

ANOREXIA NERVOSA AND REFUSAL OF NASO-GASTRIC TREATMENT: A REPLY TO SIMONA GIORDANO

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'It is undoubted awful to watch someone – possibly a young someone – die when they can so easily be saved.'¹ The problem with feeding those who have anorexia nervosa against their stated wishes is clearly based on a tension between respecting (supposed) autonomy on the one hand, and not preventing an avoidable death on the other. Anorexic nervosa (along with other eating disorders) poses particular problems because the nature of the disorder makes it extremely difficult to establish the extent to which the sufferer is competent to make *any* decisions related to food. Thus, the question raised is whether following the wishes of someone with anorexia nervosa not to be fed is actually respecting autonomy at all since it is not obvious that this wish is autonomously held. What is obvious, however, is that naso-gastric feeding will achieve its aim of extending the patient's life. Given that the patient will die if feeding is withheld, and given that it is far from obvious that patients with anorexia nervosa are autonomous where food is concerned, it is not surprising that the default position is to feed, even in the face of objections from the patient. Moreover, where there are genuine doubts about the autonomy of the patient, and assuming that it is a good thing to keep a patient alive, doctors have a duty to continue with feeding.

Where the assumption is that the patient is not autonomous, the ethical issue shifts to whether naso-gastric feeding is in the patient's best interests. Naso-gastric feeding will keep the patient alive. It may help to restore her to a sufficient state of health to engage in other therapies necessary to combat anorexia nervosa. However, naso-gastric feeding is not itself a cure for anorexia

¹ Heather Draper. Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification. *Bioethics* 2000; 14: 133.

nervosa; on the contrary, forcing someone to eat may actually worsen the condition. On balance, however, not feeding results in death whereas feeding opens up the possibility of ultimately being able to live a normal or near normal life. Hence, the default assumption is that tube feeding is the right thing to do when someone with anorexia nervosa is close to starving to death.

Many anorexics do go on to recover. Some never recover completely, but learn to live with their obsession with food and weight loss. Almost all go through phases of partial recovery and relapse, which may continue for years, before ultimately leading some normal or near normal life. Some patients take their own lives and we will never know if they could have recovered or not. Some never recover and ultimately die because of this dreadful disease.

In my earlier paper,² I addressed three issues:

- Whether it is ever possible to judge sufferers from anorexia nervosa to be competent enough to refuse food (whatever the mode of delivery).
- What weight should be given to the fact that some people with anorexia nervosa never recover, but remain trapped in a cycle of naso-gastric feeding they do not want, partial recovery, and gradual decline to more naso-gastric feeding they do not want.
- Whether, if someone with anorexia nervosa was sufficiently autonomous to refuse naso-gastric feeding *on the basis of their poor quality of life*, a clinician who complied with this refusal of consent would be guilty of euthanasia – or murder in many constitutions. I made this connection with euthanasia because of wide-spread criticism of an article arguing for the possibility of taking a palliative approach in some cases of long-standing anorexia nervosa,³ but also because quality of life decisions are an important aspect of decisions about euthanasia.

IS SOMEONE WITH A HISTORY OF ANOREXIA NERVOSA EVER COMPETENT TO REFUSE CONSENT TO NASO-GASTRIC FEEDING?

In my earlier paper I hoped to establish that in principle it might be possible for someone with anorexia nervosa to be competent to refuse naso-gastric feeding, where this decision was related to his or her quality of life. I was, however, careful to state repeat-

² Ibid. pp. 120–133.

³ J. O'Neill, T. Crowther, G. Sampson. Anorexia Nervosa: Palliative Care of Terminal Psychiatric Disease. *American Journal of Hospice and Palliative Care* 1994; Nov/Dec: 36–8.

edly that only a very small minority of those with anorexia nervosa was likely to be competent in the way that I outlined.

