The Pregnant Jehovah's Witness

How Nurse Executives Can Assist Staff in Providing Culturally Competent Care

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Case Review

A 28-year-old woman is admitted on her 29th week of pregnancy for acute sickle cell pain crisis. Despite her being severely anemic (Hgb 5.7) and the presence of indications of fetal distress, the patient, who is a Jehovah's Witness, refuses blood transfusions and a C-section. After transfer to the ICU, a 1,410-g baby girl is delivered vaginally, but dies shortly thereafter. The woman also dies the following day after 11 days in the hospital, despite clinicians having tried all alternatives to blood therapy. What could have been done to avoid this tragic outcome? This article will explore the background and alternatives available to providers dealing with patients who refuse transfusions, and will provide information regarding the nurse executive's role in this process.

Background

There are 6,500,000 Jehovah's Witnesses in the world and over 1,000,000 in the United States. They are distributed throughout the states with no particular concentration in any one area. The ethnicity of the witnesses population is diverse, including African Americans, among whom the incidence of sickle cell disease is known to be higher than other ethnic groups. According to their strictly held religious beliefs, Jehovah's Witnesses refuse blood transfusions. All Witnesses refuse whole blood and the 4 major blood components: red blood cells, white blood cells, platelets, and plasma. Acceptance of minor blood fractions such as albumin and cryoprecipitate are up to each individual to decide, although it is not forbidden. Many Jehovah's Witnesses will also allow their blood to be reinfused into them such as with a cell-saver. No blood storage is allowed. A Jehovah's Witness who willingly accepts a blood transfusion and later admits such to their elders would be carefully counseled. The elders would try to determine the reason for the transfusion acceptance. For instance, was it accepted in a moment of spiritual weakness that the person later regrets? If so, the person would be assisted to regain their spirituality. If the person did not express regret over their acceptance of the transfusion, their actions would demonstrate that they no longer wanted to practice their religion. Such a person would no longer be considered a practicing Jehovah's Witness.

In 1991, the United States passed the Federal Patient Self-Determination Act. This law requires that healthcare providers inform patients regarding their right to have their decisions respected by healthcare personnel. Treatment, even if determined by physicians to be life saving, may not be performed on competent patients without their consent. The 2003 American Hospital Association Patient Rights and responsibilities document specifies that patients be involved in their care. Informed choice involves the discussion of the risks and benefits of treatment before any written consent is signed. This process protects the patient's right to consent or refuse treatment. Competent adult patients, such as those who have a religious prohibition against blood transfusions, can be offered a simple document to sign that clearly states their refusal. Once executed, this document releases hospitals and caregivers from liability regarding the blood transfusion refusal. Advance Directives can also be useful in proceeding with the care of patients who have refused blood transfusion because these documents often spell out what blood transfusion alternatives the patient will accept. A Durable Power of Attorney also provides a designated healthcare representative to insure that the patient's blood refusal is upheld. Once this documentation is in place, a dialog should be established between caregivers and the patient. The authors have found that this early dialog is essential in planning ahead for multidisciplinary approach, one that addresses the unique challenges of the blood-refusal patient.

In order to address the unique needs of patients who refuse blood transfusion, some hospitals are developing Bloodless Medicine and Surgery Programs. In the past, when a Jehovah's Witness patient entered a hospital, there was no organized approach to their unique needs. Many hospitals did not have adequate or proper blood-refusal chart documentation. Clinicians were not familiar with blood transfusion alternatives. They were at a loss as to offering treatment options amenable to the patient's religious beliefs. Crisis situations developed and led to adversarial relationships between administrators, clinicians, patients, and their families. Everyone was frustrated. Addressing these and other issues in an organized fashion can prevent the development of
these interpersonal problems. A Bloodless Program provides the framework of legal documentation of treatment of refusal, and a roster of physicians willing to work with the patient's treatment restriction and coordination of care at the inpatient level to insure that all appropriate blood alternatives are made available.

