

Case and Commentary

Finding the Balance in Shared Decision Making, Commentary 1

Ellen Painter Dollar

Case

Mr. and Mrs. Delgado had been closely involved in the treatment decisions and medical care of their 11-year-old son, Tony, since he was diagnosed with acute lymphocytic leukemia (ALL) at age 10. Both parents are teachers. During Tony's initial hospitalization, they alternated missing work; one's class would have a substitute teacher, then the other's would. One parent was always by Tony's side. The Delgados studied ALL so as to understand Tony's symptoms, their physiologic causes, and the blood levels that indicated how well Tony's treatment was working. They insisted on seeing all lab reports and discussing them with Tony's oncologist, Dr. Carmichael.

Dr. Carmichael supported the Delgados' endeavors from the beginning. He believed in educating his patients (or their parents) about whatever type of leukemia affected them, explaining his actions and decisions in as much detail as his listeners could absorb. Because either Mr. or Mrs. Delgado was always at the hospital, the Delgados' participation had never caused delay in Dr. Carmichael's decision making.

Tony had been in remission for 5 months when Mrs. Delgado took him to Dr. Carmichael, saying that he had a fever and flu-like symptoms. The history corroborated Mrs. Delgado's flu diagnosis, and Dr. Carmichael got a CBC and smear and ordered a peripheral blood culture, all of which were normal. Because of the viral flu explanation for Tony's fever, Dr. Carmichael suggested no antibiotic treatment and no hospitalization at the present. The Delgados disagreed, fearing that Tony's fever and fatigue signaled the return of an acute flare-up in the ALL. Dr. Carmichael cited recent pediatric hematology and oncology literature in support of his treatment decision. He advised that they watch Tony for the next few days and, if his flu resolved, wait until the next routine blood test in about 6 weeks before taking any further action. He had seen many children like Tony, he told the Delgados, and, in his judgment, the more time they spent at home living normal lives, the better.

During the discussion, the Delgados mentioned that both had used all their available personal time off during Tony's prior hospitalizations and would have to have someone else stay at home with him. They thought he would be better off in the hospital under professional care. Again Dr. Carmichael offered his medical judgment on the issue, mentioning that hospitalization carried an increased risk of other infections as well as psychological trauma for Tony. The Delgados said they didn't care much about other patients or "the literature." Tony was their son, and they wanted the best care for him. They believed the best care was hospital care. After working so well together for almost 2 years, Dr. Carmichael and the Delgados seemed to be at an impasse.

Commentary 1

I am the mother of a 4-year-old girl with a chronic disorder called osteogenesis imperfecta, or OI, a genetic disorder that causes affected people to have fragile bones. Like Tony, my daughter has frequent medical treatments and hospitalizations. Like the Delgados, my husband and I educate ourselves as much as possible about our daughter's condition by connecting with other families living with the disorder, reading current medical literature, and discussing matters in depth with our daughter's physicians. I see several reasons why the Delgados might disagree with Dr. Carmichael's "wait and see" approach to Tony's flu.

The Fear Factor

The Delgados are likely terrified by Tony's current symptoms. This case study doesn't tell us how Tony was originally diagnosed with ALL, but it's probable that initially, when he didn't feel well, his parents wrote it off as something harmless for some time before discovering that their son actually had a life-threatening illness. Seeing their child once again listless, feverish, and not "himself" may have awakened powerful feelings of helplessness and a determination not to let their guard down this time.

No matter how well-versed parents are in medical literature, no matter how convinced they are of the value of consulting research-based evidence before making decisions, there is a limit on the power of medical literature to allay parental fears and overcome parental intuition.

An example: I belong to an e-mail listserv of parents raising children with OI. Most parents who are expecting a baby known prenatally to have OI ask for a cesarean delivery, and many parents whose babies with OI were born vaginally are convinced that the delivery increased the number of fractures and amount of pain their babies had at birth. A recent study of delivery methods for infants with OI, however, shows that cesarean sections are not necessarily safer for babies with OI than vaginal delivery. While aware of the recent study, many of the parents I communicate with (who are largely very well-educated about OI and interested in medical literature) say that no study can overcome their intuitive conviction that uterine contractions and passage through a narrow birth canal are too risky for a fragile baby. When it comes to their child's safety and pain, they are unwilling to trust a medical study over their own gut feelings. I imagine the Delgados feel likewise.

The anxiety that the Delgados carry from day to day, knowing that their child has a grave illness that could resurface at any time, goes far beyond the normal worries that all parents have. Tony's flu increases the anxiety considerably. Not only are his parents worried that this illness signals a flare-up of his ALL, they are also worried about keeping their employers happy, and finding someone they trust to care for Tony while he is home recovering. The stress they are under no doubt colors their abilities to hear and accept Dr. Carmichael's medical judgment, no matter how well-reasoned it is.

How can the Delgados and Dr. Carmichael reach an agreement?

Dr. Carmichael is making valid recommendations for how to cope with Tony's flu. It would be irresponsible of him to hospitalize Tony against his better medical judgment, given his feelings that home is the healthiest place for Tony, both physically and emotionally. However, there are several things he can do that might reopen communication with the Delgados and help them problem solve as a team.

1. *Empathize.* Sharing more medical facts and research evidence won't help resolve this situation. If Dr. Carmichael acknowledges the emotions that affect the Delgados' decisions—their fear, fatigue, and anxiety—they might be more receptive to talking about alternatives to

hospitalization. Feeling understood and "heard" may help them remember that the doctor is their ally, someone who also has Tony's best interests at heart.

2. *Honor the parents' fears and intuition.* Dr. Carmichael suggested waiting until Tony's next routine appointment in 6 weeks before doing anything else. Instead, he could offer to see Tony again in a much shorter time, perhaps a week or so. This offer would help the Delgados feel that their fears about Tony's illness are not being brushed aside. They would feel more confident that something important won't be missed while Tony is recovering at home or during the 6 weeks until the next appointment.
3. *Help address their employment dilemma.* Dr. Carmichael can offer to write a letter to the Delgados' employers explaining why they need additional days off to care for Tony at home. He, or someone in his office, could refer them to a hospital social worker or the equivalent to talk about arranging home care for Tony if they absolutely cannot stay home to care with him. He could simply ask if they have any friends or family who might be able to stay with Tony for a few days. While it is not Dr. Carmichael's responsibility to solve the Delgados' employment problem, simply by acknowledging that the problem exists, asking a few questions, and offering a few suggestions, he might help them take a step back from the problem and think creatively about ways to solve it.

Ellen Painter Dollar is a freelance writer and a mother with a personal interest in the health care system. She is the author of *Growing Up with OI: A Guide for Children*. Ms Dollar and her 4-year-old daughter have Type I OI.

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