In brief, I argued that whilst people with anorexia nervosa might not be competent to make decisions about food, feeding, and eating, it was not *necessarily* the case that a decision related to naso-gastric feeding was a decision about food per se. Instead, it *might* be a decision about quality of life, and the role that balancing the burdens and benefits of any therapy might have in a person's determination about their quality of life. Thus, in the kind of cases I had in mind, the *same* individual might be incompetent to decide whether or not eating was a good thing, or whether she needed to lose weight etc, and *at the same time* might be competent to make a decision about her quality of life, given her long-standing anorexia nervosa, the therapies necessary to sustain it, and the prognosis for recovery. There might be competence where:

Those who are refusing have been afflicted beyond the natural cycle of the disorder (which is between one and eight years); have already been forced-fed on previous occasions, are competent to make decisions concerning their quality of life, have insight into the influence which their anorexia has over some aspects of their lives and are not at death's door (they may, for instance, have just been released from a section for compulsory treatment).⁴

Elsewhere in the paper⁵ I insisted that the individual should be 'broadly competent' even though she might not be competent as far as aspects of her life related to anorexia nervosa are concerned. Obviously I am drawing a fine line here, and I am clearly not including *all* those with anorexia. The description cited above is not designed to place a limit on who, amongst those who are competent to refuse, can be permitted to refuse (as Giordano suggests), but is rather a description of the kind of conditions that I argue must be met in order to establish competence with respect to this particular – quality of life – decision in the first place.

Giordano, I think, takes me to be claiming that some people with anorexia nervosa are competent and therefore autonomous per se, whereas I took myself to be making a claim for competence with regard to decisions concerning quality of life, and I repeat that this claim applies only in a minority of cases, as the majority of refusals are due to the desires flowing from having

⁴ Draper, *op. cit.* note 1, pp. 122–123.

⁵ Draper, *op. cit.* p. 132.

anorexia nervosa (not wanting to eat, not wanting to put on weight, etc) rather than being about quality of life and the relative value of naso-gastric feeding as part of their therapy. Giordano then takes the claim that she supposes me to have made, and suggests that I duck the 'brave claim' that 'people with anorexia are entitled to competently refuse artificial feeding, and that, if this is the case, they are entitled to have their decisions respected *because* they are deciding competently.'⁶

A further difficulty that I have with Giordano's position, and which I did not address in my previous paper, is the extent to which the legal definition of competence can be readily equated with autonomy. The ethical force of claiming that a patient is competent to make a decision is based on the assumption that to be competent is to be autonomous, and to undermine autonomy is a bad thing. The legal notion of competence is decision-specific, whereas in ethics autonomy tends to be a description of the person as a whole. To claim that not all the decisions made by the autonomous agent are indeed autonomously made, it has to be shown that there were factors undermining autonomy at the time such decisions were made. The mismatch between the notion of legal competence and autonomy is perhaps best illustrated with reference to children. It is now common practice in many countries to encourage children, even very young children, to become involved in medical decision-making. The standard applied in the UK is Gillick competence. A Gillick-competent child is one of any age up to 16 years old who is able fully to understand all the relevant information related to a particular decision. Such children can consent to that particular form of medical treatment for themselves. Thus, a distinction might be drawn between a child's ability to consent to have her arm set in plaster and the same child on the same day being able to consent to, for example, a sterilisation. The quasi-absolute respect for a patient's decision in legal terms, on a par with autonomy, seems to be set by age – the age of majority (currently 18 years in the UK). However, case law in the UK suggests that even when a child is Gillick-competent, or a patient is an adult, they might nonetheless be incompetent to make certain decisions under some circumstances.

Few people would argue that because a young child is legally competent to decide about having her arm set in plaster, this child

⁶ Simona Giordano. Anorexia Nervosa and Refusal of Naso-Gastric Treatment: A Response to Heather Draper. *Bioethics* 2003; 17: p. 272.

is now autonomous. Thus, whilst it is likely to be the case that someone who is autonomous is also competent to make a specific medical decision, it need not be the case that someone who is competent to make a specific medical decision is also autonomous.

