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ETHICS CASE

Autonomy and Autism: Who Speaks for the Adolescent Patient?

Commentary by Rebecca Benson, MD, PhD, and Catherina Pinnaro, MD

Jake was diagnosed with autism at the age of four. His symptoms were treated with behavioral therapy until the age of 14, when he began having frequent angry outbursts. He often shouted at his parents and had fits of screaming, occasionally at school. At the time, his mother noticed that he was very irritable and often seemed depressed. He was prescribed an SSRI and an atypical antipsychotic for his outbursts and mood symptoms.

Now 17, Jake has cognitive abilities in the low-normal range, but his ability to perform daily activities is more substantially impaired, and his mother is heavily involved in his care. He needs reminders and supervision to care for himself, including taking his medication and doing his homework, and refuses to brush his teeth or hair unless his mother insists. He experiences sensory overload. He attends an alternative high school because of his repeated angry outbursts at school and difficulties paying attention.

His physician, Dr. Mullins, greets Jake and his mother cheerfully at Jake's check-up. "How have things been going?" she asks.

Jake resentfully stares at the wall behind her. "I'm not going to take this stupid medicine anymore," he says. "I hate it. I hate taking it every day."

His mother adds to the conversation. "He does," she confesses. "But it really does make a difference. When we tried to go off the meds a year ago, Jake was out of control. He screamed at his little sisters whenever they spoke to him, he got in trouble at school; he was just difficult. When he takes his meds—and I make sure he takes them every day—he just seems less irritated and annoyed. He doesn't have these outbursts; he does better in school. I hate making him take medication, but I just can't imagine trying to take care of all my kids when Jake is as volatile as he was last year."

Dr. Mullins turns to Jake. "What do you think about that, Jake? Do you think the medications make a difference in how you feel?"

Jake doesn't answer right away. Staring at the floor, he says sullenly, "I don't care. It's just for everyone else that I take this medicine. I don't like the way it makes me feel. I don't care if everyone else doesn't want to be around me. I'm sick of it. I'm almost an adult. Why does everyone else get to decide what I do, and I don't get to have any say?"

Commentary

Before addressing the issue of who speaks for the autistic patient, we must address who speaks for the pediatric patient—that is, who makes decisions about whether to accept or refuse treatment (not who advocates for the patient).

Minors and Medical Decision Making

Autonomy is an inherently complicated issue in pediatric medicine. Pediatricians generally expect parents to be responsible for deciding what is in the best interest of their children. This parental authority was derived from common law, the constitutional right to privacy regarding family matters, and a general societal presumption that parents or guardians will act in the best interest of their legally incompetent children [1]. Patients are legally considered minors until the age of 18 in most US states, although some states have exceptions for emancipated minors. Emancipation occurs when something in the child's life—marriage, military enlistment, pregnancy—alters the relationship between the child and parents and supersedes the parent-child relationship [2].

Egregious discrepancies in conceptions of a child's best interest do arise, such as when parents refuse a medically recommended blood transfusion for a critically ill child based on religious principles. These wishes can be evaluated and handled by the judicial system or overridden by physicians in an emergency situation, based on a precedent Supreme Court decision [3]. However, in the majority of circumstances that arise in pediatric medicine, the ultimate decision maker is the parent or guardian.

That being said, the "mature minor exception" is an ethics-derived concept that reflects the belief widely accepted in pediatrics that, as a child grows and develops, his or her cognitive capacity increases substantially so that he or she may merit being treated as an autonomous medical decision maker. Interestingly, this exception is not reflected uniformly in the law. Fourteen states permit mature minors to consent to general medical treatment in either all or a restricted range of circumstances, and three states allow minors regardless of their age or maturity to consent to treatment in all or some circumstances. States' requirements for mature minor exceptions vary and comprise a combination of qualities, including age, ability to meet the informed consent standard (i.e., capacity), maturity, and having graduated from high school [4].

