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Attempting to Honor Beliefs of Jehovah's Witnesses at the Edge of Viability in an Infant Born at 23 Weeks' Gestational Age

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Study Design A
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Data Interpretation D
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Patient: **Male, 23 weeks' gestational age newborn**
Final Diagnosis: **23 weeks' extreme prematurity • intraventricular hemorrhage • anemia • respiratory distress syndrome**
Symptoms: **Hypotension • metabolic acidosis • tachycardia**
Medication: —
Clinical Procedure: **Transfusion of packed red blood cells**
Specialty: **Pediatrics and Neonatology**





Objective: **Rare disease**
Background: Infants born at 23 weeks' gestation have a poor prognosis and require intensive care, including blood transfusions, to survive. Generally speaking, the decision to forgo life support is acceptable. Jehovah's Witnesses believe that life is sacred and want lifesaving interventions except for blood transfusions. Therefore, an ethical dilemma exists when a baby is born on the edge of viability to parents that are Jehovah's Witnesses. In this case, if parents and healthcare professionals disagree on the best interests of the child, the medical team should obtain a court order from the state to intervene.

Case Report: We present the case of an infant born at 23 weeks' gestation to parents who are Jehovah's Witnesses. The parents wanted full life-support, except for blood transfusions, to be given. The clinical team obtained a court order to transfuse the infant. The infant unfortunately died despite all efforts.

Conclusions: Currently, it is nearly impossible to honor the beliefs of Jehovah's Witnesses to provide lifesaving treatments without blood transfusions for infants born at the border of viability. If the goal is to prolong life, the standard of care for a premature infant is for a doctor to obtain a court order to override the beliefs and wishes of Jehovah's Witness parents and transfuse blood products as medically indicated. Although bloodless techniques for high-risk surgeries are under development, care for premature infants at 23 weeks' gestation necessitates red cell transfusions.

MeSH Keywords: **Blood Transfusion • Infant, Newborn • Jehovah's Witnesses • Judicial Role • Premature Birth**

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Background

We report the case of an infant born prematurely at 23 weeks' gestation to parents who are Jehovah's Witnesses. At this gestational age, prognosis is poor and blood transfusions are required for survival. For infants born at 22–24 weeks' gestation, there is wide variation between institutions and practitioners in obstetric and neonatal practice, including whether to begin resuscitation for the infants [1]. Using the Neonatal Research Network Extremely Preterm Birth Outcome Data, outcomes for a 23 weeks' gestational age 580-gram male infant with antenatal steroid exposure were 37% overall survival and 22% survival without profound neurodevelopmental impairment [2]. Profound neurodevelopmental impairment was defined as having the lowest possible score, which is 2 standard deviations from the mean, on the standard screening tool for developmental delay (Bayley Scales of Infant Development II) or the inability to sit, stand, or walk independently (Level 5 Gross Motor Function Classification System) [2–4].

The parents, despite the poor prognosis, stated that they wanted full life-support given except for blood transfusions. This raised an ethical dilemma for the clinical team, in that life support is futile without blood transfusions.

Case Report

A primiparous pregnant woman presented to a community hospital at 21 2/7 weeks' gestation with rupture of membranes. At 23 weeks' gestation the woman was transferred to the regional hospital and given antenatal steroids because she wanted full intervention for her now viable fetus. The woman and her husband are both Jehovah's Witnesses. We discussed prior to delivery the likely poor prognosis and the certain need for blood transfusions for a 23 weeks' gestational age baby. The parents said they wanted full intensive care given when their baby was born, but they would not consent to any blood transfusions. On hospital day 2, the mother developed abdominal pain and tachycardia. She was diagnosed with chorioamnionitis and the decision was made to induce labor. The baby was born at 23 2/7 weeks' gestational age with a birthweight of 580 grams. The infant required intubation and surfactant at delivery and needed mechanical ventilation on admission to the neonatal intensive care unit.

The initial hemoglobin was 8 g/dL, with a hematocrit of 24%. A conference was held with the parents to discuss the need for blood transfusions and that staff would obtain a court order to transfuse blood. A court order was obtained and erythropoietin was started on the first day of life. The medical team agreed to minimize blood draws and tried to postpone giving a blood transfusion because the infant had reasonable stability. In the middle of the night on the third day of life, however, the baby became tachycardic and hypotensive, requiring a dopamine drip, with

worsening metabolic acidosis. His hemoglobin was checked and dropped to 6.6 g/dL. The decision was made to give a packed red blood cell transfusion. In response, the parents stated they would rather stop intensive care than allow the transfusion. The father asked what would happen, "if I unhooked the baby from life-support myself?" The team told the parents discontinuing intensive care instead of providing packed red cells was not an option.

