Guest editorial

Treating anorexics without consent: some reservations

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Anorexia nervosa is classified as a mental disorder in the International Classification of Diseases (ICD-10), and between 20 - 30 anorexics die each year in the UK.¹ There is no consensus about what causes the disorder or how it is to be treated. Feeding without consent usually becomes an issue when without further nutrition the anorexic will begin an irreversible decline to death. Once their weight has stabilised and they are released into out-patient care, many will begin to starve themselves again. The natural cycle for the illness is anything from one to eight years. After eight years, the chances of cure begin to diminish rapidly, and it is also thought that ultimate success can also be adversely affected by repeated episodes of forced feeding.²

In August 1997, The Mental Health Commission issued guidance on when anorexics can be detained, treated and fed without consent.³ Although these notes echoed the law as it already stood, the need for such clarification was highlighted in January 1996 by the death of Nikki Hughes. Acting on legal advice, her doctors refused to feed her without her consent, even though she was anorexic. The claim was that Nikki understood what she was doing and had the right to refuse therapy, even though it would result in her death. The Mental Health Commission guidance makes it clear that it would *not* have been illegal to feed Nikki without her consent, providing such feeding was part of a programme of therapy for her anorexia, or necessary to restore her to a condition where other therapies might have been effective.

Although detention, therapy and feeding without consent may be justified in the majority of cases, one can still have reservations which concern a minority of anorexics whose needs cannot be overlooked simply because they are a minority. For instance, in October 1997, Samantha Kendall died after eighteen years of battling with anorexia. Her case made headline news because her twin sister had died three years

earlier, also from anorexia. Her family were reported at the time as saying that Samantha wanted to die.⁴ Can it be argued that in her case, feeding would simply have *prolonged* her life rather than *saved* it in the interests of a possible cure?

Also in 1997, another anorexic, Kerry, attempted to gain some control over treatment decisions by signing a living will in which she specifically stated that she did not want to be fed, or undergo other measures to prolong her life, if she became incompetent in the future. At the time she made her living will (with legal help) she was receiving therapy and felt optimistic about her recovery. Past experience, however, of being fed without consent (in her case, being literally held down and forced to swallow a high calorie drink) made her determined not to be fed without her consent again.⁵ Is it possible that in some cases living with and receiving therapy for anorexia can become so burdensome that the prospect of death seems preferable? Were the terms of Kerry's living will reasonable?

Distinction between *prolonging* an anorexic's life and *saving* it in the interests of a possible cure

In *Riverside Health NHS Trust v Fox*, the judge determined that feeding did constitute treatment for anorexia because other therapies would not be possible until there had been some steady weight gain. The claim that in some cases feeding may only be *prolonging* life, because an anorexic is incurable, is much more controversial.

O'Neill⁶ attracted more criticism than support from psychiatrists⁷ when he published a case study of an anorexic woman who was referred for palliative care. Offering palliative care to anorexics was considered to be collusion at best, giving up on them at worst.⁸ This is an understandable response because many anorexics do recover, some after many years. Anorexia is not a terminal illness in the sense that death is inevitable even if treatment is given. With anorexia it is fair to say

that where there is life there is at least the hope of improvement. It is nevertheless possible that some will never get well and that for such patients the misery of feeding and precarious, undesired weight gain will never result in the benefit of being able to look back with gratitude at the actions of carers, parents or partners who refused to give up hope. In such cases, it may be reasonable to draw a distinction between prolonging life and curing anorexia.

There is a difficulty, however, with identifying these cases. With other illnesses, it is accepted that a patient should be the lead partner in deciding when the hope of cure is outweighed by the burdens of the illness and the therapy. But because anorexia is categorised as a mental disorder - a characteristic of which is refusal to eat - and because years of starvation may affect an anorexic's competence to make her own treatment decisions, she is not allowed to call a halt to therapy. And neither are her carers, whose role it is not to give up hope either in the prospect of ultimate cure or in the abilities of the anorexic to find the cure within herself. It is an additional tragedy of anorexia nervosa that the tiny minority of incurable sufferers are trapped by the logic of the definition of the illness and the philosophy of the therapy.

Are there any circumstances under which an anorexic could be competent to refuse therapy?

In the UK, competent individuals have the right to give or refuse their consent to medical intervention. This right can be exercised with or without giving reasons, and irrespective of whether the reasons given are rational. This right also extends to the mentally ill, for the only interventions which can be given without consent are those administered in connection with their mental illness; other interventions are specifically excluded by the Mental Health Act. This was reinforced in common law in *Re C* when the court upheld the refusal of a schizophrenic patient, detained under the act, to have his gangrenous leg amputated. Professional carers are advised that the nature of the decision to be made and the nature of the information required to make it, are vital in determining competence.

Even though anorexia is a mental illness, it is not obvious that anorexics are incompetent to make *any* decisions for themselves. Some are being treated for anorexia whilst at the same time working in responsible jobs, running their own finances etc. They are likely to be totally incompetent only at the point of starvation. The view that anorexics are specifically not competent

to make treatment decisions is based on the judgments that they are somehow driven by their anorexia (and their behaviour is, therefore, involuntary) and that they hold irrational views about their body image.

My own - not uncontroversial - view is that it might be possible for anorexics to be incompetent to make treatment decisions but nevertheless competent to make decisions about the quality of their lives as anorexics undergoing therapy. Two different kinds of refusal of consent to therapy may be confused in the assessment of a small minority of anorexics. The first is the refusal to eat, which may be regarded as involuntary and irrational. The second is the decision to refuse all therapy (including food) because the quality of life with anorexia is not good enough to outweigh the burdens of the therapy. Any decision that life is not worth living can be challenged by someone else for whom life in similar circumstances does seem worth having. But whilst we are justified in questioning her decisions, are we right to exclude the anorexic from the decision-making?

Let us take a step back from the emotionally charged issue of anorexia and consider a parallel case - that of a woman who knows that with a radical mastectomy and chemotherapy she has a good chance of recovering from breast cancer but who refuses to have the surgery because, in her opinion, living with only one breast or no breasts at all will be intolerable. She is *also* making a decision based on her perception of her body image and we might think that this is an irrational perception. Nevertheless, operating without her consent is unthinkable.

Certain cases of anorexia permit a similar verdict. Anorexics who have suffered from the condition beyond the extreme end of the natural cycle are in a strong position to judge what life with anorexia is like and therefore are also in a position to determine whether prolonging treatment is worth the accompanying burdens. Crisp's experience of working with anorexics prompted him to write :

(m)any anorexics feel constantly like alcoholics, that they are just one step away from disaster. When suicide occurs, it is often within this context. The individual is seeking relief from the endless terror and exhaustion of a battle to maintain her position.⁹

Perhaps in the context of making decisions about the quality of their lives it is wrong not to allow anorexics the right to refuse therapy. It will be difficult to determine which anorexics can competently judge that they have reached the end of the road so as to protect from themselves the majority who

cannot. Equally, it will be difficult to watch them die when it is possible to prolong their lives. But these difficulties should not deter us from trying to do our best by all anorexics, not just the majority.

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References

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- 4 *Birmingham Evening Mail* 1997 Oct. 22: 1.
- 5 TV series: What's the story? Channel 5 1997 Nov 30.
- 6 O'Neill J. *American Journal of Hospice and Palliative Care* 1994;**Nov**:36.
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- 8 Russell J. Treating anorexia nervosa. *British Medical Journal* 1995;**311**:584
- 9 see reference 1: 81.