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Painted into a corner: Unexpected complications in treating a Jehovah's Witness

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A physician is obligated to consider more than a diseased organ, more even than the whole man—he must view the man in his world. Harvey Cushing

Although you are not often asked to treat members of the Jehovah's Witness denomination, you just accepted such a patient who is now in the operating suite. He is among the most suitable candidates you've ever evaluated for endovascular repair of an infrarenal abdominal aneurysm. The patient was directed to you in particular by a strongly supportive referring physician. During the informed consent process, the patient tells you that he will not accept a blood transfusion under any circumstances. You clear your throat and ease past the possibility that conversion to an open procedure, and the associated increased need for transfusion, could become necessary intraoperatively. It has been quite a while since you've seen a patient with such straightforward anatomy have problems requiring conversion, and this patient has a cushiony hemoglobin of >16 gm/dL. Notwithstanding, the patient suddenly deteriorates during the graft placement, and an expanding retroperitoneal hematoma forms. His blood pressure becomes increasingly difficult to maintain as the operating room is being set up for open surgery. The patient's deep sedation makes discussion and amended informed consent process impossible. You urgently discuss the situation with the patient's wife, who is not a Jehovah's Witness. She will sign permission for blood-transfusion therapy and strongly urges you to transfuse if necessary. What is your most ethical course?

A. Assume that the patient did not fully appreciate that he could lose his life without a transfusion and proceed to transfuse as clinically indicated.
B. Since you did not specifically agree to withhold transfusion during an emergency open procedure, transfuse.
C. Transfuse on the wife's authority.
D. Transfuse and do not tell the patient.
E. Do not violate the patient's autonomy by transfusing, even if it means the patient may die.

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A number of new religious groups emerged in the United States during the latter half of the 19th and early 20th centuries. Distinguishing themselves from well-established Christian denominations, they based themselves on novel scriptural interpretations and behavioral rituals as manifestations of what they believed to be superior righteousness and Biblical fidelity.

The Pentecostal movement was begun by Charles Parham in about 1901. Mary Baker Eddy founded the Church of Christ, Scientist in 1879. Charles Russell initiated the Jehovah's Witness movement in the 1870s. Scientology, not a Protestant denomination, was founded by L. Ron Hubbard in 1952, who declared it a religion in 1960. To one degree or another, each of these new faiths considered modern medicine a rival contradictory to its principles, and they eschewed all or some of its practices.

Some of the Pentecostal churches practiced spiritual or "faith" healing and discouraged adherents from seeking professional medical care. The most notorious offshoot of the Pentecostals, the Snake Handlers, rejects medical treatment for the venomous viper bites its adherents sometimes sustain. The Pentecostal movement has never been unitary in its teachings, however, and most members fully accept modern medical treatment. Christian Scientists typically reject all the ministrations of organized medicine. They correctly note that medicine began as a pantheistic pagan priesthood relying upon the graces of Apollo, Asclepius, Hygieia, Panaceia, and all other gods and goddesses believed to be sympathetic to healing. The original Hippocratic Oath confirms this contention. Having concluded that association with these ancient deities makes the medical profession anathema to Christianity, Christian Scientists reject medical interventions. They elect to seek health through prayer and rejection of the disease concept. Except in pediatric cases, their beliefs and practices are rarely

considered ethically problematic for physicians because there is no physician encounter. One published study showed that the longevity of Christian Scientists was significantly lower than the general population's.[1] The Church of Scientology asserts the ability to prevent and cure disease with its auditing process, obviating the need for most medical treatment, and vociferously rejects the modern practice of psychiatry, in particular, as both ineffective and harmful.

Charles Taze Russell founded the Jehovah's Witnesses by disseminating what was then an unusual interpretation of Biblical Scripture. His first converts followed publication of his new magazine, *Herald of the Morning*, which subsequently became *Zion's Watch Tower and Herald of Christ's Presence* and then *The Watchtower*.[2] First known as "Russellites," the group developed a strong foundation of believers and able leadership by the time of Russell's death in 1916. Movement membership increased throughout the world in the 20th century, and it officially named itself the Jehovah's Witnesses in 1931. The Jehovah's Witnesses consider their practices and beliefs a return to original first century Christianity.[3] Like the earliest Christians whom they emulate, they take special pride in opposing to the utmost any form of authority that would separate them by force or persuasion from their beliefs and their literal interpretation of scripture.

Prohibition of blood transfusions was added to the Jehovah's Witness dogma by its governing council, the Watchtower Society, in 1945. The basis for the doctrine is established by reference to three scriptural sources (Gen 9:3, Lev 17:14, and Acts 15:28-9) forbidding the consumption of sacrificial blood. The Watchtower Society annually issues wallet cards, effectively an advance directive, to the faithful explaining the risks (but not potential benefits) of transfused blood, require the member's signature, and admonish treating physicians against transfusion should the card holder be brought to care incapacitated and unable to speak for himself. The Watchtower Society threatens with "disfellowship," tantamount to excommunication from the faith, any Jehovah's Witness who accepts any transfused blood products other than those permitted by the Society.

