Understanding the "Big Picture": End-of-life Decisions in the PICU

Amy J. Howells
UTHHealth School of Nursing

Follow this and additional works at: https://digitalcommons.library.tmc.edu/uthson_etd

Part of the Nursing Commons

Recommended Citation
https://digitalcommons.library.tmc.edu/uthson_etd/3

This is brought to you for free and open access by the School of Nursing at DigitalCommons@TMC. It has been accepted for inclusion in UT SON Dissertations (Open Access) by an authorized administrator of DigitalCommons@TMC. For more information, please contact nha.huynh@library.tmc.edu.
Understanding the “Big Picture”:
End-of-Life Decisions in the PICU

A Dissertation
Submitted in Partial Fulfillment of the Requirements
For the Degree of Doctor of Philosophy in Nursing

The University of Texas Health Science Center at Houston
School of Nursing
By
Amy J Howells, MSN, CPNP-PC/AC

May, 2014
To the Dean for the School of Nursing:

I am submitting a dissertation written by Amy J. Howells, PhD(c),RN,CPNP-AC entitled "Understanding the "Big Picture:" End-of-Life Decisions in the PICU." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.

We have read this dissertation and recommend its acceptance:

[Signatures]

Accepted

[Signature]
Dean for the School of Nursing
Acknowledgements

Texas Children's Hospital Section of Pediatric Critical Care Medicine

Baylor College of Medicine, Principal Investigator, Intramural grant

$5,000

Dr Lara Shekerdemian

Dr Laura Loftis

Dr Fernando Stein
Understanding the “Big Picture”: End-of-Life Decisions in the PICU

Amy J Howells, PhD(c), RN, CPNP-AC

May, 2014

Abstract

Objective: Describe critical care providers’ cognitive constructions or their interpretation of the process of decision-making that influences both the technique of conversations and the recommendations given to parents regarding limitation or withdrawal of life sustaining treatments from terminally ill children in the PICU.

Design: Qualitative Medical Ethnography.

Setting: Tertiary care children’s hospital affiliated with a college of medicine.

Participants: Eleven critical care providers in the department of pediatrics (attending physicians, critical care fellows, pediatric nurse practitioners, physician assistants).

Interventions: In depth, semi-structured interviews designed to explore the experiences of providers in the participation of end-of-life care decision-making.

Measurements and Main Results: Findings from the data included concepts and themes that were then organized into a conceptual framework to help understand the decision making process for critically ill children at the end of life. The four major themes identified were: Expectations and Perspectives, Communication Enhancers and Inhibitors, Decision Enablers and Barriers, and Conversation Mechanics. Each theme consists of several concepts from the data that further inform the process. The Expectations and Perspectives theme explains differences between parents and providers that, if understood, can be managed more effectively. The themes focused on
communication and decisions elucidate concepts that will improve the process and concepts that have been identified as barriers. The Conversation Mechanics theme provides insight into the process of acquiring the skills that providers have experienced.

**Conclusions:** After conducting in-depth interviews with critical care providers who care for children at the end of life, a conceptual framework is proposed to provide a better understanding of the decision-making process and to suggest interventions to make advancements.

**Key Words:** communication; decision making; end-of-life care; PICU; qualitative research
# TABLE OF CONTENTS

- APPROVAL PAGE ........................................................................................................................ ii
- ACKNOWLEDGEMENTS .................................................................................................................. iii
- ABSTRACT ........................................................................................................................................ iv
- SUMMARY OF STUDY ...................................................................................................................... 1
- PROPOSAL ....................................................................................................................................... 2
  - Specific Aims ............................................................................................................................... 2
  - Background and Significance .................................................................................................... 7
  - Literature ..................................................................................................................................... 7
  - Preliminary Work ......................................................................................................................... 13
  - Research Design ......................................................................................................................... 15
  - Study Procedures ....................................................................................................................... 17
  - Human Subject Protection .......................................................................................................... 22
  - References ................................................................................................................................... 24
  - Appendices .................................................................................................................................. 28
    - A Letter of Information ............................................................................................................. 29
    - B Interview Schedule .............................................................................................................. 31
C Demographic Form.................................................................37

MANUSCRIPT ............................................................................38

Appendices .....................................................................................72

A Letter of Information .................................................................72

B Interview Schedule......................................................................74

C Demographic Form.................................................................76

D Participant Demographics .........................................................78

E Themes and Concepts with Exemplars ......................................83

CURRICULUM VITAE
Summary of Study

End-of-life decision making in the PICU is a process that needs attention from health care providers to foster improvement. Research is required to fully elucidate the issues surrounding end-of-life decision making and then to propose interventions designed to improve the process. This dissertation project began with a proposal to interview critical care providers and parents of children who were admitted to the PICU to allow the researcher to better understand how both view the process of decision making and whether the interaction between the providers and parents influenced the final decision.

A pilot study was conducted to assess the feasibility of the research proposal. It was determined by the principal investigator that attempting to enroll enough parent participants to adequately inform the results would require a prolonged period of time. Modifications were made to the protocol which included interviewing the critical care providers in an initial study, and then to follow up with a study with a similar design that focuses on parents. The study focusing on providers would make up the dissertation project.

The initial study was completed after 11 providers who care for patients in the PICU were interviewed and the results were analyzed. The findings are summarized in Table 1 and a conceptual model was presented based on those findings.
Communication and Decision-Making at the End-of-life in the PICU:
A Qualitative Study

Specific Aims

An estimated 22,844 children died in the United States in 2008 (Mathews et al., 2001). That number increased to approximately 45,000 in 2010, with an additional 25,000 children living with a life threatening illness (Ullrich & Morrison, 2013). Most pediatric deaths occur in the hospital, and of those children in the hospital more than 80% die in the pediatric intensive care unit (PICU) (Truog et al., 2006). The issue of death in the pediatric population is an ongoing and serious one. This study proposes to interview providers and parents to better understand their experiences regarding limitation or withdrawal of therapy for terminally ill children. The overall goal of the study is to begin to understand the process of end-of-life decision making for terminally ill children. From this increased understanding, interventions can be designed that will improve the process of end-of-life decision making for providers and, eventually, parents and their terminally ill children. Improving the process may help to alleviate the suffering of dying children while providing full information and support to grieving parents as well as decisional support to providers.

The goal of this study is consistent with national critical research needs regarding end of life issues. These identified needs include: 1. improving the understanding of the complex issues and choices underlying palliative and end-of-life care, 2. to develop and test biobehavioral interventions that provide palliative care for chronically ill individuals.
across the lifespan, including those from diverse populations, 3. to develop and test strategies to minimize the physical and psychological burdens on, and better maintain the health of, caregivers, particularly when the person for whom they are caring nears the end of life, 4. to determine the impact of providers trained in palliative and end-of-life care on health care outcomes, and 5. to create new communication strategies among clinicians, patients, families, and communities to promote decision making regarding complex treatment and care options in the face of life-threatening illness. (NINR, 2011). These research objectives are outlined in the National Institute of Nursing Research’s (NINR) strategic plan. The NINR was appointed as the lead institution for end-of-life research by the director of the National Institutes of Health (NIH) in 1997.

Despite a growing movement to improve end-of-life care, addressing palliative care needs and end-of-life decision-making, specifically in the PICU, is an area that remains sparsely researched.

Although the NIH identified the need to advance research in palliative care, a research review published in 2006 failed to identify a single intervention study targeted toward children at the end-of-life in the PICU, where most children die (Truog et al., 2006). A more recent article addressing the state of pediatric palliative care research comments that recent papers, while proposing interventions, are largely based on case studies (Ullrich & Morrison, 2013). There are several reasons to explain the scarcity of research studies. One reason is that the number of pediatric patients who die is small, especially compared to the number of adult deaths. Deaths in the PICU, therefore, do not receive as much attention. A second reason could relate to the nature of critical care
medicine. Children are not admitted to the PICU to die. The lack of research targeting improved decision-making has not yet been remedied and this lack will continue to be the case until we better understand the problem. The American College of Critical Care Medicine published a consensus statement making recommendations for end-of-life care in the intensive care unit with the caveat that recommendations were based on ethical and legal principles and not on the sparse empirical evidence that is available (Truog et al., 2008). The proposed qualitative study is designed to better understand the experience of decision-making for terminally ill, and to determine in what ways providers (physicians, nurse practitioners, and physician assistants) may influence parents in this process.

The specific aims of the proposed study are:

1. Describe healthcare providers' experiences during the process of decision-making that influences the content and style of conversations and recommendations to caregivers regarding limitation or withdrawal of life sustaining treatments from terminally ill children in the Pediatric Intensive Care Unit.

2. Describe the parents' experience during the process of decision-making that influences their decisions to continue, limit or withdraw treatment from their terminally ill child in the Pediatric Intensive Care Unit.

The research questions associated with this study are:

1. How do clinical providers construct the experience of guiding parents through the decision-making process at the end-of-life in the PICU?
2. How do parents describe the experience of making decisions to continue, limit, or withdraw treatment for their terminally ill child in the PICU?

Theoretical Background:

The pediatric intensive care unit is a good example of an environment that has been created by the medical system. Biomedicine is a distinct social and cultural system, with its own unique cultural characteristics, as well as a specific language (Kleinman, 1980). Western medicine, which follows the biomedical model seen in pediatric intensive care units in the United States, also draws upon many of the dominant western philosophical traditions (Gordon, 1988). Parents may have a difficult time navigating this foreign culture and understanding the system, especially when involved in an important and stressful decision making process. It may be particularly difficult for parents who are not of western cultures to understand the culture of PICU’s located in the United States, especially given a different cultural background and heritage. It is important that providers be sensitive to this phenomenon when engaging in information sharing to ensure that parents are as comfortable as possible with the environment in which they must make important decisions. The Cultural Negotiation Model, originally conceptualized to relate nursing practice to the influence of culture, posits the nurse and the patient, each bringing their own cultural heritage and interacting in the culture of the particular health care organization, which is embedded in the health care system and, ultimately, in an ecological context (Engebretson & Littleton, 2001). This model (Figure 1) illustrates the ecological model with the interchange between patient and healthcare provider in the PICU and embedded in the
larger cultural ethos. Experience, knowledge (both formal and informal), and cultural heritage of the parents and providers influence how they may interact during the decision making process. This model can be used to help parents and providers relate to each other and to facilitate a shared decision-making process.

*Figure 1. Conceptual Model- Modified from the Cultural Negotiations Model for nursing practice (Engebretson & Littleton, 2001).*
Background and Significance

End-of-life decisions are difficult for any population. These decisions in the pediatric population often confront a fairly universal belief that children are not supposed to die before their parents. Children do, despite this belief, die. A majority of the children who die are in the hospital at the time of their death, and many of these children are in the pediatric intensive care unit (Zawistowski & DeVita, 2004). The intensive care unit is a place where technologically advanced and very aggressive treatment is the norm. For some children who are at the end-of-life this may not be the optimal plan, however few children are transferred to a location such as hospice (Gupta, Harrop, Lapwood, & Shefler, 2013). These children may benefit from a palliative approach to their care, even while receiving care in the PICU. Limiting treatment in the pediatric intensive care unit is a difficult goal to accomplish for many reasons. A few of these reasons have been identified, such as practitioner bias and the uncertainty of prognostication (Burns et al., 2000). According to bioethics principles, many decisions are based on the best interest of the child standard. Uncertainty regarding prognosis makes the application of the best interest standard more difficult (DeMarco, Powell, & Stewart, 2011). Parents of critically ill children share in the decision making process and also may face difficulties when asked to make these decisions (Meert et al., 2000).

