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GO WISH-PEDIATRICS: PILOT STUDY OF A CONVERSATION TOOL IN
PEDIATRIC PALLIATIVE CARE

BY

MEGHAN RYAN POTTHOFF

A dissertation submitted in partial fulfillment of the requirements for the
Doctor of Philosophy
Major in Nursing
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2015
GO WISH-PEDIATRICS: PILOT STUDY OF A CONVERSATION TOOL IN
PEDIATRIC PALLIATIVE CARE

This dissertation is approved as a creditable and independent investigation by a
candidate for the Doctor of Philosophy in Nursing degree and is acceptable for meeting
the dissertation requirements for this degree. Acceptance of this does not imply that the
conclusions reached by the candidates are necessarily the conclusions of the major
department.

Mary Mintoff, PhD, RN, CNS
Dissertation Advisor

Mary Mintoff, PhD, RN, CNS
Head, Graduate Nursing Department

Dean, Graduate School

Date

Date

Date
To my amazing husband, Mike, you endured this journey with me. You provided me constant love, support, and encouragement which is the only way I was able to achieve this goal. You knew when to push me and when to let me cry. I love you with all my heart and cannot wait for the next adventure for our family.

To our beautiful, amazing children: Charlie, Betsy, & Teddy. You are everything to me and I love you with all my heart.

To my wonderful parents, Ed and Cheryl Walker, for all their never ending support and love. Because of both you, I have a passion for teaching and learning. That is what started this journey and I am so blessed to have two amazing, loving parents.

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To all the children in this study who are living with a life threatening condition and their families, every one of you is an inspiration to me and has forever changed me as a nurse and a mom.
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ABSTRACT

GO WISH-PEDIATRICS: PILOT STUDY OF A CONVERSATION TOOL IN PEDIATRIC PALLIATIVE CARE

MEGHAN POTTHOFF

2015

Problem: Difficult conversations and decisions are an unfortunate reality for parents caring for children facing life threatening conditions. Confusing, inadequate, and inconsistent communication by health care providers makes advance care planning difficult in pediatrics.

Design: A mixed methods design was utilized to evaluate the effectiveness of an advance care planning conversation tool, Go Wish-Pediatrics, on the emotional resources and distress experienced by parents caring for children in palliative care.

Methods: For this pilot study, a mailed invitation to participate was sent to 134 parents of children currently enrolled in palliative care which yielded a total of ten participants.

Results: Parents in this study reported moderate levels of perceived emotional resources. The Go Wish-Pediatrics intervention resulted in no change in pre-post comparison of guilt and worry, unresolved sorrow and anger, long term uncertainty, and emotional resources. The most value most consistently reported as very important by the parents was their relationship with their spouse or significant other. For the qualitative portion of the study, data was collected using semi-structured interviews and analyzed using a thematic analysis. The three emerging themes of the parents’ perception of the Go Wish-Pediatrics intervention included operationalizing thoughts into action, empowered to join the conversation, and a lighthouse in the fog. The mixed methods analysis utilized
comments from the participant interviews to explore a deeper explanation of how parents experienced the parental distress and emotional resources subcategories.

Conclusions: Parents identified that the *Go Wish-Pediatrics* intervention was beneficial in helping initiate conversations related to topics that are often difficult to approach. The intervention also served a communication bridge to support communication between spouses or significant others as well as with the healthcare team. The utilization of the *Go Wish* card game also revealed that parents involved with palliative care for their child have very different priorities. The use of the *Go Wish-Pediatrics* intervention helps individualize communication to the priorities and needs of families.
CHAPTER 1: INTRODUCTION

The loss of a child is an unfortunate reality for many parents given that an estimated 50,000 children die and over 500,000 children live with life threatening conditions annually (Himelstein, Hilden, Morstad-Boldt, & Weissman, 2004). The 2011 Vital Statistics report cites 20,192 deaths for patients aged 1-19 years old and 23,910 infant deaths (Hamilton, Hoyert, Martin, Strobino, & Guyer, 2013). Of these deaths, 50% were a result of a chronic or terminal illness (Hamilton et al., 2013) which suggests that approximately 20,000 pediatric patients would benefit from palliative care services including conversations about advance care planning. However, in the United States it is reported that less than 10% of the children who could benefit from palliative care are actually receiving these services at any point in their illness (CHI, 2010).

Palliative care services are equally essential for the parent whose psychological state is a predictor of overall psychological functioning of the ill child as well as the family unit (Bonner et al., 2006). Situations that increase the distress experienced by parents caring for children facing life threatening conditions include difficult conversations and decisions. Parents report that communication and facilitation of advance care planning conversations are confusing, inadequate, insensitive, and uncomfortable (Burns, Mitchell, Griffith, & Truog, 2001; Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Durall, Zurakowski, & Wolfe, 2012; Feudtner, 2007; Widger & Picot, 2008; Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009).

Healthcare team members also report feeling underprepared to facilitate these conversations (AAP, 2013; Davies, Davis, & Sibert, 2003; Farrell, Ryan, & Langrick, 2001; Levetown, 2008) for fear of upsetting the parents, yet, families are relieved when
asked about specific concerns and wishes related to the death of their loved one (Munson, 2007). It is imperative to have clear communication about what should be expected during the different stages of illness including anticipated symptoms and ongoing symptom management. Parents report lower satisfaction and dignity when they are less informed about the plan of care and expectations at end of life (Copnell, 2005; Steinhauser & Clipp, 2000).

Communication is the key to higher standards of care for families faced with caring for a child in palliative care. Part of the challenge with having emotionally difficult conversations and facilitating advance care planning in pediatrics is that parents are at different stages in adapting to their child’s diagnosis and treatment plan. There is limited literature identifying and evaluating interventions that allow for conversations to be tailored to the emotional needs and level of acceptance of palliative care goals.

**Background & Significance**

Pediatric palliative care has been a practice priority for the last two decades. This is a direct result of two key stakeholders, the Institute of Medicine (IOM) and the American Academy of Pediatrics (AAP), identifying the unmet needs of chronically ill children and their families. The intent of pediatric palliative care is to improve comfort and relieve suffering for all individuals diagnosed with life threatening illnesses (AAP, 2013; IOM, 2003). There are more children living with complex illnesses as a result of improved science and technology, this in turn has led to an increase in the number of children that could benefit from the services provided through pediatric palliative care.

The pediatric palliative care essentials include physical care, psychosocial care, spiritual care, and advance care planning (Himelstein et al., 2004). The physical,
psychosocial, and spiritual concerns have been well described in the pediatric literature, but the sphere of advance care planning has been under-utilized in the pediatric population (Beringer & Heckford, 2012; Carter et al., 2004; Hammes, Klevan, Kempf, & Williams, 2005). Adequate advance care planning requires identification of clear decision makers, discussions of illness trajectory, discussion of holistic goals of care, and specific end of life discussions (Himelstein et al., 2004). Advance care planning involves discussions with the child and family about the extent of medical interventions at the end of life and during an acute deterioration (Himelstein et al., 2004). To truly improve the care of the patient and family, the conversations and wishes of the family need to be discussed and documented so that the healthcare system as a whole can be knowledgeable regarding the current wishes of the family.

Common barriers identified by parents related to effective pediatric palliative care include failure to fully understand the prognosis, poor symptom management, inconsistencies in treatment goals, unwillingness to let go of a child, poor coordination, and limited access to healthcare team, (Beckstrand, Rawle, Callister, & Mandleco, 2010; Davies et al, 2008; Meyer, Ritholz, Burns, & Truog, 2006; Munson, 2007). These barriers are all linked to ineffective, poor communication between the healthcare team and the family. Finding means to improve conversations that relate to palliative care will help to alleviate some of these barriers identified by parents and improve outcomes for both the child and the parent.

**Pediatric palliative care continuum.** The current definition of pediatric palliative care stresses the importance of enhancing the quality of life for the child and the family while minimizing the suffering for children (AAP, 2013; IOM, 2003). Curative
and palliative care need to be combined to best achieve the goals of care (AAP, 2013). The continuum of care model conceptualizes the introduction of palliative care at the time of diagnosis and shows the synergy of combining curative treatment with supportive care (IOM, 2003). This movement reflects the needs of the pediatric patients suffering from chronic conditions that are life threatening but not necessarily terminal by definition. Healthcare providers are charged to respond to this by altering how they view the timing of palliative care services for pediatric patients. (Figure 1)

![Diagram of Continuum of Palliative Care](image)

Figure 1: Integrated model of the continuum of palliative care proposed by the World Health Organization.

In support of the continuum of palliative care, parents of pediatric patients suffering from life threatening illnesses have identified that they want to receive communication about end of life and palliative care measures earlier in the diagnosis (Meert et al., 2008). However, family members continue to identify that end of life conversations primarily happen after curative therapies have been stopped or death seems
imminent (Durall et al., 2012; Widger & Picot, 2007). Late introduction of palliative care services limits collaboration between parents and providers to best meet the needs of the family.

Part of the reason for late introduction of palliative care is a disconnect in the healthcare system fully understanding the intent and purposes of the new palliative care continuum model. The central goal of palliative services is to identify how to honor the child and family’s values, wishes, and goals throughout all levels of care (Rushton, 2005). These goals are similar to those of hospice, but serve a distinctly different purpose in the pediatric population. Hospice typically is reserved for patients who are in their last six months of life with a central goal of alleviating pain and suffering as end of life nears. Palliative care also has the same goal of alleviating pain and suffering along with a focus on all physical, emotional, and psychosocial aspects of care during both curative and end of life treatment.

Hospice services are not widely utilized in pediatric end of life care. Historically, providers have reserved the use of hospice care for patients no longer receiving curative treatments and with less than six months to live. A survey of 632 pediatric oncologist revealed the most common reason for not referring to or utilizing hospice service for patients at end of life was the continuation of curative therapy (Fowler et al., 2006). In pediatrics, it is uncommon to stop curative treatment. This is due to several reasons, but the most common is the unwelcoming sense of ‘giving up’ on a child’s life by both the parent and the provider. The decreased use of hospice services is a significant reason why it is imperative that pediatric healthcare teams optimize the use of palliative care services. Early involvement of palliative care and the use of advance care planning in
pediatrics can help increase the use of hospice at the appropriate time. The improved use of palliative care services can help to bridge the gap of decreased hospice use and improve end of life care for pediatric patients and their families.

**Communication.** A significant barrier to adequate palliative care services in the pediatric arena is lack of comfort by the health care team in talking about death or issues surrounding palliative care (Beckstrand et al., 2010; Contro et al., 2004; Davies et al., 2008; Lotz, Jox, Borasio, & Fuhrer, 2015; Tubbs-Cooley et al., 2011). Communication during palliative care has often been viewed as a one sided conversation in which the healthcare community provides the information but often fails to seek out the physical, emotional, and spiritual needs identified by the family. In addition to a lack of comfort, there is a lack of frequency in providing formal methods for communication (Michelson et al., 2013).

The lack of effective communication has potential negative consequences for healthcare providers and for families. A lack of comfort in communication about death and palliative care has been shown to increase the risk for healthcare professionals to experience moral distress (Davies et al., 2008). Families also have reported decreased level of care and increased sense of hopelessness because of barriers created when open communication was not facilitated (Beckstrand et al., 2010; Price, Jordan, Prior, & Parkes, 2011).

Interventions such as the SPIKE® protocol assist providers in preparing to deliver difficult news (Baile et al., 2000) and target the preparation of healthcare providers for delivery of specific information to the family. However, the facilitation of conversations is not addressed in interventions such as SPIKE. Family care conferences have been
utilized as a method to encourage better communication in the inpatient pediatric setting; however, care conferences are not consistently utilized and there is (Fox, Brittan, & Stille, 2014; Michelson et al., 2013). Psychometrically reliable and valid tools are needed to advance interventions which can facilitate repeated conversations regarding the care of the child living with a life threatening condition. These repeated conversations are essential for promoting pediatric advance care planning.

**Advance Care Planning.** Families in general do not understand the purpose of advance directives in pediatrics. Advance directives and formal advance care planning conversations continue to happen in pediatrics predominately during an acute decline or when death is imminent which is contradictory to the underlying tenets of advance planning (Durall et al., 2012). Parents of children with special health care needs have identified a lack of understanding regarding advance directives as well as a desire for more information addressing advance care planning and advance directives (Durall et al., 2012). It is possible that the terms used in adult care like ‘advance care planning’ and ‘advance directives’ have implications suggesting an impending death which contradicts the current goals to improve palliative care in pediatrics. These terms have an unnatural and abrasive tone when used in relation to care of pediatric patients.

Frequently pediatric deaths are not anticipated or expected. In line with the continuum of care model, conversations surrounding advance care planning need to occur earlier in the illness trajectory when death is not imminent. Families need to be provided the gift of time to process, discuss, and plan. This will facilitate a dignified course for their child during the entire illness trajectory. This can also avoid “planning” in a time of crisis which makes it difficult to get the true wishes of the child and family and can result
in unwanted procedures. Planning in a time of crisis can also lead to a more difficult
grieving period after a child passes away (Price et al., 2011; Surkan, et al, 2006)

Significant benefits associated with pediatric advance care planning include
improved family communication, decreased stress surrounding treatment decision
making, and improved emotional states for the parents and child (Hammes et al., 2005;
Lyon, Garvie, Briggs, McCarter, & D’Angelo, 2009; Wiener et al., 2008). Despite these
known benefits, advance care planning is not the standard of care for patients suffering
from life threatening conditions.

The National Institute of Nursing Research (NINR) has initiated a public service
campaign for pediatric palliative care, Conversations Matter © (NINR, 2013). The intent
of this campaign is to champion advance care planning and bring light to the importance
of facilitating these conversations with families and the medical team. By using
terminology similar to the NINR to address the concepts that surround advance care
planning, communication barriers can be overcome for both providers and families.

**Parental distress.** With the diagnosis and the entrance into the new world of
caring for a child facing a life threatening condition, caregivers are faced with uncertainty
related to their life and their child’s life (Davies, et al., 2008; Santacroce, 2003). This
uncertainty begins at the time of diagnosis and is one of the greatest sources of
psychosocial distress for parents and caregivers (Santacroce, 2003). Part of the
uncertainty is uncontrollable and comes from the unknown; however, the uncertainty can
be increased because of misguided communication within the healthcare system.

Caregivers of children facing life threatening conditions have identified that
communication from the medical community regarding treatment and prognosis is
confusing, inadequate, or uncaring (Feudtner, 2007; Widger & Picot, 2008; Zhukovsky et al., 2009). As a result, increased uncertainty and fear is experienced by the parent. High levels of uncertainty are associated with increased psychological distress that includes anxiety, depression, and helplessness as well as a decreased ability for decision-making (Mishel et al., 2009; Stewart & Mishel, 2000). Failure to adequately address parental uncertainty can also lead to increased uncertainty for the child (Stewart & Mishel, 2000). Knowing that children and the entire family are affected by a caregiver’s uncertainty supports the importance of identifying ways the healthcare team can alleviate some of the distress experienced by parents.

**Impact on Nursing.** The American Nurses Association (ANA) adopted its first nursing code of ethics in 1950 to provide a document that would help to establish nursing as a profession, not just a job, and to provide assistance to nurses faced with ethical challenges and responsibilities in their day to day work (Fowler, 2008). The code of ethics serves as a benchmark for responsibilities and obligations of those working in the nursing profession and to assist with difficult ethical decisions (Dahnke, M., 2009). Within the ANA Code of Ethics, provision three addresses nurses accountability to serve as an advocate for the health, safety, and rights of the patient (Fowler, 2008). In pediatric nursing, the family is included as a part of the “patient”, thus it is the responsibility of the nursing to serve as an advocate for the child and the family. The priority is making sure that the rights and wishes of the child and family are being met. To ensure that nurses caring for children facing life threatening conditions are able to effectively serve as advocates, it is essential that the families have an avenue to vocalize their wishes,
concerns, and questions. Improving communication needs to be at the forefront of all care so that the nursing team can maximize their ability to advocate.

Statement of the Problem

The literature supports that organized palliative care teams can help to improve outcomes related to children suffering from life limiting illnesses when advanced conversations and care planning are done affectively (Hays et al., 2006; Wolfe et al., 2008; Wolff, Robert, Sommerer, & Volz-Fleckenstein, 2010). Despite this knowledge, pediatric patients suffering from life threatening illnesses in palliative care and their families continue to be underserved due to infrequent and inadequate advance care planning conversations. It is imperative that palliative care teams are utilized early in the care of children facing life limiting illnesses and that conversations related to advance care planning are a priority in the care of these children. Failure to appropriately communicate raises significant risk for increased distress and uncertainty for the child, parents, and family. A gap in knowledge exists related to interventions that the healthcare team can utilize to facilitate pediatric advance care planning conversations which meet the needs of parents and the child.

Purpose

The twofold purpose of this embedded mixed method pilot study is to explore the use of an advance care planning conversation tool with parents caring for children suffering from a life threatening illness and to examine the parent experience of a child’s illness while caring for a child receiving pediatric palliative care.
Study Aims

1. Describe parents’ experience of having a child in pediatric palliative care as measured by the Parent Experience of Childhood Illness (PECI) tool [parental distress and emotional resources].

2. Explore relationships, if any, among the parents’ experience (PECI) and pediatric disease demographics including type of diagnosis, length of time in palliative care, length of time since diagnosis, education level of the parents, age of child, gender of the parent, and family income level.

3. Identify the effect of Go Wish- Pediatrics, a facilitated advanced care planning conversation tool, on parents’ experience of having a child in pediatric palliative care.

4. Describe parents’ experience of using Go Wish- Pediatrics using semi-structured interviews.

Assumptions

This study is based on the following assumptions:

1. Parents caring for children suffering from life threatening conditions experience distress.

2. Parental distress negatively impacts the family unit.

3. Advance care planning is a dynamic communication process.
Chapter 2: Review of Literature

The review of literature was conducted with searches in CINAHL, Medline, and Google Scholar databases. The following search terms were used individually and in combination with each other: “pediatric,” “palliative care,” “advance care planning,” “parents,” “advance directive,” “communication,” “end of life care,” “parent distress,” “uncertainty,” “good death,” and “dignified death.” Much of the literature related to pediatric palliative care surfaced in early 2000 resulting in a search that included articles from 2000 to 2014. The initial search of “pediatric palliative care” produced a total of 241 articles. This search was narrowed using combinations of the above mentioned terms. Additional search results included: “pediatric & advance care planning” (n=18), “pediatric & advance directive” (n=5), “pediatric & good death” (n=6), and “end of life care & pediatric (n=144). Articles were also obtained using the snowball method by reviewing the reference pages of the articles identified during the database search. The literature search will be examined within the context of three foci: a) pediatric palliative care, b) advance care planning in pediatrics, and (c) good/dignified death. These foci represent the core literature that surrounds the research aims of this study.

Pediatric Palliative Care

Pediatric palliative care has continued to grow in both research and clinical practice over the past decade. The following sections will outline the impact of existing programs on pediatric healthcare, advantages and barriers of pediatric palliative care through the eyes of the healthcare team, and parents’ perceptions and ways to improve palliative care.
**Program Outcomes.** A pediatric palliative care program implemented in a northwest children’s hospital focused on family centered ethical decision making, improving provider training and communication, and advance care planning (Hays et al., 2006). The purpose of this longitudinal project was to evaluate if there was any change in health-related quality of life for the families enrolled in the program (n=21). The parents showed improvement in the emotional domain for quality of life two years post implementation (p< 0.05). Family satisfaction also improved in three domains including communication, symptom management, and responsiveness of health plans (p<.05). The small sample size in this study limits it generalizability; however, the palliative care program did provide families in this study better emotional support, higher quality communication, increased sensitivity from the providers, and improved comfort for the child.

