical Research
Eunice Kennedy Shriver National Institute of Child
Health and Human Development

APPENDIX C (continued)



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health
Eunice Kennedy Shriver National
Institute of Child Health and
Human Development
Bethesda, Maryland 20892

Date: 2/2/2017

Dr. Catherine Vincent
University of Illinois at Chicago
1737 W Polk Street, Suite 310
Chicago, Illinois 60612

Re CC-HD-16-139 Certificate of Confidentiality Extension/Amendment Letter

Dear Dr. Vincent:

This letter is your **EXTENSION** for the original Certificate of Confidentiality CC-HD-16-139 protecting the identity of research subjects in the project "Health Caregivers' Awareness of a Child's Impending Death."

This amendment extends the Certificate protections to June 1, 2017.

The amended Certificate does not limit the number of participants for the study. Please be sure that the consent form given to research participants accurately states the intended uses of personally identifiable information (including matters subject to reporting) and the confidentiality protections, including the protection provided by the Certificate of Confidentiality with its limits and exceptions.

If you determine that the research project will not be completed by the revised expiration date, you must submit a written request for an extension of the Certificate three months prior to the expiration date. If you make any additional changes to the protocol for this study, you should contact me regarding modification of this Certificate. Any requests for modifications of this Certificate must include the reason for the request, documentation of the most recent IRB approval, and the expected date for completion of the research project.

Please advise me of any situation in which the Certificate is employed to resist disclosure of information in legal proceedings. Should attorneys for the project wish to discuss the use of the Certificate, they may contact the Office of the NIH Legal Advisor, National Institutes of Health, at (301) 496-6043.

Correspondence should be sent to:

Della Hann PhD
Associate Director for Extramural Research
Eunice Kennedy Shriver National Institute of Child Health and Human Development \\\n6710B Rockledge Drive, Room 2314
Bethesda, MD 20817

Sincerely,

Della Hann PhD

VITA

Kathie A. Kobler, MS, APN, PCNS-BC, CHPPN, FPCN

EDUCATIONAL PREPARATION

- 2013-Present *Student, Doctor of Philosophy*
University of Illinois at Chicago, College of Nursing
Anticipated program completion: December, 2017
- 2005-2008 *Master of Science*
University of Illinois at Chicago, College of Nursing
Advanced Practice Palliative Care Nursing Certificate Program
- 1981-1984 *Bachelor of Science*
Northern Illinois University, DeKalb, IL, College of Nursing
Minor, Mathematics
Graduate, University Honors

MAJOR AREA OF CONCENTRATION IN PRACTICE

Advanced Practice Nursing care for perinatal, neonatal, and pediatric patients who are experiencing serious illness and their families

EMPLOYMENT

Advocate Children's Hospital, Park Ridge, IL

2011 to Present APN Coordinator, Center for Fetal Care

2009 - March, 2017 APN, Pediatric Palliative & Supportive Care

Advocate Lutheran General Hospital, Park Ridge, IL

1996-2009 RN Bereavement Coordinator, Women & Children's Services

1993-1996 NICU RN Bereavement Coordinator & RN Clinician III

1985-1993 NICU Staff Nurse; NICU Transport & ECMO teams

AWARDS AND HONORS

- 2017 Distinguished Career Achievement Award
Hospice and Palliative Nurses Association
- 2016 Fellow in Palliative Care Nursing (FPCN)
Hospice and Palliative Nurses Association
- 2016 Nurses' Choice Award Winner: Advancing and Leading the Profession
Advocate Lutheran General Hospital & Advocate Children's Hospital
- 2014-2016 Jonas Nurse Leader Scholar

Jonas Center for Nursing Excellence

- 2008 Graduate Student Excellence Award
Department of Maternal Child Nursing, University of Illinois at Chicago
- 2008 Cardew-Mullane Award for Clinical Excellence & Leadership
College of Nursing Alumni Association, University of Illinois at Chicago
- 2007 ELNEC Pediatric Palliative Care Award for Dissemination and Implementation of the ELNEC Curriculum
ELNEC/AACN/City of Hope
- 1999 MVP Award for Compassion
Advocate Lutheran General Hospital

ASSOCIATION MEMBERSHIP

- Hospice & Palliative Nurses Association (HPNA)
- Sigma Theta Tau International (STTI)
- Pregnancy Loss & Infant Death Alliance (PLIDA)
- Greater Illinois Pediatric Palliative Care Coalition (GIPGCC)
- Chicago Alliance of Perinatal Bereavement Support Facilitators

LICENSURE & CERTIFICATIONS

- Advanced Practice Nursing License (APN)
Advanced Practice Nurse Controlled Substance License (CS)
Registered Nurse License (RN)
State of Illinois
- Certified Pediatric Clinical Nurse Specialist (PCNS-BC)
American Nurses Credentialing Center
- Certified Hospice and Palliative Care Pediatric Nurse (CHPPN)
Hospice and Palliative Credentialing Center

RESEARCH AND SCHOLARLY ACTIVITIES

Funded Projects

- 2016 - Present Primary Investigator, *Health caregivers' awareness of a child's impending death.* (PhD Dissertation Research). Seth & Denise Rosen Graduate Student Research Award, University of Illinois at Chicago School of Nursing (\$1,000).

