Re: Teenage decision-making in the context of the Jehovah's Witness faith (again)

To the Editor;

Dr Harrison's article (1) debates when paediatricians should accept a teenager's refusal of potentially life-saving or life-prolonging treatment. The article addresses only one of three necessary elements of consent: competence. Not discussed are the two other requirements – adequate information and voluntariness.

Full discussion of the three elements that are necessary for consent to medical treatment is particularly important when the adolescent patient is a member of a Jehovah's Witness (JW) family. This is a subject that can evoke strong emotions. Our paper (2) on this topic was published in the 2006 issue of *Paediatrics & Child Health*. Indeed, the governing body of JWs, the Watchtower Society (WTS), wrote to the *Journal* in protest over our then unpublished article, which had been accepted after two rounds of peer review. The editors of the *Journal* resisted the WTS's representations.

Our article presented details about three real cases of adolescents who refused blood transfusions. In each case, the information we offered came from publicly available sources, such as court transcripts or reports of court hearings. Our article, therefore, had rich grounding in actual cases and in reported alleged practices of JWs, the WTS and WTS lawyers. By contrast, the Harrison article presented and then discussed a hypothetical case. There is a place for theoretical cases and commentary thereon, but we suggest that the *Journal* follow the Hasting's Center report's example. A recent edition of the Hasting's Center report (3) presented a short hypothetical case of a JW teenager, followed by two commentaries from different perspectives. Two commentaries are preferable to one because it is unlikely that one person can fairly represent all views in this controversial bioethics matter.

We express concern also about the paucity of detail offered in Harrison's hypothetical case. When analyzing ethically fraught matters, it is customary to examine very carefully the context in which the situation arises. It is important to recognize that untold numbers of JWs, who are otherwise faithful to WTS teachings, in fact disagree with the WTS's biblical interpretations about the uses of blood. Some JWs, who have a different understanding of the relevant biblical passages, have created a Web site that we have found extremely useful (4). We suspect that the Web site will be similarly helpful to most paediatricians who may choose to offer it to families, thus permitting them to know that further information on the complexities of blood transfusion, and some alternative perspectives, are readily available.

In our article, we gave specific detail about possible problems in the quality of information an individual JW patient may have about the risks and benefits of blood. We also addressed problems of voluntariness in decision-making among teenagers. In other words, we described clearly that two of the three elements of informed consent may well have been absent – ie, adequate information and voluntariness. This discussion made it apparent that, even if an adolescent is assessed to be fully mature, the assessment does not, by itself, solve the problem of whether he or she can accept or refuse proposed medical treatment.

Indeed, cases of adolescent refusal of blood would be relatively easy if the only issue was maturity. But what is concerning are the issues that the recent article does not address: How does one establish that a young patient has good medical information when (among other problems) the religious authority's Web site contains misleading excerpts from dated medical journals (5), when medical personnel statements can be contradicted by religious people who visit hospitals (6), and when the credibility and good faith of medical personnel are constantly in question because they, like all other non-JWs, are said to be subjects of "Satan the Devil [who] really is the unseen ruler of the world! (7)"? How do physicians assure themselves that a patient is choosing without coercion when a particular medical choice will cause the loss of family and friends (8), when the patient's lawyer appears to also represent the religious authority (9,10) and when the WTS instructs individual JWs 'to squeal' – to breach medical confidentiality if, in their work as health care providers, they learn that a patient has accepted blood (11,12)? Finding answers to these questions ought to be the focus of bioethicists because these are not just difficult issues worthy of academic consideration, they are of vital practical importance to paediatricians and other physicians who must assess capacity to consent in a social context in which preventable death is a distinct possibility.

We agree that paediatricians are likely to suffer extreme moral distress if a teenage patient dies due to the lack of a blood transfusion. But we strongly disagree that it is "consistent with legal and professional standards (1)" to accept the teenager's 'decision' when the patient's quality of information and degree of voluntariness have not been considered, let alone assessed. In a supplement to our paper, we wrote:

> Paediatricians must look for all elements of consent: competence, information and voluntariness. Most difficulties among physicians, parents and adolescents are resolved amicably. We support this. In some situations, reporting to Child Welfare is a statutory duty and legal help is required (13).

Refusal of life-saving or life-prolonging treatment clearly presents paediatricians with a difficult situation.

