Nurses' Perceptions of Barriers to Pediatric Patient Advocacy in End-of-Life Care

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NURSES’ PERCEPTIONS OF BARRIERS TO PEDIATRIC PATIENT ADVOCACY IN END-OF-LIFE CARE

by

Layla J. Eaton

A Thesis Submitted in Partial Fulfillment of the Requirements for a Degree with Honors (Nursing)

The Honors College
University of Maine
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Abstract

Nurses responsible for caring for pediatric patients during end-of-life care find themselves in any number of ethical dilemmas as they attempt to balance providing care, educating family and patients spanning a large developmental spectrum, working collaboratively with extensive medical teams, ensuring proper therapy and bereavement services for parents and siblings, as well as advocating for the voices of their patients who do not yet have legal authority to make decisions regarding their care. These issues are multifaceted and require considerations from multiple disciplines if proper assessment of potential barriers to patient advocacy is desired. This thesis explored the barriers perceived by nurses’ caring for pediatric patients during end-of-life at Maine Medical Center and Eastern Maine Medical Center. A survey was sent to 121 nurses’ on the pediatric floors and PICUs at these two institutions with a response rate of 36.7%. This study identified the top five barriers at MMC which included parents/guardians not ready to acknowledge their child has incurable disease, physicians not initiating a discussion with family or patient on forgoing life sustaining treatments, physicians who are overly optimistic to the family about the child surviving, continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family, and family members not understanding what lifesaving measures means. The top four barriers at EMMC included parents/guardians not ready to acknowledge their child has incurable disease, the nurses’ workload being too heavy to adequately care for the dying child and grieving family, one parent is ready to “let go” before the other parent is ready, and continuing painful treatments or procedures when the patient has expressed interest in stopping. This thesis aims to highlight the barriers to pediatric patient advocacy during end-of-life care perceived by nurses’ with hopes for further research to identify solutions to these barriers.
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Background Literature

Introduction

Nurses responsible for caring for pediatric patients during end-of-life care find themselves in any number of ethical dilemmas as they attempt to balance the necessity of providing high-acuity care, educating family and patients spanning a large developmental spectrum, working collaboratively with extensive medical teams, ensuring proper therapy and bereavement services for parents and siblings, as well as advocating for the voices of their patients who do not yet have legal authority to make decisions regarding their care (Ball, Bindler, & Cowen, 2014). Any one of these aspects of care is enough to exhaust a nurse if the proper resources and services are not available; however potentially one of the most difficult is being able to advocate for patients who span a broad developmental spectrum. These issues are multifaceted and require considerations from multiple disciplines if proper assessment of potential barriers to patient advocacy is desired. Nurses may find themselves in precarious situations where they must choose between advocating for the wishes of their pediatric patient and performing medical interventions desired by parents or other medical team members. One must consider the nurse’s role as well as perceived role, the legal perspective of minor assent and consent as well as parental rights, conflicts within the interdisciplinary team, and available resources.

Regardless of patient population, nurses in all disciplines must adhere to a code of ethics that assists them in navigating through ethically dynamic situations. The American Nurses Associations in 2001 outlined 9 provisions that embodied the current revised Code of Ethics for Nurses that can essentially be summarized in a four tiered framework comprised of beneficence, autonomy, nonmaleficence, and justice. The nurse can use these concepts to help them in the
decision making process while caring for pediatric patients and even more extensively when
caring for pediatric patients in end-of-life care. At times, the nurse may be placed in situations
where their opinion, and the opinion of the physicians, the parents, or the patients may differ, and
an ethical dilemma presents itself. As the nurse assesses all parties’ perspectives, adherence and
application of the four main pillars of ethical decision making can allow for the development of a
therapeutic relationship between nurse and family, maintenance of professional integrity, and
advocacy for the best possible outcome for the child. These guidelines can bring some sense of
consistency to decisions and interventions that are difficult at best (Ball, Bindler, & Cowen,
2014).

**Parental Perspective of Obstacles During End-of-Life**

This becomes crucial in the pediatric end-of-life setting due to the high likelihood of
ethical dilemmas arising, specifically around pediatric patient participation in health care
decisions. It is the natural role of a parent to make decisions for their children, with the
foundational belief that they know what is best for their child. Within a social context, parents
find it unnatural to be caring for a dying child and often rely heavily on nursing staff and other
medical team members to make the decisions for their children, placing the nurse in an intensive
role of educating the family and the patient, as well as facilitating open communication among
all team members (Butler, Copnell, & Willetts, 2014). There have been a number of studies that
have examined the perspective of parents who have children in end-of-life care and the obstacles
(2011) performed a literature review of parental perceptions of having a child in the pediatric
intensive care unit and identified that parents are battling with overcoming denial that they may
or may not be aware of, assimilating the new information, and attempting to culminate
everything into a decision that reflects their child’s wishes. In addition this study found that parents often develop feelings of mistrust and unease when more than one healthcare professional was delivering information regarding their child’s diagnosis and treatment, which often led to inconsistency in the medical information provided. Parents emphasize the importance of receiving information in a timely manner, in an open and honest manner, and in common language (Longden, 2011). The nurse must also be aware that the parental role is shifting from one of protection and providing to one where they must relinquish control, and they may feel threatened by this loss of control, which they attempt to preserve by continuing to make all medical decisions. It is vital that the nurse understands this change in parental role, as parents have also identified that they feel marginalized and that there is a lack of acknowledgment by the healthcare professional of the contribution the parent provides in the child’s care. Lastly, this review noted that several studies have shown parents feel that there are few resources available for bereavement or palliative care and that these resources when available came into play very late in the end-of-life process. This need for bereavement and palliative care services further strains the nurse as parents become dependent on the emotional support provided by the healthcare team. This literature review highlights the influence and significance of the parents’ perceptions in end-of-life care and demonstrates that it is critical for the nurse to incorporate these into the family-centered care in the pediatric end-of-life care.