2014 - 2016 Primary Investigator, *Bereaved parents' experience of a hospital memorial service*. Russell Institute for Research and Development Small Projects Grant, Advocate Lutheran General Hospital, Park Ridge, IL (\$24,000).

Publications (peer reviewed)

Kobler, K., & Limbo, R. (Eds.). (2017). *Conversations in perinatal, neonatal, and pediatric palliative care*. Pittsburgh, PA: Hospice and Palliative Nurses Association.

Limbo, R., Kavanaugh, K., **Kobler, K.** (2017). Honoring relationship and hope. In Kobler, K., & Limbo, R. (Eds.). *Conversations in perinatal, neonatal, and pediatric palliative care*. Pittsburgh, PA: Hospice and Palliative Nurses Association.

Duncan, J., & **Kobler, K.** (2016). Communication in pediatrics. In Dahlin, C., Coyne, P. J., & Ferrell, B. R. (Eds.), *Textbook in advanced practice palliative nursing* (pp. 597-608). New York, New York: Oxford University Press.

Limbo, R. & **Kobler, K.** (2015). Moments matter: Exploring the evidence of caring for grieving families and self. In Black, B. P., Wright, P. M., & Limbo, R. (Eds.). *Perinatal and pediatric bereavement*, (pp. 345-372). New York, New York: Springer Publishing Company.

Kobler, K. (2014). Leaning in & holding on: Team support with unexpected death. *MCN: The American Journal of Maternal-Child Nursing*, 39(3), 148-154.

Friedrichs, J., **Kobler, K.**, Roose, R., Meyer, C., Schmitz, N., & Kavanaugh, K. (2014). Combining regional expertise to form an alliance of perinatal bereavement facilitators. *MCN: The American Journal of Maternal-Child Nursing*. 39(3), 198-204.

Kobler, K. (2014). Matching strides. *Illness, Crisis & Loss*, 22(1), 73-76.

Kobler, K. (2014). Continuing competence in palliative care. *Illness, Crisis & Loss*, 22(1), 67-69.

Limbo, R. & **Kobler, K.** (2014). Introduction to Voices. *Illness, Crisis & Loss*, 22(1), 71-72.

Limbo, R. & **Kobler, K.** (2014). Editorial. *Illness, Crisis & Loss*, 22(1), 1-2.

Limbo, R. & **Kobler, K.** (2013). *Meaningful moments: Ritual and reflection when a child dies*. La Crosse, WI: Gunderson Medical Foundation.

Kobler, K. (2013). Honoring relationship in pediatric palliative care. In Cox, G. R. & Stevenson, R. G. (Eds.). *Final acts: The end of life, hospice and palliative care*. Amityville, NY: Baywood Publishing.

Kobler, K. (2012). Listening with the ear of your heart. *Illness, Crisis & Loss*, 20(3), 305-307.

Kobler, K., Limbo, R. & Oakdale, C. (2012). Childbirth education for parents receiving perinatal palliative care. *International Journal of Childbirth Education*, 27(2), 26-32.

Kobler, K. & Limbo, R. (2011). Making a case: Creating a perinatal palliative care service using a perinatal bereavement program model. *JPNN*, 25(1), 1-10.

- Boss, R., Kavanaugh, K., & **Kobler, K.** (2011). Perinatal and neonatal palliative care. In Hinds, P., Wolfe, J., & Sourkes, B. (Eds.) *Textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Saunders, 387-401.
- Limbo, R., and **Kobler, K.** (2011). Bereavement and perinatal loss in childbearing families. In M. Craft-Rosenberg (Ed.). *Encyclopedia of family health*. Thousand Oaks, CA: Sage Publications.
- Limbo, R. & **Kobler, K.** (2010). The ties that bind: Relationship in perinatal bereavement. *MCN: The American Journal of Maternal Child Nursing*, 35(6), 316-321.
- Limbo, R. & **Kobler, K.** (2009). Will our baby be alive again? Supporting parents of young children when a baby dies. *Nursing for Women's Health*, 13(4), 302-311.
- Kobler, K.**, Limbo, R., & Kavanaugh, K. (2007). Meaningful moments: The use of ritual in perinatal and pediatric death. *MCN: The American Journal of Maternal-Child Nursing*, 32(5), 288-29.
- Kobler, K.**, (2005). Concept analysis of ritual in perinatal death.
UIC NUSC 526 Course, Website resource as model paper, 2006-present.