Continued on page 332

LETTERS TO THE EDITOR

Continued from page 330

Nevertheless, we agree with the conclusion regarding the JW case published in the Hasting's Center Report: "Physicians have a sacred charge to do no harm. If we err, I prefer it to be on the side of life" (3).

Ian Mitchell MA MB FRCPC
Department of Paediatrics,
Juliet Guichon BA BCL MA SJD
Office of Medical Bioethics,
University of Calgary, Calgary, Alberta

REFERENCES

1. Harrison C. "Only flesh with its soul – its blood – you must not eat" (Genesis 9.3:4). Paediatr Child Health 2007;12:867-8.
2. Guichon J, Mitchell I. Medical emergencies in children of orthodox Jehovah's Witness families: Three recent legal cases, ethical issues and proposals for management. Paediatr Child Health 2006;11:655-8.
3. Orr RD. Case study. Old enough. Commentary. Hastings Cent Rep 2007;37:15-6.
4. Associated Jehovah's Witnesses for Reform on Blood. New light on blood <http://ajwrb.org> (Version current at March 11, 2008).
5. Louderback-Wood K. Jehovah's Witnesses, blood transfusions, and the tort of misrepresentation. J Church State 2005;47:783-822.
6. H(B) (Next friend of) v. Alberta (Director of Child Welfare), (2002) 95CRR (2d) 333, aff'd (2002) 95 CRR (2d) 362.
7. The Watchtower Society. Who really rules the world? <http:// www.watchtower.org/e/t22> (Version current at March 11, 2008).
8. Alter, S. Jehovah's Witnesses: Disfellowshipping and shunning – Canadian parliament report. <http://www.culthelp.info/index.php?option= com_content&task=view&id=289&Itemid=8> (Version current at March 11, 2008).
9. The Alberta Court of Appeal. Hughes (estate) v Brady, 2007 ABCA 277. <http://www.canlii.org/en/ab/abca/doc/2007/2007abca277/2007abca277.html> (Version current at March 11, 2008).
10. Blackwell T. Witness for the family: Debate over role of sextuplet case lawyer. <http://www.rickross.com/reference/jw/jw281.html> (Version current at March 11, 2007).
11. Anonymous. "A time to speak" – when? The Watchtower Society, 1987:12.
12. Muramoto O. 'Medical confidentiality and the protection of Jehovah's Witnesses' autonomous refusal of blood.' J Med Ethics 2000;26:38-6.
13. Guichon J, Mitchell I. Response: Medical emergencies in children of orthodox Jehovah's Witness families: Three recent legal cases, ethical issues and proposals for management. Paediatr Child Health 2007;12:385-6

The author responds;

Assessing decision-making capacity is context dependent. It involves determining the person's ability to understand their health condition, current health problems, the treatment that is being proposed and its potential harms and benefits, other treatment alternatives and potential harms and benefits, and potential consequences of accepting or refusing treatment. It also involves determining that the person is able to contextualize this information to his or her own circumstances.

As part of the assessment process, the health care provider doing the assessment should provide the person with the information about the matters detailed in the previous paragraph, and ensure that he or she appreciates that there are options.

Continued on page 334

LETTERS TO THE EDITOR

Continued from page 332

If he or she is not able to understand the information and appreciate that there are options, then the health care provider would not likely deem him or her capable to give or withhold consent.

I concluded in my article that "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." Because having decision-making capacity entails being fully informed and having the ability to understand the information that has been provided, and appreciating that one has options, when a person is found to be both capable and making a free choice, I would be interested in the ethical argument that would justify overriding this person's wishes.

Christine Harrison PhD
The Hospital for Sick Children, Toronto, Ontario

Re: Faith held by Jehovah's Witnesses does not always forbid blood transfusions

To the Editor;

It appears that Dr Harrison confuses official church doctrine with 'family values and religious beliefs' (1). This mistake presents a false and perilous premise for medical ethical deliberations.

Families among Jehovah's Witnesses (JW) do not form and maintain a doctrine forbidding themselves from conscientiously accepting transfusion of blood or else they are "choosing not to be members of the church and its community" (1). Rather, it is an elite religious hierarchy ('governing body') that makes and enforces this doctrine, including the caveat that to accept blood is an act of disassociation (2). Contrarily, there is evidence demonstrating that a considerable number of JWs do not fully accept this doctrine (3,4). Drs Gyamfi and Berkowitz state that, "it is naïve to assume that all people in any religious group share the exact same beliefs, regardless of doctrine… Why should that not also be true for Jehovah's Witnesses?" (5). Official church doctrine should never be confused with personal belief.

