

Patients at the end of life: as peaceful as possible



When Karrie Cummings Hendrickson decided to become a nurse, she wasn't drawn to the traditional path of treating patients who after a short hospital stay were going to get better and go home. Hendrickson wanted to help children with terminal illnesses, young patients for whom some measure of peace and a painless death were about the most they could hope for.

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Hendrickson, who is a third-year doctoral student at YSN, is doing her dissertation on end-of-life care for children with cancer. “Not every child can be cured,” she says. “For those who can’t, I want to help them have a good death.”

By a “good death,” Hendrickson doesn’t just mean trying to make her patients happy, although certainly that’s important. Hendrickson means doing what’s best for the child in the context of addressing the emotional needs of the whole family. “Families suffer a lot when a child is terminally ill,” she says. “They may want to keep the child alive as long as possible on an ICU ventilator, or they may want to try an experimental procedure that probably won’t work. The patient’s health care team may think the best thing would be to let things happen naturally, to spare the child more pain or stress. The tricky part is managing the best outcome for everyone,” says Hendrickson.

Although this work couldn’t be more central to a nurse’s mission, Hendrickson, who has been a staff nurse, head nurse, and nurse manager at Baptist Memorial Hospital in Oxford, Mississippi for five years, has been surprised by how little research there is on the subject. “I really enjoy working with special-needs children. It’s a group that needs our help, but it’s an area where there isn’t a lot of information to draw on,” she says. Hendrickson’s goal is to help fill that void by focusing on her other professional interest—research.

While still an undergraduate at the University of Mississippi, Hendrickson thought she had found her calling when a professor invited her to help him conduct research in his invertebrate taxonomy laboratory. That experience convinced her that she wanted to be a researcher. “I loved it,” she says. “I loved learning new things and sharing my findings.” But Hendrickson had reservations about devoting her life to the study of primitive marine invertebrates. “I missed people. I didn’t think I’d be happy dividing tiny creatures into class and phyla.”

When Hendrickson heard about the nursing program at Vanderbilt University, she thought she’d found what she was looking for—a career that combined her desire to make a difference in people’s lives with her interest in research. After she joined a study of the pediatric population and collaborated on a research proposal for a multi-disciplinary approach to diagnosing bulimia nervosa, she knew she’d made the right choice.

“I’ve always liked old people and very young people,” Says Hendrickson, who is 31. “They demonstrate so much courage. They’re so tough and inspiring. People my age don’t handle things as well.” Hendrickson thinks she’s drawn to these two age groups because of her close relationship with her grandfather and because she had a sister who was stillborn.

At Yale, Hendrickson is continuing her patient-based research. She’s studying end-of-life care for children, focusing on the current practice of administering clinical care until the patient’s outcome is terminal and then switching to palliative care. Rather than making the two disciplines mutually exclusive, Hendrickson wonders if patients should be treated more holistically. “Some oncologists feel uncomfortable talking to patients and families. They just want to pass the patient on to the palliative care team,” she says. “But patients don’t want to suddenly have to get to know somebody new. They want a health care team that’s going to stand by them from the time of diagnosis to the end.”

Hendrickson’s work, which involves data analysis of the Connecticut Tumor Registry and hospital records, also touches on health care policy and insurance coverage. For example, she’d like to explore whether it would be cost effective, in terms of reducing sick days, to cover bereavement counseling for families who lose a child to a terminal illness.

Hendrickson’s research has been aided by her classmates and professors at YSN. “I love Yale. The best thing is the faculty and classmate support,” she says. Hendrickson gets guidance and advice from a range of professors. “There’s no faculty member whose area of interest is the same as mine,” she says, “but everybody’s been very nurturing and helpful.”

Her work at Yale has also been enhanced by her own teaching at Quinnipiac University, and by her clinical

experience. She and her Quinnipiac students spend one day week at a hospital in New Britain, Connecticut where they have clinical contact with children ranging from survivors of serious car accidents to babies who were born with severe genetic abnormalities. “You learn by doing,” she says. “I love research, but I also love being at the bedside. Patients and families—that’s the focus of everything we do. That’s why we’re in health care.”

Hendrickson knows many people wonder why she’s drawn to such a seemingly depressing area of health care. Two anecdotes offer an explanation. The first involves a young woman with terminal colon cancer who Hendrickson was treating. She knew she was terminal, but her husband and son either didn’t understand the severity of her condition or were in denial. When she died they were stunned, and Hendrickson realized the patient’s health care team had failed her. “We should have gently brought them along, so they would have been better able to accept it.”

The second anecdote involves a story she heard told at a conference about a patient who had AIDS and knew he was going to die. He figured his funeral would be fun, and he didn’t want to miss it. So he scheduled it for when he was still alive. “It was a wonderful plan to end a life—with a celebration,” Hendrickson says.

The lesson, as Hendrickson sees it, is that the end of life is an event of primal significance; it can be bad or it can be good or it can be bad. Hendrickson’s mission, with the help of the training she’s getting at YSN, is to make it as peaceful and positive as possible.

“There’s nothing I can think of that I would rather do,” she says.

