Cultural Relevance during Pediatric End-of-Life care

Helen Jahna  
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Cultural Relevance during Pediatric End-of-Life care

Abstract
Abstract: Cultural competency is essential to patient and family centered care, and signifies recognition of the patient’s and family’s healthcare beliefs, customs, and values. Understanding these concepts opens communication with families and healthcare providers and brings out information needed to make the End-of-Life process as meaningful, respectful, and comfortable as possible. This study explored pediatric nursing attitudes on education for cultural relevance and cultural consideration during the end-of-life process. A cross-sectional survey was emailed to pediatric nurses working in the Neonatal Intensive Care Unit (NICU) and Pediatric Cardiac Care Center (PCCC) in a children’s center associated within a teaching hospital in 2017. In total, 326 pediatric nurses were sampled. The overall response rate was 9.6 percent with matching pre and post-surveys. Most held BSN (76.7%), 80% of participants worked in the NICU, and 90% of participants had some end-of-life education during their nursing education and/or career. Cultural relevance and its consideration is an important part of the pediatric nursing role. Improving awareness and education related to cultural relevance and understanding family needs can immeasurably improve the End-of-Life experience for dying children and their families.

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Christine Nelson Tuttle

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Nancy Wilk

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Cultural Relevance during Pediatric End-of-Life Care

By

Helen Jahna, RN, BSN

Submitted in partial fulfillment of the requirements for the degree

Master's in Advanced Practice Nursing

Supervised by

Dr. Nancy Wilk

Dr. Christine Nelson-Tuttle

Wegmans School of Nursing

St. John Fisher College

May 2016
Cultural Relevance during Pediatric End-of-Life Care

St. John Fisher College

Helen Jahna

April 12, 2017
Abstract: Cultural competency is essential to patient and family centered care, and signifies recognition of the patient’s and family’s healthcare beliefs, customs, and values. Understanding these concepts opens communication with families and healthcare providers and brings out information needed to make the End-of-Life process as meaningful, respectful, and as comfortable as possible. This study explored pediatric nursing attitudes on education for cultural relevance and cultural consideration during the end-of-life process. A cross-sectional survey was emailed to pediatric nurses working in the Neonatal Intensive Care Unit (NICU) and Pediatric Cardiac Care Center (PCCC) in a children’s center associated within a teaching hospital in 2017. In total, 326 pediatric nurses were sampled. The overall response rate was 9.6 percent with matching pre and post-surveys. Most held BSN (76.7%), 80% of participants worked in the NICU, and 90% of participants had some end-of-life education during their nursing education and/or career. Cultural relevance and its considerations is an important part of the pediatric nursing role. Improving awareness and education related to cultural relevance and understanding family needs can immeasurably improve the End-of-Life experience for dying children and their families.

1. Introduction

Each year, tens of thousands of children die in the United States. In 2014, approximately 40,000 children died during their first year of life [1]. Leading causes include both unintentional and intentional injuries, prematurity, and congenital defects [2]. The Institute of Medicine report of the dying, including seriously ill children, emphasized the lack of adequate data and scientific knowledge to deliver effective care, to educate, and to design supportive public policies [3]. Improvement in the quality of
End-of-Life care for children is identified as a research priority by federal and private health organizations. Evidence-based guidelines of communication strategies for use by health care providers when planning and conducting end-of-life discussions about pediatric patients and family members have yet to be established [3].

Caring for dying children and their families can be stressful, and death can be difficult to accept. Healthcare professionals continually face and accept the reality of death [2]. Current research has identified cultural barriers as a major obstacle to pediatric nurses caring for dying children and their families [2, 3, 4, 5]. Nurses spend the most time with patients and families, and have an important role in providing high quality, culturally relevant End-of-Life care. For many parents, the support that nurses provide can have a pivotal effect in the family’s response to a child’s death. The recognition and understanding of a dying child’s culture may help facilitate interventions by nurses to help guide parents through the end-of-life process.

