Intrauterine Transfusion: Ethical Issues Involving a Jehovah's Witness Mother

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DR. THEODORE G. GANIATS (*Acting Chief, Division of Family Medicine*): Hemolytic disease of the newborn may occur when the fetus inherits erythrocyte antigenic determinants from the father that are not present in the erythrocytes of the mother. The most severe manifestation of this disease occurs with Rho (D) antigen, that is, a process brought about when anti-Rho (D) antibodies from a "sensitized" Rho (D) negative mother cross the placenta and hemolyze the erythrocytes of an Rho (D) positive fetus. The clinical course of this disease may have drastic consequences: profound anemia, high-output congestive heart failure, and kernicterus—a severe form of central nervous system damage resulting from the toxic effect of indirect bilirubin on the fetal brain. Severe cases require intraperitoneal or direct intravascular transfusion of the fetus to treat underlying anemia.[1,2]

With the advent of Rho (D) immune globulin prophylaxis, a method for preventing maternal Rho (D) sensitization was found, and many cases of hemolytic disease of the newborn are averted. Immunoprophylaxis has not been completely effective in preventing the disease, however, but in pregnancies of sensitized mothers, the modern surveillance techniques of amniocentesis, ultrasonography, and fetal monitoring have allowed us to follow these fetuses with a high degree of safety.[3]

The patient's right to self-determination often conflicts with what we consider is best from a medical viewpoint. Today, Dr. Norcross will present a case of hemolytic disease of the newborn in which the religious beliefs of the parents brought to light a host of interesting ethical issues.

DR. WILLIAM A. NORCROSS (*Associate Clinical Professor, Division of Family Medicine*): E.C. is a 25-year-old gravida 2, para 1, married woman at 28 weeks' gestation. She is a housewife and mother of a healthy 4-year-old son. She is a Jehovah's Witness. During her first pregnancy prenatal laboratory studies revealed that the patient's blood type was A negative with negative antibody screening results. The risks of Rh sensitization and hemolytic disease of the newborn in subsequent pregnancies were carefully explained to the patient and her husband, who was also a Jehovah's Witness. The risks and benefits of antenatal and postpartum immune globulin prophylaxis were also discussed. Nonetheless, both antenatal and postpartum Rh immune globulin prophylaxis were declined by the patient and her husband, even after their newborn son was determined to be Rh positive.

Four years later she presented to the Family Medical Center for prenatal care. Dates and size were compatible with an intrauterine pregnancy at 12 weeks' gestation. The prenatal antibody screening revealed the presence of anti-Rho antibody in high titer. The patient was referred to the High Risk Obstetrics Clinic. The risks of Rh hemolytic disease were carefully explained to the patient and her husband. Serial amniocenteses revealed worsening hemolysis, and serial ultrasound studies suggested early fetal hydrops. At 28 weeks' gestation the obstetricians recommended fetal transfusion. The patient and her husband refused fetal transfusion on the basis of religious beliefs.

This case brings to light a number of questions:

1. What are the parents' rights in denying therapy, perhaps lifesaving therapy, to their unborn child?
2. Does a fetus at 28 weeks' gestation have the same "rights" as a newborn infant?
3. How do we reconcile the parents' right to autonomy with the physicians' moral obligation to preserve life?

DR. GANIATS: Thank you. Today we are fortunate to have two members of a local congregation of the Jehovah's Witnesses, who will give their thoughts about the case as presented.

MR. MIKE ALEXANDER (*Jehovah's Witness representative*): To begin with, we'd have to say that Jehovah's Witnesses truly appreciate the medical profession. We feel very strongly about properly caring for our children and our families in all aspects, including medically. This is well illustrated by individuals who become pregnant and

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are expecting a child. They take all the measures they can for proper prenatal care. All aspects of child care, including the medical, come under the parents' jurisdiction.

From our standpoint, the unborn has every right of a child that has actually gone the full nine months. As far as transfusing blood to someone in the womb, our stand is exactly the same for a fetus as for a child or an adult. The Bible says to abstain from blood, and that means all age groups, whether it is the born or the unborn. Therefore, we feel parents have the responsibility to care for their children, and we don't believe in transfusions.

