# Case Commentary

**S** arah is a 39 year old woman who has suffered from anorexia nervosa since her teens. Her condition worsened once she got married and became severe after the birth of her fourth child a few years ago. Despite hospital admissions, individual, couple and family therapy she deteriorated to the point where she collapsed. She was not expected to live. Her family said their goodbyes, and were not ashamed to say that there was some relief at the resolution of a problem that had tormented them for years.

The next day she regained consciousness and immediately asked how many calories she was being given through her IV line

She remained in hospital long enough to gain a few kilograms, then left against advice and refused to attend our service for follow up. However when she again began to have hypoglycaemic attacks she accepted readmission after the threat of committal under the Mental Health Act.

The problem is that we are participating in a process which maintains Sarah's weight just above a fatal collapse. We are not able to engage her in therapy which could deal

with the underlying problems and have no power to coerce her to do so since therapy requires her active participation. On the other hand we cannot seem to be able to extract ourselves from the position of coercing her to accept food, partly because her family look to us for help, partly because we regard anorexia as a mental illness which diminishes Sarah's ability to take responsibility for herself and partly out of a fear of criticism if we do not do so. Sarah has never expressed a wish to die and resists help because she claims that she is ready to give up anorexia and is able to look after herself.

It may be that Sarah will die in spite of our efforts (indeed we wonder how much we are part of the problem and not just impotent bystanders) or we may together stumble on a way out. Either way we are left with troublesome questions. At what point could we regard it as acceptable to treat a patient with anorexia as terminally ill? What would terminal care for such a patient consist of? If we participate in Sarah's death by withdrawing nasogastric feeding will we be bravely giving her a chance to take responsibility for herself, wisely acknowledging the limits of our power or abandoning a patient out of fear and anger? How can we move from terminal care of one patient to advocacy for recovery with the next and not do both badly?

#### COMMENTARY ONE

Dr John Adams Medical Director Ashburn Hall

The dilemmas brought into focus by this case are faced every day in some measure by those working with chronic self destructive conditions, such as eating disorders, self mutilation, or chronic persistent suicidality. It is therefore a case with immediate clinical relevance to many professionals and families.

There are also issues presented in this clinical vignette that have similarity to the debate over physician assisted suicide. Does a patient have the right to decide on their own death and have others help them?

Anorexia Nervosa is a curious syndrome. Even those like myself who have worked with many people with anorexia, find the spectacle of a potentially physically healthy person looking as profoundly emaciated as a person in a famine, or a prisoner from the holocaust, yet refusing food or vomiting it back, very disturbing.

There are few images that provoke a stronger wish to help than someone who is starving. Yet in anorexia, that help is refused usually through passive and dishonest ways that defy understanding. Moreover, the strength of the patient's denial and distorted thinking challenges the helper's values and sense of reality. Frequently, families and professionals become entangled in the patient's processes to the extent that they join the denial in the same way as people around an alcoholic can protect their drinking.

In 1947 DW Winnicott, a paediatrician turned psychoanalyst and one of our foremost psychoanalytic theorists, wrote a paper entitled "Hate In the Countertransference". To quote from this paper:

What we analysts call countertransference needs to be understood by the psychiatrist too. However much he loves his patients he cannot avoid hating them and fearing them, and the better he knows this the less will hate and fear be the motives determining what he does to his patients.

Although Winnicott's comments are about the treatment of psychotic patients, it is apparent to me that anger and hate are mobilised strongly in patients not usually classified as psychotic. Patients who do not get well, patients who refuse help, those who cannot express their aggression and turn it towards themselves when the physician is trying to help them not do so, are classes of patients towards whom hateful countertransference feelings can be evoked easily. If the treating team is not aware of these feelings, and sometimes even if they are, it is easy to abuse the patient in one way or another. A patient who is steadfastly (and sometimes smilingly) refusing to eat can certainly stir such countertransference reactions.

Anorexia Nervosa is a multifactorial problem, a true biopsychosocial disorder. Individual factors have to be acknowledged and all treatments have to take the context of the family and social world into account. Biological factors also contribute. There is special importance here when it comes to treatment, as we know that starvation brings its own changes that add to the syndrome.

·We know that cognition, judgement and perception are altered by the effects of malnourishment. We are now in an era where the patient's right to refuse treatment is rightly and clearly defined in ethical rules and in courts. Is this such a situation? We must remember that death can be caused by commission or omission. In the case of someone who has the disturbed thinking characteristic of Anorexia Nervosa, withdrawal of active treatment, which at times of low weight involves ensuring adequate nutrition, has a likelihood of causing death. Where do we stand as professionals when the abnormality that the patient is struggling with is self destructive thinking? Is this the same as someone who is terminally ill from cancer, or quadraplegic, who in the context of a competent mind decides that their life no longer holds for them any purpose and that the pain and suffering is too much to bear?