Bloodless Programs are usually run by a nurse who is a strong patient's rights advocate. This individual coordinates everything from prehospitalization anemia treatment to physician referral. The nurse administrator has an important role to play in the development, the primary challenge of which is to identify the needs of the individual institution and marry them to the unique needs of the Witness patient population. After a thorough review of any existing policy and blood refusal forms, the nurse administrator must rework them into a user-friendly format that reflects the attitude of respect for the patient's right to refuse treatment.

The nurse administrator also assumes the role of educator for both clinicians and patients. This means becoming familiar with treatment options that are acceptable to Witness patient and then acting as the primary resource of this information for hospital staff. Re-educating busy physicians can be a formidable challenge. Nevertheless, this is essential because it prepares physicians so that they know what to do when the situations arise. As physicians become familiar with nonblood treatments options, they gain experience and enthusiasm. The nurse administrator can then begin to assemble a roster of physicians from which to make referrals when potential patients call for help in locating a physician who will treat them. The nurse administrator also serves on various hospital committees such as Bioethics and Blood Usage Evaluation. In these roles, he or she can assist in integrating the concept of bloodless medicine throughout the facility.

Rounds are made by the Bloodless Program staff on all patients daily. Attention is given to the clinical, emotional, and spiritual needs. Crisis intervention is another role of the Bloodless Program staff. Usually planning ahead helps to avoid a crisis, but when one happens, the Bloodless Program staff assists patient, family, and other staff in very unique ways, often diffusing difficult situations. Situations involving maternity patients can be especially fraught with emotion on the part of the family and the healthcare providers. Bloodless Program staff can be especially valuable in such high-stakes situations, where 2 patients, the mother and the fetus, are involved.

Discussion

It is understandable that some healthcare providers may feel that the unborn child of a Witness patient should have rights that equal, or even surpass, the mother's right to follow her religious practices and beliefs. Professor George Annas⁴ from Boston University Schools of Medicine and Public Health has stated “Favoring the fetus radically devalues the pregnant woman and treats her like an inert incubator, or a culture medium for the fetus.” A woman who uses illegal drugs, smokes, or abuses alcohol is probably putting her unborn child at risk. But what about the woman who chooses a suboptimal diet, misses prenatal doctor appointments, or decides to deliver her baby at home with a nontraditional practitioner? All of these choices might pose an element of increased risk in some pregnancies. What does society owe these fetuses? Should there be laws against “fetal abuse” or does the pregnant woman still control her body?

Taking a look at some court cases that have been decided, may argue in favor of the bodily self-determination of the pregnant woman. For example, in the case of In re Baby Boy Doe, an Appellate Court in Illinois affirmed a trial court ruling and held that a competent woman in the 36th week of her pregnancy should not have been compelled to submit to a cesarean section for religious reasons. The appellate observed that “the right to withhold consent and refuse treatment does not depend upon whether the treatment is perceived as risky or beneficial to the individual.” (1994) 632 N.E. 2nd 326 at 330. The Court noted that:

A woman's right to refuse invasive medical treatment derived from her rights to privacy, bodily integrity, and religious liberty, is not diminished during pregnancy. The woman retains the same right to refuse invasive treatment, even if lifesaving potential impact upon the fetus is not legally relevant ... A woman ... cannot be compelled to do or not do anything merely for the benefit of her unborn child. Id. at 332.

Accordingly, the Doe court held that a woman's competent choice to refuse treatment during pregnancy must be honored "even in circumstances where the choice may be harmful to her fetus." Id. at 326 (see also, the case of in re A.C.)⁵

In the case study cited here, that of a Jehovah's Witness refusing blood transfusion while pregnant, the choice of treatment by the mother is based on her strongly held religious conviction. From the mother's perspective, this is not abuse or even neglect, as evidenced by the fact that she sought out medical care. Is it fair to call all such refusals of care neglect, especially when it involves
refusal of only some elements of care, but not all? The debate over choice of care in this case is further heightened by the sickle cell aspect of her health issues which made this a complicated pregnancy. However, once identified as such, could healthcare providers have offered alternatives to blood transfusions if they had known early in the pregnancy? If high-risk management was employed, might the outcome have been better?

