Cambridge Quarterly of Healthcare Ethics (2024), 33: 4, 558–569
doi:10.1017/S0963180124000367

CAMBRIDGE UNIVERSITY PRESS

RESEARCH ARTICLE

"Terminal Anorexia", Treatment Refusal and Decision-Making Capacity

Anneli Jefferson

School of English, Communication and Philosophy, Cardiff University, Cardiff, UK
Email: jeffersona1@cardiff.ac.uk

Abstract

Whether anorexic patients should be able to refuse treatment when this refusal potentially has a fatal outcome is a vexed topic. A recent proposal for a new category of "terminal anorexia" suggests criteria when a move to palliative care or even physician-assisted suicide might be justified. The author argues that this proposed diagnosis presents a false sense of certainty of the illness trajectory by conceptualizing anorexia in analogy with physical disorders and stressing the effects of starvation. Furthermore, this conceptualization is in conflict with the claim that individuals who meet the diagnostic criteria for terminal anorexia have decision-making capacity. It should therefore be rejected.

Keywords: anorexia nervosa; decision-making capacity; physician-assisted suicide; terminal illness; treatment refusal

Introduction

While many people suffering from anorexia nervosa recover, some suffer from the condition for years or even decades and some die. Recently, Jennifer Gaudiani and colleagues proposed a new diagnostic category of "terminal anorexia" for patients who meet the following criteria: they are over 30, have persistently engaged with high-quality multidisciplinary eating disorder treatment, have decision-making capacity and clearly state their understanding that further treatment will be futile and that cessation of treatment will lead to death.[1] In cases of terminal anorexia, the authors argue, the patient should have the option to move to palliative end of life care or medically assisted dying, rather than receiving further treatment or dying on their own without access to care. In one of the case studies discussed in the article that proposes the new diagnosis, the option to move to palliative care is not only presented but the patient is also encouraged to take this route.

The terminal anorexia diagnosis seems to provide an option for accepting treatment refusal and even physician-assisted death that sidesteps the vexed question of whether these steps can be justified for mental health conditions purely on the basis of suffering. The idea that death may be preferable to (apparently) incurable mental illness has been defended by philosophers and clinicians[2] and has influenced legislation in countries like Belgium and the Netherlands, where assisted suicide for severe mental health conditions is legal.[3] But many are troubled by the idea of allowing euthanasia for mental health conditions. If there were such a condition as terminal anorexia, discontinuing treatment could instead be justified on the basis of futility, without having to make morally fraught judgments about quality of life. It will also provide a path to assisted dying in countries where only terminal conditions come with a right to physician-assisted suicide.

The proposal to label some cases of anorexia as terminal has drawn considerable criticism from clinicians, researchers, and people with lived experience of anorexia. In this article, I argue that this proposed diagnosis in essence tries to solve the moral problem of when to allow a patient to discontinue

treatment in a way that makes it seem ethically palatable by introducing a scientific-sounding diagnosis that invites associations with paradigmatic terminal illnesses such as late-stage cancer or dementia. This helps doctor and patient gloss over the fact that there is no such certainty of death in anorexia. A careful analysis of the wording of the proposal shows a vacillation between two different interpretations of what is happening in cases of so-called terminal anorexia: on one understanding, the patient understands that death is inevitable, the inevitability of death is a fact that holds independently of the patient's attitude to treatment, particularly weight restoration, and treatment refusal merely hastens death. However, a second, more accurate interpretation of the situation we find in severe anorexia acknowledges that terminality is not independent of the individual's beliefs and attitudes, only if the patient and clinicians give up on treatment does death become inevitable. The proposed diagnosis therefore relies on conceptual ambiguities in an unacceptable way which also has the effect of obscuring the questions of whether and when informed treatment refusal in anorexia is possible.

