Clinical Report

A Harm-Reduction Approach for a Child with Avoidant/Restrictive Food Intake Disorder

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ABSTRACT

Involuntary treatment of adolescent patients with treatment-resistant eating disorders poses a unique ethical problem. As pediatric patients mature, the burden on parents and the care team to justify and authorize involuntary medical treatment grows significantly. Essential considerations for the authorization of involuntary treatment for an adolescent include the ratio of risk to benefit for involuntary intervention and the decision-making capacity of the patient.

The involuntary administration of hydration and nutrition to adolescent patients who have eating disorders poses unique challenges, particularly as these patients approach the age of majority and when there is insufficient evidence regarding the long-term effectiveness of involuntary artificial nutrition and hydration as a part of treatment for eating disorders.

In this article I suggest that a harm-reduction approach is an ethically defensible approach to balance commitments to respect the patient's autonomy with obligations to minimize harms and create an opportunity for benefit.

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CLINICAL PRESENTATION

The patient was a 17-year-old male who admitted to the hospital with an infected peripherally inserted central catheter (PICC) line site. The PICC line was placed at another institution to provide hydration because the patient refused oral fluids intake due to reported pain and discomfort.

CASE DISCUSSION AND BACKGROUND

The patient's medical history included diagnoses of autism spectrum disorder (ASD), an eating disorder characterized as avoidant/restrictive food intake disorder (ARFID) or pain induced anorexia, anxiety, and depression. He was previously admitted for suicidal ideation. Multiple prior hospital admissions across three different healthcare systems had previously occurred. The patient started to complain of pain with fluid intake approximately 18 months prior to admission. Despite significant efforts to identify a cause, physicians at all three hospitals identified no anatomical, physiological, or other organic basis for an inability to tolerate oral liquid intake. The patient refused liquids except for sips to take medications and would otherwise eat solid foods. As a response to ongoing inability to tolerate oral liquid intake, hydration had been provided through a peripheral intravenous (IV) line, either in repeated admissions to the emergency department or scheduled through outpatient appointments.

The patient overtly rejected any possibility of a psychiatric or psychological basis for the condition, and refused to participate in any psychiatric or psychological evaluation or intervention.

The patient began to complain of pain with oral fluid intake around the time of the dissolution of his parent's marriage. His parents are divorced, with joint custody. Both parents participated in decision making for the patient, and the patient's mother took a more active role. His parents also generally rejected the idea that there was a psychosocial basis to the condition, and demanded escalation of medical interventions to resolve the problem, including medical or surgical interventions that would be consented to by the patient's parents but over the patient's objection and without his assent.

Shortly after admission, the PICC line was removed due to infection and clot formation. The patient initially refused to consent to PICC line removal, but it was removed without the patient's assent and over his objections, due to emergent medical risks. Following removal of the PICC, he received fluids via peripheral IV catheter and continued to refuse oral fluid intake. He also refused placement of a nasogastric (NG) tube and a percutaneous endoscopic gastrostomy (PEG) tube and demanded a new PICC line to allow him to hydrate himself at home.

Previously, the risks of a PICC line were explained to the patient and his parents. As a result, the patient's parents were opposed to replacement of the PICC line. Furthermore, the medical team remained concerned about the near certain recurrence of infection or a clot. The patient's parents advocated for ongoing and indefinite hospitalization with potentially involuntary treatment, including hydration and nutrition via NG or PEG tube, despite assertions by the patient that he would pull them out, attempt to harm himself, or attempt to leave against medical advice. Clinical ethics was consulted about how to proceed. The ethics team recommended the following:

- Assess the patient's decision-making capacity.
- Engage the patient in discussing the available options, with a proposal to transition to a harm-reduction-informed plan of care, specifically, placement of a central line for hydration or scheduled IV or subcutaneous fluids.
- A harm-reduction-based plan of care was the most ethically defensible option out of the range of ethically problematic options. It was the most defensible because it minimized risks for harm and death, minimized intrusions on the patient's autonomy, and provided some opportunity for an open future.