One of the most compelling arguments against physician assisted suicide is the "slippery slope" argument, especially as applied to societal attitude about killing. The argument goes that if we allow in our professional ethical rules and in the law instances where people can be killed, where is the line drawn, and what will the eventual distinction be? If, for instance, it is right to actively kill someone with terminal cancer, then it is not fanciful to envisage argument emerging about it being right to kill someone who is disabled, such as a newborn with a congenital difficulty where the suffering and the burden falls on families and society. There are very important reasons why as a just society we have clear laws about killing and about the sanctity of human life. If we assist patients in their deaths are we beginning to chip away at our respect for each other?

It may seem extreme to involve arguments like the above in this situation. As I have already said, however, the issues in this case have wide ramifications that go beyond the individual patient. As psychiatrists we are in the business of trying to prevent the mortality and morbidity of emotional conditions. The "slippery slope" argument also applies to us in our everyday work. If it was right to withdraw active treatment and allow a patient with Anorexia Nervosa to die, then would it be right to give a suicidal patient a

rope or not prescribe antidepressants or psychotherapy to someone who was chronically depressed and wanted to die?

The issues in this case are, of course, of competence and prognosis. Is this a situation where a patient in sound mind is making a decision in a context where the prognosis is clearly of death, or of inevitable permanent and severe disablement and suffering?

I think not. Not only is it clear that the patient's competence to make such a decision is severely compromised by her state of mind and her disorder, it could not be accepted that the prognosis was inevitably poor. There are few clues in the story, but enough to see that the severity of this person's problem has varied through her life. Although the eating disorder is chronic, she has functioned emotionally and physically well enough in the past to form meaningful relationships and have children. I think the issue is more what has changed and altered this for her, than whether she should be allowed to kill herself.

All psychiatric treatment to be maximally effective has to proceed in the context of a "holding environment". This is a term originally used by Winnicott when talking about what a mother needs to provide for her infant. "Holding" means physical security, but much more. It means a secure emotional and structural framework that provides the context in which normal development can proceed safely.

In the treatment of patients sometimes this "holding" is needed for a long time until the patient can recover. For an anorectic patient the holding includes keeping them alive when they lose the capability to do so for themselves for periods of time.

There is skill in this, as the patient must also have the space for their autonomy and independence, and there will be many times when it is right clinically to hand the responsibility to the patient to have the motivation to get better. The bottom line is, however, that the patient must know that the framework will ultimately be held and they will be kept alive. I would submit that when the carers begin to

say that perhaps it is best for the patient that they are left to die, the holding is inadequate and the patient's response to this unsafety will be increased anxiety and therefore increased symptomatology.

To turn to this specific case, the treatment team are feeling powerless, and they are right that therapy requires her active participation when she is able. Until then they must keep the framework for her, and a Compulsory Treatment Order may well be an appropriate course of action. Ideally treatment decisions should not be based on generalised philosophical standpoints such as Anorexia being an "illness", or out of a fear of criticism by others but on an in depth understanding of the forces operating to produce and continue the symptoms in that particular patient that is, a thorough formulation. Although she has never expressed a wish to die, she is doing this to herself and the treatment team need to be guided by what is actually happening, not by her denial which is part of her disorder. It should be remembered again that her thinking will be disturbed by the effects of her disorder.

Of course the team may well be part of the problem. That is, the transference and countertransference may not be understood and may be augmenting the continuance of the symptoms. The question is asked when can a patient with anorexia be regarded as terminally ill. Surely the answer is the same as for any other person, that is when their physical state indicates that recovery is unlikely despite available treatment. You will see that I do not regard "terminal care" as a realistic alternative and I will therefore not answer the question about this. In withdrawing naso-gastric feeding the team may be doing all three of the possibilities outlined in the second to last question, depending on the circumstances which may vary over time for an individual patient. The key is again in understanding in as much depth as possible what is happening in the patient's emotional world.

I believe that the answer to the last question is part of the resolution to the team's overall dilemma. That is that the team should be large enough to share the load of such patients, and that adequate time must be given to the team talking together about their reactions and emotions regarding the case. It is by clarity about their own

feelings that the team will be clear about what is right for the patient. Team supervision (possibly by an outside supervisor) needs to be available, so that the team is "held" themselves when they are required to treat such demanding cases. In the same way adequate practical support and resources are necessary to avoid insecurity in the team, which will be reflected in increased anxiety in their patients.