Furthermore, there is a danger that in labeling anorexia as terminal, the dynamic of the condition is shifted in such a way that terminal anorexia becomes a self-validating category: by pronouncing a condition terminal, doctors are creating a new reality. Ian Hacking has characterized mental disorders as looping kinds,[4] which means that they are responsive to the way they are conceptualized. So, anorexia that is characterized as terminal thereby becomes significantly more likely to be terminal because the label influences patients and clinicians felt ability and willingness to try to overcome the condition. The interaction between the label and the way the condition manifests has been stressed by people with lived experience of anorexia, who have emphasized the importance of medical experts' judgments on curability and prognosis for the ability of those suffering from the condition to envision recovery as possible and to work toward it. They also stress the way the label may interact unhelpfully with preexisting thought patterns in anorexia.[5]

These factors provide strong reasons to reject the proposed diagnostic category. Nevertheless, much can be learned from considering what the conceptual problems with the proposal are: my analysis highlights the problems that arise when we focus on the wide-ranging physical effects which reinforce the psychological features. This can lead to confused thinking about treatment refusal, which is seen as a result of malnutrition and the illness trajectory while at the same time being characterized as a competent decision. These characterizations are in tension with each other. This means that a terminal anorexia diagnosis cannot replace difficult moral decisions concerning ongoing suffering and patient autonomy.

The article is organized as follows: In the section "The proposal," I outline the proposal and some preliminary criticisms from the literature. In the section "What makes anorexia terminal?" I discuss problems with the way terminality is defined in the proposal, then I turn to the question of whether individuals suffering from anorexia (generally) have capacity to refuse treatment in the section "Refusal of treatment and decision making competence in anorexia." Finally, in section "Decision making capacity and the characterization of terminal anorexia," I argue that the way terminality is defined together with the heavy emphasis on the physical aspects of malnutrition is at odds with the statement that patients who meet the other criteria for the terminality diagnosis have capacity to refuse treatment.

The proposal

Let me start by stating that irrespective of my assessment of the value of their proposal, I take Jennifer Gaudiani and colleagues' proposal of a terminal anorexia diagnosis as a good faith intervention in a difficult area of medical decision-making.[6] The question of how to approach anorexia sufferers who are on a trajectory that looks likely to end in death and who have had enough of fighting against their condition is a difficult and serious one. Even so, I will argue that the terminal anorexia diagnosis is conceptually confused and has great potential for harm.

With this in mind, let us have a look at the four proposed clinical characteristics of patients with terminal anorexia nervosa that Gaudiani et al. put forward. These are:

1. A diagnosis of anorexia nervosa
2. Age of 30 or older

3. Prior persistent engagement in high-quality, multidisciplinary eating disorder care
4. Consistent, clear expression by an individual who possesses decision-making capacity that they understand further treatment to be futile, they choose to stop trying to prolong their lives, and they accept that death will be the natural outcome.[7]

The authors state that "Some deviation within the second and third characteristics is to be expected and must be individualized to the patient situation. However, the first and fourth must be met in full."[8] While this is not the vocabulary clinicians favor, we may assume that what is being said here is that the four criteria are jointly sufficient for a diagnosis of terminal anorexia, and that both 1 and 4 are also *necessary* criteria.

Criteria 2, 3, and 4 have all generated heated discussion. Clinicians and service users have questioned the assumption that age is predictive of mortality, which is implicit in criterion 2.[9] There has also been significant criticism and questioning of criterion 3, with a common refrain in commentaries being that it is precisely because people have not received high-quality care in the past that their anorexia has become so intractable. Angela Guarda and colleagues point out that in-patient treatment with weight restoration is considered to be high-quality care and that two of the patients the Gaudiani and coauthors present in their case study did not receive that kind of care:

> For adults who have not responded to outpatient care, inpatient treatment in a behavioral specialty program is recommended and achieving a healthy weight in intensive treatment is the strongest predictor of recovery. Concerningly, two of the cases described by Gaudiani et al., were offered PAS [physician assisted suicide] without ever receiving adequate inpatient specialty care.[10]

Sam Sharpe and coauthors point out the lack of accessibility to high-quality care, but also the fact that a general definition of high-quality care ignores many cases where care provision was traumatizing for individual patients, especially when it involved forced treatment.[11] These are important topics and various stakeholders have made valuable contributions. In this article, I want to focus on criterion 4 as well as the question what justifies the label "terminal."