Publications in Press (*peer reviewed*)

Book Chapters

- Kobler, K.** (in press). Relationship-based approach to caring for children with serious illness. In Pridham, K., Limbo, R., & Schroeder, M. (Eds.), *Guided participation in pediatric nursing practice: Relationship-based teaching and learning with parents, children, and adolescents*. New York, New York: Springer Publishing Company.
- Limbo, R., **Kobler, K.**, & Davies, B. (in press). Grief and bereavement in pediatric palliative care. In Ferrell, B. R. & Paice, J. A. (Eds.), *Oxford textbook of palliative nursing* (5th Ed.). New York, New York: Oxford University Press USA.

Presentations (* denotes invited, +denotes refereed)

International

- Kobler, K.** (Jun 2017). *Opening Keynote Presenter – *Honoring Health Care Professionals' Experiences of Suffering, Grief, and Hope*. International Death, Grief, and Bereavement Conference, LaCrosse, WI.
- Havalad, V., Greening, H., & **Kobler, K.** (Jan 2016). +Workshop - *I Never Know What to Say: Enhancing Communication Skills through Death & Dying Simulations* IMSH Society for Simulation in Health Care International Conference, San Diego, CA.
- Kobler, K., & Limbo, R.** (Nov 2014). *Main Session - *Ritual & Reflection*. 19th International Perinatal Bereavement Conference, San Antonio, TX
- Kobler, K.** (Nov 2014). *Concurrent Session – *There's No Place like Home: Transitioning Care when Baby Outlives the Perinatal Palliative Birth Plan*. 19th International Perinatal Bereavement Conference, San Antonio, TX.

Kobler, K., & Limbo, R. (Apr 2013). *Concurrent Session – *Suffering, Hope, and Ritual: Comfort for the Caregiver*. 18th International Conference on Perinatal and Infant Death, Minneapolis, MN.

Kobler, K., & Stahl, D. (Apr 2013). +Concurrent Session – *Continuing Competence in Perinatal Loss*. 18th International Conference on Perinatal and Infant Death, Minneapolis, MN.

Kobler, K. (Jun 2012). *Keynote Presenter – *Honoring Relationship in Pediatric Palliative Care*. International Death, Bereavement & Grief Conference, La Crosse, WI.

Kobler, K. Limbo, R., & Kobler, K. (Nov 2010). *Plenary – *Being in Relationship*. International Conference on Perinatal and Neonatal Death, Washington, DC.

Kobler, K., & Limbo, R. (Nov 2010). *Concurrent Session – *Follow-Up to Being in Relationships: Small Group Work*. International Conference on Perinatal and Neonatal Death, Washington, DC.

Kobler, K., & Cassidy, S. (Nov 2010). +Poster – *NICU Bereavement Breast Milk Donation Program*. International Conference on Perinatal and Neonatal Death, Washington, DC.

Kobler, K. (Jul 2000). +Paper – *KAYLA's Hope Bereavement Mailing Program*. International Family Nursing Conference, Chicago, IL.

National

Kobler, K. (Mar 2017). *Narrative Medicine and Pediatric Palliative Care. Grand Rounds, Boston Children's Hospital, Boston, MA.

Kobler, K. (Mar 2017). **Honoring the Search for Meaning and Well-Being: Spirituality in Nursing*. Association of Pediatric Hematology and Oncology Nursing's Resiliency Workshop, Chicago, IL.

Flanagan, E. & **Kobler, K.** (Feb 2017). **We Understand, We Agree, But We Cannot Do It: Deferring Compassionate Extubation as an Exercise in Parental Autonomy*. Moral and Ethical Dilemmas in Pediatric Palliative Care, Texas Pediatric Palliative Care Consortium, Fort Worth, TX

Kobler, K. (Dec 2016). **Perinatal and Neonatal Palliative Care*. National Academy of Sciences Roundtable on Care of Patients with Serious Illness, Washington, DC.

Greening, H., Havalad, V., & **Kobler, K.** (Oct 2016). +Poster - *Communicating Death and Dying Through Simulation: A Project with Pediatric Residents*. American Academy of Pediatrics National Conference, San Francisco, CA.

Kobler, K. (Sept, 2016). *Keynote – *Telling Our Stories: The Art and Science of Narrative Medicine in Perinatal Settings*. 20th International Perinatal Bereavement Conference, Phoenix, AZ.

Kobler, K. (Sept, 2016). *Concurrent Session – *Finding Our Way through Valleys Low: Navigating Caregiver Suffering, Grief, and Moral Distress*. 20th International Perinatal Bereavement Conference, Phoenix, AZ.

