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Pediatric ICU Nurses' Suggestions for
Improving End-of-Life Care

Jeremy Ratliff

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Master of Science

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ABSTRACT

Pediatric ICU Nurses' Suggestions for Improving End-of-Life Care

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Introduction: Of the 34,000 children who die annually, over 28,000 are four years old or younger. Nurses working in pediatric intensive care units (PICU) provide end of life (EOL) care before, during, and after death of these children. The purpose of this study was to determine the suggestions PICU nurses have for improving EOL care for dying pediatric patients and their families.

Methods: A sample of 1047 PICU nurses, who were members of the American Association of Critical-Care Nurses (AACN), were sent a 70-item questionnaire. One open-ended item asked nurses to offer a suggestion for improving EOL care for dying PICU patients.

Results: Responses were received from 235 of the 474 (49.6%) nurses who returned the questionnaire. Eight themes were identified: (1) providing a better environment; (2) physician honesty about prognosis; (3) having a plan for dying; (4) ending futile care; (5) physicians on "same page;" (6) having more staff; (7) receiving more EOL education; and, (8) providing better pain control.

Discussion: Patient centered principles begin with creating an environment that allows the dying process to be centered on the family while fostering dignity. Fostering dignity includes providing an environment that is conducive to supporting quality EOL care. The importance of providing privacy and an appropriate place for the patient and family to feel more comfortable during the dying process was suggested. The need for better communication between providers and families, ending suffering, and having enough staff to support a "good death," were also high priorities.

Conclusion: PICU nurses overwhelmingly suggested that the environment in which health care workers monitor, care for, and support patients and families during death is the greatest area for improvement. Unit design teams need to assure that care areas for dying pediatric children are created to accommodate a dignified and peaceful passing to improve pediatric End-of-Life Care.

Keywords: end-of-life care; dying; pediatric; child; obstacles; suggestions, PICU

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Pediatric ICU Nurses' Suggestions for
Improving End-of Life Care

In 2010, over 34,000 children died in the United States, of whom 28,902 were four years old or younger.¹ Accidents were the leading cause of pediatric deaths followed by cancer and congenital malformations, deformations, and chromosomal abnormalities.¹

Nurses caring for these ill children are with them at the end of life (EOL). However, there are many obstacles that affect EOL care for dying children.² In a survey of 474 pediatric nurses working in pediatric intensive care units (PICU) in the U.S., Beckstrand, Rawle, Callister, and Mandelco discovered the two highest perceived obstacles in pediatric EOL care were (1) language barriers and, (2) parental discomfort with withholding and/or withdrawing respiratory support.²

In a replication of Beckstrand, et al.'s² study, researchers in Spain attempted to identify aspects of care considered to be obstacles to providing EOL care to patients and families. Pediatric nurses, working in PICUs, reported physicians providing hope in tangible terms as least helpful in EOL care. These pediatric nurses viewed physicians as evading family members and families not accepting a poor prognosis as major obstacles.³ Obstacles seen as minimal problems for these pediatric nurses included the nurse having previous knowledge of the patient's poor prognosis and the nurse caring for brain-dead organ donors.³ No other specific research was found regarding pediatric nurses' suggestions for EOL care.

This report is the qualitative portion of a mixed-method study building on other research documenting nurses' perceptions of obstacles in providing EOL care among critical care nurses,⁴ emergency room nurses,^{6,7} rural emergency nurses,⁸ and oncology nurses.^{9,10} However, these past research reports focused mostly on quantitative results. Therefore, a need was identified to

report the rich qualitative data regarding suggestions for improving EOL care from the perspective of pediatric nurses.

Methods

The research question for this study was: *If you had the ability to change just one aspect of end-of-life care given to dying pediatric patients, what would it be?*

A cross-sectional survey research design was used for this study. Descriptions of instrument, setting, sample, procedures, and study design follow.

Instrument

The *National Survey of Pediatric ICU Nurses' Perceptions of End-of-Life Care* questionnaire was used to assess nurses' perceptions of the magnitude and frequency of a set of listed obstacles to providing EOL care in PICU. The instrument was modified from questionnaires used in previous EOL care studies^{4, 6} and was then adapted to focus specifically on perceptions of PICU nurses. This 70-item questionnaire included 52 Likert-type items, 14 demographics questions, and 4 open-ended items. Following initial development, the questionnaire was pretested by 27 pediatric nurses experienced in the care of dying pediatric patients. Findings for the quantitative data were published previously.² This article reports findings from one open-ended question.

Setting and Sample

Following Institutional Review Board approval, a sample of 1047 PICU nurses was purchased from the American Association of Critical Care Nurses (AACN). AACN members who read English, cared for pediatric patients, and had experience in caring for at least one pediatric patient at the EOL were considered eligible for the study. Consent to participate was assumed upon return of the questionnaire.