Literature. A small body of literature is developing on the topic of decision making in critically ill children. This issue has seen greater attention in recent literature, with the national interest in palliative care issues. This interest has been reflected in the growing number of research grants awarded for palliative care studies. Although there is
an increasing amount of literature in palliative care, most studies have focused on adults or neonates. There are significant differences between caring for adults or neonates and caring for the pediatric population, such as types of disease processes and life stages that call for more research in this area. Lack of end-of-life research on critically ill children may also be due specifically to their hospitalization in intensive care units. The intensive care unit location, itself, adds unique challenges to the care of these children that must be taken into account, such as the stressful, fast-paced environment and the focus on curative medicine. This focus on curative medicine and the success in reducing mortality in the pediatric population creates a treatment momentum that becomes self-sustaining. With these challenges in mind, there are a few studies that address the issue of decision making at the end of life in critically ill children.

Studies focused on Parents. Parents have been the focus of many studies regarding decision making at the end-of-life in critically ill children. A 2002 survey in which the objective was to identify priorities for quality end-of-life care from the parents’ perspective, identified several priorities when considering limitation of life sustaining treatment. These included: valuing quality of life, the perceived likelihood of improvement of the child’s condition, and their perception of the child’s pain. (Meyer et al., 2002). The study authors sent anonymous questionnaires (Parental Perspectives Questionnaire) to a total of 96 households, representing children who died after withdrawal of care in 3 Boston PICUs between 1994 and 1996. A total of 56 completed questionnaires were included in the analysis. The questionnaires were developed by the study authors after a literature review and were pilot tested by a group of 6 parents, an
intensive care physician and a psychologist. It consisted of 28 likert scale items and 5 open ended questions. In a follow up qualitative research study, the authors analyzed data from 4 of the 5 open ended questions that were included on the questionnaires from the previous study and addressed them separately (Meyer et al., 2006). These open-ended questions found that parents had the following recommendations and needs to improve the process when faced with end-of-life decisions for their child: complete and honest information, ready access to staff, communication, care coordination, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and faith (Meyer et al., 2006). A prospective qualitative study focused on the factors that influence parents when making the decision to limit treatment at the end-of-life (Sharman et al., 2005). This study consisted of 14 semi-structured interviews of parents whose child was currently being cared for in the PICU and for whom the physician had recommended limiting life support. A total of 14 parents of 10 children were interviewed. The authors found that parents struggle with feelings of guilt and selfishness during the decision making process and the recommendations of medical personnel, a review of all options available, and a joint formulation of a plan were factors identified in the facilitation of the decision making process. Another study focused on how parents viewed being involved in research concerning end-of-life decision making (Michelson et al., 2006). End-of-life interviews were conducted with seventy-four parents of children who were admitted to the PICU. At the end of the interview parents were asked to evaluate the experience. Sixty-one percent of parents viewed their participation as beneficial, with only a very small
minority (1%) voicing the opinion that the interview process was too invasive or too painful (Michelson et al., 2006).

Studies focused on providers. There are several studies that focused on the decision making perspective of health care providers. A review of the literature on decision making for critically ill children found that the main determinates of deciding to withdraw or withhold treatment at the end-of-life were: age, premorbid cognitive function, functional status, pain or discomfort, probability of survival, and quality of life (Masri et al., 2000). Early integration of palliative care into the care of a child with a life limiting disease was found to be associated with ease of decision making and the avoidance of being poorly prepared (Mack & Wolfe, 2006). The authors concluded that decisions are easier to make when the child is not in an intensive care setting, when decisions would have to be made in an emergent situation. To further illustrate this point, more decisions to limit or withdraw treatment at the end-of-life occurred when children were located on the regular pediatric floor as opposed to being located in a specialty unit, such as the pediatric intensive care unit (Tan et al., 2006). These data were elicited in a retrospective chart review that included 236 children who expired in the hospital. The timing of an end-of-life decision may also be relevant, with most critically ill children dying within hours of the limiting of treatment (Garros et al., 2003).

In a prospective, descriptive study the intensivist involved with the case was surveyed after every death in the PICU over an 8 month period (99 deaths). Data were obtained about the time to death after forgoing or withdrawing life-sustaining treatment as well as in patients that instituted a do-not-resuscitate (DNR) order. When therapy was
withdrawn the median time to death was 3 hours. When a DNR order was established the median time to death was approximately 24 hours. The short amount of time to death in patients that have therapy withdrawn or a DNR order enacted suggests that an intensive care paradigm is used for too long in these patients. Palliative care may be more appropriate and spare the child burdensome treatments that are unlikely to evidence benefit.

**Studies focused on Communication.** Research studies focusing on the end-of-life for children have identified additional issues that warrant further investigation. One of the articles described a multi-center study that pertained to health care providers and their experiences in providing care for critically ill children at the end-of-life (Solomon et al., 2005). A total of 781 clinicians in 7 PICUs were surveyed. The objectives were to determine the extent to which physicians and nurses in critical care, hematology/oncology, and other subspecialties are in agreement with one another and with widely published ethical recommendations regarding the withholding and withdrawing of life support, the provision of adequate analgesia, and the role of parents in end-of life decision-making. The study found that there was a lack of awareness of key ethical guidelines, but that most providers felt that they were knowledgeable about ethical issues. Many respondents were found to hold views that were widely divergent from published recommendations. Particularly concerning is the report of health care providers who feel that they have acted against their conscience in providing aggressive therapy for a dying child (Solomon et al., 2005). A case study presented in the literature outlined how communication between the health care team and parents is often less
than optimal when making end-of-life decisions, particularly in the busy intensive care
environment (Cole, 2003).

**Gaps in the literature.** This study will attempt to characterize the relationship
between how providers present information to parents when a poor prognosis has been
identified and the experience of parents when making end-of-life decisions by
interviewing both providers and parents who have been involved in this process.
Although decision making at the end-of-life in critically ill children has been partially
addressed in the literature, health care providers are still far from a having good
understanding of the issues surrounding this topic. The majority of research that has
been completed is descriptive, with the majority of those studies using surveys.
Additional descriptive studies, that can provide robust data, will help to better define
the nature of the problem. The complexity of the process of shared decision making that
needs to occur in these highly emotional situations requires a more in-depth
understanding than has been obtained by survey data. Utilizing qualitative interviews as
a methodology may be able to provide the type of data needed to better understand
how end-of-life decisions are made. Absent from the present literature pertaining to
decision making at the end-of-life in critically ill children is information related to
preparing providers to engage in an appropriate decision making process with families.
This study will attempt to ascertain how providers are prepared for these difficult
situations and their perception of whether this preparation adequately prepares them
for end of life decision making. The lack of robust information is largely due to the
recent nature of the exploration of this topic and the scarcity of published data (Truog
et al., 2006). Findings that suggest a link between how providers communicate and present information and parental experiences of the decision making process at the end of life in the PICU may suggest approaches toward improving end-of-life decision-making for children. The information from this study will allow focusing of intervention strategies on issues that may be found regarding the decision-making process

Preliminary Work

The primary investigator is a doctoral student who will be under the guidance of an experienced researcher well versed in qualitative research methodology and a seasoned bioethicist who is familiar with the setting for the study. The primary investigator is also a pediatric nurse practitioner with eight years of experience in critical care medicine, who is familiar with the intensive care unit environment and the vulnerability of the population in question. The researcher has experience with the types of interactions that are of interest in this study and has had the opportunity to establish relationships with many of the stakeholders that will be important to the success of this study. The qualitative nature of this study makes the field environment an important consideration, and the primary investigator's familiarity with this environment will be of benefit.

A pilot study was conducted to ascertain the feasibility of conducting a qualitative study of this nature in the PICU. The pilot design included interviewing parents and providers of children admitted to the PICU, after witnessing a conversation where end-of-life issues were discussed. The pilot study design also included obtaining field data from observed conversations between parents and providers, during which
the topic of withdrawal would be addressed. Several issues were identified while completing the pilot study. Participants were to be recruited only if they were either a parent or provider of a child who was currently in the PICU and suffering from a life-limiting illness or disease. This meant the population from which participants were recruited was a small percentage of the overall pediatric intensive care unit population as the overall mortality rate in the PICU is 3-4%. It proved difficult to be present for these conversations as they were infrequent and they happened without prior planning. These conversations were often conducted in the middle of the night or at a time when the investigator was unavailable, most often because of other patient care obligations. As the pilot study was also a feasibility study, this experience will be taken into account in the research design for this proposed study. Interviews that can be scheduled would alleviate many of the issues encountered in the pilot study, however, opportunities to observe conversations will be sought after and the data will be used to enrich the field notes.

During the pilot study, an interview was conducted with a parent from whom preliminary data was gathered. The conversation between parent and provider was not witnessed in this instance. The parent was willing to talk about his experience and expressed that he hoped it would “make it easier on the next parent.” This parent interview generated good data that supported the research question and aims of the study. Additional parent interviews will be sought after to further enrich the data that is collected during the study. In order to maintain the feasibility of the study in a reasonable time frame, provider interviews will be the focus.
Research Design

Study Design. This study is an interpretive clinical or medical ethnographic study (Roberts, 2009). Applied medical ethnography will be used to elicit information in the context of the sub-culture of the pediatric intensive care unit (Pope, 2005). Ethnography will allow the researcher to understand the interactions between groups (or cultures) and to understand how the beliefs and values are reflected in these behaviors and interactions (Denzin & Lincoln, 2003). It is important to note that ethnography does not simply refer to different ethnic groups (particularly, ethnic minorities), but to the beliefs and values of a group of people (Engebretson, 2011).

Clinical settings have been described as a unique subculture of biomedicine and the decision making process occurs in a negotiation across the biomedical and lay culture (Kleinman, 1980). Clinical providers who participate in end-of-life discussions in the PICU will be recruited to participate in semi-structured interviews with the researcher regarding communication with parents and the end of life decision-making process. Semi-structured interviews will also be conducted with parents who have been involved in end-of-life decision-making. A demographic tool will be filled out by all participants of the study to collect data regarding age, gender, ethnicity/race, religion, marital status, and SES. Field notes will be recorded by the researcher during the course of the study.

Setting. The setting for this research study is Texas Children’s Hospital located in Houston, Texas. Texas Children’s Hospital is a tertiary teaching hospital affiliated with Baylor College of Medicine. The hospital is located in the heart of the world’s largest medical center. The PICU is a 31 bed, medical intensive care unit staffed with a medical
team that consists of attending physicians, critical care fellows, pediatric nurse practitioners, physician assistants, and resident physicians in training.

