Angela's compliance will increase only if she gains weight, even if that requires forced-feeding.

In a round table meeting (which included an ethicist and a hospital lawyer), the proposed further attempt at forced-feeding was discussed. All the members of the ward, including the treating team and other patients, are extremely stressed by Angela's impact on them. What are the best treatment options in this situation? Is a palliative approach viable, or would a more aggressive plan be beneficial?

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doi:10.1017/S096318011200014X

Commentary: Staying the Swinging Pendulum

Erica T. Goode

In the case of Angela, whose anorexia nervosa developed during preadolescence and continued throughout seven years of treatment, her background makes it difficult to predict the likelihood of successful treatment. Without more details as to Angela's neuropsychiatric, social, and medical status, an ethics committee would find it difficult to determine whether the duty to treat should take precedence or whether the patient's seemingly irrational choice of palliative care would be considered a viable option. Her youth and the wishes of her parents and family to do all that is possible are added features in this complex case. If it could be determined that her years of treatment were suboptimal in terms of the current standard of practice regarding effective eating disorder treatments, the duty would fall toward providing all possible care. A confounding issue is that suffering from anorexia nervosa (AN) since age 11 places Angela in the category of a chronically afflicted individual. This is important because the duration of illness, with presumably no periods of remission, is central to whether Angela is more or less likely to respond to treatment, no matter how well rendered.[1]

Because there are multiple unknowns in this case, it is important to determine whether Angela's care has been provided by professionals trained in the management of complex, entrenched eating-disordered patients, with a high degree of continuity of care. A review of her case would almost certainly require speaking to a number of involved parties, to determine the level and appropriateness of Angela's care. What this consists of is still being debated in the literature.[2]

Ideally, two or more ethics committee members would need to meet individually with Angela, and her parents, as well as perhaps other family members, to gain their observations of Angela's behavior, including resistance to interventions over time. Perhaps, through these interviews, a better understanding could be reached based on some level of information about Angela as a preadolescent. We are not told of any precedent triggers, such as sexual trauma, that may have led Angela to begin restricting. Often these issues take years to tease out. If this is relevant to Angela's situation, providing more time for recovery would be an important factor in the decision to provide ongoing team care. Because we are first hearing of her plight at age 18, and knowing that early intervention is closely linked with long-term survival (the overall premature death rate is stated to be at least 6 percent per decade in patients suffering from AN), we can conclude that her situation is already a problem, because of chronicity and the associated altered

https://doi.org/10.1017/S096318011200014X Published online by Cambridge University Press

neurobiology.[3] The problem could be more convoluted as well, because many AN patients begin bulimic purging at some point, thus shifting the diagnosis and altering the statistics.[4,5]

It may be important to know if there is any family history of Angela's mother or other family members carrying the diagnosis. Family history is hard to interpret, and whether genetic or related to family dynamics, the chance of familial incidence or prevalence is high, and this may include other compulsive behaviors as well. Again, because this is a difficult topic, it has not been adequately studied. Sometimes emulation of another youngster or public individual (e.g., various film or gymnastic stars) leads youngsters to adopt restrictive behaviors.[6] With the Internet, social media, and other websites encouraging youngsters toward groupthink restriction, plus an overabundance of images portraying unrealistic body types, the triggers are all too many.

We don't know if a good attempt at family-based therapy (FBT), such as the Maudsley Method, has been employed during an outpatient phase of Angela's care. FBT has been found to be a helpful approach when done early in adolescence. The case description does not include a clear statement regarding a team approach using some type of comprehensive, skilled care over a period of time. This would need to be rendered by a team that includes psychologists (for individual and group sessions), nutrition and medical care practitioners, individual and/or group therapy, and careful work with the parents. Further, teams must have collaborative meetings to avoid splitting by the manipulative patient.[7]

With patients such as Angela, although she is not deemed to be psychotic, the neurotransmitter shifts in low-weight individuals are often very much altered from baseline. A clue to her personality (whether it shifts or remains very much entrenched over some period of time) would need to be assessed by the medical or psychiatric team and reviewed by the ethics committee. Have a variety of eating disorders and other inventories of psychological functioning been conducted during the hospitalization? From the parental perspective, has there been a change in Angela's personality? Is she now isolating, irritable, angry? How different is Angela's behavior from a "normal" 18-year-old, recognizing that few teens are as pleasant as their preadolescent selves?[8]

"Angela has a manipulative character" is thus open to question as well. This is the universal state of an entrenched AN patient.[9] The goal as seen by the patient is to either maintain current weight or lose more weight. Any loss is, in her eyes, the new norm, to be defended against any further rise. At times, willful deviousness, as interpreted by the uninformed observer, is thought to be a constant quality of that individual's character, whereas the literature indicates that such characteristics are induced by aberrant neurotransmitter changes.[10] A typical AN patient is intellectually competent and often remarkably bright, until weight decline renders the severely starved brain hypoglycemic and confused. Almost before the final decline to near-death weights, the AN patient is fully engaged, demonstrating obsessive, seemingly bizarre, entrenched behavior, while defending an untenable weight. This might be viewed as suicidal behavior, if it were not associated with the changes seen in extreme starvation. Most remarkably, AN individuals are of the opinion that they look just fine; patients are genuinely astonished when hearing a comment about their extreme thinness. If family members voice their concern, the individual typically responds with annoyance or secretive dismissiveness.

