

ANOREXIA NERVOSA AND REFUSAL OF NASO-GASTRIC TREATMENT: A RESPONSE TO HEATHER DRAPER

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ABSTRACT

Imposing artificial feeding on people with anorexia nervosa may be unethical. This seems to be Heather Draper's suggestion in her article, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification'.¹ Although this is an important point, I shall show that the arguments supporting this point are flawed. Draper should have made a brave claim: she should have claimed that people with anorexia nervosa, who competently decide not to be artificially fed, should be respected because everybody is entitled to exercise their autonomy, not only 'in the middle' of their life, but also at the end of it, or when their own life is at stake, because autonomy also extends to the most difficult moments of our life, and, ultimately, 'stretches [. . .] far out into the distance'² at the end of it. I explain why Draper should have made the brave claim, and why she has not made it. I conclude that a defence of people's entitlement to competently refuse artificial feeding cannot rest upon the arguments developed by Draper. Whether or not we should respect competent refusal of artificial feeding depends on the normative strength that we are ready to ascribe to the principle of autonomy, to the moral relevance that we ascribe to the circumstances in which a person's autonomy is exercised, and, perhaps, eventually, on our sense of compassion.

*... Dell'inumano varcando il confine
Conoscemmo anzitempo la carogna*

¹ H. Draper. Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification. *Bioethics* 2000; 14: 120–133.

² M. Kundera. 1991. *Immortality*. London. Faber and Faber: 73.

*Che ad ogni ambito sogno mette fine:
Che la pietà non vi sia di vergona . . .*³

I INTRODUCTION

This paper is a commentary on Heather Draper's article 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification.'⁴ Draper's article represents a development of previously expressed arguments.⁵

As the title suggests, Draper *seems* to argue that *in some cases* imposing artificial feeding on people with anorexia nervosa may be unethical.

Although this is an important point, the arguments that support this point are, I believe, flawed. If we want to defend the entitlement to competently refuse artificial feeding, we cannot convincingly appeal to Draper's arguments. This should not be taken as a claim that morality necessarily requires respect for the competent refusal of artificial feeding in cases of anorexia nervosa. Whether or not we should respect this decision depends on our beliefs relating to what the principle of respect for autonomy requires of us, on the normative strength that we are ready to ascribe to the principle of autonomy at the end of our life, on the moral relevance that we ascribe to the circumstances in which a person's autonomy is exercised, and, perhaps, eventually, on our sense of *compassion*.

II MAY PEOPLE WITH ANOREXIA BE COMPETENT TO REFUSE NASO-GASTRIC FEEDING?

Draper points out that '[t]here may be circumstances under which a sufferer's refusal of consent to treatment should be respected. This argument will hinge upon whether someone in the grip of an eating disorder can actually make a *competent decision about the quality of life*.'⁶

To evaluate the plausibility of this claim, it is first necessary to delineate the notion of 'competence', and then to look at clinical analyses of eating disordered behaviour.

³ 'Crossing the border of humanity/ We met before time the carrion/ Which kills all desires and dreams/ Don't disdain pity.' F. De André. 1969. Corale. Milano. BMG Ricordi. Copyright 1990 Casa Ricordi.

⁴ H. Draper, *op. cit.* note 1, p. 120.

⁵ H. Draper. Treating Anorexics Without Consent: Some Reservations. *JME* 1998; 24: 5–7.

⁶ H. Draper, *op. cit.* note 1, p. 120. My emphasis.

'Competence' is a task specific concept,⁷ that is, a person may be able to make a competent decision at one time, but not at another, or they may, at the same time, be able to make one decision but not another.⁸ Moreover, competence is independent of the result of the choice.⁹ People are acknowledged to have the right to be unwise¹⁰ and wrong,¹¹ and to refuse treatment for reasons which are irrational, unreasonable, or for no reason at all.¹² People are considered competent to make a medical decision when they are able *to understand the nature and purpose of treatment, and to weigh its risks and benefits*.¹³ Moreover, 'being classed as suffering from a mental illness is [not] necessarily an indication that one is an incompetent individual';¹⁴ for example, in the case of a prisoner with a diagnosis of personality disorders who refused food, coercive feeding was deemed unlawful, because, despite the ongoing mental disorder, he was found competent to refuse that treatment.¹⁵

In all discussions about competence, fundamental importance is given to the understanding of correct information.¹⁶ The Law Commission has stated that a person is lacking capacity: 1) when unable to *understand or retain the relevant information*; 2) when,

⁷ I am referring to the English law, to which Draper also refers. *Gillick v West Norfolk Wisbech AHA* [1985] 3 ALL ER 402 at 409 e–h per Lord Fraser and at 422 g–j per Lord Scarman; see also *Estate of Park* [1959] P 112; *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819, (1993) 15 BMLR 77; J. Harris. 1992. *The Value of Life*. London. Routledge: 200ff.

