

Egosyntonicity as Pathology in At-Risk Anorexia Nervosa Patients

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ABSTRACT

Can a physician force life-saving feeding treatment on patients of anorexia nervosa? Common intuition finds such an act not only permissible, but perhaps even obligatory. Yet, such cases present as difficult issues for physicians, as a great number of anorexia nervosa patients both refuse such treatment and pass standard tests of capacity. As a result, there seem to be very few grounds on which a physician can prescribe such treatment. Still, there seems to be a sense in which refusing life-saving treatment ought to undermine a patient's claim to capacity, at least in the case of anorexia nervosa. That is, it is highly doubtful that a person not suffering from the disorder would decline such needed treatment; hence, the refusal must be pathological, and the consent capable of being overwritten. However, there are a few reasons to think that such refusals are not pathological. Indeed, recent research by Tan, Stewart, Fitzpatrick, & Hope (2010) suggests that values and beliefs associated with anorexia nervosa are occasionally egosyntonic—that a patient takes the values, behaviours, feelings associated with the disorder as critically part of their personal identity. In this way, the treatment decisions evinced by anorexia patients ought perhaps to be considered with equal force of, say, Jehova's Witnesses refusing life-saving blood transfers: the matter is not so easily dismissed of. The challenge, then, is to locate the pathology of this egosyntonicity; a task made difficult in the face of apparently non-pathological dieting mentalities. In this paper, I argue that narrative evidence supports the pathology of egosyntonicity for anorexia nervosa patients. In particular, that anorexia patients post-treatment recognize the pathology of their apparently egosyntonic values, and that even those who strongly embody the disorder would rather continue to live so that they could live with that disorder. In this light, there are apparent grounds for physicians to force life-saving treatment on anorexia nervosa patients, though I note that the specific pathological determinants of egosyntonicity require further research.

KEYWORDS

Anorexia Nervosa, Bioethics, Consent, Egosyntonicity, Medical Ethics, Paternalism, Pathology, Pathological Identity, Personal Identity

Patients of anorexia nervosa present a difficult problem for standard notions of consent. Whereas anorexia nervosa patients typically pass measures of the capacity for consent, they make decisions which seem to undermine their claim to that very capacity. In particular, such patients typically refuse life-saving feeding interventions, leaving physicians in a difficult situation: the intuition stands that such decisions must be pathologically caused, but our measures of capacity reveal nothing pathological in their ability to make decisions. Where, then, might one locate the pathology of such decisions? In this paper, I argue that our current understanding of the concept of egosyntonicity provides a basis for the forcing of life-saving treatment on anorexia nervosa patients, although further studies into the phenomenon of egosyntonicity are required in order to highlight the specific pathological determinants.

This paper has four sections. In §1, I provide a brief introduction to the difficulties surrounding measures of capacity in anorexia nervosa patients. In §2, I examine some possible responses to the difficulties raised, motivating in particular an exploration of egosyntonicity. Finally, I examine identity and the possible pathology of egosyntonicity in §3, and comment toward future research on the phenomenon. I offer brief concluding remarks in §4.

1. CAPACITY AND ANOREXIA NERVOSA

The question of whether a patient has the capacity to make decisions regarding their healthcare is one which concerns caregivers and ethicists alike. In order to make an informed decision about one's health and care, one must demonstrate the capacity to access the appropriate information and make decisions with regard to that information. Capacity here is usually taken to consist in: (i) presenting a choice about their participation in a treatment, (ii) an understanding of the relevant issues, (iii) rational manipulation of information, and (iv) an appreciation of the nature of the situation (Appelbaum and Roth 1982; see also Marson et al. 1997). When an individual does not demonstrate such capacity, it is often considered permissible for a caregiver to make decisions on the part of that person. Compare, for example: (a) a six year-old child repeats ceaselessly that they do not want to continue their cancer treatment, (b) a thirty-six year-old adult repeats ceaselessly that they wish to discontinue their cancer treatment. Typically, young children are not considered to possess the full capacity to access and interpret life-changing information, such that legal guardians are permitted to

make decisions for them. Hence, the ethical intuition prevails that a caregiver may continue the course of treatment on the child—given the intervention of the appropriate surrogate decision makers—but not on the adult: it is largely considered unethical to make treatment decisions against the will of a patient with capacity for consent, unless there are strong and available countervailing reasons.

