

“Only flesh with its soul – its blood – you must not eat” (Genesis 9.3:4)

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The Jehovah's Witness faith forbids whole blood transfusions, and Witnesses who willingly accept transfusions are in effect choosing not to be members of the church and its community. Should adolescents ever be allowed to refuse blood products that their religion prohibits when it may save their lives?

ON THE ONE HAND... WE SHOULD SUPPORT A CAPABLE ADOLESCENT'S DECISION

In recent years, it has become an ethically and legally accepted norm that adults may refuse life-sustaining medical treatment when they are capable of appreciating the very significant consequences of such a decision. While family members and health care professionals may deeply regret an individual's decision to refuse treatment, they are bound to accept it when it is made by a capable adult. This obligation rests on the ethical principle of respect for autonomy or self-determination. It acknowledges an individual's right to live their life according to their own deeply held beliefs, to preserve the integrity of their body from unwanted medical interventions and to believe that there may be some things more important to them than life itself.

Adolescents have many of the ethically relevant characteristics possessed by adults. Research suggests that the abilities of rational problem solving are typically as developed in most, but not all, 14-year-olds as they are in adults. Adolescents may be in the process of consciously committing to values and beliefs that are important to them. Children as young as seven years of age may be able to understand the permanency of death.

One of the governing ethical principles in the provision of health care is nonmaleficence (refrain from causing harm to others). Health care professionals who are required by a court to administer blood transfusions to an unwilling patient have to physically restrain that person. Depending on the size and strength of the patient, sedation may be required, and it may take several health practitioners to hold the person down so that treatment may be administered. Physical and psychological harms are significant risks, not to mention the effect on the person's dignity.

Finally, paediatricians are committed to an ethic of care, providing treatment to the child within the family context. This requires understanding and respecting the family's values and religious beliefs.

ON THE OTHER HAND... WE SHOULD OVERRIDE A CAPABLE ADOLESCENT'S DECISION

Some argue that adolescents are still children, and believe that while we should certainly give serious consideration to their views, we should not support them in refusing life-sustaining medical treatment. We have obligations to protect children from harm, and to provide them with life's necessities.

Children sometimes refuse medical interventions. They do so for many reasons – fear, anxiety, or for reasons that are meaningful and important to them. Their refusal is often overridden because it is believed that treatment is in their 'best interests', and that they may suffer or even die without it. When providing treatment in these circumstances, many paediatric health care practitioners are skilled at minimizing the distress caused to both the children and their parents. The ethical principles of beneficence (to do good for others) and respect for the sanctity of life, appear to support these decisions.

Finally, it might be argued that adolescents may be overly influenced by their parents and church elders in these circumstances and are, therefore, not autonomous. A valid informed consent (or refusal) requires voluntariness, as well as decisional capacity.

FINDING THE BALANCE

These situations are ethically complex, and ethical principles may be invoked to support different and conflicting courses of action. Should a Jehovah's Witness patient need blood, you will be faced with a tragic choice. In all cases, there should be medical certainty that blood is necessary, and that there are no reasonable alternatives.

If the patient is capable, and freely choosing to forgo treatment, you should honour his or her wishes, or transfer care to someone who will. While this may be difficult and

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may cause paediatric practitioners moral distress, it is consistent with legal and professional standards.

If the patient is not capable, and his or her substitute decision-makers refuse blood on his or her behalf, you likely have a duty to seek legal advice. Families should be aware that this may be a consequence of their decision. Should child protection authorities become involved, and a hearing be held, it is fair and respectful to the family to communicate this to them in a timely way so that they may seek their own legal counsel.

RECOMMENDED RESOURCES

1. Canadian Paediatric Society, Bioethics Committee [Principal author: C Harrison]. Treatment decisions regarding infants, children and adolescents. *Paediatr Child Health* 2004;9:99-103.
2. Bodnaruk ZM, Wong CJ, Thomas MJ. Meeting the clinical challenge of care for Jehovah's Witnesses. *Transfus Med Rev* 2004;18:105-16.
3. Kuther TL. Medical decision-making and minors: Issues of consent and assent. *Adolescence* 2003;38:343-58.
4. The Hospital for Sick Children. Jehovah's Witnesses and Blood Products (unpublished guideline, contact author for more information).

If the patient is not aware that he or she has received blood, parents may wish to postpone informing the patient until he or she is through the crisis. While truth-telling is an important value and practice in the patient-practitioner relationship, unless the patient is explicitly asking if blood has been received, delaying disclosure would be reasonable in these circumstances.

Finally, the patient, their family, and the staff who have ordered and administered the blood transfusion, will need ongoing understanding and support.

CPSP QUIZ

Canadian Paediatric Surveillance Program 2007 quiz – Answers

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8. The two-year CPSP neonatal severe hyperbilirubinemia study confirmed nearly 260 cases (mean total bilirubin of 468 $\mu\text{mol/L}$) needing readmission at a mean age of less than five days in 74% of cases. To identify the at-risk population, the CPS recommends that a transcutaneous or serum predischarge bilirubin be measured in the first 72 h of life and that results be plotted on the predictive nomogram based on age in hours and gestational age. Because nearly 75% of cases were breastfed, community support and close follow-up of all infants need to be in place before discharge to prevent kernicterus.
9. Worldwide, tuberculosis remains endemic in many countries. Altogether, 665 (27%) CPSP respondents to the 2005 international adoption survey identified 111 confirmed cases infected with tuberculosis in the previous two years. Survey results identified gaps in knowledge and practice, potentially putting children and their contacts at risk. As per expert recommendations, a tuberculosis skin test should be performed even if the child had received the bacille Calmette-Guérin vaccine, and a repeat tuberculosis screening is needed within three to six months of arrival, if poor nutritional status initially may have led to a false-negative result.
10. Anaphylaxis, an extreme systemic allergic reaction, occurs within minutes or hours of a susceptible person's exposure to his or her 'trigger factor(s)', and is a potentially life-threatening medical emergency requiring immediate recognition and treatment. As soon as the diagnosis of anaphylaxis is suspected, the first-aid treatment of choice is an intramuscular injection of adrenaline. The correct dose is 0.01 mg/kg of a 1:1000 solution, to a maximum of 0.3 mg (0.3 mL). After this first-aid treatment, the child should be taken to the nearest hospital for further evaluation and treatment.

The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Canadian Paediatric Society and the Public Health Agency of Canada, which undertakes the surveillance of rare diseases and conditions in children and youth. For more information, visit our Web site at <www.cps.ca/cpsp>. Accepted for publication November 5, 2007