**Population.** The population for this study is composed of providers (attending physicians, fellows, nurse practitioners, and physician assistants) who are involved in the decision making process for critically ill children admitted to the pediatric intensive care unit and the parents of critically ill children who are, or have been, admitted in the pediatric intensive care unit.

**Sample.** Providers who have participated in end-of-life discussions for a child admitted to the PICU or were involved in the decision making process that led to such discussions will be invited to participate in the study. A good representation of different experience levels of providers (nurse practitioners, physician assistants, fellows, and attending physicians) will be sought after during the sampling process, in an effort to exemplify the different levels of experience of providers who may be called upon to make these decisions. The parents of children for whom an end-of-life discussion was initiated will also be invited to participate, regardless of what their final decision was. Providers and parents of children over the age of 12, or who do not speak English, will be excluded.

**Sample Size.** The investigator will attempt to recruit a purposeful sample of providers/parents who meet the study inclusion criteria (Coyne, 1997). Providers from different educational backgrounds will be identified by the investigator and asked to participate in order to capture data that covers a wide range of experience and provides for a diverse sample of providers. The goal will be to interview advanced level providers
(nurse practitioners and physician assistants), intensive care fellows and attending physicians. The number of participants will be based on a focused ethnographic design, which allows for a smaller number of participants (Higginbottom, 2004). The investigator will sample participants with the intent of learning in detail and with depth about their experience. Due to the qualitative nature of this study, in which one samples until saturation and redundancy, a small sample size is anticipated (Tuckett, 2004). It is anticipated, based on other qualitative studies that saturation should occur around 25-30 participants. The majority of those are expected to be provider interviews. When parent interviews can be obtained they will contribute supporting and/or contrasting data. Interviews may be solicited from parents who have a child currently or recently in the PICU.

**Study Procedures.** Potential participants will be identified by the investigator and asked to participate in this research study. A written explanation of the study and waiver of consent form will be given to each potential participant. If the participant agrees to be interviewed after a full explanation of the study has been received, then consent will be implied. A written consent form will not be required, because identifying information is not going to be recorded and a written consent form would then be the only potential for a breach of confidentiality. After the waiver of consent form and written explanation of the study have been given to the participants, the investigator will interview providers and parents, focusing on communication and decision-making. All participants will be asked to fill out a short demographic/information form to be able to describe the sample (see appendix 3. Participant Description Form). The investigator
will ask for permission to interview study participants on at least one occasion with the possibility of additional interviews for clarification as needed. The investigator will interview providers who have been involved in the decision making process for a child in the PICU. The investigator will interview parents after a decision regarding limitation or withdrawal of therapy for their child has been made even if the decision was to continue all therapies. All interviews will be semi-structured, and will also be audio recorded and transcribed verbatim for analysis. Field notes will be taken by the investigator during the study.

**Instruments.** A short demographic form regarding age, gender, ethnicity/race, religion, marital status, SES, years of experience and educational preparation will be generated by the investigator. This form will be filled out by both providers and parents (see appendix 3. Participant Description Form). Semi-structured interview questions will also be generated by the investigator (see appendix 2. Interview Guide). These will be used when interviewing parents and providers regarding their decision-making and communication regarding end of life issues in the pediatric intensive care unit to guide the interactions. The interview questions serve as a guide to the conversational style of the interview and may be revised during the course of the study as investigators discover issues that could be addressed more systematically, however the main areas of interest in the interview guide (see appendix 2. Interview Guide) will be followed. The interviews will be conducted in a conversational style in a private area. As questions are answered by the participants during the interview, the investigator may add additional
follow up questions or probes to ensure that the information gathered is as complete as possible. Data will be collected with the aim of providing thick description of the topic.

**Analysis.** The audio tapes of the interviews will be transcribed by a transcription service and then verified by the principal investigator. The transcription service will have a confidentiality agreement with the investigator. The Nvivo 9 computer program will be utilized to assist with the management of data generated by the parental/provider interviews. All primary documents (transcriptions of conversations and interviews) will be entered into the software program for data management. Data will be analyzed on an ongoing basis as the interviews are completed. (Miles & Huberman, 1994).

In a thematic analysis approach, coding of interviews is done by the investigator to identify themes and develop schematics in the data. Initial data coding will serve several purposes. These are to provide focus, elicit meaning, determine pragmatics, and reduce the data to manageable units of analysis (Miles & Huberman, 1994). Data will be collected and analyzed with the aim of providing thick description of the topic. After initial coding has been completed the data will be scrutinized again to allow for revision and refinement of the codes. When revising codes the researcher may use the following strategies: filling in (adding to schemas), extension (examining codes with new themes or relationships), bridging (identifying new or poorly understood relationships), and surfacing (identifying new categories) (Lincoln & Guba, 1985).

Once major themes have been identified and well described and material begins to repeat in the data, saturation and redundancy will have been achieved. Patterns and linkages will be extracted from the data through inductive reasoning (Higginbottom,
2004). An integrated schema will be developed to display and understand the patterns and linkages and to facilitate the final descriptive product. This descriptive analysis of the data will be used to help understand the experience of the parents and providers of critically ill children in the PICU.

The analysis will be completed with the specific aims of the study in mind, which are to understand the providers’ constructions of the process of decision-making that influences the content and style of conversations and recommendations regarding limitation or withdrawal of life sustaining treatments from terminally ill children in the Pediatric Intensive Care Unit, and to understand the parents’ experience during the process of decision-making that influences their decisions to continue, limit or withdraw treatment from their terminally ill child. Rigorous documentation of the analysis process and appropriate investigator credentials will help establish the credibility of the study. Study validity will be maximized using several techniques, such as maintenance of an audit trail and utilizing expert peer review (Sandelowski & Barroso, 2003). Detailing of the data entry process and examining transcripts for accuracy will determine “factual accuracy”, which is a component of descriptive validity (Maxwell, 1992). Descriptive validity is also obtained by checking with study participants during or after the interview to be certain that the investigator has interpreted the participant correctly. Theoretical validity will be enhanced by utilizing consensus regarding the terms and descriptions used in the analysis process (Maxwell, 1992). This consensus will be established using peer debriefing, which will utilize the input of several established qualitative researchers. Applicability of the knowledge gained from this study to understanding
issues concerning communication and decision-making at the end-of-life in the PICU will contribute to pragmatic validity (Kvale, 1995).

**Study Limitations.** A limitation for this study is the assumption that participants will be able to articulate their experience in a manner that will generate complete and useful data. Open-ended interview questions and careful observation will be used to minimize this limitation. In addition, this study will be conducted in one institution. There may be institutional and regional issues that could influence the data.

**Timeline.** This study will commence in June of 2013 with a goal of completion by December of 2013 as seen in table 1.

<table>
<thead>
<tr>
<th></th>
<th>MAY</th>
<th>JUN</th>
<th>JUL</th>
<th>AUG</th>
<th>SEP</th>
<th>OCT</th>
<th>NOV</th>
<th>DEC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proposal defense</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data Collection</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data Analysis</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissertation Writing</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissertation Defense</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

*Table 1. Study Timeline*
Human Subject Protection

Potential risks to subjects: There are no physical risks to subjects enrolled in this study. Subjects may be at risk for psychological distress due to the nature of the study content. The primary investigator will conduct all interviews with participants and will remain sensitive to the potential for distress caused by this subject matter. Subjects will be advised that they may withdraw from participation at any time during the process. The greatest risk to participants is the maintenance of confidentiality.

Protection from risks: This study will be approved by the Institutional Review Board at the University of Texas Health Science Center and Baylor College of Medicine as well as the Human Rights Protection Committee before participants are enrolled. A waiver of consent will be obtained before enrolling participants. Confidentiality will be maintained by the following: original data collected for this study will be stored in a locked file cabinet and all identifying information will be removed with each participant being assigned a number for reference. Data will then be entered into Nvivo 8 under the assigned number into a password protected computer. The threat to confidentiality will be managed by using deidentified data for analysis. Participants have the right to withdraw from the study at any time without penalty.

Inclusion of Women and Minorities: Both men and women will be invited to participate in this study. Potential subjects will not be excluded on the basis of ethnicity or heritage, with the limitation that the participant must speak English.

Inclusion of Children: This study will focus on the adult parents and providers of children admitted to the PICU. Children will not be enrolled in this study.
Potential benefit to study participants and others: There is no direct benefit to the enrolled subjects. Findings from this study could lead to interventions that will improve the communication and decision-making at the end-of-life for terminally ill children in the PICU. Improved communication and decision making may lead to decreased suffering at the end-of-life, not only for the children, but for the parents, as well. Improved communication and decision making may also lead to an increase in provider satisfaction with the process and a decrease in ethical dilemmas that can contribute to burn out.

Vertebrate Animals: Not applicable.
References


Sandelowski, M., & Barroso, J. (2003). Writing the proposal for a qualitative research methodology project. Qualitative Health Research, 13(6), 781-820.
Sharman, M., Meert, K. L., & Sarnaik, A. P. (2005). What influences parents' decisions to limit or withdraw life support? [see comment]. Pediatric Critical Care Medicine, 6(5), 513-518.


Appendix A

Letter of Information
Letter of Information to Join a Research Study

Dear Potential Research Subject:

You are being asked to join a research study conducted by Pediatric Nurse Practitioner Amy Howells and Dr. Joan Engebretson, from the University of Texas Health Science Center Houston. This study is being done to fulfill requirements for Amy Howells to receive a doctoral degree in nursing from UTHouston. The purpose of this study is to explore how the experience of members of the health care team and parents influences decision-making for children in the Pediatric Intensive Care Unit (PICU) of Texas Children’s Hospital. You have been asked to join this study because you are either a parent or health care provider who will be involved in making decisions for a patient in the PICU.

If you agree to be in this study, you will be asked to complete a questionnaire and have an interview with the researcher. The questionnaire will be completed at the time of the interview with the researcher. The interview will focus on your experiences surrounding discussions and other forms of communication that occur in the PICU. The interview should last about one hour and will be audiotaped by the researcher. The interview will take place in the PICU of Texas Children’s Hospital.
Children’s Hospital. In some cases the researcher may contact you for a brief follow up interview. The audiotapes will be destroyed once they have been transcribed. All information obtained for the study will be kept confidential.

Your decision to take part is voluntary and you may refuse to take part, or choose to stop taking part, at any time. You may refuse to answer any questions asked or written on any forms. A decision not to take part or to stop being a part of the research project will not change the services available to you, from your doctor, or the hospital, or affect your employment with the hospital in any way.

It will not cost you anything to let your child join this study. You will not be paid to join this study. There may be no personal benefit to you by joining this study. However, the information from this study may help doctors better understand and treat others in the future. There are no physical risks to you for joining this study. However, completing the questionnaires and taped interviews could have effects such as loss of confidentiality, or emotional stress or discomfort.

