



## Self-Reported Experiences of Pediatric Nurses Regarding Care of Children at the End-of-Life

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### Background

Pediatric nurses in children's hospitals frequently provide care to dying children. Little is known, however, about the nurses' feelings, beliefs and experiences when a child dies.

This qualitative research was part of a larger quantitative study (Feudtner, Santucci et al., 2007) asking nurses to rate their competency, attitudes, and self-reported beliefs about palliative care.

### Methods

- We conducted a web-based survey of nurses at the Children's Hospital of Philadelphia. All CHOP nurses were asked to participate with an e-mail request. Participation was voluntary and anonymous. The Committee for the Protection of Human Subjects approved this study.
- Forty-four percent of eligible nurses responded (410 of 932) to the entire survey. The survey consisted of questions inquiring about nurses' knowledge, attitudes, practices, and experiences regarding several domains of palliative care i.e., competency in pain and symptom management, communication, role of hospice, comfort with providing psychosocial support, appreciation of spiritual, cultural and ethical issues, advance directives and limitations of care using a 5-point Likert scale response format.
- The final question was open ended and intended to better understand, in the nurses' own words, a difficult experience when caring for a dying child. Not all respondents had this type of experience. Of the 410 nurse respondents, 240 answered this question. **"In 60 words or less, please describe your most difficult experience with a dying child and specify what made it so difficult"**.
- Data from the responses were analyzed using qualitative content analysis. Each quote was independently read several times by two nurses. Each identified codes representing the words of the subjects with the intention of capturing their experience. Codes were then collapsed into categories independently and then discussed together. Themes were identified in 2 ways, through collapsing categories representing like concepts and by identifying exemplar quotes. Each method complemented the other and provided a degree of confirmation across the entire analysis.

### References

Feudtner C., Santucci G., Feinstein JA., Synder CR., Rourke MT., Kang T. *Hopeful thinking and level of comfort regarding providing pediatric palliative care: A survey of hospital nurses*. Pediatrics 2007;119:186-192

### Exemplars

Quotes representative of each theme are presented below:

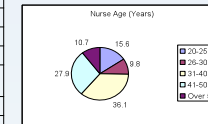
Area	Freq.	%
<b>Miscommunication</b>		
♦ "Most difficult experience generally with a dying child and their family have always centered around issued related to miscommunication about the impending death and what has-or has not been discussed the child and family members"		
♦ "My most difficult experience was with a child who was end of life. Miscommunication between the health care team and the family was horrible. Different attendings presented different views, such as one presenting transplant as an option, when it wasn't"		
♦ "My experience with a dying child was very difficult because the family was divided and there was a great deal of bickering going on between the parents and the welfare of the child was not being considered"		
<b>Ethical Dilemmas</b>		
♦ "My most difficult experiences have involved giving prescribed medication to ease the suffering when you know that you may have facilitated the end result"		
♦ "A seven year old child was beaten...and came to us near death. His end of life was so painful and lonely and we the ED abused his body more in a futile attempt to save him. I will never forget him"		
♦ "The family did not want us to tell the child she was dying even when the child asked direct question about death and angels"		
<b>Professional Boundaries</b>		
♦ "The hardest situation I had was with a child whose family I became very close with and therefore very close to the baby. Being connected by the parents always makes the child's death more difficult"		
♦ "When I was a newer nurse I was unable to maintain professional boundaries and literally grieved over a patient to where it hindered my home life for a very brief, but notable period of time"		
♦ "It's difficult because though you know it may be the best thing for the child or there may be no other options- it's hard because as a nurse you want to make people and situations better. You also become attached to the patient and the family"		
<b>Making meaning</b>		
♦ "Traumatic deaths-the child who was healthy in the morning and dead by midnight. They hit too close to home as a mother. They remind me that death has no reasons or prejudices. It is a random act of tragedy"		
♦ "It was about 25 yrs ago-a beautiful newborn, born without kidneys. It was heart wrenching to be with the family over the few days that the baby lived. Difficult, but an experience that I am glad to have had; profiles in love and courage"		
♦ "I helped a young boy (11 years old) write a card to his parents before he died thanking them for all their love and support"		
<b>Advocacy</b>		
♦ "A child's struggling to breathe because we were not permitted to give additional sedation. It was heartbreaking to see a parent watch their infant struggle so hard when I could have made them more comfortable"		
♦ "Feeling the medical team became invisible as death approached, having to cover for this to the family"		
♦ "Knowing that a situation is ultimately going to end with the death of a patient and continuing to enforce or reinforce interventions that are not of benefit and sustain false hope"		

### Demographics

N= 244 Nurse Respondents

This sample represents 60% of the original study sample. The majority of the respondents were female (90.2%), less than 40 years of age (n=150, 61.5%), and in nursing practice for 15 years or less (n=139, 57%). Nurses worked in a variety of clinical settings.

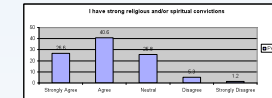
Area	Freq.	%
Oncology	38	15.6%
PICU	43	17.6%
Cardiac ICU	26	11.5%
NICU	18	7.4%
ED	26	10.7%
Medical/Surgical	41	16.8%
Rehab	12	5%
Other	38	15.6%



# Yrs. in Nursing Practice	Freq.	%
0-5	70	28.6%
6-10	41	16.8%
11-15	38	15.6%
16-20	42	17.2%
21-25	24	9.8%
26-30	20	8.1%
>30	9	3.6%

All ICU n=87 (35.7%)

A majority of nurses (67%) reported they have strong religious or spiritual beliefs



### Results

Data from qualitative content analysis yielded five general themes:

- Miscommunication between nurses, physicians and/or families regarding goals or limitations of care
- Ethical dilemmas regarding goals of care or withdrawal of care
- Difficulty in maintaining professional boundaries when caring for a dying child
- Complexity of making meaning or making sense when a child dies
- Ability to advocate for the patient and family at the end-of-life

### Conclusions

Pediatric nurses recognize the importance of providing care for children at the end-of-life. These results highlight their concerns regarding providing this type of specialized care. Implications for practice include providing support and nursing education that addresses the particular needs of dying children and their families. Additionally, the findings emphasize that didactic methods of instruction may be insufficient to meet the needs of nurses, recognizing instead that nurses often express a need to process (i.e., debrief) particularly difficult end-of-life nursing care experiences, and thus, the time and resources required to accomplish debriefings must be provided. For example, many nurses recognized their first experience with a dying child and their family as particularly challenging. Identification and supportive interventions for nurses in this situation would be valuable.