Pediatric nurses are challenged to provide End-of-Life care to their patients and families that are culturally appropriate, but many feel unprepared. Currently, there is minimal published material dealing with cultural education needs of pediatric nurses in End-of-Life care. The education of nurses about cultural relevance during End-of-life care and the management of infants and children during the dying process are needed. End-of-Life care is important to prevent physical, emotional, social, and spiritual suffering [5]. Understanding and sharing information about End-of-Life care options with dying children and families is essential to ensure parents comprehend the focus and benefits of having their child receive this care, while integrating their cultural beliefs and
values. This nurtures trust between the nurse, other healthcare providers, and the family to help promote a meaningful death for their child [6,7].

The evaluation of the educational needs for pediatric nurses in regards to cultural relevance during the End-of-Life process can contribute to strategies for improving care and outcomes for patients and families. Potential benefits for patients, families, healthcare providers, and organization are that increased cultural relevant education can increase patient and family satisfaction, establish standards of End-of-Life care, establish unit-based care, increase nursing expertise, and improve interdisciplinary communication among health care professionals and families [8].

2. Purpose

The purpose of this study was to evaluate the effectiveness of the End-of-Life education in the confidence level of pediatric nurses to provide culturally relevant End-of-Life to the Native American (Seneca Nation) and Amish cultures. The research questions were: (1) what is the confidence level of pediatric nurses during the End-of-Life process for infants and children, (2) is there a difference in nursing confidence and importance of cultural awareness on providing End-of-Life care between pre and post survey answers of nurses who read the given educational material, and (3) will nurses who read the educational material have higher scores of nurse’s confidence in End-of-Life care related to cultural relevance?

3. Design and Methods

3.1 Sample size and Recruitment

A cross-sectional survey of pediatric nurse was administered at an eastern United States tertiary care children’s hospital in the spring of 2017. Participants were registered
nurses in the NICU and Pediatric Cardiac ICU who were recruited via an email listing of registered nurses in the NICU and Pediatric Cardiac ICU. A convenience sample was used and expected to be homogenous. Inclusion criteria were all nurses working in either of these two units that were proficient in English. Education was offered to the two pediatric units about the recognition of family centered decision making in a cultural context and how to bridge the gap between cultural competency and End-of-Life care. Understanding family structure, the meaning of illness, suffering, and death, healing practices and rituals, communication, and certain considerations for End-of-Life care for Native Americans (Seneca Nation) and Amish communities was explained as part of the education for this project.

3.2 Survey Development

A search of published literature on “nursing”, “pediatric”, and “palliative” or “end-of-life” specifically identifying nurses that used questionnaires was done. A composite of questionnaires [4,9,10] were used to develop a survey that addressed nurse’s confidence regarding End-of-Life care that was taken pre and post poster distribution.

3.3 Other Demographic Variables

Demographic information including years of experience, educational background, experiences with pediatric death, and personal and professional End-of-Life education was also obtained.

3.4 Data Collection

Participation was voluntary and anonymous. Surveys were administered by means of a web-based questionnaire (Qualtrics). All nurses received an initial
solicitation to participate. The solicitation included a URL link to the questionnaire. One follow-up solicitation and two reminders followed by email.

The pre-survey was administered two weeks prior to the distribution of educational material. Educational material in the form of poster presentations was available to all participants on each pediatric unit to view at their convenience.

3.5 Procedure

Institutional approval to conduct the study was obtained prior to distribution of surveys and educational material from the Associate Director of Pediatrics and Nurse Managers of the participating units. IRB approval was obtained from the participating college for this study. Participation was voluntary and anonymous. Educational material was obtained from pertinent research and clinical literature, in addition to knowledge from a doctorally prepared nurse practitioner that works with the Amish community, a representative of the Department of Health including the Cattaraugus Seneca Indian Reservation and a member of the Cattaraugus Indian Reservation. The posters were titled “Amish: Cultural Consideration during the End-of-Life Process”, “Native American: Cultural Consideration during the End-of-Life Process”, and “Cultural Relevance for Nurses”. The educational poster related to cultural relevance focused on the meaning of cultural competency, how to learn cultural values, beliefs, and practices, health practices of different cultures, cultural needs, cultural outcomes, and implications for nursing practice. The other posters focused on family structure, communication, healing practices and rituals, meaning of illness, suffering, and death, the dying process, and other considerations related to the Native American and Amish communities.
4. Results

