The Case of Jehovah's Witness: A Minor Requiring Blood Products
Case Study: Novak V. Cobb County - Kennestone Hospital – Blood Transfusions
Auth. N.D. Ga. 1994, 849 F. Supp. 1559

Summary (Facts)

A sixteen-year-old male member of Jehovah's Witnesses incurred injuries in an auto accident. The injuries required surgery.

He had informed both ambulance personnel and the hospital of his wish not to receive blood transfusions. Surgery was performed without use of blood transfusions.

Frequent blood tests revealed steadily declining hemoglobin and hematocrit readings. Physicians attempted to persuade patient and his mother (divorced, with custody of her son) to consent to blood transfusion, but they resolutely declined.

After the surgeon expressed his opinion that patient was in imminent danger of life-threatening consequences, legal counsel for the hospital filed a late afternoon petition in the state court for appointment of a guardian ad litem, without notice to either the patient or his mother. On same evening, informal hearing was held by the state judge, attended by only the hospital's risk manager and two hospital attorneys. The state judge appointed a guardian ad litem.

The following morning, the state judge was told by the risk manager that the patient's condition had deteriorated more during the night. The judge directed that a further hearing be held forthwith at the hospital and directed who should be present (did not specify either patient or his mother, and neither attended nor was consulted). Surgeon and a second treating physician testified to medical need for transfusion. State judge, at guardian ad litem's request, entered order permitting transfusion. Patient was physically restrained and transfused with three units of packed red blood cells, on afternoon of day of the hearing and order.

Patient recovered, without adverse physical reaction from the transfusion, and was discharged one and one-half months later.

Subsequently mother initiated this action in federal court, on behalf of her son and for-herself, against the hospital, the risk manager, the surgeon, the second treating physician, and the two hospital attorneys (also sued another physician, but shortly conceded to that physician's exclusion). The claims were premised on various theories of liability under the Civil Rights Act (1983) and on various state law claims (ultimately dismissed, without determination of the merits, for lack of federal court jurisdiction upon dismissal of all federal law claims).

All defendants filed motions for summary judgment in their favor on each of the federal law (civil rights) claims (asserting that no genuine issue of fact existed on the respective claims and theories of action).

Holding

Federal trial court sustained all motions for summary judgment in favor of the respective defendants (on the claims of both the patient and the mother), ruling on each claim and theory as follows:

1. As to claim of both patient and mother for breach of constitutional right of non-interference with familial relationship (under fourteenth amendment), held that actions of risk manager (conceded to have been "state actor," under civil rights law) were not shown to rise to requisite showing of "shocking and egregious conduct" necessary to support a substantive due process violation; and held that procedural due process was not violated for lack of a showing calling into question the emergency need, real or perceived, to forego pre-deprivation motive to the patient or parent, where evidence was that the involved parties all perceived that an emergency existed (distinguished from issue whether, in fact, emergency existed).

2. As to claim of patient for breach of constitutional right of free exercise of religious beliefs (under first amendment), while acknowledging some protection of a minor's religious freedom, held that parents "can and must" make judgments as to treatment and that parent's right as to such issue is subject to right of court to order treatment over religious objection, and that thus no substantive due process violation occurred.

3. As to the claim of the patient for breach of constitutional right to direct medical treatment, held that patient, as a minor (even if mature) had no constitutional or common law right to refuse treatment and that guardian ad litem (then “standing in the shoes" of the mother) had consented, and, in any event, the "legal cause" of any such deprivation of right was the order of the court (not a party) and not the actions of the individuals that led up to the order. (Also found no procedural due process violation in lack of notice of the hearing, where the situation was reviewed by three doctors, an impartial judge; and a guardian ad litem.)

As to liability of defendants other than the risk manager (assuming that any breach of civil rights had occurred), ruled that no requisite showing , in detail, was made of any conspiratorial conduct (stating that, "at best" only an abuse of state judicial procedures was shown).

Declined to retain jurisdiction of the separately asserted claims premised on state law, where the federal law question claims had "dropped out of the lawsuit in its early stages" (dismissing those claims "without prejudice").

CONTRAST THE PREVIOUS CASE WITH THE FOLLOWING CASE:

Nicoleau vs. Brookhaven Memorial Hospital

(from Hospital Ethics. 1990. March/April.)

The New York Court of Appeals has expanded the individual's right to refuse lifesaving medical care by ruling that the state could not compel treatment, even if a child's interests would be harmed by the death of a parent who refused the treatment.

Arguments on behalf of saving the child's life have been accepted in the past by lower courts to force medical care on an unwilling patient, but this new ruling, made on January 18, 1990, makes clear that this tactic could no longer be used.

The case that prompted the ruling involved a Long Island woman who had hemorrhaged shortly after giving birth and was given a blood transfusion, a procedure the hospital considered necessary to save her life.· The woman, a thirty-five-year-old Jehovah's Witness, had objected to the transfusion on religious grounds, and the Court of Appeals ruled that her wishes should have been respected. A lower court had quickly ordered the transfusion without holding a full hearing, and the woman survived.

The woman, Denise J. Nicoleau of Moriches, New York, filed a civil lawsuit against Brookhaven Memorial Hospital in Patchogue for rejecting her instructions.

