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## Competence to refuse treatment in anorexia nervosa

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### 1. Introduction

Anorexia nervosa is a serious mental disorder that raises questions concerning the use of compulsory treatment. Particular difficulties arise because a distinctive feature of the disorder is that patients have difficulty cooperating with attempts to help them to regain weight, even when their health is endangered (Beumont & Vandereycken, 1998). Moreover, many patients refusing treatment appear to possess the capacity to refuse treatment. At the same time they are often significantly ill and would benefit from treatment, whether they are at immediate risk of death. An additional difficulty is that this disorder typically strikes adolescent and young women near the age of legal majority. As a result, there are differing views among mental health professionals over the use of the mental health legislation or other means of compulsory treatment (e.g., Vandereycken & Beumont, 1998). For example, there appears to be considerable variation in practice across the UK, both under common law and the Mental Health Act, with regard to the provision and use of inpatient admission and compulsory treatment in cases of anorexia nervosa (Royal College of Psychiatrists, 1992).

In English common law, patients have a right to refuse treatment as long as they possess the capacity to do so,<sup>1</sup> even if their reasons are irrational or unreasonable<sup>2</sup>—this is because of the central tenet of the right of the patient to make his or her own treatment choices (Kennedy & Grubb, 2000). The legal criteria for capacity focus on patients' understanding of their illness and its consequences; the various treatments and their risks and benefits; believing this information; and the use of this information to come to a decision (British Medical Association, 1995,2001).<sup>3</sup> All of these are largely intellectual abilities.

Competence is the clinical equivalent of capacity (Tan & Jones, 2001). Factors relevant to the consideration of competence, particularly in psychiatric patients, may encompass a range of factors which are not included in standard legal definitions of capacity, such as appreciation of information as applying to the self and the influence of mental illness (Grisso & Appelbaum, 1998), but at present these are poorly defined. The MacCAT-T (Grisso & Appelbaum, 1998) is the most fully developed standardised method of assessing competence, which closely

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<sup>1</sup>Re C (*Adult: Refusal of Treatment*) [1994] 1 W.L.R. 290; [1994] 1 All E.R. 819.

<sup>2</sup>Re T (*Adult: Refusal of Treatment*) [1992] 4 All ER 649.

<sup>3</sup>Re C (*Adult: Refusal of Treatment*) [1994] 1 W.L.R. 290; [1994] 1 All E.R. 819.

follows the definitions of capacity as reflected in the common law of England and the United States (Appelbaum, 1999).

There have been few studies examining capacity to consent to treatment in patients and no studies generating empirical analyses of capacity or competence in patients diagnosed with anorexia nervosa. A recent review of the literature has found little research in the area of competence and consent in children and adolescents (Tan & Jones, 2001). The empirical studies that have been done on capacity and competence to consent to treatment in psychiatric patients have used instruments based on the legal criteria of capacity, with focus on understanding and reasoning (Billick, Edwards, Burgert, Serlen, & Bruni, 1998; Grisso & Appelbaum, 1995; Grisso, Appelbaum, & Hill-Fotouhi, 1997; Grisso, Appelbaum, Mulvey, & Fletcher, 1995; Moser et al., 2002).

There have been no empirical studies of the factors relevant to the wider clinical concept of competence, nor any empirical studies exploring the nature of the difficulties that patients diagnosed with anorexia nervosa experience. Given the excellent understanding and relatively intact reasoning abilities that the majority of these patients appear to exhibit, there is insufficient evidence to warrant the prior development of any theoretical constructs for an investigation of this nature.

Sociological methodology provides well-established methods by which to conduct an exploratory study that can give precedence to the participants' views and accounts, in preference to the constraints of prior theoretical assumptions (Flick, 1998). The grounded theory approach to qualitative analysis allows the discovery of new ideas and views, with themes emerging from the interviews themselves, which give rise to a range of disparate themes which are then grouped to enable their consideration (Glaser & Strauss, 1967). This makes grounded theory the ideal approach to this study, enabling a fresh consideration of the issue of competence using a 'ground up' approach and respecting the perspectives of patients and their families themselves.