What makes anorexia terminal?

The criteria for when patients should be considered to have terminal anorexia are supposed to provide some guidance for hospice and palliative care. Rather puzzlingly, there is no mention of expected survival time in the criteria, though in a number of places the authors define anorexia as terminal if it is likely to lead to death within 6 months: "consistent with literature on duration of life during hunger strikes resulting in death, a prognosis of less than 6 months can fairly be established when the patient acknowledges further treatment to be futile and stops engaging in active recovery work."[12]

While the 6-month period is common in definitions of terminal illness for conditions such as cancer, it should be pointed out that even definitions of terminal illness for bodily diseases are not as uniform as one might expect.[13] Importantly, a period of 6 months life expectancy is also considered a precondition for medical assistance in dying (MAiD) or physician-assisted suicide in some of the jurisdictions that permit it, such as Oregon. Given the aim to make MAiD available to some patients with severe anorexia including two of the individuals the authors present in their case study, it is likely that one of the motivations for choosing the 6-month window is that it is required to allow for the in principle possibility of medically assisted suicide in these regions.

But what does it mean to say that anorexia will lead to death in 6 months? It cannot be enough for a condition to be considered terminal that the untreated condition will lead to death. Otherwise, any condition that can be managed by medical intervention but would otherwise be fatal in short order would be terminal. For example, kidney failure would be terminal, as it will lead to death without dialysis or a kidney transplant. But that is not how the term is normally used. Rather, the claim is that treatment itself will be futile, that the most it can do is slightly extend the life period.

This, of course, raises the question of how we can be sure that a condition will be fatal. It is tempting to exaggerate the contrast with the certainty we can have in classic terminal conditions such as various

forms of cancer. Even for terminal cancer, the prognosis is often uncertain, especially when it comes to making precise predictions of the patient's remaining life span.[14] Most readers will be aware of remaining life-span predictions for individual cancer patients that were proven wrong. But when a condition is declared terminal, the expectation is nonetheless that treatment can only slow down the inevitable process of death from the disease and there is an according shift in treatment method.[15] A further point worth drawing out is that terminality is not a fixed property of diseases—as our treatment options change and medicine progresses, conditions that used to be terminal no longer are. We have seen this shift in the curability and consequently, whether diseases move to a terminal stage, in cancer but also, notably, in AIDS over the past decades.

Terminality is not commonly something that is diagnosed for mental health conditions. However, in their definition, the authors try to move our conceptualization of some cases of severe and enduring anorexia toward that of physical terminal conditions where death is the predicted outcome. This can be seen by the fact that anorexia is described as a metabolic disease in a way that contrasts it with other mental health conditions: "Indeed, highly regarded eating disorder authorities now consider AN to be a 'metabolo-psychiatric condition,' a claim not generally made for the other psychiatric disorders listed. No one would argue that metabolic disorders can't progress to terminal phases."[16]

The authors are in effect trying to produce a kind of gestalt shift in the way these cases are conceived. Rather than considering them as psychiatric disorders in need of psychological/behavioral treatment, they should be considered as metabolic disorders which, at a certain stage of the illness, have a certain expectable trajectory and can rightly be characterized as terminal before the affected individual actually dies. We can see this in another aspect of condition 4, where it is stated that the individual needs to "understand that further treatment is futile." This phrase suggests there is an independent fact about treatment outcome that the patient comes to realize.