Another pediatric palliative care program implemented in Germany was designed to improve care at end of life by instituting weekly inpatient palliative care rounds and home based medical care (Wolff et al., 2010). This program was unique in the sense of adding home visits provided by the physician and nurse. A total of 51 patients between 2001 and 2003 were enrolled in the program with varying diagnoses. On average, the home visits increased from 14 per month in the first year to 39 per month in the final year. Parent satisfaction after two years in the program was high on a Likert scale of 1-6 with 1 equaling *very good* (mean=1.6). Since the United States health care system focuses on reimbursement for services, the likelihood for home visits from palliative care providers is less probable unless insurance companies and policies change to allow for better reimbursement of these services.
The Pediatric Advanced Care Team (PACT) was developed in 1997 to meet the palliative care needs of children at an urban children’s hospital. In a pre/post design research study, program effectiveness was evaluated through chart reviews and interviews with parents of children who had died between 1997 and 2004 (n=119) and 1990-1997 (n=102) from a previous preliminary study (Wolfe et al, 2008). Patients in the post intervention group were significantly more likely to have hospice discussions documented in their chart (76% vs 54%; p<0.01), hospice introduced as a care option (52 days before death vs 28 days; p=0.02), and earlier documentation of do not resuscitate orders (18 days before death vs 12 days; p=0.031). The location of death within the hospital also significantly changed with a 16% decrease in the number of deaths that occurred in the intensive care setting compared to the medical-surgical floor (p=0.024).

Partners in Care: Together for Kids (PIC:TFK) was one of the first state wide integrated palliative care program developed in the United States. This Florida based program was developed as a referral program for nursing case coordinators working with special needs children (Knapp et al., 2009). Evaluation of the program revealed that nurses working in areas with direct access to the PIC-TFK program were more likely to refer earlier in the course of the disease when compared to non-PIC-TFK sites for all eleven disease states (p<0.01).

A study at a National Cancer Institute compiled baseline data on patients referred to a newly developed pediatric palliative care team (Zhukovsky et al., 2009). Over the nine month study period a total of 954 patients with various oncologic diseases were seen by the pediatric oncology service, 44 patients passed, and 15 children received a palliative care referral. The implications of this study were significant, identifying that
only 1.6% of the patients on an oncology service received the option of palliative care services and only 34% of the children that passed away received palliative care services. Of the 15 patients receiving palliative care, 73% were receiving palliative care and curative care simultaneously (n=11). The pediatric palliative care consult resulted in identification of symptoms not previously documented by the primary team with a median of three newly identified symptoms per patient. The small sample size of the palliative care population in this study limits its generalizability; however, the low referral rate is important to recognize in light of the large number of patients seen by the primary service.

**Summary.** Despite multiple palliative care programs developing internationally, there has been limited research evaluating the quantitative outcomes of the programs. A limitation of much of the research, and a reality of conducting palliative care research, is small sample sizes that impact the generalizability of the results. Despite these limitations, the research does identify that palliative care programs in pediatric settings can significantly impact care at end of life by providing families with more options (Wolfe et al., 2008) and improving family satisfaction (Hays et al., 2006; Wolff et al., 2010). Also highlighted in this research is the concern of missed treatment opportunities related to low referral rates to palliative care programs (Zhukovsky et al., 2009).

**Healthcare team perspective.** Several studies have evaluated healthcare team member’s perspectives related to pediatric palliative care including comfort, attitude, confidence, education, and barriers. The current state of the science for nursing regarding perspectives on pediatric palliative care is discussed in the following section.
A large descriptive survey study included an inter-professional sample composite of nurses (n=456), residents (116), and physicians (n=209) on their knowledge, attitudes, and self-reported behaviors related to the national ethical and legal guidelines for pediatric end of life decision making (Solomon et al., 2005). Nurses’ were twenty times more likely to agree with the statement “Sometimes I feel we are saving children who should not be saved” as compared to the statement “sometimes I feel we give up on children too soon” (p<0.05) (Solomon et al., 2005). This suggests nurses were significantly more worried about saving a pediatric patient that should pass on then giving up on patients too early.

A large cross sectional analysis of registered nurses (n=410) working in a large urban children’s hospital described pediatric nurses’ perceptions of caring for dying children and end of life care goals (Tubbs-Cooley et al., 2011). Approximately 47% of the nurses felt they had the capability to care for a dying child well and 53% reported they were comfortable working with dying children and families. Despite half of the nurses expressing comfort in the care of dying children, approximately one third felt it was difficult to talk about death and dying with children and families.

Davies et al. (2008) surveyed physicians (n=81) and nurses (n=117) regarding barriers to providing palliative care in the pediatric setting. There were four barriers that were frequently or almost always occurring including uncertain prognosis (54.6%); family not ready to let go (51.1%); language barrier (47.3%); and time constraints (47.1%). There were three significant differences identified when nurses’ responses were compared to physicians. Physicians more frequently reported cultural differences (p<0.001) and conflict between healthcare team and family about plan of care (p=0.04) as
barriers and nurses more frequently reported the lack of availability of an ethics committee to assist in care (p=0.002).

**Summary.** A significant concern for nurses when considering the implications for conversations related to advance care planning is a fear of saving a child that should be allowed to pass on (Solomon et al., 2005). Pediatric nurses also identify a comfort in providing care to dying children; however lack a confidence in communicating with families and children about end of life care and express a desire for support services to facilitate this care (Davies et al., 2008; Tubbs-Cooley et al., 2011). Having thorough, documented conversations that address the tenets of advance care planning can support nurses in advocating for the family and patient.

**Parent perspective.** Caregivers of dying pediatric patients have identified a need for honest, open communication, visualization of emotional expression from the healthcare team, and the opportunity to talk about death as it relates to their faith or spirituality (Contro et al., 2002; Mack et al., 2006; Meyer et al., 2006). This section discusses the current literature on parents’ needs and perspectives surrounding pediatric palliative care.

A mixed methods study evaluated end of life priorities and recommendations of parents who had lost a child in the pediatric intensive care setting over the past one to four years (n=56; Meyer et al., 2006). The qualitative results identified six priorities including: honest and complete information, access to staff, communication and care coordination, emotional expression by the care team, preservation of the integrity of the parent-child relationship, and faith. Parents identified that a need for more frequent meetings with the healthcare team and a consistent familiar individual to discuss
palliative care issues. They also identified that conversations related to advance care planning occurred too late despite them seeking them out and that the conversations seemed superficial and rushed (Meyer et al., 2006).

The quantitative analysis for this study included adequacy of pain management, decision-making support, and social support during and after death of their child (Meyer et al., 2006). Approximately half of the parents (56%) identified that they felt little to no control over the situation during the final days preceding death and 25% felt they would have made different decisions now looking back. This study did not report or identify which of these patients had documented advanced care planning, but these findings support literature that a time of crisis is not the ideal time for advance care planning.

A small qualitative study that evaluated parents perspectives of the care of their dying child at home (n=10) found similar results to those from the intensive care setting (Vickers & Carlisle, 2000). Parents identified that they wanted choices and to be actively involved in decision making related to their child’s end of life cares. Parents identified that being at home gave them a sense of control over the environment, brought their family more together as a whole, and more involved in the care of their child. For these parents, having the option to go home and knowing that the acute care services had been exhausted provided families a sense of peace.

Prior to the development of a formal pediatric palliative care program, a qualitative study was done to identify parent’s perspectives for improving end of life care for their child. Interviews with parents (n=68) who had a child pass away explored their interactions with hospital personnel, support provided, and experiences at time of death (Contro et al., 2002). Parents consistently identified it was importance to feel actively
involved in the decisions. They identified the most influential caregivers were honest, provided detailed and accurate clinical information, demonstrated compassion, were familiar to the family, and were readily available. A novel finding that surfaced in these interviews conducted was the lasting impact of a single negative experience. Several families were able to specifically recall the details of a negative experience that occurred months to years prior. The majority of these experiences were related to communication with the healthcare team or feeling dismissed.

A study in 2008 evaluated parent’s perception of end of life care related specifically to conversations regarding organ and tissue donation (Widger & Picot, 2008). In this study 70% of the families that had lost a child (n=39) expressed a desire to have conversations with the healthcare team about the possibilities of organ and tissue donation; however, only 38% reported they had a conversation regarding these topics. Parents also identified a barrier to care was inadequate communication of the care plan to all individuals caring for that patient, both healthcare and family.

**Summary.** Parents consistently express a desire to be involved in the decisions that impact their child’s care (Contro et al., 2002; Meyer et al., 2006; Vickers & Carlisle, 2000). Parents remember negative situations in which communication was ineffective or inadequate (Contro et al., 2002). In order to avoid the potential negative memories and increased emotional distress for parents related to their child’s care, it is imperative that there be consistent information with open lines of communication to the healthcare team.

**Advance Care Planning in Pediatrics**

The advance care planning movement is widely seen in the adult literature and is being pushed by public service initiatives like *the Conversation Project* out of the
Institute for Healthcare Improvement (IHI). Advance care planning can provide families, patients, and the healthcare team a sense of peace (IHI, n.d.). The concepts related to the benefits of advanced care planning align with the definition and mission of the pediatric palliative care movement; however, the literature reveals a gap in how advance care planning is utilized in the care of children facing life limiting illnesses. The literature below discusses parent and provider perspectives related to advance care planning, advance care planning programs in pediatrics, documentation, and timing.

**Perspectives of advance care planning.** A qualitative study that evaluated parents of children with Duchesne Muscular Dystrophy (DMD) (n=24 parent/adolescent dyads) identified that some parents coped with the reality of the declining illness of their child by denying the reality and avoiding the realities of the future (Erby, Rushton, & Gellar; 2006). Some parents felt it was more important to live in the moment than talk about the future. The reality of denial as a coping mechanism for some families with DMD was a significant new finding in the literature. This study had a small sample size isolated to one diagnosis, therefore it lacks generalizability, but the basis of the information raised concern for how to best approach families living with illnesses that follow a disease trajectory similar to DMD. The parents in this study identified that a priority was establishing trust and ongoing relationships; they felt this would help them to be more likely to openly discuss difficult questions related to end of life for their children suffering from DMD (Erby et al., 2006).

A descriptive quantitative study took a broad look at advance care planning choices related to location of death for parents who had lost a child to cancer (n=140) (Dussel et al., 2009). A total of 63% were able to plan a location of death with their
provider and of those 97% were able to accomplish the plan. In general, parents and families who were given the opportunity to communicate a plan for end of life care resulted in more home deaths and fewer hospitalizations at end of life. Parents also reported having a higher comfort level and being more prepared at the time of death. Through the planning process for location of death, some families identified that the hospital was more ideal for their needs and wishes. These families revealed that planning for location of death increased the likelihood to be on the floor at time of death instead of an intensive care environment and less likely to be intubated at time of death. Implications from this study suggest that taking the opportunity to plan location of death with individual patients and families can improve quality end of life.

A descriptive study surveyed physicians and nurses familiar with advance care planning in pediatrics about attitudes and barriers to the process (Durall et al., 2012). In this study, 71% of all clinicians (n=255) felt that advance care planning was happening too late in the child’s care and 92% believed that the ideal discussion for overall goals of end of life care should be initiated at time of diagnosis and during a period of stability. Despite this, approximately two thirds of the respondents (60%) felt that discussion for advance care planning took place during an acute deterioration. Nurses were less likely to report a barrier of not knowing the right thing to say related to advance care planning when compared to physicians (p<0.05) One of the main barriers identified was a perception that parents were not ready for discussion related to advanced care planning and continued to have unrealistic expectations that providers felt would impede any conversations.
A 2015 qualitative study of 17 healthcare professionals (physicians: n=9; nurses: n=6; social work: n=2) evaluated the attitudes and needs of health care professionals towards pediatric advance care planning (Lotz, Jox, Domenico-Borasio, & Fuhrer). The participants identified that the healthcare team members were uncomfortable and experienced uncertainty on how to approach end of life decisions and communication about advance directives with families. They identified that when an advance care plan is in place, it is helpful to guide both treatment decisions as well as future conversations. The needs identified in this study included repeated discussions with the family, education related to advance care planning, and a qualified facilitator to aid in the communication (Lotz, Jox, Domenico-Borasio, & Fuhrer, 2015). This study had a small sample size; however their findings were consistent with what is found in the literature.

**Summary.** There are positive and negative implications associated with advance care planning depending on the family’s needs at any particular time (Erby et al., 2006). This highlights the importance of the health care team meeting parents at their individual emotional needs related to advance care planning. When considering location of death, the findings suggest that it is not that home or hospital is a better place to die, but rather the ability for healthcare providers to have conversations with families to identify their “better” place for end of life care. Providers recognize their failures related to advance care planning and have recognized a need to improve it in pediatric health care.

**Advance care planning programs.** A systematic review in 2013 sought to assess current practices, effects, and perspectives related to pediatric advance care planning (Lotz, Jox, Domenico-Borasio, & Fuhrer, 2013). This systematic review identified three pediatric advance care planning programs that had been discussed in the
literature. This section summarizes the research findings related to these three pediatric advance care planning programs.

The Footprints program developed from a Robert Wood Johnson Foundation grant had three components including clinical advance care planning, research, and education (Toce & Collins, 2003). The advance care planning component of this program was directed by a continuity physician with a focus on encouraging shared decision making through advance care planning. Families involved in the program also received coordination of inpatient and community based care and spiritual support through bereavement. Evaluation of the program revealed that 90% of the families that interacted with this program (n=83) felt their needs were met during and after care by the advanced care planning meetings and written documents. All participants enrolled had a documented advanced directive.

Hammes et al. (2005) evaluated the process for adolescent patients enrolled in a pediatric advance care planning program through a non-profit health system. This program involved two to three organized visits between the advance care planning team and the family. The purpose of the visits was to help parents & adolescents better understand the diagnosis, consider types of medical treatments available, and the decisions they will likely be faced with overtime. Nearly all the families after the sessions (94%) requested no cardiopulmonary resuscitation, 77% requested no intubation or mechanical ventilation, and 75% (n=12) wanted antibiotic use. Adolescent patients that participated in the intervention (n=38) for advanced care planning were significantly more likely to have an official advance directive documented three months after the
intervention (11% at baseline vs 95% post intervention; p< 0.05). The study did not address the role of the adolescent in the conversations.

The researchers also conducted interviews with 13 families (Hammes et al., 2005). The interviews revealed that the process of advance care planning was helpful to ensure best care (92%), provided time for information to make decisions (92%), improved communication of care wishes (67%); and improved peace of mind (67%).

Lyon, Jacobs, Briggs, Cheng, & Wang (2013) utilized the concepts identified in previous work by Lyon et al. (2009) to evaluate the formal advance care planning process in adolescent patients with HIV. In a randomized control trial, a total of 30 adolescents and their families were enrolled with 13 in the control group and 17 in the intervention group. The control group received standardized care in relation advance care planning. They did receive a brochure with information related to advance care planning at the baseline assessment. The intervention group received a baseline brochure and then three 60 minute facilitated conversations weekly discussing advance care planning. The intervention group had significantly higher congruency rates between family and patient wishes (p< 0.05). This identified that for this group the formalized advance care planning sessions led to a higher likelihood of families identifying, understanding, and honoring the adolescent’s wishes at end of life.

**Summary.** The process of advance care planning when guided by a healthcare professional does help to capture adolescent treatment preferences, improve intra-family communication, and decrease stress related to difficult treatment decisions (Lyon et al., 2013). All three pediatric advance care planning programs demonstrated that the process can increase the likelihood of completing advance directives as well as improve universal

**Documentation in pediatric advanced care planning.** A retrospective chart review evaluated how end of life planning is documented in the medical records of 48 children who died from oncologic or neurologic related deaths in the United Kingdom (Beringer & Heckford, 2012). There was evidence of a discussion about the general nature of end of life care on 73% of the charts. Of the charts that had documentation of a discussion, the majority of the initial discussions occurred within six months of death. There was documentation of only one child being involved in the discussion related to end of life care planning. The majority of the health records did not have a written plan and those that did had it on a narrative note that was filed within the daily notes making it difficult to locate. There were only 42% of the charts that identified a discussion related to the families preferred location of death for the child.

The *Five Wishes®* tool was originally developed for use in the adult population to facilitate identification of personal wishes related to end of life care. A small study with adolescent and young adults suffering from cancer or HIV was the first to evaluate the impact of this *Five Wishes®* document in a pediatric population (Wiener et al., 2008). In this exploratory, descriptive study, 20 patients age 16-28 years old (n=9 for patients age 16-19) were asked to complete and then evaluate the *Five Wishes®* document. The majority of participants (95%) reported that the document as a whole would be helpful or very helpful in their own end of life situation and 90% felt it would be helpful to others their age living with life limiting conditions. None of the participants felt the document
as a whole was stressful or very stressful. Approximately 35% felt it was somewhat stressful and 45% felt is not stressful at all. The wish associated with the most stress was “The wish for the kind of medical treatment I want or don’t want” (40%). The wish that was most helpful was “My wish for what I want my loved ones to know.” All participants reported that these discussions and opportunities to plan ahead were important to them. Less than half (45%) reported they had a discussion with their healthcare team related to advance planning prior to this study.

The development of the Seattle Pediatric Palliative Care Project, led to the creation of the Decision-making Tool which was modified from the ethical clinical decision making model (Hayes et al., 2006). This tool was a dynamic document that included four domains: medical indications, patient and family preferences, quality of life, and context. The document was primarily used in the acute care setting; however, the intent was for it to be used as a resource across health care settings by patients, family members, and the healthcare team. A barrier identified in the study was the communication of the information once patients were not actively being treated in the acute care environment (Hayes et al., 2006). In this particular project, parents were provided with a paper copy of the Decision-making Tool, but it left the risk of outdated forms and inconsistencies across settings if not everyone was operating off the updated version. With computerized charting, some of these barriers are being eliminated but it is essential that when developing and documenting advance care planning discussions that all members of the healthcare team consider how that information will be communicated across settings.
Some of the frustrations and realities with pediatric advance care planning is the lack of an appropriate form that fits the needs of the pediatric healthcare team, the parents, and the child (Beringer & Heckford, 2012). Research has tried to bridge this gap by adapting forms utilized in the adult population (Wiener et al., 2008). This research has predominately been done with the adolescent and young adult population.

**Timing.** Edwards, Kun, Graham, & Keens (2013) completed a retrospective chart review on pediatric patients that had passed away who were on long term assisted ventilation. Over a twenty year period, they identified that 72% had documented discussions related to advance care planning. The discussions resulted in advance directives approximately half of the time (45%). Discussions related to advance care planning occurred in response to an acute deterioration 41% of the time and 60% of the conversations occurred in the pediatric intensive care unit.

Another retrospective chart review evaluated the end of life care received, symptom management, and other circumstances surrounding the care at time of death for children who passed away in the hospital setting (n=105) (Carter et al., 2004). The majority of the children died in the intensive care environment (87%). The majority of the patients (90%) received some form of pain medication in the final 72 hours before death; however once a decision was made to withdraw or discontinue support only 26% received additional analgesia or sedation. Nearly all patients (98%) received life sustaining support with some form of assisted ventilation leading up to death. Following this, 63% had some form of support either ventilation or cardiovascular removed in the last 48 hours prior to death. Similarly 96% of patients had nutritional support initiated at some point in the final stages with 23% making decisions to withdraw nutrition in the last
48 hours. The median length of stay in the intensive care setting for these patients was more than one week which implies that the death was not sudden or unexpected. These findings suggest that care planning is occurring too late and increasing the potential for difficult decisions. Due to the retrospective nature of this study, the authors were not able to explore if the decision to withdraw medical support was more representative of the families true wishes and desires.