If you have any questions about this questionnaire or the study, please contact Amy Howells at 713-817-9101. If you have additional questions about your rights as a research subject, contact the Institutional Review Board for Human Subject Research for Baylor College of Medicine & Affiliated Hospitals at (713) 798-6970 or the Committee for the Protection of Human Subjects of the University of Texas Health Science Center at (713) 500-7943.
By completing the questionnaire, this means you have agreed to be in this research study.

Thank you for your time.

Sincerely,

Amy J Howells, MSN, RN, CPNP
Appendix B

Interview Schedule
For parents:

Descriptive questions

1. Could you tell me why your child was admitted to the PICU and what your experience has been like?

2. Tell me about discussions you have had with providers to make decisions about the care of your child.

   A. When you are talking with a member(s) of the team taking care of your child, how does that normally take place? Do you talk at the bedside? Is there somewhere else to talk? Who comes to talk with you? How long do these conversations last?

   Who initiates the conversation?

   B. Describe the kinds of things that are said during conversations with the team.

   Who does the talking? Is the information easy to understand?

3. When there are decisions to be made about how to take care of your child and the treatments to be given, how does that happen? Who is involved?

4. Can you discuss your experience with death and dying?

   A. Could you tell me about religious and cultural views about death?

5. What was important to you in your decision-making?

   A. What do you think was important to your doctors and nurses?

6. If the prognosis was uncertain, how did this affect your decision making?

Structural questions

1. Are there different kinds of conversations? (if so) How do you know what kind
of conversation will take place?

2. Are there different kinds of decisions to be made? What are these?

Contrast questions

1. Do you see a difference in decisions you are asked to make and decisions that are made by the health care team?

For Providers:

Descriptive questions:

1. Tell me about your approach to end-of-life decision making for critically ill children.

2. Describe for me how you go about engaging parents in conversation regarding their child. This could be for a current case or one you were previously involved with.
   
   A. Do you talk at the bedside? Elsewhere? Are there other members of the team with you? How do you decide?

2. Could you describe for me the contents of a typical conversation?
   
   A. What kinds of things are said? How do you phrase information so that parents will understand?

3. When you have to discuss bad news with parents, could you describe what happens? (tell me about a time when you felt that went well, and a time that it did not.)

4. How do you arrive at decisions for the plan of care for this child?
   
   A. Is the team involved? Are there certain things that you feel you must decide?

   Are the parents involved?

5. What is important to you in your decision-making?
A. What do you think is important to parents?

6. How do you feel you have been prepared to have these conversations with families?

A. Do you think personal philosophy plays a role in your decisions?

7. How does an uncertain prognosis affect your approach to decision making?

8. Tell me about a time when the conversation went well and a time when it did not go well.

Structural questions:

1. Are there different types of conversations for different situations?

2. Are there different types of decisions? What are these?

Contrast questions:

1. What is the difference in decisions that you make versus decisions that parents make?

2. What is different about how you talk with parents regarding day to day decisions versus overall plan of care decisions?

3. How is it different when you are discussing bad news?
Appendix C

Demographic Form
Communication and Decision-Making at the End-of-life in the PICU: A Qualitative Study

HSC-SN-08-0584

Participant Description Form

1. Age: ____
2. Marital status: ________________
3. Gender: __________
4. Number of children: ________________
5. Ethnicity: ________________
6. Religious/Spiritual affiliation: ________________
7. Highest grade in school: ________
8. Highest degree (if any): __________
9. Household income per year: __________

Additional items for providers:
1. Professional degree:
2. Years in profession:
3. Years of experience in PICU:
Understanding the “Big Picture”: End-of-Life Decisions in the PICU

End-of-life decision making for children in the pediatric intensive care unit (PICU) is not well understood (Truog, Meyer, & Burns, 2006). Parents of a critically ill child have to make difficult decisions especially as the child nears the end of life. Those decisions are not made alone, however, and it becomes increasingly evident that critical care providers should play a significant role in these decisions. The intensive care unit is a place where technologically advanced and very aggressive treatment is the norm. Cure is the initial treatment focus of both providers and parents. If cure becomes less likely, a more palliative approach may be beneficial for the child. A change in focus from curative to palliative care is oftentimes difficult to accomplish. Among the many reasons for this difficulty are practitioner bias and the uncertainty of prognosis (Zawistowski & DeVita, 2004). Recommendations by the physician and effective communication have been shown in previous studies to affect how parents collaborate in the decision making process, so a better understanding is crucial to improve the delivery of the most appropriate care to children in the PICU (Meyer, Ritholz, Burns, & Truog, 2006a; Sharman, Meert, & Sarnaik, 2005a).

Background and Significance

The body of literature addressing the topic of decision-making for children in the PICU is far from comprehensive. More research is needed on this topic in order to fully understand the issue and to design interventions that will improve the decision making process for critically ill children at the end of life. Much of the research that has been published in pediatrics comes from the oncology and neonatology disciplines. While
research published from these disciplines may contribute to the overall understanding of decision-making for critically ill children, there are differences in the patient populations that make it necessary for focused research to be continued in the pediatric intensive care unit. For example, oncology patients often die under the care of a palliative care service and after parents have had time to understand and accept their child's diagnosis and prognosis (Heinze & Nolan, 2012). Neonatal patients are more likely to die with relatively stable physiology, with life sustaining treatments being withheld or discontinued for quality of life reasons versus PICU patients who are usually unstable and often on mechanical ventilation at the time of death (Fontana, Farrell, Gauvin, Lacroix, & Janvier, 2013).

The small body of literature that is available concerning decision making at the end-of-life for critically ill children focuses, generally, on parents. Investigators have identified several parental priorities when considering limitation of life sustaining treatment such as valuing quality of life, perceived likelihood of improvement, and their perception of the child’s pain (Meyer, Burns, Griffith, & Truog, 2002). Parents struggle with feelings of guilt and selfishness during the decision-making process, making the recommendations of medical personnel and a joint formulation of the plan important facilitators in this process (Sharman, Meert, & Sarnaik, 2005b). When asked how the decision-making process could be improved, parents recommended complete and honest information, ready access to staff, communication, care coordination, preservation of the parent-child relationship, and faith (Meyer, Ritholz, Burns, & Truog, 2006b). A review of the literature that explored decision making for critically ill children,
found that communication is a strongly recurring theme in the majority of articles (Longden, 2011).

Research studies that have focused on providers also found that communication is a key element in the decision-making process. A documented case study outlined how communication between the health care team and parents is often less than optimal when making end-of-life decisions, particularly in the busy intensive care environment (Cole, 2003). A review of the literature on decision making for critically ill children has found that providers’ main determinates of deciding to withdraw or withhold treatment at the end-of-life are: age, premorbid cognitive function, functional status, pain or discomfort, probability of survival, and quality of life, but did not comment on the role of communication with parents for these decisions (Masri, Farrell, Lacroix, Rocker, & Shemie, 2000). A retrospective review conducted in a Spanish PICU found that parental involvement with decisions to forgo life sustaining treatment was high, indicating that providers are, in fact, discussing these decisions with parents, however there is no indication of the quality of that communication (Launes, Cambra, Jordán, & Palomeque, 2011).

The pediatric intensive care unit is a good example of an environment that has been created by the medical system with a culture and language all its own. Parents may have a difficult time navigating this “foreign” culture and understanding the system, especially when they are involved in an important and stressful decision-making process. The Cultural Negotiation Model was originally conceptualized to relate nursing practice to the influence of culture and can be used to help parents and providers relate
to each other and speak the same language when communicating (Engebretson & Littleton, 2001). This theoretical framework suggests that experience, knowledge (both formal and informal), and cultural heritage of both parents and providers influence how they may interact during the decision making process.

The goal of this research project was to describe the providers’ cognitive constructions or their interpretation of the process of decision-making that influences both the technique of conversations and the recommendations given to parents regarding limitation or withdrawal of life sustaining treatments from terminally ill children in the PICU. Interview data obtained from providers with varying levels of experience provides valuable insight into their decision making process. A conceptual framework based on these data that helps to better understand this difficult decision-making process was identified. From this framework, interventions to improve the process can be designed and studied.

Methods

*Study Design, Setting, Participants, and Data Collection.*

This study is a qualitative medical ethnography (Roberts, 2009). Applied medical ethnography is used to elicit information in the context of a health related sub-culture (Pope, 2005). Medically applied ethnography can focus on the beliefs, values and behaviors in a clinical setting, and the interchange between patients and providers in the setting of the biomedical culture (Engebretson, 2011). The sub-culture for this study was the pediatric intensive care unit, which provides the penultimate experience of medical providers and parents coming together with different values, backgrounds,
experiences, and, often, a different language. Communication, expressed through language, reflects culture, values, and perspectives of the provider/parent encounter in a unique cultural environment (Wood, 2013).

Setting: The study was conducted in a freestanding pediatric hospital located in a major medical center. The hospital's medical staff is faculty appointed through an affiliated college of medicine. The PICU is a 31-bed, high acuity unit, which serves a busy metropolitan area. Before beginning any data collection, the institutional review boards (IRB) of both the college of medicine associated with the hospital and the university overseeing this doctoral project approved the study. All data was de-identified and participants were given a letter of information (see appendix 1: Letter of Information) regarding the study protocol. The IRB approving the protocol did not require a written consent form, as that would have been the only documentation of the participant names and, therefore, a risk to confidentiality. The participants agreed to waive written consent by participating in the interview process.

Participants: Clinical providers who had participated in end-of-life discussions at any point during their service in the PICU were recruited to participate in semi-structured interviews with the researcher regarding their constructions of the communication with parents in the end-of-life decision-making process. Critical care providers were purposively recruited to represent a variety of levels of practice (attending physicians, fellows, nurse practitioners, and physician assistants) who were involved in the decision making process for critically ill children admitted to the pediatric intensive care unit. Purposive sampling as described by Coyne (1997) was used to obtain
a good representation of different levels of providers in an effort to exemplify the
different levels of experience of providers who may be called upon to make these
decisions. All participants of the study filled out a demographic tool (see appendix 3:
Participant Description Form) to collect data regarding age, gender, ethnicity/race,
religion, marital status, level of practice, and socioeconomic status.

Data Collection: Data consisted of long individual interviews and field notes
(Morse & Richards, 2002). The semi-structured interview guide (see appendix 2:
Interview Schedule) was developed after an extensive review of the literature and is
based on the clinical experience of the primary investigator as recommended by
Spradley (1979). An expert panel that included a bioethicist and a researcher
experienced in qualitative research then reviewed the interview guide. Questions
included: describing the approach to end-of-life decision-making, how parents were
engaged in conversation, the content of typical conversations, and reflection on how
personal values influenced decision-making. The interviews were semi-structured, which
allowed for revision during the data collection process based on an ongoing data
analysis approach (Miles & Huberman, 1994). Interpretation of the participant’s
comments by the researcher was clarified during the interview process. Data were
collected until no new information was voiced and the concepts were discussed in
depth, indicating that saturation was achieved. Data saturation provides confidence that
conclusions drawn by the researcher will be reliable (Morse & Richards, 2002).

