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And the Patient Chose: Medical Ethics and the Case of the Jehovah's Witness

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THE PHYSICIAN PROVIDES TREATMENT for the patient's benefit; in most instances, this benefit is clear. For example, a person with a fractured femur clearly benefits from having the fracture reduced in order to ensure healing and return of normal function. The principle of beneficence—that the physician intervenes medically to help the patient—is thus fulfilled. But what does the physician do when the "best" interest of the patient is unclear or when the interests of the patient and physician conflict? In these cases, the study of moral theory may aid the physician. Physicians are trained specifically and intensively to make decisions about therapy, such as calculations of the risk–benefit ratio of diagnostic and therapeutic interventions. Frequently, however, medical decisions are influenced by nonmedical considerations. For example, legal considerations are often a factor in medical decisions because of the medicolegal climate, currently perceived as threatening. Ethical considerations also influence physicians' decisions. Since physicians usually have little or no formal training in this area, the tendency is to make ethical decisions intuitively (*i.e.*, without conscious reasoning) rather than critically (*i.e.*, with conscious reasoning). Although it will not improve diagnostic or therapeutic acumen, moral theory may help the physician to evaluate the moral implications of medical decisions and may shed light on concepts that are taken for granted, such as health, normalcy, and harm.

Using the following hypothetical case involving a Jehovah's Witness, we will discuss the ethical and legal considerations involved when the interests of the patient and the physician, as a preserver of life, are in conflict.

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During bowel resection and abscess drainage in a mentally competent, 37-yr-old woman with a 1-yr history of Crohn disease, a problem arose from acute, unplanned hemodilution. A Jehovah's Witness, this woman had clearly stated, preoperatively, that she did not want under any circumstances to be transfused with blood products. With the exception of a hematocrit of 30%, her preoperative tests, including coagulation studies, were normal. Upon opening of the abdominal abscess cavity, she lost approximately 3 l blood, a loss that ultimately resulted in a hematocrit nadir of 4%. Her physicians obtained, with permission of the family, a court order, and despite the patient's expressed desire, administered blood. She was discharged from the intensive care unit after 24 hr and recovered without further medical problems.

This case contains facets of several classic problems in the definition of health and healing—the relative priorities of temporal and spiritual well being; the autonomy of the patient; the responsibility of the physician; and conflicts among values held by the patient, the physician, and the patient's family, and at least one social organization, the court, whose judge granted the order.

The Position of the Physician

The position of the physician is familiar: blood transfusion is an accepted treatment used in a variety of situations to preserve life and promote healing. However, less familiar is the situation in which administration of blood against a patient's expressed will may result in a suit for civil damages.[1] Because the physicians caring for the woman were concerned with her survival, they transfused blood against her expressed wishes. Was their action justified? Since the woman is alive and is with her family, is it even relevant that blood was transfused against her wishes? Should she actually be grateful for the transfusion after she had recovered?

Indeed, a physician could argue that a person's religious beliefs, however rational or irrational, should not result in that person's death. On the other hand, a mentally competent adult may want to sacrifice his or her life for a Supreme Being. Should a physician ignore this wish because it does not appear to be in the patient's best medical interest? Perhaps the physicians in the above case believed that they would be abetting suicide if they allowed the patient to die. Legal precedent, however, suggests that

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permitting death to occur from a cause that is not self-inflicted is not abetting suicide.[2–4] In addition, other examples of self-sacrifice for a belief (*e.g.*, a soldier's sacrifice in war) are not considered, by most people, to be suicide and even are encouraged in our culture.

The Position of the Jehovah's Witness

The belief of Jehovah's Witnesses that prevents them from accepting transfused blood originates in scriptural passages suggesting that "life" or the "life force" resides in blood and therefore must be treated respectfully.[5,6] Whereas the biblical passage specifically forbids the *eating* of blood, the interpretation accepted generally by Jehovah's Witnesses also precludes the receipt of banked blood products, but, at the believer's discretion, not the receipt of plasma protein factor, clotting factors, or albumin.[7] Also, intraoperative, pre-blood-loss hemodilution with a continuously flowing circuit may be deemed acceptable by the Witness. Followers of this faith interpret the pertinent Biblical passages literally. They also consider life on earth a temporary period that will be followed by eternal life after death and resurrection.[7] Therefore, a Witness who knowingly allows transfusion of blood or selected blood products risks losing "eternal life" and risks suffering damnation on earth.[8] There are no religion-based consequences for a Witness who has been "forced" to receive blood, but the loss of "innocence" is considered so serious that the Witness might attempt to castigate the health care team legally.[1,9,¶] Conversely, we are aware of no legal decisions that have been made against physicians for withholding blood or blood products under clearly defined preoperative conditions.[8]