**Summary.** The main barriers reported by providers related to advance care planning were concerns about taking away hope, uncertainty about prognosis, how to address uncertainty, and difference between provider and parents related to understanding the diagnosis. Families are being underestimated in their awareness of situations both consciously and subconsciously. The fear of the discussion is resulting in inequitable care and a lack of consistency across settings thus not allowing for maximal comfort for children and families.

This literature has identified that advance care planning is currently not happening in manners that are congruent with the concepts of pediatric palliative care. Advance care planning and advance directive discussions are often happening concurrently or immediately following an acute deterioration which results in abrupt transitions from curative focused care to palliative. Most pediatric literature for advance care planning and palliative care in pediatrics has focused specifically on the oncology population. There has been limited research looking at the effectiveness and consistency of advance care planning in children that suffer from chronic life threatening conditions.
Good Death/Dignified Death

Dignified dying has been identified as an area of concern for nursing care and outcomes for patients facing life threatening conditions (IOM, 2003). The idea of a good death, which is often utilized interchangeably with dignified death, developed from the adult hospice and palliative care movement with the goal of creating a more positive environment surrounding the transition of an individual from life to death. The purpose of the good death initiative for adults was to have open communication, relief of symptoms, acceptance of death, and dignity for the patient as they pass (Costello, 2006). The purpose of advance care planning aligns directly with the concepts surrounding good death.

The actual terminology ‘good death’ and the definition can be easily viewed as applicable to the geriatric population, but it is difficult for many individuals to accept those specific terms when referring to the passing of a child. It is without a doubt that healthcare providers want to assist in a dying process for pediatric patients and their families that encompasses much of the definition of good death. A more accepted and applicable term often mentioned in the literature is a “dignified death.” For a provider to tell a parent that they want to help their child experience a good death is often viewed as lacking compassion and empathy despite their good intentions. The following sections explore the attributes as identified in the literature of a dignified death in pediatrics.

Comfort. All articles reviewed regardless of the population studied emphasized the importance of being pain and symptom free at the time of death. Concerns for current pain control and symptom management and the fear of future symptoms lead to a fear of the dying process (Steinhauser & Clipp, 2000; Ternestedt, Andershed, Eriksson, &
Johansson, 2002). In addition to wanting physiologic comfort, the pediatric literature revealed the need for comfort in the communication offered by providers (Docherty, Miles, & Brandon 2007; Hopkinson & Hallett, 2002). Parents identified that compassion, tenderness and the emotional availability of their provider allowed them to feel comfort despite the terrible situation they were enduring (Munson, 2007). Feeling the patient is free of any suffering or discomfort during the dying process is also a benchmark that nurses’ use when describing a dignified death (Morgan, 2009).

**Family centered care.** Allowing a patient to die on their terms or the families’ terms is key to experiencing dignity at the end of life (Volker & Limerick, 2007). In order to be able to provide this aspect, the family and the child need to be the focus of care and decisions. Any decision made needs to take into full consideration the effects on the family as a unit (Hopikinson & Hallett, 2002). This stresses the importance of having adequate communication with the family.

**Shared decision making.** Families, parents, and older children facing the dying process are often afraid initially to voice their concerns and wishes for fear of embarrassment around the medical team. Despite this, the literature supports that parents want an active voice in the care that is provided to their child during palliative care as well as wanting to participate in decisions related to specific therapies at the end of life (Copnell, 2005). One article specifically spoke to the importance of this by saying that “it gives parents’ permission to talk about end of life issues without feeling like they are abandoning their core identity as the patient’s mother or father” (Munson, 2007, p. 776). Allowing parents the opportunity to participate and voice opinions can help to alleviate some of the uncertainties ahead of them (Hendrickson & McCorkle, 2008).
**Clear communication.** Health care providers often are uncomfortable when faced with the situation of having to speak to families about the dying process for fear of upsetting them. Families report feeling support and relief when asked about specific concerns and wishes related to the death of their loved one (Munson, 2007). In addition, it is imperative to have clear communication about what should be expected during the actual dying process including anticipated symptoms and how they will be managed (Copnell, 2005; Steinhauser & Clipp, 2000).

**Warm, welcoming setting.** Creating a comfortable environment as well as knowing the family and patient’s wishes related to the surrounding environment can help to create a feeling of dignity. The literature mentions dim lighting, music, accommodations for multiple family members, comfortable bed and seating, and familiarity with staff as elements to a welcoming environment in the creation of a dignified death (Miyashita et al., 2008; Munson, 2007).

**Spiritual awareness.** Familiarity with the family’s spiritual and cultural preferences can help to empower parents and help them to feel they are an active member of the team (Munson, 2007). A providers’ belief or acceptance of some aspect of an afterlife was important to several adults during the dying process as well as parents preparing for the death of a child (Leung, Liu, Cheng, Chiu, & Chen, 2009). Many providers described the observation of dignified death when they felt the family and patient found themselves and experienced spiritual connectedness (Volker & Limerick, 2007).

**Barriers to a dignified death.** A major barrier identified in the literature is failure to fully acknowledge the terminal nature or possibility of their diagnosis (Welch,
Depending on the age of the child, children suffering from life threatening conditions may or may not have awareness of the terminal nature of their disease, but the parents must have acknowledgment of this in order to progress to a dignified dying process. If parents are not willing to accept the possibility of death of their child, they will not be in a situation where the attributes can work together to create a dignified death for their child. Providers often try to identify a specific point in which the illness has transitioned to a terminal nature; however, the reality of identifying this point is very difficult in the pediatric population because of the resilience of children and the uncertainty of many pediatric disease courses. It can be difficult for health care providers to counsel parents to accept this diagnosis when they themselves are unsure (Morgan, 2009). This is why it is imperative that the pediatric healthcare community in particular embrace the concept of curative and palliative care coexisting from the time of diagnosis. One way that the healthcare team can assist parents in overcoming the barrier of not accepting the life threatening nature of their child’s illness is through repeated conversations with the family that work gradually at the parents pace towards an acceptance of the possibility of death.

Theoretical Framework:

There are many frameworks that explore the dynamics of family stress. Reuben Hill’s Family Stress Theory (1949, 1958) serves as the basis for many of the family stress frameworks that have developed to explain family dynamics. Hill’s original theory developed from his post-World War II research where he studied families’ responses to separation and reuniting. The theory is founded in three events that lead to a crisis which includes a stressor, family’s existing resources, and the family’s perception of the stressor
In the early 1980’s, McCubbin & Patterson conceptualized the original Family Stress Theory to reflect that there is family adaptation that occurs to the stress over time (LoBiondo-Wood, 2008). This re-conceptualized theory emphasizes that the outcome of the theory is adaptation that happens as the family experiences the stress and crisis over a period of time. To reflect this change, it was renamed the Double ABC-X Model of Family Adaptation (LoBiondo-Wood, 2008). It is noted that with extensive research over the years, there have been many adaptations of the Double ABC-X Model of Family Adaptation which reflect changes that occur over longer periods of time. For purposes of this study, the original Double ABC-X model of Family Adaptation by McCubbin & Patterson in the 1980’s fit most appropriately with the population and intervention. The following sections will describe each component of the Double ABC-X model of Family Adaptation and how it will apply to this research. (Figure 2)

**Pre-crisis.** The model developed by McCubbin & Patterson take into account that prior to the crisis there is existing stressors, perception of those stressors, and existing resources. These vary dependent on the family but exist for everyone. For purposes of this study, the pre-crisis is not being evaluated; it is assumed that each family enters with varying existing stressors.

**Crisis.** The crisis is an event or situation that prevents a family from continuing with normalcy in their family functions (LoBiondo-Wood, 2008). This model recognizes that in the pre-crisis stage all families encounter stressors but through their perceptions of the stressor and resources, they are able to continue with normal family functioning. At the point of crisis, there is an event from a new or existing stressor that tips the balance scale for the family that produces a crisis and the family’s inability to meet the demands
of the stressor event. For purposes of this study, the crisis is caring for a child with a life threatening condition.

**Pile-up factor.** The pile-up factor is a result of strain of the stressors and crisis over time. Over time families experience a longitudinal effect of the stressor that has an impact on the whole family has a unit (LoBiondo-Wood, 2008). There are highs and lows as families deal with the crisis but overtime there is a ‘pile up’ of the emotions and strains that accompany the stressors. This also represents the pile up that can occur from the crisis as well as all the other stressors that families are encountering prior to the crisis event. For purposes of this study, the pile up is representative of the parental distress. This pile up of parental distress includes emotions that are endured by families faced with the challenge of caring for a child living with a life threatening condition. These distress emotions like sorrow, anger, uncertainty, and guilt come and go at different points in the child’s illness but can have a cumulative effect on the parent and family (Bonner et al., 2006).

**Existing and new resources.** This identifies that when families are exposed to new resources as well as assisted on maximizing existing resources there is opportunity for the family to adjust to the demands of the crisis (LoBiondo-Wood, 2008). In this study, the use of the conversation intervention *Go Wish- Pediatrics* will help parents to identify areas where resources are needed which in turn will allow opportunities for the palliative care team to guide the family to appropriate resources both new and existing.

**Family perception.** This is how the family or caregiver identifies with the significance of the stressor and crisis (LoBiondo-Wood, 2008). In sum, it is the overall meaning that the family assigns to the total situation. For purposes of this study, the
family perception of the stressor will not be directly evaluated quantitatively; however, it is believed that the qualitative data will explore how families identify with the stressor of having the conversation related to advance care planning using the intervention *Go Wish-Pediatrics*.

**Coping.** Coping is defined as an active process in which individuals use the resources available to them to strengthen the core unit, in this case the family, which in turn reduces the negative effects of the stressors on the core unit (LoBiondo-Wood, 2008). For purposes of this research, coping is represented through the facilitated conversation intervention which allows a third party to help families identify their resources and appropriate coping mechanisms to help maintain the core family unit as a functional system. In this model, coping is meant to represent ways to decrease situational stressors, not eliminate them which is appropriate with the palliative care concept as the stressors will not go away.

**Adaptation.** In the model by McCubbin & Patterson, adaptation occurs as an outcome when a family adequately uses their resources to cope (LoBiondo-Wood, 2008). When adaptation is reached, it means that the family or individual has given some level of meaning to the crisis which has allowed the family to balance the needs and the stressor. This can happen at the level of the individual, the family unit, and the community. The use of the Double ABC-X model in patients with chronic illness has identified that achievement of adaptation is not an expected outcome but rather an adaptation to the stress (LoBiondo-Wood, 2008). For purposes of this study, it is not believed that adaptation is the final outcome. It is anticipated that following the
intervention, that the parent experience of the child’s life threatening condition is
adjusted.

**Nursing Research.** The double ABC-X Model has been used extensively by a
research group led by LoBiondo-Wood. This group has evaluated and tested several
components of the Double ABC-X Model of Family Adaptation in the pediatric
transplantation population (LoBiondo-Wood, Williams, Kouzekani, & McGhee, 2000;
Lobiondo Wood, Williams, & McGhee, 2004). A significant finding of their research in
this population using this model is that adaptation does not serve as an ending to the
process. Similar to living after a liver transplant, parents and families involved with
palliative care are battling the realities of chronic illness and the peaks and valleys of
differing stress and crisis points in the illness. This is important to identify that this is not
a linear process that ends at adaptation but rather a process in which families move back
and forth with different points of adjustment needed to maintain parent and the family
functioning (Bonner et al., 2006; Lobiondo-Wood, 2008). The palliative care team serves
as a facilitator with the goal of positively adjusting the parent’s experience of their child’s
illness.
Conceptual and Operational Definition of Terms

The principal variables being evaluated in the quantitative portion of this study are parental distress and resources. Conceptual and operational definitions of the principle variables are offered in Table 1.

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<thead>
<tr>
<th>Conceptual Phenomena</th>
<th>Conceptual Definition</th>
<th>Operational Definition</th>
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<tr>
<td>Parent Experience of Child Illness</td>
<td>Adjustment to the new stressors of caring for a child facing a life threatening condition. This adjustment can be positive or negative (Bonner et al., 2006)</td>
<td>Parental Distress and Emotional Resources [Parent Experience of Childhood Illness (PECI)]</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>A result of new and existing stressors that evoke emotional responses in parents concerned with the future and wellbeing of their child and their family; anger and grief directed at the stressor, and sadness and fear of the</td>
<td>Guilt &amp; Worry Unresolved Sorry and Anger Uncertainty</td>
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unknown. (Bonner et al., 2006; Bonner et al., 2008)

| Resources | Utilization of self-reliance, family networks, social support, and group action to strengthen how an individual or family to respond to stress crises. (Wallander, Varnni, Babani, Banis, & Wilcox, 1989) | Emotional Resources |

**Other Definition of Terms**

**Pediatric Patients**

Pediatric experts agree that the pediatric population begins at birth. The upper limit of the pediatric population varies depending on the source. For purposes of this paper, the pediatric patient will be defined as any child or adolescent between 0-17 years old. In most states, once an adolescent turns 18 years old, they become a legal adult to make their own health care decisions.

**Pediatric Palliative Care.** Pediatric palliative care is the all-encompassing care of a child with a life limiting or life threatening illness and the family (AAP, 2013; IOM, 2003). This includes caring for the child & family’s’ mind, body, & spirit (IOM, 2003). For purposes of this paper, palliative care refers to care aimed at improving the quality of life for the child and family with a life threatening illness by addressing the physical, emotional, and spiritual needs regardless of curative treatments.
**Parent.** Parent, for purposes of this study, is defined as the legal guardian of the child.

**Life-threatening illness.** Life threatening illness for this study is defined as any illness developed as a child in which the child is likely to die before the age of 40 as a result of the illness or complications related to the illness (Lenton, Stallard, Lewis, & Mastroyannopoulou, 2001).

**Advance Care Planning.** Advance care planning is defined as the formal process of assisting the patient and family to become aware of their wishes related to their illness, care, and specific desires for end of life with a focus on what will be provided throughout the care plan in terms of medical interventions (NINR; 2013).

**Quantitative Research Questions**

1. What is the parent’s experience of having a child in pediatric palliative care when as measured by the PECI [Parent Experience of Child Illness]?

2. Do relationships exist between the parent’s experience as measured by the PECI and pediatric disease demographics including type of diagnosis, length of time in palliative care, length of time since diagnosis, educational level of the parents, age of child, gender of parent, and parent income?

3. Does the intervention *Go Wish- Pediatrics*, a facilitated advance care planning conversation tool, impact the parent’s experience of having a child in pediatric palliative care measured by the PECI?

4. How do parents value (very important, somewhat important, not important) the items in the *Go Wish- Pediatrics* cards?

**Qualitative Research Questions**
1. What is the parent’s overall experience and perception of the Go Wish-Pediatrics intervention?

2. How do parents describe their experience of utilizing Go Wish-Pediatrics as a tool to facilitate advance care planning?

3. What could be done to improve the Go Wish-Pediatrics intervention?
   a. Were any values or items missing from the Go Wish-Pediatrics intervention?

**Mixed Methods Research Question**

1. How do the qualitative findings from the interviews with parents provide an enhanced understanding of the Go Wish-Pediatrics intervention?
Chapter 3: Methodology

This embedded mixed methods pilot study addressed the effect of using the *Go Wish-Pediatrics* conversation tool on parent’s experience (parental distress and emotional resources) of caring for children receiving pediatric palliative care services. A mixed methods design was used in which qualitative data was embedded within the main pre-post, exploratory quantitative design. The quantitative data was analyzed to evaluate the impact of the *Go Wish-Pediatrics* conversation tool on parental distress and emotional resources as measured by the Parental Experience of Child Illness (PECI) Scale. The qualitative data was embedded within the quantitative study for the purpose of describing the parents’ experience of using the intervention to direct conversations with their healthcare team.

Philosophical Underpinnings

Philosophical assumptions serve as a guide for research inquiries. Pragmatism is widely accepted as the philosophical foundation for mixed methods research. A key concept of pragmatic science is that the meaning, truth, and value of an idea are judged by the practicality or usefulness of its consequences (Kim & Sjostrom, 2006). As a group, the early pragmatists rejected the idea of absolutes and believed that the epistemology of pragmatism came from human experience (Kim & Sjostrom, 2006). Pluralism and humanism are important themes in the foundation of pragmatism. The philosophical founders of pragmatism believe that pluralism is essential to the movement because people live in an ever changing and shifting world. Things are never just one way, rather, there is change and adaptation. Thus, scholars need to view ideas through different approaches or philosophies to find meaning (Koopman, 2006). To best answer
some research questions, the two historically purist paradigms, positivist and constructivist need to merge. A pragmatic approach was suitable for this pilot study because to fully evaluate the feasibility and usability of this new intervention both the quantitative impact as well as the perception of the participants was essential. The knowledge of how quantitative data explains an intervention is only one piece of evaluating the value of the intervention. If it is not accepted or viewed as usable in the eyes of the participants, a pragmatist would ponder the purpose of the intervention regardless of the quantitative data. Thus, it is essential to consider both paradigms together to truly evaluate the feasibility and usability of a new intervention.

**Mixed Methods Research**

Mixed methods research is described as the emerging third paradigm in research (Creswell & Plano Clark, 2011). The mixed methods paradigm has gained increasing attention over the last decade in many fields including education and nursing research. The mixed methods paradigm purports that both qualitative and quantitative data are essential to fully understand some research questions. Using the participant’s views and words to frame the quantitative data can provide a deeper, richer analysis (Creswell & Plano Clark, 2011). This concept is familiar to the nursing profession. When assessing a patient, nurses continually utilize both quantitative data (e.g., vital signs, physical assessment) combined with the patient’s qualitative description of symptoms. Utilization of quantitative and qualitative data allows nurses to provide best practices and care to patients. One example is pain evaluation. A nurse must collect the numerical rating of the pain, observe physical manifestations, and seek the patient’s subjective description; analysis of these data components together results in adequate care of the patient’s needs.
Evaluation of the number alone does not adequately provide a description of the pain for that patient.

There are multiple types of mixed methods research designs. All designs are considered and the research questions are matched to the most appropriate design so that rigor and trustworthiness are upheld. The researcher must consider the paradigm, theoretical lens, and research questions. For the proposed pilot study an embedded mixed methods design was selected. This design allowed the researcher to identify a traditional purist paradigm (quantitative or qualitative) as the main focus of the study that is supplemented with the collection and analysis of a second data set before, during, or after the original data collection (Creswell & Plano Clark, 2011).

An embedded mixed methods design is often used in the development and/or testing of new interventions and instruments. The embedded component allows for the quantitative evaluation of an intervention to be the focus of the study; the qualitative views and experiences of the participants supplement the quantitative focus. The researcher collected the qualitative and quantitative data separately, and then integrated the findings of both the quantitative and qualitative research in the interpretation of the findings. The use of the supplemental qualitative data served to strengthen the study by providing deeper meaning and explanation to the quantitative findings.