- Kobler, K.** (Sep 2016). *Keynote – *I Saw What I Saw and I Can't Forget It: Understanding & Addressing Caregiver Suffering*. 40th Annual Conference, Association of Pediatric Hematology/Oncology Nurses, Indianapolis, IN.
- Kobler, K.** (Jul 2016). *Workshop– *Integrating Ritual into the Care of Children with Serious Illness*. Pedi-Hope 2016 Sailing into the Future: Innovations and Advances in Pediatric Palliative Care, League City, Texas.
- Kobler, K.** (Jul 2016). *Plenary– *Who Tells Your Story? Honoring Healthcare Professionals' Experiences of Suffering, Grief, and Hope*. Pedi-Hope 2016 Sailing into the Future: Innovations and Advances in Pediatric Palliative Care, League City, Texas.
- Jutila, S., Limbo, R., **Kobler, K.**, & Stephens, C. (May 2016). +Concurrent Session - *Walking Through the Desert of Grief: Developing and Sustaining System-wide Bereavement Care across Professions and Clinical Settings*. 2016 Pediatric Chaplains Network National Conference, Scottsdale, AZ.
- Kobler, K.** & Barnes, M. (Mar 2016). +Poster – *Bereaved Parents' Experience of a Hospital Memorial Service*. 2016 Annual Assembly of Hospice & Palliative Medicine, Chicago, IL.
- Kobler, K.** (Oct 2015). *Panel Presenter – *Moving Forward on Continuing Competence: The Lived Experience*. American Board of Nursing Specialties Fall Assembly, Rosemont, IL.
- Kobler, K.** (Jul 2014). *Panel Presenter – *Many Faces of Leadership in Palliative Nursing*. Hospice & Palliative Nurses Association Leadership Weekend Conference, Pittsburgh, PA.
- Fleig, D., **Kobler, K.**, Rudolph, N., & Wiesbrock, J. (Oct 2013). +Poster – *Advanced Practice Nurses Filling the Gap: The Creation of a Center for Fetal Care*. ANCC National Magnet Conference.
- Kang, T., Frieber, S., & **Kobler, K.** (Mar 2013). +Concurrent Session - *A Whirlwind Tour for Pediatric Programs Seeking The Joint Commission's™ Advanced Certification In Palliative Care*. 2013 Annual Assembly of Hospice & Palliative Medicine.
- Kobler, K.** (Oct 2012). *Keynote– *Strategies for Maintaining Relationship in Difficult Situations*. Geisinger Health Care System: 4th Annual Perinatal & Early Infant Loss Conference, Danville, PA.
- Kobler, K.** (Oct 2012). *Concurrent Session Presenter – *Making a Case: Creating a Perinatal Palliative Program Using Strengths of Existing Prenatal Services*. Geisinger Health Care System: 4th Annual Perinatal & Early Infant Loss Conference, Danville, PA.
- Kobler, K.**, & Limbo, R. (Aug 2012). *Closing Session – *Suffering, Hope & Ritual: Comfort for the Caregiver*. RTS Blueprint for Perinatal Palliative Care Conference, La Crosse, WI.
- Kobler, K.** (Aug 2012). *Plenary – *Comfort Care: Using the Neonatal Advance Care Plan as a Guide*. RTS Blueprint for Perinatal Palliative Care Conference, La Crosse, WI.

- Kobler, K., & Mangurten, H.** (Mar 2012). +Poster – *Fostering Collaboration between Hospital and Community Pediatric Palliative Care Programs*. 2012 Annual Assembly of Hospice & Palliative Medicine, Denver, CO.
- Kobler, K., & Cassidy, C.** (Mar 2012). +Poster – *NICU Bereavement Breast Milk Donation Program*. 2012 Annual Assembly of Hospice & Palliative Medicine, Denver, CO.
- Kobler, K., & Limbo, R.** (Oct 2011). +Concurrent Session – *The Art of Being in Relationship*. NHPCO's 12th Clinical Team Conference and Pediatric Intensive Conference, San Diego, CA.
- Kobler, K.** (Oct 2011). +Poster Presentation – *NICU Bereavement Breast Milk Donation Program*. NHPCO's 12th Clinical Team Conference and Pediatric Intensive Conference, San Diego, CA.
- Kobler, K.** (Jun 2011). *Presenter – *Comfort Care for Babies with Life-Threatening Conditions: Using the Neonatal Advance Directive as a Guide* Online Webinar, RTS Bereavement Services.
- (Kobler, K.** May 2011). *Plenary Presenter – *What Matters Most: Honoring Relationship through the Co-Creation of Ritual*. Child Life Council 29th Annual National Conference, Chicago, IL.
- Kobler, K.** (Oct 2010). *Concurrent Session Presenter – *Strategies for Maintaining Relationships with NICU Families in Challenging Situations*. Contemporary Forum's The Fetus & Newborn: State-of-the-Art Care, Chicago, IL.
- Kobler, K., & Limbo, R.** (Sep 2009). +Concurrent Session – *Meaningful Moments: The Use of Ritual in the Care of Children and Families*. NHPCO's 10th Clinical Team Conference, Denver, CO.
- Kobler, K.** (Aug 2009). *Opening Keynote – *Making a Case for a Perinatal Palliative Care/Hospice within a Bereavement Program: A Call to Action*. RTS Blueprint for a Perinatal Palliative Care/Perinatal Hospice Program, La Crosse, WI.
- Kobler, K.** (Aug 2009). * Concurrent Session – *Engaging Families in Developing Their Birth Plan and Advance Directive*. RTS Blueprint for a Perinatal Palliative Care/Perinatal Hospice Program, La Crosse, WI.
- Kobler, K.** (Oct 2008). * Concurrent Session – *Meaningful Moments: The Use of Ritual in the Care of Infants and Children*. 16th National Perinatal Bereavement Conference, Clearwater, FL.
- Kobler, K.** (Sept 2008). *Keynote – *Meaningful Moments: The Use of Ritual in the Care of Infants and children*. Association of Pediatric Hematology/Oncology Nurses National Conference, Albuquerque, NM.
- Kobler, K.** (Aug 2008). *Opening Keynote – *Honoring Relationship in Perinatal Palliative Care*. RTS Advanced Coordinator Training Conference, La Crosse, WI.
- Kobler, K.** (Oct 2006). +Concurrent Session – *Walking Through Valleys Low: Perinatal Bereavement 101*. 15th National Perinatal Bereavement Conference, Chicago, IL.

