Using a Shared Decision-Making Model: Navigating Parents' and Patients' Refusal of Blood Products

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ABSTRACT

Religious-based refusals of transfusion of blood products have traditionally been a source of clinical conflict, particularly in pediatrics, where parents and clinicians share a fiduciary duty to the young patient but have differing views of what is in the child's best interest, for example, protection from eternal spiritual harms or protection against life-threatening anemia. While legal precedent is fairly straightforward in truly emergent situations—clinicians should act to save a child's life—it is less clear how to approach the foreseeable but unpredictable iatrogenic need for transfusion of blood products.

Shared decision making (SDM) is widely accepted as the gold standard in Western medical decision making, but hasn't conventionally been applied to such cases. Furthermore, nuances and complexity arise in the care of pediatric, especially adolescent, patients. We apply a pediatric SDM process with additional considerations for adolescents to the case of a young Jehovah's Witness, who sought to undergo autologous bone marrow transplantation with a high likelihood of needing the transfusion of blood products.

INTRODUCTION

Within Western medical practice, it is widely accepted that adults with decision-making capacity have the right to refuse any treatment for any reason. However, in pediatrics, decision making can potentially involve

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a triad of stakeholders—parents, patient, and careprovider—unless the patient has been designated a mature minor with the power to make autonomous decisions.[1] Parents generally have wide latitude in medical decision making for their children because they are most likely to know what is best for their children (because they know their children well and they have the right to pass on their values to their children) and they are responsible for bringing children to medical therapies and delivering care, such as medications, at home. However, parents' latitude is limited because their authority is rooted in, and dependent on, fulfilling their parental duty to care for their child.[2] Physicians have a fiduciary duty to promote a child's health and well-being, and even to intervene when parental decision making places a child at risk of serious harm. To add to the complexity, older children and adolescents develop autonomy as they mature cognitively and emotionally, and should therefore also be involved in medical decision making.[3]

Although the rights of parents and the duties of physicians are sometimes seen as opposing and balancing forces, SDM has emerged as a collaborative process in which parents (with and without pediatric patients) and clinicians make healthcare decisions together, based on the patient's and family's values, goals, and preferences, as well as the best scientific evidence.[4] While there is no unified definition or approach to SDM, there are well-considered models that can guide individual practice.[5] We will use a case study to demonstrate how the principles of SDM may be applied in a circumstance that has historically been viewed as conflictual—refused blood transfusion for a minor, based on religious beliefs.

CASE VIGNETTE

"Maria" is a 15-year-old young Hispanic woman and practicing Jehovah's Witness who was referred to a tertiary children's hospital for further management of relapsed/refractory classical nodular sclerosing Hodgkin lymphoma. She achieved a very good partial response to a combination of chemotherapy and immunotherapy, at which point the medical team recommended proceeding to an autologous hematopoietic cell transplantation (AutoBMT) for the greatest likelihood of cure. Pancytopenia is an expected side-effect of AutoBMT, and patients regularly require transfusions of packed red blood cells and platelets to prevent life-threatening anemia and hemorrhagic complications. Maria and her mother wanted to pursue the recommended AutoBMT, but stated they would not consent to transfusion under any circumstance. A review of institutional experience confirmed that all children who had this type of AutoBMT received at least one transfusion, and a literature search yielded no case reports of a bloodless AutoBMT in pediatrics, although examples in adults do exist. The clinical team requested an ethics consultation to help advise further decision making.

TRADITIONAL MANAGEMENT OF REFUSED TRANSFUSION

In pediatrics, conflict occasionally occurs when a child's parent or legal guardian refuses to consent to the potential transfusion of blood or blood products. Opposition to transfusion is more common among individuals whose religious affiliation is identified as Jehovah's Witness. Established in the 1870s by C.T. Russell initially as a Bible Study Movement, Jehovah's Witness (JW) is a growing religious organization now with more than 8.5 million Jehovah's Witnesses worldwide.[6] The church's ban on blood transfusion did not occur until 1945. The prohibition is based on interpretation of several biblical passages, including Genesis 9:3-4, Leviticus 17:10-12, and Acts 15:28-29.[7]