Procedure

Questionnaires were mailed, with a cover letter explaining the purposes of the study, along with a self-addressed stamped return envelope. An incentive for quick return, a one dollar bill, was included with each questionnaire in the first mailing. One additional mailing to non-responders was completed several months after the initial mailing of the questionnaire. In addition to the quantitative results that were published previously,² study participants responded to an open-ended question regarding suggestions they would have for improving pediatric EOL care for dying PICU patients and their families.

Of the 474 nurses who returned useable responses for the original study, 235 (49.6%) answered the open-ended question offering one or more suggestions to improve EOL care. Content analysis was used to identify categories of qualitative responses. Open-ended survey responses were read individually by a research team consisting of three research experts and two content pediatric experts and then coded with an inter-rater reliability of .96.

Results

Of the subjects who reported gender ($n = 225$), 210 were women (93.3%) and 15 (6.7 %) were men. Subjects ranged in age from 25-64 years old ($M = 41.8$ years, $SD = 10.2$). Subjects reported working as direct care or bedside staff nurses = 187 (82.4%), clinical nurse specialists = 19 (8.4 %), or charge/staff nurses = 16 (7.0%). Hours worked per week were nearly full time ($M = 35$, $SD = 8.7$), with these nurses being highly experienced as RNs, ($M = 16$ years, $SD = 10.6$), including as RNs in pediatric care ($M = 14.4$ years, $SD = 10.0$) (see Table 1.)

After analyzing the suggestions to improve EOL care, eight themes were identified. Themes for improving EOL care were: (1) providing a better environment; (2) physicians providing more honesty about prognosis; (3) having a plan for dying; (4) ending futile care; (5)

physicians on “same page”; (6) having more staff; (7) receiving more EOL education; and, (8) providing better pain control (see Table 2). Ten items could not be categorized and were excluded from analysis.

Themes

The following themes highlighted these nurses’ suggestions for individualized care as children transition from life to death.

Providing a better environment. PICU nurses overwhelmingly suggested providing a better environment at the EOL ($n = 52$) including a bigger space for patients and families, with more privacy, leading to a quieter and more peaceful atmosphere. Suggestions for improvement described a designated quiet place of privacy and increased space for patient and family as one nurse suggested:

To create a "death suite" where [there is] a large adjoining room to the patient's room so extended family can be present but yet not interfere with taking care of the patient. This may require moving the patient...but [the room] would be great for families. [The room] would need to be located where the traffic does not disrupt the rest of the unit.

Another nurse suggested the need for privacy and the impact not having privacy had on one family of a dying child.

I wish all families could have as much privacy as they need. In our PICU we have 2 private rooms [and] we try to put patients in them if end-of-life issues arise but when that is impossible we only have curtains. One mom wrote us several months after her daughter died and said the hardest part [at the time of death] was hearing people laughing outside the curtains.

Another nurse had a similar vision regarding an ideal physical environment. *“More privacy from other patients and families in [the] unit. Patient rooms seldom have enough [space] to accommodate all of [the] family and friends . . . during the last hours of life.”*

Clear frustration was noted in this nurse’s suggestion of watching a child die in an environment not conducive to death.

We would have a room designated/designed for a dying child. A place for parents to sleep/shower. A window with a rocker and a set up for suction IV poles/etc., to accommodate holding a dying child. We watch kids die all the time and yet we don’t accommodate this process.

Physicians providing more honesty about prognosis. Numerous nurses ($n = 43$) directly suggested that physicians provide more “honest,” “realistic,” and “truthful” communication to families about children’s prognoses. One nurse stated, *“I think the biggest obstacle I have to deal with in pediatric EOL care is that parents are not given a truthful realistic picture...and their decisions are based upon this [inaccurate information].”* Similarly, another nurse stated, *“The biggest problem has always been physicians. They give families unrealistic hope and options.”* A third nurse stated, *“MD’s giving parents unrealistic expectations and ungrounded hope for recovery of their child thus prolonging the pain and suffering.”* One nurse provided a comment summarizing the suggestions of many nurses on this topic, *“Be more honest with families.”*

Having a plan for dying. Many nurses suggested that a plan for dying be developed for terminal children where care could include hospice, home, or complementary/holistic care ($n = 38$). One nurse stated, *“It would be great to give families of children more power in deciding where the death would occur and under what circumstances.”* Another nurse’s vision was of a

plan that extended beyond the child's death, as in, "*Planning the death experience....not just the support of hand & foot prints [for a] memory box but a real plan that includes structured follow-up at six months and a year after death.*"

Ending futile care. Nurses also suggested ways to reduce suffering, including initiating EOL care earlier rather than continuing futile care ($n = 31$). One said, "*Extubate sooner. Why do kids have to die on machines? We were born without machines; our interventions [should be] reduced when dying prevails.*" Similarly, another nurse suggested in their clinical experience,

We offer too many invasive, costly treatments just because we can, not because they will change the outcome. I am saddened by how often we prolong the inevitable. Children often look unrecognizable when they're on ECMO, edematous, bleeding, etc. It's unfair to ask parents if they want to stop care, in certain situations, because they feel like they are causing the death. I would like for us to be okay with saying, 'it's time to stop' when it objectively is.

