Medical emergencies in children of orthodox Jehovah's Witness families: Three recent legal cases, ethical issues and proposals for management

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Three recent Canadian legal cases have dealt with the proposed blood transfusion of adolescent members of Jehovah's Witness (JW) families. In each case, the court permitted transfusions if medically necessary. Much critical analysis of the issue of forced treatment of decisionally competent adolescents focuses exclusively on competence and questions why mature minors may not decide for themselves. The authors argue that a focus on decision-making competence alone is too narrow. Before one may legally give or refuse consent to medical treatment, three conditions must be met: competence, adequate information and lack of coercion. In striving to find agreement on medical treatment, physicians, patients and JW family members seek and, in fact, often achieve mutual understanding and cooperation. Coercion by actual or threatened shunning and excommunication can occur, and these factors may affect adolescent decision-making. In this context, a court order authorizing medical treatment can, therefore, be seen as enhancing patient freedom. The authors suggest that, in addition to fulfilling existing statutory duties to report a child in need of protection, health care professionals caring for acute patients of JW families should actively look for evidence that the patient has accurate medical information and is acting without coercion. The authors also explore suggestions on how to deal with the unusual complexities of such cases.

Key Words: *Blood; Children; Emergency; Ethical issues; Jehovah's Witness; Management*

Les urgences médicales chez les enfants de familles orthodoxes Témoins de Jéhovah : Trois causes judiciaires récentes, des problèmes éthiques et des propositions de prise en charge

Trois causes judiciaires canadiennes récentes ont porté sur la transfusion projetée de sang à des adolescents de familles Témoins de Jéhovah (TJ). Dans chaque cas, le tribunal a autorisé les transfusions si elles s'imposaient d'un point de vue médical. Une grande partie de l'analyse critique du traitement forcé d'adolescents compétents à prendre leurs décisions est exclusivement axée sur la compétence et sur les raisons pour lesquelles des mineurs matures ne peuvent pas décider eux-mêmes. Les auteurs font valoir que la seule compétence de prise de décision constitue un point de vue trop restreint. Avant d'accorder ou de refuser légalement le consentement à un traitement médical, trois conditions doivent s'appliquer : la compétence, l'information pertinente et l'absence de coercition. Dans leur recherche d'une entente quant au traitement médical à administrer, les médecins, les patients et les membres de la famille TJ s'efforcent de parvenir à une entente mutuelle et à une coopération. Souvent, ils y réussissent. Il est toutefois possible d'exercer une coercition par des mesures ou des menaces de fuite ou de reniement et d'excommunication, et ces facteurs peuvent influer sur la prise de décision de l'adolescent. Dans un tel contexte, l'ordonnance d'un tribunal autorisant le traitement médical peut donc être perçue comme une accentuation de la liberté du patient. Les auteurs postulent qu'en plus de respecter leur obligation statutaire de déclarer un enfant qui a besoin de protection, les professionnels de la santé qui soignent les patients en soins aigus de familles TJ doivent évaluer activement si le patient possède l'information médicale exacte et s'il agit sans coercition. Les auteurs évaluent également des suggestions sur la manière d'affronter les complexités inhabituelles de ces cas.

Three legal cases in the past four years involving teenagers from Jehovah's Witness (JW) families in Western Canada have created disquiet among paediatricans about the potential conflict between religious beliefs and the proposed medical or surgical treatment of children.

A 2002 Alberta case involved a 16-year-old patient (case 1) with acute myeloid leukemia, subtype M1; she received 38 transfusions under court order before her death (1). A second Alberta case (case 2) in 2003 upheld a court order to transfuse a 16-year-old with dysfunctional menstrual bleeding who required a dilation and curettage (2). In a third case (case 3) in British Columbia in 2005, a judge ordered that a 14-year-old girl with osteogenic sarcoma be transfused if her condition abruptly deteriorated and as adjunct to the oncology treatment, which had a 70% chance of success (3).