A study conducted by Butler et al., (2014) showed that some parents believe the responsibility for medical decisions falls on the healthcare team. Often times this responsibility falls upon the nurse, as they are the individuals who build trusting relationships with families and provide care for the dying child around the clock. The intent in any healthcare situation is to have the family and patient be working cooperatively to determine treatment goals, and more
importantly to make choices surrounding withdrawal of treatment. Butler et al. (2014) further notes that in order to provide proper family centered care there needs to be negotiation among all individuals involved as well as a clear definition of roles that acknowledge the flexibility of both parent and nurse. This can present many challenges for the nurse, as Butler et al. (2014) report that in a previous study 45% of nurses surveyed stated there was no specific healthcare team member allocated to communicate medical information to the family and that the primary role of the nurse was to support the family and not provide this form of information. Parents may turn to nurses for honest sharing of medical information; however nurses may not be ready to participate in these types of discussions. In a cross-sectional study conducted by Tubbs-Cooley et al., (2011), it was revealed that nurses feel very ill-equipped to provide detailed medical information to parents. The nurses’ focus is primarily on the care and comfort of the death and dying of a child and family. They were unfamiliar with available palliative and end-of-life resources that could assist them in conversations and identified a lack of training and education in this area as factors that prevented them from properly communicating with parents. Lastly, a metasummary conducted by Stevenson, Achille, & Lugasi, (2013) found that an overarching theme among studies exploring parental needs in end-of-life included having access to peer groups for the parent and child, access to palliative and hospice care from the time of diagnosis, more continuity and consistency of interactions between staff and families, bereavement needs, psychosocial needs, spirituality needs, pain and symptom management, cultural needs, decision making, and needs of siblings. Cumulatively these studies show that in end-of-life care circumstances where emotions are already strained, parents may be turning to nurses for guidance even though the nurse may not feel prepared for these situations. This can create further
discomfort on the part of the parents and the nurse as the parental and family needs are attempting to be accommodated and supported.

**Nurse Perspective of Obstacles During End-of-Life Care**

Research is rich in the parental perspective of barriers, obstacles, and difficulties surrounding end-of-life care of pediatric patients (Brien et al., 2010; Longden, 2011; Price et al., 2013). However, there is a lack of research with respect to nurse-specific perspectives of barriers to end-of-life care. In order to provide care for dying pediatric patients that is fulfilling and satisfactory for all, there needs to be clear delineation of where the care is falling short. The parental perspective is valuable in that it aids family-centered care and begins identification of the child’s needs, as parents often are more intuitive into their child’s desires. But it is lacking because it does not incorporate the knowledge of nurse training and education, the dynamic multidisciplinary approach used in end-of-life care, as well as available resources and avenues of change, making the nurse perspective a crucial addition to the complexities encompassing end-of-life care in the pediatric population. Tubbs-Cooley et al. (2011) identified several factors that nurses perceive as obstacles in pediatric intensive care units caring for dying children. These included lack of communication among physicians, nurses and families, lack of a defined treatment plan, discomfort with death and dying, unnecessary prolongation of life, and lack of awareness of end-of-life practices and resources. Tubbs-Cooley et al. (2011) also found that only 38% of the nurses surveyed were involved with pediatric palliative care in these situations, leading to extreme gaps in the consistency of care. Similarly, in a focus group study, Price, Jordan, & Prior (2013), discovered that healthcare professionals believe truth-telling, symptom management, communication issues within the family, personal emotional impact, withdrawal of feeding and sibling support as the most significant obstacles in end-of-life care of children. This
particular study did not isolate the perspective of the nurse, however the obstacles identified were consistent with other nurse perspective studies. Professionals note that “truth-telling” becomes an issue when there is a discord between what professionals believe needs to be shared with the child and family and the parents’ instinct to protect their child from further upset. This supports what previous studies of parental perspectives suggest, that there needs to be clear and isolated roles as well as delegation of responsibilities surrounding the communication with the family and child to avoid any sort of conflict. Price (2013) specifically found that professionals perceived breakdown in communication in regards to discussion about death with the child, whether or not to resuscitate, addressing sibling need, location of care, securing services, withdrawal of treatment, food, or fluids, and parental denial. As these barriers accumulate, healthcare professionals caring for dying children stated that they felt powerless to alleviate either their own or parental stress, which led to further exacerbation of their sense of frustration and perceived inability to provide adequate care.

A study conducted by Beckstrand, Rawle, Callister, & Mandleco (2010) examined nurses’ perspectives of obstacles as well as supportive behaviors in providing end-of-life care to pediatric populations. The greatest perceived barrier was language barriers, which consisted of not just the dynamics of communication, but are highlighted when families are not fluent in English. These findings were supported by the authors as being congruent with other studies of nurses which identified the influence of language and cultural differences on the nurse’s interactions with the patient and families. Additional barriers included parental discomfort in withholding and or withdrawing mechanical ventilation, discontinuity of care of the dying child due to lack of communication between interdisciplinary team members, and nurses’ opinion about the direction of the patients care not being valued. This study largely supports factors
identified in previous studies, showing similarities between perceived barriers by the parents’ and the nurse. Specific to this study is the concept that the nurse’s opinion about the direction of the patients care not being valued. Nurses caring for end-of-life children carry the responsibility of advocating for the individual desires of the patient, and at times this means advocating for limited technological intervention or continuation of treatment. Nurses found it challenging to be able to convey these pediatric requests in a setting where their opinion felt undervalued by both parents and other members of the healthcare team. In addition, in the intensive care unit (ICU) nurses faced the ethical challenges of discussing discontinuing mechanical ventilation or the possibility of a do-not-resuscitate order. Research has shown that these types of discussion in ICU settings are not always received well, as a large portion of pediatric patients who die, do so while intubated and sedated in the pediatric intensive care unit (PICU), whereas those patients on intermediary units tend to have less medical life-sustaining treatments. This further exacerbates the nurse’s challenge of advocating for the patient when preconceived life-sustaining goals are the commonly accepted viewpoint.

**Gaps in Research Regarding Obstacles During End-of-Life Care**

Patterns within the research start to emerge showing distinct areas where nurses and other healthcare professionals fall short of providing adequate end-of-life care to pediatric patients. As Stevenson et al. (2013) state, research has shown that the United States and Canadian health care systems do not adequately meet the needs of children with life-threatening and life-limiting illnesses or those of their families, making identification and resolution of these barriers a principal aspect of nursing care for end-of-life pediatric patients. The themes that have been noted thus far reflect parental perceptions or nursing perspectives as they pertain to logistics and factors external to the child. However, one of the greatest responsibilities a pediatric nurse has is
being able to effectively and proficiently advocate the needs and desires of their not yet legally competent patients. Little research has been conducted focusing on the nurses’ perceptions of barriers specifically as they relate to patient advocacy. There are a number of obvious barriers such as the wide spectrum of developmental abilities and legal implications. For example, a minor patient is not legally allowed to refuse treatment, which forces the nurse to make ethical decisions regarding whether or not to provide an intervention to a patient who has expressed conflicting desires. Studies have also shown (Whitty-Rogers et al., 2009), that due to the range of developmental abilities of children, their competency is often immediately called into question when they express medical decisions that do not reflect the wants of the parent or healthcare team. This places a large responsibility on the nurse to be able to adequately educate both the child and family to maximize the possibilities of informed assent and consent (Gormley-Fleming & Campbell, 2011). Stevenson et al. (2013) further note that research is in strong support of healthcare professionals deeming it necessary and advantageous for letting the child choose where to die, which creates another situation in which the nurse must be able to communicate successfully with the pediatric patient and advocate effectively to both parents and the healthcare team. As stated before, the research exploring nurses’ perceptions of these scenarios is sparse and requires further investigation. The nurse must have a keen understanding of the child’s perceptions surrounding end-of-life care in order to adequately access where shortcomings exist and where improvements would be amenable.
Methods

Purpose

The purpose of this study was to identify barriers that exist for nurses that potentially hinder a nurse’s ability to advocate for their pediatric patients in end-of-life care. This study investigated nurses’ perceptions of barriers to pediatric patient advocacy during the end-of-life care period in hospitals. Pediatric nurses employed at Eastern Maine Medical Center, Maine Medical Center, and The Barbara Bush Children’s Hospital were selected to participate in this study. These institutions are the only hospitals in Maine with general pediatric units and pediatric intensive care units (PICU).