There are three main advantages of using sociological analysis in this study. First, it allows detailed interviews with a range of patients at different stages of anorexia nervosa and ages. Second, the interviews can focus specifically on exploration of beliefs and attitudes relevant to the understanding of competence to refuse treatment. Third, it allows a comparison between the qualitative analysis of participants' own accounts of their difficulties and the participants' performance on a standardised test of competence, the MacCAT-T, as well as standardised psychiatric measures of psychopathology.

The qualitative analysis in this article suggests that the current legal concept of capacity and a comprehensive standardised test of competence are inadequate to assess the difficulties in treatment decision making many patients diagnosed with anorexia nervosa experience. Perceptual distortion associated with starvation (e.g., Probst, Vandereycken, Vanderlinden, & Van Coppenolle, 1998) and comorbid depression are well known, and their impact of competence is not controversial (e.g., Herpetz-Dahlmann, Muller, Herpetz, Heussen, et al., 2001). However, there may be other factors influencing competence in anorexia nervosa that need to be taken into account.

## 2. Objective

This study aims to explore the beliefs and values relevant to competence to refuse treatment, in females with anorexia nervosa, and to examine the extent to which these affect the assessment of competence using the MacCAT-T (Grisso & Appelbaum, 1998).

### 3. Method

#### 3.1. Participants

Ten women diagnosed with anorexia nervosa or atypical anorexia nervosa as defined by DSM-IV criteria, aged between 13 and 21 years, were recruited through the eating disorders services in Oxfordshire.

The selection criteria required that they had anorexia nervosa, with the diagnosis of atypical anorexia nervosa allowed if they were below 16 years, as defined by DSM IV (American Psychiatric Association, 1996). The participants had a range of body mass indexes (BMI) ranging from 12.57, which is dangerously severe weight deficit, to 19.62, which is close to standard goal weights usually set by eating disorder treatment teams at 18 or 20, with a median BMI of 17.10. Normal BMI is defined as 20 to 25 for the general population. In terms of treatment, the participants covered a wide range of treatment situations, including compulsory treatment (Table 1).

Seven mothers of the young women were interviewed separately, as well as one set of parents of a young woman who gave consent for their participation but declined to be interviewed herself.

#### 3.2. Qualitative research methodology

The participants were interviewed using an open and then semistructured format focusing on a broad range of issues that could be relevant to competence, with audiotape recording of the interview. In accordance with the principles of grounded theory (Glaser & Strauss, 1967), the topics explored in successive interviews developed according to ongoing analysis of the previous interviews. The interviews were fully transcribed and independently coded for content by J Tan and A Stewart. The coded transcripts were analysed to elicit the diversity of themes emerging from the interviews. Three themes relevant to competence and capacity will be discussed: impact of anorexia nervosa on attitudes to death and disability; impact of anorexia nervosa on values and personal identity; and ambivalence to treatment and recovery.

#### 3.3. The MacCAT-T test of competence

The MacCAT-T test of competence (Grisso & Appelbaum, 1998) was administered to the participants after the interviews. The MacCAT-T is a structured interviewer-rated interview in which a previously prepared script giving patient information on anorexia nervosa as well as a choice of treatment options is administered in a standardised way to each participant. Understanding, reasoning, and appreciation of illness are rated using a three-point scale for each item within these categories. The areas covered by the MacCAT-T include all the English legal criteria of capacity, with the additional dimension of participants' application of the understanding of facts to themselves.

#### 3.4. Psychopathology questionnaire

Five self-administered rating instruments were completed by each participant to assess the level of psychopathology: the Beck Anxiety Inventory (Beck & Steer, 1993a); the Beck Depression Inventory (Beck & Steer, 1993b); the Eating Attitudes Test (EAT-26) (Garner & Garfinkel, 1979; Garner, Olmsted, Bohr, & Garfinkel, 1982); the Eating Disorder Examination (EDE-Q4) (Fairburn & Beglin, 1994; Fairburn & Cooper, 1993); and the Rosenberg Self-Esteem Questionnaire (Rosenberg, 1965).

## 4. Results

### 4.1. Levels of psychopathology

The participants showed a wide range of psychopathology in the self-completed questionnaires for anxiety, depression, and eating disorders, ranging from within normal limits to severe levels of psychopathology, demonstrating a spread of illness severity in this sample of participants. The median scores of the participants on all these questionnaires, however, were well above the normal limits, indicating that the majority of the participants had significant levels of psychopathology. The participants' scores on the Rosenberg Self-Esteem Questionnaire, which measures levels of self-esteem, also covered a wide range, with a median score of 21.75 out of maximum possible score of 40, where high scores would reflect higher self-esteem.