If this analysis is correct, no one can assert with confidence that because a person with anorexia nervosa is able to make one competent decision, he or she is actually autonomous. However, whereas my argument largely hinged on the justice of treating like cases alike (hence my drawing attention to the similarities with decisions made by people who do not have anorexia nervosa), Giordano goes further and appeals to autonomy even though she also recognises that a person can be competent on some levels but not at others.⁷

So, there are two versions of the 'brave claim.' The first asserts that if someone is competent to make a decision, then that decision should be respected if we respect the competent decision of other people in comparable situations. The second asserts 'people with anorexia nervosa, who competently decide not to be artificially fed, should be respected *because* everybody is entitled to the exercise of their autonomy... (t)he principle of autonomy binds us to respect people's competent decisions.'⁸

In the case of anorexia nervosa, I find it easier to support the 'brave claim' in the first formulation than the second because of the unresolved confusion of competence and autonomy. Far more work would have to be done to establish that the person concerned was autonomous as well as decision-specific competent. However, I also accept that the force of the first claim may ultimately lie in respect for autonomy. What needs to be established, and what is very difficult to establish in the case of anorexia nervosa, is whether the person with anorexia nervosa is an autonomous agent who is incompetent to make some judgements, or a non-autonomous agent who is competent to make some judgements.

Neither Giordano nor I have given this sufficient consideration, though in the paper Giordano criticises I did start this work by looking at the ways in which the decision to refuse feeding could be described as irrational or not.

⁷ Ibid. pp. 265–266.

⁸ Ibid. p. 271.

WHAT WEIGHT SHOULD BE GIVEN TO THE FACT THAT SOME PEOPLE NEVER RECOVER FROM ANOREXIA NERVOSA AND SUFFER A POOR QUALITY OF LIFE, LOCKED INTO CYCLES OF THERAPY?

It can take many years for someone with anorexia nervosa to recover. This is not the place to start an argument about what it means to recover from anorexia nervosa. For the purposes of this discussion, I will take recovery to mean being able to live a relatively normal life in terms of food – obviously there is a spectrum of recovery and some people have only recovered in the sense that alcoholics have recovered (they learn to live with anorexia nervosa, may need continued medical support to do this but the ordinary running of their life is little, if at all, affected). One of the objections to the idea that there may be a role for palliative care in the management of anorexia nervosa is that one can never be certain that a given individual will not recover, however long they have been ill. This is true, but we do know that some people die as a result of having anorexia nervosa without recovering, and that others take their own lives. In my paper, I tried to balance the position that we can never be certain that someone will not recover, with the view that some people will never recover.

It is right for clinicians to treat all *new* referrals for anorexia nervosa as potential recoveries. This means that if the patient comes close to death, they should be fed even if they say that they do not want this intervention. In the case of new referrals, I would argue that this is justified because the refusal may not be autonomous. However, at what point, or after how many years, should a clinician consider the possibility that the patient is chronically, or even terminally, afflicted? The truthful answer to this question is that I really do not know. I do not know because the terms themselves are vague and therefore open to interpretation, and incorporate a potential spectrum of cases. I am supposing that it is in principle possible to make such a judgement, and that it is indeed logically the case that there must be a chronic and terminal version of the illness, since some people have it all their lives and some people die prematurely from it.

But this also matters in determining competence, because the length of time that one has to cope with an illness adds invaluable information for the ‘informed’ aspect of one’s decisions about it, and adds greater weight to the view that there is a quality of life judgement to be made here, and not just one about whether or not to feed.