The legal result of these cases is that, in Alberta and British Columbia, the expressed wishes of a minor, who can understand and appreciate the nature of the proposed treatment and the consequences of accepting or refusing it, may nevertheless be circumscribed by society's obligation to protect the welfare of a child in a life-threatening situation (4). These decisions are not binding in courts in other Canadian provinces and territories because they concerned specific provincial statutes. But these three recent Western Canadian decisions are of general interest to Canadian physicians because, in our view, each court reached the morally correct conclusion in light of two factors:

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1. the serious nature of the ailment and the life-threatening risk of not receiving blood; and
2. the recently described (5-9) social factors that affect the medical decision-making freedom of minors in the JW religious community, which are summarized below.

ORTHODOX AND UNORTHODOX JW BELIEFS

These legal developments have occurred because differences of opinion within the JW community regarding the blood doctrine and the JW church's social practices are reported on Internet sites (with supporting scientific references) (10). The cases raise two related ethical concerns. The first is whether the respect for religious freedom requested by orthodox JW officials and in court by JW lawyers is extended by such leaders to individual adherents. The second is whether sensitivity toward the issue of religious freedom can obscure the fundamental question for medical practitioners when seeking a patient's consent: "Is the patient in a position to give or refuse consent to proposed medical treatment?"

Orthodox JWs

Orthodox Canadian JWs are members of the Watchtower Bible and Tract Society (WTS), an organization founded in Pennsylvania in the 1870s, which now has over six million members worldwide (11). Generally, orthodox JWs seek and accept the benefits of modern medical care with one notable exception: since July 1, 1945, the WTS has held that blood transfusions, even autologous transfusions, violate God's will. Citing these Biblical passages – "only flesh with its soul – its blood – you must not eat (Genesis 9:3,4), "[You must] pour its blood out and cover it with dust" (Leviticus 17:13,14), and "Abstain … from fornication and from what is strangled and from blood" (Acts 15:19-21) – the WTS claims that the Bible prohibits transfusions of whole blood, packed red blood cells and plasma, as well as white blood cells and platelet administration (12). The WTS asserts that these Biblical passages do permit adherents to use components such as albumin, immune globulins and hemophiliac preparations, and to receive organ transplants (13).

Dissident and Reform JW concerns

Lack of information on which to base decision-making: Critics of the orthodox WTS blood dogma, including dissident and reform JW members (10), claim that the WTS inaccurately finds justification for its blood ban in Biblical passages (codified in the fifth century) concerning rules governing meat preparation, which have nothing to do with blood transfusion. Critics state that it is illogical for the WTS to claim that a blood transfusion is an 'eating' of blood, because a transfusion is more akin to a cellular organ transplant than the administration of nutrition. They claim it is also illogical to permit some blood parts but not others when the Bible itself does not distinguish among blood components. Critics particularly condemn the inconsistancy of medical bans generally and of the blood ban in particular. They note that the WTS used to ban vaccinations and organ transplantations but has reversed these positions, and that the WTS has altered the blood dogma itself over time. According to neurologist Muramoto, "Official church publications show that the use of serum was prohibited by the church from 1964 to 1973, the use of clotting factors by hemophiliacs was prohibited until 1978 and the use of albumin was forbidden until 1981" (14). The anesthesiologist Doyle (15) states that the WTS reversed its position on the acceptability of the use of hemoglobin-based blood substitutes in two years (1998 to 2000). Critics claim that the precedent of other policy reversals (in removing the vaccination and transplant bans) and these piecemeal changes in the blood ban will lead eventually to acceptance of all blood in medical emergencies (10). The poignancy of someone refusing a life-saving transfusion and dying the day before a rule change is obvious.

According to Kerry Louderback-Wood (8), the official WTS pamphlet describing the blood policy – *How Can Blood Save Your Life* (16) – misrepesents secular facts, historians' writings, the current medical risk of accepting a blood transfusion, the necessity for blood in certain medical situations, the safety and efficacy of medical alternatives to blood transfusion, and the organization's policy in 2005 as to the scope of allowed products.

