Chapter 6
Ethical Care of the Children of Jehovah's Witnesses

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Abstract The right of adults with full decision-making capacity to refuse specific treatments such as a blood transfusion is well-established in the legal and ethical realms. In adults who have lost their decision-making capacity, the principle of substituted judgment has also been well-defined. However, in the case of parents or guardians who refuse a child's recommended medical treatments for religious or other reasons, conflicts may arise. In this chapter, we examine the clinical case of an adolescent with a malignancy requiring surgery and, quite likely, a blood transfusion whose parents are some of Jehovah's Witnesses (JW). We also discuss the ethical, legal and medical ramifications of this clinical situation.

Keywords Capacity • Consent • Assent • Jehovah's Witness • (Refusal of) Transfusion • Decision-Making • Pediatric

Case Presentation
A 16-year-old African-American female presents to the emergency room with complaints of flank pain and hematuria. Medical evaluation reveals a large mass in her left kidney. The patient subsequently undergoes a transcutaneous biopsy of her kidney which reveals that the patient has renal medullary carcinoma. The patient is then referred to a pediatric oncologist who, after consulting with the pediatric surgeon, recommends a radical left nephrectomy with

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intraoperative lymph node evaluation. The medical team, adolescent patient, and her parents agree that surgery is in her best interest and offers the only reasonable chance of cure. The family understands that refusal of surgery would result in spread of the cancer and ultimately death. As practicing Jehovah's Witness (JW) followers, the patient and her parents desire "no blood" and do not provide consent to allow the receipt of blood products during surgery. An ethics consultation is requested after the surgeon and anesthesiologist state that they could not "in good conscience" allow a pediatric surgical patient to hemorrhage in the operating room should complications develop during the nephrectomy**.**

Introduction

Jehovah's Witnesses are an international religious organization and comprise approximately 0.6–0.8% of the adult population in the United States with the greatest percentage residing in the South (36%) or West (29%) [1]. Interestingly, the majority of Jehovah's Witnesses (63%) have no children [1]. However, Jehovah's Witnesses have the lowest retention rate of any religious group with only 37% of individuals raised in the faith as children keeping this religious affiliation into adulthood [2].

JWs began as a sect of Christianity in 1870, as a bible study group formed by C. T. Russell in Allegheny, Pennsylvania. Among other things, JW's have their own translation of the bible and believe that it is inspired by Jehovah and is scientifically and historically correct. The global headquarters of Jehovah's Witnesses is located in Brooklyn, New York where a governing body has ultimate authority over all issues of doctrine.

Though JWs started in 1870, it was not until 1945 that a ban on blood transfusions was placed for JW's [3]. This ban on blood transfusions was based on quotes from the Bible, especially the following: (*New World Translation of the Holy Scriptures – 2013 Revision*) [4].

> Genesis 9:3 - …. Only flesh with its life – with its blood – you must not eat
>
> Leviticus 17:10–12 - 'If any man of the house of Israel or any foreigner who is residing in your midst eats any sort of blood, I will certainly set my face against the one who is eating the blood, and I will cut him off from among his people (Leviticus 17:10). For the life of the flesh is in the blood, and I myself have given it on the altar for you to make atonement for yourselves, because it is the blood that makes atonement by means of the life in it (Leviticus 17:11). That is why I have said to the Israelites: "None of you should eat blood, and no foreigner who is residing in your midst should eat blood" (Leviticus 17:12).
>
> Acts 15:28–29 - …to keep abstaining from things sacrificed to idols and from blood…

A 1951 *Watchtower* article explained the reasoning that led to this ban on blood transfusion: "…when sugar solutions are given intravenously, it is called intrave-

nous feeding. …The transfusion is feeding the patient blood and …(the patient) is **eating it (blood)** through his veins" [bold type added] [5].

It is a common misconception that if you give a JW blood against his or her will, then the JW is still subject to eternal damnation. Another misconception is that if a JW accepts blood then he or she, too, would be subject to eternal damnation with no chance of repentance. Neither of these is true. According to an e-mail communication with the JW lead office:

> "A forced blood transfusion would not be viewed as a sin. Also, if under extreme pressure & while experiencing undue stress a JW was to compromise their belief and accept blood transfusions, in other words, if they caved in at a moment of spiritual weakness yet still held to their beliefs, that individual would not be ostracized by the JW community, rather, kindness would be shown and pastoral help offered. Nevertheless, a forced transfusion or a compromise with one's conscience may leave the patient with deep emotional scars."

In fact, since 2000 JWs are not "disfellowshipped" for accepting blood. JWs are considered to have voluntarily "disassociated" from the Church. This means that if a JW does repent he or she can remain in the fold.

