

How nurses can better support families of dying children

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Most nurses that work in a children's critical care unit feel prepared and trained to help parents during the final moments of their child's life and the difficult hours that follow.

The biggest challenges in helping families cope play out earlier than that tragic moment, concludes a new study by Brigham Young University professor Renea Beckstrand and graduate student Nicole Rawle.

Based on research involving nearly 500 pediatric nurses, Beckstrand and Rawle identify the three biggest obstacles to supporting families of dying children:

- Language barriers (including medical jargon as a foreign language)
- Parental reluctance to withdraw life-support technologies
- Mixed signals from different specialties on the medical team

Improving end-of-life care is Beckstrand's expertise, and Rawle came on the project with a background in pediatrics. Together they gathered comments from nurses around the country. These nurses have on average 13 years' experience in the field of pediatric critical care. More than half have cared for at least 20 dying children.

"Their opinions matter," said Rawle. "They are the experts in caring for the dying child."

The study appears this week in the *American Journal of Critical Care*, a top nursing journal.

"[Parents](#) are looking for hope," said Beckstrand, who teaches and researches in BYU's College of Nursing. "If a nurse tells parents that the child squeezed their hand, parents think the child will get better. If any one of the specialists returns a positive report, they think the child will survive. What we teach is to be very clear with the family from the beginning and cover all aspects of assessments and provided care."

Beckstrand notes that accidental injury is the leading cause of death among children. Too often counseling and comfort measures are not introduced until the child's recovery is beyond hope.

Other research has documented that when physicians are up front about prognosis and options, more parents plan to spend the final moments with their child at home in peaceful surroundings.

Rawle will complete her master's degree next summer and is a co-author on the study. She says conducting this research motivated her to make her nursing practice both evidence-based and compassionate.

"I am walking away with increased respect and admiration for those pediatric [nurses](#) that stand at the bedside holding the hands of dying children, comforting the parents, and serving as liaison between family and physician," Rawle said.

Provided by Brigham Young University

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