Perceptions of Pediatric Home Care and Hospice: How Family-Centered Care Can Help

By Lisa Yarkony, PhD
“Seth died as we had often talked about,” the father of a young leukemia victim recalled. He was “cuddled in our arms before a blazing fire in utter peace and quiet. We have such good feelings about the peace of that moment that it has been immeasurably easier to deal with this reality.” The facts are that Seth was just 19 months old at the time and he was one of more than 53,000 children and teens who die in the United States each year. Like Seth, some of them are able to die at home where, hopefully, there’s always someone to hug them and hold their hand. This is what happens when parents work with pediatric home care and hospice nurses as part of a family-centered team.

To lose a child is a profound emotional shock, even if the child is not your own. Understandably, the family members aren’t the only ones who feel anxious and sad when a child is seriously ill. Home care and hospice providers face their own stresses when they care for children with life-limiting conditions. The experience involves deeply held beliefs about child rearing, hope, and death. Left unexplored, these beliefs can make it harder for nurses to support patients and their families. So a pediatric model of home care and hospice must address the perceptions of providers and how they relate to those of parents, siblings, and young patients themselves.

Most families want home care because it allows the child to be in a more “normal” environment than a hospital or other institution. The true value of home care is realized only if the resources and supports in the home allow children and their families to lives as normally as possible and relieve the emotional and physical strain associated with having a medically fragile child. Parents depend on nurses for help with medication and the technology that keeps these kids alive and at their healthiest. With the assistance of home care nurses, parents can safely care for a child who has a tracheotomy and/or requires a ventilator, for example. And they can cope better with their child’s condition when a nurse also gives them emotional support — something nurses may find it a challenge to provide.

Most professional caregivers aren’t well trained to deal with the death of a child. Nurses are trained to operate medical devices and perform the tasks required of care regimens. But they receive little guidance in sorting out their personal attitudes toward death, especially the death of a child. When they face a child’s potential death, many emotions can boil up and come into play, and failure to deal with those feelings might make it appear as though some nurses lack compassion and patience. But the reality is that they may just be overwhelmed by unchecked and difficult emotions.

This can be especially true when a nurse has a long-term relationship with a child. Home care nurses are often involved from the time of a child’s diagnosis through up-and-down phases of hope and despair, recovery and relapse, deterioration, and death. It is heartbreaking and emotionally draining to watch a child’s condition decline over time, especially when a close bond has formed, as it often does. This is, first of all, part of the nature of home care, which engages patients in a far more personal environment and interaction than the more sterile, removed-from-the-personal exchange often associated with a visit with a health care professional. And there’s a tendency to cross professional boundaries when working with children, so nurses come to feel more like a friends. This can lead to even more stress, as a group of nurses revealed in study conducted by researchers at Duke.

The nurses described crossing the boundary as “becoming overly involved,” “not being objective,” and “wearing their hearts on their sleeves.” They said this made it difficult for them to give hospice care to children and their families. It led to professional strife, as one nurse explained: “Nurses are chastised when they take it all too personal. It makes it difficult, and professional boundaries get crossed time and time again. It is not good practice in terms of patient care, and it takes a very high toll on the staff. If they are going to survive in this work, they need some better skills to know how to transition into palliative care.”

One of the first coping skills that providers must learn is the ability to come to terms with their own feelings about children with life-limiting conditions. Nurses must gain comfort in working with seriously ill children and must be able to move toward instead of away from them as they are dying, when that is the case. They must dedicate time to interests outside of work, and they must learn to set boundaries with both families and their children. Nurses should remember they are part of a team and they are not responsible for meeting all the patients’ and families’ needs all by themselves.

The problem is where to draw necessary lines at a time when technology allows medically fragile children to survive for weeks, months, and even years. With support from home care, many of them can live at home and go to school, but
the triumphs of technology can bring even more challenges in the field of pediatric home care. Because nurses can be in patients’ homes for what amount to long periods of time, they often provide more than medical care. They also foster a child’s normal development and growth. This is an added benefit for parents of medically fragile children, who are often prone to exhaustion and social isolation yet are unwilling, naturally, to cede their roles as the primary caregivers of their child.