In order to keep up with advances in medicine (for example, renal dialysis; cardiopulmonary bypass; blood harvesting including cell saver (cell salvage), acute normovolemic hemodilution and autologous blood donation; and organ transplant), new guidelines for JWs have been developed to aid members in addressing these clinical situations [6]. Table 6.1 shows a timeline of significant events in the Jehovah's Witness faith and transfusion medicine.

Alternatives to Blood Transfusion and What a Practicing Jehovah's Witness Will Accept

There are few if any true substitutes for a blood transfusion if one is truly needed and an exhaustive discussion of these is beyond the scope of this chapter. However, there are some measures that can be taken to decrease the need for a blood transfusion. It is important to define which, if any of these, will be acceptable to an individual JW patient.

Just as in any organized religion, there can be a difference between official doctrine and personal belief. Therefore, it is not always the case that a patient

Table 6.1 Events in the history of the Jehovah's Witness Church and transfusion

1870	Study group formed
1879	First issue of Watchtower published
1901	Discovery of ABO blood groups
1914	First blood bank transfusion
1931	Changed name to Jehovah's Witnesses
1945	Ban placed on transfusions
1961	Transfusions become a "disassociating" offense
2013	7.9 million members worldwide and 1.2 million members in U.S.

professing to be a JW will not accept any blood products. In a study of pregnant JW patients, up to 10% of these patients stated that they would accept blood products in an emergency situation; however, it was not confirmed whether these patients were baptized [7]. Furthermore, there is a sect known as "Advocates for Jehovah's Witness Reform on Blood" formerly called "Associated Jehovah's Witnesses for Reform on Blood" whose members will accept blood and blood products in many circumstances [8, 9]. They have also worked to reform the Church from the inside [9]. Despite the fact that some JWs accept blood products, in general, few practicing Jehovah's Witnesses will accept whole blood, packed red blood cells, plasma, platelet concentrates, or white blood cell transfusions [6]. Few practicing JWs will accept pre-donated autologous blood since the blood is out of contact with their body for a significant period of time, yet acute normovolemic hemodilution is acceptable to many of the faithful. With cell saver, acute normovolemic hemodilution (ANH), cardiopulmonary bypass, and renal dialysis, *The Watchtower* states that it is an individual JWs decision to receive these treatments if the blood is kept in a continuous circuit with their body and is not stored for any period of time. Cardiopulmonary bypass and dialysis would always involve a continuous circuit. Of course with cell saver and ANH a continuous circuit is not routinely used, but a continuous circuit can easily be created. Other products and procedures are also left to the "discretion of the practicing Christian" including albumin, cryoprecipitate, cryo-poor plasma, individual factors, as well as organ and bone marrow transplantation (Table 6.2).

When faced with major surgery, it is imperative that the anesthesiologist and surgeon determine, in as much detail as possible, what if any of the "optional" products the patient will accept. In addition, it will often become necessary to educate the patient not only on what each of these products and techniques entails, but also on the fact that they are indeed optional.

Ethical and Legal Issues in the Care of Pediatric Jehovah's Witness Patients

The ethical and legal right of capacitated adults to make medical decisions for themselves is well-established [10]. Autonomous decision making provides adults with the leeway to make authentic choices consistent with their beliefs and values [11]. If an adult patient makes a "bad decision," the clinician may confirm capacity and attempt to use gentle persuasion to redirect the patient, but little precedent exists to override their refusal. It may even be considered battery if consent is not obtained from a capacitated adult patient and his or her known preferences are overridden.

When adult patients are unable to make medical decisions on their own behalf, clinicians try to identify a person to act as the patient's "surrogate" and make decisions as his or her proxy. In other words, clinicians ask the surrogate to make decisions based on the patient's previously expressed wishes (if known), or to make decisions consistent with the patient's known values and interests. In pediatrics, children have developing and evolving decisional capacity as well as beliefs and

Table 6.2 Blood product guidelines for Jehovah's Witness patients

Type of blood product or procedure	Accept/refuse/personal decision (PD)[a]	Specific concerns
Whole blood	Refuse	
PRBC's	Refuse	
Plasma	Refuse	
Platelets Platelet gel	Refuse PD	
White cells	Refuse	
Cryoprecipitate	PD	
Cryo-poor plasma (cryosupernatant)	PD	
Fractionated factors	PD	
Albumin	PD	
Erythropoetin	PD	Most erythropoietin is albumin coated and is a PD. Darbepoetin contains no albumin
Recombinant factors VII and IX	Accept	Not made from blood, though some may still object
Cell saver	PD	If kept in continuous circuit
Acute normovolemic hemodilution	PD	If kept in continuous circuit
Cardiopulmonary or veno-venous bypass	PD	Continuous circuit rule
Renal dialysis	PD	Continuous circuit rule
Stored autologous blood	Refuse	Not in continuous circuit
Organ and bone marrow transplant	PD	

The worksheet that many JW's have does not include all of these products and/or techniques, but those not on the worksheet have been verified by The Watchtower.