Perhaps this agonizing dilemma could have been resolved, or at least eased somewhat by better communication. The responsibility for good communication lies both with the patient and the physician. The physician should provide an environment that makes the patient feel comfortable. This is especially so in the presence of what Jehovah’s Witness patients know about the past. Before the Patient Self-Determination Act, it was routine for Jehovah's Witness patients to be disrespected, coerced, overruled, or even denied basic care. The media would get wind when a controversy was playing out and further the controversy by publicizing the case throughout the community. Therefore, many Jehovah’s Witness patients have a deeply held distrust of the medical establishment. In spite of whatever mistrust the Jehovah’s Witness patient has, they need to realize that unless they bring up the subject of blood refusal, the physician cannot be expected to know. It is the responsibility of the Jehovah’s Witness patient to clearly identify themselves as a blood-refusal patient at the very beginning. If this is not communicated to the caregivers, the caregivers have no opportunity to plan interventions with the blood refusal in mind. Most actively practicing Jehovah's Witnesses carry a “mini” Advance Directive in their wallet. This wallet card, if properly signed and witnessed, is a legal document. Unfortunately, these documents are not always utilized by patients; but, when they are, they provide a useful framework upon which to build a successful proactive nonblood plan of care. If patients present without this document, caregivers can refer them back to their congregation elders for assistance.

Physicians who know about the patient’s religious belief against blood transfusion at the onset of care have the opportunity to plan the care with this prohibition in mind. What alternative treatment could be offered? Because a woman who is pregnant and has sickle cell disease will have more frequent crises, she needs both a high-risk perinatologist and a hematologist. In this case, did the original obstetrician make such a referral? There are no published court cases involving lawsuits of Jehovah's Witnesses or their families against practitioners who respected the patient’s documented blood refusal. The risk such patients willingly take is the possibility of a bad outcome, which is clearly stated when the patient signs a Release From Liability Form. On the other hand, Jehovah’s Witness patients have successfully sued those who transfused them against their will.

The case presented here illustrates the difficulties encountered by clinicians when patients’ right to refuse treatment results in a bad outcome. The Patient Self-Determination Act addresses the treatment of pediatric patients. For those pediatric patients whose parents refuse to consent to life-saving treatment, hospitals must report the situation to child welfare authorities. Those agencies are obligated to provide administrative consent under the Parens Patriae principle. What that means is that the state is obligated to act on behalf of minors to protect them from harm. The murky area is pregnancy. Whose rights prevail: mother or fetus? In fact, does a fetus have rights?

What about in practice? Improvements need to continue in the area of communication. Where does the responsibility lie for communicating vital information that impacts treatment choices, such as in the case of the pregnant Jehovah's Witness refusing blood transfusion? This is a 2-way street, but the facilitator should be the clinician. The clinician needs to provide a supportive and trusting environment for that patient. how far do clinicians go in providing patients alternative care? Nonblood management is becoming more and more sophisticated and less and less difficult.

**Implications for Nurse Administrators/Managers**

If a hospital does not have a Bloodless Medicine and Surgery Program, what steps can be taken by nurse administrators and managers? Reaching out to the Jehovah’s Witness community is the first step. The Witnesses have specially trained elders referred to as the Hospital Liaison Committee. These individuals can be called 24 hours/7 days a week for crisis intervention. Phone numbers are listed in the phone book usually under headings for Jehovah's Witnesses or Kingdom Hall. These elders make themselves available for emergencies arising with hospitalized patients. They can diffuse situations acting as a liaison between the patient and the staff. They also act as a helpful resource in that they have access to an international service provided by the Witness’ headquarters known as the Hospital Information Services Department. A huge repository of medical articles on nonblood treatment options will be faxed immediately to any facility to assist clinicians in treatment planning. Once these steps are taken, frustration of the staff can be relieved because the staff has options that can be tried. Also, staff should be offered spiritual counseling through the hospital pastoral care department for help in dealing with their own feelings, should this be indicated.
An important part of this process is ongoing staff education. Jehovah's Witness representatives give lectures regarding their beliefs relative to medical care. Physicians and experts in the medical-legal field are available as well. Regularly scheduled staff education that addresses these topics offers clinicians opportunities to expand their knowledge base on clinical as well as ethical and legal issues.

