

Addressing Issues of Autonomy and Beneficence in the Treatment of Eating Disorders

Karen E. Faith, B.S.W., M.Ed., M.Sc., R.S.W.

A number of studies of experiences of individuals with severe eating disorders given life-sustaining treatment without their consent have found that a significant proportion later express goodwill towards their care providers, and for the treatment they received^{1,2,3}. Such findings highlight the significant ethical challenges encountered by health care teams when a teen, severely ill with an eating disorder, resists medically necessary treatment.

These challenges relate to the dilemma of how to respect the individual's autonomy, or right to make an informed choice, while doing what is considered beneficent or "good" on behalf of those who are very ill. Questions like, "When does care become coercive?" ought to be raised by health care teams so that, in addition to clinical concerns, health care providers consider important ethical concerns like autonomy and beneficence.

The principles of autonomy and beneficence

In general terms, the principle of autonomy recognizes that an individual who is competent has the right to make an informed choice about medical treatment. This choice must be made without coercion or undue influences from others. The principle of beneficence requires that health care providers do that which is considered "good", or in the best interests of the person for whom they are providing care.

In caring for a teen with an eating disorder, the individual's autonomy and the principle of beneficence will conflict when the teen resists medically necessary treatment. Treatment avoidance is a common characteristic of those with anorexia nervosa and therefore is faced regularly in providing care to affected individuals⁴. Many health care providers wonder whether a person whose illness impairs their ability to make health decisions can exercise true autonomy. Such concerns for those afflicted with serious psychiatric illness led Dutch ethicist Marian Verkerk⁵ to defend the concept of "compassionate interference". The idea of compassionate interference, which would include treating certain seriously ill people without their consent, challenges the ethical notion of autonomy. However, Verkerk argues that involuntary treatment can be a means of actually helping patients with serious psychiatric illness to regain their autonomy, particularly when such illness threatens their survival.

Autonomy, consent and relationships

In providing treatment to teens who struggle with serious eating disorders, the ethical obligations of protecting autonomy while doing what is "good" for that person, is particularly challenging to

parents and health care providers. A first consideration is whether all teens have the opportunity or the maturity to build the kinds of decision-making skills one requires in order to achieve true autonomy. Secondly, is a teen's consent to treatment made without coercion or outside influences when parents refuse to have their child remain at home if they decline treatment?

Canadian ethicist Susan Sherwin⁶ suggests that the concept of autonomy needs to be viewed within the person's circle of relationships, particularly family relationships. Rarely do individuals make important health care decisions without taking into consideration the advice, feelings, and cooperation of those close to them. Therefore, although we may have the right to make choices about our health, these choices are often influenced by significant "others" in our lives. An important ethical concern is the extent to which these natural influences become coercive or forced upon the person who is asked to make a choice regarding their health care.

A family-centered approach

Ethicists Pelligrino and Thomasma⁷ warn health care providers not to underestimate the impact of serious illness on an individual's ability to exercise their autonomy and decide on treatment options. Ideally when a person is seriously ill, decision-making ought to be an "interpersonal transaction", one in which there is a shared sense of obligation to do what is "good" for the individual at a time when they are seriously ill. These decision-making models have influenced many treatment programs for teens with eating disorders to adopt a "family-centered" approach. Such an approach to providing care respects "the complex nature of parent-child relationships, the dependence and vulnerability of the child and the child's developing capacity for decision-making"⁸. Ideally treatment decisions regarding a seriously ill teen are reached by understanding her wishes and health goals, those of their family (or guardian in some instances), while weighing clinical concerns and best medical practices. Health care teams must ensure that the teen assumes as much autonomy as possible given their state of health, experience and life skills. Ethical concerns arise when treatment planning includes limiting personal freedoms like going to the bathroom alone, or eating how much or how little one wants. Can a teen with a serious eating disorder ever consent to treatment but not to the restrictive nature of this treatment? Here the ethical challenges become still more complex.

Coercion and choice

Most teens who agree to treatment for their serious eating disorder will face coercive or restrictive elements in the treatment they will receive. The teen's decision to receive treatment is frequently influenced by the urgings of family, friends and physicians. Medical care for teens under the age of 16 is also a legal concern. Most provincial child welfare legislation requires that children receive necessary medical care. Because of these factors, treatment programs for adolescent eating disorders must provide sufficient information about the program and enough support to the teen and their family so a decision can be reached. Disclosure of information needs to include the more coercive or restrictive aspects of treatment, like nutritional requirements and limited activity, so that the teen can make an informed choice.

