The Pediatric Jehovah's Witness and Other Dilemmas

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Jehovah's Witness patients may present a special challenge to anesthesiologists when there is a risk of blood loss and the possible necessity of a life-saving transfusion of blood products. Care of the pediatric patient adds another layer of complexity to peri-operative management as their parent or guardian acts as their legal consenting agent. In some instances this situation may demand that we consider a life-threatening belief that we may disagree with both professionally and personally. One important concept is that minimizing blood loss applies to all surgical patients. Regardless of our professional, ethical or legal concerns few would argue with the fact that may learn to improve our approach in this aspect of our medical care.

Jehovah's Witnesses History

The Jehovah's Witnesses are Christian sect dating back to the 1870's first formed in Pennsylvania, USA. The official journal is called The Watchtower and there are 6 million worldwide and at least 1 million in the United States. The basic interpretation of the Bible is a literal reading and it is believed above all else that salvation is to be provided only to those who follow the strict tenets of their faith. Any hope of eternal life or salvation is forfeited if they do not adhere to biblical directives. In 194,5 it was determined that blood transfusion should be forbidden to Jehovah's Witnesses as it violated God's law by their literal interpretation of the bible based upon the following passages:

From Genesis, God commanded "every moving thing that liveth shall be meat for you; even as the green herb have I given you all things. But the flesh with the life thereof, which is the blood thereof, ye shall not eat"

From Leviticus, "therefore I say unto the children of Israel, ye shall eat the blood of no manner of flesh: for the life of all flesh is the blood thereof: whoever eateth it shall be cut off"

Therefore the transfusion of blood is tantamount to "eating" blood once separated from the body, even if it is autologous. The body may be cured, but the spirit is compromised which leads to a meaningless life perhaps worse than death. Jehovah's Witnesses readily seek out medical relief and will accept all aspects of treatment other than transfusion. Another consideration is that there is no consistency among different churches. There are subsets of Jehovah's Witnesses who find the policy hypocritical (Associated Jehovah's Witnesses for Reform on Blood). This is a small minority who believe that intravenous administration is not tantamount to "eating" blood. One difference that varies is the specific guidelines from each church leader that may or may not include the use of

albumin, for example. The best approach is a discussion, in advance, so that the patient may have an opportunity to find out what the acceptable products include. Usually the unacceptable products are whole blood, packed cells, white cells, platelets, plasma, and <u>pre-deposited</u> autologous blood.

Physicians in the United States all take the Hippocratic Oath: "The regimen I adopt shall be for the benefit of my patients according to my ability and judgment, and not for their hurt or for any wrong...Whatsoever house I enter there will I go for the benefit of the sick"

Physicians are taught to preserve life and may have a conflict of conscience when asked to stand by and allow a patient to die for want of a life sustaining blood transfusion. Is it possible to have an Ethical "Compromise"? Jehovah's Witnesses ask to be considered a medical challenge and we must ask: what are the consequences to the patient and their family? For example, is the sin forgiven if done against the will of the patient?

Legal Issues

We must weigh our beneficence versus patient autonomy plus the consideration of the legal issues. The legal precedent for adult Jehovah's Witnesses was set in 1914 in Schloendorff v. Society of New York Hospital by Judge Cordozo. Schloendorff consented to an exam under anesthesia, but a procedure (fibroid excision) was performed which led to a brachial plexus injury and finger amputation. Schloendorff sued the non-profit hospital, but lost on the basis that the hospital was a charitable institution and immune from liability. It is this case that established premise of informed consent.

Judge Cordozo concluded, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body"

For minors these conflicts have been resolved on a case-by-case basis. The argument from Jehovah's Witnesses is that in view of the well-recognized right of paternal responsibility, the moral, principled and consistent position for a doctor is to recognize the responsibility of loving, concerned parents to make decisions for their minor children.

The legal precedent for minor Jehovah's Witnesses set in 1944 from Prince vs. MA. Prince sued for right of 9-yr-old child to sell Watchtower and preach the gospel on the street, but the court ruled against Prince with a decision that has been quoted in many rulings up to the present:

"Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstance, to make martyrs of their children before they have reached the age of full and legal discretion...the right to practice religion freely does not include the liberty to expose...the child...to ill health or death"

In all cases where pediatric blood transfusion was deemed medically necessary, the courts have quoted this decision and followed this reasoning for emergency transfusions. When a child's life is clearly in danger, the courts have characteristically intervened over the religious objections of the parents reasoning that the state is obligated to take an overriding interest in the health of its citizens.

The legal procedure is as follows: A petition is made to declare the minor as a "neglected child" and appointment of a guardian. It is then filed by hospital administrator and medical evidence is presented by the physician concerning the necessity of transfusion. The administrator is then appointed guardian and consents to the transfusion. Rulings have been inconsistent for elective procedures for minors whose parents protest transfusion.

In 1999, Alexis Demos, a 17-year old Jehovah's Witness with an injured spleen won in appeals court where "mature" minors were given a voice in deciding whether to refuse life-saving medical treatment. This landmark ruling allows courts to consider a child's maturity to reason through an informed decision. An important consideration is the ability self-sufficient and emancipated minors to legally control their own consent. This includes patients under 18 who may live separate from their parents or guardian and manages his/her own financial affairs, entered a valid marriage, are on active duty with the armed forces or received a declaration of emancipation.