MR. PAUL HUNDERTMARK (*Jehovah's Witness representative*): We're certainly not professionals. You people are. We're not coming here with any kind of expertise in the medical profession. We are Jehovah's Witnesses, and as such, we study the Bible and accept it as God's word. As Mr. Alexander brought out, we go along with everything doctors want us to do as far as possible. We recognize that there is a disagreement regarding blood, but the point is that we, as Jehovah's Witnesses, feel that the Bible prohibits the taking, eating, or storing of blood. In the Bible, Book of Leviticus, it says that blood is to be poured out because God chose that life is in the blood, and so we feel that blood is sacred. We do not believe in transfusions because we feel it is against God's law. It is an eating, an intravenous feeding. It is quicker than giving the patient iron orally and letting him build up his blood that way. It is a feeding on blood, to nourish the body.

DR. NORCROSS: Are Jehovah's Witnesses vegetarian? In beef and pork there is some blood.

MR. HUNDERTMARK: We eat meat as long as it is properly bled. Naturally, some blood will remain, but the Bible, in Leviticus, says that an animal is to be bled. After the flood Noah was given permission to eat meat, but was prohibited from eating the blood as stated in Genesis 9: 4. This law was restated to the Israelites in Leviticus chapter 17 and again in Jesus' day in Acts, the 15th chapter, verses 28 and 29.

> For the Holy Spirit, and we ourselves, have favored adding no further burden to you except these necessary things. To keep abstaining from things sacrificed to idols and from blood and from things strangled and from fornication. If you carefully keep yourselves from these things, you will prosper. Good health to you.

You notice, it refers to "abstaining from blood," not just eating it; and it is interesting that he says, "Good health to you." We see that has been really a protection: by abstaining from blood, one diminishes the possibility of AIDS, hepatitis, and other complications.

DR. DAVID M. BAUGHAN (*Assistant Clinical Professor, Division of Family Medicine*): Could you clarify the consequences should someone ingest blood or get transfused? Particularly in this case, what would be the spiritual, moral, or physical consequences to the fetus and to the mother?

MR. HUNDERTMARK: If one of our members were to take a blood product, it would constitute a violation of God's law, and that person, if not repentant, would not inherit God's kingdom. Some have secretly succumbed to pressure from the medical field to go against what we feel is a Bible-trained conscience. Generally speaking though, Jehovah's Witnesses remain firm because they view it as a command, the same as the commands against fornication, drunkenness, thievery, or any other command in the Bible. As we mentioned, parents have the responsibility for their children until they get to an age when they can reasonably make their own decisions. Up to that point the parents are responsible for what happens to their children, and we feel God holds parents accountable.

DR. BAUGHAN: In cases where there has been a court order and someone is transfused, is there the possibility for forgiveness?

MR. ALEXANDER: Yes, there always is that possibility, just as there is when persons who commit other wrongs repent.

MR. HUNDERTMARK: We are talking about intentional wrongdoing. We all do wrong. There is no one here that is perfect. That is why we have the sacrifice of Christ Jesus for forgiveness of sins. There are areas that are gray areas, like serum, which is made from blood. In that case, because it is such a gray area, we leave it up to the individual conscience to decide.

DR. GANIATS: Are people who receive a court-ordered transfusion ostracized from the rest of the congregation?

MR. ALEXANDER: It depends on whether the person has done everything he reasonably can to refuse.

DR. LINDA S. FORTUNA (*Third-Year Family Practice Resident*): People can set aside their own blood for surgery. Is auto-transfusion also prohibited?

MR. HUNDERTMARK: We do not believe in the storage of blood. Regarding hemodialysis, where one's own blood is used and it circulates through the machine, there isn't a stopping or storing. In that case we would say it would be permissible. Blood substitutes should be used to prime the machine.

DR. NORCROSS: At the time of the first Communion, Christ said, "Take, drink, this is my blood, given for thee," or something to that effect. How is that reconciled in your belief? I understand that Christians do not actually drink blood, that it is symbolic, but why would he have said that?

MR. HUNDERTMARK: Translations of the Bible are different on that point. In certain translations he said, "this means my blood"; so it was a symbol or representation. The wine did not actually turn to blood.