Legal Considerations

> It seems to be clearly established that the First Amendment of the United States Constitution, as extended to the individual States by the Fourteenth Amendment . . . protects the absolute right of every individual to freedom in his religious belief and the exercise thereof may properly be limited by governmental action where such exercise endangers, clearly and presently, the public health, welfare or morals.
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> . . . Even though we may consider [an individual's] beliefs unwise, foolish or ridiculous, in the absence of an overriding danger to society we may not permit interference therewith . . . for the sole purpose of compelling [an individual] to accept medical treatment forbidden by [his or her] religious principles, and previously refused by [him or her] with full knowledge of the probable consequences.[1]

In this widely recognized decision, an Illinois Appellate Court held that a competent Jehovah's Witness—who was a married adult woman with no minor children and who, aware of the probable consequences, had refused recommended blood transfusions—had a federal constitutional right to refuse medical treatment based on her religious convictions.[1]

At the outset, it is important to review some fundamental legal principles. Adults in the United States have a common-law right (*i.e.*, nonstatutory and by virtue of court decisions) to refuse medical treatment, even if it is life-sustaining.[10] Adults also have a constitutionally based right to refuse life-saving medical treatment[1]; this right is grounded in the provisions of the first amendment to the United States Constitution that "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof" and that "the commands of the First Amendment to the United States Constitution relating to religious freedom are embraced within the Fourteenth Amendment and by it extended to the States."[11]

There is, however, a legally significant distinction between religious *belief*, which is a constitutionally guaranteed freedom, and the way in which people practice their religion, which is *not* an absolutely guaranteed legal protection. Thus, in the face of constitutionally based assertions of a right to engage in certain religious practices, courts have upheld a variety of laws on the theory that society has an overriding interest in protecting the lives of its citizens. Laws requiring compulsory vaccinations,[12] laws against polygamy,[13] and laws prohibiting the handling of snakes during religious rituals fall into this category.[14]

In cases in which Jehovah's Witnesses have refused life-saving blood transfusions, the distinction between the protections that are accorded to such individuals and their religious beliefs and the restrictions that are constitutionally sanctioned against certain conduct has manifested itself in a variety of ways. Most notable have been those cases involving Jehovah's Witness parents who refuse to consent to life-saving blood transfusions for their minor children. Courts in these cases have consistently approved the appointment of temporary guardians to consent to blood transfusions where it has been evident that the risk associated with the transfusion was low and that without this procedure significant harm would result. The theory underlying these decisions is that society has a serious interest in protecting the rights of immature children, who are considered incapable of making a knowing and informed decision with respect to such matters.[15,**] In

¶ The *Holmes v. Silver Cross Hospital of Joliet, Illinois* case is also interesting because it was an action against a private hospital and various physicians for violation of civil rights under the Civil Rights Act, 42 U.S.C. Section 1983, an action which the court held could be sustained under the facts it cited.

** But see also the case of *In re E.G., a Minor,* 133 Ill. 2d 98, 549 N.E. 2d 292 (1989), in which the Illinois Supreme Court held that a mature Jehovah's Witness minor, who was within 6 months of her eighteenth birthday and who had been shown by clear and convincing evidence to appreciate the consequences of her refusal to accept medical treatment, had a common-law right to consent to or refuse medical care.

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other cases, courts have considered as legally significant certain facts—such as whether the Jehovah's Witness refusing life-saving blood transfusions is married or has minor children who might become wards of the state in the event that the parent died—in determining whether societal interests should prevail over an individual's choice of religious conduct.[9] Nevertheless, it is at least relatively clear that single adult Jehovah's Witness patients with no minor children have a constitutionally protected right to refuse blood transfusions.

Moral Theory

Facts *Versus* Values

In relation to the moral problems in treating a Jehovah's Witness, we emphasize the distinction between facts and values. For example, a hematocrit of 4% is a fact; its truth or falsity depends on empirical evidence. But a claim such as "one ought not to harm one's patients" is a value. Values are not descriptions, and they do not assert facts; rather, values prescribe a standard or state a person's preference. Therefore, it is inappropriate to ask if a value is true or false. A value such as "one ought not to harm one's patients" establishes a norm for conduct. Although facts can be relevant to the rationale for a norm, the norm prescribes a standard of behavior and not a factual state. If values were derived in the same way that we derive facts—for example, by actually measuring the hematocrit—then there would be no moral disputes, but instead a series of empirical ones.

Unfortunately, it is easy to confuse facts with values because, in attempting to make a difficult decision, we may act as if values can be determined as absolutely as facts. Physicians often work with patients who have mistaken factual beliefs about their illnesses or the recommended course of treatment. Correcting a patient who has incorrect information, however, is not the same as disagreeing with a patient's moral objection to a medical procedure. A physician may attempt, wrongly, to dismiss a patient's preferences, concerns, or moral qualms about a diagnostic or therapeutic strategy, simply on the basis of the patient's lack of medical expertise.