The case was the first before the Court of Appeals in which a patient refusing lifesaving treatment was the parent of a minor, and thus it was the first time that the court decided whether a child's "overriding interest" could be cited to deny the parent's wishes. In a decision written by Chief Judge Sol Wachtler, the court gave a firm no.

Article: **The Jehovah's Witness and Blood: New Perspectives on an Old Dilemma**

By Janicemarie K. Vinicky, Martin L. Smith, Russell B. Connors, Jr., and Walter E. Kozachuk

This article was written by Janicemarie K. Vinicky, Martin L. Smith, Russell B. Connors, Jr., and Walter E. Kozachuk in their private capacities. No official support or endorsement by the Clinical Center of the National Institute of Health, the Cleveland Clinic Foundation, or St. Mary Seminary (Cleveland) is intended.

This article presents the case of a Jehovah's Witness, the mother of a severely retarded man, who required surgery to treat an acute subarachnoid hemorrhage that developed from a cerebral artery aneurysm. The authors present the facts of the case, the ethical issues that arose in its evolution, and the medicoethical decisions that were implemented. The authors further discuss caveats, including their conclusion that a Jehovah's Witness's acceptance of death in lieu of blood transfusion is not synonymous with his or her acceptance of permanent disability and total dependency.

Case Study

History

The patient, a 42-year-old white woman, presented to the emergency room with a severe occipital headache of acute onset, mild dizziness, nausea, and vomiting and, later, diplopia. The headache began while the patient was at a restaurant, and it had become so severe within three hours that she required hospitalization. She denied any head trauma, fever or chills, loss of consciousness, visual symptoms (other than diplopia), dysphasia, dysarthria, or limb weakness.

The patient had an eight-year history of hypertension, which was treated with hydrochlorothiazide. There was no history of transient ischemic attacks, stroke, or migraine headaches. There was no history of transient ischemic attacks, stroke, or migraine headaches. Her family history was negative for aneurysms, stroke, hypertension, and migraine headaches.

Her social history revealed that she was married and the mother of three adult children. She was a newly baptized Jehovah's Witness; her husband, although a Christian, was not a Jehovah's Witness. She worked full time as a school secretary and her paycheck provided significant proportion of the family's income. Her husband had an eighth-grade education and worked the second shift in a local laundry, earning minimum wage without benefits. Two daughters were married and living away from home. Her son, age 20, was severely retarded and attended a state day school for the mentally handicapped where he was progressing slowly, having attained a preschool level of self-care. The patient and her husband had arranged to work different shifts in order to maintain their separate incomes and to be available should their son become ill and need parental assistance at home. The son related primarily and preferentially to his mother.

Physical Examination Findings

The patient was alert and oriented to person, place, and time. Kernig's sign was negative, while Brudzinski's sign was positive. A right VI nerve palsy was present. Her pupils were 4mm and reactive to direct and consensual light, and photophobia was evident. Motor power and tone were normal. DTRs were 2+ and symmetrical, with plantars flexor bilaterally. The remainder of the neurologic exam was normal. General examination was normal except for an S4 heart sound on cardiac auscultation.

Laboratory Findings

A computed tomography scan of the head revealed a diffuse subarachnoid hemorrhage with mild ventricular dilation. On angiogram, an aneurysm was evident at the bifurcation of the left internal carotid artery. The results of an initial laboratory evaluation were as follows: hemoglobin, 9.5; hematocrit, 28.8; platelet counts, Z35,000; prothrombin time, 12.4 sec; and partial thromboplastin time, 22.3 sec.

Hospital Course

The patient's labile blood pressure was controlled with a nipride infusion. The medical chart indicated that the patient was a Jehovah's Witness who refused blood transfusions ("even if it means death") but was not specific about her willingness to accept autotransfusion or cell-saver therapy; the chart also did not note discussion with the patient regarding specific anticipated risks of the proposed surgery, such as vasospasm and stroke, if blood products were needed but not given.

The patient underwent a craniotomy with clipping of the L. anterior cerebral artery aneurysm. A mild right hemiparesis developed the first day after surgery. Angiography revealed cerebral vasospasm. Volume expanders were used, and four days after surgery the patient's hematocrit was 22.6 and her hemoglobin was 7.5. She developed global aphasia and a complete right hemiparesis.

The patient's husband and sister, neither a Jehovah's Witness, requested that she be given blood. The attending physicians had determined that transfusion should not be performed because of the patient's religious beliefs. The patient's primary intensive care nurse suggested consultation with the hospital ethicist and possibly with the institution's ethics committee.

The patient's primary caregivers and her husband and family were invited to a multidisciplinary conference. During the discussion it became apparent that the patient's husband was uncertain of the depth of his wife's religious convictions. She was a new Witness, having been baptized four months earlier. The patient's husband "sensed" that his wife found the community support and the social interaction with the church more important than its teachings about blood. Unfortunately, they had never specifically discussed her wishes concerning transfusion. Furthermore, he stated an uncertainty about what treatment course his wife would choose if she knew that failure to transfuse would result in permanent disability. He reported that she had mentioned to both him and her sister (while caring for a cousin in the end stages of cancer) that she wished "never" to become permanently bedridden or unable to communicate. She also frequently expressed a strong and primary commitment to her son, declining invitations to vacation away from him.