Overall, based upon the strong legal precedent for giving blood, no child should be allowed to die because of parent refusal to consent for the administration of blood products in emergency, life-threatening situations.

Anesthesia Considerations

Plan, in advance, for possible hemorrhage and consider the use every indicated, available and patient accepted method to limit blood loss. A child of Jehovah's Witness parents should not die for lack of transfused blood without seeking a court order, but there is no reason to attempt to get a blood transfusion consent. Inform the parents that, in the event that blood products would be life saving, a court order will be sought and document the discussion in the chart. You can assure the family that you will make every effort to administer an anesthetic in accord with the parents' religious beliefs and again explore with the family the exact requirements of their beliefs. No guarantees should be given that blood will not be transfused.

Prospective court orders may not be necessary if hospital legal counsel has a relationship with the local judiciary to obtain a quick court order. If the local judge is not familiar with the case law, then waiting until an emergency exists may be a mistake. If the parents seek to discharge the child, it need not necessarily be opposed if it is to another heath care facility. If the child requires immediate treatment then an emergency order to keep the child at your hospital should be strongly considered. If blood loss is expected, then it may be advisable to obtain the court order pre-operatively. The social worker or administrator will require a letter or a form by a physician with: Diagnosis, Treatment, Risks and Why the Transfusion is Important. The form or letter is faxed to a court clerk who walks the form through the court process. Courts have uniformly intervened to

order hospitals to give blood transfusions to minors over the religious objections of their parents.

Pre-Operative Evaluation should include a CBC, Coagulation and Iron Studies and anticoagulants should be discontinued if possible. In small children it will be important to minimize pre-operative blood samples and in all patients, consider staging of complex procedures.

Erythropoietin is a sialoglycoprotein produced by the kidney and is the primary hormonal regulator of red cell hematopoiesis. It stimulates division and differentiation of committed erythroid progenitors in the bone marrow. It has been commercially available through recombinant DNA technology for some time. Formulations contain Albumin so this needs to be addressed with the patient's family before initiating therapy. Use of erythropoietin requires iron supplementation and may have the side effects of hypertension, seizures and thrombotic events.

It is important to consider the physiology of anemia when caring for these patients. Anemia and hypovolemia will eventually lead to inadequate oxygen delivery by reduction in cardiac output and oxygen content. Compensation will occur through increased heart rate to increase cardiac output, higher oxygen extraction and decreased hemoglobin affinity for oxygen. At high levels of hemodilution, flow redistributes in favor of the heart and brain away from other organs.

Maintenance of normovolemia may allow for compensatory increase in cardiac output and decreased blood viscosity will increase organ flow by decreasing resistance. The maximum effect occurs from a HCT to approximately 30% after which oxygen content begins to significantly decrease. Under maximum compensation, oxygen extraction as high as 70% can be reached in the myocardium. Higher oxygen extraction will eventually lead to metabolic and hemodynamic deterioration and the heart is the organ most at risk because it has the highest extraction ratio with limited metabolic reserve.

Acute Normovolemic Hemodilution may reduce the amount of red blood cell transfusion requirement or may reduce the need for transfusion at all. Major surgical procedures can be performed without donor blood replacement and the blood lost has low red cell volume.

The decreased viscosity may improve organ perfusion and the diluted blood gives clearer surgical field. A predetermined volume is drawn into CPD bags to reduce HCT to 20% with a 3:1 replacement with crystalloid. Furosemide and controlled ventilation may be used post-operatively. The tubing from the blood withdrawn is kept connected to the patient's intravenous (IV) tubing so that the blood remains within the patient's "circulation".

Calculation Removable Blood

Volume to be removed = EBV X (HCTi-HCTf)/HCTavg

(EBV-estimated blood volume, HCTi-initial, HCTf-final, HCTavg-average of HCTi and HCTf)

Schaller, *et al* reported use of ANH in 25 infants and children, 50% were <2 years. Only 6 were transfused with banked blood and the youngest was 1 month and 3.1 kg. This was combined with cell salvage and mild hypothermia (32 degrees centigrade).

Using Cell Salvage when indicated my allow50-80% of the shed red blood cells to be retrieved and is contraindicated with malignancy, contaminated bowel or infection. Complications include electrolyte abnormalities (decreased bicarbinate, Ca, Mg), air or fat embolism coagulopathy and sepsis. The suction is kept in the patient at all times and the collection bag is connected to the patient's IV tubing before the suction is disconnected to keep the salvaged blood in the patient's "circulation".

Some pharmacologic maneuvers may also be considered intra-operatively. DDAVP, a synthetic analogue of vasopressin raises circulating factor VIII and von Willebrand factor. Aprotinin, a serine protease inhibitor may be beneficial by protecting platelet function, but only for prophylaxis Aminocaproic acid and Tranexamic acid which are antifibrinolytics may be used for prophylaxis or therapeutically.