4.1 Characteristics of Sample

Data were analyzed using Statistical Package Social Science 24 for frequencies, means, and percentages. Paired t-tests were conducted to ascertain statistical differences between pre and post survey groups. A total of 30 nurses with matching ID numbers from the eligible 326 nurses participated. Most held BSNs (76.7%), followed by RN-associate (20%), and RN-diploma (3.3%). Of participants, 20 percent worked in the PCICU and 80 percent in the NICU. Approximately 53 percent had 15 years or greater experience being a nurse. Standard deviation for this was 5.51. Ninety percent of participants had some End-of-Life education during their formal nursing education and/or career (See Table 1). Also, it was asked for participants to quantify their personal and professional number of experiences with hospice/palliative care (See Table 2).

Table 1

<table>
<thead>
<tr>
<th>Years</th>
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<tr>
<td>Less than one year</td>
<td>2</td>
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<tr>
<td>1-2 years</td>
<td>4</td>
</tr>
<tr>
<td>3-5 years</td>
<td>3</td>
</tr>
<tr>
<td>6-10 years</td>
<td>4</td>
</tr>
<tr>
<td>11-15 years</td>
<td>1</td>
</tr>
<tr>
<td>Greater than 15 years</td>
<td>16</td>
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Table 2

<table>
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<tr>
<th>Number of experiences</th>
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<th>Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>1-2 experiences</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>3-5 experiences</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6 or more experiences</td>
<td>7</td>
<td>11</td>
</tr>
</tbody>
</table>
4.2 Data Analysis

To understand nurses’ confidence, nurses were asked to rate their level of confidence regarding their perception of End-of-Life care and cultural relevance, using a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). To answer the research question, “is there a difference in nursing confidence and importance of cultural awareness in providing End-of-Life care”, pre and post-survey answers of pediatric nurses who read the educational material were compared using paired t-tests. All questions were found to have significant differences ($p<0.05$) (See Table 3).

Table 3

<table>
<thead>
<tr>
<th>Paired t-test, (paired Confidence level=95%)</th>
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<tbody>
<tr>
<td>Pair 1: awareness of the End-of-Life process</td>
<td>-4.892</td>
<td>0.000</td>
</tr>
<tr>
<td>Pair 2: feel prepared to provide End-of-Life care</td>
<td>-3.340</td>
<td>0.002</td>
</tr>
<tr>
<td>Pair 3: comfortable helping patients/families with EOL</td>
<td>-2.213</td>
<td>0.035</td>
</tr>
<tr>
<td>Pair 4: confident in caring different cultures with different needs coping EOL</td>
<td>-4.753</td>
<td>0.000</td>
</tr>
<tr>
<td>Pair 5: aware of different cultures with different needs with coping in EOL</td>
<td>-4.130</td>
<td>0.000</td>
</tr>
<tr>
<td>Pair 6: understand patient’s culture leads to better care</td>
<td>-3.181</td>
<td>0.003</td>
</tr>
<tr>
<td>Pair 7: encourage families to use culture beliefs, values, and customs</td>
<td>-3.808</td>
<td>0.001</td>
</tr>
<tr>
<td>Pair 8: confident addressing cultural needs</td>
<td>-5.856</td>
<td>0.000</td>
</tr>
<tr>
<td>Pair 9: comfortable allowing practices and customs</td>
<td>-2.628</td>
<td>0.014</td>
</tr>
</tbody>
</table>

Attitudes and understanding of pediatric nurses improved through the use of cultural competency and relevance during End-of-Life care education. Three questions had significant shifts from the pre to post-survey after the educational posters were
distributed to staff. These questions were “when nurses understand the patient/family’s
culture it leads to better care”, “encouraging families to use their cultural beliefs,
customs, and values during the End-of-Life process”, and “nurses feeling comfortable
allowing families to practice their customs and beliefs during the End-of-Life process.”

