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Is Resistance (N)ever Futile? A Response to “Futility in Chronic Anorexia Nervosa: A Concept Whose Time Has Not Yet Come” by Cynthia Geppert

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As a former chronic, treatment-resistant anorexic, I would like to preface this commentary by saying that that I am incredibly grateful that mine was not considered a futile case despite meeting the widely accepted criteria of the time (Draper 2000). I also agree with Geppert’s (2015) conclusion that the illness itself may compromise a chronic patient’s ability to make a fully competent decision to reject treatment in order to continue to “live” with anorexia, to the extent that overriding her¹ autonomy can be justified under weak paternalism, a view I have argued for strongly in my own work on the topic (McKinney 2010). I would also add that while treatment resistance should not be conflated with treatment futility, it must also be recognized that the illness provides benefits that are valuable to the patient (Abbate-Dega et al. 2013), including membership in a ready-made—and highly judgmental and competitive—community. As Sacha Kendall has argued elsewhere (Kendall 2014), the diagnosis of anorexia affirms such an anorexic “identity” while simultaneously justifying the assumption that patients are unable to make competent (negative) decisions regarding their own treatment. Such actions reinforce resistance to intervention, and if we are going to successfully impose treatment in such situations it is important to understand the significance patients place on the illness and the risks and fear that accompany giving up an anorexic identity.

However, complete rejection of the concept of treatment futility, particularly qualitative futility, risks forcing a small but significant group of chronic patients into an intolerable situation. Although Geppert concedes that the wishes of a capable chronic anorexic to refuse treatment should be legally protected, she then goes on to question whether such a patient exists. It can be (and has been) argued that because the reason that weight gain is unbearable is rooted in the illness, the anorexic’s decision to refuse life-sustaining treatment is not freely made and

therefore the state’s interest in protecting life justifies intervention (viz. Case E, cited by Geppert). However this interpretation fails to recognize the reality of living with long-term anorexia. Regardless of an anorexic’s willingness or otherwise to undergo treatment, the process of recovery is traumatic and distressing. Imagine that you suffer from a phobic fear of snakes. In most countries this would not be a major problem; snakes are easily avoided, and you can live quite happily despite this quirk. In India, where snakes are encountered daily, you would be unable to relax or enjoy the normal pleasures of life, work, and family for fear of encountering one of these nightmarish creatures. Imagine then being locked in a room full of snakes three times a day as “desensitization” therapy. Even knowing this was meant to cure you, intellectual understanding is of little defense against the primal terror that you experience in “therapy.” This is what anorexics feel in an inpatient treatment unit. You are confronted with the challenge of having to put food in your mouth,² while being constantly supervised to ensure you do: Not only are you breaking all the anorexic rules, other people *know* that you are. In addition, you are prevented from carrying out any of the activities that allow you to compensate for eating, so you live with the constant knowledge that every calorie that you take in will eventually manifest itself physically as weight gain. Now not only will the people who see you eat know that you do, so will everybody else. They will see and hate you for the greedy, lazy, selfish person you really are, or decide you are fine and have no problems and expect you to cope on your own.

In the short term this can be survived, if you have a genuine hope that things will eventually get easier. What if, however, you go through the process of weight gain and therapy (with its accompanying guilt and self-loathing), only to find all the rest of the thoughts and feelings remain even though you are “healthy”? The more cycles of

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1. Although anorexia affects both males and females, I use the female pronoun in this commentary for the sake of clarity.
2. And not just any food, *forbidden* food.

this you go through the less possible escape from the nightmare you live in seems and the harder it is to endure the slow, painful process of starvation. For some people, death feels like the only solution, and they may refuse life-sustaining treatment because they consider their quality of life so poor and the prospect for recovery so slight that they want to be allowed to die. Even if there is a small possibility that some future treatment might eventually be successful, the pain of life with the illness and the burden of therapy (and its consequences) outweigh the low probability of this occurring.

In such difficult cases, it is critical that we establish a framework to balance the patient's desire to die against legitimate concerns about allowing somebody whose autonomy is at least questionable and for whom potentially effective therapy may be available to refuse treatment. Such decisions need to take into account a broad range of factors. First, in order to be considered competent, she must make this refusal at a stage where her cognitive ability is not too compromised by her physical state. She must understand that this refusal is likely to lead to her death, that this is what she really wants, and that she has been consistent in communicating this desire. Her decision would need to be based not on pathological values regarded as arising from the illness itself, such as preferring death to gaining weight, but on a realistic assessment of both her current quality of life and the low probability of any therapy succeeding.

In addition, it must also be recognized that in such situations an end-of-life decision has profound implications for others, particularly family, that the patient may not have fully considered. Because the consequences of such decisions are irrevocable, and death is entirely preventable, the consequences for the family in particular are likely to be considerable. The difficulty lies in establishing an ethical and clinical framework for such decisions when treatment can be considered qualitatively futile. As Geppert rightly argues, this needs to be more than an arbitrary set of conditions such as duration of illness. A history of treatment resistance is not in and of itself sufficiently flexible to accommodate the numerous variables that contribute to a person's response to therapy, including quality of treatment received and exhaustion of all available therapeutic options. In my case it was more than 12 years before I began to recover, and I experienced numerous failed interventions at different times, including behavior modification (a reward/punishment system), Freudian, group, individual, occupational, and cognitive behavioral therapy. The successful treatment program was far more comprehensive than any I had previously experienced.

In addition to considering factors such as duration and severity of illness, response to prior intervention, and whether all other options available had been exhausted, I favor the assessment of procedural and psychological competence suggested by Margery Gans and William Gunn

(Ganns and Gunn 2003) in such situations (mentioned but not directly addressed in Geppert's article). This combines both cognitive and emotional assessments of the patient, including her awareness of the effect the choice will have on her family, and whether her family's views on her death confirm or disaffirm her understanding. In the American case on which Gans and Gunn based their criteria, the hospital ethics committee raised questions about the patient's emotional competence. But in direct contrast to the case of E, rather than being used to justify compulsory treatment, assistance was provided to ensure that the emotional criteria were also met before her refusal of treatment was accepted. The advantage of this approach is that it takes into consideration both the patient's desires and the effect that her decision will have on those close to her. It also ensures her family members are psychologically and emotionally prepared for her death.

That said, Geppert is correct to identify the problem of how we assess the probability of treatment succeeding as a critical factor in such situations because the decision to allow an patient to reject further treatment reflects not only an assessment of her current quality of life, but also a belief that recovery in the foreseeable future is highly unlikely, if not impossible. As we understand more about the disorder and develop more effective treatments, such tragic situations should become increasingly rare. But to declare that unless treatment has a 100% failure rate it is never futile is to avoid the hardest question of all. As difficult as it is to say, having lived through the nightmare and survived, sometimes the presumption in favor of life must give way to compassion. ■

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