Hochberg, T. & **Kobler, K.** (Oct 2002). +Concurrent Session – *In Your Eyes: Bereavement Photography*. 14th National Perinatal Bereavement Conference, Austin, TX.

Hochberg, T. & **Kobler, K.** (Sep 2000). *General Session – *Bereavement Photography*. 12th National Perinatal Bereavement Conference, Cincinnati, OH.

Regional

Kobler, K. (Mar 2016). *Concurrent Session – *Palliative Care in the Perinatal Setting*. 41st Annual March of Dimes Perinatal Nursing Conference, Lombard, IL.

Kobler, K. (Sep 2015). *Keynote – *Where Grief and Hope Meet: Approaching Families with Difficult News*. Chicagoland Perinatal Conference, Park Ridge, IL.

Kobler, K., & Limbo, R. (Jun 2015). *Keynote - *I Saw What I Saw & I Can't Forget It: Understanding and Addressing Caregiver Suffering*. Greater Illinois Pediatric Palliative Care Coalition Annual Conference, Bloomington, IL.

Kobler, K., & Limbo, R. (Jun 2015). *Concurrent Session - *Meaningful Moments: Ritual for Families and Care Providers*. Greater Illinois Pediatric Palliative Care Coalition Annual Conference, Bloomington, IL.

Kobler, K. (Mar 2014). *Concurrent Session– *Honoring Relationship in Perinatal and Neonatal Palliative Care*. 39th Annual March of Dimes Perinatal Nursing Conference, Chicago, IL.

Kobler, K. (Jun 2013). *Concurrent Session– *Honoring Relationship in Perinatal & Pediatric Palliative Care*. GIPCC Conference: Regional Collaboration-Improving Care for Children, Bloomington, IL.

Kobler, K. (May 2013). *Main Session – *Comfort Care using the Neonatal Advance Care Plan as a Guide*. NW Illinois Perinatal Center's Annual Perinatal Conference, Rockford, IL.

Kobler, K. (May 2013). *Main Session – *Honoring Relationship in Pediatric Palliative Care*. 12th Music in Health and Healing Conference, Park Ridge, IL.

Limbo, R., & **Kobler, K.** (Oct 2012). *Main Session– *Relationship Centered Care*. Chicago Alliance of Perinatal Bereavement Facilitators' 20th Annual Spotlight on Support, Chicago, IL.

Kobler, K. (Sep 2011). *Main Session – *Strategies for Maintaining Relationship with NICU Families in Challenging Situations*. Eliot Hospital's NICU Conf.: The Fragility of a Neonate's Life, Bedford, NH.

Kobler, K. (Oct 2010). *Main Session – *Will Our Baby be Alive Again? Developmental Perspectives on Death and Grief*. Chicago Alliance of Perinatal Bereavement Facilitators' 18th Annual Spotlight on Support, Chicago, IL.

Kobler, K. (Oct 2010). *Panel Presenter – *What Will We Say” Explaining Death to Children* Chicago Alliance of Perinatal Bereavement Facilitators’ 18th Annual Spotlight on Support, Chicago, IL.

Kobler, K. (Apr 2010). *General Session – *Using Ritual in the Care of Infants and Children*. Association of Hematology/Oncology Nurses, Chicago Chapter, Oak Lawn, IL.