The basis for the embedded design for this pilot study lies in the proposition that a single data set will not sufficiently answer the research question(s). When developing and testing new interventions, quantitative data is essential in evaluating outcomes. However, the researcher must also consider the usability, feasibility, and acceptability of
the intervention. This deeper context can be gained through framing the quantitative results with the words of the participants.

A key component to mixed methods research is the clear identification of the design for both the qualitative and quantitative data. The quantitative design for this study was a pre-posttest, exploratory design. A qualitative descriptive design was utilized to describe the parent’s perception of the Go Wish- Pediatrics intervention. The intent of a qualitative descriptive design was to provide a summary of an event in the language of the participants (Polit & Beck, 2012). This type of design has been utilized to describe participants experience with a particular intervention (Polit & Beck, 2012; Sandelowski, 2000). Sandelowski (2010) describes that the purpose of this descriptive design is to provide a thorough, complete summary of a specific event in the everyday terms of the participants. This design fits well within an embedded mixed methods design in which the researcher is seeking to strengthen support of an intervention by seeking participants’ perception of it. A visual depiction of the mixed methods embedded design is provided in Figure 3.

**Study setting and sample.** This study utilized a convenience sample of parents of children enrolled in a pediatric palliative care program in a non-profit Midwest, free standing 145 bed children’s hospital. For purposes of this pilot study, a child enrolled in the pediatric palliative care program was considered as suffering from a life threatening condition.
Figure 3. Embedded Mixed Methods Research Design

The maximum number of parent participants that was contacted to participate in this study based on the inclusion criteria was 136 families. This was a pilot study; therefore no power analysis was completed. A minimum sample was unpredictable due to the sensitive nature of pediatric palliative care and limited population. Potential participants were only contacted two times due to the vulnerable situation. It was felt that contact more than two times would be intrusive to the family.

**Inclusion and exclusion criteria.** Inclusion criteria were: 1) Families who have had inpatient or outpatient contact with the palliative care team between January 2013-December 2014; 2) legal guardian of a child actively enrolled in pediatric palliative care; 3) 19 years of age or older; 4) the ability to read and speak English. Parents were
excluded from this study if their child passed away prior to or during the study. This time frame was chosen to ensure that the parents were currently involved with the pediatric palliative care program and been involved with palliative care for a minimum of two months prior to the request to participate in the study.

**Recruitment.** The pediatric palliative care team was in full support of this study as a department and helped with facilitation of recruitment (Appendix A). Following Institutional Review Board (IRB) approval from Children’s Hospital and Medical Center (Appendix B) and South Dakota State University (Appendix C), the nurse researcher worked directly with the palliative care program coordinator and nurse practitioner to begin recruitment. The palliative care program coordinator and nurse practitioner identified eligible participants via their database. They were the only individuals that had access to this list of names contacted by the mailed invitation letter. Potential participants received a letter directly from the pediatric palliative care program coordinator in a bright orange envelope which provided an overview of the research study and invited potential participants to contact the nurse researcher via email, phone, or permission to contact card that was included with a stamped return envelope if interested in participating in the study. A sample of the recruitment letter is provided in Appendix D. A second letter was sent three weeks after the initial letter as a final invitation to the families.

**Description of Intervention.** The intervention for this study, titled *Go Wish-Pediatrics*, was a facilitated advance care planning conversation tool. This was an adapted version from *The Go Wish™ Game* developed by Dr. Elizabeth Menkin and the Coda Alliance for use in the geriatric population. With the permission of Dr. Elizabeth
Menkin, the original version of *The Go Wish™ Game* was modified using the pediatric advance care planning and palliative care literature (Appendix E).

The original *The Go Wish™ Game* was developed in 2007 in response to the Coda Alliance community coalition for end of life care in California. Coda is the term used for the last part of a musical piece in which the song is brought to a harmonious end (Menkin, 2007). This name reflects the Coda Alliance purpose to improve palliative and end of life conversations among older adults to allow for a more “harmonious” passing. One objective for the organization was to encourage advance care planning discussions to happen earlier with aging individuals. To achieve this objective, the organization decided to target individuals living in assisted living facilities and develop a tool that could facilitate conversations between them and their health care proxy to promote better discussion and awareness of individual’s wishes. The group decided that Likert scales and ranking systems were too scripted and did not allow for adequate discussion and true expression of the individual’s needs, so they developed a card game that had individual goals on each card. The cards were given to residents at assisted living facility who were asked to sort the cards into three piles: very important to them, somewhat important to them; and not important to them.

In the initial testing of the cards, some of the cards were consistently in the “not important” pile which resulted in a revision or removal of these cards. The Coda Alliance has found that the *Go Wish* cards have helped to improve conversations and expressions of wishes and values within the family and the medical team (Menkin, 2007). The intent of the *Go Wish* cards is for conversations to be oriented to the priorities and
concerns of the individual instead of the healthcare team trying to guess the priorities of the individual.

In 2010, Dr. Menkin and colleagues published a feasibility study of using the *Go Wish™ Game* patients in the Veteran hospital in Los Angeles (Lankarani Fard et al., 2010). Individuals being cared for in the inpatient setting (n=33) were asked to sort the cards into the three piles as previously discussed. Following the sorting of the cards, a member of the research team sat with the patient to discuss the different piles and what the top ten most important issues/values were in the “very important” pile. The purpose of the study was to evaluate the feasibility of implementing this end of life conversation tool in an inpatient setting facing acute serious illnesses. In addition, the authors identified which values on the cards were ‘provider focused’, actionable by the medical team, versus ‘patient focused’. In the analysis they found that the top ten most frequently identified values were split equally between patient and provider focused, this identified that while the medical team can take action on cares like pain and symptom management to facilitate palliative care, there are also many things that the provider can help to empower patients to take action on like intra-family communication.

A thorough review of the pediatric palliative care literature was undertaken to develop a revised *Go Wish- Pediatrics* set of cards. The initial set of 41 cards reflected both values from the original geriatric version that are pertinent to the pediatric population as well as items that are more relevant to parents caring for children suffering from a life threatening condition (Appendix F). Prior to implementing *Go Wish- Pediatrics* with the participants, the 41 prototyped cards were sent to a panel of experts in pediatric palliative care to assist with evaluation for appropriateness and face validity of
the content on the cards. This panel of individuals included a pediatric palliative care physician, a pediatric palliative care nurse practitioner, a pediatric palliative care social worker, and a pediatric hospitalist. These individuals were asked to provide feedback on the wording of the cards, appropriateness of the topics, and any missing content. The feedback from the panel included only grammatical changes to the wording on the cards. Feedback did identify that some cards were repetitive to the same concepts like addressing needs of siblings and the parent’s ability to care for the child; however, the committee recommended leaving all the cards as it may help parents relate to the cards when the same concept is addressed in a different way. The committee felt that while some of the cards addressed similar concepts, they were different enough to leave in as part of the pilot test that would allow parents to provide feedback. The committee also felt that no additional cards were needed. Following the feedback, the researcher made appropriate grammatical revisions to the cards for the final prototyped version to be implemented in the proposed pilot study (Appendix G). The final version of the cards was be printed on cardstock with a number in the corner specific to each card and laminated for ease of use with the participants.

Once the parent participants completed the card game, the researcher reviewed the cards in each pile with the parents and recorded which piles the cards were placed into. The researcher then met with the pediatric palliative care nurse practitioner with whom the family had an established relationship with to go over the cards and identify key points from the conversation.

Instrumentation. Parent demographic variables and pediatric disease demographics were collected for this research. Previous research has identified that
certain demographic variables can impact how parent’s experience their child’s illness including child’s age, diagnosis, time since diagnosis, parent age, parent gender, race, and education level (Bonner, et al, 2008). A sample of the demographic survey for this study is provided in Appendix H.

The Parent Experience of Child Illness (PECI) scale was used in this pilot study to measure parent distress (Guilt & Worry; Unresolved Sorrow & Anger; and Long-term Uncertainty) and perceived emotional resources. This instrument was developed in collaboration with a pediatric neuro-oncology group at Duke University Medical Center after identifying a gap in the literature on quantitative methods to accurately measure a parent illness related distress and perceived emotional resources as they cared for a child suffering from chronic illness (Bonner, 2006). The PECI is a 25-item instrument written at a fourth grade level that measures four constructs including guilt and worry; unresolved sorrow and anger; long-term uncertainty; and perceived emotional resources. The author of the instrument categorizes the first three subscales (guilt and worry; unresolved sorrow and anger; long-term uncertainty) as parent distress subscales (Appendix I). Parents are instructed to score each item based on their thoughts and feelings over the past month utilizing the five point Likert scale [0=never; 1=rarely; 2=sometimes; 3=often; and 4=always].

The authors initially developed the instrument using exploratory factor analysis while testing it in 202 parents of children suffering from brain tumors. This resulted in five factors; however, one factor was eliminated due to significant cross loading on four of the factors. The four subscale PECI instrument was then validated against four additional instruments including the Caregiver Strain Questionnaire (CSQ), Impact on
Family Scale (IFS), Brief Symptom Inventory (BSI), and the Impact of Event Scale (IES) (Bonner, et al., 2006). The subscales of the PECI were compared to scores from these instruments to determine construct validity (Bonner, et al, 2006). Internal consistency for each subscale was also determined using Cronbach’s α (Guilt and Worry = 0.89; Unresolved Sorrow and Anger = 0.86; Long-term Uncertainty = 0.80; and Emotional Resources = 0.72, Bonner et al., 2006).

An additional study to further validate the instrument was completed on 125 caregivers of children diagnosed with brain tumors (Bonner et al, 2008). Convergent and discriminant validity was seen for all fours subscales of the PECI when tested against the Hearth Hope Index (HHI), Anticipatory Grief Scale (AGS), and the Global Assessment of Functioning (GAF) (Bonner, et al, 2008). Test-retest reliability demonstrated statistically significant Pearson’s correlation for all four subscales (p<0.001, Bonner et al., 2008).

The PECI scores all subscales individually by totaling the score for the subscale and dividing by the total number of items in that subscale. There is no cumulative score given for this instrument. Permission from the author to use the PECI instrument is provided in Appendix J.

**Procedure & data collection.** After parents interested in the study contacted the researcher, a meeting was agreed upon with the parents at a location of their choice that allowed for privacy. This meeting allowed for them to be in an environment that was non-threatening and comfortable to them. At the meeting, the researcher reviewed the purpose of the study, the intervention, and data that would be collected and how it would be shared with the palliative care team that was already involved in their child’s care.
Participants were given time to ask questions and the option to not participate in the study. If the participant expressed interest in participating in the study, they were given an informed consent form (Appendix K). Following consent, the researcher provided them the demographic questionnaire with an assigned participant ID number and PECI instrument with the assigned participant ID number. Following completion of the instruments, the researcher explained the Go Wish-Pediatrics game. Participants were given the cards and instructed to go through each of the 41 cards and place them into one of three piles: “very important”, “somewhat important”, and “not important”. The researcher remained close by the participant but not directly interacting with the participant during this time. It took participants approximately 15-20 minutes to sort the cards. Once the participant had completed the card game, the researcher recorded the card numbers for each of the three piles.

A semi-structured interview was then conducted by the researcher with the participant related to the Go Wish-Pediatrics intervention. The first part of this interview included review of the participant’s card game with a discussion as to the meaning of each card and the significance of it to that parent. Following this, there were three qualitative questions that served as the foundation for the qualitative analysis of the feasibility and usability of the intervention from the parent perspective. A copy of this interview guide is provided in Appendix L. All of the interviews were recorded and transcribed verbatim by a transcriptionist.

The researcher then met with the pediatric palliative care nurse practitioner within two days of the interview to discuss the parent’s priorities according to their Go Wish-Pediatrics card game. A post PECI was completed three weeks after the initial interview.
It was noted that scheduling difficulties results in some of the post PECI data collection to be between 3-5 weeks after the intervention. Participants were offered a $20 gift card for their time and participation in the research study.

The data for the demographics, pre PECI, and post PECI were recorded in an Excel database maintained by the researcher.

**Quantitative Data Analysis.** The quantitative analysis for this study will be utilized the SPSS statistical software (version 22) as well as Statistical Analysis System software by the statistician assisting with the statistical analysis. The anticipated analysis for the demographic data and the sample distribution of the Go Wish- Pediatrics cards included descriptive statistics with frequencies and percentages.

Data collected utilizing the PECI instrument was scored according the PECI instrument guidelines provided with permission by the original author. The score for each subscale was totaled and divided by the number of items in that subscale (Guilt & Worry; Unresolved Sorrow & Anger; Long-term Uncertainty; and Emotional Resources). It is noted that an item in the Guilt & Worry subscale and an item in the Unresolved Sorrow & Anger subscale was reverse coded according to scoring guidelines when summing the scores. Anticipated analysis for the PECI subscales included the use of descriptive statistics to summarize the mean and standard deviation for each subscale.

It was anticipated a linear model would be utilized to examine if relationships exist between each individual subscale score and the demographic variables related to the child (age; diagnosis, time since diagnosis, time in palliative care); to the parent (age, gender, level of education, income level), and advance care planning (current advance directive, previous advance care planning conversations). A statistically significant p
value less than 0.1 was set to determine if variables will be retained in the model. The researcher utilized a p-value of 0.1 in this pilot study to avoid the risk of missing significant change with an intervention that is being tested in a new population.

The anticipated statistical test to evaluate if the intervention had an impact on the parent’s experience as measured by the subscales of the PECI was a paired t-test. Participants pre and post test data was labelled with the participant ID so that it could be paired for analysis using a comparison of the means of each subscale.

The researcher acknowledged that there were threats with a pre-posttest one group design. The main threats to the quantitative data collection for this study included history, maturation, and testing (Polit & Beck, 2012). The researcher acknowledged these threats as part of this pilot study and considered them in the analysis and limitations of this research.

**Qualitative Data Analysis.** All interviews were recorded and transcribed verbatim. This included both the interview of the researcher and the participant discussing the Go Wish cards as well as the qualitative interview guide questions at the end of the first visit. A thematic analysis was first completed to examine the interview transcriptions specifically looking at the three questions from the qualitative interview guide that sought to explore the participant’s experience with the card game. The researcher began by reading this portion of the transcript once to gain a base knowledge of the interview as a whole (Creswell, 2013). While doing this, the researcher completed the processes of recording ideas and key concepts that began to surface on initial read. Next the researcher started the process of classifying and interpreting the data by forming codes. Initially there were 8 codes identified that represented themes identified by the
reader. Typically 20-30 codes will be identified that represent the words and statements of the participants that are relevant to the research questions; however this portion of the interview for participants was not very lengthy (Creswell, 2013). The codes were reviewed and collapsed into themes that represented the views of the participants. The researcher extracted comments and quotes verbatim from the transcriptions that were representative of the identified themes.

A second qualitative analysis occurred during the mixed methods portion of the study where the transcripts from the interview between the researcher and the participant discussing the Go Wish cards were analyzed for comments that connected to the quantitative portion of this study including the three parent distress categories (guilt & worry; unresolved sorrow & anger; and long term uncertainty) and emotional resources.

The rigor and trustworthiness of the qualitative portion of this study was maintained using the following criteria: credibility, dependability, confirmability, transferability, and authenticity (Polit & Beck, 20012). To ensure these criteria were met, the researcher employed several techniques during the data collection including prolonged engagement, persistent observation, and member checking. Member checking occurred during the interviews with probing questions to confirm the meaning that was intended by the participant was accurately understood by the researcher (Polit & Beck, 20012). Member checking also occurred after the analysis when the researcher contacted some of the participants from the study to discuss the emerging themes from the qualitative and mixed methods analysis. Data analysis occurred simultaneous with data collection. During data analysis, the researcher and an independent reviewer that is familiar with thematic analysis reviewed the transcriptions and coding process. This
process allowed for investigator triangulation, which helped to reduce the possibility of biased conclusions and enhanced the credibility and dependability of the data (Polit & Beck, 2012).

**Mixed Methods Interpretation.** The qualitative data and quantitative data for this study was mixed during the interpretation phase. The purpose of this analysis was to explore how the qualitative data explains and enhances the quantitative findings (Creswell & Plano Clark, 2011). The mixed methods analysis involved reviewing the interviews related to the cards to identify general concepts that emerged from the card game intervention and how they connected to the parental distress and perceived emotional resources subscales of the PECI instrument.

**Protection of Human Subjects.** To protect the rights of the potential participants in this study and adhere to ethical standards, Institutional Review Board (IRB) approval was received from South Dakota State University and University of Nebraska Medical Center which oversees IRB applications for Children’s Hospital and Medical Center. An information and informed consent form was utilized for this study (Appendix J). This form was reviewed with all participants that contacted the researcher after receiving the initial invitation letter provided by the palliative care team at Children’s Hospital and Medical Center. Participants voluntarily expressed interest in the study by responding to the initial call to participate. These participants were given an opportunity to ask questions after reviewing the information about the study and prior to signing the consent form. The researcher offered the individuals the opportunity to decline participation. Participants in the study were offered a $20 Target card as reciprocity for the time and
participation in the study. The card was given at the completion of the qualitative data collection.

It was essential for ethical standards that confidentiality was ensured throughout the research process. The researcher had no access to the list of potential participants as the initial recruitment letter was sent by the palliative care department which had ethical access to the population. Once participants contacted the researcher about their interest in the study, they were ensured of the confidential nature of the project and how anonymity was maintained. Once consent was received, the participant received a study identifier number which was recorded onto the consent form and accessible only to the researcher. This number was utilized in the collection of data to ensure anonymity and allow the researcher to pair the data for analysis without using any patient identifiers.

Data was collected and maintained on an excel spreadsheet in a password protected flash drive accessible only by the researcher. The quantitative data was provided with complete anonymity to the statistician assisting in the analysis phase. The statistician was only provided the raw data and participant identification number but no ability to connect the number with the participant. The researcher recorded the results of the quantitative research into an excel database utilizing only the participants identification number assigned to them. This ensured that no patient identifiers were accessible. The researcher was the only individual who conducted the interviews for the qualitative portion of the study. The transcriptionist only had access to the recordings which only included the participants study identifier and nothing else. The consent forms, data collection forms, and excel sheet were stored in a locked file cabinet in a locked office that only the researcher has access to for three years.
As with any research, there are possible risks and benefits for the participant. The informed consent noted that there is risk associated with the study. Participants could have experienced negative emotions due to the sensitive nature of the phenomena. The researcher was aware of these potential risks and monitored for them throughout both the quantitative and qualitative data collection process. If there was any concern for increased or excessive negative emotions by the participant, the researcher would have recommended further counseling. No participants experienced any excessive emotional responses during this study.

This research posed minimal risk to the participants. There was concern as to whether asking for participation during this vulnerable time was ethical. The process of caring for a child suffering from a life threatening condition is difficult both emotionally and physically; however, the emotional and physical pain is something that these parents and children encounter once they palliative care with or without participation in the research. To best avoid increasing the risk, the researcher ensured that they are conducting research on families who had already consciously entered the palliative care process with their child.

There was the potential and the hope of the researcher that the research process for this study would be beneficial for the participants. Research has shown that parents who have participated in descriptive pediatric palliative care research have found the interviews and research process to be therapeutic (Hinds, Burghen, & Pritchard, 2007; Mongeau, Champagne & Liben, 2007; Rapoport, 2009). There is a combined effect that has been seen in the literature where parents report being emotionally challenged but
despite this having an overall a positive experience (Hinds et al., 2007; Mongeau, Champagne & Liben, 2007).
Chapter 4

Introduction

This chapter presents the description and analysis of pilot data for the use of the Go Wish-Pediatrics intervention with parents whose child was receiving formal pediatric palliative care services. Given the mixed methods design, the first section of this chapter focuses on the quantitative analysis organized by research question. The second section presents analysis of the qualitative data specific to the feasibility and usability of the Go Wish-Pediatrics intervention. The third component of the mixed methods analysis will evaluate the parents’ subjective experience of the Go Wish-Pediatrics intervention through analysis of the qualitative interview data and the quantitative Parent Experience of Child Illness (PECI) data.

