

Adolesc Med 022 (2011) 283–288

Treatment of Anorexia Nervosa against the Patient's Will: Ethical Considerations

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INTRODUCTION

Practitioners of adolescent medicine are frequently the medical consultants responsible for determining the hospitalization of patients with anorexia nervosa (AN), deciding whether they may require nasogastric tube feeding, and potentially recommending measures that may restrict their freedom. Thus the treatment of adolescents with AN can include ethically concerning practices such as privation of liberty, nonacceptance of treatment refusal, and limits on privacy and confidentiality, to name a few. Treating professionals are thus often caught between the conflicting values of respect for patients and their duty to prevent nutritional injury and even death. Therefore there is always a potential tension between obtaining the patient's trust (fiduciary fidelity) and having to make recommendations that threaten this working relationship (fiduciary protection). In many, if not most, instances of treatment for AN, patients receive some form of treatment against their will. The situation can become even more difficult to address once patients reach the age of majority. This article explores the ethics of treatment of AN against the patient's will. The following case presents a typical scenario in the treatment of AN.

Case: Amy, a 16-year-old honor student who has AN comes for a follow-up visit. She looks worse than her previous visit to the doctor: She has lost weight and is cold, her hands show acrocyanosis, her breath is ketotic, and her pulse is weak. She is orthostatic. Her parents are in tears and tell how she is hardly eating and constantly complaining that her stomach hurts. The physician completes her assessment and explains to her that she is in danger and hospitalization is required and that the reason she is in pain is because she has developed delayed

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stomach emptying and impaired intestinal motility, which are treatable. Amy listens with increasing despair and interrupts the physician screaming, “You cannot do this to me, I can’t miss school . . . besides this is *my* body! I do not want to go to the hospital and you cannot make me!”

PATERNALISM AND JUSTIFIED PATERNALISM

The ethical and legal issues that are inexorably part of the treatment of eating disorders are still strongly debated around the world, leading to different interpretations about a patient’s capacity to consent to or refuse treatment and conflicting medico-legal advice.^{1–33} To complicate matters further, during the course of the treatment, it is not unusual to find significant disagreements among members of the treatment team, among the parents, between parents and child, and between parents and staff. These events and their combination or permutation, commonly referred to as “splitting,” tend to raise the passions. Professionals are not immune to frustrations and anger, and this increases the risk for impulsive and unethical behavior on the part of the clinician. In a rather sinister manner, treatment failure and issues of countertransference can lead to abuse of power, especially when using behavior modification approaches and nasogastric tube placement. Indeed often unavoidable paternalistic practices have pervaded the field of eating disorders, and although clinical outcomes are being thoroughly researched, less attention has actually been given to the ethical implications of such treatments.^{1,9,12,17,23,29,32}

This article is not intended as an interdiction or elimination of appropriate limit setting and therapeutic interventions: nobody wants to throw away the proverbial baby with the bath water. Rather it proposes to transform inchoate paternalistic inclinations into deliberate, thought-out, justified paternalism (JP). The case for JP should only be made if first one understands: a) that paternalism involves violation of a moral rule, and b) that therefore a strong reason needs to be advanced to justify doing so. Silber prescribes a test for considering whether an intervention fulfills the prerequisite for JP. The test requires 2 conditions to be fulfilled: 1) that the danger to the adolescent’s health be significant enough to trump her autonomy, and 2) that there is reasonable evidence that obsessions, irrational fears, and compulsions significantly diminish her developing capacity for autonomy. In a similar vein, Fost² had reached similar conclusions that allow for interventions against the patient’s will when the following characteristics existed: a) imminent physical harm is likely; b) intrusion probably protects the person from harm; c) the person is likely to be thankful for the treatment at a later time, d) the intrusion is generalizable, in the sense that those supporting it would wish the same on themselves.

AUTONOMY

The principle of autonomy has been squarely at the center of the emergence of patient rights, all but displacing paternalism from the clinical repertoire. The concept of autonomy in medicine is central because it ensures that the patient

has jurisdiction over his or her body and what is done to it. It is clear that our profession has abandoned the long tradition of paternalism for the new practice of shared decision-making. It should therefore come as no surprise that there are passionate proponents that patients with AN should never be treated against their will. In their mind autonomy trumps all other considerations.^{9,17} In addition many argue that the consequences of overriding autonomy are deleterious, and that clinicians will reap their rewards if they are patient and allow the patient to make decisions: in due time this approach would result in a better clinical outcome.^{9,17} Arguments against compulsory treatment and in favor of allowing treatment refusal have also been marshaled by clinicians, philosophers, and attorneys concerned with the potential for professional abuse of power and the potential encroachment on fundamental individual rights.^{9,17} They further advance the autonomy argument by declaring that patients with eating disorders meet all the conditions required to give informed consent and hence meet the capacity standards for competency.