### Commentary two

**Ann** New Zealand

This case history made me so angry when I read it - a classic case of professionals and family "taking over" and diminishing and even ignoring Sarah as a person, as the person with the battle. Where is Sarah in all this? The family want relief from a problem that has tormented them for years. It is not their problem or battle. What's it done to Sarah? How does she feel? She has already been abused and threatened by this and then along come family and professionals and offer more threats and abuse, under the Mental Health Act!

You state that "the problem is, we are participating in a process", "coercing her to accept food", "because her family", "because we regard anorexia as a mental illness" and "out of a fear of criticism". What about Sarah? What does she want? You further state that "Sarah has never expressed a wish to die and is ready to give up anorexia". For goodness sake give Sarah back her personhood, her dignity and her life. You already think of her as dead, it's a wonder you haven't already organised the funeral.

Sarah is not a disease or crazy. She is suffering from a food eating disorder that would seek to diminish her as a person of value and importance, and now you are contributing and even pushing that thought along with your current methods of treatment.

Why would you think her death would be imminent if you withdrew force feeding? Giving Sarah back her dignity (the right to make choices) and responsibility would give her a will to live and fight back for herself. Stop thinking of her as a patient! Stop thinking of her as terminally ill! Stop

being concerned with how the family thinks or feels and what the critics (whoever they are) think! Start thinking of what Sarah wants, feels and has expressed. Yes, Sarah needs to recognise she can't do it on her own and accept help, but help to help herself, not to lose control of her life altogether. Yes, there are troublesome questions, but then this is a troublesome question, FOR SARAH! The answers are within Sarah and your job is to encourage and support her to find the power and keys to unlock these answers not beat her down with the same weapons the problem uses. What about Sarah!

## Commentary three

#### Lorraine Grieves

Vancouver Antianorexia/Antibulimia League

Dear Sarah
Because I don't know you and because I only know some of your history and current circumstances, I apologise for any commentary that may not fit with your experience. But since anorexia/bulimia seems to display many characteristics that are common to a number of women I have met through letters or in person, I am hopeful that some of this will ring true for you.

I understand that you have expressed the desire to give up anorexia and to begin a new relationship with yourself, although anorexia seems to be employing many of its tactics to keep you stuck in its grips. Because one of anorexia's tactics is its seductive nature (by that I mean it manages to convince its victims that they need it in order to be\_\_\_\_, eg. happy, successful, loved, worthy, thin ... etc) I am curious as to how you have outsmarted it and realised the truth behind the lie.

I know from my own experience I began to see that instead of giving me positive benefits, anorexia was actually taking away all that mattered to me, including my relationship with my daughter. I also realised that anorexia's ultimate goal was my death. Although I was aware of that possibility for others in similar situations, I was blind to that possibility for myself.

My point is that in order to begin to leave the relationship with anorexia, it takes a lot of outsmarting, because it is so tricky and malicious. As I continue my fight, I am becoming more and more aware of the ways that it works in convincing its victims and their supporters that they are on an "unstoppable path". This story of an unstoppable path is completely false and is one that anorexia uses to gain power.

The business of discovering what the real truths are is a tricky task, but because you have already done this I am confident that you are able to continue. I must warn you that as you continue, anorexia will try to take away your supporters and may try to convince you that in fact you do not need them. It has a way of convincing its victims that those who care about them are "the enemy". I must let you know that this is another untruth, because, in fact, the real enemy is anorexia - not you - and any anger, frustration that is occurring is not a reflection of you - Sarah's choices and designs for her life but for anorexia's vicious plots against those plans for

Something to consider might be how you and your supporters might band together to fight anorexia's lies because when it faces an army of people who are aware of its constant lies, its power is diminished. Also, I must let you know that each anti-anorexic move you make will quite possibly be followed by a strong move by anorexia to draw you back. These are the times to hang onto the fact that the loud anorexic voice is really a cry of panic from anorexia as it notices you moving away from it. Even if that voice manages to pull you back for a short while, as I know that it has in my case, might it be a time for you to survey anorexia to better learn what its tactics are? As I have done this myself, I have come out of it realising that knowing its ways has given me a strong tool for fighting it off and for moving forward and eventually beyond its tyrannical

I hope that this has been of some assistance to you. I look forward to hearing that you and your supporters have called anorexia's bluff.