DR. GANIATS: Thank you. So, in summary, we have a fetus at 28 weeks with a disease best treated by trans-

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fusion. A treatment option is delivery, but there is a high chance of morbidity, if not mortality. By waiting, the chances of morbidity and mortality will increase. The family, for deep religious reasons, feels it is a sin to transfuse the child. To help us sort through this, we have invited Dr. Schneiderman to discuss the ethics of this case.

DR. LAWRENCE J. SCHNEIDERMAN (*Professor, Division of Health Care Sciences*): Thank you. I have just one additional question. What is the risk to the fetus in this pregnancy without fetal transfusion? Can you give me an order of magnitude of what the mortality or serious morbidity would be?

DR. GANIATS: Without transfusion the child will have over an 80 percent chance of severe morbidity, such as a coagulopathy or hyaline membrane disease or death.

DR. SCHNEIDERMAN: Knowing that is important because we face the high probability of serious consequences to the unborn child.

In doing an ethical analysis of this case, there are two major principles we can discuss, autonomy and paternalism. Autonomy is simply defined as the right to do whatever you want to do with your life and certainly with your own body. In our society it is regarded as a fundamental value. In fact, it has such high priority that in the State of California a person has a right to refuse even life-saving medical therapy. Not only that, in this country we go even a step further, for if you look at the Roe vs Wade decision of the Supreme Court, the freedom of choice of the woman in the first trimester of pregnancy takes precedence over the life of the fetus.

Paternalism is the other ethical principle with which we will deal, and is best defined as forcing someone to do something for that person's own best interests. We won't have time now to discuss what is meant by "forcing" and "best interests," and who decides what they are. However, in this case we see a clear example of a patient's autonomy conflicting with all the paternalistic inclinations that guide us as medical providers and led to the discovery and application of medical technology exemplified by Rh immune globulin prophylaxis.

With respect to autonomy, we will be talking about the mother and also about the fetus. With respect to paternalism, we'll be talking about the mother acting on behalf of the child, the physician acting on behalf of the mother and child, and the state's position with respect to all three—the physician, the mother, and the child.

First, let's talk about autonomy. We said specifically that autonomy is a fundamental value: that a person has a right to do what he or she wants with his or her own body. Under this principle, an adult person has a right to refuse any kind of medical therapy. However, a woman carrying a fetus is obviously not alone. We might ask, what about the autonomous right of the fetus? Can we determine that? I think we would have to conclude that there is no practical way that we could know what a fetus would want for itself. Would it—if it could project into the future—adopt the mother's religion and perhaps prefer death to a tainted life? Such speculation would be a flight of imagination. As the fetus develops, enters the world, and grows into a child, we accept the fact that parents might rightly speak for the child and say, for example, "Johnny would prefer peach-flavored penicillin," or something like that. We also understand that a wife might speak for her husband who is in coma and no longer capable of making decisions. She might say, "Joe would never want to be kept alive in this state with a feeding tube."

We use the concept of "substituted judgment" as an expression of what we judge to be the person's autonomous wish when that person himself cannot utter it. But as we said, we are really not able to make an honest guess of what the autonomous wish of the fetus would be. So, we are left with the conclusion that the mother may speak for herself, but that no one really can speak for the child. We must take the next step and ask, "Well, what is in the best interest of the child?"

Again, we customarily make certain assumptions. We assume that parents usually will act in the best interests of their children. We have plenty of experiences to support that assumption, and the exceptions are rare; but how does one weigh the best interests without considering benefits vs burdens? Clearly the religious beliefs of the mother have led her to calculate the benefits vs burdens to her own soul in the direction of refusing RhoGAM. We have also said that the Supreme Court has given the mother the right to make personal choices even if it means the sacrifice of the fetus in the first trimester; but what about the situation where the mother's choices affect the fetus, which then goes on to full development? A close analogy would be if the mother knowingly gave birth to an infant affected with Tay-Sachs disease for which we have no treatment and which meant that the newborn child would be condemned to certain suffering and death. If we concluded that no life was better than a life of meaningless and incomprehensible suffering, would we be prepared to demand the mother undergo abortion under such circumstances?

In other words, are we entitled to override the mother's autonomy and act in what we regard to be a benevolent, paternalistic manner? What is the physician's role in all this, and what is the physician ethically entitled to do?

