Informed Refusal

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The Case

A 41-year-old female with hepatitis C cirrhosis complicated by hepato-pulmonary syndrome is listed for liver transplant. She has high priority status due to the severity of her pulmonary disease, which is usually reversible with liver transplant. Pertinent lab results are: hemoglobin 12, INR 1.1, bilirubin 1.0, creatinine 1.0, and platelet count 75,000. Her situation is further complicated by the fact that she is a Jehovah's Witness and will not accept blood transfusions.

Should this patient be a candidate for liver transplant, given the relatively common need for blood transfusion during the operation? What are the anesthesiologists' obligations to the patient, to themselves, and even to other patients on the transplant recipient list? Is the decision to follow through with this case different from any other major surgeries, such as coronary artery bypass surgery or liver resection?

Jehovah's Witnesses

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Jehovah's Witnesses (JWs) began as a Bible study group formed in 1870 by C.T. Russell in Allegheny, Pa. Members of this group believe that God's name is Jehovah, which is an English translation of the name that appears in Hebrew texts. They also believe in the literal interpretation of the Bible, except in cases in which it is obvious that it is allegorical. JWs believe that only one government is owed allegiance—God's Kingdom. They do not salute flags, serve in the military, or vote in political elections. They also believe we are living in the "last days" of the present system.[1]

As with many religions, JW beliefs and teachings have evolved as society has evolved. In 1945 there was a ban placed on blood transfusions based on three quotes from scripture:[2]

> Genesis 9:3–4—Every moving animal that is alive may serve as food for YOU. As in the case of green vegetation, I do give it all to YOU. Only flesh with its soul—its blood—YOU must not eat.
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> Leviticus 17:10–16—As for any man of the house of Israel or some alien resident who is residing as an alien in YOUR midst who eats any sort of blood, I shall certainly set my face against the soul that is eating the blood, and I shall indeed cut him off from among his

> people. For the soul of the flesh is in the blood, and I myself have put it upon the altar for YOU to make atonement for YOUR souls, because it is the blood that makes atonement by the soul [in it]. That is why I have said to the sons of Israel: "No soul of YOU must eat blood and no alien resident who is residing as an alien in YOUR midst should eat blood." As for any man of the sons of Israel or some alien resident who is residing as an alien in YOUR midst who in hunting catches a wild beast or a fowl that may be eaten, he must in that case pour its blood out and cover it with dust. For the soul of every sort of flesh is its blood by the soul in it. Consequently I said to the sons of Israel: "YOU must not eat the blood of any sort of flesh, because the soul of every sort of flesh is its blood. Anyone eating it will be cut off." As for any soul that eats a body [already] dead or something torn by a wild beast, whether a native or an alien resident, he must in that case wash his garments and bathe in water and be unclean until the evening; and he must be clean. But if he will not wash them and will not bathe his flesh, he must then answer for his error.
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> Acts 15:28–29—For the holy spirit and we ourselves have favored adding no further burden to YOU, except these necessary things, to keep abstaining from things sacrificed to idols and from blood and from things strangled and from fornication. If YOU carefully keep yourselves from these things, YOU will prosper. Good health to YOU!

A 1951 article in *The Watchtower,* a publication of the JW governing body, explained the ban:

> "…when sugar solutions are given intravenously, it is called intravenous feeding. … the transfusion is feeding the patient blood and .. [the patient] is *eating it [blood]* through his veins."

Over the years, adaptation has been required to keep up with advances in medicine. Guidelines have been developed to help members deal with renal dialysis, cardiopulmonary bypass, blood harvesting including cell saver, acute normovolemic hemodilution (ANH), and autologous blood donation as well as organ transplantation. See Table 1 for a timeline of significant events in the JW faith.