⁸ M. Brazier. 1992. *Medicine, Patients and the Law*. London. Penguin: chapters 2, 4, 5.

⁹ *St George's Healthcare Trust v S R v Collins and others*, ex part S [1998] 3 All ER 673.

¹⁰ *Lane v Candura* [1978] 376 NE 2d 1232 Appeal Court of Massachusetts.

¹¹ *Hopp v Lepp* [1979] 98 DLR (3d) 464 at 470 per J. Prowse.

¹² *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] 1 All ER 643 at 509 b per Lord Templeman; see also *R v Blame* [1975] 3 All ER 446.

¹³ *F v West Berkshire Health Authority* [1989] 2 All ER 545; see also *State of Tennessee v Northern* [1978] 563 SW 2d 197; [1985] 3 All ER 402 at 409 e–h per Lord Fraser and at 422 g–j per Lord Scarman.

¹⁴ H. Draper, *op. cit.* note 1, p. 129. See also the Law Commission Report on Mental Incapacity, No. 231, 1995; *Who decides? Making Decisions of Behalf of Mentally Incapacitated Adults*. A Consultation paper issued by the Lord Chancellor's Department, December 1997; Mental Health Act Review Expert Group. April 1999. *Draft Proposals for the New Mental Health Act*. <http://www.hyperguide.co.uk/mha/rev-prop.htm>

¹⁵ *Secretary of State for the Home Department v Robb* [1995] 1 All ER 677.

¹⁶ *Re C* [1994] 1 FLR 31, *Re MB* [1997] 8 Medical Law Report 217; *Banks v Goodfellow* [1870] LR.5 QB 549 at p. 569 per lord C.J. Cockburn.

although able to understand the relevant information, is prevented from *using* it by her mental disability.¹⁷

With regard to clinical studies of anorexia nervosa, cognitive psychology has specially focused on the *information process* leading to eating disordered behaviour, and has shown that this process appears dysfunctional at all levels: *perception* of the input of information, *interpretation*, *decision-making process* and *output*. For example, typically, people with anorexia are unable to recall the information stored in the memory and to utilise it to identify new information coming from the outside; the interpretation of information is also distorted: 'You look good, today' is typically interpreted as 'You've put on weight.'¹⁸

It has also been shown that people with eating disorders do not have a realistic perception of actual signals of appetite and satiety. They never know, by inner and unreflective awareness, if they should eat, how much they should eat, whether they have eaten enough, and when they should stop.¹⁹

The use of information about food is also dysfunctional. Although people with eating disorders are typically very well informed about food, they seem *unable to apply* this information. Rather than using it to improve the quality of their diet or their general well-being, they use it as an 'excuse' for both restrictive diet and food selection.²⁰

It has also been stressed that their capacity to make medical decisions may be affected by fears of obesity or denial of the consequences of actions.²¹

¹⁷ See: the Mental Health Act Review Expert Group, *op. cit.* note 14, para. 152.

¹⁸ E. Faccio. 1999. *Il disturbo alimentare, modelli ricerche e terapie*. Roma. Carocci: 83.

¹⁹ M. Selvini Palazzoni. 1998. *Anoressia mentale, dalla terapia individuale alla terapia familiare*. Milano. Feltrinelli: 70.

²⁰ H. Bruch. 1974. *Eating Disorders: Obesity, Anorexia Nervosa and the Person Within*. London. Routledge: 384.

²¹ Law Commission. 1993. Consultation Paper No. 129. *Mentally Incapacitated Adults and Decision-Making. Medical Treatment and Research*. – Para. 2.18 from *Re W* [1992] 3 WLR 758, HMSO; in particular para. 2.3.2. The legitimacy of force-feeding is a highly controversial issue. Anorexia nervosa is considered a mental illness, and therefore patients can be compulsorily detained and treated under sections 2 and 3 of the Mental Health Act 1983. According to s.63 of the Act, consent to treatment *for the mental disorder* will not be required to sectioned patients, and polemics arose as to whether naso-gastric feeding should be considered as a treatment for the mental disorder and could therefore be legally imposed under s.63, or should instead be considered as a treatment for the physical conditions, for which consent must be obtained. Despite the cases of *Re KB* (adult) (mental patient: medical treatment) [1994] 19 BMLR 144, *Riverside*

These considerations, of course, do not pretend to be an exhaustive overview of anorexia. They are only meant to outline the features that characterise anorexia and that may somewhat jeopardise the sufferer's competence to refuse treatment. In fact, whereas people with anorexia may be competent to manage most areas of their lives, these typical features may make them unable to competently decide about food and the body, and, consequently, about the therapy that is inevitably related to these.