Lack of voluntariness in decision-making: Concerns about voluntariness have also been raised. Quoting the official WTS publication, *The Watchtower*, Muramoto claims that JWs are warned in harsh language against reflecting upon the WTS Biblical interpretations (5):

> Avoid independent thinking. From the very outset of his rebellion Satan called into question God's way of doing things. He promoted independent thinking. 'You can decide for yourself what is good and bad,' Satan told Eve. 'You don't have to listen to God' … How is such independent thinking manifested? A common way is by questioning the counsel that is provided by God's visible organization [ie, The Watchtower Society] …

This WTS discouragement of the independent gathering and sharing of information is the general background against which a number of specific autonomy-limiting practices are said to take place. According to critics and to dissident JWs, these practices include: the completion of advance directives during group Bible study sessions without the provision or encouragement of private, independent legal advice (6); the official church suggestion that it is ethically appropriate for hospital personnel to breach patient medical confidentiality and to report the religiously unauthorized medical treatment of a JW to religious leaders (5); the requirement that orthodox JWs disassociate themselves from and actively shun members who have accepted religiously unauthorized medical treatment (5); and the excommunication of JW members who accept religiously unauthorized medical treatment (5). These practices of shunning and excommunication have been known to cause severe emotional distress to estranged JWs, occasionally even leading to their suicides (17). Indeed, one individual described the loss of family and friends through shunning and excommunication as a fate "worse than death" (18).

RELEVANCE OF CONCERNS TO PAEDIATRIC PRACTICE

The concerns raised by some critics and dissidents about poor information and coercion relate to the legal requirements for consent to medical treatment. Before one may legally give or refuse consent to medical treatment, three conditions must be met: competence, information and voluntariness (19,20). Cases involving adolescents in JW families can be confusing because they may focus attention solely on the first condition: competence. Yet competence alone is not a sufficient condition for valid consent. Even if conscious and alert, and with sufficient cognitive function and maturity to comprehend and appreciate information, a patient may still be unable legally to give or refuse consent. If a patient does not understand and appreciate the risks and benefits of a proposed procedure or a course of treatment, the patient is not in a position to accept or reject the proposal. Patients need reliable information. They also need the third element of consent: voluntariness. It may be difficult to accept a treatment option if that particular choice will lead to the loss of important relationships. To give or refuse consent to medical treatment, the law requires not just decision-making competence but also accurate information and lack of coercion.

The three cases illustrate some of the concerns raised about the quality of information and voluntariness.

Lack of information

In both case 1 and case 3, the judges determined that orthodox adherents and religious advisers contradicted the statements made by medical personnel. In case 1, the judge ruled that (1):

> Because of incorrect information and the behaviour of some around her, [case 1] now believes that she will not die if she does not have the transfusions … [T]he undue influence put upon her in the last few weeks has taken away her ability to make an informed choice.

In case 3, the court specifically admonished the JW lawyer for attempting to give false information: "Counsel, you're spinning. You're saying something the doctor has not said" (21). The lawyer was attempting to argue that osteogenic sarcoma is not serious when clearly it is (3).

In addition to being offered misinformation regarding the medical situation, patients and their families can be presented with problems if they seek independently to evaluate the alleged Biblical basis of the blood ban.

Lack of voluntariness

Coercion can be a great concern in paediatric cases involving JW families. Breach of medical confidentiality can permit coercive practices to begin. Even though the fact that a person is in hospital is a private matter, the confidential medical information of children of JW families can become nationally and even internationally broadcast, yet the source of the medical information is not known. The public attention from the news broadcasts can place the patient in a difficult and potentially coercive situation by becoming the focus not just of the patient's congregation, but of JW congregations internationally. With media involvement, discussions and positions may become more rigid. The patient may feel the pressure of being the focus of such attention in addition to the pressure of threats of shunning and excommunication. The religious advice may be positioned as if it were as accurate as the medical advice.