The primary physician informed the patient's husband that, without transfusion, his wife's death was far less likely than permanent disability. Consequently, the patient's husband found himself attempting to balance his wife's religious beliefs with a previously expressed wish "never" to become a burden to her family and a strong and freely chosen dedication to their retarded son. The inability of the patient's surrogate to prioritize his wife's values left the health care team uncertain about her transfusion refusal. The autonomy dilemma, juxtaposed against the probability that transfusion would reverse some of the patient's debility, [1*] posed a significant ethical quandary.

The Issues

The primary ethical issue in this case was whether the physician was obligated to abide by this Jehovah's Witness's previously expressed wish not to receive blood, or whether there were factors that would justify overriding her religiously motivated convictions against blood transfusion. There is something both old and new in this case. What is old is the familiar but no less troubling dilemma for health care providers: the obligation to respond to this patient's medical needs and to do what one can to promote life and, on the other hand, the obligation to respect her previously expressed wishes not to receive blood transfusion.

But there are also some new wrinkles in this case that cause one to pause and reexamine the classic dilemma. Does this woman's relationship with her 20-year-old, severely mentally handicapped son influence whether or not to respect her wishes concerning transfusion? If so, does that relationship make the critical difference, that is, does it ethically justify transfusion? Is an aspect of Christian matrimonial "headship" operative here, namely, does this patient's husband, himself not a Witness, have the religious authority to override his wife's wishes concerning transfusion? Are this woman's previously expressed wishes to accept death rather than blood transfusion synonymous with a willingness to accept a life of permanent disability and dependency on others? In our discussion of this case, we will not only be addressing some of the fundamental issues in cases involving Jehovah's Witnesses but also the more precise issues raised by this specific case.

We intend to summarize the beliefs of Jehovah's Witnesses concerning blood and "headship." We will then offer an ethical analysis of the case in view of its specific circumstances. Finally, we will offer reflections on some insights gained from this case concerning not only Jehovah's Witnesses, blood, and "headship" but also ethical decision making in the health care setting.

Jehovah's Witnesses and Blood

Jehovah's Witnesses are a Christian sect founded in the 1870s in Pennsylvania. Their beliefs, based on a literal interpretation of the Bible, include a refusal to acknowledge the authority of earthly powers and a refusal "…to take blood into their system either by eating or by transfusion."[2] These convictions concerning blood are based upon biblical texts that prohibit the taking of blood or drinking of blood by God's people (Genesis 9:3 and Leviticus 17:13-14)

Including this passage from the Acts of the Apostles (15:19-20): "It is my judgement, therefore, that we ought not to cause God's Gentile converts any difficulties. We should merely write to them to abstain from anything contaminated by idols, from illicit sexual union, from the meat of strangled animals, and from eating blood."

Witnesses do not view these passages as relating merely to dietary or ritual laws. In biblical perspective, blood represents a most sacred life source.[3] The biblical laws concerning blood are not peripheral but central to the Witnesses' faith and are taken with the utmost seriousness: "The issue of blood for Jehovah's Witnesses, therefore, involves the most fundamental principles on which they as Christians base their lives. Their relationship with their Creator and God is at stake."[2]

Because these convictions are at the center of the faith life of Jehovah's Witnesses, they should be respected by health care personnel. However, as experience bears out, not all Jehovah's Witnesses interpret this prohibition in the same way. Jonsen[4] has identified two questions to which Witnesses are found to give diverse answers: 1) What ae the consequences of violating the prohibition? And 2) To what exactly does the prohibition apply?

Violating the prohibition means for some Witnesses the loss of salvation; for others, it is a forgivable sin. Some hold that one who receives blood – regardless of the circumstances – is cut off from the community; others do not take such a stand. Some Witnesses insist that the negative spiritual effects are incurred regardless of whether the person actually chooses the transfusion; others assert that one is not spiritually affected if transfused against one's will or while unconscious.[4] Nonetheless, awareness of this diversity of opinion is not an invitation either to weaken consideration of an individual's beliefs or to manipulate the patient. Rather, an exploration and an awareness of the beliefs of a particular Jehovah's Witness should enable attending medical personnel to treat the patient contextually, with understanding and sensitivity to specific needs.

To what then, does the prohibition against receiving blood apply? That question, too, yields diverse answers. Witnesses are generally prohibited not only from receiving whole blood but also packed red cells, plasma, white blood cells, and platelets.[5] Questions remain, however, concerning dialysis, plasmapheresis, and various forms of autotransfusion.[6] Physicians treating Jehovah's Witnesses would do well to determine in fine detail the types of products and the specific procedures with which the particular patient is comfortable. A physician willing to treat

Witnesses on their own terms must keep abreast of the developing body of: "…ancillary means, technical variations and alternatives to standard procedures in order to minimize risks and achieve acceptable results."[7]

Jehovah's Witnesses and Headship

Another relevant circumstance in this case is that the patient's husband was not a Witness but identified himself as a Christian. The Jehovah's Witness faith tradition places emphasis on the husband/father role of headship, which holds that “the head of every man is the Christ, in turn the head of a woman is the man; in turn the head of Christ is God” (1 Corinthians 11:3). This tradition gives the husband/father authority as the designated head of his family and requires him to 1) recognize Christ as his own head and as his model for behaving as a Christian husband/father; 2) recognize that the “Christ-like” husband/father has been given "priority" over women and is thereby responsible for directing the decisions and worship of his family; and 3) responsibly provide both materially and spiritually for his household.[8] This tradition provides that the headship position be revoked when a husband/father engages in "unscriptural conduct" as interpreted by the Jehovah's Witness faith tradition.[9]