TABLE 1: Events in the history of the Jehovah's Witness church and transfusion

1870	study group formed
1879	first issue of *The Watchtower* published
1901	discovery of ABO blood groups
1914	first blood bank transfusion
1931	changed name to Jehovah's Witnesses
1945	ban placed on transfusions
2008	7.1 million members worldwide and 1.1 million members in the United States

Ethical Principles

Ethical dilemmas can be examined in the context of the four basic principles of medical ethics defined by Beauchamp and Childress: 1) respect for autonomy—a norm of respecting the decision-making capacities of autonomous persons, 2) beneficence—a group of norms for balancing benefits against risks, 3) nonmaleficence—a norm of avoiding harm, and 4) justice—a group of norms for distributing benefits, risks, and costs fairly.[3] In the U.S., the principle of respect for patient autonomy is usually the most heavily weighted of the four, while in many European countries, the principle of beneficence may weigh more heavily than respecting individual autonomy (see *CSA Bulletin,* Volume 61, Number 1, pages 36–46).

Adults with appropriate decision-making capacity express their autonomy through the informed consent process. Physicians demonstrate respect for the autonomy of competent patients by accepting their informed decisions, whether or not they consent to medical treatment. It seems self-evident that without respect for informed refusal, the concept of informed consent is invalidated: "consent" would then merely be acquiescence of the patient to the physician's recommendations. Adults are therefore even allowed to make what doctors may sometimes consider unwise or foolish decisions. The physician does not have to agree with the patient, but neither can a physician be compelled to give inappropriate, bizarre, or substandard care.

In order to give informed consent, a patient must have appropriate decision-making capacity; be able to understand the nature of the procedure and the risks, benefits and alternatives including that of doing nothing; and the probable outcomes of both acceptance and refusal of the proposed procedure. In addition, the decision must be made free of coercion. Coercion is present if the patient feels threatened, bullied or subjected to irresistible pressure to make a decision he or she would otherwise not make.

Legal Precedents

Although legal decisions are not always synonymous with "ethical" ones, a review of some legal precedents regarding JWs and how they have changed provides some insights into how medical ethics have shifted in the U.S. from a paternalistic and/or beneficence-based emphasis to one of respect for autonomy.

In 1964, two U.S. courts compelled transfusion for adult patients. In *Georgetown College v. Jones*[4] the court of appeal ruled that the "patient's religion merely prevented her from consenting to a transfusion, not from receiving one" and a transfusion was ordered. In *Raleigh Fitkin-Paul Morgan Memorial Hospital v. Anderson,* a pregnant JW was not permitted to refuse a necessary transfusion.[5]

Over the last 40 years, U.S. courts have rejected these cases and consistently upheld the rights of adult JWs to refuse blood even when a transfusion would be lifesaving—and even when others, such as dependent children, may be indirectly affected. On the other hand, when the patient is a minor child and hospitals have sought court orders to give blood believed to be absolutely necessary to preserve life, such orders have usually been granted. Exceptions have sometimes been made when an older teenager is committed to his/her religion and seems to fully understand the scope and consequences of his/her decision. Legal precedents in many European countries have paralleled those in the U.S.[6–9]

Specific Issues to Consider in This Case

Key questions arise in most cases involving JWs and others who refuse certain types of treatment on religious or other grounds.

Does the Patient Have Appropriate Decision-making Capacity? All patients over the age of majority are assumed to have adequate decision-making capacity unless proven otherwise. Anesthesiologists can usually tell whether patients have decision-making capacity, which is generally present if the patient understands the nature of his/her illness/condition, the nature of the proposed procedure and its inherent risks and benefits and alternatives, and the consequences of refusing treatment. In doubtful cases, evaluation by a psychiatrist may be helpful.

Have All Appropriate Risks, Benefits and Alternatives Been Explained? There are other important issues in this case that need to be addressed, aside from the usual explanation of anesthesia and surgical risks. These include assuring that the patient understands that there are some blood cells in solid organs; explaining the specifics of blood conservation techniques; and clarifying the risks of not accepting blood in the face of massive hemorrhage.

In non-emergent cases such as these, there is also often time to plan. Patients should be encouraged to discuss their options not only with the surgical team, but also with the local hospital liaisons from their church (who can be a resource for physicians as well). Preoperative treatments with erythropoietin, iron supplements, or other methods to improve baseline hematocrit should be discussed. Consideration should also be given to intraoperative use of desmopressin and any other measure that will minimize blood loss during the procedure.