Kobler, K. (Nov 2009). *General Session– *Meaningful Moments: The Use of Ritual in the Care of Infants and Children*. Florida Association of Pediatric Tumor Programs Annual Conference, St. Pete Beach, FL.

Kobler, K., Mullaney, E., & Misasi, J. (Oct 2009). *Co-Presenter - *Pediatric Palliative Care*. Chicago Area NAPNAP Meeting, Chicago, IL.

Kobler, K. (Sep 2009). *Presenter – *Meaningful Moments: The Use of Ritual in the Care of Children and Families*. Child Life Therapy Council Quarterly Education Session, Park Ridge, IL.

Kobler, K., & Boyle, D. (Oct 2004). *Main Session – *Putting the Tools to Work: Pediatric Palliative Care*. Chicago Alliance of Perinatal Bereavement Support Facilitators : 12th Annual Spotlight on Support, Chicago, IL.

Hochberg, T., & **Kobler, K.** (Oct 2002). *Plenary Session – *In Your Eyes: Bereavement Photography*. Conference for Wisconsin Perinatal Bereavement Providers, Milwaukee, WI.

Local

Kobler, K., & Barnes, M. (May 2016). +Poster Presentation – *Bereaved Parents’ Experience of a Hospital Memorial Service*. Advocate Children’s Hospital Research Conference, Oak Brook, IL.

Kobler, K., & Barnes, M. (Apr 2016). +Podium Presentation – *Bereaved Parents’ Experience of a Hospital Memorial Service*. Advocate Nursing Research Symposium, Oak Brook, IL.

Kobler, K. (Mar 2016). *Guest Instructor – *Caring for Families Experiencing Perinatal Death*. University of Illinois at Chicago, School of Nursing, NUSP 588.

Mangurten, H., & **Kobler, K.** (Sep 2014). *Co-Presenter - *End of Life Care for Infants and Children*. Pediatric Residency Lecture, Advocate Children’s Hospital, Park Ridge, IL.

Kobler, K., Mangurten, H., & Tinkle, B. (Mar 2014). *Co-Presenter - *Changing Expectations for Infants/Children with Trisomy 13 & Trisomy 18*. Pediatric Grand Rounds, Advocate Children’s Hospital, Park Ridge, IL.

Fleig, D., **Kobler, K.,** Rudolph, N., & Wiesbrock, J. (Nov 2013). +Poster – *Advanced Practice Nurses Filling the Gap: The Creation of a Center for Fetal Care*. Advocate Research Forum, Park Ridge, IL.

Moore, C., **Kobler, K.,** & Mangurten, H. (Aug 2013). *Co-Presenter - *It’s Bigger than Just DNR*. Pediatric Grand Rounds, Advocate Children’s Hospital, Park Ridge, IL.

- Kobler, K.,** & Stephens, C. (July 2013). *Co-Presenter - *The Pediatrician's Role in Supporting Grieving Families*. Pediatric Grand Rounds, Advocate Children's Hospital, Park Ridge, IL.
- Kobler, K.,** Lamprecht, M., & Mangurten, H. (Nov 2012). *Co-Presenter - *Palliative Care: Assuring Quality of Living for Children with Complex Medical Conditions*. Pediatric Grand Rounds, Advocate Lutheran General Hospital, Park Ridge, IL.
- Kobler, K.** (Sep 2012). *Main Session – *Making a Case: Creating a Perinatal Palliative Program Using Strengths of Existing Prenatal Services*. Perinatal Outreach Conference, Park Ridge, IL.
- Kobler, K.** (Apr 2012). Hospice Foundation of America's Annual Living with Grief Conference *Local Panel Presenter – *Ethics at End-of-Life*. Advocate Lutheran General Hospital, Park Ridge, IL.
- Parilla, B., George, J., & **Kobler, K.** (Mar 2012). *Co-Presenter - *Twin-to-Twin Transfusion Syndrome, Multiple Risks in Multiple Gestations & Center for Fetal Care* Pediatric Grand Rounds, Advocate Lutheran General Hospital, Park Ridge, IL.
- .
- Kobler, K.** (Aug 2011). *Main Session – *Pediatric Palliative Care & Moral Distress*. Nursing Grand Rounds, Children's Memorial Hospital, Chicago, IL.
- Kobler, K.** (May 2011). +Poster Presentation – *NICU Bereavement Breast Milk Donation Program*. Advocate Research Forum, Park Ridge, IL.
- Kobler, K.** (Apr 2011). Hospice Foundation of America's Annual Living with Grief Conference *Local Panel Presenter – *Spirituality in End-of-Life Care*. Advocate Lutheran General Hospital, Park Ridge, IL.
- Kobler, K.** (Apr 2011). *Panel Presenter – *Demystifying Palliative Care in Acute Care Settings*. Hospice of Northeastern Illinois, Pediatric Palliative Care: The State of the Practice Symposium, Barrington, IL.
- Kobler, K.** (Jan 2011). *Presenter - *What Matters Most: Honoring Cultural and Religious Preferences at End-of-Life*. Nursing Grand Rounds, Advocate Lutheran General Hospital, Park Ridge, IL.
- Kobler, K.** (Oct 2010). *Presenter - *Saying Goodbye: Loss, Grief, and Bereavement in Pediatric Care* Pediatric Bioethics Lecture Series: Advocate Lutheran General Hospital, Park Ridge, IL.
- Kobler, K.,** & Fleig, D. (Jul 2010). *Concurrent Session – *Seeing Through Their Eyes: Strategies for Maintaining Relationship with Patients and Families in Challenging Situations*. Advocate Pediatric Nursing Conference, Oak Lawn, IL.
- .
- Kobler, K.** (May 2010). *Presenter – *Reflecting Out: Creating and Providing a Professional Presentation*. Advocate Research Forum, Park Ridge, IL.
- Mangurten, H., & Kobler, K.** (Apr 2010). *Co-Presenter - *Humility When Giving a Prognosis for an Abnormal Newborn*. Pediatric Grand Rounds, Advocate Lutheran General Hospital, Park Ridge, IL.