We can see this conceptualization of what is at stake in the notes of the third co-author of the Terminal Anorexia paper, Alyssa Bogetz. Bogetz asked to be included as a co-author posthumously, as she was suffering from severe anorexia and in the final stages of her life when the paper was written and it was published after her death. Bogetz noted down her thoughts about her situation and the condition which were incorporated into the paper. (During this period, she obtained the means to be able to take her own life through medication but did not in the end take the medication, as she died naturally.) I quote her thoughts on terminal anorexia at some length:

> Anorexia specifc—for me, a big issue that caused most ethical debate was whether my case of anorexia nervosa was "reversible." Many physicians misunderstand SEAN (not even an official DSM diagnosis) and that while anorexia nervosa is a psychiatric illness, it comes with severe medical complications that ultimately are the reason for death. Some of the physicians I worked with could not believe my illness was indeed terminal, but rather felt that there would be something that could be done to reverse the physical damage done to my body that would somehow lengthen my life (even if not for very long—i.e., 1 year).[17]

What we see here is a foregrounding of a perceived unavoidability of death and the physical damage that results from extreme starvation. It is indeed true that psychiatrists can be unwilling to discontinue treatment even in the face of apparent futility.[18] However, it is unclear what evidence against the possibility of physical recovery Bogartz is drawing on.

As Simona Giordano[19] points out, death can be avoided by putting the patient on a drip or a feeding tube. Furthermore, it is very hard to predict when damage to the body is such that death is to be expected. In a lived-experience response to the terminal anorexia diagnosis, Rosiel Elwyn recounts that "Throughout my ED treatment in inpatient and outpatient services, I was repeatedly told by clinicians that I was 'beyond clinical help'. I was told that my AN would be fatal, and that my death was predicted within weeks, months, or a few years."[20]

Sharpe and coauthors point out that while Gaudiani and colleagues claim that anorexia can rightly be considered terminal because extreme malnutrition will lead to death they also refuse to give clear physiological criteria for terminal anorexia.[21] None of the criteria in the diagnosis provide physical

markers that would distinguish terminal from nonterminal anorexia. Furthermore, a recent study has investigated whether patients that would meet the terminal anorexia diagnosis show specific physiological markers. The authors of the study claim that there is "a pattern of biological objectivity and increasing network density of disease-related parameters within truly terminal illnesses that should replicate across the definition of terminal."[22] However, they found that patients who would meet a terminal AN diagnosis according to Gaudiani et al.'s criteria show more variability on biomarkers associated with terminality (white blood cells, markers for liver function) than a control group with anorexia that did not meet the terminality criteria when admitted to treatment. They also found that physical improvement with treatment was equally good for both groups. It therefore seems that there is no physiological marker of terminality that corresponds to the proposed diagnosis.

What follows from the above discussion is that the inevitability of death posited by the diagnosis is not down to physiological facts, despite the language that suggests this. It is instead inextricably linked to *continued* lack of nutrition.[23] Furthermore, this is an inescapable feature of the account, because while the fact that starvation naturally leads to death plays an important role in making a claim of terminality, it cannot do the work on its own. What makes anorexia terminal is that *if* the disease continues without intervention or unexpected and unlikely change in attitude to treatment and eating, the person will die. The insistence on the closeness to metabolic diseases in distinction from other psychiatric illnesses obscures the crucial fact that anorexia is only terminal and treatment is only futile if the patient feels that they can no longer engage with treatment. Treatment futility is not an independent fact that a patient merely observes, it depends on the patient's attitude and behavior. This does not mean that there may not be situations where the patient feels they can no longer engage in treatment (more on this in section "Refusal of treatment and decision making competence in anorexia"). Rather, it means that the patient's attitude toward nutrition plays a pivotal role in diagnosing terminality. Cancer can be terminal whether or not the patient continues to embrace and want treatment. Anorexia cannot.