How do these principles and this concept relate specifically to this case? According to an authoritative Jehovah's Witness source (Rev. Michael Randolph, Chairman, Greater Washington Jehovah's Witness Hospital Liaison Committee, Bethesda, MD, 1989), the non-Witness (Christian) head maintains the position only if he authentically represents the wishes of his wife as an autonomous individual following the faith tradition. Conversely a Jehovah's Witness wife whose husband is a non-Witness urgently requiring blood transfusion is obligated to represent her husband’s wishes and faith tradition and not impose those of the Witness upon him. She should not ask that blood be given to her husband because that is against the law Jehovah; rather, she should express the wishes of her husband to have a blood transfusion if such a request authentically represents his stated wishes. Witnesses are urged to discuss these potentially conflictual situations with their spouses and to respect each other's stated wishes. Many Witnesses carry a card, a Jehovah's Witness Transfusion Refusal Card, identifying themselves as such and stating their wish to refuse blood or blood products even when facing death. Because the expressed wishes of this patient and those of her husband appear to be in conflict, the Witnesses interpretation of this request for transfusion on behalf of his wife would likely be that of "unscriptural conduct,” which would justify removing the husband from his position as head and possibly requiring Jehovah’s Witness elders to step in on the patient’s behalf.

Ethical Analysis

In its report entitled *Deciding to Forgo Life Sustaining Treatment*,[10] the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concludes that competent, informed patients have the authority to male their own health care decisions, including those to forgo treatment and allow death to occur. The Hastings Center's *Guidelines on the Termination of Life Sustaining Treatment and the Care of the Dying*[11] echoes this general principle by affirming patients' rights to control what happens to their bodies, including the use of life-sustaining treatment. More specific to the case at hand, the Hastings Center's *Guidelines*, also assert that among the treatments a patient may choose to forgo is the administration of blood and blood products.

These authoritative statements on patient autonomy and treatment refusal are helpful, broad brush stroke guidelines for approaching dilemmas involving conflicts between patient wishes and the health care team's perception of beneficial treatment. But if ethics and medicine are to avoid the "tyranny of principles," the uniqueness and particularity of each clinical case must also be considered. Different ethical evaluations can emerge from analyses of cases in which a blood transfusion is refused by a 70-year-old widow who is her own decision maker and by parents on behalf of their 25-year-old, mentally handicapped daughter. Furthermore, differences in the circumstances surrounding blood product refusals by a 25-year-old single woman and a 25-year-old mother of two children under the age of 5 (specific innocent third parties) could lead to different ethical conclusions. Guiding principles (usually abstracted from similar cases) and case specific circumstances must be addressed in the process of arriving at sound medicoethical decisions.

The factors to be considered and evaluated in the case at hand were mentioned above and include 1) the 20-year-old dependent, mentally handicapped son (a specific innocent third party), whose life would be significantly affected should death or disability result from his mother's treatment refusal; 2) the patient's husband, not a Jehovah's Witness, who clearly and firmly requested that his wife receive the necessary blood transfusions and who, by Jehovah's Witness standards, held and consequently relinquished the position of head of his family and marriage; and 3) the informed consent and informed refusal process, which included the patient's understanding of the risk of death if necessary blood transfusions were not administered intraoperatively but did not include a discussion of the possibility of life with disability if necessary blood transfusions were not provided intraoperatively or post-operatively. Each of these circumstances must be evaluated for ethical relevance and weight. Do any or some combination of these considerations influence the respect usually given the previously expressed wishes of a mentally capacitated patient?

Jonsen[4] has stated that, as amoral argument, responsibility, to others (innocent third parties) has its perils and is "reprehensible paternalism" when used to override a competent patient's wishes. In his view, the decision to override the Jehovah's Witness's freedom in order to enable the Witness to fulfill responsibilities freely is a contradictory one. Furthermore, Jehovah's Witnesses live within close, supportive communities, so it is not clear that the care of survivors would fall upon the public. Finally, Jonsen asserts, a physician's social responsibilities do not weigh so heavily that they override his or her duty to respect the wishes of a particular patient.

We agree with Jonsen that restricting patient autonomy on the basis of responsibility to others has its inherent dangers. The ethicist and the clinician should tread on this ground with great caution. Nevertheless, this is ground that at times must be traversed.

Throughout their lives, both inside and outside the health care system, individuals freely make choices that place resulting restrictions on their freedom and on present and future options. The decision to have a child, to keep and care for a handicapped infant, and to be educated and employed can all be made freely but nonetheless result in a restriction of one's freedom. It would be paradoxical and paternalistic but, in our view neither reprehensible nor contradictory to hold someone accountable to responsibilities that have been freely undertaken but that are also inherently restrictive. The argument seems even stronger for restricting autonomy and holding someone accountable when these freely embraced responsibilities are for another person who is dependent upon their fulfillment. Such is the case at hand. The death or significant disability

that would result from the patient's refusal of blood products would prevent her from meeting her freely chosen responsibilities to her son.