Providers who had participated in end-of-life discussions for a child admitted to
the PICU or were involved in the decision-making process that led to such discussions
were invited to participate. A total of 11 providers who care for patients in the PICU were interviewed over the span of 2 months, from September 2013 to October 2013. The participants consisted of 5 attending providers, 1 physician assistant, 1 nurse practitioner, and 4 critical care fellows (see appendix 4: Participant Demographics). The majority of participants were male and married with a mean age of 38 years. Experience in the PICU ranged from a new provider who has been in the unit for a year and a half, to a veteran of thirty-five years.

Data Analysis.

The interviews were audio recorded and transcribed verbatim and checked for accuracy by the PI, and then entered into Dedoose, a web-based data manager software program. The principal investigator coded all data. From the initial coding, the interview schedule was revised and further coding was completed to elicit patterns and concepts (Miles & Huberman, 1994). Subsequent interview data were analyzed using the previously identified codes and screened for any new codes. Once little new information was elicited in the interviews and the coding and categories were well described in the ongoing analysis, data collection was completed (Lincoln & Guba, 1985). An experienced qualitative researcher supervised this process. After data collection was complete, the concepts and categories were used to identify themes. These themes were organized into a framework by the principal investigator, and then a peer review session was used to validate the findings (Maxwell, 1992). The peer review sessions with other researchers familiar with qualitative analysis served as a critique method to assure that the data confirmed/supported the framework proposed by the investigator.
Findings

Findings from the data included concepts and themes that were then organized into a conceptual framework to help understand the decision making process by providers for critically ill children at the end of life. The framework is based on the acknowledgement that illness is a continuum that has the potential to either improve or deteriorate and that therapies that are most appropriate at any given time depend on where the child is on that continuum. Furthermore the ability to make decisions is influenced by the perspectives and expectations of the individuals involved and how these impact the way conversations are conducted and how goals are set for the child.

Major Themes.

Four major themes were identified during the data analysis: Expectations and Perspectives, Communication Enhancers and Inhibitors, Decision Enablers and Barriers, and Conversation Mechanics. Appendix E lists the themes with the concepts that make up each theme and provides exemplars for each. The identified themes and concepts provide insight into the decision-making process and how providers carry out the difficult task of communicating with parents to achieve reachable goals during their child’s hospitalization.
I. Expectations and Perspectives
   A. Understanding the big picture
   B. Goals
   C. Role
   D. Values

II. Communication Enhancers and Inhibitors
   A. Communication Enhancers
      1. Clarity
      2. Honest/Consistent Message
      3. Open Discussion
      4. Parent Receptiveness
   B. Communication Inhibitors
      1. Delay in Communication
      2. Disregard of Parental Verbal/Non-Verbal Cues
      3. Lack of Consistency
      4. Loss of Trust
      5. Parental Denial

III. Decision Enablers and Barriers
   A. Parental Decision Enablers
      1. Clear Recommendations
      2. Prognosis is Clearly Explained
      3. Rapport with Providers
      4. Parent and Providers have Similar Goals
      5. Emotional Readiness
   B. Parental Decision Barriers
      1. Unrealistic Expectations
      2. Uncertain Prognosis
      3. Unclear Recommendations
C. Provider Decision Enablers
   1. Experience
   2. Support/Respect of Team
   3. Clear Prognosis

D. Provider Decision Barriers
   1. Uncertain Prognosis
   2. Conflicting Parent Wishes
   3. Concern of not Offering Potentially Beneficial Treatment

IV. Conversation Mechanics
   A. Strategy
   B. Technique
   C. Style
   D. Learning

*Figure 1. Themes and Concepts*

I. *Expectations and Perspectives*. This theme illustrates the issue that often providers and parents have a different viewpoint of the same situation that is influenced by their own life experiences and role. This is reflected in how they perceive the situation, or understand the “big picture”, the goals, their respective roles and values.

A. **Understanding the Big Picture**. The concept of “understanding the big picture” refers to the ability of providers to discern whether interventions are going to contribute to the overall improvement of the child. For example, medical providers iterated that it is not medically reasonable to list a patient for heart transplant if they are neurologically devastated from an inoperable brain tumor that is terminal. During the interviews, the phrase “understanding the big picture” was used by 9 out of the 11 providers, indicating the perceived
importance of this concept. Providers described cases where interventions were being performed because they are technologically possible even though the interventions were not likely to benefit the child. “I think that we do things because we can, not because we should.” The reasoning given for performing these interventions was often that parents don’t understand the inevitability of the child’s condition and therefore would request interventions that they have heard about from other parents or sources like the Internet. It was often noted that providers from another specialty service would recommend interventions to parents and it became the critical care providers’ responsibility to explain how some interventions may have a short-term benefit for a certain organ system, but that it would not change the overall prognosis for the child. “The oncology/bone marrow transplant patients or generally that group of physicians is sort of, you know, all in...willing to go to, you know, to the end of the earth to do everything whether we should be doing everything or not and whether it is within medical reason or not.”

B. Goals. This concept represents another example where providers noted that parents might have different expectations and perspectives that needed to be reconciled before decisions could be made. Participants talked about cases where a parent initially asked for “everything to be done”, including intensive interventions and CPR. “The context of everything we do in the PICU typically is pretty invasive and pretty painful, so the way we decide if a procedure’s worth it or not is if we think that in the end the pain is going to be worth it.” After
discussing goals for the child, oftentimes the parent would verbalize that comfort and the absence of pain were most important to them. "If they say, 'No matter what, I want her to be comfortable' then you use that." Several providers noted that it was during discussions of parents' goals for a sick child that the provider has the opportunity to explain how intensive interventions (dialysis, for example) would negatively impact comfort and absence of pain. "These are the things, when parents say, 'Do everything', these are the kinds of things that we would do, stick big needles in, and give lots of blood pressure medications, and even do painful chest compressions when the heart stops. I am telling you those things will not help your baby and I would suggest that we not do them". The parents' preconceived expectation that interventions carried out in the hospital are always going to benefit the child, sometimes resulted in seemingly incongruous requests during initial discussions, but were often resolved after setting goals of care.

C. Role. Participants most often described the parent role using the ethical term "autonomy". Providers commented that parents and even some providers have the perception that autonomy means that all decisions are made by the parent. "I think the single biggest problem is a misunderstanding of autonomy... in that doctors are supposed to offer all of these options and let the family pick." Two different provider roles were elucidated during the interviews. In one role the provider responsibility is simply to explain all pertinent facts of the case and let the parent make decisions. "What I have presented is a range of reasonable
options.” The second described role emphasizes the providers’ responsibility to make recommendations based on their professional knowledge and experience. The majority of critical care providers interviewed felt that the second described role was preferred. “Be clear in your own mind what you think is medically reasonable to do and what is not. Understand, that would be my big plea, that you are not obligated to offer things you think are not medically reasonable”.

D. **Values.** The participants identified the role that personal values played in this process. Everyone involved in the decision-making process has his or her own set of personal values. Many sources including, culture, religion, and upbringing will heavily influence those values. One participant noted that one cannot predict or categorize a person’s values: “Even if they are same religion, they still have different values, so value, spirituality, social background, and everybody is just different and you know the path that they have taken together, being so different, so every conversation to me is different.” Providers reported that their personal values must influence decision-making, though most attempted to recognize this and minimize the extent to which personal values affected the process. Ascertaining the values of parents is also an important part of a provider’s ability to understand their perspective and expectations. “And so it’s understanding exactly what mom and dad’s values and their goals and their decisions are and ... effectively ... and um ... rightly passing that on to your colleagues.”
II. **Communication Enhancers and Inhibitors.** Providers identified several concepts relating to effective communication with parents. These concepts are categorized into enhancers that promote effective communication and inhibitors that can impede effective communication.

A. **Communication enhancers.** The concepts identified by providers that enhance communication included; clarity, an honest/consistent message, open discussion, and parent receptiveness.

1. **Clarity.** The majority of participants verbalized the importance of communication with clear terms. Actually saying the words “death and dying” instead of using euphemisms such as “passing” were frequently given as an example. “I try to use the word ‘dead’ or ‘dying’, if it's appropriate. A kid in the PICU who is obviously dying, I will use that word because you can beat around the bush but until you say it, sometimes families don’t get it.” Another interview participant commented, “You have to use lay terms 'cause we get caught up in our jargon... that’s what I learned from that family. ‘Why didn’t you just tell me that, like, the medicine is not working, like, if you just said that, we could have ... it would have been so much clearer’.”

2. **Honest/Consistent Message.** A consistent message, preferably by the same provider, where the provider does not try to protect the parent from emotional distress by softening the message, makes communication more effective. "Listen, I'm not here to take away your hope, but I also
have to be honest with you.” One provider remarked that consistency is crucial “so that the family is not hit from different people with different ideas, different plans and different perceptions.”

3. **Open discussion.** Discussions that have equal participation by parents and providers greatly enhances communication. “I ask an open ended question just to kind of see where they are emotionally.” When the provider dominated conversations, parents were described as less likely to be willing to communicate their thoughts.

4. **Parent Receptiveness.** Participants also expressed the importance of assessing parental receptiveness to information. “Talks that went well, or at least what I perceive to be well, is when the parents are generally accepting of what the outcome is.”

**B. Communication inhibitors.** Concepts identified that inhibit effective communication include: a delay in communication, disregard of parental verbal and non-verbal cues, lack of consistency, loss of trust, and parental denial.

1. **Delay in communication.** Some providers found that there had been a delay in communicating bad news to parents. “A lot of times even when you ask them (provider) has ... have these discussions ever been brought up to mom and dad and they’ve said no, we’re deferring to this service or we’re deferring to that doctor because they have a better relationship or they ... yeah ... delay for whatever reason.” In instances where providers found themselves having an initial end-of-life
conversation with parents of a child who had already suffered a prolonged hospitalization, the parents were described as less receptive. This decrease in receptiveness was attributed to a perceived difficulty in accepting bad news after having received communication that was more hopeful in nature. “When a parent hears that one medical team says, ‘Oh! Bad, bad, bad!’ and the other medical team says, ‘Well, I don’t know,’ they are going to go with that ‘I don’t know’.”

2. Disregard of parental verbal and non-verbal cues. Providers reported when having a discussion with parents, it is just as important to listen, as it is to relay information. If the parent feels like their concerns are not being heard, or the provider continues to talk when the parent is clearly confused or upset, communication becomes compromised. “As learners, I feel like one of the biggest mistakes is ... is not reading what the family is saying non-verbally or verbally”

3. Lack of consistency. A lack of consistency in the message that is given also creates a communication barrier. This lack of consistency creates the potential for parents to misunderstand their child’s status and contributes to confusion that can lead to distrust and contentious interactions. “I think being on the same page with all your subspecialists before having these conversations is important and should be done, again, so the family doesn’t receive mixed messages.”
4. **Loss of trust.** Providers have described situations where parents either did not trust the medical team because of prior experiences or a negative experience during their child’s hospitalization. Once this happens, effective communication becomes almost impossible. “That is the family that is usually a little bit more angry, you know, because they have already dealt with some of the medical teams and now you are telling them there is a new problem and that takes a long time to usually get in there and get them to listen to you and trust you again.”