Participant Eligibility

Eligible participants were nurses who were currently working on either the pediatric floor or in the pediatric intensive care unit and met the criteria of having previously cared for a dying child. Screening criteria were implemented at the beginning of the survey, preventing potential participants from advancing in the survey if they had not actively cared for a dying child.

Study Tool

The tool used in this study was a survey adapted from a previous research study (Beckstrand, 2010). Permission was granted by the researcher to use the survey tool (Beckstrand, personal communication, September 19, 2014). The original tool used by Beckstrand was validated in the following manner as described by the researcher:

“...adapted from 3 similar surveys with critical care nurses, 9 emergency nurses, 11 and oncology nurses. In order to strengthen content validity, information from experts was used to further revise questionnaire items. The questionnaire was pretested by 27
pediatric nurses experienced in the care of dying children. Changes in items were made on the basis of the nurses’ comments and suggestions.” (Beckstrand, 2010, p.545).

The tool was adapted for the current study by removing certain questions that were deemed irrelevant to the intent of the current study. The final tool used consisted of 20 Likert style questions and five demographic questions and one open-ended question inquiring for participant feedback. This tool can be found in the appendix.

**Institutional Review Board**

Once locations, participant population criteria, and the survey tool were completed, a proposal of protocols was submitted to the Institutional Review Board at the University of Maine, Orono and participating institutions. Approval was granted from the IRB at the University, Eastern Maine Medical Center and Maine Medical Center.

Criteria eligibility was built into the survey similarly to the informed consent. The first question in the survey asked participants if they had ever previously cared for a dying child. An answer of no would bring participants to an end message and no further responses were collected. This insured proper screening of participants so only those meeting eligibility criteria were allowed to complete the survey.

**Confidentiality**

To maintain confidentiality, the survey was distributed electronically using Qualtrics, an online survey program used by the University of Maine that allowed for anonymous collection of responses. Due to electronic distribution, informed consent of participants was obtained by participants answering “Agree” to the informed consent displayed on the beginning of the survey. If a participant clicked “Disagree” on the informed consent, the survey program brought them to an end message thanking them for their time and preventing them from completing the
survey. There was no compensation offered for participants, and informed consent included the completely voluntary aspect of this study.

**Survey Distribution**

Contact was made with nurse managers or charge nurses on pediatric floors and PICUs at Eastern Maine Medical Center and Maine Medical Center. The Barbara Bush Children’s Hospital was included Maine Medical Center contact and analysis as this institution is a division of MMC. The contacts were provided with a cover letter which explained the intent of the survey as well as contact information of the researcher. The cover letter included a link to the Qualtrics survey with the appropriate informed consent for the specific institution. The nurse managers and charge nurses at the institutions were asked to distribute the cover letter to all nursing staff employed on the pediatric floors or pediatric intensive care units. The contacts provided the researcher with the total number of individuals who received the survey.

The survey was distributed to 24 pediatric floor nurses and 21 pediatric intensive care unit nurses at Eastern Maine Medical Center and 47 pediatric floor nurses at Barbara Bush Children’s Hospital and 29 pediatric intensive care unit nurses at Maine Medical Center, for a total of 121 survey’s distributed. Prospective participants were given seven days to answer the survey at which point a reminder email was sent out by institution contact persons. The participants were given another seven days to respond. After a total of 14 days from the initial distribution of the survey, the survey link was terminated so no further surveys could be completed.

**Analysis**

Data was analyzed using descriptive statistics which included frequencies of each Likert scale option for each barrier listed. For each institution, the top five largest barriers were
selected. This was based on the barriers with the highest frequency of ‘large barrier’ or ‘extremely large barrier’ as responses based on the original intent of the study to identify the largest barriers perceived by nurses. Barriers whose frequencies identified them as ‘small barrier’ or ‘no barrier’ were also determined.
Results

Participants

Of the 121 pediatric and PICU nurses who received the survey, 120 (99%) met the eligibility criteria of having previously cared for a dying child. Out of the 120 eligible participants, 44 (36.7%) completed the survey. The mean age of participants was 44.7 years, with a range between being 26 and 65 years of age. Participants had on average 19.2 years of experience as a registered nurse and 14.6 years as a registered nurse on a PICU or pediatric floor. A majority (73.8%) of participants held a bachelor’s degree in nursing or higher, while 16.7% held associates degrees in nursing, and 9.5% held a diploma in nursing. See table 1 for data. The remaining results were kept segregated for the two institutions based on significant differences in responses.

Of the nurses who responded from Maine Medical Center (MMC) 43% had provided direct nursing care to more than 30 dying children, while 5% of Eastern Maine Medical Center (EMMC) participants had this degree of exposure to dying children. A majority (40%) of EMMC participants had cared for between five and 10 dying children. Participants caring for under five dying children accounted for 20% of EMMC responses and 17% of MMC responses. (Table 2).

Top Five Barriers Identified by MMC Nurses

The top five barriers which were identified by MMC nurses as being the largest barriers to providing adequate end-of-life care to pediatric patients included parents/guardians not ready to acknowledge their child has an incurable disease (47.8%), physicians not initiating a discussion with family or patient on forgoing life sustaining treatments (43.5%), physicians who are overly optimistic to the family about the child surviving (30.4%), continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by
the family (30.4%), and family members not understanding what lifesaving measures means (30.4%). Nurses at MMC identified the following as being small barriers to providing adequate end-of-life care to pediatric patients: nurse’s opinion about the direction of their patient’s care is not valued (52.2%), cultural/religious differences that families and the patient employ in grieving for the loss of life (47.8%), developmental barriers (39.1%), the nurse not knowing what to say to the grieving family with respect to their child’s desires (34.8%), and one parent is ready to “let go” before the other parent is ready (34.8%). Maine Medical Center nurses identified lack of nursing education regarding quality end-of-life care in pediatric patients (30.4%) as not being a barrier. The remainder of results for Maine Medical Center can be found in table 3.