Before 1945, there was no evidence suggesting that the general population of JWs held a taboo against blood transfusion and, in fact, the governing body at the time expressed praise when relating experiences in which allogeneic blood was used to save lives (6). In 1945, the governing body then taught that it was morally wrong to accept blood transfusions. In 1961, this doctrine began to be enforced under the pain of organized shunning (7). Speaking retrospectively and specifically about its blood taboo, in 1966, the governing body put it bluntly to the JW community by reminding them of the "placing of additional obligations on each [Jehovah's Witness] individually" (8). The governing body placed these obligations. No measurable, prevailing, communal view of JWs asked for it. This shunning imposes a duty to conform so extreme that JWs are required to refrain from even private spiritual socializing with a family member who has conscientiously accepted a forbidden blood product (9). Extreme pressure to conform in the face of such a threat to social and family support is unavoidable, and should be realized by judges, clinicians, social workers and ethicists.

Members of the Associated Jehovah's Witnesses for Reform on Blood encourage doctors to treat patients as those patients want to be treated, rather than treating them as a religion would want them treated.

Lee Elder, Director
Associated Jehovah's Witnesses for Reform on Blood

Continued on page 341

hypersensitivity (including skin rash, urticaria, fever, arthralgia, exfoliative dermatitis, erythema multiforme with histopathological findings of necrotizing vasculitis, and thrombocytopenic purpura); anorexia; nausea; dizziness; headache; dyskinesia; drowsiness; blood pressure and pulse changes, both up and down; tachycardia; angina; abdominal pain; weight loss during prolonged therapy. There have been rare reports of Tourette's syndrome. Toxic psychosis has been reported. Although a definite causal relationship has not been established, the following have been reported in patients taking this drug: instances of abnormal liver function, e.g., hepatic coma; isolated cases of cerebral arteritis and/or occlusion; leukopenia and/or anaemia; transient depressed mood; a few instances of scalp hair loss. Very rare reports of neuroleptic malignant syndrome (NMS) have been received, and in most of these, patients were concurrently receiving therapies associated with NMS. In a single report, a ten-year-old boy who had been taking methylphenidate for approximately 18 months experienced an NMS-like event within 45 minutes of ingesting his first dose of venlafaxine. It is uncertain whether this case represented a drug-drug interaction, a response to either drug alone, or some other cause.

Table 1.3: Adverse Events Occurring in Long-Term Safety Trials

Frequency	Very Frequent	Frequent	Frequent	Less Frequent
Body System	**>10% - <50%**	**5-10%**	**<5% and ≥1%**	**<1%**
Body as a Whole	headache	accidental injury, abdominal pain, fever	flu syndrome, allergic reaction, infection, aggravation reaction, pain, extremity pain, back pain	surgery procedure, accidental overdose, chest pain, cyst, infection fungal, photosensitivity reaction, malaise, asthenia, neck pain
Cardiovascular System			hypertension	cardiovascular disorder, tachycardia, migraine
Digestive System		anorexia, vomiting	gastroenteritis, diarrhea, nausea, dyspepsia	rectal disorder, gastritis, increased appetite, nausea and vomiting, periodontal abscess, tongue disorder, tooth disorder, constipation
Endocrine System				diabetes mellitus
Hemic and Lymphatic System				ecchymosis, petechia, lymphadenopathy
Metabolic and Nutritional System			weight loss	dehydration
Musculoskeletal System			myalgia	arthralgia, leg cramps
Nervous System	insomnia		twitching, nervousness, emotional lability, anxiety, depression, somnolence, hostility, dizziness	apathy, neurosis, hallucinations, speech disorder, sleep disorder, tremor, thinking abnormal, abnormal dreams
Respiratory System	upper respiratory tract infection	pharyngitis, cough increased, rhinitis	sinusitis, respiratory disorder, asthma, bronchitis, epistaxis	dyspnea, pneumonia, voice alterations, laryngitis
Skin System			rash, contact dermatitis	pustular rash, urticaria, eczema, pruritus, skin benign neoplasm, acne, alopecia, nail disorder, psoriasis, herpes simplex
Special Senses		otitis media	conjunctivitis	ear disorder, diplopia, ear pain
Urogenital System				albuminuria, urinary frequency, urinary tract infection, urinary urgency

