



Bioethics at the bedside: considering the adolescent voice in withdrawal of life-sustaining therapy

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Abstract

Durable mechanical circulatory devices are commonly used to support children and adolescents in end-stage heart failure. However, these patients remain at high risk of acute medical complications, which may lead to significant impairment in functional capacity, altered quality of life, or death. We explore the incorporation of adolescent directives into medical decision-making in this scenario through a clinical case vignette.

Case

(This is a fictional case vignette based upon clinical experience).

Rudy was a 15-year-old boy with a family history significant for dilated cardiomyopathy who was admitted to critical care with end-stage heart failure. He remained in a low-cardiac output state despite escalating medical management and therefore implantation of a left ventricular assist device as a bridge to cardiac transplantation was recommended. Family history revealed the death of a sibling due to complications of left ventricular assist device support, so parents initially refused a mechanical support option for Rudy. However, in extensive discussion with Rudy and his parents, the benefits and potential complications (including stroke, infection, and major bleeding) were explored. Rudy felt differently than his parents and agreed with medical recommendation for left ventricular assist device as a means of supporting him until transplant. He also expressed his explicit wish that, should complications arise such that he would be unable to communicate or mobilise, for example, additional interventions to prolong life should not be undertaken. The parents accepted and honoured Rudy’s decision. Following left ventricular assist device insertion, Rudy was extubated successfully and responded to commands. However, in the following day, he was observed to have a deterioration in level of consciousness requiring re-intubation, and CT of the brain revealed a thromboembolic stroke. Despite successful endovascular thrombectomy¹ and optimal anticoagulation, follow-up imaging demonstrated a new thrombus in the aorta and ventricle. He subsequently returned to the operating room for surgical thrombectomy and left ventricular assist device exchange. Unfortunately, he remained neurologically compromised with clinical signs of severe brainstem dysfunction, a very abnormal EEG, and corresponding multifocal extensive ischaemia on CT brain. Over several days, his neurologic prognosis remained one of severe compromise with limited potential for rehabilitation or improvement. It was anticipated that he would be unable to breathe or feed independently, nor carry out any activities of daily living, or be able to ambulate or communicate. This outcome was inconsistent with Rudy’s previously stated quality of life goals and expressed values, as discussed prior to pursuing left ventricular assist device support. Incorporating his condition and expressed wishes, the medical team recommended transitioning to end-of-life care with compassionate deactivation of his left ventricular assist device. His parents agreed to this recommendation and were supported by the medical team in left ventricular assist device deactivation and through Rudy’s subsequent death.

Discussion

When do paediatric patients become the decisional authority in their health?

The rights of a child with capacity to have their opinions considered in matters regarding their person is supported by Article 12 of the United Nations Convention on the Right of the Child.

In Ontario, Canada, where the authors practice, the Canada Health Care Consent Act (1996) does not stipulate an age of medical consent, thus any child who is able to both understand the proposed treatment and appreciate the consequences of pursuing or foregoing intervention should be given the opportunity to consent. While most jurisdictions internationally do stipulate an age of consent, legal rulings in many countries have led to flexibility based on assessment of maturity. For example, in the UK, Australia, and New Zealand, Gillick competence dictates that mature adolescents be granted decision-making authority.^{2,3} In the US, case law is evolving to support the adolescent with capacity's right to consent or decline treatment.⁴ In this case, our patient, despite his critical condition, demonstrated a clear understanding of left ventricular assist device insertion and appreciated the potential complications and their implications.

In clinical practice, the determination of patient capacity is expected to be judged by the physician who may be deemed to have capacity if capable of understanding and appreciating the nature, risks, benefits, and alternatives to a decision, as well as the consequences of that choice.⁵

Our patient was able to state his views on the potential risks both with parents present and without. He clearly understood the treatment plan and was able to appreciate the information to understand consequences of his decisions and discriminate between risks that were or were not acceptable to him. He was explicit in his stated preference to proceed with left ventricular assist device insertion but not have medical interventions pursued for the sole purpose of prolonging life. In this case, parents accepted their adolescent's decision and were supportive of proceeding with ventricular assist device insertion despite their initial reluctance. Should this not have been the case, legal decisional authority would lie with the adolescent in Europe and Canada given that he was assessed to have capacity and the healthcare team would be expected to respect the patient's consent.^{6,7} In the US, however, there is significant variability in the age of medical consent across jurisdictions and decisional authority is often granted on an age-based requirement.⁸ In scenarios where disagreement exists between an adolescent with capacity and their caregivers' wishes, the medical team should consider a Bioethics consult and support from other teams (e.g. social work, Adolescent Medicine) to help with respecting the capable adolescent's wishes while preserving where possible a good relationship with the caregivers. This is supported by the American College of Physicians, which stipulates that even where surrogate decision-makers are used, decisions should be consistent with patient's stated preferences. Legal action should only be pursued if it is deemed to be in the patient's best interests.⁵

Is it ethical to stop the ventricular assist device?