The power of all these pressures should not be underestimated. For example, the father who rejected WTS teaching by agreeing to a blood transfusion for his daughter (when his daughter's hemoglobin was at 45 g/L) (22) sat alone on one side of the court room (during case 1 appeal hearings); his wife, healthy daughters and former friends sat on the other.

SUGGESTIONS FOR MEDICAL MANAGEMENT

Possibly compromised information

In such a charged atmosphere, it is especially important to maintain mutual respect among families and health care professionals. It is often possible both for agreement to be reached on a treatment plan, and for the child's life to be safeguarded. But a paediatrician cannot ignore the possibility of contradictory medical information, and the reality of sanctions for those who do not follow official JW rules. The physicians should verify with the patient alone and with her family, on an ongoing basis, that they, individually and as a group, understand the physician's assessment of the patient's medical condition, the risks of blood transfusion and the risks of foregoing blood transfusion when it is urgently recommended.

Communication of medical information may be the source of the greatest difficulty. If the patient and/or parents consistently request that JW clerics be present, the paediatrician should direct his or her comments and information to the patient and family, notwithstanding the presence of others. The paediatrician needs to recognize that because of the threat of sanctions, it would be unwise to ask the patient, when JW members are in the room, whether the patient will accept blood or blood products. (The sensitive nature of this situation is similar to that when a teenager's parents and/or religious officials are present in clinic when contraception is discussed.)

We agree that, in general, "patients are more likely to be better served by too much information rather than too little" (23). While we do not suggest that paediatricians engage in theological disputation, questioning that attempts to elucidate the patient's belief is within the scope of a physician's duty. Muramoto advises physicians to ask the patient:

> In view of the changing blood policy of the Watchtower Society, the component you now refuse may be considered acceptable in a few years. Are you sure you want to refuse it and die now even if you may not have to do so in the near future? (24).

This language may be considered accurate and direct by some paediatricians or strong and blunt by others. Hence, not all paediatricians will find it useful.

Possibility of coercion

A patient may want to accept blood or blood products but refuse because of fear of social and religious effects of such a

choice. Physicians should speak to decisional-competent paediatric patients when they are alone, and also with their families, and explain that blood may be administered in the absence of visitors. Physicians and hospital administrators should ensure that a patient's medical information is kept strictly confidential and should preface any discussion with "What we are about to discuss is confidential … ".

Physicians should also consider it possible that the patient may welcome the intervention of the legal system. Apparently, the WTS does not require JWs to shun members who have received a transfusion under court order. By taking the apparent choice out of the patient's hands, the law can remove the young person from an impossible social position.

Triggering the intervention of the state may be difficult for health care professionals in these situations. But physicians and all other adult members of Canadian society (irrespective of their occupations) have a legal obligation to report that the child is in need of intervention or protection when the child's life is in danger. If, after a hearing, the court transfers custody to the Director of Child Welfare, the Director will consult with the physicians regarding the appropriate medical treatment. It is not a question of physicians forcing a transfusion, but the state ensuring that minors receive essential medical treatment.

Nonetheless, it remains distressing that blood was forced on teenagers who apparently refused it. As noted, case 1 was transfused 38 times, and was physically and chemically restrained to do so because she fought transfusion (1). The troubling nature of the court order was described by one medical professional, who told us, "It became increasing difficult to walk into her room holding the IV tubing primed with blood and say, 'I'm sorry to do this to you'." Yet, we do not see an easy solution to the problem of the state discharging its duty to protect children when the family's religious community advises them (often based on misinformation) to refuse life-saving treatment and the children know that serious social consequences are almost certain to follow if they disobey. In such an unusual social situation and given the duty of the state to protect minors, distress experienced by all parties seems inevitable.

CONCLUSION

A teenager's ability to consent must be assessed by looking for all its constituent parts: competence, information and freedom from coercion. Such assessment may reveal that patients in JW families, even though competent, can be in the unusual position of not having two of the three legal elements necessary for consent to, or refusal of, blood transfusion.

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