

Family-Centered Care and Evidence-Based Medicine in Conflict: Lessons for Pediatricians

In contemporary medical education and pediatric practice, “family-centered care” and “evidence-based medicine” (EBM) are frequently promoted simultaneously, as if the 2 are natural partners in the provision of high-quality care. These 2 concepts appear side by side in clinic and hospital mission statements, medical school course aims, and pediatric residency milestones.

In fact, the 2 paradigms approach medical practice from radically divergent perspectives. Family-centered care rests on a biopsychosocial model of healing, is fundamentally holistic, and prioritizes the perspectives of patients and families in medical care, whereas EBM is, at its essence, the systematic application of science to practice. For most providers, EBM connotes provision of the highest-quality care based on the available medical science and is intended to minimize unwarranted variation in care that might result in patients receiving therapies that are unsafe, ineffective, costly, or untimely, compared with the gold standards of care derived from scientific evidence and ideally randomized controlled trials, in which “bigger” often means “better.” EBM has gradually supplanted experience-based medicine of decades past, wherein the “experience” is that of the physician. In both evidence- and experience-based systems, the provider is still at the center of the medical encounter.

The following case explores several interrelated conflicts during a seemingly routine admission for febrile neutropenia, chiefly between family-centered care and EBM, but which also involved Western biomedicine and alternative healing practices, and social and medical models of disability.

CLINICAL ENCOUNTER

A 3-year-old boy with Down syndrome and high-risk pre-B acute lymphoblastic leukemia presented to our oncology clinic for a transfusion, after routine blood counts. He had been diagnosed 8 months previously and had received chemotherapy with vincristine and PEG-asparaginase 2 days previously. Although he had been feeling well at home, his temperature in clinic rose to 101°F and his absolute neutrophil count (ANC) was 10 cells/ μ L. After admission to the inpatient unit and administration of intravenous cefepime, he had no further fevers. He was well-appearing, active, and playful, without so much as a sniffle or a sneeze to explain his initial fever. Blood cultures obtained on arrival were negative.

After 5 days, his ANC remained effectively 0, with no signs of imminent bone marrow recovery. The inpatient team updated the family at the bedside and explained the

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ABBREVIATIONS

ANC: absolute neutrophil count
 EBM: evidence-based medicine
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plan to continue cefepime until count recovery. His parents expressed their frustration with the length of the stay and were skeptical that count recovery was “around the corner.” They had each separately mentioned these concerns previously, as well as their mutual preference for complementary and alternative therapies over the perceived excesses of Western biomedicine. The boy’s father was concerned that the outcome of the current management would be weeks of admission for little more than observation. They were a reliable family, he argued, with easy access to transportation and a good comprehension of their son’s medical needs, allowing them to rapidly return if his condition changed at home.

In response, our team explained that because the young boy had been on antibiotics throughout the entire hospitalization, we worried that the antibiotics might have masked an infection that his weakened immune system could not completely eliminate. We also explained that, although the unit policy of patients remaining inpatient and on parenteral antibiotics until count recovery was uniformly applied to all patients, our heightened concern stemmed from the increased risk of infection during chemotherapy seen in patients with Down syndrome.¹⁻⁴

At the mention of Down syndrome, the patient’s father stood up abruptly. He was furious that, since his son’s birth, physicians had always been quick to tell them what he “would never be able to do,” yet never seemed to realize that their son had defied all expectations, avoiding previous serious infections and aspiration pneumonia (despite an abnormal swallow study) and demonstrating above-average cognitive development. Although we tried to

acknowledge their child’s strengths, our bias was clearly toward the data showing children with Down syndrome and acute lymphoblastic leukemia died of infection at worryingly high rates. We also reminded the parents that the risk of increased toxicity was the reason that their son had received less-intensive chemotherapy than a child with the same type of leukemia who did not have Down syndrome.¹

As tension escalated, we tried to redirect the conversation back to our concern for masked infection and our desire to minimize potential harm, while admitting that a poor outcome was unlikely. Although the parents expressed understanding, they were willing to assume responsibility for the risk and leave against medical advice if not discharged. The father then apologized for his outburst, explaining that he saw his job as a parent to advocate for his son by persuading people to view him as an individual and see beyond his diagnosis.

Finally, we proposed a compromise, which the family accepted. The young boy was switched to an oral antibiotic, monitored for 24 hours, and then discharged the following morning. He was followed in clinic daily until ANC finally exceeded 100 after 4 days (10 days after initial admission), although sustained bone marrow recovery did not occur until 1 month after admission. He had no further fevers and was not readmitted.