**Top Four Barriers Identified by EMMC Nurses**

Nurses at Eastern Maine Medical Center identified only four barriers as being large barriers. These barriers included parents/guardians not ready to acknowledge their child has an incurable disease (42.9%), the nurses’ workload being too heavy to adequately care for the dying child and grieving family (42.1%), one parent is ready to “let go” before the other parent is ready (33.3%), and continuing painful treatments or procedures when the patient has expressed interest in stopping (28.6%). Of these barriers, only parents/guardians not ready to acknowledge their child has an incurable disease was a common identified large barrier between the institutions. There were two barriers that were identified as medium barriers to end-of-life care, and these included the nurse having to deal with distraught family members (35.0%) and family members not understanding what lifesaving measures means (25.0%). EMMC nurses also identified several barriers in the survey as not being barriers to providing adequate end-of-life care in pediatric patient populations. Among those that were considered to not be barriers were physicians who are overly optimistic to the family about the child surviving (28.6%), the
unavailability of standards of patient involvement in care decisions (28.6%), cultural/religious differences that families and the patient employ in grieving for the loss of life (38.1%), continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family (35.0%), limited access to hospice services due to physicians not making referrals because the physicians are not ready to accept that the child is dying (35.0%), and language barriers (42.0%). For the remainder of barriers identified as either being extremely small barriers or small barriers by EMMC nurses see table 4.
Table 1. Demographic Data

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean</th>
<th>Range</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants (n=44)</td>
<td>**</td>
<td>**</td>
<td>**</td>
</tr>
<tr>
<td>MMC, n=24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EMMC, n=20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td>44.7</td>
<td>26-65</td>
<td>**</td>
</tr>
<tr>
<td>Years as RN</td>
<td>19.2</td>
<td>3-35</td>
<td>**</td>
</tr>
<tr>
<td>Years as pediatric RN</td>
<td>14.6</td>
<td>0.5-35</td>
<td>**</td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>**</td>
<td>**</td>
<td>73.8%</td>
</tr>
<tr>
<td>Associates degree</td>
<td>**</td>
<td>**</td>
<td>16.7%</td>
</tr>
<tr>
<td>Diploma</td>
<td>**</td>
<td>**</td>
<td>9.5%</td>
</tr>
</tbody>
</table>