However, we should not conclude that all people with anorexia are necessarily incompetent to refuse treatment. On the contrary, we should 'be open to the possibility that sufferers are actually *as competent as anyone else* to make decisions about the quality of their lives, and to assess the relative value of their lives in the light of its quality.'²² Draper asks:

[W]hat of the sufferer from anorexia who refuses therapy, not because she thinks that her condition is not life-threatening, nor because she refuses to accept that she has a problem at all, but because for her [...] the burden of therapy and the side-effects of successful therapy – in terms of the body with which she will be left – are such that she prefers to take her chances with death?²³

According to Draper, a person with anorexia nervosa is competently refusing artificial feeding when she²⁴ decides 'to withdraw from therapy not on the grounds that she didn't want to eat, nor that she was "fat" but because the quality of her life was so poor that the therapy was no longer of benefit to her, or that it was on balance more of a burden than benefit.'²⁵

Health NHS Trust v. Fox [1994] 1 FLR 614, *B. v. Croydon District Health Authority* [1995] 1 All ER 683, where the Court decided that artificial feeding could be imposed, debate on the legitimacy of force-feeding is ongoing. In April 1999, the Mental Health Act Review Expert Group suggested that feeding contrary to the will of the patient should be included among treatment that should deserve special safeguards. See: Mental Health Act Review Expert Group, *op. cit.* note 14, para. 19.

²² H. Draper, *op. cit.* note 1, pp. 132–133. My emphasis.

²³ *Ibid.* p. 131.

²⁴ For easiness, given that the majority of sufferers are women, I shall follow Draper in the choice of female pronouns. However, it should be reminded that eating disorders also affect the male population. See: H.G. Pope, H.G. Pope Jr., J.I. Hudson, D. Yurgelun-Todd & M.S. Hudson. Prevalence of Anorexia Nervosa and Bulimia in Three Student Populations. *IJED* 1984; 3: 33–51; see also the Eating Disorders Association reports at www.edauk.com, section 'Men's Issues.'

²⁵ H. Draper, *op. cit.* note 1, p. 122.

In other words, the sufferer may be unable to manage with food;²⁶ however, she may still be able to decide that she is no longer willing to live under conditions such as these. She may therefore be incompetent at the level of diet management, but competent at the level of medical decisions. At this level, in fact, she may *possess all necessary information* about herself and the quality of her life, and may be *able to use* it to arrive at a choice. It may be on the grounds of her considerations about herself and the quality of her life that she may refuse therapy.

The refusal of artificial feeding may thus be considered as a competent decision if the sufferer is able to judge the quality of her life and when she founds her decision on such a judgement, rather than on the basis of her fears and cognitive dysfunctions. This probably only concerns a 'tiny minority'²⁷ of sufferers, but this does not mean that they do not deserve our moral respect.

The problems that I shall discuss from now onward do not relate to this characterisation of competence, which is perfectly acceptable, but to the arguments that follow this characterisation.

III FOLLOWING ARGUMENTS

From the above arguments we understand that, for Draper, if someone in the grip of anorexia is able to make a competent decision about the quality of her life, and, in the light of this judgement, decides not to be treated, her refusal of treatment should be respected.

Surprisingly, however, Draper does not argue this. Draper, instead, suggests that the refusal of force-feeding, *under some circumstances*²⁸ should be respected (we shall see Draper's words in section 8). According to Draper, the reason why *in these cases* the refusal of artificial feeding should be respected is because *in these cases it is not a request for euthanasia*.

In the next section, we shall ask why Draper, rather than following her arguments, tries to demonstrate that the refusal of artificial feeding is not a request for euthanasia and whether she succeeds in her attempt.

²⁶ This apparent inability to control eating often leads to the thinking of anorexia as a form of addiction. Besides generic similarities between the two conditions, however, they present crucial differences that make the comparison improper, even at a logical level. See: S. Giordano. Addicted to Eating Disorders? Eating Disorders and Substance Use Disorders, Differences and Fallacies. *IJPBS* 2001; 11: 73–77.

²⁷ H. Draper, *op. cit.* note 1, p. 133.

²⁸ *Ibid.* p. 122.