Jonsen's two other supporting reasons for his characterization of "reprehensible paternalism" also deserve comment. At root, both call into question the role of the physician as an agent of society, or "gatekeeper," when fulfillment of that role comes into conflict with the responsibility to honor the patient's expressed wishes. Jonsen believes that the close-knit nature of such religious communities supports the reasonable expectation that an innocent third part (e.g., a mentally retarded child) will receive appropriate care and will not impose demands on public assistance. This may be a reasonable presumption in many cases, but in this case, not all members of the family unit belonged to this religious group. Community support may not have been as comfortable, continuous, or committed because the primary surviving caregiver was not a community member. Furthermore, we are not concerned simply with the addition of another client to the public resources roll but with the deprivation of parental/maternal nurturance and care that had become familiar to and were expected by the child as a result of 20 years of assistance and rearing. Jonsen is correct that, in the abstract, it is dubious that physicians' social responsibilities should override their duty to respect the wishes of a particular patient. Nonetheless, the circumstances of this case suggest to us that a given case may contain an accumulation of circumstances that supports a paternalistic action (i.e., the intentional overriding of an individual's wishes) to provide medical benefit to the patient and promote the personal and social good of someone other than the patient.

The second relevant circumstance that must be considered in the ethical analysis of this case is the role of the non-Witness (Christian) husband in the decision-making process. From an ethical perspective, a proxy or surrogate decision maker should make choices consistent with, and reflective of, the patient's own values, if those values are known to the proxy. But in this case, the surrogate decision maker found himself in a conflictual situation. It appeared, initially, that he was inadequately reflecting, or even ignoring, the religious value system of his wife.

The third and final consideration for the case at hand is the process and content of the informed consent and informed refusal. There is general agreement that an ethically sound informed consent process includes active patient participation and physician disclosure of the nature, purpose, risks, benefits, and alternatives of the proposed treatments.[12] Dialogic disclosures between physicians and patients allow opportunities for patients to articulate and prioritize their values with reference to the single value the individual places above all others, particularly when forced to choose between values.[13]

Generally, patients agree to the foreseeable and accompanying pain, discomfort, side effects, and risks (including death) or particular treatments because they value health and biological life above the avoidance of such burdens and risks. However, even though they too value health and biological life, most Jehovah's Witnesses hold as a greater good their understanding of the will of Jehovah. This unique belief may lead the Jehovah's Witness to rank values differently that a non-Witness facing similar health care decisions under similar circumstances.

In this case, what was the patient's hierarchy of values of "goods" as she anticipated surgery, with its many foreseeable intraoperative and postoperative complications and risks? From the chart notes it appears that she viewed compliance with the will of the Creator as more important than the avoidance of death. In relation to the judgements of Jehovah concerning blood

transfusions, where did this patient rank not just death, but lifelong permanent disability, paralysis, and total dependency?

Although the medical directive card states generically that the witness accepts any risk stemming from the refusal of blood transfusions, what individual decision would this Jehovah's Witness have made had the informed consent process included a discussion of the foreseeable probability of postoperative survival in a dependent, debilitated state? The inability to answer this question with some certainty is significant. The physician's obligations to respect one of the patient's previously stated wishes (to choose death over transfusion) is weakened by the presence of a conflicting wish ("not to be a burden") and the lack of an opportunity for the patient to consider a potential danger that she is implicitly accepting: life with permanent disability.

The Ethical Conclusion

The immediate and critical question before the health care team was whether or not to transfuse, an old and familiar dilemma for those called upon to provide treatment to Jehovah's Witnesses. It is our belief that the circumstances of this case, especially the presence of the dependent, mentally retarded son, as well as the narrow focus of the patient's informed refusal and her previously expressed with not to burden her family, create a different and new situation that supports a regrettable but justifiable decision to override the patient's previously expressed wish against blood transfusion.

The ethics consultants in this case advised the surgical and intensive care teams that there was strong ethical support for transfusing the patient. We concur with that opinion.

Reflections and Recommendations

<u>The Informed Consent Process</u>

We concur that the informed consent process should always include a consideration of the religious beliefs of the patient, particularly in cases where the patient's religious belief system is likely to be an issue in his or her management. With Jehovah's Witnesses, it is important to discuss the decision not to accept blood in light of the specific and foreseeable risks. If there is a significant difference in prognosis with and without transfusion, the patient should be informed of the increased risk. Furthermore, this risk should be discussed in light of alternatives to transfusion, such as blood conservation devices and volume expanders.

During the consent process, patients should be questioned directly about their willingness to accept potential life-long disability. In the case presented here, the risk of stroke and significant physical and mental incapacity was greater than the risk of death. It is important that the Witness be told as clearly as possible what refusal of blood may mean so that he or she may make arrangements for the fulfillment of parental and spousal responsibilities.

<u>Psychosocial Data</u>

We strongly recommend a thorough investigation of the psychosocial factors operative in the patient's life at the initiation of the informed consent process. For a capacitated patient, this

process would include a discussion of family and financial responsibilities, the religious convictions and obligations, the patient's value system, and the prioritization of the patient's obligations and beliefs. Indeed, there is an endless variety of human situations and unique facts that may influence the health care team's decisions.