**Conclusion**

Awareness of the options available in caring for patients who refuse blood products can greatly assist the nurse manager and nurse executive in dealing proactively with the patients. By taking a proactive approach, the nurse in a supervisory position can assist her nursing staff to deal with these patients in a professional and respectful manner, while maintaining high standards for patient safety.

**Sidebar**

**Belief's of Jehovah's Witness**

Jehovah's Witnesses believe that the entire Bible is the inspired word of God (2 timothy 3:16,17). All their doctrine is thoroughly referenced in Scripture. Respect for life as a gift from God is a strongly held tenet. According to Genesis 9:3-6, blood represents the life of the person or animal. Animals that are to serve as food are to be properly bled prior to consumption (Deuteronomy 12:23-25). This principle can also be found at Acts 15:22-29. Jehovah's Witnesses believe that the only proper use of blood is the sacrificial shed blood of Jesus (Revelation 1:5).

**Biblical References to Blood Prohibition**

- **Genesis 9:3 and 4** "Every moving animal that is alive may serve as food for you ... Only flesh with its soul–its blood you must not eat."
- **Leviticus 7:26** "You must not eat blood."
- **Acts 16:29** "Keep abstaining from blood."

**What is a Bloodless Medicine and Surgery Program?**

A Bloodless Medicine and Surgery Program is a hospital-wide service that formally addresses the legal, clinical, and cultural aspects connected with patients who refuse blood transfusions. Approximately 100 such programs exist in the United States. Patients who refuse transfusions are offered a user-friendly chart documentation system for them to sign. These forms release the hospital and caregivers from liability connected to the patient's blood refusal. The patient is identified by a special no-blood wristband, chart label, and bedside sign. There is a systematic multidisciplinary approach to planning the care of the patient utilizing whatever modalities are appropriate based on the diagnosis. Patients enrolled in the program are monitored daily. Bloodless Program nurses make daily rounds, check laboratories, and assist in case management for the patients. Patients frequently comment that they feel that this attention to the unique aspects of their care contributes to less anxiety. they know that the institution is addressing their specific cultural needs in a truly patient-centered fashion. Outcomes are generally improved because this attention to detail provides a proactive approach.

**Sickle Cell Anemia**

Sickle cell anemia is a chronic, incurable, hemoglobinopathic anemic condition. Patients with this condition produce abnormal erythrocytes characterized by a distorted (sickle) shape and fragility. Sickle cell crisis occurs as an acute episodic condition when the misshapen erythrocytes aggregate and occlude blood vessels. A crisis can be primarily pain, infection, or chest syndrome. The type of crisis is defined by the symptoms. Treatment varies depending on the severity of symptoms and the type of crisis. Hydration, bed rest, and analgesia may be adequate for a moderate pain crisis. Antibiotics are used if there is an accompanying pneumonia. Frequently, there is also a rapid drop hemoglobin. The results can be acute pain, respiratory distress, and increased susceptibility to infection. Transfusions of packed red blood cells are given in cases of more severe anemia to relieve symptoms, treat complications, and prevent complications. Jehovah's Witness patients accept all treatments except transfusions. The use of erythropoietin (r-HuEPO) has not shown promise because the bone marrow of the sickle cell patient will simply produce more of the
misshapen cells. In 1995, a study conducted by the National Heart, Lung and Blood Institute showed that daily doses of the anticancer drug hydroxyurea reduced the frequency of pain and chest crises in sickle cell patients. Currently, the use of hydroxyurea combined with r-HuEPO as treatment for pregnant sickle cell patients shows some promise, but further studies are required.²

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References

8. In re A.C., 573 A.2d 1235. 1244(D.C. 1990) (“fetus cannot have rights...superior to those of a person who has already been born”; “in virtually all cases the question of what is to be done is to be decided by the patient—the pregnant woman—on behalf of herself and the fetus”).