Data was entered into an Excel database during the data collection process and organized by participant identification number. Data from the demographic questionnaire were coded using one through seven. Data from the PECI instrument were coded zero through four according the original author guidelines. Equations were entered into the Excel flow sheet to calculate the means of each subscale for both pre and post data, including reverse coding of one item in the guilt and worry subscale and one item in the unresolved sorrow and anger subscale. The author and statistician calculated by hand the subscale mean for each participant to confirm accuracy of the excel equations. Data for the distribution of cards was coded one through three based on the pile they were placed in for each participant. There was no missing data from any of the surveys. The data from the Excel file was then loaded into SPSS (edition 22) for analysis.
Results and Analysis

Description of sample. A total of 136 initial invitation to participate letters were sent to participants. A total of seven families returned emails or phone calls to inquire about the research study. From these seven families, one parent chose not to participate due to other family issues. Another parent set up an initial visit but prior to that visit her child passed away. From the remaining five families both parents were invited to participate in the study. This resulted in a total of eight participants recruited. A total of 120 follow up invitation letters were sent three weeks after the initial letter. There was a smaller number of invitation letters sent the second time due to deaths, already contacted the researcher, or family had contacted palliative care saying they were not interested. From this letter, a total of three families responded. One participant scheduled a visit however her child was very sick in the intensive care unit and she postponed the visit twice due to time constraints and her sick child. Her child ended up passing away prior to having an initial visit for the study. Another family initially contacted the researcher via email for more information and then did not respond despite follow up from the researcher. There was a total of one family which resulted in two participants from the second request letter that completed the study. The final sample for this study consisted of a total of six families from which came ten participants.

Descriptive statistics were used to analyze the independent variables in this study including: (a) gender; (b) marital status; (c) race; (d) employment; (e) income; education; (f) advance care planning conversation; and (g) advance directive. Parents also identified the main diagnosis for their child being cared for in palliative care. The diagnoses reported included: (a) trisomy 18; (b) septo-optic dysplasia; (c) hypoplastic left
heart syndrome; (d) congenital anomalies; (e) neuroblastoma; and (d) anoxic event as an older infant. The independent variables were examined using descriptive statistics in SPSS version 22.

**Age, gender, ethnicity, and marital status.** Most respondents were currently married (90%; n=9). The sample was split by gender with 60% of the respondents female (n=6) and 40% male (n=4). The majority of respondents were between 35-44 years of age (60%, n=6). This study had predominately Caucasian/white participants (90%, n=9).

Table 2 depicts the gender, marital status and age range of the participants.

**Table 2**

Sample Demographics Gender, Marital Status & Parent’s age, and Race (N=10)

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<th>Frequency</th>
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<td>Female</td>
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</tbody>
</table>

**Parent Employment, Education, and Income.** Most parents were working with 60% working full time (n=6) and 30% part time (n=3). This finding also coincided with 80% of the annual household incomes being reported to be greater than $50,000 and 70% of the participants having completed a bachelor’s degree or higher. These socioeconomic
demographics limit the generalizability of this study. The results for these demographics are depicted in Table 3.

Table 3

*Sample Demographics Parent employment, education, & income (N=10)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working Full time</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>Working Part time</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td><strong>Parent Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School Diploma</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Some College, no degree</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td><strong>Parent Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $24,999</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>$25,000-$49,999</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>&gt;$100,000</td>
<td>2</td>
<td>20</td>
</tr>
</tbody>
</table>

*Advance Care Planning.* None of the participants in this study had an advance directive in place; however, half (50%, n=5) of the participants reported that they felt they had participated in an advance care planning conversation at some point (Table 4). Parents identified that this was not necessarily identified as advance care planning, but they felt they had participated in a conversation related to the concepts of advance care planning. No definition or explanation was provided to participants when they answered these questions.
Table 4

Sample Demographics Advance Care Planning Conversation & Advance Directive (N=10)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Care Planning Conversation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>Advance Directive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>100</td>
</tr>
</tbody>
</table>

Reliability analysis. When looking at reliability for the PECI instrument with the small sample in this study, a Cronbach alpha was computed for each of the subscales (Table 5). Overall the reliability for each subscale was similar to those found in the initial evaluation of the instruments reliability (Bonner et al., 2006). The exception was with the long term uncertainty subscale with a Cronbach’s alpha of 0.57 compared to 0.80 in the original reliability study (Bonner et al., 2006).

TABLE 5

PECI Cronbach Alpha Results

<table>
<thead>
<tr>
<th>PECI Subscale</th>
<th>Cronbach’s Alpha for this study</th>
<th>Initial Reliability from Bonner et al.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>0.78</td>
<td>0.89</td>
</tr>
<tr>
<td>Unresolved Sorrow &amp; Anger</td>
<td>0.80</td>
<td>0.86</td>
</tr>
<tr>
<td>Long Term Uncertainty</td>
<td>0.57</td>
<td>0.80</td>
</tr>
<tr>
<td>Perceived Emotional Resources</td>
<td>0.67</td>
<td>0.72</td>
</tr>
</tbody>
</table>

A test-retest analysis was completed for each of the subscales to test reliability of the instrument with this sample. The test-retest reliability of a scale is assessed when the same individuals complete the same instrument on two separate occasions (citation). In
this study, all the participants completed the PECI on initial interview and then again 2-3 weeks later. A nonparametric test was used with a Spearman Rho correlation to evaluate the test-retest reliability (Table 6). It is noted that long term uncertainty and perceived emotional resources demonstrated the highest correlation coefficients and guilt and worry the lowest. All correlation coefficients were significant with a p <.05.

Table 6

Test-Retest results

<table>
<thead>
<tr>
<th></th>
<th>Guilt &amp; Worry</th>
<th>Unresolved Sorrow &amp; Anger</th>
<th>Long term Uncertainty</th>
<th>Emotional Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation Coefficient</td>
<td>.673*</td>
<td>.766**</td>
<td>.930**</td>
<td>.838**</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.033</td>
<td>.010</td>
<td>.000</td>
<td>.002</td>
</tr>
<tr>
<td>N</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

Quantitative analysis.

**Research question 1: What is the parent’s experience of having a child in pediatric palliative care as measured by the PECI?**

The PECI questionnaire operationalized the parental distress and emotional resource variables based on four subscales: guilt and worry; unresolved sorrow and anger; long term uncertainty, and perceived emotional resources. The scale does not produce a cumulative score, but rather a score for each subscale. In this study, the mean scores ranged from 1.69-2.66. The scores for each subscale are reported in table 7. Parents had moderate high responses to perceived emotional resources with a mean of 2.66 which is between “sometimes” and “often” on the survey scoring. In the initial development of the PECI instrument, the perceived emotional resources subscale is described as a way to evaluate parents’ feelings of self-efficacy and competence in caring.
for their child. An example of a question from this subscale is, “I trust myself to manage the future, whatever happens.” The parents in this study had lower scores for the third subscale, unresolved sorrow and anger, with the median between “rarely” and “sometimes”.

Table 7

**PECI Subscale Descriptive Statistics**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>n</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>10</td>
<td>2.09</td>
<td>.580</td>
<td>1.27-2.91</td>
</tr>
<tr>
<td>Unresolved Sorrow &amp; Anger</td>
<td>10</td>
<td>1.69</td>
<td>.643</td>
<td>.75-2.63</td>
</tr>
<tr>
<td>Long term Uncertainty</td>
<td>10</td>
<td>2.02</td>
<td>.545</td>
<td>0.8-2.6</td>
</tr>
<tr>
<td>Perceived Emotional Resources</td>
<td>10</td>
<td>2.66</td>
<td>.433</td>
<td>2.2-3.4</td>
</tr>
</tbody>
</table>

In addition to looking at the subscale scores, a descriptive analysis was completed on the individual questions of the PECI to evaluate frequency of scoring within each individual question (Appendix M). The majority of the participants were at peace with the circumstances of their life [item 2] with 90% reporting often (n=8) or always (n=1). However, half of the participants worry that at any minute, things may take a turn for the worse with their child (often: n=2; always: n=3). For item 6, 40% reported that they sometimes (n=4) worry they may be responsible for their child’s illness in some way. The participants rarely (n=8) to never (n=2) had regrets about decisions made concerning their child’s illness. Also, a majority of the participants (n=6) reported that it is difficult to socialize with people who do not understand what being a parent to their child means [item 15].

**Research question 2: Do relationships exist between the parent’s experience as measured by the PECI and pediatric disease demographics?**
An analysis was completed to evaluate the parents’ experience of childhood illness when accounting for the gender of the parent. Independent t test were performed to evaluate for any difference in the subscales based on gender of the parent with a p value set at 0.1. The results showed no statistically significant difference in any of the subscales based on gender. It is noted that females had a higher mean on the unresolved sorrow and anger subscale that neared statistical significance (p=.105). The means and standard deviations broken down by gender are provided in table 8.

Table 8

*Descriptive statistics for Male vs Female by Subscale*

<table>
<thead>
<tr>
<th>Group Statistics</th>
<th>Gender</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>female</td>
<td>6</td>
<td>2.21</td>
<td>.583</td>
<td>.238</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>4</td>
<td>1.91</td>
<td>.608</td>
<td>.304</td>
</tr>
<tr>
<td>Unresolved Sorrow&amp; Anger</td>
<td>female</td>
<td>6</td>
<td>1.96</td>
<td>.650</td>
<td>.265</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>4</td>
<td>1.28</td>
<td>.413</td>
<td>.207</td>
</tr>
<tr>
<td>Long term Uncertainty</td>
<td>female</td>
<td>6</td>
<td>1.97</td>
<td>.612</td>
<td>.250</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>4</td>
<td>2.10</td>
<td>.503</td>
<td>.252</td>
</tr>
<tr>
<td>Emotional Resources</td>
<td>female</td>
<td>6</td>
<td>2.77</td>
<td>.463</td>
<td>.189</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>4</td>
<td>2.50</td>
<td>.383</td>
<td>.192</td>
</tr>
</tbody>
</table>

The type of diagnosis for the pediatric patient as reported by the parent was coded as an illness since birth vs an acute illness. A t test was completed to evaluate if there was any significant difference within the four subscales on the PECI instrument based on these 2 illness categories. The group of parents with an acute diagnosis (not known from birth) (n=4) were noted to have a higher mean on the Guilt & Worry, unresolved sorrow & anger, and long term uncertainty subscale, but there was no statistically significant
difference found. The mean scores for these two groups (chronic vs acute) are reported in table 9 by subscale.

Table 9

Descriptive Statistics by Type of Diagnosis

<table>
<thead>
<tr>
<th>Group Statistics</th>
<th>Chronicity</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>Chronic</td>
<td>6</td>
<td>1.91</td>
<td>.656</td>
<td>.268</td>
</tr>
<tr>
<td></td>
<td>acute</td>
<td>4</td>
<td>2.36</td>
<td>.356</td>
<td>.178</td>
</tr>
<tr>
<td>Unresolved</td>
<td>Chronic</td>
<td>6</td>
<td>1.56</td>
<td>.770</td>
<td>.314</td>
</tr>
<tr>
<td></td>
<td>acute</td>
<td>4</td>
<td>1.88</td>
<td>.421</td>
<td>.210</td>
</tr>
<tr>
<td>Sorrow &amp; Anger</td>
<td>Chronic</td>
<td>6</td>
<td>1.87</td>
<td>.653</td>
<td>.267</td>
</tr>
<tr>
<td></td>
<td>acute</td>
<td>4</td>
<td>2.25</td>
<td>.252</td>
<td>.126</td>
</tr>
<tr>
<td>Long term</td>
<td>Chronic</td>
<td>6</td>
<td>2.77</td>
<td>.408</td>
<td>.167</td>
</tr>
<tr>
<td></td>
<td>acute</td>
<td>4</td>
<td>2.50</td>
<td>.476</td>
<td>.238</td>
</tr>
</tbody>
</table>

Research question 3. Does the intervention Go Wish Pediatrics, a facilitated advance care planning conversation tool, impact the parent’s experience of having a child in pediatric palliative care as measured by the PECI?

The Wilcoxon Signed Rank Test was used to evaluate a change in the pre/post scores for the four subscales of the PECI instrument. This non parametric test was used due to small sample size. There was no significant difference identified in the pre/post scores of the PECI (Table 10). The median scores for all four subscales remained predominately unchanged.

Table 10

Pre-Post Comparisons by Subscale

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
<th>Wilcoxon Test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>IQR</td>
<td>Median</td>
</tr>
<tr>
<td>Guilt &amp; Worry</td>
<td>2.1</td>
<td>0.77</td>
<td>2</td>
</tr>
</tbody>
</table>
Research Question 4: How do parents value (very important, somewhat important, not important) the items on the Go Wish Pediatric cards?

Descriptive statistics were used to describe the distribution of cards. It was found that card 1 “my relationship to my spouse or significant other” (n=9); card 3 “discuss my fear of my child having an event when I am not there” (n=7), and card 4 “maintaining my child’s memories” (n=8) were consistently reported as “very important” to the participants. On the opposite end, card 8 “involvement of my child in decisions and communication” (n=7), card 17 “define the palliative care team’s role in caring for my child and family” (n=7), card 22 “my child being free from machines” (n=7), and card 26 “Communication with my child about what to expect” (n=7) were frequently reported as “not important” to the participants. For the majority of the cards, distribution was dispersed across all three piles. There were no participants that identified card 40 “having a written advanced directive for my child” as very important.

Post hoc analysis. A post hoc analysis using the Fisher Exact test was completed on each card to see if gender had any impact on how participants distributed the cards across the three piles. The results indicated that only card #34 “identifying and honoring my child’s wishes” was significant (p=0.0095) on how the distribution differed according to gender with males identifying this as “very important” more often (Table 11).
Table 11

*Distribution for Card 34 “Honoring my Child’s Wishes”*

<table>
<thead>
<tr>
<th>Gender (Gender)</th>
<th>Card 34 (Card 34)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>F</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>M</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

There were four couples that participated in this study. Each study participant’s study visit and interview were conducted completely separate from their spouse. As a post hoc analysis, a descriptive analysis was completed to look at the pre/post subscale scores within each of the four couples (Appendix N). Anecdotally, Couple 1 had similar scores on each of their subscales both in the pre and post. The other three couples showed larger difference between the scores when looking at the husband vs the wife and the difference remained consistent in the pre and post test data.

A paired sample correlation using spearman rho calculation was also completed as a post hoc analysis to evaluate if any relationship existed between the first three subscales (guilt & worry; unresolved sorrow and anger, and long term uncertainty) and the perceived emotional resources subscale for both the pre and post data (table 12). The purpose of this test was to look for possible relationships. The results indicated that there was a significant correlation between long term uncertainty and emotional resources for both the pre and post data (pre: p=.000; post p=.001). This indicates that for this sample, as parents had lower perception of emotional resources, they had increased scores for long term uncertainty.
Table 12

*Post Hoc Correlation of Subscales*

<table>
<thead>
<tr>
<th></th>
<th>Emotional Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Correlation Coefficient</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
</tr>
<tr>
<td>Pre Data Long term Uncertainty</td>
<td>-.920**</td>
</tr>
<tr>
<td>Post Data Long term Uncertainty</td>
<td>-.866**</td>
</tr>
</tbody>
</table>

*p value < 0.05

**Power analysis.** A power analysis was completed as a post hoc analysis to aid in future expansion of this pilot study by estimating needed sample size (N). There was no cumulative score for the PECI, so a Cohen’s D was calculated for each subscale using a power of 0.8 and an alpha (p) of 0.05. The effect size and estimated sample size was estimated by utilizing the pre/post means, standard deviations and correlations in G*Power. Table 13 provides the effect size and estimated sample size by subscale. The subscale long term uncertainty had four outlier values creating a small effect size and large estimated sample size. This would need to be considered when developing a larger study.

Table 13

*Power Analysis*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>d</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>0.27</td>
<td>111</td>
</tr>
<tr>
<td>Unresolved Sorrow &amp; Anger</td>
<td>0.22</td>
<td>166</td>
</tr>
<tr>
<td>Long Term Uncertainty</td>
<td>0.15</td>
<td>332</td>
</tr>
<tr>
<td>Perceived Emotional Resources</td>
<td>0.32</td>
<td>81</td>
</tr>
</tbody>
</table>
Note. d=effect size; N=projected sample size; power of 80%

*p value < 0.05

Qualitative analysis.

The qualitative portion of the study focused on understanding the parents’ experience and perception of the Go Wish-Pediatrics intervention. A thematic analysis was used to review the transcribed interviews. The author coded the initial interviews and then collapsed them into three common themes to describe the experience of the participants with the cards. These three themes included operationalizing thoughts into action; empowered to join the conversation and a lighthouse in the fog. These three themes will be described in the section below with participant data.

Operationalizing thoughts into action. Participants spoke to the importance of tangible nature of the card game. It was important to be able to manipulate the cards and put them into the piles. One participant said, “to have the cards where you can actually physically seem them and lay them out instead of trying to see them in your head was really helpful, this made it more real for me.” This participant discussed the many other checklists and “talks” she had with her healthcare team, but that this activity of physically moving the cards into specific piles was different because she had to make the decision on where it belonged and she could see it.

Another participant identified that, “leaving these thoughts in your head allows you to get distracted.” He spoke to the fact that with this activity, you had to make decisions and wasn’t as easy to get distracted because you had to finish the “game.” Similarly, another participant said that “if you just are thinking these thoughts in your head when you are talking with someone you get distracted by other things and you forget to write them down or acknowledge if it is important to you or not.” She spoke to
the fact that the physical process of going through the cards was important to make the thoughts turn into real conversation and plans.

Participants also identified that an important component of the tangible activity was that it allowed them to organize and identify their priorities. The process of them placing the cards in order of importance allowed them to find their goals and priorities for their child, themselves, and their family. One parent said,

“I think it is great to be able to prioritize things, I think it is important to have priorities, you know you can’t go anywhere if you don’t have a goal and you can’t make goals unless you acknowledge your own priorities….so it was helpful to sort things out find my priorities so I can find my goals.”

The visual activity of the card game allowed parents to operationalize a priority to a goal. This same participant felt it would be important to do this activity when people start the palliative care journey because it helps the team to know the parents priorities and provides a starting point. It the team knows where the starting point is, they can be facilitators in operationalizing the priorities to goals.

**Empowered to join the conversation.** The second emerging theme was that the participants felt that the cards empowered them to join the conversation. All of the participants reported that they felt like they were involved in the care of their child, but that there were values/items on the cards that they had a desire to talk about but were not comfortable or sure it was a conversation for them to have with either the palliative care or treatment team. Several participants said that the cards “gave them a voice.”

Participants talked about not knowing what to ask or what their needs were because there was just “so much.” The interviews repeatedly portrayed parents that
advocated for pieces of the conversation related to both palliative and curative care for their child but felt abandoned or oblivious to other parts of the conversation. One parent reported that the cards “opened her eyes to things she wouldn’t have even thought to ask about but really wanted to talk about with someone about.” Another parent said that the he felt like the cards “invited me to the table to talk about things that I think my wife has been talking to the healthcare team about, but these cards actually let me join that conversation with them.”