A common misconception is that JWs universally refuse all blood products. However, there exists a diversity in individual beliefs among practicing JWs regarding which blood products are acceptable, particularly those labeled by the church under "personal decision." Therefore, physicians should always ask families what products and treatments are acceptable to them.[8]

If parents decline therapies that physicians deem necessary to protect a child's life and well-being, state intervention is needed to adjudicate whether the physicians' assessment of medical necessity should outweigh parental authority. Rooted in English Common Law, the legal doctrine of *parens patriae* governs that the state has the power and authority to protect persons who lack the capacity to act on their own behalf, which, in the United States, commonly includes children, the mentally ill, or anyone found legally incompetent.[9] Another legal precedent for state intervention was established under *Prince v. Massachusetts,* in which the U.S. Supreme Court ruled that parental authority is not limitless and could be restricted if doing so was in the interest of a child's welfare. It famously wrote, "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."[10] Although this case did not involve medical decision making, the legal precedent outlined by the Court has been widely applied to parental refusals in the context of medical care.

Depending on regional variation and other contextual features, physicians may ask the state to intervene when a parent declines a blood transfusion for their child, either via a report to Child Protective Services or petition for a court order. Additionally, most states allow for the transfusion of pediatric patients in the event of a medical emergency when those routes are impractical (that is, acute trauma resulting in hypovolemic shock and acute resuscitation in the emergency department). However, many refused transfusions occur under less emergent medical circumstances, when the need for transfusion may be anticipated in advance, as in the case vignette above. Determining the "right" course of action may be particularly challenging when a child's potential need for a transfusion of blood products will be iatrogenic; for example, a surgical procedure with a high likelihood of blood loss or administration of myelosuppressive medications (for example, chemotherapy, hematopoietic cell transplantation, et cetera). In these cases, providers may struggle to balance respect for parental decision making in authorizing the recommended therapy with protection of the welfare of the child if the child needs a transfusion.

Physicians also have a fiduciary duty to promote a child's health and well-being, and even to intervene when parental decision making places a child at risk of serious harm.

Shared Decision Making

In contrast to the conflictual model described above, we propose that SDM can be a useful tool in this case. Although there are many models of SDM, we have found Opel's four-step framework for SDM in pediatrics to be a clinically useful tool when evaluating parental refusals of recommended blood products.[11] Briefly, the four steps are:

1. Determine if more than one medically reasonable option exists. Only in those instances when there is more than one medically reasonable option to choose between is there a decision to be shared. If a family declines all medically reasonable options, then the harm principle should help guide further action.[12] One consideration in determining what the medically reasonable option or options are, or whether state intervention should be sought according to the harm principle, is how likely the intervention is to bring about the desired result.

Those options with less likelihood of success are less compelling.[13]

2. Determine whether one option has a more favorable medical benefit-to-burden ratio compared with the other option or options. If one option is more favorable medically, this indicates that SDM should be guided to a greater extent by physicians. When all of the options are equally favorable, SDM that is more guided by the parents is in order.

3. Determine how preference-sensitive the options are to the parents. Physicians should help parents articulate their values, goals, and preferences, and how strongly they hold these preferences. How preference-sensitive the options are will determine how strongly or weakly the SDM should be guided by physicians or parents. If one medically reasonable treatment option has a superior benefit/burden ratio (as in step 2), and the choice is not preference-sensitive to the family (as in step 3), decisions can be more strongly guided by physicians. However, if the choice is preference-sensitive to the family (as in step 3), decisions should be weakly guided by physicians with significant family input. When all medically reasonable treatment options have roughly equal benefit/burden ratios (as in step 2), and the choice is highly preference-sensitive to the family (step 3), this should be a strongly parent-guided decision. However, if the choice is not strongly preference-sensitive to the family (step 3), it can be weakly guided by the family with more input from physicians.

Physicians should help parents articulate their values, goals, and preferences, and how strongly they hold these preferences.

4. Calibrate the SDM approach. Factors beyond preference-sensitivity also may influence the calibration of the SDM approach, such as the urgency of the decision, whether the treatment is onetime or ongoing, and whether the parent or physician will implement the treatment.

Adolescent Decision Making

Opel's framework applies most clearly to young patients who lack the capacity to be involved in complex medical decision making. For adolescents, this framework is still useful, albeit with a more nuanced approach that incorporates the patient's viewpoints and desire to be involved in the decision.