Table 2. Frequency of number of dying pediatric patients cared for

<table>
<thead>
<tr>
<th>Number of dying pediatric patients</th>
<th>EMMC</th>
<th>MMC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 5</td>
<td>20%</td>
<td>17%</td>
</tr>
<tr>
<td>5-10</td>
<td>40%</td>
<td>22%</td>
</tr>
<tr>
<td>11-20</td>
<td>25%</td>
<td>9%</td>
</tr>
<tr>
<td>21-30</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>More than 30</td>
<td>5%</td>
<td>43%</td>
</tr>
</tbody>
</table>
### Table 3. Maine Medical Center Responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Not a barrier</th>
<th>Extremely small barrier</th>
<th>Small barrier</th>
<th>Medium barrier</th>
<th>Large barrier</th>
<th>Extremely large barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians who are overly optimistic to the family about the child surviving.</td>
<td>8.70%</td>
<td>8.70%</td>
<td>13.04%</td>
<td>26.09%</td>
<td>30.43%</td>
<td>13.04%</td>
</tr>
<tr>
<td>Parents/guardians not ready to acknowledge their child has incurable disease.</td>
<td>0.00%</td>
<td>0.00%</td>
<td>8.70%</td>
<td>39.13%</td>
<td>47.83%</td>
<td>4.35%</td>
</tr>
<tr>
<td>The nurse having to deal with distraught family members.</td>
<td>8.70%</td>
<td>8.70%</td>
<td>26.09%</td>
<td>47.83%</td>
<td>8.70%</td>
<td>0.00%</td>
</tr>
<tr>
<td>One parent is ready to “let go” before the other parent is ready.</td>
<td>0.00%</td>
<td>4.35%</td>
<td>34.78%</td>
<td>26.09%</td>
<td>26.09%</td>
<td>8.70%</td>
</tr>
<tr>
<td>The unavailability of standards of patient involvement in care decisions.</td>
<td>21.74%</td>
<td>17.39%</td>
<td>21.74%</td>
<td>30.43%</td>
<td>4.35%</td>
<td>4.35%</td>
</tr>
<tr>
<td>Cultural/religious differences that families and the patient employ in grieving for the loss of life.</td>
<td>17.39%</td>
<td>13.04%</td>
<td>47.83%</td>
<td>8.70%</td>
<td>13.04%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Lack of nursing education regarding quality end-of-life care in pediatric patients.</td>
<td>30.43%</td>
<td>13.04%</td>
<td>26.09%</td>
<td>26.09%</td>
<td>4.35%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Physicians not initiating a discussion with family or patient on forgoing life sustaining treatments.</td>
<td>4.35%</td>
<td>4.35%</td>
<td>17.39%</td>
<td>17.39%</td>
<td>43.48%</td>
<td>13.04%</td>
</tr>
<tr>
<td>Continuing painful treatments or procedures when the patient has expressed interest in stopping.</td>
<td>13.04%</td>
<td>13.04%</td>
<td>21.74%</td>
<td>21.74%</td>
<td>21.74%</td>
<td>8.70%</td>
</tr>
<tr>
<td>Continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family.</td>
<td>8.70%</td>
<td>26.09%</td>
<td>8.70%</td>
<td>17.39%</td>
<td>30.43%</td>
<td>8.70%</td>
</tr>
<tr>
<td>The nurses’ workload being too heavy to adequately care for the dying child and grieving family.</td>
<td>4.35%</td>
<td>13.04%</td>
<td>26.09%</td>
<td>26.09%</td>
<td>21.74%</td>
<td>8.70%</td>
</tr>
<tr>
<td>The nurse not knowing what to say to the grieving family with respect to their child’s desires.</td>
<td>17.39%</td>
<td>26.09%</td>
<td>34.78%</td>
<td>17.39%</td>
<td>4.35%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Family members not understanding what lifesaving measures means.</td>
<td>4.35%</td>
<td>13.04%</td>
<td>21.74%</td>
<td>21.74%</td>
<td>30.43%</td>
<td>8.70%</td>
</tr>
<tr>
<td>Limited access to hospice services due to physicians not making referrals because the physicians are not ready to accept that the child is dying.</td>
<td>8.70%</td>
<td>17.39%</td>
<td>21.74%</td>
<td>21.74%</td>
<td>21.74%</td>
<td>8.70%</td>
</tr>
<tr>
<td>Developmental barriers.</td>
<td>13.04%</td>
<td>21.74%</td>
<td>39.13%</td>
<td>21.74%</td>
<td>4.35%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Language barriers.</td>
<td>8.70%</td>
<td>34.78%</td>
<td>21.74%</td>
<td>21.74%</td>
<td>13.04%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Nurse’s opinion about the direction of their patient’s care is not valued.</td>
<td>4.35%</td>
<td>13.04%</td>
<td>52.17%</td>
<td>17.39%</td>
<td>13.04%</td>
<td>0.00%</td>
</tr>
<tr>
<td>The discontinuity of care of the dying child from lack of communication between interdisciplinary team members.</td>
<td>8.70%</td>
<td>21.74%</td>
<td>13.04%</td>
<td>26.09%</td>
<td>26.09%</td>
<td>4.35%</td>
</tr>
<tr>
<td>Having the physicians involved in the child’s care disagree about the direction of care.</td>
<td>4.35%</td>
<td>8.70%</td>
<td>17.39%</td>
<td>26.09%</td>
<td>21.74%</td>
<td>21.74%</td>
</tr>
</tbody>
</table>
### Table 4. Eastern Maine Medical Center Responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Not a barrier</th>
<th>Extremely small barrier</th>
<th>Small barrier</th>
<th>Medium barrier</th>
<th>Large barrier</th>
<th>Extremely large barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians who are overly optimistic to the family about the child surviving.</td>
<td>28.57%</td>
<td>9.52%</td>
<td>19.05%</td>
<td>14.29%</td>
<td>23.81%</td>
<td>4.76%</td>
</tr>
<tr>
<td>Parents/guardians not ready to acknowledge their child has incurable disease.</td>
<td>4.76%</td>
<td>0.00%</td>
<td>19.05%</td>
<td>19.05%</td>
<td>42.86%</td>
<td>14.29%</td>
</tr>
<tr>
<td>The nurse having to deal with distraught family members.</td>
<td>10.00%</td>
<td>20.00%</td>
<td>10.00%</td>
<td>35.00%</td>
<td>25.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>One parent is ready to “let go” before the other parent is ready.</td>
<td>4.76%</td>
<td>4.76%</td>
<td>9.52%</td>
<td>28.57%</td>
<td>33.33%</td>
<td>19.05%</td>
</tr>
<tr>
<td>The unavailability of standards of patient involvement in care decisions.</td>
<td>28.57%</td>
<td>14.29%</td>
<td>23.81%</td>
<td>19.05%</td>
<td>14.29%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Cultural/religious differences that families and the patient employ in grieving for the loss of life.</td>
<td>38.10%</td>
<td>33.33%</td>
<td>19.05%</td>
<td>4.76%</td>
<td>4.76%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Lack of nursing education regarding quality end-of-life care in pediatric patients.</td>
<td>14.29%</td>
<td>19.05%</td>
<td>28.57%</td>
<td>19.05%</td>
<td>14.29%</td>
<td>4.76%</td>
</tr>
<tr>
<td>Physicians not initiating a discussion with family or patient on forgoing life sustaining treatments.</td>
<td>14.29%</td>
<td>14.29%</td>
<td>38.10%</td>
<td>9.52%</td>
<td>19.05%</td>
<td>4.76%</td>
</tr>
<tr>
<td>Continuing painful treatments or procedures when the patient has expressed interest in stopping.</td>
<td>23.81%</td>
<td>9.52%</td>
<td>9.52%</td>
<td>19.05%</td>
<td>28.57%</td>
<td>9.52%</td>
</tr>
<tr>
<td>Continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family.</td>
<td>35.00%</td>
<td>25.00%</td>
<td>15.00%</td>
<td>5.00%</td>
<td>20.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>The nurses’ workload being too heavy to adequately care for the dying child and grieving family.</td>
<td>15.79%</td>
<td>5.26%</td>
<td>10.53%</td>
<td>15.79%</td>
<td>42.11%</td>
<td>10.53%</td>
</tr>
<tr>
<td>The nurse not knowing what to say to the grieving family with respect to their child’s desires.</td>
<td>5.26%</td>
<td>15.79%</td>
<td>15.79%</td>
<td>52.63%</td>
<td>10.53%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Family members not understanding what lifesaving measures means.</td>
<td>10.00%</td>
<td>20.00%</td>
<td>25.00%</td>
<td>25.00%</td>
<td>10.00%</td>
<td>10.00%</td>
</tr>
<tr>
<td>Limited access to hospice services due to physicians not making referrals because the physicians are not ready to accept that the child is dying.</td>
<td>35.00%</td>
<td>15.00%</td>
<td>15.00%</td>
<td>10.00%</td>
<td>20.00%</td>
<td>5.00%</td>
</tr>
<tr>
<td>Developmental barriers.</td>
<td>15.00%</td>
<td>35.00%</td>
<td>30.00%</td>
<td>15.00%</td>
<td>5.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Language barriers.</td>
<td>42.11%</td>
<td>21.05%</td>
<td>5.26%</td>
<td>0.00%</td>
<td>15.79%</td>
<td>15.79%</td>
</tr>
<tr>
<td>Nurse’s opinion about the direction of their patient’s care is not valued.</td>
<td>30.00%</td>
<td>20.00%</td>
<td>35.00%</td>
<td>10.00%</td>
<td>5.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>The discontinuity of care of the dying child from lack of communication between interdisciplinary team members.</td>
<td>20.00%</td>
<td>25.00%</td>
<td>10.00%</td>
<td>20.00%</td>
<td>20.00%</td>
<td>5.00%</td>
</tr>
<tr>
<td>Having the physicians involved in the child’s care disagree about the direction of care.</td>
<td>5.00%</td>
<td>50.00%</td>
<td>10.00%</td>
<td>5.00%</td>
<td>30.00%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>
Discussion

Barriers Identified by MMC Nurses

Maine Medical Center nurses perceived five different barriers as being potentially large barriers to providing adequate end-of-life care in pediatric patients. The first was parents/guardians not ready to acknowledge their child has incurable disease. This result was inconsistent with a similar study conducted by Beckstrand 2010, in which this was not found to be one of the top five perceived barriers by nurses surveyed. One of the key attributes of effective nursing is treating a patient holistically, which for a child often means the incorporation of parents and their desires. If a parent has not yet fully accepted that their child is terminal, the nurse is faced with having to still provide care for the dying child, while facilitating coping and acceptance for the parents. Al-Gamal & Long (2010) conducted a study of 140 parents that examined the anticipatory grieving of parents with children diagnosed with terminal cancer. They compared a group of parents who had children that were newly diagnosed and a group of parents who had known for 6-12 months. They found that fewer than half the parents in both groups reported being at peace with themselves or the situation of their child’s condition. This supports the nurses’ perception that parents not being willing to acknowledge, or ready to acknowledge, their child’s impending death can be a significant barrier to care and is a real experience for both nurses, parents, and children.

This result can further be explained by the work of a pediatric oncologist. Bearison (2012), notes that healthcare providers are faced with the obstacle of providing hope for parents, which is often the element that limits parental acceptance of a terminal diagnosis but allows them to stay in a place of positive emotion, or facilitating their navigation through the grieving process (Bearison, 2012). He further notes the length of time and the ways in which parents accept the
condition of their child is highly contingent upon their spiritual and cultural influences. Potential solutions for this are not easy; however acknowledgment by the nurse that there needs to be a balance between proper facilitation of grief for parents and providing meaning and hope to the end of a child’s life is the first step. The nurse must have an avid understanding of anticipatory grieving, the steps of grief, and the large differences in time and resources each individual parent will need to be successful in acceptance of their child’s terminal state and being able to make decisions with healthcare professionals to provide quality of life during the end-of-life phase.

