CLINICAL ETHICS DILEMMA

Religious Decision-Making in a Teenager

Robert D. Orr, MD, CM; Ferdinand D. Yates, Jr. MD, MA (Bioethics): Column Editor

Editor's Note:[1]

This column presents a problematic medical-surgical case that may pose a medical-ethical dilemma for patients, families, and healthcare professionals. As these cases are based on real medical situations, identifying features and facts have been altered to preserve anonymity and to conform to professional medical standards. In this case, the physician needs to ascertain whether or not a teenager's statement of religious faith should be allowed to direct her life-sustaining medical treatment.

Question: May we accept this adolescent Jehovah's Witness refusal of blood transfusion?

Story:

Debbi is a 13½-year-old girl who was well until two weeks ago when she developed knee pain without obvious trauma. She subsequently developed a fever and was admitted to the hospital with a septic knee found to be caused by Staphylococcus Aureus. She was started on appropriate antibiotics, but developed toxic shock and has subsequently been found to have staphylococcal sepsis,[2] osteomyelitis[3] of the femur and bilateral staphylococcal pneumonia with large pleural effusions.[4] Her osteomyelitis has been surgically drained. Her sepsis has come under control with the use of two antibiotics (Vancomycin & Cefotaxime). She is on supplemental oxygen and Total Parenteral Nutrition. The pneumonia is improving, but it has not been possible to relieve the pleural effusions with either needle aspiration or placement of chest tubes, and surgery was proposed for this afternoon.[5] Her Red Blood Cell count has dropped from normal level on admission (hemoglobin = 11.5) to a very low level (6.1). She was begun on erythropoietin (an enzyme to stimulate her bone marrow) several days ago.

Debbi is the oldest of six children in an intact family. The family has a long and strong Jehovah's Witness tradition. Her parents were baptized as adolescents, her maternal grandfather and uncle are Jehovah's Witness pastors. The patient is an excellent student in the 8th grade. She was accepted as a full member of the church five months ago after examination by the elders found her to be of sufficient understanding.

I spoke with the patient (parents, uncle and grandfather present) and she clearly articulated the Jehovah's Witness position on receiving blood or blood products. She quoted scripture and explained her understanding of Jehovah's prohibition and did not "want it on [her] conscience" to accept blood. She asked that blood not be used, "if possible." When challenged on this last point, she clearly stated that she did not want blood even if it meant that she might die as a result. She repeated this sentiment on re-discussion without her family present and after being told that I would accept her statement as her true desire rather than assume she wanted us to override her refusal.

Her physicians believe they must proceed with more aggressive intervention because of the lack of response of her pulmonary condition. I spoke with the pediatric thoracic surgeon, and he reports that decortication is likely to involve significant blood loss. Because her anemia makes surgery risky, repeat chest tube placement under fluoroscopy will be attempted today while waiting a few more days for a response to erythropoietin.

Discussion:

The Jehovah's Witness belief about blood transfusion is a deeply held rational belief based on their interpretation of scripture. There is strong ethical precedent for honoring such a request from an adequately informed patient with decision-making capacity, even if non-use of blood will lead to their death. Some suggest that many Jehovah's Witnesses will state the church's position but secretly hope that medical or legal professionals will override their refusal in order to save their lives. It is my belief that we should not engage in this charade, but should honestly accept their statement as their desire.

There is legal precedent to obtain a court order to transfuse children of Jehovah's Witnesses over the objection of their parents if the non-use of blood is likely to lead to death or disability. There is growing sentiment, however, that it is not the legal age of majority which is morally relevant, but the child's level of understanding, so that the refusal of a mature minor should be honored as if she were an adult.

In this case, I believe this adolescent is making an informed, non-coerced, choice against potentially life-saving blood transfusion.

Recommendations:

It is my recommendation that this patient's physicians and the hospital should respect her refusal of blood products and should continue to do everything possible short of using blood products to improve her condition. Should she deteriorate to the point where she will surely die without blood, I believe we should reluctantly accept that tragic outcome.