Another comparable suggestion was,

I wish we didn't have to 'keep dead children alive' just because the family does not understand/believe the child is gone. We have had several children that barely pass the brain death testing (i.e., one breath every five minutes) and we end up keeping them alive indefinitely because [the] family is unable to understand [the] situation.

Similarly, other participants spoke of the need to "*stop aggressive treatment before the [child] becomes unrecognizable.*" Providing extensive treatment leading to distortion of physical appearance or actually seeming to cause harm was supported by the realization from another nurse who stated, "*We have so much technology today, that at times I feel like many children*

truly suffer at the end of life, with a terminal diagnosis or accident or injury. I just wish the families could be with their children in peace.”

Physicians on the “same page.” While some nurses suggested the entire care team to be on the “same page” regarding prognosis and orders, overwhelmingly the most common request, in this theme, was that physicians needed to consult with each other about the plan of care ($n = 28$). One nurse stated, *“Force the MDs to talk to each other and [then] represent each other when talking to families.”* Another nurse agreed writing, *“That all [physicians] would be on the same page and present the same picture to the family.”* A third nurse noted the need for teams to work together by stating, *“When there is more than one service—having all the teams on the same page.”*

Having more staff. Suggestions regarding the need for more staff encompassed two general topics ($n = 27$). First, the need for ancillary personnel to help care for the child and family including social workers, clergy, and child-life specialists. As one nurse suggested, *“Having appropriate support staff available [such as] clergy, social workers; especially on off-shifts.”* Second, the need for extra nursing staff so that the primary nurse caring for the dying child would not have to care for a second patient but could devote all their time to one-on-one care of that child. *“All EOL care should be provided 1:1; in other words, [the] nurse should NOT be assigned another patient,”* stated one nurse.

Receiving more EOL education. More EOL education was suggested for nurses, physicians and other health care providers, and families [$n = 24$]. EOL education for nurses seemed to gravitate toward empowering nurses with skills to provide holistic care for patients and families. One said, *“I wish I was more comfortable around the family. I’ve been a nurse a long time, but still seem at a loss for words in these situations.”* Another said,

I wish I knew what to say to parents. I never feel like I say the right thing. Some nurses I work with are so good at working with grieving families and I wish I could learn from them.

Several spoke of the importance of learning more about culture and death, as suggested by one who said, *“My unit does a very nice job of EOL education for all our nurses. The difficulty I have is our cultural competence. I think we miss this sometimes.”*

EOL education for physicians and other health care providers revolved around education on how to talk to families and deliver bad news. The importance of having *“physicians sit with families and listen”* rather than being in *“a rush to leave”* was also suggested.

Education for families included information about terminology such as phrases like *“brain death”* and *“withdrawal”* or teaching families how to say goodbye to their dying child. Another suggestion for families was, *“providing education on organ donation now and in the future.”*

Providing better pain control. Nurses focused on effective pain management to minimize suffering ($n = 21$), suggesting implementing *“effective pain management protocols,”* noting that, *“Too many physicians are hesitant to treat pain aggressively.”* One nurse said it would be helpful, *“not having to fight with physicians for adequate pain control/comfort medications due to physician fear that ‘it might make them stop breathing,’ etc.”*

Another nurse expressed the desire to, *“be able to provide care in a manner that does not cause discomfort to the child/family. So many of our activities cause discomfort and pain...when[the] child is terminal we continue with activities such as suctioning, turning, mouth care, etc.”*

Summary

The overarching suggestion by these PICU nurses was centered on supporting the child making a good transition from life to death while providing individualized care to both patients and families. One nurse emphasized the importance of providing individualized EOL care by stating, *“Every family deals with death so differently. We have to be flexible with each individual situation. No one family has the same expectations or deals with the stress the same way.”*

Discussion

Nurses’ suggestions for improving pediatric EOL care are closely tied to patient- and family-centered care principles, including demonstrating respect and fostering dignity, sharing information with patients and families, sharing in decision-making, and family/professional collaboration.¹¹⁻¹³ Patient centered principles begin with creating an environment that allows the dying process to be centered on the family while fostering dignity.