Here, anorexia nervosa presents a possible dilemma. Anorexia nervosa is a feeding and eating disorder, with three primary diagnostic criteria: (i) engaging in a restrictive diet with the intent to keep one's body weight below a healthy BMI, (ii) an intense fear of gaining weight, and (iii) a disruption in the way one's body-image is experienced (Brown, Holland, and Keel 2014). Patients of anorexia nervosa often demonstrate full capacity, passing those tests designed to determine capacity in patients. However, many anorexia nervosa patients refuse to eat during treatment, and refuse life-saving treatments, even when a full recovery is likely, a refusal which seems so plainly irrational as to suggest that the patient's capacity is affected (Thiels 2008; see also Watson, Bowers, and Andersen 2000). Yet, those measures of capacity do not locate any failure in capacity on their part. Whereas physicians and caregivers are usually inclined to force life-saving treatment upon patients of anorexia nervosa, there seem no ready means by which to permit the action. Accordingly, to support the intuition that forced live-saving treatment is permissible, we need to locate defeasors for capacity in patients of anorexia nervosa.

2. RESPONSES CONSIDERED

In this section, I consider three apparent responses to the dilemma posed concerning: the inadequacy of the current measures of capacity (§2.1), the possibility of defeasors in the refusal to eat (§2.2), and the possibility of locating defeasors in the refusal of life-saving treatment (§2.3).

2.1 New measures of capacity

A first rejoinder might be raised: if there is wide-spread doubt about the capacity of a patient of anorexia nervosa in refusing life-saving treatment, then surely this may be reflective of the invalidity of current tests. That is, new conditions for capacity might be introduced which can account for the

compromised capacity which is intuitively present in these cases. Yet, a few responses can be made to this suggestion.

Firstly, those measures of capacity which patients of anorexia nervosa pass (in particular, the MacCAT-T) have been measured as having very high validity, both in terms of face validity and of content validity (Dunn et al. 2006; Grisso, Appelbaum, and Hill-Fotouhi 1997; Sturman 2005; Zapf and Roesch 2005). While there may be those who argue otherwise, it is not clear what other factors must be included in the measures of capacity which are not already present. The MacCAT-T, in particular, measures understanding, reasoning, and appreciation of the relevant information for the relevant situation (Grisso, Appelbaum, and Hill-Fotouhi 1997; see also Sturman 2005), and it is not immediately clear what measurable factors could be added to the test without promoting undesirable consequences for its application in other medical cases.¹ Furthermore, these measures of capacity are not just used in a healthcare setting, but also in legal settings (Zapf and Roesch 2005). Hence, an amendment to the measures of capacity would be far reaching, and it is not yet clear (i) what axes of analysis are improperly excluded from current measures, (ii) whether other desired factors are sufficiently quantifiable or measurable, (iii) that intuitions regarding the case of anorexia nervosa necessarily proves the measures of capacity wrong, and (iv) whether the addition of those new measures will negatively impact discourse and function regarding other matters of capacity. While these criticisms are not exhaustive, they indicate that burden of proof falls to the proponent of this position to indicate just how such measures ought to be amended. An argument demonstrating precisely how the tests fail to account for capacity in anorexia nervosa is required before changes in testing and policy.²

In the remainder of the paper, we will explore the ways in which the capacity to consent might be found compromised in patients of anorexia nervosa.

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1. For example, Charland (2006) proposes that the addition of emotions into this framework might account for the differences between test and intuition; but it is unclear what role emotion plays in anorexia nervosa.
 2. Granted, those arguments may still be insufficient to warrant a change. For a further criticism of amending capacity measures—and particularly as regards Tan et al. (2006)—see Grisso and Appelbaum (2006).