This claim should however not be read as a naïve assertion that anorexia patients should just eat and then everything will be fine. There are good medical and psychological reasons to stress the impact of anorexia and malnutrition on both the body and the individual's psychological processes. Severe anorexia can have long-term health implications, even if individuals do recover. Furthermore, one of the benefits of describing anorexia in strongly physical terms and stressing the impact of malnutrition on the body in general and the brain in particular is that it highlights the difficulty anorexic individuals experience in eating and how anxiety laden a process this becomes. Guidance for eating disorder sufferers and for carers highlights the fact that malnutrition entrenches anorexic thinking and makes recovery harder. For example, the Maudsley guide to eating disorders for carers states that: "One of the reasons that people become stuck with an eating disorder is that brain damage resulting from starvation makes it more difficult to change."[24] However, there is evidence that brain changes brought about by starvation are reversible[25] and that some psychological symptoms improve with weight restoration.[26] Knowledge of brain changes can supplement and reinforce our understanding of psychological difficulties in decision making, even though it cannot replace a detailed psychological description and analysis of agential capacities.[27] So, it is important not to neglect the influence of starvation on the mind and on decision-making when considering a patient's ability to accept and participate in treatment.

Nevertheless, the way anorexia is reified as a metabolic condition in the proposed terminal anorexia diagnosis is problematic in that it glosses over the reversibility of the psychological and physiological trajectory of continued starvation. The fact that weight restoration makes a difference to the ability to engage with psychological treatment explicitly contradicts the narrative of a preset illness course. Importantly, it also casts some doubt on the feasibility of criterion four, which states that terminal anorexia is compatible with informed consent or informed treatment refusal. There are two questions here: One is the more general question of whether patients in the grip of severe anorexia do have decision-making capacity, specifically the capacity to refuse treatment, as Gaudiani and colleagues suggest in their criteria. The second one is whether the narrative that treatment is futile because of the effect the condition has on the ability to engage with treatment is compatible with the further claim that patients have decision-making capacity. These questions are important in order to assess the internal consistency of the

proposed diagnosis. But they are also of moral importance, as the expressed aim of the terminal anorexia diagnosis is to make moving to palliative care or accessing MAiD easier.

I will start by discussing the issue of decision-making competence in anorexia generally. Generally, refusal of treatment, a request for MAiD (where this is legal) or palliative care requires decision-making capacity/competence. I will then turn to the more narrow issue of whether the claim that patients with severe anorexia nervosa have decision-making capacity is compatible with the way terminal anorexia is characterized by the authors.

Refusal of treatment and decision-making competence in anorexia

Patients normally have the right to refuse treatment, even if such refusal can be detrimental to the course of their illness and in some cases even be fatal. However, this right to refuse treatment does not obtain if the patient lacks decision-making capacity. Patients can be judged to lack decision-making capacity due to a mental health problem, but also in cases of immaturity, as is the case with young children, or cognitive disability. Nevertheless, as Jacinta Tan and colleagues mention, some forms of forced treatment are permitted by the Mental Health Act in the United Kingdom.[28]

Whether patients suffering from anorexia should have the right to refuse life-saving treatment has been debated extensively in the literature. Normally, this discussion takes the shape of considering the question of whether patients have decision-making capacity,[29] though there are also people who claim that decision-making capacity should not be the sole deciding factor.[30] A further question which affects the permissibility of compulsory treatment is whether it benefits the patient. Given that compulsory treatment is, at the very least, morally contentious, it is important to know whether it is likely to benefit patients in their recovery. If it only prevents short-term deterioration but causes problems in treatment acceptance and the therapeutic relationship which undermine recovery further down the line, this would undermine justifications that propose a trade-off between respecting patient autonomy and benefiting the patient.

As a matter of fact, refusal of treatment by anorexic patients is not always respected and compulsory treatment does occur, for example, in the form of nasogastric tube feeding. This may seem surprising at first glance, because decision-making capacity, which is required to refuse treatment, is normally thought to require an understanding of the medical facts and the consequences of treatment/nontreatment, and individuals suffering from anorexia have this understanding. The criteria generally listed for informed consent to medical treatment, that is, the ability to make and express a choice, the ability to understand and appreciate the choice and the ability to reason about the facts,[31] all seem to be present in anorexic patients, at least at first pass. As Tony Hope and colleagues point out, on a (superficial) way of looking at their decisions, individuals suffering from anorexia just have very unusual (and self-destructive) preferences, in that they sometimes fear weight gain more than they value staying alive, but do intellectually understand the consequences of not eating and refusing treatment that leads to weight restoration.[32]