Yours Anti-anorexically / Antibulimically L Grieves **Dr Glen Simblett**Consultant Psychiatrist

This case commentary tackles a important dilemma verv fundamental to traditional treatments of anorexia nervosa and other eating disorders. I agree with the commentary where it says "Either way we are left with troublesome questions". I believe that only by looking at troublesome questions can we hope to learn more effective ways of helping people fight back against problems such as anorexia nervosa, problems which threaten to describe and determine people's very lives and existences.

Looking at the troublesome questions one at a time, I would personally regard a patient fighting against anorexia as terminally ill only when they are indeed dead. I believe that is the only time when it is legitimate for us to give up hope. I would (rather radically) suggest that the terminal care of people fighting against anorexia might include making mistakes such as:

- 1. Confusing the problem with the person and beginning to accept that they are anorexic through and through! In other words, believing that this is their free choice which we (as good therapists) should ethically support.
- Defining anorexia nervosa solely in terms of eating behaviours and ignoring the other methods of control and punishment that it wields.
- 3. Beginning to use anorexic methods (eg coercion, bribery, force, threats, isolation, secrecy etc). in our treatment of the "anorexic".
- 4. Failing to recognise that the problem is also affecting us in this process
- 5. Giving up hope as the problem begins to thrive on the unwitting sustenance that we have been feeding it.
- 6. Convincing ourselves that there are only anorexic solutions (torture or death) to anorexic lifestyles.
- 7. Providing research evidence to back these statements up and render them scientifically unchallengeable.

Ethical Issues in Nursing Geoff Hunt Routledge Press 1994 ISBN (hardback) 0-415-08144-0 ISBN (paperback) 0-415-08145-9

This is one of a series of books on Professional Ethics. Overall I found this a readable book which would be accessible to any nurse with an interest in the topics covered. With a strong focus on the United Kingdom, it would be necessary to consider the relevance of some of the information presented to your own country of practice.

At first glance I had some reservation about the number of authors who were not nurses, particularly that the editor was "out of" the nursing profession. However, the familiarity that these authors have with the position of nursing within the wider health care sector was to some extent reassuring, even if it goes no way towards affirming that nurses could, for themselves, make a valuable contribution.

In his introduction Hunt clearly recognises the unique position of nurses in the delivery of patient care. While giving care they are expected to meet the requirements of the medical profession and health care institutions, to obey orders, while maintaining a moral responsibility to patients, themselves and the profession. As he notes in page two of his introduction, many of the ethical issues nurses raise, are based on their unease, in one way or another, in dealing with their lack of freedom to care for patients and their families as they feel they should.

The book is divided into two parts. In the first part specific issues such as informed consent, privacy and dignity, research, care of the elderly and the person who is not eating are addressed. The second part of the book considers some more general issues including accountability, codes of conduct, law and professional conduct, ethic of care, health care resources and the right time to die. Each topic is made relevant to nursing. As might be expected many of these issues are little more than introduced, however, as such they provide useful starting points for nurses wishing to further research a topic. With both an index and a bibliography at the end of the book there is a clear starting point for other reading. The concise approach taken by most authors, along with the stories presented would make this a useful resource for teaching nursing students about ethics.

Given the nursing literature currently available on the ethic of care, I was disappointed that Linda Hanford's chapter, an appraisal of Nodding's theory, was not followed with a chapter looking more specifically at nurses' models of the ethic of care. The primary focus of a nursing ethic is not concluded in this book. Hunt suggests that nurses 🤸 should ally themselves with patient groups to ensure accountability of institutions and other professional groups, seeing this as a way to overcome the difficulties of accountability for the nursing profession which often finds itself caught between obeying orders and professional integrity. Many of the authors acknowledge the relationship of advocacy that is commonly expressed by nurses as appropriate to the nurse patient relationship, they recognise also the strength of character that this requires if individual nurses are to take a stand. The best they seem to offer in response is that nurses should keep trying to make their concerns heard.

The fact that many nurses do not take a stand is also recognised in the contributions to this book. While some remind nurses of their responsibilities within the UKCC's Codes, others recognise some of the reasons for nursing silence. These issues all have relevance for the nurse working within other countries, such as New Zealand, however it would be important to consider the relevant Codes and delivery of health care and not assume that these are the same as in the United Kingdom.

In conclusion this book certainly presented a less traditional approach to nursing ethics than some of the standard texts. The issues raised would be familiar to many nurses and have been commented on in numerous journal articles, however it is useful to be able to find them in a book which covers a variety of nursing situations and deals with the issues in a clear and informative manner.

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