### 4.2. The MacCAT-T test

The participants generally had a good understanding of the facts of their illness, its consequences, and the treatment that was being offered. Two participants did not fully accept that they suffered from anorexia nervosa despite having good understanding and reasoning.

In the category of 'understanding,' participants had a median score of 6.0 out of a maximum of 6.0. In the category of 'appreciation of illness,' the participants had a median score of 4.0 out of a maximum possible score of 4.0. In the category of 'reasoning,' the participants had a median score of 6.0 out of a maximum of 8.0. These scores reflected the excellent performance of the participants in the MacCAT-T task.

### 4.3. The qualitative study

On qualitative analysis there were clear themes of difficulties with competence, which are described under three headings and illustrated with quotations.

**4.3.1. Impact of anorexia nervosa on attitudes to death and disability**—Many participants described alterations in attitudes to the risk of death and disability. Some alterations clearly related to feelings of depression and worthlessness, for example some participants felt that they wanted to give up, or that it did not matter whether they died.

I do sometimes [feel like giving up], when I'm really, really depressed. I did last year when I was in [treatment centre], I felt that I wanted to die. (Participant G)

Some participants, however, expressed quite different attitudes to the risk of death and disability, which, although not depressive in nature, were nevertheless relevant to competence to refuse treatment in anorexia nervosa.

One such attitude was that although not wanting to die or suffer disability, the relative value of anorexia nervosa was such that death or disability was given less importance than the disorder.

Although I didn't mind dying, I really didn't want to, it's just I wanted to lose weight, that was the main thing. (Participant I)

Another nondepressive attitude was that death and disability had a particular meaning in the context of anorexia nervosa, which altered the perception of these risks.

I remember getting some tests back saying how my liver was really damaged and all this, and I thought it was really rather good! I can't imagine that I thought it, it felt like really quite an accomplishment! It was just I'd just done something that I knew hardly anyone else could do. (Participant D)

**4.3.2. Impact of anorexia nervosa on values and personal identity**—Several participants described giving such importance to anorexia nervosa in their lives that relatively little significance was put on other aspects of their lives, such as academic achievement, friendships, and family relationships.

It's awful to admit, but in general it's [the anorexia nervosa] the most important thing in my life.... In comparison with relationships, it's much more important than that, with university and work it's a difficult decision, but as it goes I can't say anything but that I did drop my university and that I was in pursuit of thinness at the time. And even now if I were given the opportunity to go back [to university] now but I'd have to be a lot heavier, I'd say no. (Participant C)

When I was losing weight it was something I'd have a lot of comfort in. When everything was going bad, college was going bad, well at least I was losing weight; I'd get on the scales and I lost weight, and that would put me on a high for the day. (Participant E)

Some participants described feeling that anorexia nervosa was a part of themselves and not a disease that could be eradicated by the acceptance of treatment.

Interviewer: If your anorexia nervosa magically disappeared, what would be different from right now? "Everything. My personality would be different. It's been, I know it's been such a big part of me, and—I don't think you can ever get rid of it, or the feelings, you always have a bit in you." (Participant I)

The issue of anorexia nervosa and its impact on participants' sense of personal identity is expanded upon in a separate article (Tan, Hope, & Stewart, 2004).

**4.3.3. Ambivalence to treatment and recovery**—A theme of ambivalence emerged towards the illness, the treatment, and the prospect of recovery, with the participants expressing the great difficulty they experienced in accepting treatment.

One difficulty was that there were clear positive as well as negative aspects to having anorexia nervosa, which affected participants' motivation to engage in treatment.

It kind of protects you as well, I think, from coping with other things. It just distracts you the whole time. Basically punishing you all day long, bullying you about something. It just fills your mind. It distracts you so completely about things you don't want to think about, to lose that is quite scary. (Participant F)

Interviewer: What does being thin achieve for you? "People would like you more, it's just all I want to be". Interviewer: So if you achieve that, what kind of person would you be? "I'd be much happier, and people would like me more." (Participant B)

Despite clear understanding of the benefits of treatment and a wish to recover, some participants had difficulties making a decision to change their behaviour or accept treatment. Such difficulties experienced were complex in nature.