ETHICAL ANALYSIS

The recommendations made by the clinical ethics team sought to balance commitments to respect for the adolescent patient's autonomy, with obligations to use medical interventions in a way that minimized harm, provided opportunities for future benefit, showed compassion to the patient, and sustained an effective therapeutic relationship between the patient and the medical team.

Respect for Autonomy and Dignitary Harms to Adolescents

The involuntary treatment of a patient is ethically problematic. Generally, there is a fundamental right for a patient with decision-making capacity to refuse unwanted interventions that conflict with their goals and values. The right to refuse unwanted treatment may only be overridden under certain circumstances, when other duties or commitments supersede obligations to respect the patient's autonomy. The burden to prove that involuntary treatment is ethically appropriate falls on the clinicians who seek to perform an intervention, and does not fall on a patient to justify their refusal. Circumstances when involuntary treatment may be appropriate include a patient's lack decision-making capacity, such as young children, or in an emergency when a patient's values and choices are not known. For involuntary treatment to be ethically defensible, the proposed intervention must have a high probability of conferring a significant benefit or opportunity for benefit, and there must be no other, less intrusive means to confer the benefit.

The burdens or harms of involuntary treatment are relevant to the evaluation of its ethical appropriateness. The involuntary treatment of a patient who has impaired decision-making capacity or who has less ability to meaningfully construct and assert their own values, goals, and interests may pose less of an intrusion than the involuntary treatment of a patient who has mature and effective capacities.

The involuntary treatment of young children occurs routinely because young children do not possess the capacity to meaningfully construct and assert their own interests in matters related to medical treatment. In addition, the dignitary harms of limiting the choices of young children are less severe than limiting the same choices in adults. However, as children grow older, their ability to construct and assert their own values, goals, and choices increases. As such, obligations to respect a child's autonomy increase as they grow older, and the possibility of dignitary harms from involuntary treatment increase.

The notion of dignitary harms is worthy of attention since adolescents may be particularly vulnerable to it.[1] The harms of an inappropriate medical intervention are not reducible to the physical or material and include psychological, social, and moral harms. Furthermore, these intangible harms are not reducible to a duty to respect a patient's autonomy or defects in informed consent; these are harms that are not merely constraints on self-rule. Dignitary harms stem from a denial or disregard of a person's moral worth.[2] Examples include violations of privacy, loss of status, stigmatization, and a contempt or disregard for a patient's preferences and participation.[3]

The legal age of majority creates conditions that increase the risks for older adolescents to suffer from dignitary harms when their values, choices, and interests are not taken seriously and they are forced to endure involuntary treatment and a decision-making process that may not appropriately weigh their growing autonomy.

In this case, the patient was 17 years old and on the boundary of legal adulthood. The patient's parents held decision-making authority and sought involuntary treatment of the patient in ways that would have minimized his preferences and his input. Even though initiating involuntary artificial nutrition and hydration (ANH) with the use of restraints would have been legal and arguably ethical, there would be harms to the patient's dignitary interests and autonomy even if we took into account his mental, emotional, and behavioral issues.

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Harm Reduction for Eating Disorders

In a recent article, Bianchi and colleagues proposed that a harm-reduction model of care for patients with severe and enduring anorexia nervosa may be ethically defensible.[4] The authors assert four general areas of reasoning that support a harm-reduction model. First, in following well-accepted commitments to respect for patients' autonomy, a harm-reduction-based approach allows a patient to direct their own treatment goals based on their own values, and avoids paternalism and involuntary treatment.

Second, moving away from rigid principlism, the authors suggest that a virtue-ethics perspective may justify providing a harm-reduction-based plan of care as an expression of compassion for a patient's suffering and pain while not aiding and abetting harmful behavior.

Third, the authors argue that harm reduction may help demonstrate the trustworthiness of the care team to the patient.

Finally, the authors suggest that the use of a harm-reduction approach may be ethically defensible as it may save or prolong a patient's life and/or improve the patient's quality of life.