My argument about competence concerns the kind of decision that is being made: namely, whether this is a decision about whether or not to accept food, or whether this is a decision about whether, on balance of all things being considered, the therapy (including naso-gastric feeding) on offer is beneficial (given the prognosis and quality of life that is possible if therapy continues). In practical terms, it would be easier to maintain the position that people with anorexia nervosa are never competent to make decisions related to their illness because of the nature of this illness: namely that it is a *mental* illness and one which focuses on not eating. However, this is a position that both Giordano and I seek to reject. We both argue that a competent decision should be respected, and we both recognise that the treatment for anorexia nervosa can impose a terrible burden on the person receiving it. My argument is that in the chronic and/or terminal stages of the disease process,⁹ the decision-making has more dimensions, because at this stage it becomes appropriate to consider whether the burdens of the therapy and the quality of life make the ever-diminishing prospect of success worthwhile. Not only is it appropriate to consider these things, but until this point is reached someone with anorexia nervosa is *less* competent to make them: it is only at this point that they have experienced the dreadful-ness of living with the condition in the long-term. Until they have lived with chronic anorexia nervosa and the treatment for it, they are not in a position to claim that living with this cycle is not worth it for them. The qualifications that I make concerning which people with anorexia nervosa can refuse treatment are related, therefore, to determining competence.

There are at least two potential criticisms of this position. The first is that it could be generalised into a claim that no one, however mature or generally autonomous they are, is in a position to make a decision about something that they have yet to experience. Accordingly, clinicians could ignore a refusal of consent in the early stages of *any* illness. This would be one of the up-shots of not accepting the 'brave position' as outlined by Giordano. What this kind of criticism ignores, however, is the fact that anorexia nervosa is a *mental* disorder. However uneasy we might feel in singling out not eating for special attention,¹⁰ we cannot ignore the fact that anorexia nervosa is accompanied by disordered thinking, and disordered thinking in relation to

⁹ Though not at the terminal stages of starvation, because starvation at this level would impair competence – as I say in the 2000 paper.

¹⁰ In the 2000 paper, I explore this in relation to over-eating.

eating/feeding, the very thing that is at issue in naso-gastric feeding. The comparison to anyone making any decision, about which they have no experience, is therefore not a fair one. A person in the early stages of anorexia nervosa is not likely to be refusing food because she is imagining a future chained to her eating disorder and she cannot bear this prospect. She is making this decision *because* she has the disorder.

The second point is that Gillick-competent children, no matter how long they have been ill, are not in a position to make decisions about their own quality of life because, whilst competent, they are not autonomous. This kind of criticism ignores the fact that there are two reasons why people should be permitted to make decisions about the quality of lives for themselves. The first and stronger reason is that if they are autonomous we should respect their decisions because this is part of respecting them as autonomous beings. The second reason is that quality of life decisions are by their nature intensely personal, making it difficult for someone else to argue that 'they know best' what is a good or bad quality of life. However, in the case of children, a similar argument to the one that I have just proposed is also used. Children's quality of life decisions are more likely to be respected when they have been ill for many years, and when the prospects for recovery have become so small that the question of whether treatment is worthwhile naturally arises from the burdens which the illness itself, and the therapies given, cause. If a child were to start speaking of a poor quality of life when the illness was acute and the prognosis good, we might reasonably wonder what else was going on in the child's life that made the prospect of living seem such a burden.

Giordano's paper offers us three potential escapes from the 'brave claim', without wholly committing herself to any one of them:

- Playing safe because the numbers involved are small.
- Over-riding a competent refusal because the person can be saved and it will cause acute distress and grief to their family if they die when they could have been saved.
- Pity or compassion, which is nothing to do with competence, but has to do with our '(i)dentification with the patient and participation in her suffering.'¹¹

I have already addressed, and rejected on principle, the first claim. We may disagree about the numbers involved, but

¹¹ Giordano, *op. cit.* note 6, pp. 277–278.

Giordano and I do seem to agree that however small a minority is involved, their situation must be accommodated in decisions about treating anorexia nervosa in general.