As physicians we commonly exercise our paternalistic powers. We restrain a delirious patient. We hospitalize a seriously depressed patient, if necessary, against that patient's wishes. Under those circumstances we certainly feel entitled to force the patient to do something for his or her own good. So, one of the ethical justifications for overriding a person's autonomy is if that person doesn't have the capacity to understand what he or she is doing. Another ethical justification for overriding a person's autonomy is if the person's choice of action is likely to cause

serious harm to others. This forms the basis for breaching confidentiality, for example, in the event of suspected child abuse. Is this mother's act tantamount to child abuse?

If so, then the courts and the many agencies that take as their responsibility the health and safety of all citizens will assert their right to act paternalistically. Through a variety of laws and licensing requirements, the State of California controls and monitors the health and safety of its citizens. In some instances the courts have compelled women to have blood transfusions and cesarean sections when the physicians testified that the life of the fetus was in danger. Interestingly enough, the State of California also seems to have a vested interest in protecting the physician's reputation, which is one of the arguments that has been used to oppose physicians' involvement in euthanasia. Why? Because if patients lost trust in their physician's moral duty to constantly protect life, then as far as the State of California is concerned, the reputation of physicians and their assigned role in society will be jeopardized. How can we weigh all these competing interests and ethical principles?

First of all, we have to ask, "How important is individual autonomy to us?" Does the woman's autonomous right extend in this particular situation to making a decision that is highly risky to the infant? If we oppose her right with laws and court actions that coerce her to undergo medical treatments against her will, where will this lead with respect to society as a whole? What will be the next justification for intervention—intrauterine surgery for congenital hydrocephalus? Abortion for cleft palate? And so on down the slippery slope.

In a society that treasures individualism and religious freedom, we must be very cautious before we dismiss a moral view that is contrary to our own. Thus the physician's religious inclinations are not at issue so much as his or her professional duty. The physician cannot ignore the serious consequences to others of the mother's autonomous acts. Yet the physician cannot arbitrarily force an unwanted medical treatment. What to do? Unfortunately the only way out that I can see is to take the case to court—a procedure that is actually rarely necessary in most ethical dilemmas. But in this situation, the courts represent the standards of ethics and moral values for a society as a whole, and where there is a close and serious conflict in the balance, they are there to adjudicate. That is their purpose.

You can see then how important it is for the courts to be a true repository of society's moral values as a whole. One of the things that concerns me is the trend today to impose one or another ideology on the court systems. If we are to trust the courts to be impartial and to allow them to make choices on our behalf, to look upon conflicting rights and interests in as neutral a way as possible, we cannot afford to let the courts be dominated by one particular legal theology.

DR. EDWIN H. CABRERA (*Second-year Family Practice Resident*): The uterine transfusion is not without risk to the mother. Even now under sonography in our institution there is a 3 to 4 percent risk of morbidity. Usually we present risks and benefits to patients, but here we're saying, "You, the mother, are bearing these risks for the benefit of the baby."

DR. SCHNEIDERMAN: I think these are important points. We estimate a 3 percent morbidity risk to the mother for the sake of avoiding an estimated 80 percent chance of death of the child. At some point we're going to have to admit there is a gray zone. In other words, if the mother had to undergo a cesarean section, which has a much greater risk to her, to achieve the benefits to the child, we might begin to hesitate and admit medical estimates and predictions are uncertain. At some point we would have to admit we do not have a strong case to force the mother to do something for the sake of the child. Once again, this is where the courts might have to adjudicate, taking into account all the medical and nonmedical factors. For example, what if the mother already has two healthy dependent children? The mother's death under those circumstances would have serious consequences to these children. Or, on the other hand, if the mother and father convincingly argue that she is fearful of an eternity in hell, and the father is quite prepared and capable of caring for the other children, the court might decide differently. In other words, these are issues that presumably neutral parties would weigh. I don't believe physicians are entitled to do this sort of thing by themselves. There are so many factors outside our expertise that I don't think physicians can say this or that choice is "medically indicated."

DR. ROBERT E. GARRETT (*Assistant Clinical Professor, Division of Family Medicine*): We have been talking about risks and benefits, and the understanding in the dialogue so far has been physical risks and benefits. There is a real risk of spiritual harm in this kind of situation. One can see how a situation would develop where a risk of spiritual harm would be considered graver by the person involved than would the risk of physical harm. This is not something that would be limited to Jehovah's Witnesses or purely to the issue of transfusion.

