case study

Old Enough

Joy is a thirteen year old from a Jehovah's Witness family who developed knee pain without obvious trauma two weeks ago. Several days later she was admitted to the hospital with fever and an infected knee joint caused by Staphylococcus aureus. Doctors started her on antibiotics, but the infection spread to her blood, her bones, and her lungs, where it developed into pneumonia.

Joy's multiple infections improved with further antibiotic treatment, but her chest cavity still has a lot of thick pus and scar tissue in it. Doctors propose surgically removing the pus and tissue. Her blood count, normal when she was admitted, has dropped to a very anemic level from the infections. She has been given erythropoietin, an injectable enzyme to stimulate her bone marrow, for several days now. (Erythropoietin, although derived from human blood, is one of several blood components considered "matters of conscience" by Jehovah's Witnesses—some accept it, and others decline it.)

Joy is the oldest of three in a family with a long and strong Jehovah's Witness tradition. Her parents became Witnesses as adolescents; her maternal grandfather and paternal uncle are elders in Jehovah's Witness congregations. Following instruction by her family, she was accepted as a full member of the Jehovah's Witness community five months ago after examination by the elders found her to have sufficient understanding of pertinent matters of faith. She is also an excellent student, and her teacher told her nurse that Joy is one of the most mature eighth graders she has ever encountered in many years of teaching.

In the presence of her parents, uncle, and grandfather, Joy clearly articulates the Jehovah's Witness position on refusing blood products in response to doctors' inquiries. She quotes scripture and explains her understanding of Jehovah's prohibition, then says she does not "want it on [her] conscience" to accept blood. She asks that blood not be used during surgery, "if possible." When gently challenged on this last point, she clearly—but tearfully—states that she does not want to receive any of the forbidden blood products, even if it means that she might die as a result. She repeats this when doctors speak to her without her family present.

Her pediatrician and infectious disease consultant believe they must proceed with surgical intervention. The consulting pediatric surgeon reports that surgery is likely to involve significant blood loss. Using the Cell Saver (a device to suction and filter surgical blood loss and return it to the patient's circulation) will not be possible because the blood in the surgical field would be contaminated with Staphylococcus. Joy's degree of anemia makes surgery risky, and the surgeon is not willing to operate without first giving her blood. He requests that the pediatrician seek a court order for this.

Should the pediatrician do so, or should this adolescent's refusal of potentially lifesaving treatment be accepted?

commentary

by Robert D. Orr

All adult Jehovah's Witnesses refuse whole blood, packed red blood cells, white cells, platelets, and plasma. There is strong ethical precedent for honoring voluntary refusals from adequately informed adults with decision-making capacity, even if withholding blood will lead to death. Treating children of Jehovah's Witness parents is a different matter. Then the legal precedent is to obtain a court order allowing doctors to transfuse children of Jehovah's Witnesses over their parents' objections if withholding blood is likely to lead to death or disability. Statutory law suggests doctors follow this precedent until the child reaches majority, which in most states is eighteen years of age. However, legislators recognize the arbitrary nature of this line. Many states accept treatment decisions from an emancipated minor, and some also recognize the mature minor—a child under eighteen who demonstrates adult decision-making capabilities. Most states also list situations in which a child may consent to treatment without parental involvement, often designating an age limit below the age of majority.

Following this line of reasoning, more and more ethicists believe that the morally relevant feature for such critical decisions is the child's level of understanding, not her age. Many would honor the refusal of a mature minor as if she were an adult. My personal yardstick on this matter is to assume that children

under age twelve do not have capacity to make critical treatment decisions, that those fifteen and older generally do, and that those between twelve and fifteen should be assessed on an individual basis.