2.2 Refusal to eat

Although patients of anorexia nervosa pass capacity measures such as the MacCAT-T, it may be that there is a defeasor for the understanding and reasoning axes³ to be found in the general refusal to eat. Surely, that eating is necessary for living—which is necessary in turn for making decisions which regard the self—suggests that a refusal to eat demonstrates a lack of understanding or reasoning (Cf. Graham 2013, 157–159). This, then, is not directly to say that the measures of capacity are invalid, but that they are too-situational. Indeed, the MacCAT-T was designed in part to be situational and to regard a situation at hand (Grisso, Appelbaum, and Hill-Fotouhi 1997; see also Sturman 2005).

Yet, a refusal to eat is not itself sufficient to undermine one's capacity. Indeed, it is a common trend to diet, with recent surveys citing a dieting incidence in the United States between 20% and 56% (IFICF 2013; NPD Group 2013). Indeed, to consider only a refusal to eat seems insufficient unless we want also to permit the force feeding of dieters. Rather, we might instead consider as irrational the refusal of food *in a life-threatening situation*: surely those who are dieting for aesthetic or health-improvement motivations (etc.), and who do not meet pathological criteria for anorexia nervosa, would not refuse life-saving treatment. We will explore this below.

2.3 Refusal of life-saving treatment

Turning from unqualifiedly refusing to eat food, to refusing life-saving treatment (such as force-feeding) provides us with a narrower scope of analysis, and may serve to discriminate the case of anorexia nervosa from that of mere dieting. Indeed, it seems that a mere dieter would accept food in a life-saving situation, and that a person with anorexia nervosa can be distinguished by their failure to regard the severity of the situation at hand. However, it is not immediately clear that the decisions which patients make not to eat or to refuse life-saving treatment—even if made through skewed value systems, such that patients of anorexia nervosa can be distinguished from mere dieters—arise necessarily from pathological values. Indeed, we do not tend to consider individuals participating in a hunger strike to be irrational or lacking capacity, and forcing feeding upon a person on a hunger strike seems intuitively impermissible,

3. The MacCAT-T does not merely examine capacity holistically, but also categorically, according to those three axes outlined in §2.1.

even when they are facing death—the impact and value of such acts seem to arise from the hunger striker’s knowledge and understanding of the risks of not eating. The challenge, then, is to identify a characteristic of anorexia nervosa that might separate these cases.

Egosyntonicity refers to the sense that a patient of a disorder has of embodying a disorder, or taking it to be an important part of their identity. In particular, many patients of anorexia nervosa indicate that they feel the apparent disorder to be a part of their identity, and not an external matter needing treatment. It seems, then, that the apparent irrational behaviours in which patients of anorexia nervosa participate may arise from these internalized values: a patient who has internalized values of anorexia nervosa and thinness is unlikely to welcome feeding, as it contradicts their very *identity*. Indeed, interviews by Tan, Hope, Stewart, and Fitzpatrick (2006) have found exactly these responses in patients with anorexia nervosa:

Interviewer: Let’s say you’ve got to this point, and someone said they could wave a magic wand and there wouldn’t be anorexia any more.

Patient 1: I couldn’t.

Interviewer: You couldn’t.

Patient 1: It’s just a part of me now.

Interviewer: Right. So it feels like you’d be losing a part of you.

Patient 1: Because it was my identity.

...

Interviewer: What does your anorexia nervosa mean to you?

Patient A: As I said before, it’s quite a lot. It feels like my identity now, and it feels like, I suppose I worry that people don’t know, they don’t know the real me.

As a result, we might be concerned that to grant the right to force treatment on a patient of anorexia nervosa with these values would be roughly the same as to force treatment against a religious individual’s beliefs: it would be to act against those values which a patient has internalized and holds sacred, even if they may pose a threat to their health.⁴ It seems, then, if we wish to identify anorexia nervosa patients as lacking the understanding or reasoning which is relevant for

4. Cf. Jehovah’s Witnesses refusing life-saving blood transfusions. See, for review, Muramoto (1998).

tests of capacity, and if it appears that the reason those patients demonstrate a deficit in reasoning is because they have these internalized values, then it remains for us to demonstrate that the set of values—and one’s egosyntonicity on a whole—is pathological and inauthentic. For, if those values are pathological—if they are causally onset with or after the onset of anorexia nervosa—rather than authentic then there may be basis for rejecting their capacity.⁵