Compliance is almost universal among the faithful, who are steadfast in their refusal to be transfused with erythrocytes that have been separated from their bodies. If the tubing remains connected to them, as in cardiopulmonary bypass or with use of erythrocyte retrieval and salvaging devices, they will usually accept reinfusions of the original autologous contents and postoperative drainage. The Watchtower Society does not prohibit acceptance of albumen, leaving this decision to each individual. Almost all Jehovah's Witnesses will accept treatment with erythropoietin, but they should be informed that the biological is suspended in human albumen.

By refusing to accept transfusion of erythrocytes, one of the pillars of surgical therapy, Jehovah's Witnesses impose a handicap on surgeons who accept them for major procedures.[4] These cases thrust physicians into the unusual position of agreeing to the possibility of allowing an otherwise salvageable, mentally competent adult to die.

Seventy-nine percent and 84% of physicians responding to a pair of surveys reported that they had encountered at least one Jehovah's Witness patient needing urgent interventions like emergency surgery.[5,6] More than half these physicians reported having transfused the patients when they believed that blood was needed, whether or not there was a signed refusal statement. If a Jehovah's Witness patient were exsanguinating, more than half the physicians surveyed said they would transfuse against the patient's wishes, and 26% of them would not tell the patient what had been done.[7]

The informed consent process with a Jehovah's Witness patient may seem at first specific to this group and of little relevance to the care of the enormous majority of patients who do not subscribe to extraordinary religious beliefs that conflict with standard medical practice. On the contrary, informed consent actually encompasses the patient's right to an informed refusal to consent, including a refusal to accept life-sustaining care, for whatever reasons the patient finds the conditions of that care unacceptable.

Physicians will easily accept a patient's refusal of open-ended life support in a persistent vegetative state without skeptically weighing the patient's value system against their own personally held beliefs. Almost certainly, physicians find it easier to cooperate with concepts of patient autonomy when treatment decisions closely reflect the values that they hold themselves and can therefore understand more readily. Seemingly alien value systems, including those based in extreme religious or supernatural beliefs, are more likely to be interpreted by physicians as mistaken, coerced, or suggestive of severe mental illness. As suggested by the recent surveys, many physicians will attempt to somehow circumvent the instructions of these patients, particularly when the patient's decisions may have irreversible consequences that the physician believes are contrary to the patient's best interests.

For the Jehovah's Witness patient, the prospect of avoidable death in service to the religion's precepts, a tragic catastrophe in the view of most surgeons, would be of little importance when compared with righteous preparation for the eternal life to come. The apparently impossible reconciliation of two value systems at utter variance with one another—one supernatural and religiously based, one scientific and humanistically based—becomes the substance of the surgeon's ethical paradox. What is ultimately more ethically valid, the patient's autonomy, even unto death, or the surgeon's obligation to preserve the patient's life and restore him to health?

Option A may in fact be your first instinctive response as a surgeon. Particularly when you are almost certain that with a routine procedure you can restore the patient to full function and a comfortable resumption of his daily life, it is practically impossible for a surgeon to imagine that a patient with an adequate understanding of the risks and benefits would surrender his life for a religious principle. In this case, it would be you who is laboring under the

misunderstanding, however. Jehovah's Witnesses are well-educated about the mortal risk associated with their refusal of transfusion, and their resistance almost always becomes more adamant in direct correlation to the immediacy of the danger and the intensity of arguments urging them to accept transfused blood. The advance directive they carry is reissued annually by their leadership, and members renew their fidelity to it annually with their signatures. You have no objective evidence for assuming that your patient has inadequately considered, or poorly understands, the consequences of his decision. You have in fact a great deal of evidence that his understanding is clear. Option A cannot be your ethical choice.

The failure to fully discuss the ramifications of converting to open surgery is an error entirely of your own making, and you cannot ethically proceed to use the mistake to justify forcing a sedated or anesthetized patient to undergo a procedure he would normally reject. Despite your abbreviated version of the informed consent process, the patient spontaneously made clear his refusal to accept transfusion. To justify disregarding his wishes on the basis of a linguistic trick is clearly unethical, and you cannot properly select option B.