This position has been challenged. There is a trap in the assessment of patients with eating disorders: Although their skills are congruent with what is required for legal capacity tests, so an assumption could be made that they are legitimately entitled to making decisions without the interference of others, this does not consider at all the role that pathology and emotions play in decision-making.^{16,19} Recent studies have shown that patients with AN, even though they have no problems with cognitive functioning, nevertheless perform less well than controls on decision-making tests.²⁰ Moreover, recently Uher's study of the ventromedial prefrontal cortex in patients with eating disorders has shown evidence of impairment.²² The development of autonomy is problematic in patients with AN who are known for a "pseudoautonomous" stance by which they convey the impression of not needing others as they are paradoxically placing themselves at risk in a way that demands rescue.³²

Andersen²⁸ used a strikingly powerful image to illustrate the complicated discussion of autonomy, as he described the progression from starting food restriction to full blown AN: "The situation resembles that of a person boarding a canoe headed for Niagara Falls on a journey that begins voluntarily but ineluctably transforms into a non voluntary propulsion towards the falls, with the person at times not recognizing that the upcoming Falls even exist."

A NEW PARADIGM: AN ENRICHED UNDERSTANDING OF AUTONOMY

There have been important changes in the treatment of AN. Rather than parents being seen as "the cause of the problem" they are now being viewed as part of the solution.³⁴ Congruent with this view is a criticism of the existing individualistic concept of autonomy. An "ethics of caring" approach proposes that each one of us is embedded in relationships and that because of this it is legitimate to raise

an alternative concept of autonomy that includes sensitivity to the interrelatedness with others.³² According to this view, family and social networks are not only an important part of an individual's life, they are the very thing that makes possible autonomous human existence in the first place.³² As we progress in delivering family-centered care, the justification for the incorporation of those closest to the patient into the decision-making process can be based on such an enriched understanding of autonomy.

RESEARCH

There has actually been scant research about the effects of treating patients against their will.^{10,19,27,30} Ramsay et al¹⁰ compared patients who were hospitalized against their will with those that had a voluntary hospitalization and found that there were no differences in short-term weight recovery. There was an increase in long-term mortality, but this was due to selection factors associated with the severity of their intractable disease, such as childhood physical and sexual abuse and self-harm. A decade later, Thiels³⁰ reproduced the same finding: there was no difference in weight recovery between those who were treated voluntarily and those who were not. Guarda et al²⁷ studied perceptions of the admission process in hospitalized patients. Most felt high levels of coercion. Nevertheless after only 2 weeks of nutritional rehabilitation, a significant number had already changed their minds and welcomed their hospitalization. (This was less so for teenagers.) Tan et al¹⁹ did a qualitative study on how patients with AN ($n = 29$) and their parents viewed involuntary hospitalization. Interestingly they all agreed that patients should have their treatment refusal overridden if their life needed to be saved.

WHAT REALLY MATTERS: VALUES

The quality of the relationship of the patients and parents with the treating professional is the basis of sound decision-making. Patients have repeatedly described that having freedom of choice was often less important than relationships and the attitudes of clinicians and those around them.³³ A majority of patients and their families say that their decisions are based on trust and good relationships rather than on theoretical disquisitions about capacity. Most patients initially treated against their will eventually do not seem to resent their experiences or perceive them as coercion. For those who remain resentful it is usually not because of restrictions but because of feeling “dismissed, belittled or punitively treated.”³³ The central issue surrounding involuntary treatment is not whether the patient lacks the capacity to consent or refuse treatment but rather the context and relationships involved in quality care. At the end it is always values that underlie and strengthen the good work. These include fundamental respect for the person, even as liberty is restricted; beneficence; and truth telling.

So what happened with Amy? The doctor allowed her to express herself and then firmly but kindly, looking into her eyes, told her that she cared for her and was

going to protect her. She then explained the protocol, how the nurses would be helping her, and how extra care is taken during very gradual refeeding, including a slow nocturnal nasogastric pump that would improve her stomach pain. It was difficult, but the alliance continued throughout the course of the treatment.

DISCUSSION

The advantage of incorporating ethical reflection into clinical care is the development of a common language and understanding. Experience has shown that rather than the ethical concerns being the abstract and abstruse musings of philosophers removed from patient care, they are instead intimately related to the lives of all those involved in treatment protocols. Unaddressed ethical concerns can generate professional self-doubt, contribute to burn out, and may even lead to misguided parental abdication from their protective role. Thus ethical issues are not to be considered curiosities at the margin of treatment plans but should be incorporated into the mix of case discussions, morning rounds, treatment plans, and formal presentations.

CONCLUSION

Treatment interventions for eating disorders need to include not only the biopsychosocial and spiritual components that have enriched the field over the years, but also need to incorporate a philosophical dimension that takes into account a reflective understanding of patient autonomy; patients' rights; obligation to protect; respect for persons; right to treatment refusal; and, last but not least, justified paternalism and an expanded concept of autonomy.

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