The second and third largest perceived barriers identified by MMC nurses were physicians not initiating a discussion with family or patient on forgoing life sustaining treatments and physicians who are overly optimistic to the family about the child surviving. These results are consistent with the Beckstrand et al. (2010) study. Nurses can be faced with significant frustration in crucial situations because they are often the interface between families and physicians. Nurses spend significantly more time with patients and families than physicians, and nurses come to recognize what may potentially be best for the patient. Physicians may not have this same understanding; therefore the nurse must advocate for their patients and families. The very nature of nursing is to treat patients holistically, which often allows nurses to recognize the need for an EOLC conversation long before a physician does. Having a do-not-resuscitate conversation with parents of a dying child is not an easy task and should not be one that falls on the shoulders of one provider or nurse, but rather be done using a supportive, team-centered approach. According to the American Nurses Association (ANA), “Nurses must advocate for and play an active role in initiating discussions about DNR with patients, families, and members of the health care team” (ANA, 2012). It is vital that although this may be a barrier if a physician does not initiate these conversations, the nurse must remember that they play a pivotal role in
advocating for what is best for their patients, regardless of the sensitivity around the topic. This perceived barrier is further supported by a study conducted by Holley, Kravet, & Cordts (2009) which found that younger patients and cardiovascular patients have a decreased rate of DNR orders written compared to other patients. This adds to the need for nurses to be willing to initiate and promote these conversations when the patient’s condition has progressed to a terminal point.

In regards to the third barrier of physicians who are overly optimistic to the family about the child surviving, this can potentially be explained again by the very foundations of nursing. Nurses are trained to view their patients holistically and advocate for effective care not just for the physical illness, but also the spiritual and psychosocial. Physicians conversely focus more on curing the physical illnesses and hold more value in curative measures. While it takes both of these views to allow medicine in a hospital setting to be successfully delivered to patients, it can places nurses in a position where it seems that their holistic care of a patient is being hindered by unrealistic expectations of curing. It perhaps is easier for a nurse to accept that all has been medically done for a patient, especially a child, than a physician because the nurse’s approach to provide nursing care for all aspects of the child’s life, not simply getting rid of illness.

The fourth barrier was continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family. This is an interesting barrier because it was one of few barriers that focused less on care, communication, or ethics, but rather a policy or political issue. MMC is a larger institution than EMMC and provides critical care to a wider variety of patients, which potentially means that they are placed in situations where litigation may be likely due to loss of life or limb more often than EMMC. MMC also provides care to a larger population, increasing the likelihood of litigation based solely on increased
patient contacts. It is unknown what the history of lawsuits has been at MMC and whether or not there is a potential culture around this barrier that is specific to that specific institution. However, it is important to note that regardless if this is specific to MMC or is able to be generalized to other nurses’ caring for dying patients, nurses perceive that they are providing life-sustaining care for patients with poor prognoses based on fear of legal action. This disruption in the nurses’ ability to advocate for their dying pediatric patient compromises the culture of safety and advocacy within the health care system. It is crucial that nurses are able to provide care within an environment that promotes communication and proper ethical and professional decision-making for the best interests of their patients.

The final barrier identified by nurses at MMC was family members not understanding what lifesaving measures means. The fundamental subject of this barrier can be reduced to health literacy. At large, the populous is profoundly health illiterate, while many health care decisions surrounding end-of-life care require a certain level of health proficiency. Health literacy is defined as the extent to which people can access, process, understand, use and communicate health-related information (oral, print and numerical), skill and services (Lambert & Keogh, 2014). This issue is further compounded for children as Lambert & Keogh (2014) states because of their extreme variation in cognitive and developmental levels. Parents therefore are placed in an even more precarious situation as they themselves try to understand various interventions while also trying to educate their children about what’s going on. Lambert & Keogh (2014) further remark that low parental health literacy is linked to undesirable parenting, poorer child outcomes, and more frequent misunderstanding of medication dosage and administration.

Many times nurses, physicians, patients, and families who are in EOLC situations find themselves in the position of having to make decisions quickly because the patient’s condition
has deteriorated rapidly. This time table does not allow for families to have the necessary time to inquire about options or ask questions about topics that may be unclear. Furthermore, physicians and nurses may feel some degree of discomfort when telling parents that their child’s condition has now become terminal because of the natural empathy that occurs. This may hinder healthcare providers’ ability to accurately discuss various interventions in a way that is understood by the parents. In addition, parents who are being faced with the impending death of their child have a tremendous psychological and emotional burden they are caring, which can deplete their capacity to think abstractly and thoroughly understand the different medical interventions that may be presented to them by a healthcare team.

Pediatric nurses’ at MMC identified several barriers as being large that were physician focused, potentially because there are larger numbers of physicians and residents at MMC that provide care for patients, whereas EMMC has fewer physicians that nurses and patients interact with. This has the potential to impact the relationships that exist between physicians and nurses, how effectively they communicate, and therefore impact the potential barriers perceived by nurses’ while caring for pediatric patients in end-of-life.

**Barriers Identified by EMMC Nurses**

Except for the barrier parents/guardians not ready to acknowledge their child has incurable disease EMMC identified different barriers than nurses at MMC. The second barrier identified by EMMC nurses as being large was the nurses’ workload being too heavy to adequately care for the dying child and grieving family. Nurse to patient ratios in the PICU at EMMC are 1:2 and if the patient is critical it is 1:1, while the pediatric floor at EMMC is no greater than 1:4 (Harding, personal communication, April 3, 2015). Nurse to patient ratios on the pediatric floors at MMC are 1:3 and on occasion 1:4 and vary on the remaining intensive care
units (Manchester, personal communication, April 3, 2015). The nurse must have time to facilitate conversations with the families of dying pediatric patients as well as the pediatric patients themselves if effective advocacy can be accomplished.

The next barrier identified by nurses at EMMC was one parent is ready to “let go” before the other parent is ready. The nurse may find this to be a barrier because it causes role strain for both the nurse and the child. When parents at different levels of acceptance may present the nurse with difficulty interacting with each parent. The pediatric patient is ultimately the primary focus of the nurse, but attention may be taken away from the needs of the patient if there is conflict between parents and the stages of grieving that they are at.