A lighthouse in the fog. A theme woven through several interviews was reality of living in a “fog.” There were four parents that spoke of a “fog” in different aspects and how the cards provided a reference point out of the “fog”. A parent said, “This fog of medical terminology and words that we were living everyday was so overwhelming that we didn’t even know what to ask, the cards gave me a focused point to organize my thoughts.” Parents come into this medical world overwhelmed with tragedy. The combination of the emotional crisis and the entrance into the new medical world is daunting and difficult for them to navigate. Many of the parents reported have no idea where to start, feeling lost with no way out. A mother said,

“I remember that first week we were in the hospital, I was just in a fog and was searching for something to grasp onto physically. I think these cards would have really helped me at that point to feel like I at least had a direction. I needed something to point me in a direction. I felt like I was wondering in a fog and just couldn’t see my way out.”

It was a reality for this mom that she was never going to “get out” of the fog, but she needed something to give her direction as she navigated her way in this fog.
Another parent spoke about the “fog” that he and his wife were living in as a married couple. He spoke about how after the diagnosis they shifted to going “through the motions” and how they both knew what their “tasks were” so that they could survive, but as a couple they were living in a fog because they were not communicating anymore like they used to. He said, “These cards would help us to find a starting point to communicate with each other again. Yeah, I think they would be good for us with our medical team, but also for us as a couple.” A different mom similarly talked about it being hard for the marriage and how it changes the marriage. She said,

“You look at the stats and feel doomed as a married couple, I mean you have to make these decisions that most people don’t even have to think about and you’re trying to make the decisions as a couple…..but it is so hard, you can’t even see where you are going.”

She felt like the cards would help to serve as a conversation point for the team to help the parents communicate with each other to get on a similar path.

**Improvements and recommendations from the participants.** The final piece of the qualitative interview included recommendations and feedback from the participants that could make the intervention better. A powerful recommendation from participant 4 was to change the piles to include “very important to me now”; “important to me but not right now”, and “not important to me”. The participant discussed how the middle pile of “somewhat important to me” allowed her to not commit one way or the other so she felt she tended to put cards there without really thinking about it. She recommended that changing the piles would more truly reflect the decisions she feels like parents have to make when they think through these values/ideas. This recommendation was discussed
with the participants that followed. They agreed that changing the middle pile would be more representative of what they are thinking as they sort the cards.

The participants only had a couple recommendations related to the values/ideas on the cards. One suggestion was that card 40 “Minimizing arguments within our family related to care decisions” was important but only in the sense of minimizing arguments with her spouse. If her and her spouse were on the same page, she felt like she did not care about opinions or objections from anyone else in the family. The main stress for her was when they argued or disagreed as a couple about their child’s care. During member checking some parents were concerned about other family members in addition to their spouse, therefore, their recommendation was to leave the card 40 but add another card that specified minimizing arguments with my spouse.

One consistent theme that came up through the wild card was the importance of maintaining some level of independence with their child. One participant reported that her number one thing she focuses every care decision on is what it will do for her and her son’s independence. Other parents commented that this would be something that would be important to be included because it is a constant thought with every decision they face, what will this mean for how we “live” our life.

Participants felt like that card 18 “define my role in caring for my child” was redundant to concepts on other cards and not necessary. Through member checking, it was agreed that this card implied that they did not know their own role and it was not as well received as similar concepts on other cards. This card was removed in the final version. A final version of the cards is provided in Appendix O.
Another consistent theme from the four couples that completed the intervention was the importance of both parents completing the cards. One mom said,

“We had things we agreed were important, but we both had our own priorities and there were definite differences. I am not sure we were both heard or that both of our priorities were addressed, these cards would have helped that.”

They felt it was important for each parent to complete the cards individually, but it was helpful for them to then come back together to talk about them as a couple. It helped them to understand where their spouse was coming from with some things.

**Mixed methods analysis.**

*How do the qualitative findings from the interviews with parents provide an enhanced understanding of the Go Wish-Pediatrics intervention?*

For the final analysis in this study both the quantitative data from the PECI instrument and the interview data collected during the review of the participant’s card distribution were combined for a mixed method analysis. This allowed for triangulation of the data. The intent was to allow the qualitative data from interviews driven by the *Go Wish Pediatric* intervention to further expand an understanding of how the parents of children in palliative care experience their child illness. The transcribed interviews were reviewed for comments and themes that further described how the participants experienced the four scales of the PECI tool. The qualitative data from the interviews helped to increase the understanding of the participants meaning of the guilt & worry, unresolved sorrow & anger, long term uncertainty, and perceived emotional resources experienced during a child’s illness.
Guilt and worry. A reoccurring theme in several of the interviews revolved on around the guilt that participants experience related to the constant need to rely on others. Both mothers and fathers talked about always being a “drain” both at their work and their home life because they are constantly needed to have people cover for them or help out with small things. One parent said,

“I feel bad every time I have to ask for more help. There is a constant expectation with my family and friends that they have to help me. It just stinks knowing how much you have to rely on others to just get things done.”

There was a sense of parents feeling like they are always “taking” from people. Another mom said, “I am tired of being the person at work who always has to ask for a favor.” These parents acknowledged that it is part of caring for a child living with a chronic illness but it never gets easy to ask for the favor.

The other constant worry was related to something happening to their child. This worry existed with every parent. The interesting aspect of the comments is that there was a range of worry that existed for these parents ranging from parents worried about “normal” kid things to specific worries related the reality of caring for a child with a life threatening illness. One dad said, “I worry she will get hurt, but not different than any other kid playing soccer. The difference is that I feel like she has been through enough and shouldn’t get hurt anymore.” He spoke to the fact that this worry is true for all parents but he thinks it is just different for parents of kids with terminal or chronic illness. Another mom said “I worry every minute I am not with her that something really bad is going to happen and I will have missed the last moment.” The stress that accompanies this worry is a significant reality for these families. The decision to leave their child to
do necessary things like going to the store, going to work, or just a “break” is constantly accompanied by the reality and stress that something terrible may happen while they are gone.

Alongside the worry that something horrible may happen while the parent is gone, the parents also expressed an associated guilt. This guilt exists for these parents in two ways. First they spoke of the guilt they would have for themselves if they were not there. They spoke of this being a guilt that they felt “they could never get over if it happened.” In that same tone, there is worry about having guilt if another person is there to endure a difficult or bad situation. One mom said, “My parents help us a lot and I am constantly thinking about how I would live with myself if my mother had to be there during a bad event for her granddaughter.”

*Unresolved sorrow and anger.* The use of the *Go Wish Pediatric intervention* resulted in several themes to further explain how the participants in this study experienced unresolved sorrow and anger while caring for a child in palliative care. The most significant was the cards that talked about their spiritual advisor. As parents prioritized this card and then discussed it in the interview there was several themes that emerged tying a spiritual journey that has significant moments of unresolved sorrow and anger. One participant said,

“I was pissed at God and did not even want to go there, at the beginning of this journey it was not my priority, she was and I had separated God from all of it. But I slowly worked my way to a different place, I slowly let people connected to my spirituality back in. I had to. If I would have stayed there I wouldn’t have been
able to make it. I am still angry sometimes, but it is now a priority to me to have God as part of my life.”

Another parents said,

“People would say God will never leave you and my response was … ’He is not here.’ I have moved past that response, but I still don’t feel connected, I am just not there and it is not my priority because my kid is.”

The card simply said “role of my spiritual advisor” and it opened up an entire conversation about the spiritual struggle these parents experience. Every parent is in a different place. It is essential to have the conversation to find out where they are, not just offer services.

Parents also talked about being judged by the nurses and doctors. They felt labelled at times as that parent that is “difficult”, “pushy”, or “overbearing”. When they spoke about these labels, it was clear there was anger and frustration with having to endure the label on top of everything else. Card 21 “discuss my fear of leaving my child” triggered most of the conversation about being labelled. These comments came only from the female participants. These mothers face the reality of not wanting to ever leave their child in the hospital because of a fear of a medical mistake or the nurses not doing care the way the parents request it to be done. They talk about knowing their child inside and out because they live it every day, but the nurses are just there to get the task done and will do it however best fits their schedule. One mom said,

“I am tired of constantly having to defend how or why I want things done a certain way, don’t I have enough other battles to face. I should be able to feel like
I can go get a cup of coffee but I get so angry when I come back and everything is changed or something has happened just because they wouldn’t listen to me.”

There is a lack of trust that deep seeded in the parents that comes across as anger and frustration with the system, but a reality they know they have to live with.

A final theme related to unresolved sorrow was related to maintaining memories of the child. Several parents reported that it was important to them to maintain memory of their child, but through the conversation with some parents the biggest concern was actually trying to maintain the memories of their child not sick. One dad said, “My only memories are of her sick, everything I reference or think about is related to this time in the hospital or that time when she got sick here.” He proceeded to talk about how hard it was to try to have memories that were not tied to a hospital, a procedure, a nurse, etc. Those memories are important to him still, but when he placed the card in the pile, what became evident that the real priority is to try to have memories separate from the sickness.

**Long term uncertainty.** Parents in this study identified several areas where they experience the distress of uncertainty. The most prominent uncertainty was related to the constant uncertainty of when or if their child will pass away. An interesting component was that some parents talked very realistically about the uncertainty of when their child will pass away, while other were more focused on the uncertainty of if their child’s illness would ever take their life. Regardless, all of the parents in some sense spoke to the uncertainty of the future for their child and the fear of death being part of that uncertainty. One parent said, “Dying…the thought is always there, even if it isn’t “real” right at that moment, it is always there for us.” Another parents said,
“Every day I have a fear of what will happen to him, it crosses my mind every single day but the hardest thing is that there isn’t anyone who can answer that for me because no one has a crystal ball and I don’t think anyone can make that feeling go away.”

The parents acknowledged that anyone can live with an uncertainty of what will happen tomorrow, but their uncertainty is different. It is a reality that “something bad for sure is going to happen, for me it is just that I don’t know when that is going to be.” For these parents it is not an “if”, rather it is “when”.

Parents were also uncertain about their relationship with their spouse or significant other. During the quantitative analysis, the participants that were married or in a committed relationship identified that card 1 “my relationship to my spouse or significant other” was very important. The conversations surrounding this topic identified uncertainty on the future of their relationship as well as uncertainty about how their relationship will continue to change as they move through the journey of caring for a child receiving palliative care. One mother when asked specifically about why her relationship with her husband was her priority said, “You look at the stats and feel doomed.” She was speaking to the statistics of the increased divorced rates for families who have lost a child. There was a sense of constant uncertainty about how their relationship would survive this. There was a sense of uncertainty centered around the resources available to them as a couple, outside the care of their child. The parents commented on whether or not they felt it was the responsibility of their child’s healthcare tema to worry their marriage on top of caring for their child even though it was one of their biggest priorities. One mom said,
“I don’t really feel comfortable talking to the people who are responsible for my daughter about my marriage. Truthfully I feel like they would look at me like …really lady, can’t you see that we are trying to help your daughter.”

This comment really brought to light the uncertainty of the marriage as well as the uncertainty about their resources outside the medical needs of their child.

*Perceived emotional resources.* The most significant finding from the interviews that expanded on the concepts surrounding perceived emotional resources related to families feeling reassured. When the *Go Wish* card that addressed managing their own anxiety came up, several participants identified that one of the most important ways they have been able to manage this it by surrounding themselves with people in similar situations. For some parents this was formal support groups and for other parents it was patient families they connected with while in the hospital. Parents identified that having these communities gave them reassurance that they could continue to do care for their child and allowed them to not “drown in their own self-pity” because other people are “having to live this everyday too and some others way worse.” One parents said,

“Hearing people say that, ‘Oh yeah, I have this family that is in the same spot.’ And knowing that you are not the only one who’s walked this path, you’re not the only one who’s thought these things, or had to struggle or have these doubts. It is just nice to know that you are not alone, that’s a huge thing, to not feel isolated. That reassuring can calm your anxiety.”

Parents verbalized the pressure of constantly making all the “hard decisions” and how that can be exhausting on a marriage. One parent spoke specifically about the importance of knowing there are “other people making these same hard decisions you are making and
that there isn’t a right answer always, and that it is ok to just try to make the best decision you can once you have all the information.” A single mother identified that she felt supported by her medical team when she was making all these hard decisions and it was important for her own emotional stability to not feel like people were second guessing her decisions.

A final aspect of perceived emotional resources that became evident through the conversations was the reality that most parents identified there primary “support” resource was their primary care physician or the palliative care team. Parents spoke to the importance of the specialists (surgeons, oncologists, and pulmonologists), however it was always related to direct medical care for their child. It was typically tied to a specific story about an emergent “medical care” need. One parent (mom) said, “That surgeon came in and said he was going to get that tumor after the oncologists shrunk it and he had the confidence that I knew he was going to do those things for our child.” This mom later described the balance of different providers by saying, “You have to have a balance of arrogant and confident providers that have the skills, but also as a mom you need a realistic one that could be real with me.” Another parent said, “Things were fine until one night he pulled out his central line and it was really the only time I threw a fit demanding that the surgeon be called immediately….I never really wanted to see him except for those times. I guess that is the only part that I really needed him for, but I did need him.” This mom went on to say,

“If I need to really talk about things, you know real conversations that involve my heart or I am worried about a decision I have to make, I call my doctor at home because he know us and our family best. I would also talk to the palliative care
team because they seem to just ‘get it’ but I would go to my doctor who has known us from the beginning for that kind of stuff. He doesn’t know what medicine to always give, but he knows our family well enough…he can read us better which is helpful to know that he knows us as a real person outside the hospital.”

These comments really identified that all members of the healthcare team have a role. However, as far as being perceived as helpful to parents’ emotional resources, the parents in this study identified that the primary care providers are extremely important. Parents also identified that the palliative care team also strengthens them emotionally.
Chapter 5

This chapter will summarize the results of this study, the impact of the results on the current state of the science with pediatric palliative care, study limitations, and implications for future research.

Discussion of Results

The first purpose of this mixed method pilot study was to explore the use of the Go Wish-Pediatrics intervention as an advanced care planning conversation tool with parents caring for children receiving pediatric palliative care. In the sample of ten parents, all reported the Go Wish-Pediatrics intervention was beneficial and helped to initiate a conversation that is sometimes difficult for them to broach and one which providers sometimes avoid. The literature strongly supports that parents expect more accessible, individualized communication from their providers (AAP, 2013; Levetown et al., 2008; Meyer, Rutholz, Burns, & Truog, 2006). Additionally, failure to explore and incorporate families’ values into the plan of care has resulted in increased legal actions and dissatisfaction with overall care (Hobgood, Tamayo-Sarver, Elms, & Weiner, 2005). Utilization of the Go Wish-Pediatrics cards will empower parents to initiate some of the communication and will guide healthcare professionals to allow these difficult conversations to be individualized to the needs of the family.

Families identify that closed question techniques like yes or no surveys, can be viewed as insensitive and lacking a personal interest in the needs of the family. These types of questionnaires and forms are frequently used in the healthcare setting due to time constraints and providers wanting to control the duration of interactions (Feudtner, 2007; Levetown et al., 2008). Time is a significant constraint in the modern healthcare
community, however, the incidence of increased legal actions in health care related to poor communication (Duclos, et al., 2005; Huntington & Kuhn, 2003; calls attention to promoting interventions like the Go Wish- Pediatrics cards that will guide conversations as well as serve as a springboard for future conversations. Ultimately, the intervention provides an avenue to allow a care plan to unfold related to the immediate concerns and needs of the family.

The Go Wish- Pediatrics intervention also can serve as a communication bridge between the parents. This study demonstrated that the parents’ experience of the child’s illness can be very different when considering the four subscales of the PECI instrument. The Go Wish- Pediatrics intervention facilitated conversations that brought meaning to the parental distress experienced. The utilization of the cards in this study helped parents identify their own priorities and stresses as well as provided insight to the experience of their spouse. Mothers and fathers communicate differently during pediatric illness and have different experiences of distress related to uncertainty (Mu, 2005; Stewart & Mishel, 2000); however, there is a gap in the literature regarding communication interventions related to promoting the couple’s concerns about end of life and palliative care needs.

Shared decision making is a key factor in pediatric palliative care (AAP, 2013; Feudtner, 2007; Himelstein, Hilden, Morstadt-Boldt, Weissman, 2004). Shared decision making includes both parents, when appropriate, being involved in decisions with the medical team. A recent study identified that asking both parents and physicians to talk as a team about their hopes and problems related to all aspects of their child’s illness can help to improve the quality of shared decision making and ensure both parents and the medical team are in agreement (Hill et al., 2014). The Go Wish- Pediatrics intervention
was viewed by parents as a vehicle to operationalize their thoughts and empower them to be a part of the critical conversations that they felt needed to happen.

The parents in this study demonstrated a desire to be a part of the conversation and have their needs heard. An emerging concept that came out of this research was the concept of “shared conversations”. It was evident that parents do want to be involved in decisions, but more importantly what was seen in this study was parents desire to just be a part of the conversation so that their needs were heard. The concept of “shared conversations” could potentially allow for the opportunity of shared decision making if that is something important to the parent; however, it is possible that before you can have shared decision making though, you need to have “shared conversations”. The idea of shared conversations aligns with current practices in health care like family conferences, (Fox, Brittan, & Stille, 2014). The use of the Go Wish- Pediatrics intervention can help the conversation during the family conference as well as provide insight into the frequency that parents would like “shared conversations” through family care conferences. This will need to be further explored with future research but was an emerging concept with significant implications in nursing and healthcare.

Similarly, the parent’s relationship with their spouse was consistently the most important issue for participants in this study. The qualitative data further explored the reality of the couples feeling separated and operating in “silos” during their child’s illness. They identified that there is a reality of “divide and conquer” during the crisis which changes their relationship. The couples did not necessarily identify this change as a negative outcome but rather a reality for them. Literature supports that there is significant impact on the entire family and specifically the parent’s marriage when taking
on the care of a child suffering from a life limiting illness (Knapp, Madden, Curtis, Sloyer, & Shenkman, 2010; Vickers & Carlisle, 2000). It is imperative that the healthcare team identify the parent’s relationship as a significant component that impacts all aspects of care for the child. The initial findings related to the “divide and conquer” or “silo” parenting in this study has implications of parents may be adapting to the stress.

The majority of parents in this study identified that they utilize their primary care providers or the palliative care team as the main resource for general questions and conversations related to the needs of their family as a unit. They identified that it was important to have a trusted, established relationship when communicating about the difficult concepts surrounding palliative care. Parents typically have an established relationship with their pediatrician or primary care provider which creates an opportunity for open communication and an understanding of where the parent is coming from. Parents also felt that their primary care provider or the palliative care team was more accessible to them than their subspecialist. This focus on the primary care provider is an important take away from this study as it strongly supports the American Academy of Pediatrics position statement on palliative care. In this report, it is clear that primary care is a setting that needs to be further explored into what role it will play in pediatric palliative care medicine (AAP, 2013). The position statement by the AAP supports that pediatricians have a responsibility to assist families of children suffering from a life threatening illness as they navigate specialists and the complex medical system (AAP, 2013).

Approximately half of the participants felt they had participated in a conversation related to advance care planning but none of the participants had a written advance care
plan. Similarly, the majority of the participants felt it was at least somewhat important to get more information about advance care planning. This finding supports literature that has identified a lack of education for both the provider and the family related to the use and benefit of advance care planning documents in pediatrics (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Durall, Zurakowski, & Wolfe, 2012).