Beneficence

As the case of the Jehovah's Witness shows, distinguishing facts and values is often impossible during an emergency. Health workers are tempted to use their certainty about medical facts to deal with situations that involve a patient's values. For example, if medical decisions are based on the principle of beneficence, then under ordinary conditions, a patient and physician will agree about what this principle signifies. Chemotherapy for a malignancy benefits the patient, even though it may also cause suffering. Understanding that the treatment is ultimately beneficial helps the patient accept the technique of chemotherapy because the patient and physician agree on what constitutes the patient's best interest. However, if being a Jehovah's Witness were a disease and the treatment were conversion to another faith that allowed use of transfused blood, many Witnesses would not accept treatment as being in their best interest, no matter what the facts are about transfusion therapy. The patient might hold that the physician's proposal for treatment is wrong, even if the physician explained the medical benefits of a higher hematocrit. That a condition is undesirable, abnormal, or immoral is not a fact, but rather a boundary embedded in norms. This is taken for granted when the judgment of the physician and the preference of the patient do coincide, but needs to be brought into focus when the physician and the patient disagree over what constitutes the patient's best interest.

To extend our example further: that a hematocrit of 4% is incompatible with normal physiologic function and that this pathophysiology involves oxygen delivery and oxygen consumption have been determined from clinical experience and research; therefore, they are matters of fact. We may prove or disprove that the hematocrit is 4% and that oxygen delivery is not consonant with demand. But this knowledge, applied to our case, neither resolves the question of whether the patient ought or ought not to receive transfused blood, nor determines which decision best serves the patient's interests. If, during the operative procedure, the Jehovah's Witness could have argued her case, she probably would not dispute the hematocrit or its medical significance. Rather, she would have refused blood transfusion *despite* the hematocrit, because of her moral beliefs. The physicians caring for the Jehovah's Witness in our example shifted their authority from medical facts—its acknowledged domain—to a presumed authority to overrule a patient's explicit, value-based preference not to receive transfused blood.

Autonomy

Unfortunately, the distinction between fact and value does little to resolve this difficult case. The physicians, acting without malice, did what they believed was in the best interest of the patient. According to the physicians' best judgment, the patient, without a blood transfusion, would have died, and therefore it would have been wrong not to act. Prior to the operation, the patient had understood, however, that her physicians would not overrule her expressed moral preference. The principle of the patient's autonomous right of decision appears just as important as the principle of beneficence, appealed to by the physicians. It is, for example, the principle of autonomy that prohibits a physician from treating a patient through deception.

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Are the actions of a patient's physicians any less problematic if, prior to induction, *they did not believe* that there was a high likelihood of significant blood loss? We think not. The patient's request, based on religious beliefs that were well considered, was a serious one. When physicians caring for a Jehovah's Witness agree to perform a procedure but not to transfuse blood, they are agreeing to precisely that. Massive blood loss is not a reason to break confidence with the patient. Only if the physicians believed the patient had been coerced into her decision or that she truly did not understand its implications would they be justified in reversing their earlier promise not to transfuse.

Critical *Versus* Intuitive Thinking

In critical reflection, a person takes the time and has the freedom to speculate about moral decisions, to experiment with moral reasoning, and to analyze the "intuitions" from which our morals normally spring. Moral reflection allows the entire framework and set of rules to be examined, refined, and, if necessary, replaced. Physicians, often called upon to act in situations in which there are value conflicts, should use critical moral thinking and learn the limitations of basing decisions solely on intuition at times of crisis.[16] In our above-described case, there was enough time for the physicians to have considered the situation reflectively.

Should the physicians have given the patient a blood transfusion against her will? The moral paradox here is between answering yes, based on the principle that a physician ought always to preserve a patient's life—which the transfusion did—and answering no, based on the principle that the physician ought not to violate the patient's deeply held values, which, to the patient, is in his or her best interest. Has the principle of autonomy been violated by the principle of beneficence? *Our example depends on the fact that the operative procedure was elective.* If a patient enters the emergency room for treatment of a life-threatening condition, a deep discussion of values before initiating therapy is not appropriate; the physician must, and does, take all necessary steps to prevent the loss of life. But in a nonemergency situation, when physician and patient have had time to communicate and when the patient has expressly stated a preference, the patient has every reason to believe that the stated preference will be honored if the physician agrees to proceed. Thus, the problem at the reflective level is whether the survival of the patient is possible in conditions in which patient autonomy is discounted. Again, the problem is not that some physicians find certain patients' views idiosyncratic; that is to be expected. Rather, the conflict involves a physician's treatment of a patient as if the patient's preferences were not relevant to the moral decision; this type of treatment impairs the patient–physician relationship by devaluing the patient's preferences.