Parents with medically fragile kids, especially those who are dependent on technology, often work alongside nurses to meet the child’s complex care needs. The simple truth is that in home care, client-nurse relationships tend to last longer and go deeper than those in traditional health care settings and they require a delicate balance. Parents may want nurses to blend into the day-to-day routine while keeping a professional distance. Parents may want nurses to take a role in the care of the child while they maintain control over major decisions. Parents want family-centered care, and most home care agencies have tried to make this the basis of what they do.

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Family-centered care is based on four beliefs: (1) families want to participate in the care of their children; (2) parents should be viewed as equal partners; (3) parents are the ultimate experts in their child’s care; and (4) services should provide care and support that focus on family/professional collaboration. In addition, family-centered care defines the home as a private place for family bonding. But there’s a catch: the constant presence of nurses in the home is not the norm. According to one mother, “Nursing care has been my greatest difficulty. I was always a really private person. It was quite a shocker to have somebody in my house all day long that I didn’t know” — and this can lead to conflicts over how to raise the child.

Some of these conflicts are about child-rearing, according to a recent study comparing the attitudes of home care nurses and those of parents with technology-dependent kids. Nearly all the parents described the experience of raising a child with technology needs as the same as raising any other child, almost obstinately willing it to be so. As one mother stated, “He’s no different than the rest of the kids, he just has a trach.” But a tracheotomy does make a big difference, home care nurses noted based on what they had seen.

Unlike the parents, few nurses described the experience of raising a child with technology needs as the same as raising other children. Several nurses felt that parents — despite what they might say — treated the technology-dependent child differently from other children in the household. One nurse observed that “the parents just don’t use normal behavior expectations for the technology-dependent kids.” And this might be for a number of reasons: differences in parental expectations because of the child’s health problems, parents’ denial of the child’s health problems, or even discipline that was affected because the child “had respiratory distress when disciplined.”

Fortunately, we can all breathe easier knowing this isn’t a common occurrence. Technology-dependent children may not be capable of many types of behavioral problems that would require disciplinary action. Few nurses involved in the study mentioned discipline beyond the occasional “time out.” Instead, most simply said they would follow the parents’ child-rearing decisions as long as the child “remained safe,” a response that showed their intent to do the right thing and put the young patient first while respecting parents’ wishes.

Parents want nurses who truly care for their child, but at the same time they also have trouble “sharing the child,” the study showed. Mothers generally felt nurses should engage in child-rearing activities. One mom even went so far as to say, “Everything I’m doing as a parent, they’re supposed to do.” But most described certain cases in which the nurse should stand in the wings. For example, the nurse should not guide the child’s moral development. “Teaching him right from wrong, that’s responsibility I won’t relinquish to anybody,” one mother insisted. Other parents noted differences in how they and the nurses interacted with the child. One boy’s parent, for instance, felt that “the nurses overprotect and treat him like a baby.”

Since a child is always the parents’ baby, first and foremost, parents want nurses to hear their views. But this presents challenges, as one parent saw when she spoke with the nurses who...
helped care for her child. “You’re training them not on medical skills but your parenting skill,” she said, “and I don’t think that’s always easy to do with another adult.” And things can be even harder because parents want to avoid friction, another mom added: “I feel, well, I’m not a nurse, and I don’t feel like I should be telling them how to do their job. But I know I should open up my mouth more. I feel intimidated, but I really should do that.” Indeed, communication — as it is in so many other situations — is the core of family-centered care, according to Heather Bowie, the mother of a severely disabled child.

“Unfortunately, one of the common barriers between the medical community and parents is a perceived lack of respect for information parents have about their children. Parents usually do not have a medical background and may even have limited formal education, but no one knows a child like a parent,” she explained. “Parents of children with special health care needs have been living with their child, performing medical procedures, obtaining medical information from a variety of professionals, and relying on the nuances of their child’s behavior to interpret pain and joy. They want to be respected for what they know and be seen as one of the team caring for their child.”

Nurses can show their respect for parents, Bowie continued, by treating them like partners. “Pediatric nurses can and should encourage parents to believe in what they know about

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their children and seek their advice on management strategies for care in the home or hospital. They should also encourage and support parents in seeking clarification of information until they truly understand what is being told to them about the child’s condition or treatment plans from the multiple providers involved,” she said. “We as parents should be viewed as having reliable, valuable information about our children and should expect the health care professionals caring for our children to have reliable and valuable information. This is how effective teams function.”