In reaching a decision about treatment, Rathner⁹ supports the use of “informal coercion” with patients who are seriously ill with an eating disorder but argues against the use of compulsory or forced treatment. Forms of informal coercion or outside influences can include convincing, applying consequences or coaxing a person into accepting treatment. The pivotal ethical issue is that the individual consents to treatment that they know will include restrictive or coercive elements. Of course how free the teen actually is to decline treatment should always be of great ethical and clinical concern.

Rathner maintains that the person with an eating disorder should be provided with as much choice and time as possible to make informed decisions about treatment. He supports the use of treatment termination or interruption when a person is seriously resisting or undermining their care. His approach is influenced by the fear that if treatment is forced, an escalating dance of control emerges between the person who is resisting treatment and their care providers who are determined to treat the illness.

But what of those people who after receiving involuntary or forced treatment for their eating disorder expressed goodwill about their care and towards the care providers who carried out the treatment? Is it possible that compulsory treatment with certain very ill individuals is a way of achieving the “good” or being beneficent? Such ethical concerns emphasize the importance of regularly instituted opportunities for health care teams to talk about ethical issues in the course of treatment rounds and discussions.

Compassionate intervention

But let’s bring the discussion back to the idea of compassionate intervention being mindful of the warnings about providing treatment without consent or by using coercion. Let’s also bring the discussion back to seriously ill teens who may be resisting care, whose autonomy may not be fully developed, and whose capacity to make health decisions is in question due to the severity of the eating disorder. How would you wish to be treated if a psychiatric illness rendered *you* so ill that making a decision to get better felt impossible? This is the terrible position in which many teens with an eating disorder find themselves. How many of us who are parents would argue for the autonomy of our child while our child continues to starve and refuses, or undermines, treatment? Our moral and parental instinct is to get them help and to get them nourished. It sometimes takes great effort over time to persuade a seriously ill teen with an eating disorder that they need treatment, and in particular, treatment that would require them to eat and gain weight. Providing the teen with sufficient time to decide on treatment options while keeping them medically safe is vital to protecting autonomy. However, while parents, health care providers, friends and family members try to support and influence the teen, they must also be prepared to intervene compassionately if the teen can no longer function and becomes desperately ill. This is when autonomy must give way to preserving beneficence and the sanctity of life. This said, there is a slippery slope on which health care providers who intervene compassionately must tread very carefully.

Autonomy is a primary ethical obligation, protecting a person's right to self-determined choice. As Pellegrino and Thomasma⁷ stated, "healing does involve restoring autonomy". Therefore, once the life-threatening stage of illness has been treated, the emphasis must again be placed on giving the individual as much say as is possible and appropriate over treatment decisions.

Recommendations for discussion

This discussion about autonomy and beneficence and the treatment of teens seriously ill with an eating disorder highlights the ethical complexity of this clinically challenging illness. In a family-centered model for decision making, the ethical principles of autonomy and beneficence should serve as guide posts.

Treatment programs for teens with eating disorders would benefit from regular opportunities to review the ethical dilemmas they face in their work. This is particularly indicated because coercive measures are often needed and difficult treatment decisions must be made. As many treatment teams can become complacent about ethical matters due to time constraints, clinical and fiscal demands, scheduling time dedicated to discussing ethical concerns is highly recommended.

Some ethical concepts or concerns to be examined by treatment program staff could include: the process of achieving informed consent; determining capacity to make health decisions; withdrawal of consent through behavior or expressed wish; use of coercive influences in treatment; and the ethical implications of life-sustaining involuntary care.

To ensure that a teen's choices, wishes and goals are understood and considered in treatment decisions, treatment teams are encouraged to ensure the following:

- That the teen expresses their choices, wishes and goals directly when treatment decisions are being considered, or that a health care team member acts as an advocate on their behalf.
- Treatment teams institute a means of regular communication with the teen and her family about treatment options. In the event of a conflict in decision-making, there are instituted procedures for negotiation and if necessary, mediation.
- Health care teams request feedback from teens and their families about communication and decision-making within treatment, use of coercive influences and/or involuntary care. Utilizing this feedback to adjust or create program policies or procedures where needed.

Health care teams could also benefit from discussing these ethical concerns with other eating disorder programs, and through consultations with the hospital's ethics services or the health ethics committee. Such measures can assist health care providers, the teens who struggle with a serious eating disorder and their families to promote healing as well as the ethical ideals of autonomy and beneficence.

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