The harmful consequences of such paternalism would affect not only the patient. The physician also would bear a heavy and unnecessary responsibility to adjudicate a patient's preferences and moral beliefs, and to determine for each one not only the appropriate treatment (as demanded by the principle of beneficence) but also the patient's ultimate interests. Besides mistaken medical judgments that can result from not knowing a patient's preferences, the physician would be unlikely to know what would constitute a patient's best interest, and yet the physician would bear the burden of responsibility for any error that occurs. Communication between patient and care-giver, already difficult,[17] becomes even more complicated when decisions about deeply held precepts are adjudicated privately by the physician.

The decision, based on reflection, to accept as binding a patient's fundamental preference, even if it would cost his or her life, does not mean that a physician should not discuss or even argue the case with the patient and, if necessary, ultimately withdraw from the relationship if there is an irrevocable conflict. We simply are pointing out the difference when a physician, rather than trying to resolve a dispute of values by intuition or with rules designed to serve in emergency situations, shifts to a reflective or critical level of moral reasoning.

Some may be disturbed if they assume that the position presented here is based on a relativism that holds all moral views as equally defensible. In part this seems true, because we do treat all preferences as equal; but we still can criticize those preferences, especially if we consider the implications of a choice as it applies to all persons affected. The relativity of values is actually most apparent at the intuitive level. In fact, one way to encourage critical thinking is to note the diversity in moral intuitions due to differences in upbringing, culture, and religion. If all that we could invoke was the intuitive "grip" that values have over people, we would, indeed, have either to grant a certain relativism, or simply assert, by domination, the superiority of our views over those of others.

But we do not have to do that. With critical reflection, we can defend values that can only be assented to at the intuitive level. At the critical level, judgment can, and should, be made about the consequences of a moral decision.

Comment

The term "autonomy," derived from the Greek terms meaning self rule, implies the rights both to receive information and to act upon it by giving or withholding consent.[18] The right of autonomy would be violated if, after providing a patient with detailed information about a procedure, the physician denies that person the opportunity to make a decision about whether to undergo that

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procedure. If patient and physician seriously disagree, but the latter does not or cannot withdraw from the case, moral "protection," at least, is afforded when the physician writes a progress note in the chart detailing the disagreement.[19] Because patients do have the right to make decisions we judge as bad, we, and others,[18] consider it proper to override that right only if the patient does not understand the consequences of that decision. Moreover, although there are data suggesting that detailed discussions between physicians and patients are infrequent and difficult,[8] patients can make sound choices about a therapy or procedure only if we talk with them.

When an emergency procedure is required for the child of a Jehovah's Witness, we agree that life should be preserved at any cost. Assuming that many world views exist, allowing that of a parent to result in the loss of a child's life seems unconscionable. We would not hesitate to use whatever therapy is medically indicated in such a case, including the transfusion of blood against the wishes of the family. A court order allowing transfusion may be obtained if time allows, but this is not always possible in an emergency. In other than an emergency, however, the wishes of the parents should be disregarded only if the intervention would be less likely to harm the child than would the parental decision itself.[4,15,20]

Finally, although we have not directly addressed this matter here, there are controversies and disagreements even about "facts": for example, not all physicians agree on the "lowest acceptable" hematocrit compatible with physiologic function.[21] Although we have little doubt that the hematocrit of 4% reported in our case was incompatible with life, we are less sure of the pathophysiology of a hematocrit of between 8 and 15%. Determination of a "minimally acceptable" hematocrit in critically ill patients may require invasive monitoring to evaluate oxygen delivery and consumption.

In the case of the Jehovah's Witness, our suggestion that the patient's autonomy should play a large role is based on moral reasoning that, paradoxically, the patient, who was trained in a traditional religious community, likely would find alien and unconvincing. The patient's original decision not to allow blood transfusion probably results from acceptance of direct religious authority, but it can still be addressed on the critical level. This does not mean, however, that the physician can ignore the moral preference or should act at the intuitive level. There is potential for agreement between patient and physician. By not transfusing blood, the physician would not have been confirming the patient's religious beliefs but would have been supporting, after critical reflection of the moral reasoning involved, the patient's autonomous decision over the medically beneficent decision of transfusing blood. Differences in the type of moral reasoning may not be evident from the final decision alone, since the same result can be justified by both patient and physician on different grounds. Different value judgments' resulting in apparently identical decisions is a sign that values are not facts: the difference that value judgments make may be empirically indiscernible but is morally significant.

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