Despite key differences between a 17-year-old patient with ARFID and ASD and adult patients with severe and enduring anorexia, the reasons presented by Bianchi and colleagues are both relevant and convincing, and a harm-reduction-informed plan of care is the most ethically defensible.

In this case, the team agreed that a transition to a palliative only plan of care was ethically problematic. Allowing the patient to die by his refusal to drink liquids, even when made at his own request, would enable the effects of a mental, emotional, or behavioral problem to cause the patient's death.

The team agreed that a plan of care for ongoing and indefinite hospital-based involuntary ANH, with varying degrees of sedation and restraint, would be ethically problematic, as they would severely harm the patient's autonomy and dignity without clear benefits other than his short-term survival. The significant intrusions on the patient's autonomy were not clearly outweighed by the opportunities for benefit.

While involuntary and ongoing ANH would have kept the patient alive, there was no clear evidence that there was an effective intervention to treat the underlying mental, emotional, or behavioral issue, and the patient continued to refuse to participate in any interventions targeted towards mental, emotional, or behavioral issues.

A harm-reduction-based plan, in this case a surgically implanted accessible port to instill IV fluids, offered a practicable way to balance competing ethical obligations. Specifically, replacing fluids via a port allowed the patient to direct the treatment in ways that delayed or avoided serious harm, even though the approach was medically suboptimal and a continued expression of an underlying mental, emotional, or behavioral issue. This approach was similar to allowing an IV-drug user to use clean needles—which healthcare providers acknowledge is a suboptimal, even harmful behavior—but it is also a pragmatic means to reduce overall harm.

First, in following the harm-reduction rationale described by Bianchi and colleagues, this plan respected the patient's autonomy without excessive and unnecessary intrusion and minimized dignitary harms, while it avoided serious harm and death from an unsafe behavior. Second, placement of a port was compatible with compassionate treatment by the healthcare team, especially in contrast to involuntary ANH. Third, placement of a port was more likely to preserve trust and a therapeutic alliance with the patient. Finally, although hydration through a port did not treat the underlying condition, it did create additional opportunity for future treatment. The patient had demonstrated some ability to live with a port for hydration.

It was unknown whether the patient's condition was treatable, and a port was consistent with the quality of life sought by the patient. The pursuit of a clinical ideal in this case, in the view of the team, was greatly outweighed by the ethical trade-offs.

CASE CONCLUSION

After the patient's PICC site infection was treated, a port was placed for hydration at home and the patient was discharged. Four months later, the patient was readmitted for a port infection. At this time, the patient was approved for a dual-diagnosis eating disorder program in another state. The patient was transferred to the program against his wishes. At the dual diagnosis program, an ethics review was conducted, and its recommendation was to authorize involuntary treatment on the basis that the patient did not have decision-making capacity, and thus should not be allowed to make decisions regarding his own medical treatment.

As a result, the port was involuntarily removed and an NG tube was involuntarily placed as part of a broader treatment plan. The patient was eventually discharged and returned to his home. Shortly after returning home, the patient's mother reported worsening behaviors, aggression, and resumption of restricted fluid intake. The patient was readmitted 15 days following discharge from the dual diagnosis program.

The patient turned 18 years old, and was readmitted as an adult to this facility.

ANONYMIZATON OF THE CASE

The details of this case have been changed to protect the privacy of the patient and family.

NOTES

1. R.H. Hartman, "Coming of age: Devising legislation for adolescent medical decision-making," *American Journal of Law & Medicine* 28, no. 4 (2002): 409-53.
2. D.S. Davis, "The Ambiguous Effects of Tort Law on Bioethics: The Case of Doctor-Patient Communication," *The Journal of Clinical Ethics* 21, no. 3 (Fall 2010): 264.
3. B. Kuklin, "Constructing Autonomy," *New York University Journal of Law & Liberty* 9 (2015): 375.
4. A. Bianchi, K.S. Andria, and K. Sutandar, "The ethical defensibility of harm reduction and eating disorders," *American Journal of Bioethics* 21, no. 7 (2021): 46-56.