Can a Surrogate Decision-maker Refuse Transfusion for an Incompetent Patient? All JWs are encouraged to carry a durable power of attorney that explains in detail what their beliefs are concerning blood and blood products.

If this is not available and it cannot be verified that the patient is a practicing JW, then physicians generally err on the side of transfusion. Consultation with hospital legal affairs or an organization's ethics committee may be helpful if the appropriate action remains unclear.

Can a Surrogate Decision-maker Change a Plan Made by a Previously Competent Patient? A surrogate decision-maker's task is to make decisions for the patient when the patient cannot make them for himself. Ideally, surrogates are not supposed to express their own wishes, but are supposed to make the same decision that a patient would make if he/she were able to do so. Once the patient's decisions are known, whether physicians agree or not, those decisions should stand unless new information becomes available that brings the previous decision into question. This can be particularly difficult if the patient has refused a treatment that the physician thinks is lifesaving, and the physician knows, believes, or even hopes that the surrogate would capitulate and allow the prohibited treatment. That is when physicians discover if they truly believe in patient autonomy.

Is the Patient Making a Decision That Is Free of Coercion? Patients should be free of coercion from health care providers and feel safe that regardless of their personal choices their doctors will not abandon them. Additionally, providers must also strive to ensure that the choices a patient makes are *truly* his/her own. It is not unusual for members of the JW church community, as well as family members, to flock to the bedside of a JW patient, both to support their loved one and also to protect him/her from receiving blood. Sometimes the decisions JW patients express in the presence of family and church members are different from those they later express in private. In the author's experience, this is extremely rare. However, it is important that at some point prior to surgery and anesthesia, patients have an opportunity to express their transfusion preferences to the anesthesiologist in private.[10] This might be done in a preoperative holding area after the family and/or church members have been sent to the waiting room. The intent should *not* be to talk the patient into receiving blood, which would be itself coercive, but to insure that his/her true wishes are known and followed. If the patient does recant, it is then important to determine what, if anything, can/should be told to family members about whether blood products were given. Principles of patient confidentiality demand that specifics of treatment such as this only be discussed with the patient unless there is an agreement with them to do otherwise.

Which Blood Products Will and Will Not Be Acceptable? It is not a given that a patient professing to be a JW will not accept any blood products. In one study, for example, up to 10 percent of pregnant JW patients indicated that they would accept blood in an emergency.[11] Nevertheless, in general, few if any

baptized JWs will accept whole blood, packed red blood cells, plasma, platelet concentrates, or white blood cell transfusions.[12] Stored autologous blood is also not acceptable because it is out of contact with the body for an extended period. Fractionated products such as albumin, cryoprecipitate, cryo-poor plasma, and individual factors are left to the "discretion of the practicing Christian," as are organ and bone marrow transplantation.

Other "gray areas" include, but are not limited to, cell saver, ANH, cardiopulmonary bypass (CPB), and renal dialysis. In these situations, *The Watchtower* has stated that if the blood is kept in continuous circuit with the body and not stored for any length of time, then accepting its transfusion is a personal decision.

CPB and dialysis would almost always involve a continuous circuit. Cell saver and AHN do not necessarily involve a continuous circuit, but one can be created by flushing the cell saver bag and tubing with crystalloid and connecting the circuit to the patient's IV prior to blood collection. If, after collecting blood for AHN, the line to the collection bags remains connected to the patient then it, too, is considered to be a continuous circuit.

What Are the Capabilities of the Surgical Team? When large surgical procedures are planned that may involve significant hemorrhage, it is important to assess whether the surgical and anesthesia team have the skills, experience and resources necessary to perform this procedure on a patient who has limited their ability to care for him/her by refusing blood. The principle of nonmaleficence, doing no harm, might suggest refusing to do the surgery if the team does not have sufficient experience; modifying the surgical plan; or referring the patient to another center with more experience in "bloodless" surgery techniques. There are centers in the U.S., for example, that have created a niche in caring for high-risk JW patients. Accessing the official JW website may be of help.[13] Consultation with, or referral to, such centers may be useful.