IV WHAT IS 'REFUSING ARTIFICIAL FEEDING'? A PARADOXICAL DISTINCTION BETWEEN PASSIVE EUTHANASIA AND REFUSAL OF TREATMENT

Draper tries to demonstrate that the refusal of artificial feeding, *in some cases* is not a request for euthanasia. Why Draper makes such an attempt is quite obvious:

While passive euthanasia 'may be viewed as murder or a similar crime [...] respecting a competent patient's decision to refuse life saving or life prolonging therapy [...] is part of respecting the right to consent.'²⁹

Indeed, many believe that 'euthanasia' (even in its passive and voluntary form) is unethical. Moreover, euthanasia is unlawful in the UK, as it is in most European countries, and consequently practitioners could not lawfully respect the patient's wish to be withdrawn from artificial feeding, if their act counts as 'euthanasia.'

However, the refusal of artificial feeding closely resembles passive euthanasia. The doctor is asked to withhold a procedure with the consequence that the patient will die.

Therefore, Draper tries to make a distinction between passive euthanasia and competent refusal of treatment:

In passive euthanasia therapy is withdrawn or omitted with the intention that the patient will die as a result . . . The final judgement about whether *or not* to omit therapy rests with the clinician and not the patient *even when the patient is party to the decision*, or even when the patient goes to considerable lengths to persuade the clinician of her point of view. Considerable weight may be given to what the patient thinks. The clinician *may even decide to be bound by what the patient thinks*, but the final decision still rests with him . . . The moral difference between passive euthanasia and competent refusal of therapy lies in *who makes the final decision*.³⁰

Although the person 'who makes the final decision' is a pivotal figure in Draper's distinction between passive euthanasia and refusal of treatment, it is unclear what Draper means by that. There are, in fact, only three cases in which it is possible to determine who makes the final decision, or, in other words, in which the decision rests only on *one* party:

²⁹ Ibid. p. 123.

³⁰ Ibid. p. 124. My emphasis.

- (1) In case of suicide, the decision seems to rest entirely on the person who commits suicide (apart from exceptional debatable cases); if the patient, for example, pulls out the drips and, before the doctor realises it, she dies, then surely the decision *rests entirely with the patient*. But perhaps we would not think of it as a genuine case of *refusal of treatment*;
- (2) If the patient is incompetent and has left no advance directives to which doctors may refer, the decision clearly rests with doctors (putting aside the issue of the role taken by relatives – for example, in interpreting the patient's wishes);
- (3) If the patient *is competent* and *asks for* life-saving treatment, or asks to carry on with it, and the doctor refuses to comply with this wish, then the decision clearly *rests entirely with the doctor*. However, this case is precisely opposite to the one we are discussing, in which the patient *refuses* life-saving treatment and the doctor wants to administer it.

In all other cases there seems to be nothing like *the person with whom the final decision lies*. There is at most what parties *believe* about this. I may believe that I have made the final decision. You may believe the same, or the other way round. Since there is no way to decide who is right, it is impossible to distinguish between passive euthanasia and refusal of treatment on the grounds of what the parties involved in it believe (however strong their belief may be), and it is impossible to determine *on whom the final decision rests*, unless we look at what each party believes.

Since Draper's distinction between passive euthanasia and refusal of treatment 'lies in who makes the final decision',³¹ we must conclude that Draper fails to provide a persuasive distinction between the two, and, consequently, that she fails to demonstrate that refusal of artificial feeding is unequivocally 'refusal of treatment' and not a 'request for euthanasia'.³²

³¹ Ibid.

³² It should also be noticed that, in order to defend people's entitlement to make decisions relating to their life, we do not need to demonstrate that their decisions have nothing to do with 'euthanasia.' Draper assumes that 'euthanasia is unethical', and therefore tries to define 'euthanasia' in a way in which refusal of artificial feeding appears to be something different from a request for 'euthanasia.' However, a defence of people's entitlement to make decisions relating to their life would be more consistent and persuasive if we openly claim that sometimes morality demands respect for a person's decision, even if that decision results in the person's death. Rather than saying that respect for refusal of artificial feeding may be legitimate because *it has nothing to do with 'euthanasia'*, we should rather say that we should sometimes respect the request for omission or suspension of life-saving treatment, even if this involves some kind of

Another argument brought to support the view that in some cases the refusal of artificial feeding should be respected is that *in some cases* 'the decision to refuse therapy is *on a par* with other decisions to refuse life-prolonging therapy made by sufferers of debilitating chronic, or acute onset of terminal illness.'³³

In the next section we shall see that chronic anorexia nervosa cannot be considered 'on a par' with chronically debilitating and terminal illnesses, even in the cases specified by Draper.

