



Editorial

Adolescent Shared Decision-Making: Where We Have Been and Where We are Going



Most consider shared decision-making the standard of care in modern medicine [1]. While there likely exists significant variability in how individual clinicians put shared decision-making into practice, a common characterization includes sharing of information between the patient and clinician, with both parties working together to come to an agreement regarding a treatment plan that considers both medical facts and the patient's values/preferences [2].

Importantly, however, though shared decision-making is often referenced in pediatrics [3], it is less clear what shared decision-making truly means in the pediatric context [4,5]. Given the triadic nature of the patient-parent-clinician relationship in pediatrics, there are numerous legal, ethical, and practical complexities in operationalizing pediatric shared decision-making. These are only magnified when the patient is an adolescent [6], making the report of Nazal et al [7] about their care for an adolescent Jehovah's Witness with severe iron-deficiency anemia that much more poignant for practicing pediatricians.

The authors describe a 12-year-old girl with severe anemia (hemoglobin 2.6 g/dL) owing to menorrhagia, who they managed without blood transfusion to respect the requests of the patient and her parents, practicing Jehovah's Witnesses. Not without risk, the authors' strategy respected the family's preferences and included intravenous iron and multiple supportive therapies while she was closely monitored in the hospital. Notably, however, treatment did not include transfusion, which likely would have been faster, simpler, and more clearly supported by professional guidelines [8]. Transfusion would have clearly opposed the preference of both the patient's parents and the patient herself, a fact that seemed to tip the scales for Nazal et al [7].

This is not always the case, however, and there have been many instances in which such requests have not been respected, typically in attempt to protect the interests of the child. Such decisions, while supported by legal precedent, are not without controversy [9,10]. Even the American Academy of Pediatrics is rather equivocal in its guidance on this subject [11]. The American Academy of Pediatrics 2013 policy statement entitled

"Conflicts Between Religious or Spiritual Beliefs and Pediatric Care" argues simultaneously that clinicians should respect families' religious beliefs when possible but also that the interests of the child are paramount. The policy, perhaps not surprisingly, does not provide great clarity about how to proceed when these guidances support different courses of action.

One potential strategy, particularly when the treatment being refused for religious reasons is thought to be life-saving, is to seek involvement of the court system. The state has an interest in protecting minors from significant risk of serious harm – often referenced as *parens patriae* – and can supersede parental decision-making when those decisions put the child at in harm's way [3]. In the often-cited ruling of *Prince v. Massachusetts*, the United States Supreme Court ruled that "neither the rights of religion nor the rights of parenthood are beyond limitation [12]." The majority opinion continued, "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." This, in part, has informed the practice of seeking court involvement when parental decision-making is believed to not sufficiently meet their child's needs. Decision frameworks such as the best interests standard [13], harm principle [14], and constrained parental autonomy model [15] provide guidance for clinicians unsure whether a parent's request/refusal might meet the threshold of court involvement. These frameworks are not perfect, however, and do not necessarily provide a clear path forward for all decisional conflicts [16].

Importantly, these frameworks also do not consider the added complexity of an adolescent patient. It is now generally accepted that adolescents, out of respect for their burgeoning autonomy, should be included in decision-making processes in an age-appropriate and developmentally appropriate fashion [3], though it is less clear whether they should be permitted to refuse potentially life-saving treatment [3,17,18]. Courts have frequently compelled treatment in such cases,

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particularly in the setting of ailments perceived to be life-threatening but highly curable. The cases of Daniel Hauser and Cassandra Callender, teenagers diagnosed with Hodgkin lymphoma who each refused curative chemotherapy, are two such examples that made national headlines in recent years [3,6]. This is not always true, however, as demonstrated by the case of Dennis Lindberg, whose story carries several similarities to the case described here. Fourteen-year-old Dennis was diagnosed with leukemia and required blood transfusions to support him during his chemotherapy, but he refused transfusion owing to his Jehovah's Witness faith, a decision supported by his legal guardian, also a Jehovah's Witness [19]. The case went to court, with the judge ultimately ruling in Lindberg's favor, stating that he demonstrated enough maturity to make such a decision. Dennis died less than 12 hours after the court ruling [19].

These cases, regardless of their ultimate outcome, are highly public and often quite contentious, due in part to involvement of the court. Many pediatricians would do anything in their power to avoid such court involvement, but it may be thought necessary in situations where there is clear and undeniable risk of significant harm owing to a parent's (and/or adolescent's) refusal of recommended treatment. In many cases, however, risks are less clear or their magnitude less certain.

Nazal et al [7] expertly describe the navigation of such a case, acknowledging that, though transfusion might have been the recommended – and even much preferred – strategy, it was not the only *reasonable* strategy, given the beliefs and preferences of the patient and her parents. They demonstrate how shared decision-making in pediatrics can shine, integrating the medical knowledge of the healthcare team in a collaborative fashion alongside the values and preferences of the patient and family. Today, with medical mistrust/distrust at levels perhaps higher than ever before, we desperately need such strategies focused on high-quality communication and patient centeredness to promote the safety, well-being, and trust of our patients and their parents. Hopefully, this can be a model for us all as we look to the future and consider how best to make decisions on behalf of – and with – our adolescent patients.

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