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REFLECTIONS IN MEDICINE

Being There: Engaging in Conversations About a Child's Future When They Are Facing Serious Illness

Christine Bennett, MD

A young dad arrived in my office with his infant son, a bag full of medication, and a lost look in his eyes. His son was born with a complex congenital heart defect that was not compatible with life without surgery. Even after surgery, there was uncertainty about his son's prognosis.

The dad was a single parent who showed endearing love toward his son, and he was trying to give his son good medical and newborn care. He shared what happened during the infant's hospitalization in another state. He was the lone parent caring for his infant son because, after the little boy was born, his mother left the hospital and didn't return. The infant was born in Maine but had to be transferred to Boston because the surgical care he needed wasn't available locally. Now back in Maine, he and his son were living with very close friends who could provide some support. I listened, advised him on all things medical, acknowledged that his son had a serious illness, and empathized that what he was facing was very challenging. With that in mind, I invited him back to discuss their future. He accepted the offer and returned to talk with me after office hours.

I structured our conversation around a set of questions I learned to use after attending a training with Atule Gawande and Ariadne Labs in Boston. They had developed a conversation guide to use when discussing serious illness with adults.¹ I edited the guide with the help from pediatric palliative care providers so that it would be suitable for the pediatric population. I named the edited conversation guide discussion about serious illness, or DASi. Having

this set of questions gave me a roadmap to help navigate sensitive topics with the dad. The DASi also gave me a sense of security as I entered an unjust world—parents facing a situation in which their child may die is unthinkable. The DASi was a tool that I could now use when I found myself supporting families of children with serious illness throughout their child's life. The questions in the DASi are arranged in a particular order that supports a productive flow, and the answers reveal very important information about the child's situation and desires for their future.

For more than an hour, the dad and I sat in my office and talked. I asked him the questions, and he talked about his son—what he wanted for him, his goals (for him to be happy), his hopes (to be loved no matter what), his worries and fears (that he would be judged due to his heart condition), his sources of strength (deceased relatives and his friends), and what he was willing to let his son endure for a chance at a "good life" (just to be alive is important; don't give up). The dad told me about his own life. He shared many challenges he faced, which helped me to better understand the decisions he was making for his son. He was grateful for the time we spent talking, and I felt privileged to hear his story.

I shared our conversation with the infant's other health care providers so that when he had several medical emergencies as he grew up, there was no ambiguity about his dad's decision on what should be done for this little boy. Future conversations with the dad came with more ease because we had discussed the "tough stuff." This ease of conversation helped when I needed to check in with the dad before this young boy's subsequent procedures and surgeries. I was there for him and his son, and he knew that.

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In my practice, I continued to use the guide to converse with several families of children and with a teenager. Some people may feel that such a discussion will be perceived as giving up hope. But, actually, these honest conversations support hope for the child's current situation—hope for quality time together, a good day, no suffering, and a good quality of life.² It is also beneficial for providers to engage in discussions about the future of the child early in the course of the child's illness. These discussions foster a deeper emotional connection with families. The prognosis may be uncertain, but early conversations help to explore values, hopes, and fears about the future before decisions about end-of-life care may become more pressing. Emotional connection is what a parent needs the most.³

I was the primary care physician and provider of this young baby's "medical home" (a concept that originated in the 1967 Standards of Child HealthCare written by the American Academy of Pediatrics).⁴ I was the perfect person to start this conversation. I knew this dad because I was taking care of his other child from a previous relationship. We were familiar with each other and trusted one another. I was able to provide a link between this family and other health care providers, to advocate for the family, and to give family-centered health care to him and his son.

Families can benefit from such conversations in many ways. They feel less anxiety, have fewer hospitalizations, get earlier referrals to palliative care/hospice, face less regret, and experience healthier grieving.⁵ For pediatricians, interacting with families in these situations is very gratifying. These conversations emphasize the importance of human connection and being there for someone—to listen and support them during such a vulnerable time. The willingness to be by their side as they live a life with a seriously ill child is priceless.

In my personal observations, these conversations are not happening in pediatrics offices. Some conversations of this nature may be occurring in an intensive care unit at a time when the child significantly declines. But conversations at such a late stage are not the best way to care for the child or their parents. Parents want these conversations, but they often don't feel comfortable asking for them. As for the providers, when asked why they haven't conducted such conversations, they will describe

their lack of time. Also, these conversations certainly are difficult to have when you feel that you can't fix the "problem" or discuss a cure. Or when you feel vulnerable—you may face personal questions you've avoided, such as questions about your own mortality, dealing with suffering, or facing the loss of a loved one.

Pediatricians don't have as many opportunities to engage in such conversations because most children are healthy. This limited experience can affect one's confidence about being able to conduct a helpful dialogue. Thus, having a conversation guide in your "toolbox" would greatly help to diminish insecurity and anxiety around having such discussions. There are now a variety of conversation guides available to use in pediatrics, largely influenced by the work done at Ariadne Labs. The DASi conversation guide is included as a supplement to this article, and you can find information about using a guide on a web-based support and educational platform, Courageous Parents Network.⁶ Also, the American Academy of Pediatrics is offering a training module on "Talking about Serious Illness" (<https://shop.aap.org/eqipp-talking-about-serious-illness/>), which would provide maintenance of certification and continuing medical education credit.

I am happy to report that the young boy discussed earlier actually defied the odds and did very well with his condition. As he matured, he wowed us with his charisma and his smile each time he came into the office.

It is difficult to put oneself in the shoes of a parent of a seriously ill child. But imagine yourself feeling lonely, anxious, uncertain about the future, and isolated. Wait, these words describe how we have felt during this pandemic. I invite you to think about how you have felt during the past 2 years and what has helped you get through this health crisis—the human connection and knowing someone was there for you. That is what these parents are asking for. Don't pass it up.

Keywords: critical illness, physician-patient relations, pediatrics

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