- Kobler, K.** (Mar 2010). Organizer and Presenter - *Honoring Your Work: Self-care, Reflection & Renewal*. Workshops x 4 for Women's & Children's Nursing Staff, Advocate Lutheran General Hospital, Park Ridge, IL.
- Kobler, K.** (Aug 2009). *Presenter - *Honoring Relationship in Pediatric Palliative Care*. Pediatric Grand Rounds, Advocate Lutheran General Hospital, Park Ridge, IL.
- Kobler, K.** (Jul 2009). *Concurrent Session– *What is Most Important? Honoring Cultural and Religious Preferences at End-of-Life*. Advocate Health Care System's Annual Pediatric Conference, Oak Brook, IL.
- Kobler, K.** (Apr 2009). Hospice Foundation of America's Annual Living with Grief Conference
*Local Panel Presenter – *Diversity & End-of-Life Care*. Advocate Christ Medical Center, Oak Lawn, IL.
- Kobler, K.** (Dec 2008). *Presenter – *Honoring Relationship in Perinatal Palliative Care*. Advocate Perinatal Outreach Conference, Park Ridge, IL.
- Kobler, K.** (Apr 2008). Hospice Foundation of America's Annual Living with Grief Conference *Local Panel Presenter – *Living with Grief: Children & Adolescents*. Advocate Christ Medical Center, Oak Lawn, IL.
- Kobler, K.** (Apr 2008). *Coordinator & Presenter - *Pediatric ELNEC Curriculum*. Season's Hospice Pediatric Palliative Care Service, Des Plaines, IL.
- Kobler, K.** (Mar/Apr 2008). *Presenter – *Self-Care Seminar Series x 5 sessions*. Children's Memorial Hospital, Chicago, IL.
- Kobler, K.** (Sept 2007). *Presenter – *Meaningful Moments: The Use of Ritual in the Care of Infants and Children*. Nursing Grand Rounds, Children's Memorial Hospital, Chicago, IL.
- Kobler, K.** (Aug 2007). *Presenter – *Meaningful Moments: The Use of Ritual in the Care of Infants and Children*. Grand Rounds, Children's Hospital Boston, Boston, MA.
- Kobler, K.** (Oct 2006). *Guest Presenter – *Ritual Use at the End-of-Life*. University of Illinois School of Nursing, Death, Dying & Loss Graduate Class.
- Kobler, K.** (Oct 2002). *Presenter – *Perinatal/Neonatal Loss Session*. Our Lady of Pompeii Shrine's Chicago Archdiocese Pilgrimage for Bereaved Parents, Chicago, IL.
- Kobler, K.** (Oct 2001). *Presenter – *Perinatal/Neonatal Loss Session*. Our Lady of Pompeii Shrine's Chicago Archdiocese Pilgrimage for Bereaved Parents, Chicago, IL.

TEACHING

National Teaching Faculty, *RTS Bereavement Services, La Crosse, WI*, 2008- Feb, 2017

RTS 2 day Bereavement Training: Neonatal/Pediatric and RTS Coordinator Training

- 2015-2016: 3 courses taught in Florida, Illinois, and New York

RTS 2 day Bereavement Training: Perinatal Bereavement and Coordinator Training

- 2008-2017: 25 courses taught in Alabama, Arkansas, Florida, Illinois, Louisiana, Massachusetts, Michigan, New Hampshire, New York, New Jersey, Ohio, Oregon, Washington State, Washington D.C.

