Clinical Report

Adolescent Objection to Surgery: A Careful Evaluation of Current and Future Interests

Shika Kalevor and Ian D. Wolfe

ABSTRACT

This clinical report presents an ethics consultation regarding a 17-year-old adolescent, Vanessa "Venus" Marigold, who had an emergent, life-threatening cardiac myxoma. Despite parental consent and the imminent risk of death, the patient refused the lifesaving surgery, stating, "I just don't want it."

The case presented a profound ethical dilemma: respect for a patient's developing autonomy against a professional obligation to protect the patient's right to an open future. An ethics consultation was initiated to assess the dilemma and provide recommendations.

The team ultimately recommended a non-ideal care plan—a one-day delay of the emergent surgery—to secure the patient's assent and preserve the therapeutic relationship. This delay successfully reduced the patient's situational anxiety and allowed her to agree to the procedure the following day, despite the risks involved. This article explores the dilemma, ethics principles, and eventual trade-off in the non-ideal care plan.

Shika Kalevor is a Clinical Ethicist and is Program Director of Integrated Ethics at Children's Minnesota in Minneapolis, Minnesota. *shika.kalevor@ childrensmn.org*

Ian D. Wolfe, PhD, RN, HEC-C, is Director of Ethics in the Clinical Ethics Department at Children's Minnesota. *Ian.Wolfe@childrensmn.org*

CLINICAL PRESENTATION

Venus Marigold was a 17-year-old patient diagnosed with a myxoma (a noncancerous lesion on the heart). She presented to an emergency department (ED) multiple times over the course of four months with symptoms that included blood in her sputum, shortness of breath (SOB), and fatigue. She was discharged from that ED at each visit without further investigation as, per her mother, her symptoms were attributed to her weight. She then presented to a different ED, where further imaging showed a large myxoma. The definitive treatment for myxoma is surgery, as there is a potential for imminent morbidity and death if it detaches. Removal would relieve her current symptoms and allow her to return to her normal baseline physical health. She was thus scheduled for surgery to remove the lesion hours after her initial presentation in that ED and admission to the cardiovascular intensive care unit (CVCC).

CASE BACKGROUND

Venus used any pronouns. She is 17 years and five months. She had a complex mental health history, including depression, three prior hospitalizations for suicidal ideation (SI), and

past self-harm (three years earlier). Her mental health had reportedly worsened since the COVID-19 pandemic. Venus had a high body-mass index.

THE ETHICS CONSULTATION

On the morning of the scheduled surgery, a social worker reported that Venus refused the surgery. Her parents wished to proceed with the lifesaving intervention. The surgeon called for an ethics consult with the question of whether the team should override Venus's dissent or respect it. A concurrent psychiatric referral was initiated, given her mental health history and how it may have contributed to the refusal of surgery.

The ethics team met with Venus and her parents. Venus verbalized that she understood she would die without the surgery, but stated she did not care. She said that she did not want her heart taken out of her body. She expressed significant frustration that her bodily autonomy had not been respected. Through discussion, the ethics team was able to clarify the facts about what the surgery entailed. Venus showed no sign of incoherence or inability to understand that she could die. She persisted to respond that she simply did not want the surgery and understood the risk of death or significant injury. She denied suicidal ideation. After attempts at further exploration of her reasons, Venus stopped talking to the team. Ethics then met with her parents, who discussed Venus's decline in mental health and their agreement that she should have the surgery.

In discussions with the cardiac surgeon, cardiac intensivist, and bedside nurse, there was agreement that surgery was the definitive treatment. Although the surgery presented risks, especially given that it was heart surgery, it was a highly effective treatment (>95 percent 10-year survival) with a high likelihood of return to baseline without further morbidity.[1] There was about a 50 percent chance of embolization from the lesion without treatment.[1] The cardiac intensivist was concerned about proceeding over Venus's dissent, as it might require rapid sequence intubation with sedation, and potentially restraint. The intensivist was concerned about the high risk involved, given Venus's body habitus and potential for complications, including cardiopulmonary arrest. The bedside nurse reported that Venus did not allow any monitoring equipment or intravenous (IV) lines. The nurse worried about the trauma, both psychological and physical, of overriding Venus's dissent, although she also worried about the unpredictability of the myxoma detaching.