5. Discussion

As researchers have noted, incorporating cultural relevance during the End-of-Life process is important during this time for both the patient and family. The nurses who participated in this study acquired understanding and knowledge of pediatric End-of-Life care related to cultural relevance, that assisted them in realizing that they give proper support to patients and families of the Native American (Seneca) and Amish communities. This knowledge can be further applied into their daily practice. This is important because it allows for professional development, improves skills, and empowers to pediatric nurses to be advocates for their patients and families during a difficult time [11]. This is important to nursing practice because, as pediatric nurses, it is important to be culturally competent with patients and families. This allows for the development of appropriate actions, responses, and interventions to complement the patient/family’s customs, beliefs, and values.

Pediatric nurses confidence and understanding improved through education to have responses change from agree or less to strongly agree identifying the importance of cultural competency in nursing practice during End-of-Life care. Three questions had larger shifts in responses to strongly agree from agree (or less). The percentage of increase was 40 percent for “understand patients’ culture leads to better care”, 50 percent
for “encourage families to use cultural beliefs, values, and customs”, and 25 percent for
“comfortable allowing practices and customs during the End-of-Life process”.
These results show the need for sustained education for End-of-Life care because more
education will allow for a lesser disconnect from education to practice for nurses so
patients and families can benefit.

Confidence in cultural competence in End-of-Life care increased post education.
This supported the findings of Engler et al at [4] and Frederickson et al [10] who found that
nurses who had more experiences and education related to bereavement and End-of-Life
care were more comfortable providing this care. The pediatric nurses responded to open-
ended questions post education with statements such as “better meets the needs of the
patient and family from all aspects of care: spiritual, emotional, and physical”, “this
provides better nursing care and empathy as you are aware if the cultural needs of family,
“the End-of-Life process is a very sensitive time and providing culturally appropriate care
is extremely important, respecting one’s own customs and wants is essential”, and it
provides a better experience for the family” and “they were able to make their wishes and
customs known so that their love one is taken care of in a way they desire”. Pediatric
nurses felt that their role in providing cultural relevant support to patients and families
was very important to nursing care and family centered care.

Parents and families need compassion when a child dies. Nurses have been taught
to focus on cure and treatment, but there are times when there is no cure and nurses are
needed for support through the dying process. It is important for pediatric nurses to
provide high quality End-of-Life care for children and their families, many of whom
come from a variety of cultures. Allowing for culturally relevant supportive measures
during End-of-Life care can help facilitate the grieving process. Identifying cultural needs during End-of-Life care and improving communication between families and healthcare professionals is essential. Pediatric nurses need to have continuous supportive cultural education related to the patient populations that they care for. Future educational interventions are needed for nurses to improve their confidence and knowledge related to culturally relevant care. They need institutional support for their roles as advocates for patients and families during the End-of-Life process.

6. Limitations

This study showed the education of pediatric nurses related to culturally relevant End-of-Life care was important, but the results are not generalizable because the sample size was small and was from one institution. Additional research is needed on what might be helpful to patients and family members during the End-of-Life process related to specific cultures.

7. Conclusion

As pediatric nurses, it is important to be culturally aware and to provide appropriate responses and interventions to help support the family’s customs, beliefs, and values. Providing culturally relevant care to pediatric patients and their families improves the quality of care for those facing life-limiting conditions. Pediatric nurses need to develop cultural sensitivity and better understanding to integrate needs for those of different cultural backgrounds when giving care.
References


Reference


Iglesias, M.E.L., Pascal, C., & de Bengoa Vallejo, R.B. (2013). Obstacles and helpful behaviors in providing end-of-life care to dying patients


Cultural Relevance during Pediatric End-of-Life Care
Helen Jahn, BSN, CCRN, CNS-student

Objectives
- To raise awareness and enhance care for pediatric patients and their families at End-of-Life
- To appreciate cultural diversity
- To understand how cultural factors can influence End-of-Life decision-making

Purpose:
To evaluate the effect of End-of-Life education on nursing implications of culture relevance in practice and the confidence of nurses regarding End-of-Life care for pediatric patients of the Native American (Seneca) and Amish community.