V REFUSAL OF ARTIFICIAL FEEDING IS NOT 'ON A PAR' WITH REFUSAL OF TREATMENT IN DEBILITATING CHRONIC AND TERMINAL ILLNESSES

Chronic anorexia nervosa presents important similarities with debilitating chronic or terminal illnesses. The patient is severely emaciated and manifests a wide range of physical complications related to malnutrition; unless artificially hydrated and fed, she will die. In spite of efforts, this situation may sometimes persist for many years. In up to 20% of cases, unfortunately, it concludes tragically with the death of the patient (notably, mortality is mainly due to suicide).³⁴

Despite the similarities, there is a remarkable difference between chronic anorexia nervosa and debilitating chronic or terminal illnesses. The condition of those who suffer from debilitating chronic or terminal illnesses is unfortunately in any sense *unavoidable*, that is, the situation is going to be at least as it is despite the efforts of all parties involved. Both the condition and the death of people with anorexia are, instead, *avoidable*. We can avoid that the patient dies simply by feeding her and making sure that she does not commit suicide (it is another matter whether this is the right thing to do). Moreover, physical complications (the so called 'secondary symptomatology') resulting from star-

'euthanasia.' What should be demonstrated, in other words, is not that a decision does not fall under the category of 'euthanasia', but rather that some decisions, although involving the death of the person who competently makes those decisions, should be respected, and that it is unethical to violate the person's competent wishes about her own life, even if someone may call this 'euthanasia.'

³³ H. Draper, *op. cit.* note 1, p. 123. My emphasis.

³⁴ Janet L. Treasure. 1998. Anorexia and Bulimia Nervosa. In *Seminars in General Adult Psychiatry*. G. Stein & G. Wilkinson, eds. London. Royal College of Psychiatrists: 858–902.

vation are completely reversible, more or less quickly depending on the case, as normal weight is gained.³⁵ Despite the difficulties surrounding the notion of 'recovery', surely death is (at least 'technically' speaking) *avoidable*, physical complications are *reversible*, and, more significantly, people with anorexia can actually get over their misery.³⁶ Differently from debilitating chronic and terminal illnesses, at the very least there is in anorexia *someone* who can do something about it: namely, *the person herself*.

VI THE BRAVE CLAIM

The fact that the decision to refuse artificial feeding is in no case equivalent to the decision to refuse therapy in cases of debilitating chronic or terminal illnesses has important ethical implications.

In cases of debilitating chronic and terminal illnesses, the respect for the patient's decision is supported not only by the

³⁵ A.S. Kaplan & E.P. Garfinkel. 1988. The Neuroendocrinology of Anorexia Nervosa. In *Clinical Neuroendocrinology*. R. Cullu, G.M. Brown & R. Van Loon, eds. London. Blackwell: 105–22.

³⁶ Draper points out that in some cases, people with eating disorders accept to live only on the condition that they maintain abnormally low weight. In these cases, physical complications are typical, and the concern toward thinness fills the person's mind and grossly reduces the quality of their life. This shows the problematic nature of the notion of 'recovery.' We should also admit that some people never get better. As we have seen above (cf. note 34), a high number of those who have eating disorders die. The majority dies because they commit suicide. No doubt, many people who have eating disorders feel unbearably unhappy. However, we should also consider that, according to the same estimates reported by Draper, the majority of those who develop an eating disorder recover (according to Lang, *The Harvard Medical Letter*, recovery rate is between 50–70% over ten years. E.D. Eckert et al. Ten-Year Follow-up of Anorexia Nervosa: Clinical Course and Outcome. *Psychological Medicine* 1995; 25: 143–56. They report 24% full recovery and just under 50% benign outcome. Quotation in: H. Draper, *op. cit.* note 1. In this note, Draper concludes that, 'taken together these sources suggest a failure rate of between 25–50% over ten years.' Obviously, this means that the recovery rate, over ten years, is about 50–75%). Moreover, there is empirical evidence of considerable improvement when the appropriate approach is adopted. See, for example, results reported by: M. Selvini Palazzoli, S. Cirillo, M. Selvini, A.M. Sorrentino. 1998. *Ragazze anoressiche e bulimiche, la terapia familiare*. Milano. Raffaello Cortina Editore. Perhaps, it should also be considered that 50% of those who have been force-fed declare, with the insight of the 'afterward', that this was a good thing for them. See the Eating Disorders Association at the website: www.edauk.com.

principle of respect for competent decisions (an application of the principle of autonomy that is widely accepted both in morality and in law).³⁷ In these cases, the fact that the *condition* is *irreversible* and (in terminal illnesses) premature *death* is *unavoidable* represent additional moral reasons for respecting the patient's competent decision. Because of these additional moral reasons, the respect for the patient's request of omission or withdrawal from life-saving therapy is (relatively) less controversial than the respect for a similar request, when the patient does not suffer from a similar condition.