[a]The term "personal decision" is used here to denote actions that the Watchtower has said are optional. In reality these are all personal decisions for each patient

values. Parental authority and familial autonomy over their developing, vulnerable child creates a unique dynamic that is different from the moral space in which surrogates make medical decisions [12].

Infants and children lack the ability to make autonomous medical decisions and therefore parents (or legal guardians) are presumed to have a liberty interest in the "care, custody, and management" of their children [13]. Furthermore, as children age and mature they are able to play an increasing role in the medical decision making process creating a triangle of decision making between patient, parent, and provider, which may raise additional complexities [14]. While parents are allowed broad discretion in medical decision making, this right is not absolute. As was noted in the case of *Prince v Massachusetts*, "…Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion

when they can make that choice for themselves" [15]. Responding to parents who are refusing a recommended medical intervention is often challenging to clinicians. It is the fiduciary responsibility of the clinician to advocate for the interests of his or her patient (the child) in a manner that promotes the child's interests while minimizing infringements on familial autonomy and parental authority as a whole.

When a child has a reasonable prognosis, the parental refusal of a recommended therapy obliges physicians to (1) analyze the risks and benefits of the parental request versus the recommended intervention and (2) consider if other alternative interventions may be reasonable. It is generally helpful to engage in shared decision making with the family, involving colleagues skilled in communication if necessary, to reach a mutually agreeable decision. If persistent conflict cannot be resolved with referral to another clinician or through involvement with clinical ethics consultation, state intervention may be required. This is most often indicated when parental decision making is perceived to significantly violate a child's best interest or put the child at risk of serious harm.

Evaluation of Medical Decision Making Involving Minors

Child's Best Interest and the Harm Principle

The "best interest of the child" standard is based on the ethical principles of beneficence, or the "moral obligation to contribute to the good of others" [16]. In the context of medical decision making, it aspires to identify the medical care (decision) that is in the best interest of the child. When parental decision making aligns with a proposed medical therapy, the care is often delivered without deliberate consideration of this ethical standard. When differences of opinion exist, the standard may be invoked to substitute the views of a third party (the physician, the courts) over the views of the parents [17]. One expects that most parents do not seek to make decisions they perceive as harmful, so why do clinicians and families sometimes collide over what interventions are best for the pediatric patient?

The best interest standard and the evaluation of the benefits and harms of alternative medical pathways are inherently subjective, value-laden judgments. Consider a patient with osteosarcoma – based on tumor location and the response to chemotherapy, the oncologist and surgeon may recommend amputation rather than a limb-sparing technique, but after evaluation of the information and consideration of their personal preferences and beliefs, the family may still elect to pursue limb-sparing. The teenager may feel that it is in his long-term best interest to not have a prosthesis and is willing to accept any increased risks associated with declining amputation (amputation being what the physicians consider to be his present day best interest). Finally, children are highly dependent on their parents who bear the burden of their care. Parents are likely to consider familial needs – this is the balancing and rank ordering of the interests of the parents, siblings, and their child who is the patient in order to reach a determination of what is the best medical decision [18].

Because of the difficulty using best interest alone, it is helpful to consider what risk of increased harm can be tolerated before a threshold is crossed and the potential risks of harm becoming so great that it becomes necessary to pursue legal action and request that the state order a parent to comply with the medical recommendation. The pursuit of a child protective services referral for medical neglect or a court order may irreversibly damage a provider's relationship with a family and negatively color future interactions with medical professionals. Therefore, the decision to request that a state agency overtake medical decision making should not be taken lightly. If there is significant prognostic uncertainty or low risk of benefit even with the recommended intervention (i.e. chemotherapy for high risk cancer), state agencies are generally adverse to overriding parental decision making. In this context, it is helpful to consider the answers to eight basic questions, as proposed by Diekema, when considering whether to seek state intervention [19]:

1. "By refusing to consent, are the parents placing their child at significant risk of serious harm?
2. Is the harm imminent, requiring immediate action to prevent it?
3. Is the intervention that has been refused necessary to prevent the serious harm?
4. Is the intervention that has been refused of proven efficacy and, therefore, likely to prevent the harm?
5. Does the intervention that has been refused by the parents also place the child at significant risk of serious harm and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7. Can the state intervention be generalized to all other similar situations?
8. Would most people familiar with the situation agree that the state intervention was reasonable?"