These participants had a sense that change in behaviour was not totally within their control, and they were not able to change their behaviour even if they wanted to.

I couldn't stop [dieting]. Don't want to and couldn't anyway. (Participant B)

As much as I want to get over it [anorexia nervosa], every time I come to eat I just can't, I think, I dream about when I can go running and I think, if only I could just manage to eat everything, and then I will, but when it comes to it I just can't face it. (Participant H)

Another felt that she wanted or needed coercion before she could change her own behaviour.

And I've needed threats, really, like you know, like if I start losing weight I will be admitted, because that's really scared me, and I need it to keep me going. Because it's not always enough to just want to do it.... A lot of the time I just think they're not really serious when they say that [there is risk of physical harm and death], that it won't happen, then I just think, well, I don't have to do it [comply with treatment], then I feel guilty because I'm not being forced to do it. (Participant A)

The issue of control and coercion are dealt with in greater detail in another article (Tan, Hope, Stewart, & Fitzpatrick, 2003).

Ambiguity of desire was also raised, with some participants expressing that they did not want to have treatment while simultaneously wanting it.

Interviewer: What would you think about coming for treatment when you don't want to? "Me personally?" Interviewer: In general or you personally. "I think it's quite difficult to say in what sense you use the word 'want', because often you can actually want to come to treatment, but the last thing that you would ever say is that you want to come to treatment, and it could take quite a bit of coaxing to, and especially because it feels like you don't want to be a pushover and it's kind of like laying out your own rules." (Participant C)

Yet another problem of ambivalence and ambiguity was that participants often had a clear idea that treatment was better for their health and well-being, but some did not feel that this was a choice they would necessarily wish for.

Interviewer: (Using question from set script in Expressing Choice section of MacCAT-T) So there are two alternatives, really, the treatment package and not having treatment. Which of the two seems the best to you? (4 second silence)  
 Interviewer: Which one are you most likely to want? (2 second silence) "I'm most likely to want nothing, but I don't think that would help." Interviewer: Right, so they are two different questions, which is best and which do you want. "Mm. (Agreement)"  
 Interviewer: So in the end, if I were sitting here and I was your doctor, which would you choose, do you think? "Nothing." Interviewer: No treatment. "No." Interviewer: Okay. And which do you actually think is better? "The package, the treatment."  
 Interviewer: So that's a tricky one, isn't it? Because my questionnaire assumes is that what you think is better is what you want. "Yeah." (Participant I)

## 5. Discussion

This article presents a qualitative analysis of interviews of people diagnosed with anorexia nervosa with respect to the issue of competence to refuse treatment, and compares it with a standardised test of competence conducted with the same participants. The participants all had a diagnosis of anorexia nervosa and showed a range of psychopathology on standardised eating disorder questionnaires as well as on measures of depression, anxiety, and self-esteem.

The main weakness of this study is that it uses a small number of participants. Because of this, the results do not represent the whole range of views present among the population of patients diagnosed with anorexia nervosa, nor can they be claimed to be typical of these patients. However, even with a small number of participants, this study has demonstrated that there are a wide range of difficulties with competence to refuse treatment.

The participants performed on the MacCAT-T to a high standard, which was comparable to the healthy population control group in a previous study using the MacCAT-T (Grisso et al.,

1997). In fact, as all the participants were already highly conversant with the facts of their disorder, the exercise of going through information about anorexia nervosa and its treatment, with the systematic checking prescribed by the MacCAT-T, was experienced as onerous and patronising to the participants and awkward and painful to carry out for the interviewer. This suggests that the standard concept of capacity to consent to treatment, as being one of understanding and reasoning which is captured well by the MacCAT-T, may not be relevant to the difficulties that these participants may experience in their decision making.