Resources

We also recommend that institutions and physicians involved in the care of Jehovah's Witnesses seek out a Jehovah's Witness minister or a member of a Jehovah's Witness Hospital Liaison Committee (currently formalized in many major US cities) for advice in cases such as the one presented. If someone other than the next of kin can more adequately reflect the patient's religious convictions, such an individual should be consulted in the decision making process. This is not to imply that in every case someone other than the patient's surrogate should be asked for input on the patient's depth of conviction, but rather that such consultation becomes appropriate when information is either lacking or unclear.

Jehovah's Witness Hospital Liaison Committees exist to educate physicians and institutional staff members about transfusion refusals and alternative therapies that are acceptable to Jehovah's Witnesses. Such committees suggest that hospitals develop a registry of physicians willing to care for Witnesses as well as those unwilling to do so. These committees have been instrumental in the transfer of Jehovah's Witnesses to institutions willing to respect the wishes of the Witness and to provide him or her with the necessary medical/surgical care. Within each hospital the committees are willing to work with institutional ethics committees to formulate policies relating to the care of Jehovah's Witnesses and to educate Witnesses themselves about alternatives to transfusion and their obligation to be candid with this physician about their religious affiliation.

We concur that should an institution develop a policy or practice of transfusing Witnesses under certain circumstances, Jehovah's Witnesses should be informed of his practice on admission to the institution.

Involvement of Caregivers

The term *physician-patient relationships* would more appropriately be called the *team-physician-patient relationship*. Multiple caregivers, including nurses, therapists and technicians, interns, resident physicians, ethicists, social workers, and patient advocates, are directly involved in the care of any one patient. Consequently, it is imperative that primary decision makers include as many care providers as possible when discussing decisions such as transfusion refusals. Anecdotally, there have been cases in which a surgeon accepts a Jehovah's Witness patient, without consulting the anesthesiologist, who is subsequently reluctant to participate in the patient's care. To protect the Jehovah's Witness from such harm and to allow for "conscientious objection" by caregivers, discussions concerning patient management must include all team members involved in the care of any Jehovah's Witnesses.

Conclusion

This article has been written in the hope of contributing to the quality of ethical decision making in cases involving Jehovah's Witnesses. The case discussed reveals a number of elements important to such decision making. An attentive informed consent and informed refusal process should include a discussion about the risks of not only death but also other potential negative outcomes. Investigation into case-specific circumstances and relevant psychosocial data should include a consideration of innocent third parties. Physician and institutional education concerning the beliefs of Jehovah's Witnesses (e.g., headship and the various interpretations of the prohibition against blood) may be necessary and fruitful. While these factors – along with communication among health care team members, the patient, and his or her family may not simplify health care relating to Jehovah's Witnesses, they will help to ensure that such decisions are ethically responsible and appropriate.

Article: Commentary – Jehovah's Witnesses and Blood

By Albert R. Jonsen

The article by Vinicky *et al*, is an excellent example of clear, sound case ethics analysis. I have a quarrel only with its title. The authors do present a new perspective, but the "old" problem of caring for the Jehovah's Witness who refuses blood is not a dilemma. A dilemma, *Webster's* tells us, is "a choice between evenly balanced alternatives; a predicament defying satisfactory solutions." The problem posed to health professionals when a competent adult patient refuses recommended and necessary treatment may be agonizing, perplexing, and aggravating, but it is not a problem without a satisfactory solution and the alternative choices are not evenly balanced. It is clear, from ethical discussion and legal decisions, that such a patient has the right to refuse treatment and that providers have a duty to draw back. It is equally clear that the minor child of Jehovah's Witness parents should be provided necessary medical treatment.

I am sure that the authors would not cavil at my disagreement with their title. They would probably willingly correct it. I suspect that what they intended to convey was that they had a new and interesting case that illustrates a familiar, though difficult ethical problem. Indeed, in citing with approval my own article on this problem, they seem to believe that the apparent dilemma or conflict between beneficence and autonomy should be resolved in favor of the patient's choice, regardless of its medical inadvisability. They affirm the principles that support this position. Then, they present a case and a solution with which they suggest I might disagree, on the basis of the principles. They write, "We agree with Jonsen that restricting patient autonomy on the basis of responsibility to others has its inherent dangers. The ethicist and the clinician should tread on this ground with great caution. Nevertheless, this is ground that at times must be traversed." They might be surprised to learn that I have no argument with their "nevertheless." Indeed, I fully endorse not only their "nevertheless" but also their resolution of the case they present.

The reason for my enthusiastic approval is that Vinicky *et al*. present a fine piece of casuistry. They affirm their casuistical bent by stating that "if ethics and medicine are to avoid the 'tyranny of principles', the uniqueness and particularity of each clinical case must also be considered… Guiding principles (usually abstracted from similar cases) and case specific circumstances must be addressed in the process of arriving at sound medicoethical decisions." I have publicly

proclaimed myself a casuist and vigorously promote casuistry as the method for clinical ethics. Their phrase "tyranny of principles" was coined by Stephen Toulmin, my coauthor on *The Abuse of Casuistry*.

Casuistry is the analysis of moral issues in light of the circumstances of cases. Casuistry appreciates the importance of general rules and maxims of morality but recognizes that they hold true with certainty only in typical conditions and circumstances. The competent and informed adult Jehovah's Witness who will die without transfusion represents a typical case (*typical* here does not necessarily mean most frequent, but a case representing essential features of a class). This type of case is, in essence, a case of competent refusal and, as such, is ruled by the principle of autonomy. As cases depart from that type, they require modifications of that resolution that respect the peculiar circumstances. Some circumstances will not force any modifications, as they represent trivial or irrelevant features of the case. Others immediately strike us as significant and give rise to the impression that we have a difficult case and possibly an apparent dilemma.