Assent and Children's Role in Medical Decision Making

As children mature, they develop an increasing ability to evaluate proposed medical interventions and consider the risks and benefits of the alternatives. Children are not treated as rational, autonomous adults but allowed to participate in decisions in a manner consistent with their developing capacity. Meaningful pediatric assent, which is less stringent than consent, allows children the opportunity to state their preferences within the context of their developmental abilities and desire to participate [20]. The "rule of sevens" can provide general guidance for clinicians assessing developmental capacity in pediatrics. Children under the age of 7 are presumed to lack capacity, children 7–13 years of age have an evolving sense of capacity and should be evaluated on a case-by-case basis, and children over 14 are presumed to have capacity unless evidence exists to the contrary [21]. It may be helpful to consider the practical

example of a common pediatric intervention, vaccination. A 4-year-old is unlikely to want to receive a shot, but most all 4-year-old children will be unable to articulate a meaningful decline, and may actively cry or hide in anticipation of the intervention. A 10-year-old is unlikely to want a shot, and may protest against it because it may hurt, but will usually sit cooperatively for administration of the immunization. A teenager may not want the shot, but realize that it is beneficial and not protest, or they may articulate a reasonable response for declining the immunization.

It is important to remember that there will be older children who lack developmental maturity to participate meaningfully and younger children who have significant illness experience prompting greater consideration of their opinion. If the child does not have a true choice in the final medical decision, then they should not be offered a false choice.

Evaluating Transfusion Refusals in Pediatric Jehovah's Witness Patients

Refusals of transfusion should be evaluated in a manner similar to other refusals. Providers should consider if alternative interventions (or nonintervention) exist and evaluate the risks and benefits of the treatment being refused against other proposed alternatives. It may be helpful to solicit the reason for the refusal and engage in an open discussion to see if the refusing party can be gently persuaded through assuasion of fears or misperceptions. In our local experience, families have sometimes presented with inaccurate information, such as vastly overestimating infection risks associated with transfusion or expecting more immediate (within days) benefit from the use of erythropoietin. If the intervention refused is not essential or can be deferred without substantial risk, the refusual may be binding. In considering adolescent refusals, it is important to note the low retention rate in the religious tradition and consider that the 16-year-old refusing transfusion today, may be unlikely to hold the same beliefs as an adult. This may be a consideration when there are high risks of harm to the adolescent if the declination of transfusion is honored.

Families often understand that physicians have a fiduciary responsibility to their patient, the child. Some families may be willing to sign an "acknowledgement statement" which documents that the parents have been informed that emergency transfusion will not be withheld regardless of parental refusal to sign official transfusion consent. Acknowledgement statements may allow for the avoidance of state intervention. Due to variability in legal precedent between states, we recommend conferring with institutional legal counsel for appropriate language. In some circumstances it may not be possible to avoid state intervention. Also, in some circumstances it may be impractical to override refusal – for example an adolescent patient strongly opposed to transfusion who has been offered a myeloablative bone marrow transplant. In this case, the child would require multiple tranfusions over time as an iatrogenic consequence of therapy and the logistics of overriding a resistant patient on multiple occasions may alter the risk-benefit assessment. Obtaining a clinical ethics consultation is advisable for complex or challenging cases. Figure 6.1 is a

proposed model for clinicians evaluating familial refusal of transfusion for a pediatric patient.

If a pediatric patient ultimately requires transfusion, it is important to solicit familial preferences about receiving transfusion-related information and to deliver the transfusion in the most respectful manner. Consider transfusing the child when other visitors who may be Witnesses are not present, covering the blood product with an opaque bag, or transfuse while the child is sleeping if viewing the transfusion will be upsetting.

What Are the Surgeon's and Anesthesiologist's Rights and Obligations in Regard to These Patients?

