Each year, roughly 30,000 families face the difficult decision of continuing life-prolonging medical care for a terminally ill child. The heartbreaking decision to extend the life of the child while minimizing the child’s suffering can be daunting for these families.

Lisa C. Lindley first became aware of these challenges over 20 years ago while working as a human resources professional for a Fortune 500 company. Her responsibility for guiding employees through health benefits, compensation, and labor relations brought her to the front lines of a complex health care system in need of reform. Back then, lifetime and procedure restrictions limited the type and frequency of care available to children with serious illnesses. A child may have received one cancer treatment but been denied the next, resulting in desperate parents frantically searching for health care solutions.

“I could see the whole picture of chaos that went on with trying to care for these kids and how the system didn’t work,” Lindley said. “It has gotten better, but that experience has fueled my passion for these kids and families.”

Lindley went back to get her PhD in nursing from the University of North Carolina at Chapel Hill. Eventually she made her way to the University of Tennessee, Knoxville’s College of Nursing, where she had the opportunity to teach and conduct research while remaining close to her family.

“Being a Vol nurse is being involved with my community and my community of scholars,” Lindley said. “We’re really here for the community as best we can.”

In 2010, the passage of the Affordable Care Act gave pediatric patients and their families the choice of receiving concurrent hospice care, which allowed patients to continue life-prolonging therapies while enrolled in hospice. Although the regulation reduced the difficult choices faced by these families, there has been little evidence on its effectiveness in improving patient outcomes.

“This is such a vulnerable and underserved population,” Lindley said. “It’s important to understand what their experiences are and what care models can offer to them to improve both end-of-life experience and how the families can navigate through that.”
Currently funded by the National Institute of Nursing Research, Lindley is examining the effectiveness of patient outcomes using concurrent hospice care compared to standard hospice care. Sifting through a Medicaid claims data set acquired by the Centers for Medicare and Medicaid Services, Lindley and her team are analyzing the data of more than 20,000 children in hospice nationally.

By evaluating outcomes such as how many transitions the children have at end of life and the number of providers they see, then evaluating the cost associated with care, Lindley hopes to get a real understanding of what’s going on with these children and provide the evidence needed to inform nursing practice.

“What’s been so surprising so far is how many hospice episodes per child there are,” Lindley said. “These kids are cycling in and out of hospice, and you can only imagine care continuity is a problem.”

Lindley is in year two of her four-year award. Her advice to those interested in getting involved in pediatric hospice care research: “We’re a small field and everybody kind of knows each other. Connect with community. Find a way to utilize new technologies, new methodologies to really explore questions.”

Following in the steps of Florence Nightingale—the pioneer of modern nursing, who used her passion for statistics to save lives—Lindley is leading the way for concurrent care implementation by using data to evaluate its current effectiveness in pediatric hospice.

Lindley said, “Data are much more complex. We spent a year acquiring and mapping out the architecture of the data. We had to create complicated algorithms just to use the data we were given.”

Despite the complexity of the study, Lindley is inspired and motivated more than ever.

“I am so excited that concurrent hospice care has survived these past 10 years and, I’m going to say, flourished. We see kids today using this care delivery model that wasn’t available to them before,” Lindley said.

March 23 marks the 10th anniversary of concurrent care implementation through the Affordable Care Act (Concurrent Care for Children, ACA Section 2302).

For more information on Lindley’s work on concurrent care, visit pedeolcare.utk.edu.

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