This patient is not an emancipated minor. In fact, she demonstrates a close and trusting relationship with her parents and her religious community. The pivotal issue in this case is whether her doctors believe she is making an adult, informed, noncoerced choice against potentially lifesaving blood transfusion. In order to determine this, they must talk to her, her parents, and perhaps her school teacher. The "informed" aspect involves whether she understands the problem, the options, and the consequences. The "noncoerced" aspect pertains to whether her statement represents her true belief. She could be saying this merely to please her parents or the elders of her congregation. An adolescent psychiatrist might assist in assessing either aspect if her caregivers do not agree. The fact that Jehovah's Witness communities do not typically accept an adolescent into full membership until they believe he or she fully understands the basic tenets of the faith would weigh on the side of accepting her decision. Her clear articulation of the Jehovah's Witness belief about blood transfusion may indicate maturity; but it could also be the result of recent rote memorization to prepare for acceptance into the local congregation. However, the fact that she repeated her desire to avoid receiving blood after her parents left the room suggests this is her true personal belief.

Because the legal precedent of overriding Jehovah's Witness parents who refuse transfusion for their children is so strong, Joy's physicians should report this situation to Child Protective Services. If they do not believe she is making an adult choice, the purpose would be to seek a court order authorizing transfusion.

If, however, they do believe she is making an informed and voluntary decision, I think they may ethically respect it. In that case, the purpose of the report would be to seek judicial relief from the legal precedent. If judicial relief is granted, her doctors must tell Joy clearly that they intend to accept her decision as her true desire—in other words, they will not assume she wants to be rescued from it and seek a court order over her objection. And if, during surgery, Joy deteriorates to the point where she will surely die without blood, I believe they must accept that sad outcome.

commentary

by Debra Craig

The American Academy of Pediatrics asserts that every child should have the opportunity to grow and develop free from preventable illness or injury. Pediatricians thus have a compelling interest to protect children from harm, especially when that harm is irreparable.

At the same time, AAP accepts the "mature minor" doctrine and recognizes the increasing role that adolescents play in their own health care. Pediatricians follow the "rule of sevens." In general, we presume that a minor under seven certainly lacks capacity; that a minor between seven and fourteen probably does not have capacity, but that some exceptions exist; and that a minor over fourteen almost certainly does have capacity. Therefore, the burden is on the one arguing against capacity to show that a fourteen year old (or one almost fourteen, like Joy) does not have it. But what is capacity?

No objective test for decision-making capacity exists, but when trying to determine if a person has it, doctors often consider whether the person has an understanding of the risks, benefits, and burdens of the proposed treatments, of the treatment alternatives, and of the likely outcome of refusing all treatment. When determining adolescent capacity, pediatric literature suggests some additional criteria. For instance, the capable, mature adolescent should have the ability to think in hypothetical terms. She must be able to reason (if I do X it may do Y or cause Z, now or in the future). She should have prolonged experience with her disease and the benefits and burdens of its various therapies. She should not be impulsive and should have the ability to learn from past choices. And finally, she must comprehend death as personally significant and final.

When religious beliefs are involved in a minor's decision-making, the issues become even more complicated. One of the most important criteria for determining capacity in either children or adults is whether the patient is free from coercion and undue influence. Can the fear of disappointing a parent, being shunned or excommunicated by one's community, and losing eternal life and salvation ever be considered an appropriate context for making a truly voluntary decision? I think not. Moreover, I think religious belief can only be firmly held after mature thinking develops and a person has had meaningful exposure to alternative ways of thinking. Even if we judge an adolescent to have decision-making capacity generally, she still may not be capable of making an independent judgment about an issue involving a belief that she has been indoctrinated into by her parents and her community. In this case, there is no way to tell whether Joy is reciting a well-rehearsed, frequently heard phrase or speaking from personal conviction.

Unfortunately, there is also little way to tell who should make the decision if Joy cannot. Case law has been inconsistent when ruling on the rights of teens to refuse recommended therapies, and courts have granted ultimate decision-making power sometimes to the parents and sometimes to the government, or to both, or to neither.

I don't see how we can tell whether an adolescent is sufficiently mature to make this decision; and even if we could tell this with any degree of certainty, I remain unconvinced that an adolescent's decision to die should outweigh society's compelling interest in keeping her alive. Physicians have a sacred charge to do no harm. If we err, I prefer it be on the side of life.