**Strengths**

From a research design perspective, the use of mixed methods in this study allowed for a deeper, more inclusive understanding of the research questions and the value of the intervention. The quantitative portion of this study provided an understanding of the degree to which parents experience distress when caring for a child in palliative care. However, the qualitative information that came from the interviews as a result of the *Go Wish-Pediatrics* cards provided depth and breadth to the meaning of the subcategories of the PECI. For example, the long term uncertainty that was experienced by parents in this study included the more obvious worry about the impending death of their child, but there was also significant uncertainty for a majority of the participants related to the marriage or relationship with their spouse. The *Go Wish* cards provided a starting point for a conversation that gave significant meaning to the quantitative portion of this study. When conducting research in areas like palliative care that have a strong emotional component, there is value to considering a mixed methods design to more fully address palliative care inquiries.

The mixed methods component of this study was essential to better understand the meaning of the four subcategories explored during the quantitative analysis of this study. The use of the *Go Wish-Pediatrics* cards allowed parents to express their specific
concerns and needs. Through the conversations triggered by the Go Wish-Pediatrics intervention, further insight was gained into how these parents caring for a child in palliative care experience their child’s illness based on the four domains explored in the PECI. The addition of the qualitative analysis of the interviews with parents allowed for a more thorough and deeper understanding of the constructs through the eyes of the participants.

**Limitations of the Study**

This study had several limitations including a small sample size and difficulties with recruitment due to the sensitive nature of the study. Conducting research in palliative and end of life care can be difficult when considering recruitment and intruding on families during such a vulnerable time. When conducting this research, it is essential during the recruitment process to be considerate of the frequency of participant contact with requests to participate to minimize intrusion. Due to this consideration, participants in this study were only contacted twice via a mail request to participate which limited the response rate. While the small sample size in this study limits the generalizability of the findings, this was a pilot study to evaluate the receptiveness to the intervention. Another limitation of the study was the amount of time between the first and second survey. To fully evaluate the impact of the intervention on the parents’ distress factors and perceived emotional resources, there would need to be more time and multiple conversations with the palliative care team. The distress parents experience while caring for a child with a life threatening condition develop and build overtime, in the same manner it will take time to evaluate if there is change to any of these. It is a reality for these parents that they will always experience some level of distress; it will never completely go away so the
anticipated change would likely be small. Evaluation of these factors over time would enable researchers to see if there is any impact on them positive or negative or if it prevents elevation of the distress factors.

**Implications**

**Nursing practice.** Communication with families caring for sick children is essential yet it is not happening consistently. A study in 2013 that evaluated the use of family conferences in the pediatric intensive care unit found that of only 10% of patients (n=401) with a chronic condition received a family conference (Michelson et al., 2013). Parents want to talk to providers and want to be involved in the conversation but often do not feel invited to participate. The *Go Wish-Pediatrics* intervention is a tool that can help open lines of communication between parents and the healthcare team. This intervention allows parents to identify priorities and encompasses many aspects of care that may need to be addressed including physical care, spiritual, psycho-social, and emotional. Parents appreciated being asked what their concerns were and welcomed the opportunity to communicate their needs. Nursing as a profession needs to recognize the parents need to communicate with the medical team and serve as an advocate to help initiate opportunities for these conversations.

An essential component of this intervention is that the individual facilitating the card game has a level of emotional intelligence that will foster trust and be inviting to the parent. The concept of emotional intelligence identifies that an individual has the ability to recognize their own and other people’s emotions and utilize emotions to guide thoughts, interactions, and behaviors (McQueen, 2004).
Parents identified that they want more information about advance care planning. It was not a priority for the parents to have a documented advance directive; however, participants identified that they wanted information and education related to advance care planning. Nursing needs to identify a role in providing this teaching to parents in a way that is welcomed by both the parents and the medical team.

**Nursing theory.** The conceptual framework, based on McCubbin & Patterson’s Double ABC-X model of Family Adaptation, focused on the crisis experienced by parents of children facing a life threatening condition and the ‘pile up’ of stressors that subsequently follow the crisis. In this conceptual framework the key stressors were identified as the distress experienced by parents. Distress was defined as guilt and worry, unresolved sorrow and anger, and long term uncertainty. The focus of this study was identifying if introduction of a conversation tool impacted the distress experience by parents or their perceived emotional resources. The outcome of this conceptual framework is adjustment or adaptation to the stressors or distress. The purpose of this study was not to evaluate adjustment, however what became evident was that many of the parents had already made adjustments to how they experience their child’s illness just by having lived with it. Parents in this study were ready to have conversations related to advance care planning and their individual needs.

The mixed methods approach from this study supports that parents do experience distress factors and that the *Go Wish- Pediatrics* intervention did not significantly change those factors positively or negatively in a short time frame. Parents demonstrated through the qualitative interviews a need for caring, compassionate conversations. Based on the findings in this study, a new conceptual framework was developed to identify how
parents experience child illness during palliative care with the use of a conversation intervention. This newly developed conceptual framework was based on the Swanson's middle range theory of Caring. This middle range theory, inspired by Jean Watson’s grand theory of Caring, is composed of five caring processes including knowing, being with, doing for, enabling, and maintaining belief. Swanson defines caring as “a nurturing way of relating to a valued other person, towards whom one feels a personal sense of commitment and responsibility” (Swanson, 1991, p. 165). This definition encompasses the needs and emotions expressed by participants in this research study, the need to feel listened to and valued.

**Attributes of Swanson’s theory of caring in relation to the Go Wish- Pediatrics.**

**Knowing.** To demonstrate the act of knowing, an individual has to recognize that the starting point for understanding a situation or event is the other person’s experience (Andershed & Olsson, 2009). The act of listening is an essential component of caring through knowing. The intervention in this study provided a mechanism for parents to talk and providers to listen. The process of completing this intervention gives the provider permission to allow the parent to control the conversation.

**Being with.** The process of ‘being with’ involves being emotionally invested and available to the other person (Andershed & Olsson, 2009). To care means more than just being present with the person. There is an additional step of sharing the experience which requires the element of time. Vulnerable populations like the parents in this study are eager to connect with a provider emotionally and share their story and needs with them. For this intervention to be done effectively it has to be implemented by an individual that
can value time spent with individuals and poses a strong emotional intelligence that will allow them to “be with” the parent.

*Doing for.* This process requires people to do care through actions that are helpful, protective and improve comfort (Andershed & Olsson, 2009). In her original work, Swanson (1991) describes this as having the ability to anticipate the needs and comfort through actions. The use of the *Go Wish-Pediatrics* intervention can help the healthcare team anticipate the needs because it facilitates the painting of a picture of the individual needs for the parent, child, and the family.

*Enabling.* To care through enabling means to facilitate an individual’s journey through life transitions or events that are unfamiliar (Andershed & Olsson, 2009). The families in this study were all navigating unfamiliar territory every day. Allowing for an active conversation process through the card game helped give parents’ permission to recognize their fears, their needs, and what they are already doing. The focus of this process includes validating feelings, processing events, and providing feedback.

*Maintaining belief.* This process refers to believing in another individual’s ability to work through an event or transition, find personal meaning in the experience, and face the future with meaning (Andershed & Olsson, 2009). This is the foundation of caring in Swanson’s middle range theory of caring. To truly provide caring, there has to be a belief by the provider that the person enduring the tragedy can work through the transition and find meaning. The use of the *Go Wish-Pediatrics* intervention can help providers identify the strengths parents possess that will get them through the transitions ahead. Through better understanding of where the person or family is and the strengths
they possess, the healthcare team can help them work through the tragedy and find meaning.

**Swanson’s theory of caring and vulnerable, sensitive populations**

This research study approached a sensitive, vulnerable population that has high needs for caring behaviors. It is essential that when working with parents like those in this research study to remember that they are individuals that have needs on multiple levels including their sick child, their family, and themselves (Kavanaugh, Moro, Savage, & Mehendle, 2006). This is important in relation to caring for them in the healthcare system as well as in conducting research. The use of Swanson’s middle range theory of caring combined with the themes that emerged in this study provide a useful framework for conceptualizing care and use of the intervention presented in this study. The Caring Wish Conversation conceptual framework has been portrayed in Appendix P. The findings in this study supported that parents are searching for caring processes similar to those identified by Swanson’s middle range theory and that the Go Wish-Pediatrics intervention provides a vehicle for encouraging supportive, caring processes with a vulnerable population. The new conceptual framework needs to be further explored in future research with the Go Wish-Pediatrics intervention.

**Nursing research.** The purpose of this pilot study was to look at initial feasibility of the intervention and parents perception of participating in a conversation about their needs and their family’s needs through the use of a card game. The initial results of this study support that parents are receptive to the cards and view them as helpful. The next step will include adjustments to the intervention based on parent
feedback and begin a larger study where parents complete this intervention at time of enrollment into palliative care.

Future research also needs to explore the use of the *Go Wish- Pediatrics* cards with both the palliative care team as well as in the primary care setting. Parents in this study utilized their primary care provider as a central resource. The feasibility of using this intervention in the primary care setting should be evaluated as well if there is value for the provider and the parent if used in the primary care setting. In addition to exploring the use of the intervention in the primary care setting, it is important to evaluate healthcare providers’ perception of the intervention and its usability. It is imperative to evaluate the use of the tool with a multitude of members from the healthcare team including nursing, social work, nurse practitioner, and physicians to identify the best way to implement the intervention.

This initial set of cards for the *Go Wish- Pediatrics* intervention was targeted to improve communication between providers and parents. Communication between parents and providers is just one piece of the web. The adolescent population also needs to be a focus for future research. Development of cards to facilitate the communication with adolescents could help to improve understanding of needs between the child and parent as well as child and the healthcare team. There should also be exploration into cards with pictures that could help school aged children communicate their wishes and desires with their parents and providers during palliative care.

Exploring parental distress and emotional resources experienced by parents of children in palliative care was a small piece of the theoretical framework used in this study. Future research is needed to evaluate the final step of the theoretical framework.
This would include evaluating the impact of the *Go Wish-Pediatrics* intervention on parental adjustment. There is potential to impact from the intervention on how parents adjust to new or continued distress. Evaluation of parents coping as it relates to this intervention would be an important step in the further development of this theoretical framework. The adaptation or adjustment to the distress factors needs to be evaluated when the cards are utilized as a vehicle to guide multiple conversations over time.

Advance care planning is needed in pediatrics. Future research needs to explore avenues to utilize the *Go Wish-Pediatrics* intervention to help create written advance care plans for the pediatric population as well as if there is benefit of utilizing the *Go Wish-Pediatrics* intervention as part of the process for developing a pediatric advance care plan. Advance care planning needs to involve the needs of the child, the parents, and the family unit. Researchers also need to evaluate.

A final implication for future research developed as a result of the conversations during the intervention of this study. The conversations with these parents identified that parents appear to move through different levels of needs. The purpose of this study was not to identify a process for how parents needs change through the palliative care journey; however there were parts of interviews that identified that there may be some process that occurs. The adult literature has suggested that patient’s in hospice have a hierarchy of needs modified off of the original Maslow’s Hierarchy of needs (Zalenski & Raspa, 2006). From what was initially seen in this study, there does appear to be a process of needs for the parents both related to their own needs as well as their child’s and family needs. This process or hierarchy would be important to further explore within
the pediatric population because of the complexity of the parents needs intertwined with the child’s.

**Summary**

Palliative care has been a focus in the pediatric literature for the past decade. Despite this focus, the literature continues to support that there is a need to improve communication between parents and the providers. Members of the healthcare team feel underprepared and uncomfortable introducing and initiating conversations related to sensitive topics like end of life or palliative care needs. The parents in this study opening communicated about raw emotions and needs with a person that was not directly involved with their child or known to them. The use of the card game was an essential element to both give the facilitator permission to let the parent drive the conversation as well as having a vehicle to start a wide variety of conversations based on the topics of the cards. The sample in this study demonstrated that if given the opportunity, they were willing to be present in the conversation and in some instances lead it.

In summary, based on the evidence from this mixed methods study, it is reasonable to conclude that there is significant value in utilizing the *Go Wish- Pediatrics* intervention to facilitate initiation of and guidance of difficult conversations with parents caring for a child with a life threatening illness. Results strongly support further exploration of this intervention within alternate timeframes and settings. The pediatric palliative care literature is improved with the additional knowledge derived from this pilot study.
References


Steinhauser, K., & Clipp, E. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine, 132*(10), 825-832.


Appendix A

Children’s Hospital Approval Letter

6200 Dodge Rd.
Omaha, NE 68114
September 16, 2014

To whom it may concern:

Meghan Potthoff has met with the Hand in Hand/Palliative Care department at Children’s Hospital & Medical Center and discussed her proposal. Her project fits within the mission of the Hand in Hand team of ensuring quality of life for the patient and his or her family. We are in full support of her proposed project. Furthermore, her research will benefit the department by allowing us to assess for the additional needs of our families.

If you have any further questions or concerns please contact the Hand in Hand/Palliative Care office at 402-955-5428.

Sue Bace, LICSW
Program Coordinator

Julia Delcour, APRN-NP
Nurse Practitioner
Appendix B

UNMC IRB Approval Letter

January 6, 2015

**IRB #:68514 EP**

**TITLE OF PROTOCOL:** Go Wish: Pilot Study of an Advance Care Planning Conversation Tool in Pediatric Palliative Care

**DATE OF EXPEDITED REVIEW:** December 9, 2014

**DATE OF FINAL APPROVAL AND RELEASE:** January 6, 2015  VALID UNTIL: December 9, 2015

**CLASSIFICATION OF RISK:** Minimal  **SUBPART B CATEGORY OF REVIEW:** 45 CFR 46.204

**EXPEDITED CATEGORY OF REVIEW:** 45 CFR 46.110; 21 CFR 56.110, Categories 6 and 7

The IRB has completed its review of the above-titled research protocol. The IRB has determined you are in compliance with HHS Regulations (45 CFR 46), applicable FDA Regulations (21 CFR 50, 56) and the Organization's HRPP policies. Furthermore, the IRB is satisfied you have provided adequate safeguards for protecting the rights and welfare of the subjects to be involved in this study. This letter constitutes official notification of final approval and release of your project by the IRB. You are authorized to implement this study as of the above date of final approval.

Please be advised that only the IRB approved and stamped consent form(s) can be used to make copies to enroll subjects. Also, at the time of consent all subjects/legally authorized representatives (LARs)/parent(s) must be given a copy of *The Rights of Research Subjects* and "What Do I Need to Know" forms.

The IRB wishes to remind you that the principal investigator (PI) is ultimately responsible for ensuring that this research is conducted in full compliance with the protocol, applicable Federal Regulations, and Organizational policies.

Finally, under the provisions of this institution's Federal Wide Assurance (FWA00002939), the PI is directly responsible for submitting to the IRB any proposed change in the research or the consent form(s). In addition, any adverse events, unanticipated problems involving risk to the subject or others, noncompliance, and complaints must be promptly reported to the IRB in accordance with HRPP policies.

This project is subject to periodic review and surveillance by the IRB and, as part of the Board's surveillance, the IRB may request periodic progress reports. For projects which continue beyond one year, it is the responsibility of the PI to initiate a request to the IRB for continuing review and update of the research project.

On behalf of the IRB,

Signed on: 2015-01-06 17:24:00.000

Kevin J. Epperson, CIP
Appendix C

SDSU IRB Approval Letter

To: Meghan Potthoff, College of Nursing

Date: January 8, 2015

Project Title: Go Wish: Pilot Study of an Advance Care Planning Conversation Tool in Pediatric Palliative Care

Approval #: IRB-1501002-EXP

The committee approved your project using expedited procedures as described in 45 CFR 46.110. The research activity was deemed to be no greater than minimal risk, and the following expedited categories from 63 FR 60364-60367 were found to be applicable to your activity:

(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.

One-year approval of your project will be dated starting 1/8/15. If you require additional time to complete your project, please submit a request for extension before 1/7/16.

If there are any unanticipated problems involving risks to subjects or others, or changes in the procedures during the study, contact the SDSU Research Compliance Coordinator. Protocol changes must be approved by the Committee prior to implementation. Forms may be found on the Human Subjects web page. At the end of the project please inform the committee that your project is complete.

If I can be of any further assistance, don’t hesitate to let me know.

Sincerely,

Norm
Norman O. Braaten
SDSU Research Compliance Coordinator
Appendix D

Participant Recruitment Letter

IRB PROTOCOL # 685-14-EP
Title of this Research Study

Go Wish: Pilot Study of an Advance Care Planning Conversation Tool in Pediatric Palliative Care

Invitation to Participate in Palliative Care Research Study
To: Parents of children currently receiving care from the Hand in Hand Team

My name is Meghan Potthoff. I am a Pediatric Nurse Practitioner and a nurse educator. I am currently working on my PhD in Nursing. The focus of my dissertation is improving communication related to palliative care and advance care planning.

Communication is the key to adequate care for families faced with caring for a child receiving palliative care. Part of the challenge with having emotionally difficult conversations and facilitating advance care planning in pediatrics is that parents are at different stages in adapting to their child’s diagnosis and treatment plan. The purpose of this research is to explore the use of an advance care planning conversation tool, Go Wish: Pediatrics, that allows parents to set their priorities for their child & family while receiving palliative care.

I would like to extend an invitation for you to participate in a research study to explore the experience of parents receiving palliative care services and the use of the Go Wish: Pediatrics advance care planning conversation tool.

If you are interested in learning more about this research study, please contact me via the information below (email or phone).

I want to thank you for your time and consideration.

Sincerely,

Meghan Potthoff, APRN-NP

PhD Student, South Dakota State University

Pediatric Nurse Practitioner, Children’s Hospital and Medical Center

Phone: 402-280-2660

Email: meghanpotthoff@creighton.edu
Appendix E

Coda Alliance Permission Letter

September 24, 2014

To Whom it May Concern

I am writing to express my support for Meghan (Walker) Potthoff’s proposed project to develop a version of the Go Wish cards for the pediatric population.

Development of the original Go Wish cards was made possible by a grant from Archstone Foundation to Coda Alliance. I am author of the original project that developed the Go Wish cards. I was also the principal investigator for the project that successfully developed the Spanish language version of the Go Wish cards in a collaboration between Coda Alliance and The Institute for Palliative Medicine at San Diego Hospice. I am tasked by the Board of Coda Alliance to oversee the development of the pediatric version.

I am pleased to give my permission and support, and that of Coda Alliance, to Professor Potthoff and her project to develop an appropriate adaptation of the Go Wish cards for the pediatric population. I will provide recommendations for the development process based on the original and subsequent projects developing the card sets, and have already recruited leaders in the field of Pediatric Palliative Care to assist in testing the prototype versions of the cards in development. I will continue to work with Professor Potthoff and with Coda Alliance to assure that the final product is true to the intentions and quality endorsed by Coda Alliance. Coda Alliance has provided a template for Terms of Agreement to allow the development of a pediatric version that respects the copyright of the Go Wish cards, with the intention to complete a mutually acceptable agreement.

It will be my pleasure and privilege to work with Meghan Potthoff and help bring to fruition a product eagerly awaited by my pediatric palliative care colleagues.

