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## ETHICS CASE

### Conflicts in Family-Centered Pediatric Care for Patients with Autism

Commentary by Jeffrey P. Brosco, MD, PhD

Dr. Woods entered the patient exam room to meet with 6-year-old Kari and her mother. In her hand, she held the report from Dr. Hoffman, the developmental pediatrician Kari had seen two months ago, which confirmed a diagnosis of moderate to severe autism. After greeting Kari and her mother, Dr. Woods began, "I see Dr. Hoffman started Kari on guanfacine for some of her symptoms and had some recommendations for therapy."

"Yes," Kari's mother said, her voice unsteady. "She wanted us to start going to these therapists for speech and behavior and all kinds of things. And we saw a social worker, and she's going to help us with the paperwork to get it all paid for. And Kari has started the guanfacine."

"This all sounds good," Dr. Woods said gently. She knew guanfacine was the first-line treatment for irritability associated with autism, often prescribed for young children because of its low profile of side effects.

"It's just—" Kari's mother began to cry. "The guanfacine doesn't seem to be helping. In fact, I think she's getting worse. She's angry all the time, and she has these temper tantrums...I don't know what to do."

"What about the behavioral therapy?" Dr. Woods asked.

"I can't manage all these appointments. I just can't. I'm a single mom, I have two other kids, I work—there's no way I can go to all of these. I don't have anyone in town here to help me, and I can't be missing work to drive Kari to appointments every day and doing all this therapy. I know she said it's the best option for Kari, but I have to tell you, it just isn't going to happen." Looking at Dr. Woods, she added, "Don't get me wrong, I love my daughter and I would do anything for her. But to take care of all my kids, I have to work. Look. I read the pamphlets. I know there are other medications that could help. Couldn't we just try one of the stronger medications—the antipsychotics, maybe, they're supposed to help, or an antidepressant—just something that would help her calm down and make her life more manageable..." She trailed off.

Dr. Woods hesitated. While guanfacine was relatively benign, there were significant side effects associated with atypical antipsychotics, and she wasn't sure how comfortable

she was prescribing a strong psychiatric medication when behavioral therapy hadn't been attempted.

"I know it's not ideal," Kari's mother said. "But isn't it better than nothing?"

### **Commentary**

There are several keys to resolving the ethical issues in this case: distinguishing between refusals and requests, acknowledging conflicts between family-centered care and evidence-based medicine, and meeting the obligation to manage emotions and communicate effectively.

### **Refusals versus Requests**

The practice of medicine in the US has changed dramatically in the past 50 years. Until the mid-twentieth century, it was common practice for physicians to assume the role of decision maker for their patients. Following the principle of beneficence, physicians routinely chose among treatment options—including no treatment—depending on what they thought was in the best interest of their patients. Broad social changes, including the civil rights movement, feminism, and anti-Vietnam War protests, shifted the balance away from traditional sources of authority toward empowering individuals. By the 1990s, the idea of patient autonomy was central to medical practice; physicians felt an obligation to tell patients the truth, obtain informed consent to treat, and respect patients' decisions even if they led to seemingly poor health outcomes. Our society now believes that an individual can validly refuse treatment as long as three conditions are in place: (1) the patient is provided adequate information about risks, benefits, and alternatives; (2) the patient has the capacity to understand and appreciate the consequences of his or her decisions; (3) the patient is not unduly influenced by outside forces [1].

In contrast to valid refusals, patient requests need not be honored. A patient may ask for antibiotics, but, if the physician determines that the cause of a patient's upper respiratory symptoms is a virus, he or she is under no obligation to provide a prescription. Even in this era of patient autonomy, physicians retain the authority to determine the range of clinically appropriate actions.

In this case, Kari's mother is making a request for a medicine stronger than guanfacine to help her manage Kari's behavior. Dr. Woods is right to hesitate, given the recommendations of the specialist to start with behavioral intervention. The case is further complicated because Kari is only six years old, which is well below the age when she could make decisions for herself legally. With a diagnosis of moderate to severe autism, Kari is also probably much less able to participate in decisions about her health than other children her age [1]. Dr. Woods has a special obligation to attend to the best interests of her patient.

### **Family-Centeredness versus Evidence-Based Medicine**

In pediatrics, the trend toward respecting patient autonomy has taken the form of “family-centered care.” As articulated in the 2003 American Academy of Pediatrics policy statement on this topic [2], family-centered care “recognizes that the perspectives and information provided by families, children, and young adults are important in clinical decision making.” In addition to respecting the family, honoring cultural differences, and sharing honest and unbiased information, a core principle of family-centered care is “supporting and facilitating choice for the child and family about approaches to care.” Family-centered care is not just a nice idea; research demonstrates it results in improved patient and family outcomes, improved professional and family satisfaction, decreased health care costs, and more effective use of health care resources when a family-centered approach is followed [3].

Even as pediatricians are moving towards family-centered care—and adult physicians are practicing patient-centered care—there is increasing emphasis on the critical importance of using scientific evidence in clinical medicine. Physicians have long based their practice on science, of course, but in the last two decades professional organizations have sought to reduce the gaps between research findings and clinical practice. Clinical practice guidelines, decision-support tools, and health care payment mechanisms are encouraging physicians to base clinical choices on research to ensure all patients receive high-quality care.