That team should include siblings, who often suffer from isolation and psychological trauma if they’re excluded from the care of a dying child. If they help provide care at home, they tend to accept the death better, according to a study that compared a group of kids with siblings who had died at home with another group with siblings who had died at a hospital. Almost all in the home care group felt they had done everything possible for their dying sibling, compared to only 25 percent in the hospital group. Some 75 percent of the home care group felt that their presence at their sibling’s death was helpful, compared with none in the hospital group. Also very tellingly, nearly all of the home care group — 95 percent — felt that their lives were improving with time, compared with 69 percent of kids in the hospital group.

In addition, siblings who share in caregiving feel more at peace, as one 11-year-old boy did when his brother died of leukemia in the family’s home. “It was worse before than after,” he wrote. “We didn’t want to see him before he died. But then we were here that morning after he died, and it wasn’t scary at all. It looked as if he was just sleeping.”

Perhaps the child looked so peaceful because seriously ill children tend to integrate death in a more well-adapted way than others in their view of life and focus more on the living than on the dying. Acclaimed child poet and 2002 National Caring Award recipient Mattie Stepanek, who was afflicted with a debilitating form of muscular dystrophy, put it well when he wrote, “I choose to live until death, not spend the time dying until death occurs.” And this is exactly what this courageous child did until he succumbed to his disease a month before his fourteenth birthday. His illness made him dependent on a
home ventilator and trach, but Mattie never lost his sense of hope. “I don’t want to die anytime soon,” he said two years before his death. “I’ve got a lot to do while I’m here, and I hope I can do it.”25 You can read more on Mattie on the Caring Institute’s website at www.caring.org.

Mattie never gave up on life, and neither did a 10-year-old girl named Xzavia Baines, who broke her neck just below where the head and spinal cord connect. She required 24-hour home care because her ventilator could malfunction without warning, making it impossible for her to breathe. Her bones were brittle and broke easily. She had to be shifted every hour to prevent skin ulcers, and she was susceptible to respiratory infections. The chance of a long life was slim, but Xzavia always believed she would be a lawyer or nurse or teacher when she grew up.26

Mary Butzow was too young even to dream of the future when her parents made a bold decision. At two months old, Mary had serious brain damage and often stopped breathing. Rather than subject her to useless surgery and tests, Dana and Deb Butzow arranged for hospice care and brought their daughter home, where they tried to give her a lifetime of love in what came to just two precious weeks. Whenever the Butzows thought Mary wanted to be held, they were there for her. When they wanted to hold Mary, she was there for them. Hospice care allowed two-year-old Sarah Butzow to spend time with her baby sister Mary and left Deb “more at peace than I’ve ever been in my life,” the mother fondly recalled.27

In the hours before Mary’s death, Dana cradled Mary in his arms. Then he tucked her into her bassinet and watched Sarah try to push her sister’s eyelids open when they wouldn’t on their own. When the time came, he placed his infant daughter in the funeral limousine, watched her lowered into her grave, and helped shovel dirt. And even through his tears, Dana said he realized he had found something to believe in. It was a message he and Deb brought to other families of dying kids by promoting pediatric hospice. “When Mary was born, we told her, ‘We’re so happy to see you,’” Deb remembered. “Even right before she died, we felt so fortunate to have her.”28 And thanks to hospice, Mary spent her last weeks where kids want to be when they’re feeling ill: in the arms of their parents at home. Though we all hope we’ll never have to, it is the best place to say goodbye.

Endnotes
4 Ibid.
5 Ibid.
6 Sharon L. Docherty, Margaret S. Miles, and Debra Brandon. “Searching for the dying point: providers’ experience with palliative care in pediatric acute care.” Pediatric Nursing. 33(4): 335-341.
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10 Ibid.
11 Ibid.
13 Ibid.
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16 Ibid.
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26 Jeannie Kever. “Life hasn’t been the same for Xzavia Baines since the accident.” Houston Chronicle, June 14, 1998.
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