Articles to support the study
- Pediatric nurses' perception of obstacles and supportive behaviors in end-of-life care by R.L. Belonrand, N.L. Rawle, et al published in the American Journal of Critical Care
- Neonatal staff and advanced practice nurses perceptions of bereavement of life of families of critically ill infants by D. J. Engler, M.D. West, et al published in the American Journal of Critical Care
- Promoting neonatal staff nurses comfort and involvement in end of life and bereavement care by W. Zhang & B.S. Lane published in Nursing Research and Practice

Sample

Design

- Quaifecrs
- Pre survey
- Post survey
Dissemination

To provide pediatric nurses with knowledge of the importance and relevance regarding cultural competency that will enhance the delivery of patient/family centered care during the End-of-Life process.

Plans:
- Expansion of project to other cultures seen in pediatric units
- Potential publication in nursing journal
- Potential poster presentation at a conference

References:
## Supportive Behaviors and Obstacles Impacting Pediatric Nurses During End-of-Life Care

<table>
<thead>
<tr>
<th>Author Date</th>
<th>Purpose</th>
<th>Design</th>
<th>Sample</th>
<th>Behavior Obstacle</th>
<th>Data Collection Method</th>
<th>Design Limitations</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Beckstrand, et al, 2010</td>
<td>To determine PICU nurses’ perception of size frequencies, and magnitude of selected obstacles and helpful behaviors in providing EOL care in children</td>
<td>Exploratory cross-sectional design</td>
<td>536 AACN nurses</td>
<td>Obstacles: Language barriers, parental discomfort, withdrawing support, discontinuity of care d/t lack of communication, the nurse’s opinion not valued. Supportive: Allowing families adequate time alone with the child after they have died, parents holding child while life support is discontinued, and providing a peaceful, dignified bedside scene.</td>
<td>Self-reported questionnaires. Likert responses NSCCNR-EOLC questionnaire</td>
<td>Cross-sectional design. Convenient sampling. Did not distinguish between NICU and PICU nurses</td>
<td>Parents rely on nursing professionals with issues regarding EOL care. Improving communication, changing language, and integrating palliative and EOL care are important supportive behaviors and obstacles to overcome with EOL decisions and care</td>
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<tr>
<td>Author</td>
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<td>Behaviors Obstacles</td>
<td>Data Collection Method</td>
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<tr>
<td>Crump et al, 2010</td>
<td>To survey staff nurses to know perceived knowledge needs for quality EOL care. Promote quality care and overcome barriers in the critical care setting.</td>
<td>Cross-sectional design</td>
<td>56 nurses</td>
<td>Obstacles: Family continually call nurse wanting update in condition than having designated family member, nurse dealing with angry family member, sustain life saving measures after DNR papers have been signed. Supportive: Designated family support person, having family accept the patient is dying, and having a peaceful, dignified bedside scene for family members once the patient has died.</td>
<td>Self-reported questionnaires, Likert scale. NSCCNR-EOLC questionnaire.</td>
<td>Expertise may have more comfort with aspects of bereavement. Convenient sampling.</td>
<td>Nurses must strengthen their role as liaisons between patient (family) and other health professionals to promote quality of EOL care. The need to advocate for the integration of a palliative care approach.</td>
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<td>Author</td>
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<td>Davies</td>
<td>et al,</td>
<td>The goal is to explore barriers to palliative care experienced by pediatric healthcare providers for seriously ill children. To explore the perceptions of EOL in an academic children’s hospital, with the goal of describing perceived barriers to EOL care for children and families.</td>
<td>Descriptive quantitative design.</td>
<td>118</td>
<td>Obstacles: Family not ready to acknowledge incurable condition, language barriers, and time constraints. Also, staff shortages, cultural differences, lack of palliative/EOL care, lack of knowledge of EOL pain and symptom management, and conflicting family members.</td>
<td>Self-reported survey questionnaire developed from measurement tools in previous studies. Likert scale.</td>
<td>Single, tertiary institution. Did uncover interesting insights about barriers perceived by nurses according to disciplines.</td>
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<td>Author Date</td>
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<td>Behaviors</td>