If her physicians wish to honor her refusal, they should make it clear to her that her words of refusal will be accepted as her true desire; it will not be assumed that she wants to be rescued by seeking a court order over her objection.

Because of the legal precedent of over-riding the refusal of Jehovah's Witness parents, her physicians should initiate a report of this situation to Child Protective Services. If her physicians agree with my stance, the purpose of the report would be to seek judicial relief from the precedent. If her physicians disagree with my stance, the purpose of the report would be to seek the court order authorizing transfusion.

Follow-Up:

Child Protective Services and subsequently the Juvenile Court were notified of the situation. A hearing was held three days later, with testimony from pediatrician, surgeon and ethicist. By this time the patient was slightly better (no fever, some drainage from the new chest tubes). The judge felt said she would issue an order for transfusion over parental objection if the patient's

condition deteriorated. When the tube drainage slowed and her fever returned several days later, her parents chose to transfer her to a hospital where surgeons said they would be willing to operate without giving additional blood. This was done with the judge's approval. It is not known whether surgery was, in fact, done, but it is known that the patient survived the illness.

Comment:

Four of the most difficult ethics consultations I have done have been on adolescents in Jehovah's Witness families. Each was handled a bit differently, varying with the circumstances.

In this case, I felt the patient was very mature and was making a truly informed decision based on the views she had adopted when she became a Jehovah's Witness several months earlier. Her answers to my questions seemed a bit rote, but this probably reflected her recent teaching. At the same time, they seemed sincere and informed.

It has been my observation that physicians coming from a strong faith perspective usually take one of two positions in relation to transfusion of patients from the Jehovah's Witness tradition. The majority, relying on the importance they place on the tenets of their own faith, reluctantly accept the refusal of blood products. A minority, believing their own faith is correct on this issue and that the Jehovah's Witness teaching is in error, are often more willing to ignore the patient and transfuse over their objection, believing their professional mandate is to save lives when possible.

Editor's Comment:

In situations such as this, physicians speak of decision-making capacity (DMC)—and not competence—as the latter is a legal term. The granting of DMC is based on the physician's assessment of the patient's comprehension of the medical situation associated with the patient's articulation of the issues and assurance that the patient is not being coerced. The evaluation of these aspects can be quite complicated and typically take some time to ascertain. Furthermore, in this situation, the physician needs to make an assessment of the appropriateness of granting DMC to a minor child regarding the refusal of a specific treatment that may have a direct impact on her life.

The medical ethicist will often make recommendations or speak of something as being ethically permissible. However, as these medical options are appropriated, and decisions are being made, it is imperative for the attending physician—early in the course of the healthcare relationship—to put forth guidelines as to how (s)he will approach the issue of Child Protective Services and/or Juvenile Court. A minor child and parents need to be aware of how these external services will be employed in the care of the child so that they can take advantage of available alternate healthcare resources.

Robert D. Orr, MD, CM, practiced family medicine in Vermont for 18 years before receiving a post-doctoral fellowship to study clinical ethics at the University of Chicago. For the next 25 years, he served in a variety of professional and academic roles including as consultant and

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References

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[1] The article, as originally published, was untitled, and is reprinted by permission of the publisher. Robert Orr, *Medical Ethics and the Faith Factor: A Handbook for Clergy and Health-Care Professionals* (Grand Rapids, MI: Eerdmans, 2009), 293–96.
[2] A life-threatening spread of the infection throughout the body, usually through the blood stream.
[3] Localized infection of a bone, often caused by spread of the bacteria through the blood stream.
[4] Collection of fluid in the pleural space, between the lungs and the chest wall; it may compress the lungs and cause difficulty breathing; it often needs to be removed by needle aspiration or continuous drainage through a chest tube.
[5] When the fluid is collected into multiple small cavities, it is necessary to do a procedure called “decortication”, a peeling away of this thick infected layer. This is a large and bloody operation since innumerable small blood vessels have grown between the lung and the abnormal tissue.