EOL patient-centered care includes an environment that is large enough to accommodate immediate family members while being quiet--away from the normal noise that surrounds a busy nursing unit---allowing for privacy while the parents hold their dying child. Similar to our findings, other authors have also identified the importance of privacy and providing an appropriate place for the patient and family to feel more comfortable during the dying process.³ Researchers have reported that families need psychological support, privacy and appropriate space, and more personnel who are sufficiently educated in the process of dying.³ In addition to enhancing environment, improvements in communication and family support were also suggested.

Physicians sharing honest, realistic, and truthful information with patients and families, while also establishing an EOL care plan followed by all health care providers, was seen as essential for improving EOL care. Other researchers indicate the importance of the medical team

agreeing on a plan of care, the family accepting the patient is dying, appropriate space for family closeness, and ancillary support to help the family as they react to the situation.¹⁴ In addition, families need clear information and more time to visit; particularly in the case of dying children.³

Additional items included the importance of providing shared participation in decision making between family and the healthcare team as important in a total care approach. Embracing physical, emotional, social and spiritual elements which focuses on enhancements of the quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite care through death, and bereavement support should begin when terminal illness is diagnosed and continues regardless of whether a child receives treatment targeted at the disease.¹⁵

Findings presented here confirm other reports of critical care nurses' perceptions of EOL care^{4, 16-17} in PICU nurses throughout the US in a variety of clinical settings. Nurses documented the importance of improving the pediatric EOL care environment, importance of stopping aggressive treatments when futility was evident, the need for clear communication, and the need to support and strengthen caregivers. As one example, the California Children's Hospice and Palliative Care Coalition was developed to increase access to hospice services for dying children and serves as a pilot project facilitating the development of federally funded EOL care.¹⁸ Another model helpful to clinicians and nurse leaders is the Pediatric Advanced Care Team (PACT).¹⁹

Study findings support a theoretical model of peaceful EOL care, facilitating closeness to significant others²⁰ and the Respectful Death Model of EOL care.²¹ Nursing leaders can use the findings of this study to generate changes in the acute care environment that lead to facilitating peaceful passing from life to death.

Limitations of this research included using a non-random sample of PICU nurses as we mailed to the entire sample of self-identified PICU nurses who were members of AACN. Therefore, these results are only generalizable to PICU nurses who are members of AACN. A second limitation was that only nurses were surveyed. Obtaining physician perceptions of EOL care would have added to the richness of the data.

Conclusion

While the overarching theme of these nurses' suggestions focused on supporting the child through the transition from life to death, eight detailed themes were identified. PICU nurses overwhelmingly wanted an improved environment in which all health care workers would be able to appropriately care for, treat, and support the child and their family at the EOL. Unit design teams and administrators need to consider these findings as they plan for, or remodel, PICUs in their hospitals. Improving the PICU environments would be a major step toward helping nurses focus care allowing for an improved peaceful death.

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Table 1 *Demographics*

Returned: 235 PICU nurses provided 283 individual suggestions for improvement of pediatric EOL care.			
Characteristics*			
Sex	<i>n (%)</i>		
Male	15 (6.7%)		
Female	210 (93.3%)		
Age	<i>M</i>	<i>SD</i>	<i>Range</i>
	48.2	10.2	24-63
Years as RN	16.1	10.6	1-38
Years in Peds ICU	14.4	10.0	1-38
Hours worked/week	35.2	8.7	0-80
Number of beds in unit	25.4	15.4	6-120
Number of dying patients cared for:			
>30	45.8%		
21-30	12.8%		
11-20	18.5%		
5-10	18.5%		
<5	4.4%		
Highest degree:	<i>n %</i>		
Diploma	11 (4.9%)		
Associate	156 (69%)		
Bachelor	54 (23.9%)		
Master	3 (1.3%)		
Doctoral	2 (0.9%)		
Position Held at Facility:	<i>n %</i>		
Direct care/bedside nurse	187 (82.4%)		
Clinical Nurse Specialist	19 (8.4%)		
Charge nurse/staff nurse	16 (7.0%)		
Other	5 (2.2%)		

*Listed numbers are for subjects who responded to items.

Table 2 *Themes****Themes**

1. Providing a better environment including more privacy, bigger space for patient and family, and a quieter area for end-of-life care ($n = 52$).
2. Physicians more honest about prognosis and less false hope about unlikely patient recovery ($n = 43$).
3. A clear plan for dying is created leading to a “good, peaceful” death ($n = 38$).
4. Ending futile care of dying pediatric patients ($n = 31$).
5. Health care providers including physicians, specialists, and nurses, on the “same page” regarding care for dying patients ($n = 28$).
6. More nursing and ancillary staff including more nurses (for 1:1 care), social worker, palliative care specialists, and clergy ($n = 27$).
7. More end-of-life education to families, nurses, & physicians ($n = 24$).
8. Pain control managed better; less suffering ($n = 21$).

*Themes that had more than 20 responses. Ten suggestions could not be categorized and were eliminated from analysis.