A Call for Universality of Blood Availability

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Abstract

Deaths due to refusal of blood products, particularly in the Jehovah’s Witness population, is a critical but under-recognized issue. There are less than 10 million JW worldwide, with 1.2 million in US. They are highly vulnerable population, with only 9% having an undergraduate college education, and their religion prohibits blood products in varying degrees. There are several media and medical journal reports of deaths among JW patients from massive hemorrhage, after delivery, motor vehicle accidents, surgical procedures, and trauma. Our goal is not to challenge the religious beliefs of the JW community, but to raise awareness of the potentially preventable deaths due to acute blood loss anemia in those who decline blood products. We are calling for proactive and preemptive management, appropriate leveraging of EMR tools for early identification, and accelerated research into hemoglobin- based oxygen carriers. These deaths should be preventable in the modern day medical landscape and healthcare personnel should be aware of these tools for pre-emptive management of those who decline blood products but are being scheduled for elective surgical procedures.

“I don’t want blood but I don’t want to die. Make sure they do a good job”

The last few words of a 46-year old man as he was being wheeled into the interventional radiology suite for an emergency procedure to stem his severe iatrogenic retroperitoneal bleeding continue to echo in our ears. Stopping the devastating bleed was not enough to prevent his untimely demise. He needed blood products until the erythropoietic stimulating agents and intravenous iron could get to work. He was a Jehovah’s Witness (JW) and had declined all blood products based on his religious beliefs.

While patients may decline blood products for various personal reasons, those with religious objections remain steadfast about not receiving blood products in a life or death situation. Of all the religions, patients who are of JW affiliation are the ones most likely to refuse blood products. Adherents believe that the Bible unequivocally advocates abstaining from blood, based on the view that God views blood as representing life. Therefore, they avoid taking blood in obedience to God [1]. A 2022 report documented there are 8,699,048 JW worldwide, with 1.2 million members in the US [2]. A Pew Research Center article states that they constituted 0.8% of the US population in 2014. The religion has a diverse ethnic background – 36% white, 32% Hispanic, 27% Black, and 6% mixed race [3]. Compared to other religions, JW has the lowest educational level, with only 9% having an undergraduate degree.

JW cite as myth the statement that many Witnesses, including children, die each year because of refusing blood transfusion. A review of current literature offers a more sobering assessment. A retrospective study by Carson et al in 2014 [4] of 300 patients who refused blood transfusions noted that for every 1 g/dL decrease in Hb below 8 g/dL, the odds of death increased 2.5 fold. A 2014 single center study of 293 JW patients who declined blood transfusion revealed an overall mortality rate of 8.2%, with a twofold increased risk of death per each 1 g/dL decrease in nadir Hb (unadjusted odds ratio [OR], 1.04; 95% confidence interval [CI], 1.52-2.74; adjusted OR, 1.82; 95% CI, 1.27-2.59) [5]. A retrospective cohort study by Moon and colleagues in 2018 [6] assessed the effect of severe acute blood loss anemia (nadir hematocrit <21%) on postoperative outcomes. Among 48 JW patients who underwent cardiac surgery, 9 (18.8%) developed...
postoperative severe ABLA, and 39 (81.3%) did not. All deaths were in JWs who developed severe ABLA. There were two deaths in the severe ABLA group (22.2%) compared to zero deaths in the non-severe ABLA group at 30 days postoperatively (p = 0.032). Four deaths occurred in the severe ABLA group (44.4%) c to zero deaths in the non-severe ABLA group at 90-days and at 1-year postoperatively (p < 0.001). In addition, there are several media reports of women dying after childbirth, or people dying after accidents because of their decision to decline blood products.

It is our steadfast belief that it is ethically unconscionable to accept the deaths of JW patients who refuse blood products as an “expected” consequence of their religious beliefs. Even one preventable death is one too many. Hospital systems and providers must take a pre-emptive approach to patients who decline blood products. Prior to any elective procedure, JW patients should be educated about absolute risks and benefits, including risk of death due to bleeding in the absence of blood products. Electronic medical records (EMR) should identify those who refuse blood products at the point of contact with the healthcare system and all healthcare personnel who interact with the patient should be aware of the patient’s wishes regarding blood products. This will allow the physician to make critical decisions such as deciding whether to proceed with an elective procedure that could potentially have serious bleeding complications or take extra precautions before and after to minimize bleeding risk. Order sets and algorithms for earlier initiation of erythropoietin and intravenous iron should be implemented so that these agents can be used preemptively for those patients who will not accept blood products. It should also be noted that JW or any other patient have the right to reverse their decision at any point and also have the right to select what blood product they are willing to receive. All of these preferences should be clearly documented in the EMR to ensure timely treatment during emergencies.

In addition, JW and other patients who refuse blood products should be offered and treated with a full complement of red blood cell alternatives [7,8], including treatment with cryoprecipitate, iron supplementation, vitamin K, factor concentrates, and recombinant erythropoietin. Operative considerations should include autologous transfusion with a cell salvage device and acute normovolemic hemodilution. Although not currently approved by the Food and Drug Administration, the new generation of hepcidin inhibitors [9,10] and Hb-based oxygen carriers [11] (HBOCs) may be obtained for compassionate use after institutional board review. The advent of such promising therapies as HBOCs to manage trauma-associated uncontrolled hemorrhage and acute coagulopathy may provide new hope for JW patients who are at risk of severe, life-threatening hemorrhage after trauma and surgical interventions.

“I don’t want blood but I don’t want to die.” Healthcare providers who witness these deaths feel helpless and struggle to cope with the grief over the preventable loss of life. The dichotomy of refusing blood products in a life-threatening situation and wanting to survive is extremely difficult to grasp for medical professionals who have taken an oath to protect and save human life. Medical care have advanced leaps and bounds in the past 5 decades, primarily in areas with the largest impact and those with a vocal advocacy. The deaths of the JW rarely come into spotlight due to the low numbers and because of lack of advocacy for this vulnerable group. These deaths are often deemed as expected deaths due to the refusal of blood products. The medical and scientific community have a moral imperative to tackle this problem and improve the care of this forgotten few.

References