2.4 Interim Summary

Patients of anorexia pass capacity measures, but make decisions which seem incompatible with the capacity for consent. In order to permit caregivers to force life-saving treatments on unwilling patients, we must establish the source of their intuitively compromised capacity for consent. Having identified that egosyntonicity plays a role in some anorexia nervosa cases, wherein patients internalize those values deemed pathological and make decisions with regard to those values, we must determine whether that egosyntonicity is itself pathological. For, if it is pathological, it may provide an avenue for caregivers to identify compromised capacity, which may then find permissible the forcing of life-saving treatments. However, if not deemed pathological, it will remain unclear how one might permissibly force treatment on a patient otherwise deemed to have capacity for consent.

3. IDENTITY AND PATHOLOGY IN EGOSYNTONICITY

Before continuing, it might be argued that taking a pathology-oriented approach fails to fairly regard the patient. For, if these values are egosyntonic and valued by the patient, and if a caregiver is supposed to provide care for that patient, then surely these traits ought not to be considered any more grounds for defeating capacity measures than would those beliefs of a Jehovah’s Witness. By attempting to distinguish those egosyntonic values as pathological, we promote erasure of the patient’s identity. For, in working to rid the individual of those

5. N.B. That one’s set of values or egosyntonic identity is pathological here means only that they are causally intertwined or onset as a result of the onset of pathology. It is not to say that the identities themselves ought necessarily to be seen as inauthentic or requiring a “cure”, nor is that the case of pathologies in general. Rather, it provides grounds here of identifying that the decisions made through egosyntonic values may be disrupted by the disorder and are thus non-representative of the wishes of the temporally extended person, and hence may provide grounds for engaging in paternalism.

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egosyntonic values we might find pathological, we thereby work to remove those very values which constitute the patient: there is no patient left to treat, for in attempting to treat the patient we instead destroy them.

In general terms, the question is a matter of why we ought to prioritize a pathological approach to resolving the issue of permitting force feeding, rather than focusing on the subjective values which the patients hold. More broadly, we must ask how it is that a diagnosis of egosyntonic values as pathological can work at all to permit force feeding in these cases. In what follows, I will analyze narrative evidence which regards the identity of the patient, to motivate a focus on pathology from the perspectives of the patients themselves. Then, using the same data, I will briefly conclude that caregivers may be permitted to force feed individuals suffering from anorexia nervosa, and discuss the limitations of such treatments.

3.1 Identity and Egosyntonicity

The consideration that the pathologizing and treating of a patient's internalized values promotes erasure of their identity is grounded on two key assumptions. The first is that those internalized values critically make up the identity of the patient, such that treating the patient—or at least to consider as defeasible the decisions generated through those values—is to go critically against the wishes of a measurably capable person. The second is that a caregiver's Patient 1s necessarily the individual with whom they are presented, and that the caregiver is not accountable to the pre-onset or post-treatment individual. It is not clear that these assumptions necessarily meet intuitions: though individual mileage may vary, it seems intuitive that a caregiver provides care to the individual as a unified person, rather than the ephemeral entity which presents under care. A physician is accountable to the healthy individual to help return them to health as much as they are to the present patient: they are accountable to persons through time rather than merely at a time. Yet, even if our intuitions are insufficient data, it is clear from interviews with patients of anorexia who have undergone forced treatment that these two assumptions are with little basis. Indeed, even the patients seem to think both that their decisions—made through whatever values they held—were in some regard dangerous and pathological, and that the apparent disorder compromised their decision making abilities (Tan et al. 2010):

Patient 22: I think ultimately beating anorexia has to be a decision that you make yourself. But if your health is so bad that you're dying or you're at risk of very, very severe illness, then I think you should be treated until you can make the decision. Because I think if you're ill enough you can't make that kind of decision.

Patient 30: I think other people should be made to have treatment because you do get to the point where you don't know what's right for you.

Patient 36: I think if somebody's life is in danger and is threatened and they have to go into hospital then yes it's very important to obviously re-feed them and to get them to a stage where they're not, where they're medically stable.