OVERDOSAGE

Signs and Symptoms Signs and symptoms of acute methylphenidate overdosage, resulting principally from overstimulation of the CNS and from excessive sympathomimetic effects, may include the following: vomiting, agitation, tremors, hyperreflexia, muscle twitching, convulsions (may be followed by coma), euphoria, confusion, hallucinations, delirium, sweating, flushing, headache, hyperpyrexia, tachycardia, palpitations, cardiac arrhythmias, hypertension, mydriasis and dryness of mucous membranes. **Recommended Treatment** Treatment consists of appropriate supportive measures. The patient must be protected against self-injury and against external stimuli that would aggravate the overstimulation already present. Gastric contents may be evacuated by gastric lavage as indicated. Before performing gastric lavage, control agitation and seizures (if present) and protect the airway. Other measures to detoxify the gut include administration of activated charcoal and a cathartic. Intensive care must be provided to maintain adequate circulation and respiratory exchange; external cooling procedures may be required for hyperpyrexia. Efficacy of peritoneal dialysis or extracorporeal hemodialysis for CONCERTA overdosage has not been established. The prolonged release of methylphenidate from CONCERTA tablets should be considered when treating patients with overdose. Alcohol may induce the production of ethylphenidate. The amount of ethylphenidate production is proportional to the blood alcohol concentration (see DRUG INTERACTIONS; Overview). As with the management of all overdosage, the possibility of multiple drug ingestion, including alcohol, should be considered.

Product Monograph available at www.janssen-ortho.com or from Janssen-Ortho Inc. Medical Information Services (800) 567-3331.

JANSSEN-ORTHO

Janssen-Ortho Inc., Toronto, Ontario M3C 1L9
Date of issuance: August 2007
Distribution Address: Markham, Ontario L3R 0T5
CRPI070772E

Member R&D PAAB

LETTERS TO THE EDITOR

Continued from page 334

REFERENCES

1. Harrison C. "Only flesh with its soul – its blood – you must not eat" (Genesis 9.3:4). Paediatr Child Health 2007;12: 867-8
2. Watchtower Bible and Tract Society. Statement to the media, 2000.
3. Gyamfi C, Berkowitz RL. Responses by pregnant Jehovah's Witnesses on health care proxies. Obstet Gynecol 2004;104:541-4.
4. Benson K. Management of the Jehovah's Witness oncology patient: Perspective of the transfusion service. Cancer Control 1995;2:552-6.
5. Gyamfi C, Berkowitz RL. Responses by pregnant Jehovah's Witnesses on health care proxies. Comment in Obstet Gynecol 2005;105:442; author reply 442-3.
6. Watchtower Bible and Tract Society. The Golden age, 1924:163.
7. Watchtower Bible and Tract Society. The Watchtower, 1961:63
8. Watchtower Bible and Tract Society. The Watchtower, 1966:142.
9. Watchtower Bible and Tract Society. Our Kingdom Ministry, 2002:3

The author responds,

My understanding is that although Jehovah's Witnesses (JWs) seek medical care and accept most medical treatments, their religious beliefs preclude transfusion of whole blood and its major components. JWs regard donor-derived blood transfusion (whole blood, red cells, white cells, platelets and plasma) as contrary to scriptural commands. They request medical management using alternatives to blood transfusion, eg, blood conservation and 'bloodless' surgery (ie, surgery performed without the use of transfused blood).

The sources of my understanding include materials from the Jehovah's Witnesses – Office of Public Information Web site:

- <http://www.jw-media.org/region/global/english/releases/health/000615.htm>
- <http://www.jw-media.org/beliefs/beliefsfaq.htm>

A JW Liaison Committee Chair member stated that:

> If a baptized member of the faith willfully and without regret accepts a blood transfusion, he indicates by his actions that he no longer wishes to be one of Jehovah's Witnesses. The individual revokes his own membership by his actions – Chuck Goodvin, Hospital Liaison Committee for Jehovah's Witnesses (personal communication).

JWs do not necessarily reject the use of some blood fractions that may have been processed or derived from plasma or blood cells (eg, albumin, clotting factors, immunoglobulins, fibrin glue, cryoprecipitate, oxygen-carrying red-cell substitutes and interferons). Because JW patients make their own individual personal decisions on these matters, it is essential to discuss the acceptability of blood and specific blood products with each individual patient or family.

Christine Harrison PhD
The Hospital for Sick Children, Toronto, Ontario