Post-Operative Care may include oxygen support and controlled ventilation to decrease oxygen demand. Maintenance of intravenous volume is important to maintain cardiac output. As with the pre-operative consideration, limiting blood sampling and good nutrition will also aid in the recovery of these patients.

Minimizing blood loss is one of the goals of the entire OR team. It is possible for compromises between two opposing beliefs ethical systems. Advanced planning is always an aid to good medicine.

The Dilemma of the Pregnant Adolescent

The testing and presence of pregnancy in the teenage patient who presents for anesthesia and surgery is a challenging and controversial issue. There is a high incidence of sexual activity among adolescents and a significant incidence of teenage pregnancy. The great majority of these are unintended. There also exist a number of barriers to the identification of pregnant teenagers including avoidance of medical care, fear of the consequences of the disclosure to family members and lack of realization that they are pregnant.

<u>Incidence</u>

A number of institutions have published results of studies investigating the use of routine preoperative testing in adolescents. The overall incidence of a positive result is approximately 1%. In many of these studies a careful history of the possibility of pregnancy and recent menstruation did not correlate with positive HCG results. Cancellation of anesthesia and surgery was also inconsistent.

Medical Policies, The Law and HIPAA

The American Academy of Pediatrics (AAP) policy on informed consent indicated that adolescents 14 years and older may have as well-developed skills as adults for making informed health care decisions and advises informed consent for adolescents and young adults. What is emphasized is the fact that "a respect of persons involves fully and accurately providing information relevant to exercising their decision-making rights".

Most states have laws concerning minors receiving contraceptives, prenatal care, STD/HIV treatment, substance abuse treatment, mental health services and abortion services. States differ in the specific application of those laws and even the age of majority. In Pennsylvania and Puerto Rico the age is 21. Vermont and Virginia require that parents are given the results of STD/HIV testing. Twenty-four states require parental consent for abortion, but many do not enforce this law due to successful court challenges.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule requires that if a person has the right to make health care decisions then that person controls the associated information. Usually parents of minors control protected health information (PHI), but the issues outlines above including pregnancy are clear and probable exceptions. More specifically parents may not have access under the following three circumstances:

- 1) State law does not require consent
- 2) A court of law determines an alternate to the parent
- 3) The parent agrees to minor confidentiality for health care

In general, HIPAA overrides any contrary state laws except where the state law is "stricter" and provides greater protection. State laws determine the rights of parents to obtain access and or control of the disclosure of medical information concerning their children. Providers who reveal confidential medical information are in violation of the Medical Information Act and HIPAA and are guilty of unprofessional conduct. This could result in criminal and/or civil liability and put a practitioner's medical license at risk.

So, if permitted by state law, parents have access to the information and are denied if prohibited by state law. When the law is silent then it is up to the professional judgment of the health care provider to grant or deny parental access to a minor's medical information. Additionally, if the health care provider has a reasonable belief that the information will endanger the minor, the provider may choose not to disclose the information which supersedes state law. A state-by-state summary can be found at www.ermerlaw.com/PDFs/hipaa_state_law_survey_version_3_0.pdf.

An Ethical and Practical Question

In 2003, the American Society of Anesthesiologists Committee on Ethics and the Committee on Practice Parameters formed a joint task force to resolve differences of opinion regarding testing for early pregnancy and determined may not be ethically justified to test for pregnancy without consent. The information regarding pregnancy

belongs to the patient and it does not alter her right to proceed with anesthesia and surgery if she so desires. What is advocated is to offer testing but not require it by unless there is a compelling medical reason to know whether the patient is pregnant.

A blanket policy to test all adolescents may eliminate a difficult situation in the presence of parents. Also, the possibility exists for parents to be notified by proxy of a pregnancy at the time of medical billing. Some possible alternatives include the use of a questionnaire to be filled out without parental presence. A thorough history on the phone the night prior to surgery or in private in the pre-operative area is also recommended. There should be emphasis on the importance of full disclosure and include confidentiality assurance where applicable by state law and a judgment-free discussion.

If testing occurs and a minor is discovered to be pregnant on the day of surgery, disclosure of the information to parents or guardians is determined by state law as described above. Where state low does not require disclosure he physician must allow the minor to decide if she wishes to inform her parents or guardian. If state law requires disclosure of the information, it may be reasonable and ethical to give the patient an opportunity to release the information herself.

Cancellation of Anesthesia and Surgery

It is unclear if surgery and anesthesia during early gestation are hazardous to the developing fetus by either an increase in spontaneous abortion or increasing the risk of congenital anomalies. The most recent literature indicates that there is a low likelihood that women who undergo anesthesia during pregnancy have an increased incidence of congenital anomalies. Anesthesia exposure and the surgery which accompanies it during the first trimester does increase the risk of spontaneous abortion, but this is most likely sue to the medical condition necessitating surgery and/or surgical manipulation.

The decision to proceed with anesthesia and surgery is a decision made on a case-by-case basis. Consideration must be given to the necessity of the surgery and an informed discussion with the patient. There is no definitive evidence for the safety or hazard of anesthesia during pregnancy.

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