The final barrier identified by nurses at EMMC was continuing painful treatments or procedures when the patient has expressed interest in stopping. This is arguably the most challenging barrier to pediatric patient advocacy because it goes against the very essence of advocacy. Pediatric patients are unique in that while they may have the developmental capacity to make informed, rational decisions, they are not legally in control of their care. This places the nurse in a problematic position because she/he has an obligation to the pediatric patient to advocate for their wishes, however, the nurse is also interacting with parents who may be at a different stage of the grieving process and are not ready or willing to reach the same conclusions as their children. The dynamics of each family is different, and the various styles of parent-child interactions can compound the difficulty the nurse confronts when advocating for pediatric patients. In most situations nurses are able to respect and advocate for the wishes of their patients because they have the legal right and autonomy to those choices; however with pediatric patients the nurse must find a way to balance the desires of the child while facilitating communication with the parents. This by no means is an easy situation, nor is it the same for every family. This
can place the nurse in an ethical and moral dilemma as they are legally obligated to provide care even when the child has expressed opposite desires.

**Barrier Differences Between Institutions**

Each barrier has its potential causes and reasons for why nurses may perceive them to be present. These causes are not unique to a facility, but rather generalizable to all nurses’ caring for pediatric patients in end-of-life. However, some barriers may be more likely at particular institutions based on the populations they serve, location, nurse-patient ratios, among other variables. This is evident in the differences of barriers identified at the institutions included in this study. There are several reasons that these disparities may exist. There was a wide disparity in the number of dying patients nurses had cared for at MMC and at EMMC. Forty three percent of nurses’ at Maine Medical Center had cared for over 30 dying pediatric patients, while only 5% of nurses’ at Eastern Maine Medical Center had cared for this number of patients. This has the potentially to greatly impact the nurses’ ability to navigate different barriers, simply based on a larger number of experience and exposure to these situations.

Another difference that may explain variation in responses between EMMC and MMC is the level of education. Nurses at MMC had 82% of participants with a BSN in nursing or higher, while 65% of nurses at EMMC held this level of degree. There is the possibility that BSN nursing programs better prepare their nurse graduates in end-of-life care, pediatric developmental levels, family centered care, communication, and patient advocacy.

When considering these differences it is also important to note that Maine Medical Center is an American Nurses Credentialing Center Magnet recognized hospital, while Eastern Maine Medical Center is not. Magnet recognition is described by the ANCC as,
“The Magnet Recognition Program® recognizes healthcare organizations for quality patient care, nursing excellence and innovations in professional nursing practice. Consumers rely on Magnet designation as the ultimate credential for high quality nursing. Developed by the ANCC, Magnet is the leading source of successful nursing practices and strategies worldwide.” (American Nurse Credentialing Center, 2014).

Magnet status may influence the style of nursing care provided, as well as furthering nurses’ education. Nurses’ at Maine Medical Center may perceive more resources being available to them to assist in these situations as well as perceive a distinct difference in hospital culture surrounding nursing excellence.

The last noteworthy difference between the participating institutions is the degree of acuity of patients seen. Maine Medical Center has a larger number of resources and treat more critically ill pediatric patients. Most notably MMC has the capability to perform pediatric cardiovascular surgery and neurological surgery, both of which are more likely to carry associated morbidity and mortality. This places nurses providing care at MMC in situations where they are more likely to care for a dying pediatric patient. Both facilities have the capability to care for pediatric traumas, oncological/hematological patients, endoscopy, and gastroenterology.

**Non-barriers to Care**

Another finding of interest is that nurses at Eastern Maine Medical Center identified several of the potential barriers as not being barriers at all, while nurses at Maine Medical Center only identified one barrier as not being a barrier that affected effective advocacy of pediatric patients in end-of-life. The only barrier identified by MMC was lack of nursing education regarding quality end-of-life care in pediatric patients. This can potentially be attributed to the
Magnet Recognition of Maine Medical Center, as continued education and educational support within the institution are large components of Magnet Recognition. However, pediatric nurses’ at EMMC identified six barriers as not being barriers to care. These included: physicians who are overly optimistic to the family about the child surviving, the unavailability of standards of patient involvement in care decisions, cultural/religious differences that families and the patient employ in grieving for the loss of life, continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family, and limited access to hospice services due to physicians not making referrals because the physicians are not ready to accept that the child is dying, and language barriers. Interestingly, the first of these barriers listed was a large barrier identified by nurses at MMC. It is unclear why some of these barriers are identified as not being barriers by EMMC, while some of them have more obvious explanations. For example, cultural/religious differences that are employed in the grieving process by patients in families may be less likely to be a barrier for EMMC nurses because the area served by this hospital is smaller than that served by MMC and is less culturally diverse. Nurses’ may not interact with a wide array of cultural variance. This could also explain why language barriers are not perceived as barriers at all because there is a smaller percentage of patients who have a first language other than English. There is also the potential that these nurses feel that they are more culturally competent and therefore do not perceive this as being a barrier to providing end-of-life care to their pediatric patients. EMMC is also a smaller hospital that sees less acute patients than MMC so there is the potential that they have not been exposed to as many lawsuits which could potentially make them less likely to perceive this as a barrier to care. Lastly, nurses did not perceive lack of referral to hospice as a barrier potentially because there is an effective palliative
care team at EMMC that is involved in most patients care very early on. There also may be policies in place that do not require a referral to hospice from a physician.

**Limitations**

Potential limitations of this study include that gender demographics were not collected. The Institutional Review Board at EMMC thought gender identification could potentially identify participants. There could potentially be a variation in perceived barriers based on gender. Ethnicity demographics were also not collected due to the potential for identification of participants. In the comments portion of the survey participants noted that some of the barrier descriptions appeared biased toward a particular response. It was noted by participants also that there is a large difference between PICU and pediatric floor settings, and that it could potentially be beneficially to separate these categories in the future. Another limitation to this study is the small number of participants which makes it difficult to make the findings generalizable to the rest of the pediatric nurse population caring for dying children.

**Future Research**

Future research is needed to explore why these barriers exist for nurses. Many of the barriers identified as being large in this study are explained; however there is a large percentage that could have other explanations. Research is also needed in the area of solutions to these barriers and an exploration of different interventions that varying institutions have put in place. Potential areas of benefit could also be in exploring end-of-life care content in nursing curriculums as well as continued education programs that exist in this content area.
Conclusion

Pediatric patients are among some of the most unique patients that nurses’ care for, as their needs and developmental levels vary greatly. This issue is further challenged when they are not in a legal position to make decisions regarding their care, yet may be fully competent to express their desires. End-of-life is also a unique area of nursing that has many of its own challenges. When the nurse is faced with caring for both an end-of-life patient that is also a pediatric patient, entirely new barriers to care emerge. This study has explored nursing perceptions of barriers to pediatric patient advocacy in end-of-life care at two institutions in Maine. The findings of this study have illuminated several barriers that exist for nurses. Although participant numbers for this study were small which made generalizations to all nurses caring for dying pediatric patients difficult, the identified barriers raise important issues for nursing. Barriers identified include parents/guardians not ready to acknowledge their child has in incurable disease, the nurses’ workload being too heavy to adequately care for the dying child and grieving family, one parent is ready to “let go” before the other parent is ready, continuing painful treatments or procedures when the patient has expressed interest in stopping, parents/guardians not ready to acknowledge their child has in incurable disease, physicians not initiating a discussion with family or patient on forgoing life sustaining treatments, physicians who are overly optimistic to the family about the child surviving, continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family, and family members not understanding what lifesaving measures means.