Discussion

This encounter took place at a large children’s hospital that espouses many values representing different facets of care, including commitments to family-centered, culturally sensitive care;

EBM; research; and teaching. Family members are encouraged to stay in the private rooms with their children during hospitalization, and most medical teams round at the bedside with the family and the child’s primary nurse. At the same time, many teams are staffed by residents and fellows, who are encouraged to bring journal articles relevant to the care of specific patients to rounds, and some attending physicians are primarily researchers rather than clinicians. Although the future of EBM may be that treatment is always tailored to the biology of the individual, the current state of the art of evidence-based medical practice is derived from randomized controlled trials in which bigger is generally thought to be better. Increasingly, EBM does incorporate some specific patient factors to determine recommended treatment. In the area of pediatric febrile neutropenia, many studies have evaluated approaches to risk stratification that would help determine which patients presenting with fever can be safely discharged early or managed at home for the duration of the neutropenia.^{3,4} Although our institution has not adopted risk stratification nor is there a single, widely accepted approach, it is likely that the patient’s diagnosis of Down syndrome would have precluded classification as a low-risk patient under most evidence-based risk stratification systems.

With so many different demands, it is not surprising to find tension arising. What is surprising is how seldom the conflict between family-centered care and EBM is recognized and discussed as a conflict between aspirational paradigms of health care, rather than merely a conflict between an individual family and an individual provider or an

ethical dilemma of patient autonomy versus provider beneficence.

Two approaches to “grounding the concept of patient-centeredness” have been proposed, and both require understanding one of the opposing paradigms at work in a clinical encounter, namely “disease-centered medicine” and “doctor-centered medicine.”⁵ In this encounter, the disease-centered paradigm functions at the level of the biological diagnosis of Down syndrome and the associated immune system dysfunction. The doctor-centered paradigm explains the doctors’ unwillingness to tolerate even the smallest chance of a patient developing a life-threatening infection for which he was perceived to be at increased risk. A patient-centered paradigm, in contrast, is not required to reject the other 2 paradigms but must acknowledge the uncertainty inherent in biomedicine and that many of our recommendations are based on changing assessments of probability and risk. This paradigm thus prioritizes the family’s personal preferences with regard to management of risks and benefits.

Our patient’s assertive and articulate parents forced the family-centered paradigm to the forefront and ultimately led to the compromise between the providers and parents. Despite the attention given to patient- and family-centered care in many pediatric hospitals and efforts to develop more family-centered programs and facilities, a model in which the patient’s experience is truly validated in clinical decision-making has yet to truly take root. Such a model demands that providers learn to de-emphasize their own priorities and recognize the rights of families to make different choices than the providers believe

they would in similar circumstances. This poses a unique challenge for pediatric providers who feel charged with protecting young patients who cannot choose for themselves while respecting family autonomy.

For these parents, discussion of the evidence favoring enhanced supportive care to minimize risk in patients with Down syndrome represented an unacceptable dismissal of their son’s individuality and of their preferences as a family unit. Although most parents of children with chronic conditions, particularly those associated with cognitive impairment, likely share the philosophy of this patient’s parents (namely, that their main job is to advocate for their child and his individuality, to approach life with Down syndrome through a social model of disability), parents with a different relationship to Western medicine are likely to privilege the role of the medical doctor, especially the pediatric oncologist. In practice, this means that families who fully accept the tenets of biomedicine are more likely to create an exception to the desire for individuality when faced with a medical professional’s advice to treat their child with Down syndrome differently from children without Down syndrome. Therefore, it was necessary to understand not only the family’s perspective of their child’s chronic condition, but also how they integrated that perspective into their broader worldview, in which Western medicine was not a privileged system, but simply one of many they and their son had to navigate in life.

Although this case offers no simple solutions for pediatricians faced with similar dilemmas, we advocate compromises like the one achieved here. Often, “compromise” is understood as

spending more time in discussion with families, perhaps involving an ethics team to help facilitate such discussion, until the family can be convinced of the validity of the physician’s recommendation. True compromises necessitate concessions on both sides and a sincere effort to understand the perspective of the other. As the treating physicians, we agreed to sacrifice some of our own clinical judgment with regard to balancing risk and benefit to gain the family’s adherence, while the family agreed to more care than they honestly felt was necessary. Although we were not the patient’s primary oncologists, both sides were invested in continuing, indeed, in improving, the therapeutic relationship, and we were able to take away a richer understanding of family-centered care in the age of EBM.

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