Option C exposes a serious weak point in modern medicine's application of the surrogate decision-making principle. Surrogate decision making fails to reflect the patient's wishes accurately in 70% of important treatment issues.[8] Authorized surrogates (usually first degree relatives like spouses, parents, adult children, or siblings) are expected to conform to the ethical standard of substituted judgment: the surrogate should identify the patient's relevant values and beliefs and make a decision based on them. To the degree that they are known or can be determined, the patient's interests and wishes regarding his care have precedence over the surrogate's interests and wishes, should they diverge. This is also the legal standard of surrogate decision making in some jurisdictions. When those values and beliefs cannot be reliably identified, then the standard measure is the best interest of the patient. The surrogate is responsible for authorizing clinical management that will protect and promote the patient's health-related interests.[9] When it can be reliably established that the surrogate is failing to conform to the substituted judgment standard by incorrectly representing the patient's wishes, the surrogate's instructions are not binding.[10]

When treating Jehovah's Witness patients, the durability of informed consent can be strengthened by completing the process in the presence of those designated as surrogate decision makers. All those who will participate in the decision-making process should be in agreement about transfusion therapy, or a written and signed statement should be obtained from the patient about the specific protocol to be followed should the need for blood products arise. This protects the patient's beliefs and protects the surgeon from any subsequent suggestion of poor practice should an operation end disastrously because the patient withheld consent for life-saving transfusion therapy. It is clear that in this case the wife is advocating her own view rather than her husband's. Her authorization for transfusion is therefore not valid, and option C is not available.

Most surgeons understand their primary duty as the preservation of life, and can hardly imagine complicity in the willing surrender of life when a routine procedure will enable the successful completion of an operation and an almost certain restoration of the patient to full health. Most surgeons are furthermore intensely aware of working within in a closely monitored profession, with our complication and death rates carefully tabulated and our competence judged by them. Few of us indeed will gladly see these figures inflated by the peculiar whims of our patients. After years and years of intellectual and technical training, and years more of experience, it may be difficult for surgeons to suppress the sense that we know what is best for our patients. The niceties of informed consent are fine until a patient codes in our OR, and then we will do things our way.

These paternalistic instincts are at once both beneficent and self-serving, and they are not without virtue. They have nevertheless been trumped in the last century by common law and ethical theory that recognizes the surgeon as *an authority,* but places the patient *in authority* when decisions are made about his care. The physician is not entitled to impose care upon an unwilling patient, or an unwanted procedure upon a patient seeking care. A psychiatrist may not coerce or force an unwilling depressed patient requesting pharmacologic treatment to accept electroconvulsive therapy, even if the psychiatrist's long experience assures him that ECT will resolve the patient's condition more quickly and effectively.

Although physicians have a duty to provide optimal, evidence-based care, they must do so while respecting the patient's autonomous decision about the care to be given. The physician is not obligated to provide a requested treatment he has reason to believe will be harmful, such as complying with a drug-dependent patient's request for narcotics, but he cannot ethically impose a therapy that the patient specifically refuses, and he cannot deceive the patient into accepting such treatment under cover of anesthesia or concealment. In a Jehovah's Witness's world-view, the surgeon who proceeds in this manner could imperil the patient's immortal soul. Although the preservation of life may be an absolute value to us as surgeons, life on earth may be a less absolute value to individuals with a fervent sense of a life hereafter, and it is not for us to insist that they are wrong. We are obligated to serve our patients, not dominate or determine their values for them. Option D is ethically inconsistent with the principles of patient autonomy to which our profession claims fidelity.

Although it may seem a bitter pill, option E is the surgeon's correct ethical choice. The surgeon should continue surgical management of this patient without transfusing him. Although a lower percentage of seriously ill patients may survive surgery under the conditions imposed by the Jehovah's Witness faith, competent surgeons usually bring them through their operations satisfactorily, and even major surgical care should not be considered futile.

Some surgeons decline to treat Jehovah's Witnesses because they find the constraints too confining and the risks too

high. They are loath to surrender any of their therapeutic prerogatives, don't want to see their morbidity and mortality figures rise, and are unwilling to put themselves through the personal heartache of losing patients. Some others make a tiny subspecialty of treating Jehovah's Witnesses within their practices. Although they do not necessarily subscribe to the Jehovah's Witness faith, they make themselves fully conversant with its surgical prohibitions and allowances, study the special blood conservation and recycling techniques that can sometimes compensate for transfusion requirements, and readily agree to the faith's prescribed conditions for surgery. The Watchtower Society maintains an index of these surgeons and regularly refers members to them for care.

Although there are only 6.6 million members worldwide and about 1.5 million in the United States, Jehovah's Witnesses' have precipitated one of the most vexing ethical conflicts in modern medicine. The dilemma posed by the Jehovah's Witnesses becomes fascinating not only because it impinges upon the critical care of these patients in and of themselves but also because the ethical problem they present is emblematic of the extreme assertion of patient autonomy against the medical profession's instinct for protective paternalism and dedication to preserving life to the extent of its scientific capacities. Patients come to physicians—to surgeons—because they need the knowledge and service that we can provide and cannot do for themselves what we can do for them. Though it may sometimes seem that this dependence confers upon us broader entitlements, it does not. If we are fortunate enough to be able to extend or improve a life, the life nevertheless remains the patient's, to conduct according to his own lights.

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