Co-Facilitator, Pediatric Resident Palliative Care Rotation, 2009 – March, 2017

Advocate Children's Hospital, Park Ridge, IL

Adjunct Clinical Instructor (preceptor for Master's program students). Department of Women, Children, and Family Health Science,

2008 – Present

University of Illinois at Chicago

Pediatric Curriculum Provider, 2005 – Present

Adult Curriculum Provider, 2008 – Present

End of Life Nursing Education Consortium (ELNEC)

Funded Teaching/Educational Projects

2010-2012	Primary Author/Project Leader- <i>Pediatric Palliative Care Resident Education and Rotation</i> , Advocate Lutheran General Health Partner's Endowment Fund (\$6800)
2009-2010	Primary Author/Project Leader – <i>Honoring Your Work</i> , Self-care seminars for nurses in Women's & Children's Services, Advocate Lutheran General Hospital Nursing Endowment Fund (\$1900)
2007-2008	Co-Author/Project Leader – <i>Self Care Workshops</i> for Hematology/Oncology Nurses at Children's Memorial Hospital. GOAL Grant co-written with Janice Nuuhiwa (\$10,000)
1999 – 2001	Primary Author/Project Leader – <i>KAYLA's Hope Family Bereavement Mailing Program</i> , Advocate Lutheran General Health Endowment Fund (\$3500)

SERVICE

Professional

National Board for Certification of Hospice and Palliative Nurses (NBCHPN) / Hospice and Palliative Credentialing Center (HPCC) *New Name as of Oct, 2014*

2015	<i>Immediate Past President</i> , Executive Board of Directors
2015	<i>Chair</i> , Board Development Committee
2015	<i>HPCC Representative</i> , Joint Strategy Council
2014	<i>President</i> , Executive Board of Directors
2014	<i>NBCHPN Representative</i> , Joint Strategy Council
2013	<i>President-Elect</i> , Executive Board of Directors
2013	<i>Chair</i> , Board Development Committee

2010-2015	<i>Executive Board Member</i> (2 consecutive terms of 3 years/each)
2011-2012	<i>Chair, Perinatal Loss Role Delineation Study</i>
2010-2011	<i>Chair, Pediatric Exam Development Committee</i> (Led team creating first national certification examination for pediatric palliative care nursing)
2009	<i>Member, Pediatric Role Delineation Study</i>

National Alliance for Excellence in Hospice & Palliative Nursing
 2012-2013 *Member, Board of Trustees*

National Pediatric Hospice & Palliative Care Collaboration (NPHPCC)

2012-Present	<i>Co-Chair</i> with Dr. Tammy Kang
2010-Present	<i>HPNA Representative to NPHPCC</i>
2017	NPHPCC Representative: Writing Committee, National Consensus Project <i>Community-Based Guidelines for Quality Palliative Care</i>

Greater Illinois Pediatric Palliative Care Coalition (GIPGCC)

2011-Present	<i>Clinical Committee Member</i>
2011-2013	<i>Clinical Advisory Task Force Member, IL Department of Human & Family Services State Pediatric Palliative Care Work Group</i>

Hospice & Palliative Nurses Association (HPNA)

2016	<i>Lead Editor, Pediatric Publication</i>
2012	<i>Member, 2012 Annual Assembly Planning Committee</i>
2011	<i>Member, 2011 Annual Assembly Planning Committee</i>

Pregnancy Loss & Infant Death Alliance (PLIDA)

2004-2006	<i>Vice President, PLIDA Board of Directors</i>
2006	<i>Chair, National Perinatal Bereavement Conference</i>
2002-2004	<i>Board Member, PLIDA Board of Directors</i>
2000-2002	<i>Member, Organizational planning team that created this national alliance. Participated in writing of by-laws, application, and successful granting of 501c3 status</i>

MCN: The American Journal of Maternal Child Nursing

2013-Present *Reviewer*

Contributions

2012	Contributor, <i>RTS Bereavement Services Perinatal Death 2 Day Training Manual</i>
2009-2013	Item Writer & Exam Development Committee Member, <i>Pediatric Palliative Care Certification Exam, National Board for Certification of Hospice & Palliative Nurses</i>
2008	The Art of Creating Ritual Honors the Parent Child Relationship, <i>ELNEC Connections Newsletter, Summer Edition</i>
2008	PLIDA Position Statement: Bereaved Parents Holding Their Baby, www.plida.org

- 2008 PLIDA Practice Guidelines: Bereaved Parents Holding Their Baby, www.plida.org
- 2008 PLIDA Position Statement: Offering the Baby to Bereaved Parents, www.plida.org
- 2007 PLIDA Practice Guidelines: Offering the Baby to Bereaved Parents, www.plida.org
- 2007 RTS Position Paper on Perinatal Palliative Care, www.bereavementservices.org
- 2006 PLIDA Position Statement: Delaying Post Mortem Pathology Studies, www.plida.org
- 2005 PLIDA Position Statement: Infections Risks are Insignificant, www.plida.org

Consultant

2007 – 2016 RTS Bereavement Services, La Crosse, WI