Some physicians believe that caring for a patient who refuses standard care in the operating room (for example, blood transfusion) puts them in a situation of not being able to fully carry out their professional responsibilities. The American Society of Anesthesiologists has developed Guidelines for the Anesthesia Care of Patients with Do- Not-Resuscitate Orders or Other Directives that Limit Treatment [22]. These guidelines should be applicable to surgeons as well. These guidelines state [22]:

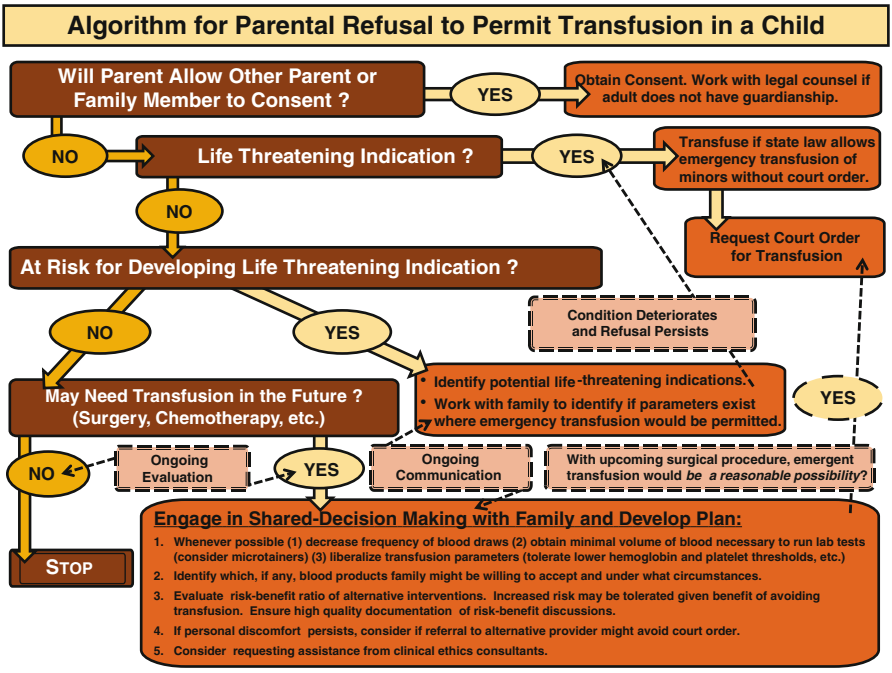

Fig. 6.1 Proposed model for clinicians evaluating familial refusal of transfusion for a pediatric patient

> When an anesthesiologist finds the patient's or surgeon's limitations of intervention decisions to be irreconcilable with one's own moral views, then the anesthesiologist should withdraw in a nonjudgmental fashion, providing an alternative for care in a timely fashion.
>
> If such alternatives are not feasible within the time frame necessary to prevent further morbidity or suffering, then in accordance with the AMA's Principles of Medical Ethics, care should proceed with reasonable adherence to the patient's directives, being mindful of the patient's goals and values.

However, it is important that physicians ensure that by objecting they are not inappropriately applying their own personal moral convictions and beliefs to the physician-patient relationship.

In reality, most ethical dilemmas raised by conscientious refusal can be prevented by forethought, communication, planning and accommodation. However, when push comes to shove, in nonemergent situations, anesthesiologists and surgeons have the right to withdraw themselves from a patient's care, as long as they refer the patient to another health care provider. Not only can the referral be to another physician, but the patient can be referred to another medical center that has expertise in caring for JW patients which may be the best way for these patients to receive optimum care.

If the situation is a life-or-death emergency with no time to make a referral, then the physician is obligated to care for the patient, trying as much as possible to adhere to the patient's and his or her parents' wishes. However, if the physician is concerned that he or she will not be able to comply, then the patient and/or the parents should be so informed.

Of note, these guidelines are similar to the Management of Anaesthesia for Jehovah's Witnesses, published by The Association of Anaesthetists of Great Britain and Ireland in 2005 [23].

Case Resolution

The patient and her mother were active members of their church and were assisted in articulating the grounds for their refusal by a member of the local Jehovah's Witness Hospital Liaison Committee. During a family care conference the surgeon and anesthesiologist shared measures they commonly employ with any patient to reduce the likelihood of transfusion. Furthermore they outlined additional preoperative measures (such as hypervolemic hemodilution) that could be employed to reduce loss of blood cells during surgery. The anesthesiologist led the mother through a checklist of interventions that she would and would not accept for her daughter [24]. The patient and mother made a personal decision to decline whole blood and its components (packed red cells, leukocytes, platelets, and plasma), immune globulin, or

autotransfusion of previously banked blood/blood components. The patient and her family were willing to grant permission for use of a cell saver intraoperatively and albumin or other volume expanders. Case consultation involved the office of legal services and the general counsel was able to draft an acknowledgement statement as outlined above.

In a similar case involving a younger child needing a nephrectomy, the family was unwilling to sign an acknowledgement agreement. In this second case, the hospital pursued a court order seeking permission to transfuse if necessary to preserve life and the request was granted. In the end, both children underwent an uncomplicated nephrectomy and neither child required the use of blood or blood products.

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