Leaving aside purely patient benefit-focused justifications for forced treatment, let us look at capacity-oriented arguments. One justification for overriding treatment refusal stems from the intuition that prioritizing thinness over survival must be a decision that is best explained as being caused by the condition or expressive of mental ill health, rather than being the individual's authentic, competent choice. We can see an analogy to an argument presented by Hane Maung,[33] who argues that suicidal thoughts are frequently understood as constitutive of depression (not as a necessary part, but a common one). In other words, this conceptualization of the relationship between depression and suicidal thoughts takes the fact that individuals desire death as one of the very features that characterize their thoughts and beliefs *as depressive.* This means that certain desires are labeled as intrinsically pathological. Whether or not it is correct way to think about these issues, this conceptualization clearly has implications for the willingness to contemplate someone's wish to die as a wish that needs to be taken seriously.

Cases of treatment refusal in anorexia are different in that they are not expressive of an active wish for death. (Though we do also have the case where death is explicitly desired.) In cases of treatment refusal

(which may then lead to death), the desire not to gain weight is prioritized over the desire for life.[34] As Jennifer Radden points out, on a purely procedural evaluation of autonomy and decision-making, these desires can be coherent and consistent. This means that we can only ascribe problems with decision-making capacity if we impose external values onto the individual.[35] In contrast, Louis Charland[36] argues emphatically that decision-making capacity can be undermined by anorexia, even if individuals might pass standard capacity tests. His reason for this is that he characterizes anorexia as a disorder of passion, one where the individual is driven by the compulsion to refuse food (or purge, depending on the exact form the condition takes) in a way that undermines their capacity for informed consent/refusal. "[A]t the later stages of their disease, persons who suffer from anorexia nervosa are in the grip of a deadly mental disorder—a passion turned deadly—that leads to disordered feeling, emoting, and thinking. Note that anorectic thinking at this stage is typically designed to rationalize that passion, as it simultaneously consumes sufferers to the point of utter exhaustion."[37]

I would add that both the use of reasoning power to rationalize and justify self-starvation and a behavior driven by fear rather than by considered values occur much earlier in the condition. Anorexia is famously characterized as an egosyntonic condition, particularly in the early stages of the disease, where the costs are not yet quite so stark. But there seems to be a creeping process of agents conceptualizing behavior as under their control when this is no longer the case.[38] Furthermore, Lucy Osler[39] has argued that even early stage anorexia can be driven by fears of the body which is perceived as threatening. But clearly, as thinking patterns become more engrained and starvation takes its toll on the individual, these features become exacerbated.

There is also some doubt whether decision-making capacity in anorexia nervosa can simply be measured by a cognitive test. In some cases, interviews with patients suffering from anorexia seem to show lack of appreciation of the medical facts, as when one participant states that they did not believe that they could actually die from the condition, even though they were aware of the medical facts. Hope and co-authors point out that it is hard to be entirely sure whether the problem lies in understanding the risk or in the salience of that information for the individuals.[40] But they also point out that anorexia can affect decision-making in more unusual ways, by changing values, so that patients care about avoiding weight gain above all else. This is reminiscent of Charland's talk of anorexia as a passion gone wrong.

Tan and colleagues rightly point out that clinicians should not be in the business of prescribing values and therefore endorsing unusual or strange values should not be seen as grounds for denying decision-making capacity. Nevertheless, they try to draw a distinction between authentically held values and those which are an expression of the illness, by pointing to the distinction between previously held values and those that are prominent at the height of the disease. "If a value or value system can be clearly determined to arise from a mental disorder rather than the person, then this value cannot be seen to be authentic to the person himself or herself, and, if it affects treatment decision making, should be considered suspect in terms of compromising competence."[41]