Unusual behaviors seen at such low weights can include taking hours to eat

https://doi.org/10.1017/S096318011200014X Published online by Cambridge University Press

a relatively small amount of food, hiding food, chewing and spitting out food, extreme care in grooming and dressing, cooking elaborate meals for others but eating nothing themselves, never eating with others (nibbling relatively noncaloric foods only in private), taking vitamins or minerals, filling up on liquids (vitamin waters, tea, coffee, etc.), and eating only rigidly limited types of foods despite no known allergic issues or food intolerances. Some subset of individuals enjoy being at a restaurant with others but having only salad or noncaloric beverages, or ordering, having several bites, and then taking the largely untouched meal home (most likely to be disposed of). Others shun restaurants, believing that the chef has stealthily introduced extra fat into some dish, hence the wish to only order salads, broiled fish, and so on.[11]

This brings us to the question of forced-feedings. Even if this were possible in Angela's case (which is unlikely, even with some type of coercive restraints, considering the questionable issues raised by forced-feeding regarding compassionate care of a conscious patient), the weight gain would almost certainly be temporary. The food would need to be provided very carefully, with small increases over time, due to her extremely low weight, to avoid organ failure, liver function issues, and so on. Furthermore, she would need to be monitored so that her weight gain could be maintained for at least a year at a BMI of 18.5. Guarding against departure against medical advice can become a problem, because a patient has a right to leave, unless there are legal constraints. Angela would very likely still require several years of team care via psychotherapy, group therapy, a primary care physician or team, and nutrition counseling.

A review of Angela's case would need to take into account several complex questions and issues:

- What is the long-term duty of the medical care system to provide such skilled, multifaceted care after Angela's seven years of relentless decline into this medically, neurologically altered state?
- What is the ethical duty of the state, the family, and the insurance carrier to provide ongoing, regular care for one individual, recognizing the enormous financial burdens and uncertain outcome of such care?
- Another ominous issue raised in the eating disorder literature is that of relapses, which occur sometimes years after the initial successful treatment, in what seems to be a decidedly vulnerable population. How much vigilance is her family and the medical care system required to provide over a lifetime? If a further severe relapse occurs, what then?
- Is there a role for early care in an assisted living setting, with removal of some degree of autonomy in someone who is intellectually competent, but exhibiting truncated judgment with respect to food, a most basic requirement for self-preservation?

There may be a role for the declaration of incompetence in this instance, and in other such individuals, because technically they do become a danger to themselves, and perhaps others, under certain circumstances such as driving. Could such a partial power of attorney be rendered, to be invoked only if weight declines to a certain level? By what means would such a contract be established? Could it be used as an incentive to weight gain and maintenance in this or other such individuals? How could it be maintained over time unless the patient were in a supervised living setting over the long term?

For Angela, without knowing a myriad of essential facts, my opinion is that even the option of assisting in developing

https://doi.org/10.1017/S096318011200014X Published online by Cambridge University Press

a treatment plan by which she could abide, and that the healthcare system would endorse, is quite dismal. Cultural factors that are not clear also enter into the analysis. In Germany, is an 18-year-old deemed to be an adult? Would her judgment or lack thereof be subsumed under an age-related norm stating that her youth precludes her own ideas being considered as part of the equation? It is known that the teen brain develops to an adult state somewhat earlier in girls than in males,[12] but is this the case in a starved brain?

Given this array of issues, an ethics committee may be of immense help in assisting the medical care team in arriving at a consensus—under best circumstances. However, if no consensus could be developed regarding a plan that states the duty and wishes of patient, parents, and the medical care system, it might be necessary for the judicial system to make a final decision about whether this patient's wishes to be provided with nothing but palliative care would be the only way to stay the swinging pendulum of this decision.

Notes

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11. See note 6, Agras 2010.
12. See note 8, Kotler, Cohen 2001.

doi:10.1017/S0963180112000151

Commentary: Where Ignorant Armies Clash by Night

Leonard C. Groopman

When I think about and imagine treating Angela—smart, skeletal, manipulative Angela—I am at my medical and moral wit's end. After a while I have a hard time telling the difference between treatment and torture, between therapy and punishment. I don't know what palliation can mean in the face of Angela's will to mortify her flesh. What is palliation, other than a word we use to soothe ourselves, when Angela's very purpose seems to be to suffer? I feel torn between violating her will by forcing her to eat (in the name of beneficence) and getting rid of her by discharging her (in the name of respecting her autonomy).

Angela does not tell us very much, and what she does we cannot rely on; she prefers to show rather than to tell. If I could get a handle on Angela's internal world, perhaps I would have

https://doi.org/10.1017/S096318011200014X Published online by Cambridge University Press