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THE ETHICS PRINCIPLES IN CONSIDERATION

Capacity versus Competence

While adolescents are not *legally competent* to consent to or refuse treatment (competence is legally set at 18 in the United States), patients older than 14 often possess the *capacity* to make reasoned medical decisions.[2] A determination regarding a patient's capacity to decide about a treatment looks at their ability to the weigh risks, benefits, and implications of a treatment. In Venus's case, considerations of her capactiy to decide included whether her immediate emotional distress compromised her decisional capacity. Venus's parents, her rightful decision

makers, consented to the surgery at the time of her dissent.

Ideally, pediatric patients can participate in decisions about their care to the extent they are capable, and this includes their *assent* to a proposed treatment.[3] When patients are capable of participating in making a treatment decision, asking them to assent to treatment protects their rights, respects them as moral agents, and honors their developing autonomy.[2] Ideally, their assent should be accorded weight, because it upholds these values while it constrains their ability to legally consent, which protects what Feinberg calls a *right to an open future*.[4,5]

Venus was at the cusp of presumed legal competency, although this presumption could be challenged. She seemed to demonstrate some capacity, although she didn't appear to be able to reasonably weigh risks and benefits. Venus seemed to be making a consequential decision that would potentially, or likely, threaten either her ongoing and future health, or threaten her future altogether.

The Right to an Open Future

The *right to an open future* is a phrase Feinberg used to describe how a choice for a child can be made with the consideration that the child will become an autonomous adult in the future. Feinberg argued that parents hold their child's autonomy rights in trust,[4] and they must consider their child's future autonomy as they make decisions for their child.

An overly narrow reading of Feinberg's principle could lead to its application as a moral maxim that overrides all other considerations in making decisions for their child, which may close a door for the child in the future.[5] The right to an open future is not a moral maxim, but rather a comprehensive evaluation of a child's many diverse interests.[5] Feinberg considered that while parents can help to create some of their child's interests that constitute their own good or self-fulfillment, as the child ages, they will have more input in their own sense of good and direction.[4]

In Venus's case, while it might be in Venus's interest to get the surgery and reduce morbidity and mortality, it is also in her interest to have her autonomy respected, at least to some degree. Of course, this is true, to the extent of her capacity, but even with questionable capacity, Venus maintained an interest in her bodily integrity. In a narrow sense—and problematically—her right to an open future argued for overriding her dissent. But a holistic evaluation of Venus's interests must consider how the process required to insure survival with surgery would violate her other interests. An evaluation of Venus's interests, such as her interest in control over her own body, required a consideration of whether and to what extent her refusal was truly an autonomous choice, and whether her long-term interests that would be met by the surgery should be given greater weight.

Autonomy and Bodily Integrity

Adolescents have burgeoning autonomy. Their decision making can be worrisome because they may make decisions without considering the long-term consequences. Diekema even called limitations to adolescents' decision making a *frontal lobe deficit disorder*.[3] But there are positive developmental reasons to include adolescents in making decisions. For one, it respects them as moral agents. It also allows them to build the skills required to make decisions as adults.

Even when patients lack adequate decision-making capacity, it is important to carefully consider decisions that may affect their bodily integrity. Clinicians must still be thoughtful about overriding patients' dissent and interfering with the bodily integrity of non-capacitated adults. Rubin and Prager developed a list of considerations (see the table on the next page) for deploying medical interventions over the objections of patients who lack decisional capacity.[6] Of Rubin and Prager's seven considerations, Fischkoff and colleagues report that, in a retrospective review of ethics consultations around overriding the objections of incapacitated patients, the most significant factors in the final ethics recommendations were the imminence of harm without treatment, and logistical barriers to employing treatment.[7] Their findings are consistent with the considerations of these situ-

ations through an analysis of proportionality of benefit to burden. Even when autonomy is in question, the harms both from forcing treatment and from forgoing treatment must be carefully taken into consideration.