So, we might encounter two different kinds of situations when it comes to decision-making capacity. In the first type of case, the patient refuses treatment outright, based on their anorexic values. They care more about thinness than they care about death. This is where an appeal to the illness as a separate entity which has changed the anorexic individual's values appears to be required if clinicians want to override refusal on the ground of lack of competence. As Charland rightly points out, this decision to override the patient's wishes involves a certain amount of paternalism, because one is in effect making the judgment that certain values are not authentically the patient's own but "the anorexia speaking." Conceptually, this is somewhat problematic. Distinguishing between the individual and their illness is a notoriously vexed issue, and there are good arguments for the conclusion that this distinction is one that is constructed by patients and clinicians rather than being an independent metaphysical fact.[42] Furthermore, if the individual identifies strongly with their condition, the distinction may not be a viable one. The patient may not have an identity that is separate from the illness anymore.[43] In order to avoid dubious claims about what the patient really wants, a justification that appeals to beneficence for the justification of treatment would be the more honest option here.

In the second kind of case, the value of thinness is not endorsed wholeheartedly, but the fear of weight gain is such that the eating disorder sufferer finds it impossible to comply with a weight restoration

programme. The problem is then primarily one of lack of control.[44] Clearly, it is possible to have both anorexic values as described above and fear of weight gain driving decision-making together. A person suffering from anorexia may both value thinness above everything else and fear weight gain to the extent that trying to gain weight would be extremely difficult for them, even if they did not positively value anorexia. The difference between the first kind of case and the second lies in the extent to which the person endorses their anorexic identity and values. This will be important for the discussion of decision-making capacity in terminal anorexia, because it is possible to feel unable to continue treatment and to believe further treatment to be pointless while rejecting anorexic values (to a greater or lesser degree). In cases where individuals are driven by the fear of weight gain, individuals feel compelled by desires they do not necessarily endorse and this makes it extremely difficult for them to take the steps necessary for recovery. The factor undermining decision-making capacity in this case is lack of control over one's decision due to strong emotions.

This parallels the control condition that we find in debates about moral and criminal responsibility, where it is thought that strong emotions but also mental illness can undermine our ability to conform our actions to what we believe to be the right course of action. Because it is so hard to assess when someone's fears or desires make it sufficiently hard to do what they think is right for them to undermine responsibility, this condition is somewhat contested in the criminal responsibility literature. So, for example, it is part of the Model Penal Code but not the M'Naghten rule, both of which provide criteria for when an individual should be found not guilty by reason of insanity in criminal law. Furthermore, on a very narrow understanding of compulsion, agents only lack capacity relevant control if they are literally incapable of performing a certain action or making a certain decision.[45] (The common metaphor is that they would be able to do what they *seem* unable to do if they had a gun held to their head.) But this is an overly restrictive notion of control that does not reflect the notion of impaired control that we find both in the law[46] and in common sense thinking. A similar principle to the one we find in the insanity defence is in play here in that some desires or fears that form part of the mental health condition are thought to undermine agency in such a way that decision-making capacity or responsibility for action are undermined.

Let us now take stock of what we have discovered about capacity to refuse treatment and anorexia before moving on to how this affects the issue of terminal anorexia and discontinuing treatment. What the discussion has shown is that the question of whether individuals with anorexia have capacity to reject treatment is far from straightforward. The fears of weight gain which come with the condition severely restrict what seems possible to individuals. There are residual worries about the authenticity of anorexic values, is this really what the individual wants or are these values better understood as compulsions? This worry remains even if we are skeptical of reifying anorexia as an entity and resist talk about "the illness speaking". All of these factors show that establishing decision-making capacity may be extremely difficult.

Decision-making capacity and the characterization of terminal anorexia

Let us now return to the relation between terminal anorexia and decision-making capacity. Gaudiani and colleagues in condition 4 marry the futility of treatment with decision-making capacity as a precondition for discontinuing treatment:

> Consistent, clear expression by an individual who possesses decision-making capacity that they understand further treatment to be futile, they choose to stop trying to prolong their lives, and they accept that death will be the natural outcome.