5. **Parental denial.** Denial of their child’s prognosis is a communication barrier that seriously affects the decision-making process, and is not easily managed by the provider. When describing conversations that were particularly challenging one provider said “I've seen a few where parents are extremely frustrated and I think that they haven’t come to grips with the reality of their child’s diagnosis and prognosis, yet”.

III. **Decision Enablers and Barriers.** Interestingly, enablers and barriers to decision-making identified by providers were further broken down into concepts that are different for parents and providers.

A. **Parental decision enablers.** Providers described several components of decision-making that appeared to facilitate the process for parents.

1. **Clear recommendation.** "My plan is to give them, to tell them risks and benefits of all of the alternatives and options and then give my
recommendation that we withdraw care." The rationale for this was when the recommendation is clear, the parent is not left to wonder what the medical team thinks is the most reasonable option.

2. **Prognosis is clearly explained.** When a child is diagnosed with a serious illness; part of the process for providers was identified as to explain how the illness will be treated. It is also extremely important, however, for the parent to understand the prognosis. “I think, I think getting into a routine, getting into a habit, having, you know, key phrases that, that you have either witnessed or tried yourself that kind of helped convey the severity of the illness and the, or prognosis associated with it, I think it helps.”

3. **Rapport with the provider.** Several of the providers talked about families who seemed to identify with a particular member of the health care team. When this rapport is observed, having that person either lead conversations with the family or be present for them was perceived as helpful. “Having a rapport with the family and developing a relationship will enable you to kind of facilitate, um, that conversation.”

4. **Parent and provider have similar goals.** It is sometimes determined over the course of a conversation that the parent has the same goals of care as the provider. Both, for example, may want the primary objective for a patient to be pain free. When these goals are aligned, it enhances decision-making regarding what interventions will be
offered. “Having similar goals helps, because then we are kind of in the same boat.”

5. **Emotional readiness.** Having a critically ill child is an intensely stressful experience for parents. Even after parents have accepted the reality of a poor prognosis, they need time to process and come to terms with their grief. “You kind of have to really go slow and see how much the family is comprehending, where they are from an emotional state.”

B. **Parental Decision Barriers.** Several concepts were identified that created barriers for parental decision-making including: unrealistic expectations, having an uncertain prognosis, and unclear recommendations by providers.

1. **Unrealistic expectations.** Parents having unrealistic expectations of what medicine can accomplish provided a particularly difficult parental decision barrier. “I don’t think many families have any idea what a real chest compression code resuscitation is like, um, because if their kid goes through that, they’re at even lower risk of surviving”. Providers expressed difficulty with overcoming expectations that were not consistent with what medicine can actually accomplish. “Specifically everybody thinks of, sort of, the television, hair on fire, you resuscitate them, and in two minutes they are talking to you again kind of thing.”

2. **Uncertain prognosis.** There are cases described by providers where a diagnosis is not made, but the prognosis remains poor because of the nature of the child’s symptoms. This uncertainty of diagnosis can
be true especially for children with progressive neurological symptoms or symptoms associated with a mitochondrial disorder. When a specific diagnosis cannot be made or a specific syndrome identified, an increased degree of uncertainty is introduced into prognostication. “You know you admit uncertainty, but also you recognize that certain things are nonsustainable, and that the likelihood of a meaningful recovery diminishes the longer the child is in said condition.”

3. **Unclear recommendations.** Unclear recommendations by the provider also created perceived decision barriers for parents. When recommendations were presented simply as a list of interventions that could be done without guidance as to what the provider thought would most benefit the child, the decision process could become overwhelming. “Be clear that just offering a family a menu of options without you interpreting it, it puts that burden on to the families, and that is not being a good doctor, that is not respecting autonomy, that’s a misunderstanding.” Many providers have also referred to this listing of options without interpretation as a “laundry list” or “menu”. “Some people give the parents a laundry list of things that they could do without actually making recommendations one way or the other”.

C. **Provider Decision Enablers.** During the interview process, several decision enablers specific to providers were identified.
1. **Experience.** Experience was cited as a decision enabler, however, providers with less experience did not absolve themselves of the responsibility to make decisions concerning their patients. They were more likely to ask a senior member of the team for advice. “I think experience is probably the best preparation.”

2. **Support/Respect of Team.** Support from team members and respect for decisions made by the primary provider, especially when recommending limitation of support for a child, was verbalized as an important decision enabler. This decision support was especially true of more junior members of the team who benefited from positive reinforcement from more experienced team members. “I would ask advice before sort of what to do what not to do, maybe even inviting that person in.”

3. **Clear Prognosis.** Having a clear understanding of the prognosis was most often cited as helpful when making decisions concerning what interventions a child will benefit from. “I think it’s largely dependent upon the prognosis when making decisions.”

D. **Provider Decision Barriers.** Three concepts were identified that create decision barriers for providers. They include having an uncertain prognosis, conflicting parental wishes, and the concern of not offering potentially beneficial treatment.
1. **Uncertain prognosis.** In the same manner that a clear prognosis enables decision-making, it is important to note that providers did not feel as though an uncertain prognosis absolved them from having to make decisions, it just created a barrier that had to be overcome. “There is always a kid who has had a significant injury and you don’t know what his outcome is going to be, just the purely traumatic brain injury, umm, that was not hypoxic, you know, and you say this injury is very, very bad, but we are not going to know for a while, you know, a lot of brain injuries do get a lot better.”

2. **Conflicting Parent Wishes.** Conflicting parent wishes, either between two parents or parents and the provider, regarding the best course of action was described as a decision barrier for providers. “In the instance where they are expecting their kid is going to grow up and be normal and that is clearly not the case, you know, I’ll kind of challenge them and you know push a little harder.”

3. **Concern of not offering potentially beneficial treatment.** Some providers voiced a concern of potentially not offering a treatment that may have, in fact, benefitted the child. “I think younger providers, um, would be more conservative and put more on the table than more experienced providers because again, it’s uncomfortable withholding a therapy that could be perceived as not life-saving, but life-extending.”
IV. **Conversation mechanics.** Providers described concepts that reflect the mechanics of holding a difficult conversation when asked how they conducted end-of-life discussions. These mechanics consist of strategy, technique, style, and learning.

A. **Strategy.** Strategy usually comprised of a plan to determine goals of care for the patient, to make recommendations, and to engage in directive counseling, if needed. Strategy may also include the determination of who participates in the discussion, planning what the content of the conversation will be beforehand and having multiple, staged conversations to make the process easier for parents.

B. **Technique.** Technique varies somewhat in execution from provider to provider, but also has components that are consistent. These include: having timely conversations, setting up the physical environment, assessing the parents’ knowledge at the beginning of the conversation, and using lay terminology. All providers, when asked how they set up these conversations had a process that could be described in detail. “In general, I try to get the conference room without the table, so I prefer not the ... the lecture conference room in the ICU. I prefer one of those rooms that has couches and little end tables, and it's a lot more intimate. Um ... Just for space and so, being close, you can do some, you know, reassuring. Hand them the Kleenex without having to get up. “

C. **Style.** Style was not as easily conceptualized, but providers recognized that each person has a distinct style. Most providers talked about “people who just seemed to be good at these conversations” or “providers who have never
quite grasped the ability” to have end-of-life conversations. Most have a sense of the enormity of these conversations and exhibit a great amount of compassion. “Being kind, being gentle, establishing rapport with the family, sitting next to them and not across from them with your arms crossed, but next to them with your hand on their shoulder and just remembering that it’s sad what you’re doing”. Style appears to be an innate quality of the individual, and as such, is not something that can easily be taught.

D. Learning. Acquiring the skill of conducting difficult conversations is not a uniform process and is an important component of conversation mechanics. Some providers described a didactic component to their educational program, while some learned this skill with video training or simulated patients. Most providers described learning how to conduct difficult conversations through observation, trial and error, self-reflection, and experience. “I’ve learned just from experience, and I’ve learned, whether it’s personal experience, and I’ve also learned from hearing other people talk about their experiences, and I’ve learned from families”. Many providers expressed the worry that they were under prepared to have these important and sensitive conversations. “I’ve never had a class. I really wish, I really wish that we did better in medicine about, like, training people for this kind of stuff.”
Discussion

The themes identified in the study results suggest a conceptual framework for understanding the decision-making process at the end-of-life for critically ill children. The condition of the child dictates whether the goals of care will be focused on cure or comfort. Curative care and comfort care do not have to be mutually exclusive, but rather exist on a spectrum.

Figure 2. Conceptual model “Decision-Making at the End-of-Life in the PICU”
At the beginning of a hospitalization the focus is almost always on curative care, unless the child is so gravely ill or injured that the outcome is inevitable. When cure is the focus, intensive therapies and interventions will likely be performed, often with significant effects to the child, including pain and distress. Causing pain and distress in a child with medical interventions, while not ideal, is considered to be an acceptable consequence if the outcome is survival of the critical illness. Comfort care is still a recommended part of the overall goals of care, but will play a more minor role if intensive therapy may be life saving. If the child’s condition worsens and death becomes imminent, comfort care becomes the priority as providers seek to minimize the pain and discomfort that intensive therapies may cause. The uncertainty that is inherent in prognostication makes the balance between curative care and comfort care one of the most difficult aspects of setting goals for critically ill children.

Establishing reasonable goals for critically ill children was identified as an important element in the process. If goals are not set, important decisions concerning what treatments and therapies will benefit the child may not be made. When this occurs, children are at risk for having to endure painful procedures, or receiving medications with distressing side effects that do not contribute to the goals of care and may not provide enough benefit to justify their use. Effective communication between parents and providers is crucial in establishing medically reasonable goals, and establishing these goals leads to making decisions regarding the type interventions that are in the best interest of the child.
Prior research reveals that effective communication is an important aspect of decision-making for critically ill children, and the results of this study indicate that there are both significant enhancers and inhibitors to communication. It is important for providers to understand that parents are generally not familiar with the culture of the PICU and the language that represents it. Providers can increase their effectiveness by giving a very clear message, using terminology that parents can understand, and by giving honest opinions even when the message may be devastating. Likewise, communication will be inhibited by a delay in communication or an inconsistent message. Even with an uncertain prognosis, it is helpful if communication happens early and often, ideally with a consistent provider of information. Assessing parental readiness to receive information and being able to read verbal and non-verbal cues is also a skill that enhances communication. If parents perceive that they are not being heard during a discussion and the communication becomes one-sided, the provider risks losing the trust of the parents.