Patients also seem to believe that the forced treatment was of essential benefit to them as individuals following the forced treatment, and for which they express gratitude (Tan et al. 2010; see also Watson, Bowers, and Andersen 2000):

Patient 30: I know last year when I was ill there was no way I would have let anybody do anything to treat me, like for my own choice I would have just carried on losing weight, I know I would have done until I didn't live anymore, but now I hate to think that just because I said "no" I would have been left.

Patient 21: If I had been left without somebody forcing treatment upon me I would have just starved myself to death. So, you know, I wouldn't have got to my target weight and got happy and have things that I'll have in the future.

Patient 20: So then although when I was back there [i.e., very ill] I'd say "no, that's a stupid idea," now being here I look back on

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it, I think “hell yeah, you can’t not treat someone who’s going to die because they’re starving themselves.”

And, other studies have indicated that nearly half of all patients who deny a need for treatment on hospital admission convert to acknowledge that they needed to be admitted and treatment forced, within two weeks of hospitalization (Guarda et al. 2007).

In general, the argument from the post-treatment perspective seems to run as follows. A post-treatment person is the same as the person undergoing treatment, and so decisions regarding treatment for those patients ought also to consider the possible future persons affected by those decisions. While it might seem that a patient of anorexia nervosa who has internalized those values of anorexia nervosa is willing to die in concordance with their identity, to allow them to die is to ensure that they cannot continue living with anorexia nervosa. And, rather than having a death wish, one with anorexia nervosa wants to live, even if it is with anorexia nervosa—and for some, especially if it is with anorexia nervosa. Finally, the experience of anorexia nervosa can affect a patient’s ability to see that they are truly at risk for continuing to live, even though they can acknowledge the risk on their capacity measures. Accordingly, forcing treatment is not a matter of erasure which opposes the internalized values of a patient of anorexia nervosa; rather, it allows them to continue to live with and as that identity.

In this way, it seems that attempting to resolve the issue of force feeding patients of anorexia nervosa by appeal to pathology rather than individual values is justifiable, and may at the same time be respectful of those individual values. For, in demonstrating that those egosyntonic values are in some way pathological, we can support the permissibility of forced treatment which extends the life of that patient and allows them to continue living according to their own values. Indeed, the statements above seem to suggest that patients too believe that their attitudes in rejecting life-saving treatment are irrational, and that they are too ill to make those decisions. Accordingly, there seems to be sufficient motivation to centre decision-making around the analysis of pathology, rather than of the concurrent values of the patient needing that treatment.

3.2 Pathology and Egosyntonicity

A solution to the puzzle of egosyntonic pathology in anorexia patients may be found in the very reports which patients provide. The combination of the narrative

evidence from §2.3 and §3.1 above indicate that: (a) patients of anorexia nervosa tend to feel that the disorder is a part of their identity, (b) patients refusing to eat in a life-threatening situation are unstable and irrational, (c) patients refusing life-saving treatment will tend to value that treatment after it is forcefully administered (See also Franko and Keel 2006), and (d) that a reflexive or external perspective on that situation—such as that of a caregiver or physician—should hold more weight than the patient’s perspective (cf. Patient 22 and Patient 30, §3.1). Accordingly, we may be content to accept the prevailing intuition that those patients of anorexia nervosa refusing lifesaving treatment are forming their decisions through a pathological filter. For, even if the anorexic patient maintains a critical desire not to eat, they also maintain a will to live and continue to be anorexic: “If I had been left without somebody forcing treatment upon me I would have just starved myself to death [...] I wouldn’t have got to my target weight and got happy and have things that I’ll have in the future.” (Tan et al. 2010).

However, while there seems to be agreement between our common intuitions and those of patients after treatment, this conclusion only readily extends to the extreme cases of anorexia nervosa patients refusing treatment in life-threatening situations. For, while narrative evidence suggests that anorexia patients can retroactively identify a pathology which compromises their decision making ability, it is not yet clear in what this might consist. That is, we might be able to readily distinguish the strong case where a Patient 1n a life-threatening situation refuses treatment, but it is not clear what this uniform intuition can tell us of less urgent cases: what of anorexia nervosa patients who may be in a life-threatening situation within a week, or a month, or a few years? The challenge, then, is to distinguish wherein this pathology arises.