The problem with this condition is that this phrasing externalizes the futility of treatment in such a way that it is doubtful that a person can meet that condition while also meeting the understanding criterion of decision-making capacity. In the case of late-stage pancreatic cancer, my understanding that treatment is futile will mean that I understand that, at most, further treatment will slow down the process of dying, but will not reverse the course of the condition. This kind of fact is not available in the case of even very severe

anorexia. Treatment becomes futile if I am no longer able to engage with it. It may well be, that at some point in their illness, a small number of anorexic patients find that they are indeed no longer willing and able to engage, and that after numerous attempts at recovery, they do not feel this is possible anymore. But even in that case, futility is the result of rejecting or giving up on treatment.

More controversially, I would argue that a patient that sees treatment futility as a fact that is independent of their own decision to discontinue treatment does not have the understanding of the situation they find themselves in required to make an informed refusal. This is because they no longer see themselves as a vital contributor to the treatment process whose attitude and engagement matters to treatment success. This is where the terminality diagnosis that presents futility as part of the illness progression is so pernicious. It is in fact, telling people who already have little hope and reduced agency because of the pressures of their anorexic fears and compulsions that the ship of recovery has sailed.

Note that I am not arguing against the claim that for some individuals, there comes a point where holding out hope for recovery is too much to ask. My claim is not that recovery is always possible or that it is never permissible to discontinue treatment or ask for medical aid in dying. It is rather that the very factors that undermine the likelihood of treatment success also undermine the person's ability to refuse treatment in an informed way. A recent court case from the United Kingdom illustrates that it is possible to make a judgment of treatment futility and accede to the patient's wish to discontinue treatment even when decision-making capacity is undermined by the illness. A young woman (age 19 years) who had been suffering from anorexia for years and was severely malnourished asked to discontinue treatment and be allowed to go home to die. The court reached the verdict that she did not have decision-making capacity but that it was in her best interest to be allowed to die, as treatment was unlikely to be successful.[47] This is not an isolated case, there have been several cases where patients have sought discontinuation of treatment the verdict was reached that while they did not have decision-making capacity, it was in their best interest to discontinue treatment or only administer those treatments they agreed to.[48] The reason I mention this type of case is because it illustrates that capacity can be lost and that the same factors causing loss of capacity also undermine the likelihood of recovery. It further illustrates the hard moral and medical decisions that have to be made in some cases of severe anorexia. It is an illusion to think we can draw on a diagnosis of terminal anorexia to avoid these hard problems.

Conclusion

Anorexia can, if not successfully treated, be fatal. I have argued that this does not license the introduction of a new diagnostic category "terminal anorexia". This diagnostic category suggests that there are cases where the condition has become so entrenched as to be terminal and that in these cases, it is justified to move to palliative care and possibly physician-assisted suicide. I have argued that the label "terminal anorexia" cannot play this role in therapeutic decisions as it does not provide any reason to believe that the condition is indeed terminal but instead operates by suggesting an illness trajectory that is independent of patient decisions. It does this by using physical illnesses as the guiding metaphor and aligning the condition more closely with physical conditions through the emphasis on anorexia being a metabolic condition and on the effects of starvation.

In addition, there is a tension between the claim that patients with so-called terminal anorexia have decision-making capacity and the characterization of the illness. In as far as anorexia is fatal, this is because patients find it impossible to engage in recovery. This being the case, the futility of treatment is not an independent fact about the illness trajectory that patients come to realize in the way the proposed diagnostic criteria suggest.

Acknowledgments. I would like to thank Jan-Hendrik Heinrichs, Lucy Osler, Jennifer Radden, Katrina Sifferd, and the audience at an Institute of Applied Psychology Interdisciplinary Series for helpful comments on draft material.

Competing interest. The author declares none.

Notes

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Cite this article: Jefferson A (2024). "Terminal Anorexia", Treatment Refusal and Decision-Making Capacity. *Cambridge Quarterly of Healthcare Ethics* 33: 558–569, doi:10.1017/S0963180124000367