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<td>Engler et al, 2004</td>
<td>To describe nurses' perception of bereavement/EOL of families of critically ill and/or dying infants.</td>
<td>Cross-sectional descriptive survey.</td>
<td>480 nurses.</td>
<td>Dying infants influential in the level of involvement, cultural/language barriers. Some participants had additional EOL care experiences.</td>
<td>Self-reported survey. Likert scale. BEACONNS questionnaire.</td>
<td>Expertise may have more comfort with aspects of bereavement. Cross sectional design. Convenient sampling.</td>
<td>Nurses who had more experience and bereavement education, worked with bereavement protocols, and who encounters dying infants were more comfortable with all aspects of EOL care.</td>
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<tr>
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<td>Ferguson et al, 2015</td>
<td></td>
<td>Understand perspectives and experiences of novice pediatric nurses about palliative/EOL communication and their perceptions about facilitating discussions with patients and their families.</td>
<td>A qualitative, empirical phenomenology design based on a group-as-a whole theory. Focus discussions regarding communication about palliative/EOL care. Open-ended questions.</td>
<td>3 major pediatric hospitals located in the Midwest United States. 12 focus groups.</td>
<td>Obstacles: Language barriers, parental discomfort withdrawing support, discontinuity of care d/t lack of communication, the nurse’s opinion not valued. Supportive: Allowing families adequate time alone with the child after they have died, parents holding child while life support is discontinued, and providing a peaceful, dignified bedside scene.</td>
<td>Identified focus group leader and a field note recorder. Focus meetings lasting 1.5-2 hours. Questions: reflecting past experiences with palliative care and EOL care. Communication with children and families, and review a list of broad data generating questions focusing on palliative and EOL communication.</td>
<td>Convenient sampling. Limited to pediatric oncology nurses.</td>
</tr>
<tr>
<td>Author</td>
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<tr>
<td>Feudtner et al</td>
<td>2007</td>
<td>To test the hypothesis that individual nurses' level of hope is associated with greater self-reported comfort and competence in providing palliative care.</td>
<td>Cross-sectional, descriptive survey.</td>
<td>420 RNs</td>
<td>Majority had less than 10 years experience, very comfortable working with dying children and their families. Concerned about pain management. Predictors: greater number of years in nursing practice, more experience of palliative education, and higher HOPE were associated with higher levels of comfort working with dying children and their families.</td>
<td>Self-reported survey. HOPE scale. Convenient sampling</td>
<td>Cross-sectional. Self-reported. 44% response rate. Findings cannot be applied to all nurses.</td>
</tr>
<tr>
<td>Author Date</td>
<td>Purpose</td>
<td>Design</td>
<td>Sample</td>
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<tr>
<td>Haut et al, 2012</td>
<td>To determine is the implementation of a formal educational program improves pediatric and PICU knowledge and attitudes regarding palliative care concepts and management of children and their families experiencing life-limiting conditions.</td>
<td>Cross-sectional descriptive survey.</td>
<td>56 RNs</td>
<td>No one received formal palliative care training in their formal nursing education. Supportive: parents holding their child in a pain-free environment, private setting, allow parents to participate in decision making, and appropriate pain and symptom management. Obstacles: Parents not accepting of poor prognosis, pain management issues, difficult death involving weeks to months.</td>
<td>Self-reported surveys using computers. Convenient sampling. Likert questions and open-ended questions. Pretest and posttest.</td>
<td>Cross-sectional. ICU nurse-physician communication questionnaire has limited reliability and validity. No evidence to support appropriate aggregation of data to unit level.</td>
<td>Pediatric nurses are uncomfortable taking care of dying children. Basic education needs to be added on. Include in hospital orientation and added curricula to nursing schools. Include parents in EOL decision-making.</td>
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<td>Purpose</td>
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<td>Sample</td>
<td>Behaviors Obstacles</td>
<td>Data Collection Methods</td>
<td>Design Limitations</td>
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<td>Iglesias et al, 2013</td>