Understanding which barriers exist or are perceived by nurses as existing places researchers in an optimal position to look at strengths and weaknesses of the end-of-life care process and identify solutions that can minimize discomfort to the nurse, pediatric patient, and
the patient’s family. Future research in this area can assist nurses in being able to provide more effective care and advocacy for their pediatric patients.
References

doi: 10.1111/j.1365-2648.2010.05381.x


http://doi.org/10.1089/jpm.2010.0409


http://doi.org/10.1177/0969733009341910
Appendix A

The following items pertain to your perceptions of barriers to providing pediatric patient advocacy during end of life care. Please mark the circle that most closely characterizes the magnitude a barrier is during your care of dying pediatric patients.

<table>
<thead>
<tr>
<th>0 = Not a barrier</th>
<th>1 = Extremely small</th>
<th>2 = Small barrier</th>
<th>3 = Medium barrier</th>
<th>4 = Large barrier</th>
<th>5 = Extremely large barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physicians who are overly optimistic to the family about the child surviving.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Parents/guardians not ready to acknowledge their child has an incurable disease.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. The nurse having to deal with distraught family members.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. One parent is ready to “let go” before the other parent is ready.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. The unavailability of standards of patient involvement in care decisions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Cultural/religious differences that families and the patient employ in grieving for the loss of life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Lack of nursing education regarding quality end-of-life care in pediatric patients.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Physicians not initiating a discussion with family or patient on forgoing life sustaining treatments.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Continuing painful treatments or procedures when the patient has expressed interest in stopping.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
12. The nurses’ workload being too heavy to adequately care for the dying child and grieving family. 

13. The nurse not knowing what to say to the grieving family with respect to their child’s desires.


15. Limited access to hospice services due to physicians not making referrals because the physicians are not ready to accept that the child is dying.


17. Language barriers.

18. Nurse’s opinion about the direction of their patient’s care is not valued.

19. The discontinuity of care of the dying child from lack of communication between interdisciplinary team members.

20. Having the physicians involved in the child’s care disagree about the direction of care.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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</thead>
<tbody>
<tr>
<td>21. How many years’ experience do you have as an RN?</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>22. How many years of Pediatric/PICU nursing experience do you have?</td>
<td></td>
</tr>
<tr>
<td>23. What is your highest completed level of education?</td>
<td></td>
</tr>
<tr>
<td>- Diploma in Nursing</td>
<td></td>
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<tr>
<td>- Associate degree, Nursing</td>
<td></td>
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<tr>
<td>- Bachelor’s degree, Nursing</td>
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<tr>
<td>24. Over your pediatric nursing career, how many patients have you given immediate end-of-life care to?</td>
<td></td>
</tr>
<tr>
<td>- Less than 5</td>
<td></td>
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<tr>
<td>- Between 5 and 10</td>
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<tr>
<td>- Between 11 and 20</td>
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<tr>
<td>- Between 21 and 30</td>
<td></td>
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<tr>
<td>- More than 30</td>
<td></td>
</tr>
<tr>
<td>25. What year were you born?</td>
<td></td>
</tr>
<tr>
<td>26. Do you have any comments about this study?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B

Informed Consent for Eastern Maine Medical Center

Nurses’ Perceptions of Barriers to Pediatric Patient Advocacy in End-of-Life Care (14-1-M-282)
You are invited to participate in a research survey being conducted by Layla Eaton, a senior in the School of Nursing at the University of Maine Orono. The purpose of this research is to gain insight into the nurses’ perspective of barriers to pediatric patient advocacy in end-of-life care.

What Will You Be Asked to Do
If you choose to participate, you will be asked to complete an online survey through Qualtrics ©. The survey may take about 10-15 minutes to complete.

Risks
As a participant of this survey there is the risk that answering these questions may have both a psychological and emotional impact on nurses. There is also the risk of time inconvenience for participants of this survey. All risks are expected to be minimal.

Benefits
This survey does not have any direct benefits for you as a participant. This research will help us to gain better insight into barriers perceived by nurses. Gathered data will help ensure nurses are given the education and resources needed to be effective advocates and maximize comfort and care of dying children.

Confidentiality
Your name or identifying information will not be attached to any data that is collected through the online survey. At no point will the survey ask you for identifying information. All data is encrypted through Qualtrics ©, stored in their firewall protected servers, and protected by HIPAA. Access to data will require a username and password. The principal investigator will be the only one who has the username and password.

Voluntary
Participation in this study is voluntary. You may stop at any point or omit any questions in the survey you do not wish to answer.

Compensation
There is no compensation for participation in this study.

Contact Information
If you have any questions about this study, please contact, me Layla Eaton at 207.460.8267 email: layla.eaton@umit.maine.edu or Mary Shea, Ph.D, FNP, PNP at 207.581.2611 or email: mary.shea@umit.maine.edu or the Eastern Maine Medical Center Institutional Review Board (IRB) at 207-973-79064

If you have any questions about your rights as a research participant, please contact Gayle Anderson, Assistant to the University of Maine’s Protection of Human Subjects Review Board at 581-1498 or email gayle.anderson@umit.maine.edu.

By clicking “agree” below, you are stating that you have read and understood the above information and are choosing to voluntarily participate in this research study.
Appendix C

Informed Consent for Maine Medical Center

Nurses’ Perceptions of Barriers to Pediatric Patient Advocacy in End-of-Life Care
You are invited to participate in a research survey being conducted by Layla Eaton, a senior in the School of Nursing at the University of Maine Orono. The purpose of this research is to gain insight into the nurses’ perspective of barriers to pediatric patient advocacy in end-of-life care.

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By clicking “agree” below, you are stating that you have read and understood the above information and are choosing to voluntarily participate in this research study.
**Author’s Bio**

Layla Eaton grew up on Deer Isle, Maine. She graduated Valedictorian of her high school class and began school at the University of Maine, Orono as a Microbiology major with intentions of going to medical school. During her freshman year she obtained her Advanced Emergency Medical Technician license and began practicing as an AEMT in Glenburn and Dover-Foxcroft, Maine. After working this intimately with patients she realized that her true passion was working with people and decided to change her major to Nursing to allow for more contact with patients. She has since fulfilled the Nursing major requirements for the University of Maine, Orono and completed clinical experiences at Eastern Maine Medical Center in Bangor. She completed her senior 192 hour partnership in the Emergency Department at Mayo Regional Hospital. Passionate about emergency medicine as well as science, she intends to pursue her nursing career in the emergency and critical care field in the Bangor, Maine area.