The Minor with Autism and Medical Decision Making

For the purpose of assessing Jake's rights to make his own decisions regarding his medical care, we will evaluate his case using the concepts of "maturity" and "capacity." Maturity as defined by courts takes into account age, level of education, grades in school, disciplinary issues, and future plans [5]. Capacity implies general understanding of one's condition and the risks and benefits of the intervention in question, the ability to communicate a choice, and the ability to reason or think logically [5].

In this particular situation, it appears that Jake's mother has his and the family's best interests in mind. The scenario clearly establishes that the medication is helpful for Jake's mood and his overall daily functioning, including his school performance and familial interactions. After a trial off the medication a year ago, the family reported that he had more moodiness and outbursts, which improved when he began taking it again. His mother is clearly concerned about his ability to have good relationships with others and to do well in school. No matter what state Jake lives in, he currently exhibits neither the capacity nor the maturity to refuse treatment. His level of education and overall daily functioning illustrate that he is not mature enough to make important health decisions unilaterally. Additionally, it does not seem that he understands the risks and benefits of his medications clearly, nor in our scenario does he demonstrate logical thinking about why he does not want to take them. For these reasons and because of his age, he certainly does not have a legal right to make his own decisions regarding his medical care. However, it is appropriate to acknowledge and address his reluctance to take the medication and to engage him in the process of shared medical decision making.

There is no standard of care for treatment of depression or other mood disorders specifically in children with autism, but the current guidelines for treatment of depression in adolescents is to try various SSRIs (fluoxetine and escitalopram would both be approved for Jake) to find one that is effective and has few or tolerable side effects [6]. It is not uncommon for patients to report that they do not like the way an SSRI makes them feel, and changing to another SSRI may allow them to find a medication that is equally effective without the unpleasant effect. Dr. Mullins certainly should explore this issue further. There are many SSRIs and atypical antipsychotics on the market, and there may be a medication that is better suited to Jake's symptoms and that has a more favorable side effect profile. Jake's mother also indicates that he does not remember to take his medicine every day. Risperidone, an atypical antipsychotic, comes in a slow-release depot formulation that he would not need to take every day [7].

Long-Term Goals

The ultimate goal should be to recognize Jake's impairment but maximize his autonomy, helping him to develop as much maturity and independence as he is capable of. This is best accomplished by listening closely to his preferences and offering options that address his concerns (e.g., finding medications that don't have unpleasant side effects). At the same time, this process of shared decision making empowers his parents to protect him from making choices that may have a negative impact on his health and overall well-being, in this case by prioritizing the goals of school success and maintaining good relationships. This process might be aided by engaging the family in formal shared decision making (SDM). The process of SDM as summarized by the Center for Mental Health Services includes several steps that may help facilitate a discussion among the

involved parties. These include identifying preferences, negotiating options/concordance, and sharing the decision [8].

Medical evaluation and decision making in Jake's case become less clear cut when he reaches the age of majority. A transition-to-adulthood evaluation should be initiated soon to ease the burden on both Jake and his parents. Autism Speaks has a free transition kit to help adolescents move into adulthood, including information about health, education, and legal matters [9].

One option for Jake's parents would be to apply for guardianship, which would grant them the legal authority to make medical decisions for him even after he reaches the age of majority [10]. They may consider this option if Jake continues to demonstrate poor ability to understand his condition, reason through the risks and benefits of treatment options, and understand the implications of his choices. This could be frustrating for Jake, but it would protect him from the potential poor health and emotional outcomes that could arise from incomplete understanding of the ramifications of proposed treatments or therapies. On the other hand, by participating in the process of shared decision making, Jake may progress to a level of maturity over time in which he demonstrates capacity to make his own health care decisions, with support from others when needed.

Optimizing Jake's medications and allowing him to actively participate in the discussion of his treatment is a good way to ensure that everyone is on the same page. Like any other patient old enough to have opinions about his treatment plan, an autistic patient should be allowed to articulate his or her needs and treatment goals. Both the clinician and his family or the facility involved should take these statements seriously, and all parties should work together to collectively do what is best for the patient.

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