Over the course of the next 10 days, the baby received a total of 5 packed red blood cell transfusions: 1 fresh frozen plasma transfusion and 1 platelet transfusion. The baby subsequently developed a left grade IV intraventricular hemorrhage (IVH) and a right grade III IVH complicated by post-hemorrhagic hydrocephalus. An ethics consult was obtained and the hospital Ethics Committee determined that it was permissible to withdraw life-sustaining treatment because of the infant's grave prognosis. The infant was compassionately extubated and died within minutes.

Discussion

If the parents in this case had not been Jehovah's Witnesses, the 2 decision points would have been: whether to resuscitate at 23 weeks' gestation, and whether to continue intensive care if the infant's prognosis worsened. The standard of care in our institution is to recommend comfort care and discourage resuscitation below 23 weeks' gestation and to encourage resuscitation above 24 weeks' gestation. At 23–24 weeks' gestation, we educate parents about the possible neonatal outcomes and work with parents to decide whether to resuscitate or allow natural death at the time of birth. Our institution's survival statistics between 2007 and 2011 for 23 weeks' gestation and 500–600 grams were 50% and 56%, respectively.

After initiating intensive care, if we diagnose a significant IVH (parenchymal hemorrhage) [5], our standard of care is to educate parents and support their wishes for comfort care if desired. Severe IVH increases the risk for a poor neurodevelopmental outcome [6]. Furthermore, parenchymal hemorrhage requiring intraventricular shunt placement and development of posthemorrhagic hydrocephalus significantly decreases scores on the Bayley Scales of Infant Development [7]. When significant IVH occurs, it is common practice to offer comfort care if life-sustaining treatment is no longer wanted. Prematurity, intubation after birth, need for mechanical ventilation, and acidosis are all risk factors to leading to IVH [7]. The profound anemia in this case likely played a role in the infant's worsening metabolic acidosis. However, because the baby had other risk factors for IVH, it is unclear how much his anemia contributed to his severe IVH.

Our institution's standard in the first week of life is to transfuse packed red blood cells if a very low birth weight infant's hemoglobin drops below 12 g/dL. Multiple studies have tried

to determine transfusion thresholds for premature infants to minimize blood product exposure as well as neonatal morbidity and mortality [8,9]. A Cochrane review of these studies concluded that “restrictive practice does not appear to have a significant impact on death or major morbidities at first hospital discharge or at follow-up. However, given the uncertainties of these conclusions, it would be prudent to avoid haemoglobin [sic] levels below the lower limits tested here [i.e., hemoglobin 11 g/dL] [10].” Below these studied threshold limits, there is potential risk of worsening blood pressure, oxygenation, metabolic acidosis, intracranial hemorrhage, and death [11]. In our case, the infant's hemoglobin of 6.6 g/dL clearly met criteria for blood transfusion. In fact, he met criteria for blood transfusion immediately after birth, with a hemoglobin of 8 g/dL. We believe that the level of parental distress may have influenced the medical team's ability to decide to transfuse this infant initially until it became clear that he needed blood.

Unfortunately, there are few alternatives to red blood cell transfusion for premature infants. Several studies associate delayed cord clamping with reduced need for blood transfusion and decreased incidence of intracranial hemorrhage in preterm infants [12,13]. When the infant in our case was born, we did not have a policy of delayed cord clamping or umbilical cord milking in place. Based on the infant's initial hemoglobin level, we suspect there may have been placental abruption in addition to immediate cord clamping. Erythropoietin is generally restricted to prevent late anemia of hemolytic disease of Jehovah's Witness newborns and families because of the limited benefits and possible increased risk of retinopathy of prematurity [14]. Routine use of erythropoietin is currently not recommended. Studies using artificial blood are ongoing in adults, but a recent meta-analysis of 16 trials involving 5 different artificial blood products and 3711 adult patients found a statistically significant increase in the risk of death and myocardial infarction [15].