In anorexia nervosa, as we have just seen, strictly speaking the condition is not *irreversible*, and death is not *unavoidable*. Therefore these additional moral reasons are lacking. Consequently, it seems that the competent refusal of life-saving or life-prolonging treatment can be respected only on the grounds that people are entitled to make competent decisions about their life (and its termination) (principle of autonomy).

This is what I call *the brave claim*: people with anorexia nervosa, who competently decide not to be artificially fed, should be respected *because* everybody is entitled to exercise their autonomy, not only 'in the middle' of their life, but also at the end of it, or when their own life is at stake. The principle of autonomy binds us to respect people's competent decisions about their life and its termination, precisely because autonomy extends also to the most difficult moments of our life, and, ultimately, 'stretches [...] far out into the distance'³⁸ at the end of it.

In the next sections, we shall see:

- *Why Draper should have made the brave claim;*
- *That she has not made it;*
- *Why she has not made it* (we shall ask whether we can sensibly defend the *brave claim* in the case of anorexia nervosa).

³⁷ Several conventions and declarations of human rights stress the importance and fundamental value of individual autonomy (General Assembly of the United Nations, Universal Declaration of Human Rights, 10 December 1948; Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms, Rome 4 November 1950; Council of Europe, Convention on Human Rights and Biomedicine, Oviedo, 4 April 1997). In coherence with this principle, in most European countries the law generally recognises individuals' right to consent to medical treatment or to refuse it. See for example: M. Brazier. *op. cit.* note 8, chapters 2 and 5.

³⁸ M. Kundera, *op. cit.* note 2, p. 73.

VII WHY DRAPER *SHOULD HAVE MADE THE BRAVE CLAIM*

Draper should have made the *brave claim*, not because the *brave claim* is indisputable (on the contrary, as we shall see in section 10, the *brave claim* is disputable), but because it follows from her premises. In fact, Draper acknowledges that having an eating disorder does not entail incompetence;³⁹ distinguishes between irrationality and incompetence;⁴⁰ and acknowledges the moral and legal right to make competent medical decisions.⁴¹

From these premises, it follows that people are entitled to refuse life-saving or life-prolonging treatment, if they are deciding competently. It seems to follow 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.

Although this conclusion follows from Draper's premises, as we have seen, she does not make it.

VIII DRAPER *HAS NOT MADE THE BRAVE CLAIM, ALTHOUGH SHE SHOULD HAVE*

Instead of making such a claim, as we have seen, Draper has tried, on the one hand, to reassure that the competent refusal of artificial feeding is not a request for passive euthanasia, and, on the other, to demonstrate that *in some cases* this decision is on a par with the decision to refuse treatment in cases of debilitating chronic or terminal illnesses. We should now focus on *these cases*.

The *cases* are the following:

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 force-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 the death's door (they may, for instance, have just been released from a section for compulsory treatment).⁴²

³⁹ H. Draper, *op. cit.* note 1, p. 122.

⁴⁰ *Ibid.* pp. 125–26.

⁴¹ *Ibid.* p. 126.

⁴² *Ibid.* pp. 122–23.

Draper contends that *under these circumstances*, force-feeding would represent a failure 'to respect their competent refusal of therapy.'⁴³

This statement is clearly wrong. In fact, coercive treatment represents a failure to respect competent refusal of therapy not only *in these cases*, but *every time competent refusal of therapy is not respected*.

Force-feeding is a violation of competent refusal of therapy in all cases in which the patient makes a competent refusal and doctors fail to comply with it. It is another matter whether such a violation *is justifiable*. So, by saying that *in these cases* force-feeding represents a failure to respect competent refusal of therapy, perhaps Draper means that, *in these particular cases*, force-feeding represents a failure to respect competent refusal of therapy *that is morally unjustifiable*.

The implication is that *in other cases* doctors may legitimately fail to comply with competent refusal of artificial feeding.

Now, it should become clear why it is significant that Draper has *not* made *the brave claim*.

In fact, we are led to ask: what is it, for Draper, to make force-feeding morally unjustifiable? Is it the fact that it is a failure to respect competent refusal of therapy? Or is it the fact that the person has 'been afflicted beyond the natural cycle of the disorder . . . [has] already been force-fed . . . [has] insight into the influence which their anorexia has over some aspects of their lives, and are not at the death's door (they may, for instance, have just been released from a section for compulsory treatment)'?⁴⁴ Draper does not clarify this point. However, this would be important, because if one claims that force-feeding is morally unjustifiable when the person is making a competent refusal, and that it is morally wrong to lack respect for people's competent choices, then why should one specify that, to claim respect, the patient must have been afflicted beyond the natural cycle of the disorder, or that she must have been force-fed before?