A scientifically based understanding of the adolescent brain and the patient's emerging and relational autonomy can help physicians tailor their approach.[14] Teams should assess adolescents' cognitive decision-making capacity, including the traditional elements of whether patients (1) understand the information related to the decision, (2) appreciate how the situation and consequences of the decision affect their life, (3) have the ability to reason to a decision, and (4) have the ability to make and communicate a choice. Moreover, care teams should consider adolescents' socioemotional maturity when there is a highly emotional decision to be made. Does the adolescent face a high-stakes, discordant, short-term decision, or a decision with long-term consequences? Pressure from parents, peers, or spiritual community may overpower the cognitive reasoning of a less mature teen. Adolescents and parents may also vary in their interest or style of sharing decisions within their family.

Furthermore, the team might consider the wide variety of judicial rulings related to whether an adolescent should or shouldn't be compelled to undergo medical therapy against their wishes.[15] This should not deter medical teams from taking up what they determine to be the right course of action; rather, it should prepare them for the unexpected when a court's intervention is sought.

SDM in Maria's Case

The medical team found Maria's case challenging. Both the team and her family wanted to proceed with AutoBMT to provide the best chance of long-term cure, but with the knowledge that it would almost certainly put her in a position to need a transfusion that she and her family would not assent nor consent to.

Step 1. On first meeting Maria, her lymphoma and bone marrow transplant (BMT) physicians considered two medically reasonable options for her cancer treatment: AutoBMT with standard protocols, or continuation of immunotherapy.

Step 2. The teams weighed the options and recommended AutoBMT with standard protocols, as this offered the most favorable benefit/burden ratio, including a higher likelihood of a durable cure of Maria's cancer. However, it would require that Maria and her family accept the risk of potentially receiving transfusions. Due to limited data and the investigational nature of prolonged immunotherapy, it wasn't considered as medically beneficial, since it involved an uncertain but likely higher chance of cancer recurrence. But Maria had previously tolerated short-term immunotherapy well, it conferred a decreased risk of anemia or thrombocytopenia, and it could potentially protect her from the psychological and spiritual harms of receiving transfusions—making it another medically reasonable option.

Step 3. The team met with Maria, her mother, an interpreter, and their invited guest—a member of the local JW Hospital Liaison Committee. Maria outlined the religious beliefs that led JWs to refuse transfusion of certain allogeneic blood products (red cells, granulocytes, platelets, or plasma) and maturely articulated how a transfusion would negatively impact her spiritual and psychological well-being. The ethics consultant reviewed the historical use of transfusion in AutoBMT at the hospital and discussed potential scenarios in which a transfusion might prevent mortality or long-term morbidity. The ethics consultant and chaplain shared information around the fiduciary responsibility of providers to act beneficently and avoid undue harm, highlighting the distress pediatric staff would feel allowing a child to die when a potentially lifesaving treatment (that is, transfusion) was available.

Maria and her family expressed understanding and were sympathetic, but continued to decline transfusion, remaining firm that death from transplant-related complications was preferable to the receipt of any transfusion. However, they continued to express agreement that AutoBMT offered the best chance of a durable cure and remained interested in undergoing this therapy.

This indicated the use of a weakly physician-guided SDM paradigm, since the family agreed with the physicians' medical assessment but requested significant treatment plan changes based on their values, goals, and preferences. This prompted Maria's physicians to convene a large interdisciplinary team that included providers/professionals with expertise in lymphoma, BMT, hematology, ethics, and the law, and chaplain services. Together, the team crafted a third medically reasonable option: AutoBMT with a modified supportive care protocol outside their usual practice.

While this modified protocol didn't alter the cancer-directed therapy, it allowed for acceptance of a greater degree of risk related to anemia and thrombocytopenia (that is, tolerance of lower hemoglobin and platelet levels), increased supportive care measures to minimize these risks, and thereby reduced potential psychological and spiritual harm. This plan included supportive measures to: (1) optimize Maria's blood counts prior to transplant (through use of an erythropoietin analogue), (2) minimize blood loss and prevent bleeding post-transplant (less frequent, lower-volume blood draws and prophylactic vitamin K and tranexamic acid), and (3) promote faster engraftment (the use of filgrastim). Each of these measures carried its own potential risk, and while the modified protocol was still considered less safe than the traditional use of transfusions, it was determined to be a medically acceptable approach for AutoBMT for this patient.