We obtained a court order granting custody to the probation service, who gave consent for a transfusion. Compared to adults, who have the right to make decisions regarding their medical care [16], minors do not have the same autonomy. In routine cases, parental consent is generally required for medical treatment of minor children [17]. However, a dilemma arises if the parents are making a decision that is incongruent with the best interest of the child. The United States Supreme Court in the case of *Prince vs. Commonwealth of Massachusetts* 1944 ruled that there exists “an interest of society to protect the welfare of children” and that “parents may be free to make martyrs of themselves” but they are not free to make martyrs of their children [16]. Therefore, the health professional should seek consent from the state except in the case of an emergency when time is of the essence [18]. The exact age at which children can make decisions for themselves is determined in individual cases. Their legal competence is determined by their

ability to understand the pros and cons of a treatment, the other options and their implications, and their ability to weigh the choices [19].

There are nearly one million Jehovah's Witnesses in the United States and more than five million worldwide [19]. Founded in 1870, the group took the name ‘Jehovah's Witnesses’ in 1931. The Watchtower Bible and Tract Society (WBTS) in 1945, the overseeing body of Jehovah's Witnesses, determined that accepting blood and blood products for medical purposes directly violated the teachings of the Bible. This determination focuses primarily on 3 Bible passages (Genesis 9: 3–4; Leviticus 17: 10–14; and Acts 15: 21–29), which forbid the ingestion of blood because it would compromise a believer's chances for everlasting life [20]. Since 1961, the Watchtower Bible and Tract Society has published a policy whereby Jehovah's Witnesses must shun fellow believers who consciously accepted a blood transfusion [19].

Several case reports describe decision-making dilemmas for minors with Jehovah's Witness parents [16,21–23]. In all cases, the minors were younger than 17 years old and the courts ruled in favor of giving a blood transfusion when medically necessary. A few cases of premature Jehovah's Witness infants have been published [24–26]. In one, the medical team obtained a court order for a 24 weeks' gestational age premature infant who required 8 transfusions with a lowest hemoglobin level of 11 g/dL [26]. In another, a 31 weeks' gestational age premature infant born with a hemoglobin of 15.2 g/dL and treated with erythropoietin never required a blood transfusion, with a lowest hemoglobin level of 8.3 g/dL [24].

The Jehovah's Witness population has encouraged development of techniques with a goal of bloodless surgery for neonates undergoing cardiopulmonary bypass surgery. In term Jehovah's Witness neonates and small children, case reports of transfusion-free surgeries with cardiopulmonary bypass have been reported, including a 3.55-kg neonate with correction of tetralogy of Fallot with absent pulmonary valve and aneurysm of the left pulmonary artery (lowest hemoglobin 8.5 g/dL) and a 3.5-kg infant who received an arterial switch operation for dextro-transposition of the great arteries (lowest hemoglobin 7.2 g/dL) [27–31]. But in most retrospective studies of bloodless surgeries with cardiopulmonary bypass, infants less than 5–6 kg received blood or blood products during their hospitalization or were excluded from the protocols [30,32]. Authors report that lower weight, younger age, and higher risk-adjusted in-hospital mortality scores independently correlate with increased morbidity and mortality regardless of the incidence of blood product transfusion [32]. This suggests that accepting a lower hemoglobin level as a transfusion threshold may be possible but needs further investigation.

Our case may have been different if the parents wanted to forgo all life-sustaining therapy, including blood transfusions. They

could have chosen comfort care at birth or when the baby's condition began to deteriorate after initiation of intensive care, because of the overall prognosis at 23 weeks' gestational age. The difference is that because of their religion, the family wanted life-sustaining intensive care except for blood transfusions [25]. The problem our healthcare team faced was that initiating intensive life-support for a 23 weeks' gestational age infant without the ability to give blood transfusions was likely to be futile. Given the parents' goals of care to prolong life, and lack of alternative therapies for anemia in prematurity, the medical team needed to ask the court to appoint a guardian with the authority to consent to a transfusion over the parents' objections. As we look at this case retrospectively, we wonder whether transfusing the infant immediately at birth would have changed the outcome.

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Conclusions

Given the current state of premature infant care, it is nearly impossible to honor the beliefs of Jehovah's Witnesses to provide lifesaving treatments without blood transfusions for infants born at the border of viability. Parental and health care provider distress may be inevitable but could be minimized with early, clear, and consistent communication.

Conflict of interest

The authors declare no conflict of interest.