Sincerely yours,

Elizabeth S. Menkin, MD, FAAHPM

535 South 13th Street
San Jose, CA 95112

Phone: 408-506-3971
Fax: 877-992-2329
## APPENDIX F

### Initial Go Wish Pediatric Cards Used in the Study

<table>
<thead>
<tr>
<th>Card number</th>
<th>topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>My relationship with my spouse or significant other</td>
</tr>
<tr>
<td>2</td>
<td>Minimizing arguments within our family related to care decisions</td>
</tr>
<tr>
<td>3</td>
<td>Discuss my fear of my child having an event when I am not there</td>
</tr>
<tr>
<td>4</td>
<td>Maintaining memories of my child</td>
</tr>
<tr>
<td>5</td>
<td>Respiratory symptom management for my child</td>
</tr>
<tr>
<td>6</td>
<td>Role of my spiritual or faith based advisor</td>
</tr>
<tr>
<td>7</td>
<td>Management of my child’s mood and behavior changes</td>
</tr>
<tr>
<td>8</td>
<td>Involvement of my child in decisions and communication</td>
</tr>
<tr>
<td>9</td>
<td>Management of nausea, vomiting, and/or constipation for my child</td>
</tr>
<tr>
<td>10</td>
<td>Wild card</td>
</tr>
<tr>
<td>11</td>
<td>Frequency of communication regarding palliative care</td>
</tr>
<tr>
<td>12</td>
<td>My decision making support</td>
</tr>
<tr>
<td>13</td>
<td>Defining what my child can do and safely participant in</td>
</tr>
<tr>
<td>14</td>
<td>Communication with my child about death and dying</td>
</tr>
<tr>
<td>15</td>
<td>Fear of talking about death</td>
</tr>
<tr>
<td>16</td>
<td>Financial concerns for our family</td>
</tr>
<tr>
<td>17</td>
<td>Define the palliative care team’s role in caring for my child and family</td>
</tr>
<tr>
<td>18</td>
<td>Define my role in caring for my child and family</td>
</tr>
<tr>
<td>19</td>
<td>Talking about what scares me related to the care of my child</td>
</tr>
<tr>
<td>20</td>
<td>Preparation of siblings for events and care ahead</td>
</tr>
<tr>
<td>21</td>
<td>Discuss my fear of leaving my child</td>
</tr>
<tr>
<td>22</td>
<td>My child being free from machines</td>
</tr>
<tr>
<td>23</td>
<td>Discuss hospice services</td>
</tr>
<tr>
<td>24</td>
<td>Emotional support services available to me</td>
</tr>
<tr>
<td>25</td>
<td>Information about creating an advance care planning document</td>
</tr>
<tr>
<td>26</td>
<td>Communication with my child about what to expect</td>
</tr>
<tr>
<td>27</td>
<td>Managing my own anxiety.</td>
</tr>
<tr>
<td>28</td>
<td>How my child’s illness is impacting me at work</td>
</tr>
<tr>
<td>29</td>
<td>Support services for siblings</td>
</tr>
<tr>
<td>30</td>
<td>Sleep/Fatigue management for my child</td>
</tr>
<tr>
<td>31</td>
<td>Define my specialists role in caring for my child and family</td>
</tr>
<tr>
<td>32</td>
<td>Identify who will manage my child’s pain and symptom management</td>
</tr>
<tr>
<td>33</td>
<td>Writing down my goals and wishes for my child</td>
</tr>
<tr>
<td>34</td>
<td>Identifying and honoring my child’s wishes</td>
</tr>
<tr>
<td>35</td>
<td>My ability to provide cares for my child</td>
</tr>
<tr>
<td>36</td>
<td>Appetite changes and nutrition plans for my child</td>
</tr>
<tr>
<td>37</td>
<td>Identifying an advocate for my child and family</td>
</tr>
<tr>
<td>38</td>
<td>Options for bringing my child home</td>
</tr>
<tr>
<td>39</td>
<td>Define my primary care givers role in caring for my child and family</td>
</tr>
<tr>
<td>40</td>
<td>Having a written advanced directive for my child</td>
</tr>
<tr>
<td>41</td>
<td>Pain management options for my child</td>
</tr>
</tbody>
</table>
APPENDIX G

Revised Go Wish Pediatric Cards Used in the Study

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</tr>
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<td>41</td>
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</tr>
</tbody>
</table>
Appendix H

Demographic Survey

1. Please indicate your relationship with your child:
   _____ Biological Mother
   _____ Biological Father
   _____ Legal Guardian Mother
   _____ Legal Guardian Father

2. What is your marital status?
   _____ Married
   _____ Divorced
   _____ Widowed
   _____ Separated
   _____ Never married

3. In which category is your age?
   _____ 19-24 years old
   _____ 25-34 years old
   _____ 35-44 years old
   _____ 45-54 years old
   _____ 55 years or older

4. What is your race?
   _____ American Indian or Alaskan Native
   _____ Asian or Pacific Islander
   _____ Black/African American
   _____ Hispanic/Latino
   _____ White/Caucasian
   _____ Other: ______________

5. What is your highest level of education:
   _____ 12th grade or less (no diploma)
   _____ High School Diploma
   _____ Some College, no degree
   _____ Associate or Technical Degree
   _____ Bachelor’s Degree
   _____ Graduate Degree/Professional
6. Please identify your current employment status:

___ Working full time (40 or more hours per week)
___ Working part time (less than 40 hours per week)
___ Retired, not employed
___ Unemployed

7. What category best describes your annual household income?

___ Less than $24,999
___ $25,000 to $49,000
___ $50,000 to $99,999
___ $100,000 or more

8. Please state your child’s primary diagnosis:

_______________________________

9. In which category is your child’s age?

___ Less than 1 month old
___ 1 to 6 months old
___ 7 months to 1 year old
___ 2-5 years old
___ 6-10 years old
___ 11-15 years old
___ Older than 15 years old

10. Does your child currently have an advance directive or advance care planning document?

___ Yes
___ No

11. When was your child diagnosed with their primary diagnosis?

   Within the last 6 months
   _____ 6 months to 1 year ago
   _____ 1-2 years ago
12. How long have you been receiving care from the palliative care group (Hand in Hand)?

- ______ 2-5 years ago
- ______ More than 5 years ago

13. Have you participated in advance care planning conversations previously?

- ______ Yes
- ______ No

  a. If so, with what service or group? ____________________
## PECI Short Form

This questionnaire is concerned with thoughts and feelings related to parenting a child who is living with, or has experienced, a chronic illness. Read each statement and then try to determine how well it describes your thoughts and feelings over the past month.

<table>
<thead>
<tr>
<th></th>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>OFTEN</th>
<th>ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is painful for me to think about what my child might have been like had s/he never gotten sick.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I am at peace with the circumstances of my life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I feel guilty because my child became ill while I remained healthy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I worry about my child’s future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I feel ready to face challenges related to my child’s well being in the future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I worry that I may be responsible for my child’s illness in some way.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I worry that at any minute, things might take a turn for the worse.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I worry about whether my child will be able to live independently as an adult.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I have regrets about decisions I have made concerning my child’s illness.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>10. I think about whether or not my child will die.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>11. I am aware of the specific ways I react to sadness and loss.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>12. I experience angry feelings when I think about my child’s illness.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>13. I am afraid of this diagnosis occurring in another member of my immediate family.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>14. I trust myself to manage the future, whatever happens.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>15. I find it hard to socialize with people who don’t understand what being a parent to my child means.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>16. When my child is playing actively, I find myself worried that s/he will get hurt.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>17. I believe I will never be as completely happy or satisfied with my life as I was before my child became ill.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>18. My hopes and dreams for my child’s future are uncertain.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>19. I am jealous of parents who have healthy children.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>20. I worry that my child’s illness will worsen return.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>21. Seeing healthy children doing everyday activities makes me feel sad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>22. I worry about something bad happening to my child when s/he is out of my care.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. I can get help and support when I need it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. I wake up during the night and check on my child.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. When I am not with my child, I find myself thinking about whether or not s/he is ok.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix J

Permission to Use the PECI

From: Melanie Bonner, Ph.D. [mailto:melanie.bonner@duke.edu]
Sent: Tuesday, August 19, 2014 3:27 PM
To: Potthoff, Meghan R.
Cc: Lindsay Anderson
Subject: Re: Parent Experience of Child Illness

Hi Meghan,

Happy to share the PECI. I am copying my graduate student Lindsay here who will forward the instrument and scoring. Best wishes with your research!

Dr. Bonner

Melanie J Bonner, PhD
Professor
Department of Psychiatry and Behavioral Sciences
Duke University Medical Center
Director of Graduate Studies
Department of Psychology and Neuroscience
Duke University
APPENDIX J

UNMC Informed Consent Form

IRB PROTOCOL # 685-14-EP

Title of this Research Study
Go Wish: Pilot Study of an Advance Care Planning Conversation Tool in Pediatric Palliative Care

Invitation
You are invited to take part in this research study. You have a copy of the following, which is meant to help you decide whether or not to take part:
Informed consent form
"What Do I need to Know Before Being in a Research Study?" The Rights of Research Subjects

Why are you being asked to be in this research study?
You are being asked to participate in this study because you have a child currently receiving pediatric palliative care.

What is the reason for doing this research study?
Communication is the key to higher standards of care for families faced with caring for a child in palliative care. Part of the challenge with having emotionally difficult conversations and facilitating advance care planning in pediatrics is that parents are at different stages in adapting to their child's diagnosis and treatment plan. The purpose of this research is to explore the use of an advance care planning conversation tool, Go Wish: Pediatrics, with parents caring for a child enrolled in pediatric palliative care.

What will be done during this research study?
As a participant in this study you will first complete a demographic questionnaire and an initial 25 item survey, the Parent Experience of Child Illness survey. Following this, you will complete the Go Wish: Pediatric intervention. To complete this intervention, you will be given a deck of 40 cards and instructions on how to complete the game. Following the intervention, a palliative care team member from Children's Hospital and the researcher will meet with you to discuss the cards. You will also be interviewed by the researcher about your perceptions of the Go Wish: Pediatric Intervention. This interview will be audio recorded for accuracy. Once this audio recording has been transcribed, the audio recording will be destroyed.

2-3 weeks following the initial meeting, a follow up survey with the Parent Experience of Child Illness will be completed. It is anticipated that the initial meeting will take approximately 45 minutes to one hour. The follow up meeting will take approximately 15 minutes.
What are the possible risks of being in this research study?
You may experience negative emotions due to the sensitive nature of caring for a child in palliative care. There is also a possible risk to you of a loss of confidentiality.

What are the possible benefits to you?
The Go Wish: Pediatric intervention is intended to be a tool that will help to facilitate advance care planning conversations within a family as well as with the healthcare team. As a participant in this study, you could benefit from these conversations with improved understanding of your child’s care and mutually agreed upon goals of care. However, you may not get any benefit from being in this research study.

What are the possible benefits to other people?
Other families caring for a child suffering from a life threatening illness could potentially benefit from this research by providing resources that can improve palliative care communication and the process of advance care planning in pediatrics.

What are the alternatives to being in this research study?
Instead of being in this research study you can choose not to participate.

What will being in this research study cost you?
There is no cost to you to be in this research study.

Will you be paid for being in this research study?
After completing the pre and post surveys in this study you will be compensated with a $20 gift card to Target in appreciation of your time.

What should you do if you have a problem during this research study?
Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

How will information about you be protected?
All necessary steps will be taken to protect your privacy and the confidentiality of your study data.

Who will have access to information about you?
By signing this consent form, you are allowing the research team to have access to your research data. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at Children’s Hospital and Medical Center, and UNMC/TNMC.
Your research data will be used only for the purpose(s) described in the section What is the reason for doing this research study?
You are also allowing the research team to share your research data, as necessary, with other people or groups listed below:
The UNMC Institutional Review Board (IRB)
Institutional officials designated by the UNMC IRB
Federal law requires that your information may be shared with these groups: The HHS Office for Human Research Protections (OHRP)
You are authorizing us to use and disclose your research data for as long as the research study is being conducted.

You may cancel your authorization for further collection of research data for use in this research at any time by contacting the principal investigator. However, the information which is included in the research data obtained to date may still be used. If you cancel this authorization, you will no longer be able to participate in this research.

**How will results of the research be made available to you during and after the study is finished?**

In most cases, the results of the research can be made available to you when the study is completed, and all the results are analyzed by the investigator. The information from this study may be published in scientific journals or presented at scientific meetings, but your identity will be kept strictly confidential. If you want the results of the study, contact the Principal Investigator at the phone number given at the end of this form or by writing to the Principal Investigator at the following address:

_Meghan Potthoff_

_2500 California Plaza_

_Omaha, NE 68178_

**What will happen if you decide not to be in this research study or decide to stop participating once you start?**

You can decide not to be in this research study, or you can stop being in this research study (withdraw) at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator or Children's Hospital and Medical Center. You will not lose any benefits to which you are entitled.

**Will you be given any important information during the study?**

You will be informed promptly if the research team gets any new information during this research study that may affect whether you would want to continue being in the study.

**What should you do if you have any questions about the study**

You have been given a copy of "What Do I Need to Know Before Being in a Research Study?" If you have any questions at any time about this study, you should contact the Principal Investigator or any of the study personnel listed on this consent form or any other documents that you have been given.

**What are your rights as a research participant?**

You have rights as a research subject. These rights have been explained in this consent form and in The Rights of Research Subjects that you have been given. If you have any questions concerning your rights or complaints about the research, you can contact any of the following:

_The investigator or other study personnel Institutional Review Board (IRB)_
Telephone: (402) 559-6463 Email: IRBORA@unmc.edu
Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830
Research Subject Advocate
Telephone: (402) 559-6941 Email: unmrca@unmc.edu

**Documentation of informed consent**
You are freely making a decision whether to be in this research study. Signing this form means that:
You have read and understood this consent form.
You have had the consent form explained to you.
You have been given a copy of The Rights of Research Subjects You have had your questions answered.
You have decided to be in the research study.
If you have any questions during the study, you have been directed to talk to one of the investigators listed below on this consent form.

**IRB PROTOCOL # 685-14-EP**
You will be given a signed and dated copy of this consent form to keep.

Signature of Subject __________ Date ____________________________

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject. In my judgment, the participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Person Obtaining Consent ____________________________ Date ___

**Authorized Study Personnel Principal**
Potthoff, Meghan phone: 402-280-2660
alt #: 402-280-2660
degree: APRN

**Participating Personnel**
Delcour, Julie
alt #: 402-955-5400
degree: APRN-NP
Appendix L

Qualitative Interview Guide

- What is the parent’s overall experience and perception of the *Go Wish: Pediatrics* intervention?
- How do parents describe their experience of utilizing *Go Wish: Pediatrics* as a tool to facilitate advance care planning?
- What could be done to improve the *Go Wish: Pediatrics* intervention?
  - Were any values or items missing from the *Go Wish: Pediatrics* intervention?
Appendix M: Go Wish Pediatric Card Distribution

Go Wish Card Distribution

*card 10 is a wild card that was only included by some participants.
Appendix N

Within Couple Comparison by Subscale (next four pages)

Couple 1

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>0.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Unresolved Sorrow &amp; Anger</td>
<td>0.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Long-term Uncertainty</td>
<td>0.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Emotional Resources</td>
<td>0.0</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Female | Male | Female | Male | Female | Male | Female | Male |

Guilt & Worry

Unresolved Sorrow & Anger

Long-term Uncertainty

Emotional Resources
Couple 2

Guilt & Worry

Unresolved Sorrow & Anger

Long-term Uncertainty

Emotional Resources
Couple 3

Guilt & Worry

Unresolved Sorrow & Anger

Long-term Uncertainty

Emotional Resources
Couple 4

Guilt & Worry

Unresolved Sorrow & Anger

Long-term Uncertainty

Emotional Resources

Female  Male  Female  Male  Female  Male  Female  Male  Female  Male
## Appendix O

Final Version of *Go Wish-Pediatric Cards*

<table>
<thead>
<tr>
<th>Card number</th>
<th>topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>My relationship with my spouse or significant other</td>
</tr>
<tr>
<td>2</td>
<td>Minimizing arguments within our family related to care decisions</td>
</tr>
<tr>
<td>3</td>
<td>My fear of my child having an event when I am not there</td>
</tr>
<tr>
<td>4</td>
<td>Maintaining memories of my child</td>
</tr>
<tr>
<td>5</td>
<td>Respiratory symptom management for my child</td>
</tr>
<tr>
<td>6</td>
<td>Role of my spiritual or faith based advisor</td>
</tr>
<tr>
<td>7</td>
<td>Management of my child’s mood and behavior changes</td>
</tr>
<tr>
<td>8</td>
<td>Involvement of my child in communication</td>
</tr>
<tr>
<td>9</td>
<td>Management of nausea, vomiting, and/or constipation for my child</td>
</tr>
<tr>
<td>10</td>
<td>Wild card</td>
</tr>
<tr>
<td>11</td>
<td>Frequency of communication regarding palliative care</td>
</tr>
<tr>
<td>12</td>
<td>Decision making support</td>
</tr>
<tr>
<td>13</td>
<td>Define what my child can safely participate in</td>
</tr>
<tr>
<td>14</td>
<td>Communication with my child about death and dying</td>
</tr>
<tr>
<td>15</td>
<td>Fear of talking about death</td>
</tr>
<tr>
<td>16</td>
<td>Financial concerns</td>
</tr>
<tr>
<td>17</td>
<td>Define the palliative care team’s role in caring for my child and family</td>
</tr>
<tr>
<td>18</td>
<td>Talk about what scares me related to the care of my child</td>
</tr>
<tr>
<td>19</td>
<td>Preparation of siblings for events ahead</td>
</tr>
<tr>
<td>20</td>
<td>Discuss my fear of leaving my child</td>
</tr>
<tr>
<td>21</td>
<td>My child being free from machines</td>
</tr>
<tr>
<td>22</td>
<td>Discuss hospice services</td>
</tr>
<tr>
<td>23</td>
<td>Emotional support services available to me</td>
</tr>
<tr>
<td>24</td>
<td>Information about creating an advance care planning document</td>
</tr>
<tr>
<td>25</td>
<td>Communication with my child about what to expect</td>
</tr>
<tr>
<td>26</td>
<td>Managing my anxiety</td>
</tr>
<tr>
<td>27</td>
<td>How my child’s illness is impacting me at work</td>
</tr>
<tr>
<td>28</td>
<td>Support services for siblings</td>
</tr>
<tr>
<td>29</td>
<td>Sleep/Fatigue management for my child</td>
</tr>
<tr>
<td>30</td>
<td>Define my specialists role in caring for my child and family</td>
</tr>
<tr>
<td>31</td>
<td>Identify who will manage my child’s pain and symptom management</td>
</tr>
<tr>
<td>32</td>
<td>Writing down my goals and wishes for my child</td>
</tr>
<tr>
<td>33</td>
<td>Identifying and honoring my child’s wishes</td>
</tr>
<tr>
<td>34</td>
<td>My ability to provide cares for my child</td>
</tr>
<tr>
<td>35</td>
<td>Appetite changes and nutrition plans for my child</td>
</tr>
<tr>
<td>36</td>
<td>Identifying an advocate for my child and family</td>
</tr>
<tr>
<td>37</td>
<td>Options for bringing my child home</td>
</tr>
<tr>
<td>38</td>
<td>Define my primary care givers role in caring for my child and family</td>
</tr>
<tr>
<td>39</td>
<td>Having a written advance directive for my child</td>
</tr>
<tr>
<td>40</td>
<td>Pain management options for my child</td>
</tr>
<tr>
<td>41</td>
<td>Maintaining independence</td>
</tr>
</tbody>
</table>
Appendix P

Caring Wish Conversation Framework