Managing expectations and understanding perspectives may be the most important aspect of facilitating effective communication and making end-of-life decisions. Providers' expectations and perspectives are influenced by their professional role, professional experiences, education, and personal values. They understand the language and environment of the pediatric intensive care unit, and understand the implications of interventions and therapies in a way that parents cannot. Professional virtues such as compassion, discernment, trustworthiness, integrity, and conscientiousness are expected to influence providers in all aspects of decision-making,
which brings a slightly different perspective to the process than parents will have (Beauchamp & Childress, 2009). Parents have different perspectives and expectations, which are influenced by the role of the parent, life experiences, and personal values. The expectations that parents have of the practice of medicine may not be consistent with the reality of the PICU, and that is where communication often breaks down.

The term “heroic” was mentioned during several interviews. This term is a good example of different perspectives and expectations between providers and parents. For parents, this term represents courageous effort that goes above and beyond and will likely result in a good outcome for their child. The media has taught us that heroism results in seemingly impossible outcomes, such as the elaborate rescue scenes or miraculous medical treatments that are acted out on a regular basis in television programs and movies. From the providers’ perspective, however, the term “heroic measures” means something completely different. It is a term that has been widely used in the medical community to describe interventions that are highly invasive, not likely to be successful, and therefore, of limited benefit to the patient. This disconnect in perspectives can result in ineffective communication, especially if the provider is not aware of parent perspectives and expectations of the medical team.

The proposed conceptual framework takes into account the importance of understanding expectations and perspectives and how they influence the decision-making process and further describes the relationship between communication, goals, and decisions. The framework also highlights factors that enhance and inhibit communication and describes decision enablers and barriers. Ideally, this conceptual
framework will help providers understand the decision-making process and will help identify areas where the process can be improved upon.

This study’s limitations include the possibility of the participants’ responses being influenced by the presence of the investigator and bias during the interpretation of the findings. Qualitative research results cannot be generalized to the population as a whole, but rather, richly describes the experience of the unit that was studied and may be applicable to similar units. Although qualitative findings are not generalizable, interventions suggested by the findings and implemented can be tested for efficacy to affirm the study results (Morse & Richards, 2002).

This study has implications for future research including interviewing parents to support the findings of the current study and to enrich the conceptual model describing decision-making at the end-of-life in the PICU. Interventions designed to facilitate communication and goal setting, leading to improved decision making will have important practice implications. Additionally, studies exploring the theme of conversation mechanics will have practice implications as educational interventions are designed to improve upon conversation skills for providers.

Conclusion

More research is needed to fully understand the process of making decisions for critically ill children at the end-of-life in the PICU. After conducting in-depth interviews with critical care providers who care for these children, a conceptual framework is proposed to provide a better understanding of this process and, hopefully, to suggest
interventions to make advancements. Continued study of this topic will serve to improve care for critically ill children at the end of life.
References


doi:10.1097/PCC.0b013e3182f13a9c


doi:10.1097/01.CCM.0000237043.70264.87


Appendix A

Letter of Information
LETTER OF INFORMATION TO JOIN A RESEARCH STUDY

Dear Potential Research Subject:

You are being asked to join a research study conducted by Pediatric Nurse Practitioner Amy Howells and Dr. Joan Engebretson, from the University of Texas Health Science Center Houston. This study is being done to fulfill requirements for Amy Howells to receive a doctoral degree in nursing from UTHouston. The purpose of this study is to explore how the experience of members of the health care team and parents influences decision-making for children in the Pediatric Intensive Care Unit (PICU) of Texas Children's Hospital. You have been asked to join this study because you are either a parent or health care provider who will be involved in making decisions for a patient in the PICU.

If you agree to be in this study, you will be asked to complete a questionnaire and have an interview with the researcher. The questionnaire will be completed at the time of the interview with the researcher. The interview will focus on your experiences surrounding discussions and other forms of communication that occur in the PICU. The interview should last about one hour and will be audiotaped by the researcher. The interview will take place in the PICU of Texas Children's Hospital. In some cases the researcher may contact you for a brief follow up interview. The audiotapes will be destroyed once they have been transcribed. All information obtained for the study will be kept confidential.

Your decision to take part is voluntary and you may refuse to take part, or choose to stop taking part, at any time. You may refuse to answer any questions asked or written on any forms. A decision not to take part or to stop being a part of the research project will not change the services available to you, from your doctor, or the hospital, or affect your employment with the hospital in any way. It will not cost you anything to let your child join this study. You will not be paid to join this study. There may be no personal benefit to you by joining this study. However, the information from this study may help doctors better understand and treat others in the future. There are no physical risks to you for joining this study. However, completing the questionnaires and taped interviews could have effects such as loss of confidentiality, or emotional stress or discomfort.

If you have any questions about this questionnaire or the study, please contact Amy Howells at 713-817-9101. If you have additional questions about your rights as a research subject, contact the Institutional Review Board for Human Subject Research for Baylor College of Medicine & Affiliated Hospitals at (713) 798-6970 or the Committee for the Protection of Human Subjects of the University of Texas Health Science Center at (713) 500-7943.

By completing the questionnaire, this means you have agreed to be in this research study.

Thank you for your time.

Sincerely,

Amy J Howells, MSN, RN, CPNP
Appendix B

Interview Schedule
Descriptive questions:
1. Tell me about your approach to end-of-life decision making for critically ill children.
2. Describe for me how you go about engaging parents in conversation regarding their child. This could be for a current case or one you were previously involved with.
   A. Do you talk at the bedside? Elsewhere? Are there other members of the team with you? How do you decide?
2. Could you describe for me the contents of a typical conversation?
   A. What kinds of things are said? How do you phrase information so that parents will understand?
3. When you have to discuss bad news with parents, could you describe what happens? (tell me about a time when you felt that went well, and a time that it did not.)
4. How do you arrive at decisions for the plan of care for this child?
   A. Is the team involved? Are there certain things that you feel you must decide?
   A. Are the parents involved?
5. What is important to you in your decision-making?
   A. What do you think is important to parents?
6. How do you feel you have been prepared to have these conversations with families?
   A. Do you think personal philosophy plays a role in your decisions?
7. How does an uncertain prognosis affect your approach to decision making?
Structural questions:
1. Are there different types of conversations for different situations?
2. Are there different types of decisions? What are these?
Contrast questions:
1. What is the difference in decisions that you make versus decisions that parents make?
2. What is different about how you talk with parents regarding day to day decisions versus overall plan of care decisions?
3. How is it different when you are discussing bad news?
Appendix C

Demographic Form
Communication and Decision-Making at the End-of-life in the PICU: A Qualitative Study

HSC-SN-08-0584

Participant Description Form

10. Age: ___
11. Marital status: _____________
12. Gender: _____________
13. Number of children: _____________
14. Ethnicity: _____________
15. Religious/Spiritual affiliation: _____________
16. Highest grade in school: _________
17. Highest degree (if any): _____________
18. Household income per year: _____________

Additional items for providers:

4. Professional degree:
5. Years in profession:
6. Years of experience in PICU:
Appendix D

Participant Demographics
## Participant Demographics (N=11)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>38</td>
</tr>
<tr>
<td>Median</td>
<td>36</td>
</tr>
<tr>
<td>Mode</td>
<td>30</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>8 (73)</td>
</tr>
<tr>
<td>Single</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6 (55)</td>
</tr>
<tr>
<td>Female</td>
<td>3 (27)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>1</td>
</tr>
<tr>
<td>Median</td>
<td>1</td>
</tr>
<tr>
<td>Mode</td>
<td>0</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>6 (55)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (18)</td>
</tr>
<tr>
<td>Indian</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Religious/Spiritual Affiliation</strong></td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>4 (37)</td>
</tr>
<tr>
<td>Christian</td>
<td>2 (18)</td>
</tr>
<tr>
<td>Jewish</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Hindu</td>
<td>1 (9)</td>
</tr>
<tr>
<td>None</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>&gt;100K</td>
<td>5 (46)</td>
</tr>
<tr>
<td>&gt;200K</td>
<td>3 (27)</td>
</tr>
<tr>
<td>&gt;300K</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Professional Degree</strong></td>
<td></td>
</tr>
<tr>
<td>MD</td>
<td>6 (55)</td>
</tr>
<tr>
<td>DO</td>
<td>1 (9)</td>
</tr>
<tr>
<td>PA</td>
<td>1 (9)</td>
</tr>
<tr>
<td>NP</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Years in Profession</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>11.2</td>
</tr>
<tr>
<td>Median</td>
<td>6</td>
</tr>
<tr>
<td>Mode</td>
<td>10</td>
</tr>
<tr>
<td><strong>Years of Experience in PICU</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.7</td>
</tr>
<tr>
<td>Median</td>
<td>4</td>
</tr>
<tr>
<td>Mode</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix E

Themes and Concepts with Exemplars
### Themes and Concepts with exemplars

| Expectations and Perspectives | “I think it is just different perspectives because we can always say we tried to put ourselves in that position, we can always say what if that was my child, but it is very different unless it IS your child, so I think regardless, no matter how you try, you never know unless you have been in that position, so I think the perspectives are always different.”

**Understand Big Picture**

“We try to be the big picture service but you might have the cardiologists who focus on their little box and they say "Well I can fix the VSD" and you've got the pulmonary doctors who say, "Oh, well I can give them a little oxygen and help their chronic lung disease. etc." The family hears these different people saying, "Oh, I can fix this little part" or "I can fix that little part and then we come in as sort of hopefully the big picture docs and say, "Yes, we can close the VSD and we can give oxygen, but that's not going to change the natural history of trisomy-18 or 13" or whatever it may be.”

“Generally that group of physicians is sort of, you know, all in, willing to go to, you know, to the end of the earth to do everything whether we should be doing everything or not and whether it is within medical reason or not.”

