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# Care of the Dying Child: Pediatric ICU Nurses' Perceptions of Obstacles and Supportive Behaviors in End-of-life Care

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Photo courtesy of National Cancer Institute

## Background

Each year 55,000 children die in the United States<sup>1</sup>. The vast majority of children's deaths, 75 – 85%, occur in hospital settings with most in pediatric intensive care units<sup>2</sup>. Oftentimes, a nurse is at the bedside of the dying child. Determining the barriers and supportive behaviors in pediatric end-of-life (EOL) care is needed.

## Research Questions

- What are the sizes and frequencies of selected obstacles in providing EOL care to pediatric patients as perceived by pediatric nurses?
- What are the sizes and frequencies of selected helpful behaviors in providing EOL care to pediatric patients as perceived by pediatric nurses?
- What are the perceived obstacle magnitude (POM) scores (the obstacle size mean multiplied by the obstacle frequency mean)?
- What are the perceived supportive behavior magnitude (PSBM) scores (supportive behavior size mean multiplied by the supportive behavior frequency mean)?

## Design

A descriptive, cross-sectional quantitative survey design

## Sample

A geographically dispersed, national sample of 1047 members of American Association of Critical Care Nurses (AACN) who had provided EOL care for inpatient children with life-limiting illnesses and who read English.

## Method

A 76-item questionnaire that was adapted from three similar surveys with critical care nurses<sup>3</sup>, emergency nurses<sup>4</sup>, and oncology nurses<sup>5</sup>, was mailed to subjects over two mailings. Subjects were asked to rate the size and frequency of listed obstacles and supportive behaviors in caring for pediatric patients at the EOL.

## Results

Return after two mailings yielded 474 usable questionnaires from 985 eligible respondents for a return rate of 48.2%. The three items with the highest perceived obstacle magnitude (POM) for size and frequency means were:

1. Language barriers
2. Parental discomfort in withholding and/or withdrawing ventilation
3. Providing a peaceful, dignified bedside scene for family members once the child has died

### Intensity Mean, Standard Deviation, and Rank; Frequency Mean, Standard Deviation, and Rank; and Perceived Obstacle Magnitude for Obstacles in End-of-Life Care

Obstacles	Intensity M*	Intensity SD	Intensity Rank	Freq. M**	Freq. SD	Freq. Rank	POM***
Language barriers	4.50	7.66	1	3.94	10.83	1	17.73
Parental discomfort in withholding and/or withdrawing ventilation	4.50	8.81	2	3.93	10.83	2	17.69
The discontinuity of care of the dying child from lack of communication between interdisciplinary team members	3.98	8.91	3	3.39	11.78	7	13.49
Nurse's opinion about the direction of their patient's care is not valued	3.85	9.93	5	3.47	12.57	5	13.36
Families not ready to acknowledge their child has an incurable disease	3.88	0.89	4	3.25	0.85	8	12.61
Dealing with anxious family members	3.11	1.22	16	3.57	0.99	4	11.10

\*Intensity of helpful behavior response choices were: 0 = Not a help to 5 = Extremely helpful.  
\*\*Frequency of helpful behavior response choices were: 0 = Never occurs to 5 = Always Occurs.  
\*\*\*PSBM = Perceived Supportive Behavior Magnitude (behavior size M multiplied by behavior frequency M).

### Intensity Mean, Standard Deviation, and Rank; Frequency Mean, Standard Deviation, and Rank; and Perceived Supportive Behavior Magnitude (PSBM) for Supportive Behaviors in End-of-Life Care

Supportive Behaviors	Intensity M*	Intensity SD	Intensity Rank	Freq. M**	Freq. SD	Freq. Rank	PSBM***
Allowing family members adequate time to be alone with the child after he/ she has died	4.71	0.53	1	4.49	0.78	1	21.15
Allowing parents to hold the child while life support is discontinued	4.64	0.59	3	3.98	0.91	2	18.47
Providing a peaceful, dignified bedside scene for family members once the child has died	4.58	0.65	6	3.96	0.90	3	18.14
Having the code status of the child clearly described in the chart	4.58	0.77	5	3.85	1.15	4	17.63
Teaching families how to act around the dying child such as, "she can still hear...it's okay to talk to her"	4.27	0.80	10	3.84	0.92	5	16.40
Physicians who are compassionate, but very clear about prognosis	4.68	0.60	2	3.14	0.96	9	14.70

\*Intensity of helpful behavior response choices were: 0 = Not a help to 5 = Extremely helpful.  
\*\*Frequency of helpful behavior response choices were: 0 = Never occurs to 5 = Always Occurs.  
\*\*\*PSBM = Perceived Supportive Behavior Magnitude (behavior size M multiplied by behavior frequency M).

## Conclusions

Pediatric nurses play a vital role in caring for dying children and their families. Overcoming language and communication barriers with families and between interdisciplinary team members could greatly improve the EOL experience for dying children and their loved ones.



<sup>1</sup> Children's Hospice International [CHI], 2004; Initiative for Pediatric Palliative Care [IPPC], 2003  
<sup>2</sup> Field & Behrman, 2003  
<sup>3</sup> (Beckstrand & Kirchhoff, 2005)  
<sup>4</sup> (Beckstrand, Smith, Heaston, & Bond, 2007)  
<sup>5</sup> (Beckstrand, Moore, Callister, & Bond, 2008)