Perhaps the most effective way to determine whether egosyntonicity is pathological is to engage in motivational studies with those perceived as at-risk for developing anorexia nervosa, and to study them on a longitudinal basis to determine what changes occur between pre-anorexic and anorexic persons. Unfortunately, the difficulty in determining the pathology of the egosyntonic values stems in part from the ambiguity of the disorder itself. Again, we do not consider dieters simpliciter to suffer from anorexia nervosa, nor those on a hunger strike. Indeed, in modern society, one easily finds many persons in fear of weight gain, and struggling to meet those social ideals of lower-than-healthy BMI (see, for example, Dalley, Buunk, and Umit 2009). Furthermore, given the high rates of

dieting, and studies indicating that anorexia nervosa may onset following either intended or unintended weight loss (Brandenburg and Andersen 2007), dieting mindsets may carry over into anorexia nervosa as a dieter develops the disorder.⁶ That is, those values of refraining from eating may pre-exist the condition. Moreover, even if it is the case that most cases of egosyntonicity are pathological, the mere possibility for authentic egosyntonic values encourages caution about acting too-readily to force life-saving treatments on anorexia nervosa patients. Accordingly, using motivational surveys may not generate very useful data.

It seems that, in order to determine whether the egosyntonic values are pathological, more research needs to be done which seeks to measure degrees of egosyntonicity and the presence of values which (i) control for individual differences and permits for analysis of ethically salient correlations, and which (ii) more closely compares those dieting against those diagnosed with anorexia nervosa, on a longitudinal basis, in order to examine shifts in values over time. If such studies are then performed, we may be able to weigh the evidence toward the pathological or authentic, or come to see that another distinction may be more fruitful.

However, these concerns remain downstream from our initial concern: how to permit forced treatment on those patients of anorexia nervosa when they refuse treatment and are otherwise deemed to have the capacity for consent. And, though we may wish to set out a broader scope which permits us to force treatment on patients of anorexia nervosa that are not yet in a life-threatening situation, it is important to recognize the immediacy of the one case over another: one is immediately life-threatening, whereas the others have potential to become life-threatening, at which time treatment might be forced. Moreover, while we have not yet established what mechanisms underlay the apparent pathology of egosyntonic values in anorexia nervosa patients, we have established a general census that a caregiver or physician is permitted to force life-saving treatments upon anorexia patients. This has met both our common intuitions—whence the very issue arose—and those narratives of patients experiencing such conditions first hand. Ultimately, though our theory is incomplete, it provides immediate means for necessary action.

6. Indeed, studies indicate that dieters and anorexia patients share similar distortions in perceived body image. See Dalley, Buunk, and Umit 2009; Guardia et al. 2010; Keizer et al. 2013; Klesges 1983; and Uher et al. 2005.

4. CONCLUSION

This paper provided a survey of the ethical landscape of consent and egosyntonicity in anorexia nervosa. It was demonstrated that, if we can determine that those egosyntonic values of individuals suffering from anorexia nervosa are pathological, then we may be able to demonstrate a compromised capacity for consent. Furthermore, although no explicit basis for a pathological interpretation of egosyntonic values was distinguished, it was shown that there is an important census among our intuitions that forcing life-saving treatment on a patient of anorexia nervosa is a permissible action; particularly given that patients of anorexia nervosa tend to applaud the forced treatment, following its enactment (Guarda et al. 2007; Tan et al. 2010).

Finally, it is worth noting that this discussion of egosyntonicity in anorexia nervosa may influence other bioethical discourse, and particularly in the discussion of ethical issues regarding mental illness. It may readily be the case that persons suffering from major depressive disorder and panic disorders equally embody values deemed congruent with those disorders, and as such, that a similar discussion of the pathology of egosyntonicity may inform ethical debates regarding capacity to consent there, as well as in cases of somatic disorders. Ultimately, further research needs to be done to determine the boundaries and implications of this examination, but the current analysis provides an important step forward for caregivers considering treatment options for anorexia nervosa patients.

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