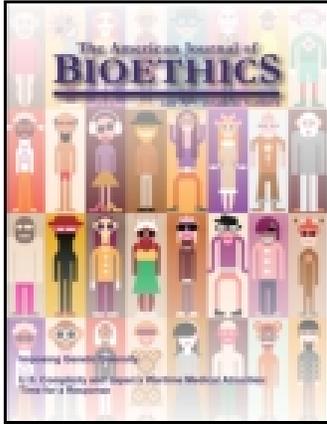


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Compulsory Treatment in Chronic Anorexia Nervosa by All Means? Searching for a Middle Ground Between a Curative and a Palliative Approach

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Compulsory Treatment in Chronic Anorexia Nervosa by All Means? Searching for a Middle Ground Between a Curative and a Palliative Approach

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Geppert (2015) has argued that mental disorders like anorexia nervosa (AN) do not fulfill the classic criteria for futility. We agree with her central thesis that “the contention that an ‘end-stage’ psychiatric disorder exists and can be reliably diagnosed is clinically unsubstantiated and ethically problematic” (36). Therefore, it is correct to refute the applicability of the futility concept to AN. Furthermore, we agree that decision-making capacity (DMC) impairment is often (but not always) an element of AN (Konstantakopoulos et al. 2011).

A question that is not entirely clear in Geppert’s paper is which therapeutic options follow from these conceptual clarifications. Does the option of palliative care collapse if the concept of futility is being refuted, and does forced feeding remain to be the only possible option? With regard to forced feeding, Elzackers and colleagues (2014) have shown that it has a direct effect on short-term survival without worsening the therapeutic relation after compulsory treatment. However, long-term benefits are doubtful and could not be shown in empirical studies (Ward et al. 2014).

Based on these empirical insights and the following case example, we argue for drawing more on resources closer to palliative care in chronic and severe cases of AN, without referring to the concept of futility and while keeping curative options open.

The 18-year-old Ms. W. with severe AN had been an inpatient at the university hospital for 2 months (for a case discussion in German, see Wild and Krones 2010). Her body weight at the time of admission was 24 kg, with a body mass index (BMI) of 9.5 kg/m². There was no acute danger to life due to adaptation of her body to being underweight over the years. However, she had not gained weight and had not reached a stabilization of her general condition since the time of admission. Ms. W. refused treatment, against the opinion of her parents. She showed a comorbid depression and an obsessive-compulsive disorder (OCD).

The patient had suffered from AN since the age of 11. By then, her parents had quickly initiated treatment. Subsequently, Ms. W. had undergone 10 inpatient treatment programs, of which 3 took place in specialized institutions with forced refeeding. At times, she had also given consent for sedation and artificial refeeding. Different therapeutic approaches had not led to enduring amelioration. Despite a high intelligence, the patient had dropped out of school after 11th grade because she had been unable to catch up with the curriculum. She had neither friends nor hobbies. She said that for years her life had only been focused on having to overcome her AN. Ms. W. indicated that she was too intelligent for the therapists, and that nobody had managed to read her face. In previous hospitalizations, she had refused most therapeutic suggestions and had become increasingly difficult to handle. Her behavior toward the staff had been aggressive and abusive at times, and it had no longer been possible to keep her on the ward. A nourishment program was set up in the university hospital. In addition, her depression and OCD were treated. The compliance was poor, and she cheated to achieve higher values on the scales.

After extensive discussions with her parents, she agreed to enteral nutrition, but after only 10 days, the patient decided for discontinuation again. A compulsory sedation and refeeding of the patient was considered until a stable general condition would be reached. At first, Ms. W. gave consent but then withdrew it. Also, the attending physicians decided against a compulsory treatment because she was not in sufficiently good physical shape to allow safe refeeding under sedation. The patient voiced that she would rather die than undergo further treatment. She didn’t want to be forced into eating any more. She wanted to finally be left alone, even if she had to confront death. Her parents insisted that everything had to be done for their daughter to at least reach a stable weight. According to them, Ms. W. would be less depressed and show

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more compliance at a higher weight. The parents imploringly begged the attending physicians for a compulsory treatment of their daughter. Occasionally, the father threatened the physicians with legal steps in case treatment was abandoned. The attending psychiatrists declared that Ms. W. possessed the DMC for refusing any further treatment with the risk of dying as a consequence. An externally consulted psychiatrist confirmed Ms. W.'s DMC in this regard. The care team stated that the patient was a master of manipulation and that her wish to end treatment was simply a result of the AN itself, and therefore that her DMC could not be given. However, the patient was very tiring for the care team, to the extent that they asked for the patient to be relocated to another unit. Ultimately, she was relocated to a unit that agreed to refrain from measures that involved forcing or controlling the patient's behavior, but that tried to gently accompany her in a process to revive the motivation to gain weight again. After some weeks, the patient decided for hospice care. It was a difficult step for the treating team, but ultimately everybody agreed. Shortly before organ failure, the patient expressed a wish to live and to try to gain weight, which she did. After a stable phase of more than a year in the ambulatory setting, the patient returned to the palliative care unit uttering that she now wanted to be admitted for end-of-life care. Her parents were terribly sad but also agreed. Ms. W. was offered best palliative care, concomitantly offering food and drinks, which she constantly refused. She finally died 1 week after the second admission.

This case study supports our argument based on the empirical insights expressed earlier that compulsory refeeding should not be the standard last resort even when DMC is in doubt. The determination of DMC strongly depends on the diagnostic methods and on the personal values of the assessing professionals (Hermann, Trachsel, and Biller-Andorno 2015), and changes over time according to the patient's actual condition (Trachsel, Hermann, and Biller-Andorno 2014).

Furthermore, we argue that refeeding should not be the last resort even though we agree that AN does not fulfill the classical criteria for futility (see Pope 2012). Although we think that the application of the futility concept is not appropriate, we also consider a dichotomous confrontation of palliative treatment (especially if only understood as hospice care) versus curative approaches (which involve measures such as forced feeding) toward AN to be not constructive for the sake of the patient. Palliative care does not mean that a patient has reached the very end of her or his life. Instead, palliative care is

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization [WHO 2014], n.p.)

The need for pain and symptom control is not dependent on remaining life expectancy. According to Russon

and Alison (1998), "palliative care does not mean giving up" (196), and in fact, cooperation between medical palliative care specialists and other disciplines can lead to optimal patient care without reducing survival chances.

Thus, in some cases of AN, we argue for drawing more on resources closer to palliative care. In the case of Ms. W. and similar patients (chronic, severe, and refractory AN; DMC in doubt) we suggest a provisional change of the therapeutic setting to empathic communication and attendance (e.g., Pollack et al. 2015) with elements of motivational interviewing without pushing or forcing the patient in the direction of weight gain. Our case study aims to show that this approach not only honors the strongly expressed personal preferences better (even if these are influenced by the disease itself), but may also yield better therapeutic results while emphasizing quality of life. At the same time, the option to return to an explicit curative therapeutic path remains wide open. ■

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