One important area, which emerged from the qualitative analysis, is attitudes to death and disability. Treatment refusal may occur, not because the patient wishes to die, but because of the relative unimportance of death and disability as compared to anorexia nervosa, or because of the particular meaning death and disability may acquire in the context of anorexia nervosa. The relative unimportance of death compared with the anorexia may play a crucial role in treatment refusal, and yet it is neither related to depression nor is it picked up by the MacCAT-T as indicating impairment of capacity. If this relative evaluation is, however, a product of the disorder, it is relevant to the issue of competence. Longitudinal studies that examine whether such evaluation changes with changes in the anorexia nervosa would help clarify the relationships between the disorder and the attitudes.

The importance of the anorexia nervosa to the participants' sense of personal identity can lead to reluctance to receive treatment. But if the anorexia nervosa is an illness then such reluctance may impair competence to refuse treatment. This raises the question of how changes in personal values and sense of identity should be assessed with regard to competence. In adolescent patients, where no clear sense of identity has developed in the absence of anorexia nervosa, the assessment of competence is particularly problematic.

The results also show that the participants had considerable ambivalence about treatment. Some philosophical analyses have suggested a hierarchy of desires, where, for instance, a person addicted to a drug may have a first order desire to take the drug, but a second order desire not to want to take the drug. It has been argued that this person's autonomy is best respected by helping him with his second order desire (Frankfurt, 1971). Our research shows, however, that some patients can experience ambivalence in several ways. First, there may be advantages to having anorexia nervosa, which the patient may not wish to give up. Second, the patient may feel that changing behaviour is not a choice she can make, even if she wants to. Third, the patient may wish to be coerced before she can comply with treatment. Fourth, the patient may feel simultaneous wishes to have and not to have treatment. There does not appear to be a clear hierarchy of desires in these experiences of ambivalence and it is therefore uncertain which action would best respect the person's autonomy.

This study suggests that the assessment of competence to refuse treatment in anorexia nervosa should be based on an assessment that includes a wider range of beliefs and values.

The beliefs and values of people diagnosed with anorexia nervosa demonstrate the inadequacy of our current understanding of, and ability to assess, competence to refuse treatment. Our lack of understanding leads to a danger of mismanagement. On the one hand, many patients diagnosed with anorexia nervosa who are in fact impaired in competence, may be assessed as having capacity using the current criteria. On the other hand, as a response to patients with apparent capacity making harmful decisions, clinicians and the courts may resort in practice to discarding the consideration of competence or capacity altogether and acting in a paternalistic fashion to safeguard the patients' best interests. To respect patient rights whilst protecting their best interests, the analysis of, and assessment of, competence in anorexia nervosa needs to be grounded in a full understanding of its components, based on empirical

research which captures the real dilemmas that patients and their parents face. This wider understanding of anorexia nervosa can potentially influence psychiatric practice as well as mental health policy in the area of treatment refusal in anorexia nervosa. Further, this approach informs the development of mental health legislation to help mental health professionals to respond to treatment refusal in anorexia nervosa in a manner which is more relevant and helpful to these patients and their families.

## 6. Conclusion

This article presents the results of a qualitative study exploring the beliefs and values relevant to competence to refuse treatment, in females with anorexia nervosa, with a comparison to a standardised test of competence. Three themes relevant to competence and capacity have been discussed: impact of anorexia nervosa on attitudes to death and disability; impact of anorexia nervosa on values and personal identity; and ambivalence to treatment and recovery. All these factors are relevant to the participants' decisions about treatment and raise questions about their competence to refuse treatment. The current legal criteria of capacity, applied by the MacCAT-T test, failed to capture difficulties that were relevant to competence to refuse treatment in anorexia nervosa. Anorexia nervosa has an impact not only on beliefs but also on attitudes and values relevant to treatment decisions. This has implications for the assessment of capacity as well as the conceptual understanding of competence.

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**Table 1**

## The participants' characteristics

Participants	Range	Median value
Age	13 years 0 months to 21 years 10 months	17 years 0 months
Duration of illness	2 months to 7 years	3 years
Age of onset	7 years old to 17 years old	14 years old
BMI	12.57–19.62	17.10
Treatment	<ul style="list-style-type: none"> <li>• 2 on (inpatient) compulsory treatment orders</li> <li>• 1 psychiatric inpatient on voluntary basis</li> <li>• 2 psychiatric day patients</li> <li>• 4 psychiatric outpatients</li> <li>• 1 in general practitioner care (opted out of specialist care)</li> </ul>	