CASE ANALYSIS

In Venus's case, the team was faced with two difficult options. Overriding her dissent could lead to physical harm through complications of physical and chemical restraint (if needed) and of a rapid sequence intubation. Overriding Venus's bodily integrity also risked causing significant psychological trauma that could threaten her long-term interests, as it could affect her accessing healthcare services in the future. It could even leave her with more psychologic morbidity. However, allowing her dissent could lead to further physical morbidity and even mortality.

Venus appeared to have decisional capacity, yet made what might be considered an unreasonable choice. She appeared make a decision that analyzed risk without reasonable thought to future consequences. Yet the harms of overriding her dissent were significant. What was known about the level of imminence of delaying the surgery had to be considered. Venus had lived with her condition for at least several months. The chance of embolization was 50 percent. Although not doing the surgery with a 50 percent chance of embolization would make most capacitated and reasonable people uncomfortable, it was hard to say that Venus was at risk of imminent death.

RECOMMENDATIONS

After discussion with the cardiac surgeon, intensive care physician, social work, and nurse, ethics recommended that, given the lack of imminence and the harms of overriding Venus's dissent, it would be appropriate to move the surgery back to the next day. This allowed the child life and psychology departments to meet with her and assist her coping with her situation in a positive way. Since there was a significant risk of delaying surgery in general, the decision was made that surgery should be undertaken the next day, even with continued dissent.

Rubin and Prager's Considerations for Overriding Objections for Incapacitated Patients

1. What is the likely severity of harm without intervention?
2. How imminent is harm without intervention?
3. What is the efficacy of the proposed intervention?
4. What are the risks of the intervention?
5. What is the likely emotional effect of a coerced intervention on the patient?
6. What is the patient's reason for refusal and can it be addressed?
7. What are the logistics of treating over objection?

From Rubin and Prager.[6]

RESOLUTION OF THE CASE

The final recommendation was discussed with Venus's parents, who also agreed with the plan. The surgery was postponed. Venus, in discussions with psychology, was relieved that a solution was found. She reported feeling overwhelmed and a loss of control in the moment.

The psychology consult found that Venus was feeling overwhelmed by the situation, with her distress amplified by a recent loss. She had made threats to pull her lines, but clarified that this was an expression of extreme distress and a way to compel the staff to listen, not a genuine suicidal action. She denied any recent suicidal ideation.

After being given space to speak with friends and process the situation, she became amenable to surgery the following day. The surgery was successful, and she was able to discharge with follow up a few days later.

CONCLUSION

This case demonstrates that a non-ideal care plan—delaying urgent surgery—can be necessary for the greater good of improved trust long-term. However, such non-ideal care plans are

not without risk. It can be easy to wield considerations of the right to an open future as an argument to override any dissent or refuse any requests that might be considered to close off any possibilities for the future adult. This would be a misunderstanding of Feinberg's principle and a narrow analysis of adolescent decision making. A careful weighing of current and future interests with the harms of respecting and overriding dissent is necessary to find the best path in these cases.

It should be noted that weight stigma may have played a role in how Venus interacted with the medical team. For several months her symptoms wer attributed to her body weight, and this may have significantly interfered with her level of trust for the care team. This is an important consideration when the team attempts to partner with an adolescent who is hesitant or resistant to accepting an intervention, even when it seems unreasonable to dissent. In this case, partnering with the adolescent by considering current and future interests led to a favorable outcome.

BLINDING OF THE CASE

Details of this case have been altered to protect the privacy of the patient and patient's family.

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