

Navigating Adolescent Decisional Capacity: A Case Study in Dialysis Refusal and Harm Reduction

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Background: Adolescent decisional capacity is nuanced, as cognitive maturity, emotional development, and external factors influence the ability to make informed, goal-aligned medical decisions. When adolescents refuse life-saving therapies, ethical analysis must go beyond traditional principles of bioethics to identify practical approaches to honor the patient's personhood and preserve an open future. [1,2]

We describe the case of a 16-year-old patient with end-stage kidney disease whose refusal to attend hemodialysis posed ethical questions about adolescent decisional capacity, the impact of a life-limiting diagnosis, co-occurring mental illness, and limited health literacy, and pragmatic responses for the healthcare team.

Decisional Capacity in Adolescents

A patient's decisional capacity is determined by their ability to understand relevant medical information, reason through their options, and appreciate the ramifications of their choice. This process is particularly nuanced in adolescent patients as their ongoing development may impact their ability to make a truly informed medical decision. In the case we present, determining whether the patient's desire to withdraw from dialysis treatment was an authentic decision was crucial to understanding his true motivations and how to best approach his care.

Throughout numerous encounters, the patient insisted on being able to self-determine the frequency of his dialysis based on how he felt. Despite repeated efforts to educate the patient, his overconfidence in self-managing his dialysis coupled with his age raised concerns about his decisional capacity. His behavior suggested a limited understanding of the medical consequences and was incongruent with his short and long-term goals as well as his explicit statements of not wanting to die.

Decisional capacity and authenticity are distinct yet intertwined concepts. A patient's capacity speaks to their cognition while authenticity reflects how aligned their choices are with their values and goals. Both must be assessed to determine whether the patient's decision to withdraw from treatment is truly informed.

Practical Approaches

- 1) Discharging the patient may seem justified from a resource allocation standpoint, as providing care to unwilling patients could strain resources. However, this neglects the ethical duty to protect vulnerable adolescents and support their evolving autonomy.
- 2) A paternalistic approach emphasizes treatment compliance but overlooks the broader impact on the patient's trust in the healthcare system. While it may improve short-term clinical outcomes, strong-arming the patient into complying may risk deepening mistrust

and hinder future engagement with the healthcare system – especially for chronic conditions where sustained adherence, like dialysis, is impractical to enforce.

- 3) An application of harm reduction involves adapting the treatment plan to a level of compliance that is acceptable to the patient. It strikes a balance between respecting the patient's evolving autonomy while ensuring *some* clinical benefit. While this approach may seem to compromise the standard of care, it ultimately prioritizes the patient's continued participation in their care rather than risking them disengaging completely from it.

We argue that the harm reduction approach, coupled with continued patient education, is the best approach in this case as it balances the potential harms to the patient's future engagement in the healthcare system with improved clinical outcomes.

References:

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2. Wightman, Aaron & Ranchin, Bruno & Goldberg, Aviva. (2021). Ethical Decision-Making in Pediatric Dialysis. 10.1007/978-3-030-66861-7_42.

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