Is It Appropriate to Undertake Liver Transplantation or Other Major Surgery in a JW Patient? In many routine surgical and anesthesia cases, distributive justice (fair allocation of scarce resources) is not a large consideration in the decision-making process. However, except in the case of a living related donor, solid organ transplantation involves use of a very limited resource. Even centers that specialize in organ transplants in JWs have strict criteria for selecting the proper candidates for organ transplantation. If there is relative certainty that the preoperative status of the patient will mandate the use of blood products during the transplantation, then a JW patient should not be a candidate if they would refuse such transfusions. On the other hand, many potential candidates for liver transplantation are not in severe failure but are at the top

of the recipient list due to other complicating factors such as hepato-pulmonary syndrome, hepatocellular carcinoma, or hepato-renal syndrome. Many of these patients have normal coagulation and hemoglobins and have a reasonable chance of receiving a liver transplantation without transfusion, whether they are JWs or not. Such patients may be appropriate candidates for organ transplantation.

What Are the Anesthesiologist's Rights and Obligations? Many anesthesia providers feel that refusal of standard care in the operating room, such as blood transfusions, places them in an untenable position in which a seemingly irrational patient choice prevents them from fulfilling their professional obligations to provide lifesaving therapy. The American Society of Anesthesiologists has developed guidelines for the anesthesia care of patients with do-not-resuscitate orders or other directives that limit treatment[14] that specify the following:

> When an anesthesiologist finds the patient's or surgeon's limitations of intervention decisions to be irreconcilable with one's own moral views, then the anesthesiologist should withdraw in a nonjudgmental fashion, providing an alternative for care in a timely fashion. … [if such] alternatives are not feasible within the time frame necessary to prevent further morbidity or suffering, then in accordance with the American Medical Association's Principles of Medical Ethics, care should proceed with reasonable adherence to the patient's directives, being mindful of the patient's goals and values.

In non-emergent situations, anesthesiologists have the right to excuse themselves from a patient's care, as long as they are willing to refer the patient to another provider. This referral could even be to another medical center that has developed expertise in caring for JW patients, and may be desirable in certain situations even if the anesthesiologist would personally be willing to care for the patient.

If the situation is a life-or-death emergency with no time to make a referral, then the anesthesiologist is obligated to care for the patient, trying as much as possible to adhere to the patient's wishes.

These guidelines are similar to the Guidelines on Clinical Management of JWs published by the National Health Service in Great Britain in 2005.[15] European countries vary somewhat in the depth of obligation a physician has to honor a patient's wishes to not be transfused. In France, for example, an autonomous patient's wishes are generally respected, but the law gives leeway to physicians acting in the course of an emergency. In Germany, transfusion even to save a life would be in direct conflict with constitutional guarantees of autonomy—although it is uncertain how this would play out in court if challenged.

Case Resolution

In this case, the patient had been advanced on the recipient list due to her hepato-pulmonary syndrome, the only cure for which was a liver transplant. In addition, her pulmonary status was worsening, and it was felt that she soon would not be a candidate at all. Though the transplant team did not have extensive experience in transplanting JWs, the most experienced surgeon did have a track record of operating on patients such as this with minimal blood loss and minimal use of blood products. The lead anesthesiologist had extensive experience with JWs in other major surgeries such as cardiac surgery. Both of these individuals committed to being involved in this case, whether on call or not, at the time a liver became available for this patient.

The patient agreed to ANH and cell saver as long as a continuous circuit was maintained. She also agreed to albumin and recombinant factor VII if necessary. At the time of surgery three units of blood were drawn off and left in circuit with the patient. The surgery went smoothly, and the patient received the three units of blood and two units of cell saver after the new liver had been revascularized. DDAVP was also administered. She tolerated the surgery and was discharged ten days later, having had a slightly extended postoperative ICU stay due to her pulmonary status.

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