<td>To identify the relative importance of helpful behaviors and obstacles that affect caring for dying patients and families in PICUs as perceived by critical care nurses. Identify facilitators or barriers to families and patients in EOL care.</td>
<td>Cross-sectional descriptive design.</td>
<td>227 questionnaires analyzed</td>
<td>Supportive: providing families with a peaceful, dignified bedside scene, and a place to cry in private. Obstacles: when physicians avoid families, when a terminally ill patient experience a painful intervention, and when families are not accepting of poor prognosis.</td>
<td>Self-reported questionnaires. Likert scale. 48 items. Questionnaire of Helps and Obstacles in providing EOL care to dying patients and their families.</td>
<td>Cross-sectional design. Convenient sampling. Questions and situation were limited to those in survey, may not reflect all barriers.</td>
<td>Communicating needs and preferences of the patient with the team is important to providing appropriate EOL care situations. Plans of care should include families providing care to the patient, allowing them to spend more time with patient and family accepts the patient is dying.</td>
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<td>Iranmanesh</td>
<td>et al, 2014</td>
<td>To determine pediatric nurses’ perceptions of intensity, frequency of occurrence, and magnitude score of selected barriers in providing pediatric EOL care in Southeast Iran</td>
<td>Cross-sectional descriptive design with quantitative approach.</td>
<td>151 participants of registered and auxiliary nurses.</td>
<td>Obstacles: Families not accepting poor child prognosis is one of the most frequent barrier to providing EOL care. No available support person for family such as a religious leader. Poor unit design does not allow for privacy of dying patient or grieving family members, and nurses having to deal with distraught family members while providing care for the patient.</td>
<td>NSCCNR-EOLC questionnaire, revised to 30 Likert scale barrier questions. SPSS for analysis of data. Kolmogorov-Smirnov rest</td>
<td>Cross-sectional design. Convenient sampling. Limited to barriers for nurses, no facilitators were discussed. Needs further research with family perceptions of behaviors and obstacles.</td>
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<td>Wright et al, 2011</td>
<td>To identify the barriers to and facilitators when providing EOL care to dying infants and their families.</td>
<td>Cross-sectional descriptive design with quantitative approach.</td>
<td>74 RNs</td>
<td>Obstacles: Inability of expressed opinions, values and beliefs regarding palliative care, less than ideal environment, technological imperatives, parental demands, and lack of in-service education. Supportive behaviors: Support of palliative care on the unit, parent’s involvement in decision-making if their infants, spending time with the family when the infant dies.</td>
<td>NiPCAS-8 demographic questions and 26 attitudinal questions using a Likert scale.</td>
<td>Cross-sectional design. Convenient sampling. Limited to nurses, need further research with family perceptions of supportive behaviors and obstacles.</td>
<td>EOL care and education continues to be limited. Examination of barriers and facilitators that inhibit or support is warranted to improve care to infants and their families.</td>
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<td>Zhang et al, 2013</td>
<td>The purpose was to evaluate the effectiveness of the bereavement seminar on the attitudes of nurse regarding EOL care of neonates. Regarding characteristics and attitudes providing EOL care, differences in nurse role and comfort, and domains of comfort.</td>
<td>Cross-sectional descriptive design using the Neonatal Palliative Care Attitude Scale. Quantitative study.</td>
<td>49 nurses.</td>
<td>Obstacles: Family not ready to acknowledge incurable condition, language barriers, and time constraints. Also, staff shortages, cultural differences, lack of palliative/EOL care, lack of knowledge of EOL pain and symptom management, conflicting family members.</td>
<td>Self-reported survey questionnaire developed from tools in previous studies. Likert scale. The NiPCAS included 8 demographic questions and 26 attitudinal questions in a Likert scale.</td>
<td>Cross-sectional design. Convenient sampling. Only NICU nurses were interviewed, no other pediatric nurses. Questions limited to those in survey may not reflect all barriers or facilitators.</td>
<td>Five barriers and 8 facilitators. Barriers: inability to express opinions, values and beliefs regarding palliative care, less than ideal physical environment, technological imperatives, parental demands, and lack of in-service education. Facilitators: palliative care in unit, parents involved in decisions.</td>
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