Despite comfort with the modified supportive care plan, significant distress remained about what the team ought to do if the plan failed to prevent life-threatening complications of anemia or thrombocytopenia. Knowing that the medical team would want to rescue Maria in such a circumstance, a court order was sought proactively to allow for transfusions despite Maria's and her family's refusal. The order, limited to emergency transfusions only, was proactively granted in family court, allowing the attending physician to authorize a transfusion if, in their medical judgment, Maria experienced a life-threatening complication despite the modified supportive care plan.

Step 4. A weakly physician-guided SDM paradigm remained appropriate when considering that transfusions, if necessary, would be administered by the treatment team through the court order rather than the patient/parent's assent/consent. If necessary, it would likely be limited to a small number, rather than required in an ongoing manner, and would be needed urgently if Maria experienced a life-threatening complication.

CASE CONCLUSION

Maria and her family were presented with the option of undergoing AutoBMT with a modified supportive care protocol, including information about the presence of the court order that authorized emergency transfusions, during subsequent informed consent conversations with her BMT physician and the ethics consultant. The family elected to consent to AutoBMT with a modified supportive care and didn't appeal the court order, and expressed their trust in the medical team to avoid transfusion if possible. They stated that God would ultimately protect her from such an emergency.

When Maria reached the nadir of her anemia and thrombocytopenia during AutoBMT, she developed symptoms: fatigue, light-headedness, and minor gastrointestinal bleeding in the setting of chemotherapy-induced mucositis. Several team members expressed discomfort with not transfusing then, but the multidisciplinary team carefully evaluated her clinical scenario and discussed it with Maria and her family. As her symptoms were not immediately life-threatening, they decided not to transfuse against the wishes of the patient and her family. The team further adjusted supportive care medications and monitored for progressive symptoms. As Maria's blood counts improved, she developed an occlusive thrombus at the site of her peripherally inserted central catheter (PICC). Although this was a risk of AutoBMT, Maria's thrombotic risk was likely increased due to the potential side-effects of several of the supportive care medications used to reduce her risk of hemorrhage. Fortunately, her platelet count had begun to improve the day the thrombus was identified on ultrasound, and her thrombogenic medications were discontinued. Maria was discharged from the hospital 20 days after her AutoBMT. Ultimately, she did not receive blood products, and she and her family expressed their appreciation for the medical team.

DISCUSSION

This case illustrates the potential power of SDM in a situation that is often fraught with conflict—refused consent to blood transfusions for a child due to religious objections. Here, the team wanted to provide the best medical therapy available in accordance with their medical judgment and Maria and her family's preferences. However, they felt conflicted about the possibility that the patient might die from complications of an iatrogenic cytopenia, even when the patient was a mature adolescent whose stated beliefs seemed well-developed and autonomous. The four strategic steps of this SDM approach made it possible to avoid unnecessary tension by encouraging open communication regarding the conflicts between the team's professional medical judgment and the family's values, goals, and preferences. The use of this framework helped team members to clearly define the medically reasonable options, and determine why it would be permissible to offer a nonstandard treatment approach that better fit Maria's and her family's goals. It also helped to disseminate these decisions amongst the myriad professionals who aided in her care in a concise and externally validated manner.

Developing a third medically reasonable option, based on evidence from published adult data and expertise from the hematology team, was a creative solution that respected everyone's goals for a durable cure and the family's religious beliefs. Seeking a court order to transfuse blood products prior to beginning AutoBMT allowed the family to incorporate that information into their decision making. In other circumstances, families may decline to consent to an intervention knowing that transfusion through the court has already been authorized, in which case another medically reasonable option could be pursued. Waiting to obtain the order until transfusion is a clinical emergency could undermine parents' authority and the patient's trust because parents would be unable to (1) withdraw consent for the medical intervention that resulted in the severe anemia or thrombocytopenia or (2) have time to appeal the decision in court before transfusion.

Finally, the early involvement of an ethics consultant facilitated SDM and transparency between the team and family, while it encouraged the multidisciplinary team to consider creative options. Involving such experts in communication and SDM before the medical team and family become locked in heated conflict may require institutional culture change.

NOTES

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