The second claim may seem particularly potent in the case of anorexia nervosa but is not one that could be generalised beyond it. In both of the examples that I used to illustrate the similarities between anorexia nervosa and other chronic or potentially terminal illness, the therapy under discussion was potentially life-saving; thus, neither met the criteria of irreversible conditions where death was unavoidable. Both illustrated a reluctance to intervene in other circumstances where patients are deemed to be competent and are refusing treatment, even potentially effective treatment. In these and other circumstances, it would not be acceptable to over-ride a competent patient's refusal of treatment on the grounds that her family will be distressed, even 'driven crazy' if she were to die prematurely.

The effect on others of her decisions is, of course, something that an *autonomous* person ought to take into account before making such a request where her condition was reversible or where death was not inevitable. However, whilst it might be reasonable to ask someone to consider whether her 'need' to die is greater than the 'need' of her family and friends for her to live on, it is quite another thing to take this decision out of her hands and impose unwanted life upon her. It may even be a bad thing to do if we think that she is wrong in her assessment – namely that her living *would* be outweighed by the benefit to her family. Under some constructions of respect for autonomy, it is not our responsibility to decide for others how they should behave; rather, they have to take responsibility for their own (bad) actions. In the case of refusing a therapy that might save one's life, the normal understanding of taking responsibility is somewhat distorted as one will not be around to be held accountable, but this is something else that the autonomous person ought to take into account when making this decision.

Giordano's own position is difficult to pin down. On the one hand, she urges the 'brave claim' (absolute respect for a competent decision); on the other, she wants to impose limits on the autonomy of those with anorexia nervosa because the condition is potentially reversible. What is not clear from her paper is whether she thinks that *no one* with a reversible condition can refuse treatment (especially if their death would have a significant impact on their family etc), or whether this restriction on normal conditions applies only to those with anorexia nervosa.

However, what of her third claim, the claim from pity? Here I take Giordano to be claiming that whilst we may respect the autonomous wishes of someone with anorexia nervosa to make a quality of life decision to die (because of the effects on her family etc, and because her death is not inevitable), we can identify so closely with her suffering that we can somehow condone her decision out of pity. But this claim seems to assume some mutual agreement about the poor quality of her life, given what is necessary to sustain it. Why else would we feel pity or compassion to the point that death now becomes an acceptable option? My objection to this solution is that the person forming the judgement about the dreadfulness of the patient's life is the carer and not the patient, and the carer remains in control of whether the patient's decision about the quality of her life will be acted upon or not. After all, we could feel pity and compassion and still think that the person with anorexia nervosa should be compelled to soldier on in the hope of recovery, however difficult this will be for her: it may be this difficulty that motivates our pity and compassion.

CONCLUSIONS

It is debatable whether anyone in the grip of anorexia nervosa can make a decision to refuse feeding competently when the feeding itself is the basis of that decision. My argument was that in a small minority of cases, this decision might not be to do with the desirability of naso-gastric feeding as feeding per se, but to do with the quality of life experienced by someone trapped for many years in a cycle of forced naso-gastric feeding, partial recovery, deterioration, and further forced feeding. I argued that irrespective of whether an individual with anorexia nervosa was able to think competently about feeding, there was a possibility that she was able to make a competent assessment about the quality of her life, and on this basis, refuse further treatment including naso-gastric feeding. This argument would apply, bravely, to all patients fitting this description.

In response to concerns that have been raised about the possibility of treating some of those with anorexia nervosa palliatively, I also argued that such a response might not be euthanasia in the conditions that I outlined. I did not argue that it was acceptable to withdraw therapy *because* this was not euthanasia, but rather that it was acceptable *and* it was not euthanasia. Respect for a competent refusal of consent need not be premised on agreement with the reasons for it, whereas agreement to euthanasia does,

because of what the term 'euthanasia' means. I also pointed out that this distinction enables clinicians to manage all patients with anorexia nervosa as potentially treatable (i.e. not to lose hope and themselves initiate a withdrawal of therapy), but still leaves room for some patients (those competently making quality of life decisions) to withdraw from treatment.¹²

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¹² Draper, *op. cit.* note 1, p. 123.