Vinicky *et al*. present a case in which two circumstances are striking. First, the patient in need of blood is a woman with a 20-year-old retarded son who is dependent on her and to whom she is devoted. Second, the patient does not need blood to survive but rather to avoid the devastating effects of a subarachnoid hemorrhage. She will not die but will probably survive with severe deficits. Both of these circumstances deserve special attention. The first forces us to wonder whether we ought to look differently in this case at the rationale that would allow care providers to override a treatment refusal because of the problems a parent's death creates for children and society. The authors argue that we should, and I agree.

The second unusual circumstance is that the use of blood is here not a life-saving procedure, as in the typical Jehovah's Witness case, but a disability preventing procedure. We are told that current opinion in neurology advises that "neurologic deficits produced by ischemia secondary to vasospasm are potentially reversible if blood flow can be restored before permanent neurologic deficits occur." If this is so, it suggests that administration of blood might prevent permanent impairment that could render this patient a long-lived invalid.

It is far from clear that this situation has been envisioned by the person who adopts the tenets of the Jehovah's Witnesses. It is not, to my knowledge, discussed in the Witnesses' explanation of their doctrine. Indeed, they prohibit the "taking or drinking of blood" (interpreted to include transfusion) quite absolutely and unconditionally. Thus, it might be fairly assumed that they have considered the problem of life with continued disabilities and still ruled out transfusion. However, this assumption does not reflect the usual approach to moral issues taken by fundamentalist groups. Fundamentalism (admittedly difficult to define) usually means that moral teachings are communicated in very absolute terms without any casuistry of exceptions and excuses. God's word is, for the fundamentalist, a clear and definitive "yea or nay." Thus, it is unlikely that adherents of fundamentalist beliefs are well informed or have seriously reflected on the exceptional circumstances.

Even this patient's words – "even if it means death" – can be interpreted as the rote expression of the absolute belief, rather than a reflective statement about her options short of death. Indeed, even an elder of the church if faced with this situation, might "forgive," even if he could not permit or tolerate. It is not unfair, then, that others such as her husband and the physicians, might reasonably presume that this patient would accept blood when faced with two

circumstances together: her life-long disability and her dependent retarded son. In my opinion, the authors have reached a sound, justifiable ethical conclusion in this case.

Casuistry is perilous (as is the moral life in general). Its sound conclusions can slip into shaky realizations. Its careful attention to exceptions can become a careless opening of loopholes. Casuistry is closely allied to conscience: The good casuist is not a clever sophist but one who comes to cases with a sincere commitment to broad, moral imperatives, such as the respect for autonomy and, at the same time, a sensitivity to those conditions that might qualify that commitment in the name of some other equally moral purpose. I can, then, maintain the position I expressed in my article on Jehovah's Witnesses and blood, namely that the competent adult Witness should not be transfused against his or her expressed wishes, and, at the same time, that this incompetent adult Witness, in these circumstances, should be transfused. This is not a dilemma or a paradox; it is good casuistry and, in my opinion, good clinical ethics.

Article: Commentary – Response from Jehovah's Witnesses

By Nathanael A. Reed

Vinicky and coauthors, in agreeing with the ethics committee that a transfusion was justified, express the opinion that "the argument seems even stronger for restricting autonomy and holding someone accountable when these freely embraced responsibilities are for another person who is dependent upon their fulfillment."

This position is, indeed, regrettably, but it clearly is not justified. The primary focus must remain on patient autonomy – the right of the competent person to choose or not to choose the medical treatment recommended by physicians, including whether or not to accept blood. Moreover, the authors would have us believe that only blood could save the patient from serious disability. Furthermore, they have not mentioned at all the risks to health and life to which one is subjected in receiving a blood transfusion.

More to the point, what the authors reveal by their reasoning in this case is how lightly they have taken the deep moral and religious convictions of this God-fearing woman. Because of her wish to obey God's law on blood, as well as to avoid the obvious medical dangers of blood, she has become, in their eyes, one who no longer makes rational decisions. She has been blinded by religious fanaticism. But by what authority would they have the members of the ethics committee impose their lack of respect for divine law on others?

Despite the clear statements of this Witness patient that a transfusion should not be given under any circumstances, the authors postulate that if she had been able to review the possibility of being critically disabled and of not being able to care for her dependent retarded son, it might reasonably be presumed that she would agree to accept blood. Therefore, they felt justified in overruling the patient's autonomy.

The authors evidently would have us accept the premise that the responsibility of a parent who freely chooses when she brings a child into the world also includes the requirement that she not do anything that puts her life or health in serious jeopardy. Following this reasoning, why not *force* (not just advise) pregnant woman to quit smoking, stop taking drugs, or forgo any other activities that would jeopardize their health.

Situation ethics is never justified, and that is true in this case. What mental trauma, what psychological anguish and trial the authors and the ethics committee would impose upon this woman for the remained of her life if she came to learn that she had been transfused with blood against her wishes!