DR. SCHNEIDERMAN: I think any burden that is perceived by the patient, whether physical, emotional, financial, or spiritual, should be entered into the ethical equation.

MR. HUNDERTMARK: This is the Jehovah's Witnesses' stand. The medical side of the issue is very important; however, the spiritual aspect is equally important and must be taken into serious consideration by the medical profession.

DR. BAUGHAN: Is a mother morally negligent in getting pregnant again if she knows there is a strong possibility of problems?

MR. HUNDERTMARK: We don't feel that would be true. Each person must conscientiously weigh all the factors and then personally decide. The person will have to answer for the consequences, whether good or bad.

DR. BAUGHAN: If the worst scenario happens, you get the deformed, retarded child who dies young or has a period of suffering. In your belief system is there anything spiritually undesirable about that, or is that one of the consequences of life that we have to accept?

MR. HUNDERTMARK: Obviously there is going to be a lot of emotional pain, because those things have happened. As we look at it, however, we have all inherited sin and imperfection, and it manifests itself in various ways. Unfortunately that's one of the ways.

DR. BAUGHAN: Is that collective or individual?

MR. HUNDERTMARK: Collective. For instance, some people say AIDS is a punishment by God on people who engage in certain practices. That's not true. The Bible, Book of Ecclesiastes, tells us that time and chance happen to all of us. If you play with fire you may get burnt, but it's not certain.

DR. BAUGHAN: There is one dilemma I would like to pass over to Dr. Schneiderman. A hundred years ago, or fifty miles south, this wouldn't be an ethical dilemma. It seems as though our science is suggesting possibilities that our theological, civil, and ethical guidelines have trouble keeping up with. My question is, "What is the civic or religious principle that says if we've got a technology we have to use it?"

DR. SCHNEIDERMAN: This is the so-called technological imperative. With respect to forcing technology, in my view—and I would hope courts adjudicating among conflicting interests would take this into account—priority for making decisions should always go to the person most likely to bear the consequences of that decision. We as physicians cannot really be sure what the outcome will be to the child, to the mother, or what is likely to happen in the future. One thing is certain—we are not going to bear the consequences, the parents are. We as physicians can walk away, and in many ways, society today walks away, turns its back, and ignores the consequences of its actions. In my opinion, that's one of the serious flaws connected with the Baby Doe legislation. The State of California claimed its right to intrude into the painfully complex decisions involved in treating severely handicapped infants. It tried to force physicians and parents to maximize aggressive therapy, but then it did not do much to help with the consequences, in terms of funding for all the necessary follow-up social and medical services. That's not moral policy. That's moral posturing.

MR. ALEXANDER: We'd like to emphasize that we definitely appreciate the understanding of the medical profession because we realize that in some respects you feel as though your hands are tied. We don't do that intentionally or because we feel that we have superior knowledge. We feel that God's laws come before man's, and His laws have proved worthy of our trust.

MR. HUNDERTMARK: We have brought a reprint from *The Journal of the American Medical Association.* It shows that physicians are facing this challenge today. Rather than fighting it to the end, they've taken it as a challenge to improve their methods, and it is working. Let me read the last part of the article,

> Understandably, caring for Jehovah's Witnesses might seem to pose a dilemma for the physician dedicated to preserving life and health by employing all the techniques at his disposal. . . . Rather than consider the Witness patient a problem, more and more physicains accept this situation as a medical challenge. In meeting the challenge they have developed a standard of practice for this group of patients that is accepted at numerous medical centers around the country.[4]

Dr. Denton Cooley, who now frequently operates on members of the Jehovah's Witnesses, has had a higher rate of success in open heart surgery without the use of blood. He has a better success rate than other physicians, and admits that one of the reasons for this is not using blood. We recognize that it is a problem, but certainly physicians are working with us, and we are finding success in this field.

DR. GANIATS: We came here today for two reasons. One was to become better acquainted with the rationale behind the Jehovah's Witnesses' beliefs. Another is to have an introduction to medical ethics and an approach to ethical problems. As is common with such cases, we were not able to come up with the definitive answer, but we hope that this process has been helpful and will assist in your future decisions.

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