“but it's usually Critical Care who steps back and wants to formulate a big picture for this kid”

“"I think that we do things because we can, not because we should”

**Roles**

“I think that we need to own the medical reasonableness bit, and be clear in our own minds what we think is medically reasonable”

**Goals**

“There needs to be the expectation that there’s going to be goals set”

“I either say, "We’re going to focus on treating pain" or "We’re going to move toward your goal of a peaceful death"”

**Values**

“I provide my assessment and observations"
<table>
<thead>
<tr>
<th>Communication Enhancers/Inhibitors</th>
<th>Enhancers</th>
<th>Inhibitors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enhancers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clarity</strong></td>
<td>“You state clearly where we’re at and clearly your expectations of the clinical trajectory and what you expect to happen in the future hours, days, and so that they, um, at least are prepared in advance for a bad outcome”</td>
<td>“Delay in communication”</td>
</tr>
<tr>
<td><strong>Honest/Consistent message</strong></td>
<td>“Hopefully you’ve developed a relationship with the family at this point where you can express honestly that we have tried various inventions to no avail”</td>
<td>“Everyone has a belief system that they are pretty well grounded in and they are going to make decisions based on their belief system”</td>
</tr>
</tbody>
</table>

| **Open discussion**               | “You have to learn to say I don’t know”                                  |
|                                  | “Um, I now don’t shy away from just being upfront with families, and I tell them that.” |

| **Parental receptiveness**        | “Talks that went well, or at least what I perceive to be well, is when the parents are generally accepting of what the outcome is” |
|                                  | “The number one advice would be to kind of try to listen with your eyes and ears about what the family ... where they're at and what they want, because that will heavily influence what you say” |

| **Inhibitors**                    | “I feel like some end-of-life discussions don’t come until right at the end” |
| Lack of consistency | “Sometimes you are forced into a conversation where you have to contradict that or what was said to them previously” “When you tell them that problem is actually worse than what they thought, when there are discrepancies with the message, they are going to go with the message they like best” “So that the family is not hit from different people with different ideas, different plans and different perceptions” |
| Loss of trust | “They've been told their child was going to die multiple times. It's this very in-the-future ether that people have been telling them about it for years, and it hasn't come true so why would it come true now? “You cannot really get back on their team because they don’t trust you, you know, you haven’t told them anything they like” |
| Disregard of parental verbal/non-verbal cues | “As learners, I feel like one of the biggest mistakes is ... is not reading what the family is saying non verbally or verbally” |
| Parental denial | “Conversations tend to not go so well when the options are limited and I would say that the best example I can give is the option really is not trach, G-tube, or withdrawal of support, that it's withdrawal of support now or later on” “I think I’ve seen a few where parents are frustrated and I think that they haven’t come to grips with the reality of their child's diagnosis and prognosis” “A lot of religious folks seem to think that that if they just wait long enough, a miracle is going to happen.” |
| Decision enablers/barriers | For parents-enablers Clear recommendations |
| | “It’s being very specific about where you think the child’s trajectory is going to be, and being able to say the “dead” word, and being able to say “I’m pretty sure”, and being able to say, “I recommend”” “When people say, doctor if this were your kid, what would you do? That is not really what they are asking. They are asking you to give a recommendation, which a lot of
Prognosis is clearly explained

people think that we not supposed to do, and I think that’s ridiculous!”

“We have to give them our expectations and, you know, giving them the likely outcomes”

“In a child that is profoundly neurologically devastated, I’ll tell them, you know, what makes us unique, what made, you know, their child their child was the brain, and that is no longer there”

Rapport with provider

“Having a rapport with the family and developing a relationship will enable you to kind of facilitate, um, that conversation”

“If I’ve been involved in patient care for an extended period of time, you know, I like to have established as good a rapport with the family as I can. So that there is a, a development of trust”

“If there was somebody else who I knew had rapport, certainly that would be someone that I would invite to the conversation as well or even just let have the conversation”

Parent & provider have similar goals

“I tell them something that is also the truth, that I have never seen a family regret stopping at a point in time, but I have seen many families regret not stopping and that gives them again a feeling, oh! We are doing the right thing”

“That I always try to get the parents on the same page”

“When the parents have sort of been in the acceptance phase, because then we are kind of in the same boat”

Emotional readiness

“Have they emotionally comprehended every ... anything you’ve said, and if they truly seem to understand that their child is dying, then I will take that opportunity to give my recommendations of where we go from here”

“That’s where you kind of have to really go slow and see how much the family is comprehending, where they are from an emotional state”

For parents-barriers

Unrealistic expectations

“Specifically everybody thinks of, sort of, the television, hair on fire, you resuscitate them, and in two minutes they are talking to you”
Uncertain prognosis

"For a child with a neurologic injury if the expectation is to take him home and enrolling him in college, that does not strike me as a realistic expectation"

"In the instance where they are expecting their kid is going to grow up and be normal and that is clearly not the case, you know, I'll kind of challenge that and you know, push a little harder"

"You know you admit uncertainty, but also you recognize that certain things are nonsustainable, and that the likelihood of a meaningful recovery diminishes the longer the child is in said condition"

Unclear recommendations

"Offering a family a menu of options without you interpreting it, it puts that burden on to the families, and that is not being a good doctor"

"I've heard the term, laundry list, like give the parents a laundry list of things that they could do without actually making recommendations one way or the other"

"You walk in, the mom is crying over the baby and you say what's wrong, well, I thought the trach was going to fix him, and it didn't fix him, and there's all sorts of other problems now"

For providers-enablers

Experience

"I think younger providers, um, would be more conservative and put more on the table than more experienced providers"

Support/respect of team

"Oftentimes you can bring in other providers from other services to kind of, kind of help, uh, augment your, um, I guess not your argument but your, your plan for their child"

"Obviously if things are unknown, you bring in people who are smarter than you to try to shed some light on it"

"Sometimes I will ask people if they think I have done everything within reason"

"Important is respect for the other members of the team that are involved in the care of the child"

Clear prognosis

"Be clear in your own mind what is going to happen to that kid, if we do everything or if
For providers-barriers
Uncertain prognosis

"Been a kid who has had a significant injury and you don’t know what his outcome is going to be. It is likely going to lead to significant injuries and his affect developmental potential, his cognitive, school, you know, or being able to do whatever..., but we are not going to know for a while, you know, a lot of brain injuries do get a lot better”

"The decision is much more difficult and with regards to what to offer and what not to offer and what is in the child’s best interests. Because that’s not always clear”

"... Well we don’t know what that neuromuscular weakness is...So, no diagnosis, no prognosis...no decision.”

Conflicting parent wishes

"in the instance where they are expecting their kid is going to grow up and be normal, and that is clearly not the case, you know, I’ll kind of challenge then run that and you know push a little harder”

Concern of not offering potentially beneficial treatment

"It’s uncomfortable withholding a therapy that could be perceived as not life-saving, but life-extending”

Conversation Mechanics
Strategy

"Another thing that I do in planning these is I go into the meeting knowing what it is I want to get out of the meeting, you know, each meeting has its own deliverable”

"I’ll use whatever that goal is to structure the conversation”

Technique

"I start off asking them sort of what is their understanding of everything that is going on, and what the team has explained to them”

"I ask an open ended question just to kind of see where they are emotionally, and/or what part of the grieving phase they’re in”

"Like, I still am so, just as kind of a newbie,”
<table>
<thead>
<tr>
<th>Style</th>
<th>still focused on what I say and how I say it, and kind of the message I'm giving and some of my favorite phrases that I'm using, “But most of it is in kind of that ... that style, uh, of how you say it, and the order in which you say it, and the exact words that you say it, and that really can change how the parents perceived, you know” “Because a lot of it is just like old fashioned, see one, do one, try to improve on your ... your technique.” “I mean, I didn't really take any communication classes so I think it's probably important for physicians and health care providers to have good communication skills.” “Any opportunity you can to get kind of formal palliative care, end-of-life, you know, lectures or talks or observing is truly a worthwhile experience.” “So yes, so we've had simulations and I mean you, I mean I've been observed doing it and I've done it solo and things like that. I think bottom line it just takes time and practice.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning to have difficult conversations</td>
<td>“I mean, I didn't really take any communication classes so I think it's probably important for physicians and health care providers to have good communication skills.” “Any opportunity you can to get kind of formal palliative care, end-of-life, you know, lectures or talks or observing is truly a worthwhile experience.” “So yes, so we've had simulations and I mean you, I mean I've been observed doing it and I've done it solo and things like that. I think bottom line it just takes time and practice.”</td>
</tr>
</tbody>
</table>
CURRICULUM VITAE
Amy J Howells, PhD, RN, CPNP- PC/AC

EDUCATION:

Undergraduate Education
Armstrong Atlantic State University
Savannah, Georgia
Bachelor of Science in Nursing
2000

Graduate Education
University of Texas Health Science Center
Houston, Texas
Master of Science in Nursing- Pediatric Nurse Practitioner
2005

Rush University
Chicago, Illinois
Post Master's Certificate- Acute Care Pediatric Nurse Practitioner
2008

University of Texas Health Science Center
Houston, Texas
Post Master’s Certificate- Nursing Education
May 2013

University of Texas Health Science Center
Houston, Texas
PhD in Nursing- Dissertation “Understanding the ‘Big Picture’: End-of-Life
Decision Making in the PICU”, Advisor- Joan Engebretson, DrPh, RN
May 2014

PROFESSIONAL POSITIONS:

Assistant Professor/Pediatric Nurse Practitioner
Department of Pediatrics, Section of Critical Care Medicine
Baylor College of Medicine @ Texas Children’s Hospital
October 2005-present

Affiliated Faculty
Center for Ethics and Health Care Policy
Baylor College of Medicine
January 2012-present
Curriculum Vitae
AMY J HOWELLS

Adjunct Clinical Instructor
University of Texas Health Science Center, School of Nursing
Summer 2013

PICU Staff Nurse
Texas Children’s Hospital
June 2003- October 2005

PICU Staff Nurse
Scott and White Memorial Hospital
July 2000- June 2003

PROFESSIONAL MEMBERSHIPS:

Society of Critical Care Medicine

National Association of Pediatric Nurse Practitioners

Association of Faculty of Pediatric Nurse Practitioners

American Society for Bioethics and Humanities

PUBLICATIONS:

NAPNAP/AFPNP/Niederhauser: Core Review for Primary Care

PRESENTATIONS:

ICU Topics for Pediatric Residents. “CXR interpretation”, “Vent Management”,
“Diabetes Insipidus/SIADH”, “Nutrition in the PICU”, on a yearly basis

ICU Topics for Pediatric Nurse Practioner Students. “Palliative care”, “CXR
interpretation”, “Vent Management”, “Diabetes Insipidus/SIADH”, “Nutrition in
the PICU”, “ABG Interpretation”, “Renal Failure”, on a yearly basis

Lecture, “Interpretation of CXR in the PICU” (PICU staff nurses), on a yearly basis

“Professional Boundaries” (ELNEC/End of Life/Palliative Care course), May 2006
Curriculum Vitae
AMY J HOWELLS

Lecture, “SPIKES- A Six Step Protocol for Delivering Bad News” (Critical Care Section), May 2012

“The Experience of a Pediatric Hospital with the Texas Advance Directives Act- 2 Case studies”- Accepted for oral presentation at the Seattle Children’s Bioethics Conference- July 2013

“The Critical Care Ethics Seminar- Intergrating the Baylor Ethics Work Up and Reflective Leadership in Practice Methods”- Accepted for oral presentation at the Baylor College of Medicine Annual Innovations Day- April 2014

AWARDS AND RECOGNITION:

1993  CCRN certification
   American Association of Critical-Care Certification Corporation

1995  Advanced Practice Nurse – Pediatric Nurse Practitioner-Primary Care
   Texas State Board of Nurse Examiners

1999  Advanced Practice Nurse- Pediatric Nurse Practitioner-Acute Care
   Texas State Board of Nurse Examiners

2013  Sigma Theta Tau Nursing Honor Society

2014  Certified Simulation Instructor
   Texas Children’s Hospital Simulation Center

GRANTS:

Texas Children’s Hospital Section of Pediatric Critical Care Medicine
Baylor College of Medicine, Principal Investigator, Intramural grant
$5,000