Family-centered care and evidence-based medicine are usually not in conflict; most families want their child to receive the most highly recommended, scientifically sound medical care. In Kari’s case, there seems to be significant conflict. Her mother is requesting a second-line medication but not following the recommendation for behavioral interventions that are the primary treatments for children with autism [4]. Although there may not be large-scale randomized trials comparing antipsychotic medications alone to behavioral interventions alone, guidelines for treating the behavioral symptoms of autism start with therapy to improve behavior and communication. Medication alone is insufficient, especially for improving long-term outcomes for patients like Kari [4].

### **Emotions and Expectations**

Patients and doctors make decisions based on emotion as much as on reason. To ignore the emotional aspects of medical practice is to overlook critical professional obligations. In this case, Kari’s mother feels sad, isolated, and overwhelmed; she is probably wondering why Dr. Woods doesn’t seem to want to do what she—the mother—has determined is in the best interest of her child and family. Dr. Woods most likely empathizes with Kari’s mother’s predicament, but may also feel—as many clinicians do when confronted with situations like this—that Kari’s mother should try harder to organize her home situation and start behavior therapy. Furthermore, when patients or

families make requests, physicians sometimes feel that giving in lessens their professional integrity—Dr. Woods’s initial impulse may be to dig in her heels. She may also feel isolated—far from specialist input—and upset that she is required to make decisions about treatment with which she has little expertise or experience.

As the professional, Dr. Woods is obligated to try to recognize her own emotions and use techniques like mindfulness to focus on solving the problem. She should empathize with Kari’s mother, exploring ways to help her feel more supported in fulfilling her responsibilities as a mother and head of household, such as referrals to social work and parent support groups. Finally, Dr. Woods should try to avoid creating an atmosphere in which the mother wants something—medication—that the doctor is withholding. This dynamic is extremely common in everyday medical practice, whether the request is for a medication or a signature on forms, and the clinician needs to reframe the situation to help everyone focus on the problem to be solved: in this case, the new framing is how best to achieve their common goal—helping Kari improve her symptoms and behavior. It is not about whether Dr. Woods will “give” Kari’s mother the prescription [5].

### **Resolution**

As suggested above, the procedure for resolving these sorts of dilemmas begins with the physician exploring and acknowledging the mother’s position, refocusing the discussion on identifying the goals of treatment, and pledging to work with the mother to reach them: “I understand that you are feeling overwhelmed by all your responsibilities, and I can only imagine how difficult this must be. You obviously love your daughter and want the best for her, and right now her temper tantrums are a big problem for you and your family. Let’s figure out the next best step” [6].

Dr. Woods should then review with Kari’s mother the risks, benefits, and alternatives of the various treatment options. How best to do this is, of course, the art of medicine. There are significant side effects with antipsychotics, but there are also dangers to inadequately intervening to prevent temper tantrums, especially as Kari gets older and stronger. Dr. Woods needs to help Kari’s mother understand that the behavior and communication therapists will help her—Kari’s mother—know what to do when Kari gets angry, and better still how to prevent the tantrums, and that they can come to her home. In the long run, this will be good for the whole family. If Kari’s mother remains firm in her demand for a short-term remedy, Dr. Woods may offer a compromise: “I’m concerned about starting an antipsychotic because of the potential side effects, but I also understand your point of view. How about we arrange for a therapist to come to your home for an hour a day to work with you on behavioral techniques, and we’ll use risperidone as a temporary measure until you feel more comfortable with managing Kari’s tantrums?”

Ultimately, Dr. Woods should respect Kari's mother's decision. There are significant risks to denying Kari's mother's request for medication: Kari's behavior will probably worsen, affecting her learning, peer relationships, and family function. Children with significant developmental disabilities are at high risk for both accidental and nonaccidental trauma [7, 8]. Although not ideal, risperidone is not completely inappropriate in this clinical scenario. (It's not like prescribing antibiotics for a viral illness, for instance.) Kari's mother is going to have to live with the decisions made about Kari's treatment, most likely for a lifetime, and as such is in the best position to make judgments about imperfect choices.

Dr. Woods should document her conversation with Kari's mother in the medical record, of course, and continue to follow Kari closely. If Dr. Woods feels unable to prescribe an antipsychotic medication, she should locate a physician who can. Communicating with the developmental pediatrician is also critical and may allay some of Dr. Woods's concerns about the medication. If over time Kari's mother is truly unable to meet her daughter's medical needs, Dr. Woods will have to consider whether to involve the child welfare system.

Treatment requests made by caring, involved families should routinely be honored when consistent with evidence about safety and efficacy. The physician's role is to outline appropriate options and help the family choose the approach that best matches the scientific evidence with the family's values. When there is doubt, a clinical ethics consultation can be helpful in analyzing the issues in a specific case.

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**Jeffrey P. Brosco, MD, PhD**, is a professor of clinical pediatrics and associate director of the Mailman Center for Child Development at the University of Miami Miller School of Medicine and chair of the Pediatric Bioethics Committee at Jackson Memorial Hospital in Miami, Florida. Board-certified in pediatrics and developmental-behavioral pediatrics, he completed his tenure as a Robert Wood Johnson Generalist Faculty Scholar in 2003 after earning an MD and a PhD in the history of medicine at the University of Pennsylvania. With Diane Paul, he co-authored *The PKU Paradox: A Short History of a Genetic Disease* (Johns Hopkins University Press, 2013). Dr. Brosco's research includes analysis of the history of health care for children in early twentieth-century Philadelphia, the historical epidemiology of intellectual disability, and the history of newborn screening in the US.

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