IX WHY DRAPER HAS NOT MADE THE BRAVE CLAIM

One of the reasons for specifying that only force-feeding of patients belonging to this group is morally unjustifiable may be 'playing safe.' The cases selected by Draper present some similarities with debilitating chronic and terminal illnesses, and there-

⁴³ Ibid. p. 122.

⁴⁴ Ibid. pp. 122–23.

fore, it seems that *in these cases* we have *additional moral reasons* for respecting the refusal of artificial feeding. As we have seen in section VI, in fact, the respect for the patient's refusal of life-saving or life-prolonging therapy may be supported not only by the principle of respect for autonomy. In debilitating chronic illnesses, the condition is unfortunately *irreversible* and, in terminal illnesses, premature death is *unavoidable*. These circumstances may provide additional moral reasons for respecting the patient's decision, and seem to make the respect for such a decision (relatively) less controversial than in cases where the death is somewhat avoidable and the condition is totally reversible, such as in anorexia. In anorexia, even in the cases selected by Draper, these additional moral reasons are lacking, and this is why the respect for the patient's decision will always be more controversial than in cases of debilitating chronic or terminal illnesses.

These considerations raise another question, which relates to the plausibility of the *brave claim* in the case of anorexia nervosa.

X CAN WE DEFEND THE *BRAVE CLAIM* IN THE CASE OF ANOREXIA NERVOSA?

One might wonder whether the principle of autonomy preserves all its normative strength in the particular circumstances characterising anorexia nervosa, and it might be argued that, taken alone, the principle of autonomy may not be strong enough to justify the respect for refusal of artificial feeding.

The premature death of a loved one is often intolerable to us, and may be a profoundly devastating experience. It is not euphemistic that sometimes it is said that people become 'crazy' after the premature death of a loved person. The tragic event of bereavement is intolerable even when it is *unavoidable*, and this is understandable. If it is understandable that people sometimes find the *unavoidable* death of a loved person intolerable, perhaps even more understandable is the fact that people may find the death of a close friend or relative intolerable when her death is *avoidable*. And this, perhaps, is not only *understandable*, but also *morally relevant*.

When artificial feeding is to be administered to a person with anorexia, it is because dehydration and malnutrition threaten her life. The person, normally young, generally declares that she is not fasting to death, and that she does not want to die, but, if dying is the price she has to pay to be thin, then she will pay

it.⁴⁵ Families literally fall apart. The person herself seems not to know how to cope, neither do her relatives. However, as we have repeatedly seen, death is *avoidable*, and the condition is *reversible*. Clinical studies show that people in desperate conditions have recovered, and such empirical evidence supports not a nebulous faith in miracles, but the concrete hope that everything could 'come back to normal', that the nightmare finishes as it started.⁴⁶

In these circumstances, does the principle of autonomy preserve intact all its normative strength? In other words, does the fact that both the condition and death are *reversible and avoidable* weaken its normative strength? Do they weaken the duty, which we all share, to respect other people's autonomy?

XI CONCLUSIONS

Draper makes an important point. She stresses that 'when a competent patient refuses therapy – whether or not she has a terminal illness or a poor quality of life or will die as a result – professional carers are ethically and legally bound to accept this refusal.'⁴⁷ She also points out that some people with anorexia nervosa, even if this is only a tiny minority, may be competently refusing naso-gastric feeding. As Draper also suggests, people with anorexia may be considered competent to refuse therapy if they make their decision on the basis of a reasoned judgement upon the quality of their lives, rather than on the basis of dysfunctional cognitive processes, or of irrational beliefs of other sorts. From these arguments, one would expect Draper to conclude that, when people with anorexia competently refuse naso-gastric therapy, professionals are ethically bound (and should also be legally bound) to respect their choice. However, as we have seen, Draper avoids this conclusion, and claims that *competent* refusal of naso-gastric therapy should be respected *in some cases* (thus, not in all cases in which it is competent).

The reason why Draper appears reluctant to draw the conclusions that follow from her initial arguments probably lies in the peculiarities of anorexia nervosa. Anorexia nervosa, strictly speaking, is not a lethal illness, and the effects of abnormal eating,

⁴⁵ A real-story-based novel well expresses the paradox of accepting misery and death, while longing for happiness and life. D. Hautzig. 1982. *Second Star to the Right*. London. Fontana Lions.