Surely, it is the height of presumption to conclude that she as a wife and mother did not give serious and profound thought to how her possible death or crippling disability would affect her handicapped son when she said she did not want blood under any circumstances. Could she not be doing just that by refusing blood? Blood can kill; it also can cause crippling disability! She wanted to live, not to die or be disabled from hepatitis or AIDS or a host of other things that can be caused from a transfusion. How would the physicians and members of the ethics committee feel if she were given a transfusion and then died because of it? Where would this leave the handicapped son?

Her decision to refuse blood need by no means reflect a lack of love or concern for her on or members of her family. Jehovah's Witnesses are noted for the love they have within the family. The Bible, the Word of God, teaches the importance of loving one's family and caring well for family responsibilities. But the Bible also shows the seriousness of disobeying God's laws, including the one that prohibits the use of another's blood to sustain one's own life (Genesis 9:3, 4; Acts 15:19-21). Obedience to God's laws not only contributes to good health now (remaining free from AIDS, venereal diseases, immoderate lifestyles, etc.) but ensures God's favorable judgement as to everlasting in a cleansed "new earth" (Revelation 21:1-5).

The patient made unqualified statements that she did not want a blood transfusion under any circumstances. Her earlier executed medical document clearly directed that "no blood transfusions be given to me, even though my physicians deem such vital to my *health or life*" (Figure 1 is a facsimile of this document). When she entered the hospital, the physical examination found her "alert and oriented to person, place, and time."

We assume the patient later became unable to express her wishes clearly. But becoming incapacitated does not render invalid the medical document she executed. In this document, she covered the contingency that she might lose consciousness by authorizing one of two signing witnesses to see that her decision to refuse blood was upheld.

While the hospital chart did not "note discussion regarding specific anticipated risks of the proposed surgery such as vasospasm and possible stroke if blood products were needed but not given," what did they discuss with the patient while she was able to make her own decisions? It is reasonable to assume that at least the general risks were discussed, including the possibility of being disabled. Was there a discussion of the risks of blood transfusions? If they did not discuss these risks with her clearly, then that would be negligence on their part. Nevertheless, her chart clearly reflects that she did not want a transfusion, "even if it means death."

The authors also gave weight to an incidental statement that the patient allegedly made to her husband while caring for a cousin in the end stages of cancer, that she "never" wanted to become permanently bedridden or unable to communicate. No one in his or her right mind would even want this. But are we to assume from this very natural and human statement that she would want to compromise the principles by which she lived, so important to her that she would be willing to die for them, in order to avoid this debilitation?

While the primary physician "informed the patient's husband that without transfusion the likelihood of his wife's death was far less probably than permanent disability," the fact is that this was an opinion. Physicians are not infallible.

The authors provide references to the medical literature to suggest the "probability of reversal of some of the patient's debility with transfusion." It is of interest that only one of these medical studies (published in 1981) suggests that a transfusion might be helpful in treating vasospasm associated with subarachnoid hemorrhage and that this recommendation is only one of several alternatives. Moreover, the latest medical literature puts the emphasis, not on giving blood, but on carefully controlled hemodilution and selected drug therapy in treating this condition.[1-4] Jehovah's Witnesses ask for alternatives to blood and invariably find physicians who treat them just as effectively without giving blood.

The authors report that the attending physicians had determined that transfusion, while recommended, was not justified because of the patient's religious faith. The physicians decided correctly. They are to be commended. They should not have been dissuaded from their decision by the recommendation of the ethics committee. While we are not told of the patient's present condition, we hope that she has recovered from her disability without having to endure the terrible psychological effects of having had a blood transfusion forced upon her.

Appendix

At the Brooklyn headquarters of the Jehovah's Witnesses, the Department of Hospital Information Services [(718) 625-3600] gives assistance in locating physicians who will treat patients without giving blood transfusions. In more than 100 major US cities, communities or trained personnel are available to assist Witness patients in talking with physicians and hospital personnel when problems arise. Invariably, they are able to defuse confrontation and help with solutions. These professionals, accessible through the elders of any congregation can call the Brooklyn office at any time on a 24-hour line for assistance in managing a case. Often a search of current medical literature and consultation with medical specialists will produce alternative ways of treating the patient without blood.

The full text of the medical document of Jehovah's Witness appears in Figure 1. A new card is personally filled out yearly and is thus a current expression of each one wishes.

JEHOVAH'S WITNESS: Discussion Questions

1. The basic issue in the treatment of Jehovah's Witnesses is not one of medicine vs. the Bible; rather, it is an issue of informed consent.

2. Is there committee agreement about the consultation by a physician not involved in the patient's care?

3. Does your hospital have in place a policy regarding emergency care of members of Jehovah's Witness? Have you reviewed the policy and found it adequate?

4. Regarding children of Witnesses, does the draft policy sound paternalistic in a bad sense its refusal to acknowledge developing autonomy in children?

Further Readings

Ackerman, Terence F. 1980. "The Limits of Beneficence; Jehovah Witnesses and Childhood Cancer." 10: 13-18.

Davis, Dena D. 1994. "Does 'No' Mean 'Yes'? The Continuing Problem of Jehovah Witnesses and Refusal of Blood Products." Second Opinion: 35-42.

"How Can Blood Save Your Life?" 1990. Watch Tower Bible and Tract Society of Pennsylvania.