Discontinuing ventricular assist device therapy is analogous to the withdrawal of other forms of life-sustaining therapy (such as mechanical ventilation, inotropic support) and is based on the principle of the best interests of the person. The intent is to remove a treatment or intervention that does not align with the goals of care; the cause of death is the progression of the underlying disease process. It is ethically and legally permissible to discontinue any medical therapy as requested by a capable patient; it is likewise permissible too when it is requested by a surrogate decision-maker whose assessment of the therapy as being disproportionately burdensome to the patient aligns with the medical team's understanding. Furthermore, in such scenarios where discontinuation of

ventricular assist device therapy is requested by the patient in circumstances as described, it may be deemed unethical not to comply with this request. Additionally, in circumstances where the medical team believes that ventricular assist device support will not achieve goals of care (such as improved functional capacity), withdrawal of ventricular assist device support should be recommended. Both of these scenarios are predicated on the informed consent of the patient or surrogate decision-maker to withdrawal of life-sustaining therapy, such that respect for patient autonomy is upheld.⁹

How do the patient's previous wishes influence decision-making?

In scenarios such as this, where previously capable patient is incapacitated and has a surrogate decision-maker, medical decisions should incorporate the patient's previously expressed wishes and values. Rudy explicitly stated that he did not wish life-prolonging measures to be pursued in the event of any complications that would render him unable to communicate or ambulate. He referenced his older brother who had previously had a stroke while on left ventricular assist device support as to his intimate understanding. As Rudy's course evolved and it became apparent that his best-case recovery would fall far short of the quality of life he was willing to accept, his care team and family reached a decision to focus on end-of-life care furnished with the knowledge that they were acting in accordance with his wishes. Disagreement by the parents would have presented a difficult dilemma, as the patient was deemed to have capacity at the time of his decision and therefore his wishes should be followed. Only in scenarios where the patient has not previously expressed wishes does the decision truly lie with the surrogate, in which case decisions should be guided by the best interests standard.¹⁰ In Ontario, Canada, there is a legal obligation to abide by the previously expressed wishes of capable patients made when they are 16 years and older—additionally, even when applying the best interests standard, surrogate decision-makers are required to take into consideration the known values and beliefs of any previously capable patient, regardless of their age or capacity.¹¹

How do we consider adolescent advanced directives when the patient is 15 years old?

Advanced care planning is the practice of establishing patient preferences around medical interventions and pursuing life-sustaining treatments in the event that they may lose decision-making capacity. The over-arching goal is to facilitate continued medical care that aligns with patient values even if they are unable to communicate their preferences at the time. While widely practiced in adult care, eliciting patient values and preferences around escalations in medical care is not common practice in adolescents and decision-making often falls to parents and guardians.

Although Advanced Care Directive is only permissible over age 16 years in Canada, the rights of a child with capacity to have their opinions considered in matters regarding their person is supported by Article 12 of the United Nations Convention on the Right of the Child. Additionally, emerging data has demonstrated most adolescents have a clear preference to be involved in such decision-making.¹² Moreover, the proportion of adolescents wishing to be involved exceeded parental perceptions of young adults' desire for involvement in important medical decisions.¹³ When adolescents are challenged with chronic or complex medical

conditions with the potential for multiple medical interventions and prolonged inpatient stays, there is a significant loss of control, and the psychological burden of this is well recognised. Including adolescents (and capable pre-adolescent children) in conversations regarding their care respects their right to self-determination and prevents unwelcome intrusion into an already-compromised sense of personal autonomy. Despite this, it is clear that adolescent involvement in medical decisions is not common enough, due to multiple potential barriers including: fears of taking away hope (particularly in cases of medical uncertainty) and the time required for parallel communication with patients and caregivers.⁷ However, it has been shown that most adolescent patients prefer to be involved in such discussions irrespective of the severity of their illness.¹⁴ In our case, while the patient did not have a formal advanced care directive, previous discussions regarding patient values and preferences ultimately facilitated the delivery of medical care, including palliative care, that was concordant with his wishes.

Case conclusion and wrap up

Our patient died peacefully surrounded by his family, in accordance with his wishes to stop life-sustaining therapy when it could no longer accomplish his stated goals.

The foundational principles of principlist medical ethics, the framework most commonly taught in North American medical schools, involve beneficence, non-maleficence, autonomy, and justice. The overarching goal of principlism is to uphold all four principles simultaneously, in the absence of this, to mitigate those that cannot be fully upheld. Often, these are used in hierarchical fashion, although this is not the intent of the framework. Upholding these principles is meant to guide ethical analysis for clinical decisions. Legal parameters in individual jurisdictions provide boundaries of action and, while often in concert, may provide additional ethical tensions in determining correct action.⁵

Integral to this case is the challenge of upholding patient autonomy through identifying the adolescent with capacity, eliciting and integrating their values, goals, and expectations of care, while also adhering to legal requirements for parental inclusion in medical decision-making. In scenarios such as this, where high-intensity therapies are being used to prolong life, adhering to the principals of beneficence and non-maleficence requires that patient and guardian perceptions of suffering are incorporated into decisions regarding care. It is important to comment that considerations of justice necessitate that clinicians consider the equitable distribution of healthcare resources. While outside the scope of this case, allocation of ventricular assist device among other expensive medical therapies should be approached at a regional or national level to ensure equitable use across populations and groups. This case demonstrates a scenario in which an adolescent patient's capacity for decision-making in their own care can be explored and their agency and autonomy respected in order to uphold their decisional authority.

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