⁴⁶ See: M. Selvini Palazzoli et al., *op. cit.* note 36, pp. 115–18.

⁴⁷ H. Draper, *op. cit.* note 1, p. 124.

severe as they may be, are completely reversible. The refusal of artificial feeding and hydration may therefore be profoundly devastating for carers, possibly more devastating than the refusal of therapy in cases of untreatable degenerative or mortal illnesses. Perhaps this is not only humanly understandable, but also morally relevant, and seems to weaken the normative strength of the principle of respect for people's competent decisions. For this reason, although it is widely accepted that people generally have both the ethical and legal right to make competent medical decisions, and to competently refuse life-saving treatment, the claim that people with anorexia should have the same right appears as an extremely *brave claim*, which may hardly be considered defensible in cases of anorexia nervosa. This does not mean that the anorexic patient's refusal of therapy should always be disregarded, but rather that the fact that the sufferer is making a competent decision may not be sufficient to bind carers to respect refusal of life-saving therapy. In other words, competence does not seem to produce, in the case of anorexia, the same moral obligation that it produces in other cases.⁴⁸

Although a substantial part of Draper's paper is about competence, about demonstrating that people have both the ethical and legal right to make competent decisions, whatever the results may be, and about demonstrating that people with anorexia may retain capacity to refuse therapy, Draper is probably allowing for the fact that the circumstances characterising anorexia nervosa may weaken the normative strength of the principle of respect for people's competent choices. For this reason, she takes a number of 'safety measures' and argues that respect for the *competent* refusal of naso-gastric treatment should only be accorded *in some cases*. She does not err, however, on the side of safety. Her mistake is a methodological one. The problem with her argument is not that the number of cases in which she would accord respect is too small, but that she moves from particular premises, and reaches conclusions that do not descend from those premises. She assumes that competent decisions should be respected, and demonstrates that some people with anorexia nervosa may be competently refusing artificial feeding. Then, instead of concluding that, on this basis, we should respect these decisions (and perhaps take extra precautionary measures, due to the peculiar-

⁴⁸ See for example, the recent case of Ms B., a woman who is paralysed from the neck downward, and who has been acknowledged by the High Court the right to have her life support machine turned off. See BBC news, Friday 22 March 2002, at the website www.bbc.co.uk

ity of the case), she tries to demonstrate that the competent refusal of artificial feeding is not a request for passive euthanasia and that, in some cases, it is on a par with refusal of treatment in debilitating chronic and terminal illnesses. This shift was not only methodologically incorrect, but also unsuccessful, for Draper has failed to demonstrate these two points.

We should now return to the fundamental issue raised by Draper. She argues that there are cases in which refusal of artificial feeding should be respected. We should ask two questions: is she right? If she is, what are these cases?

There may be cases in which the person's wishes should be respected, despite the normative 'weakness' of the principle of autonomy in cases of anorexia. It would be inappropriate, and perhaps more importantly, not respectful of the tragic peculiarities of each individual case, to provide general guidelines or to draw a list of circumstances in which the patient's wishes should be respected. These circumstances will have to be evaluated through a careful analysis of each individual case. As we have seen, we should consider both the person's competence or incompetence, and the feelings of those who are closely involved. There is also another aspect of the problem that we should not neglect. In some cases, people with anorexia literally cross the border of humanity. With their skeleton-like bodies, they survive their emaciation, while suffering, sometimes for years, the severe side effects of malnutrition. Whereas the majority of sufferers, sooner or later, recover or at least get much better, a minority of sufferers never seem to get better, and there might be a point at which further therapeutic attempts seem to condemn them to agony. From this point of view, I think it makes sense to consider how many years the person has been ill, and how many attempts she has made to recover. After many years and many therapeutic attempts, and after many reiterated competent requests for suspension of therapy, I believe we should probably consider the patient's request, not necessarily because the person is now *more competent* than before, but, more probably, *out of pity*.

As I have said above, it would be inappropriate to provide general guidelines that tell people how they should behave in these circumstances. However, I believe that carers should be encouraged to consider all aspects of the problem. Among those aspects, we should also include the condition and the suffering of the person who refuses therapy. Understanding the condition and the suffering of the person with anorexia involves not only a critical attitude toward the situation, but also *compassion* (in its etymological meaning: *com-* with + *patī* – to bear, suffer). Identi-

fication with the patient and participation in her suffering may clearly be burdensome for carers. However, compassion enables us to give the patient a genuine understanding and to cultivate a refined sensitivity, more attentive to the peculiar aspects of each individual case, and therefore is essential in order to consider the sufferer's request not to be artificially fed and hydrated.

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