

WEIGHING THE OPTIONS

Compulsory treatment, mental capacity and decision making
in anorexia nervosa

WILLEN MOET JE OOK MAAR KUNNEN

Dwangbehandeling, wilsbekwaamheid en beslisgedrag
bij anorexia nervosa

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bij anorexia nervosa
(met een samenvatting in het Nederlands)

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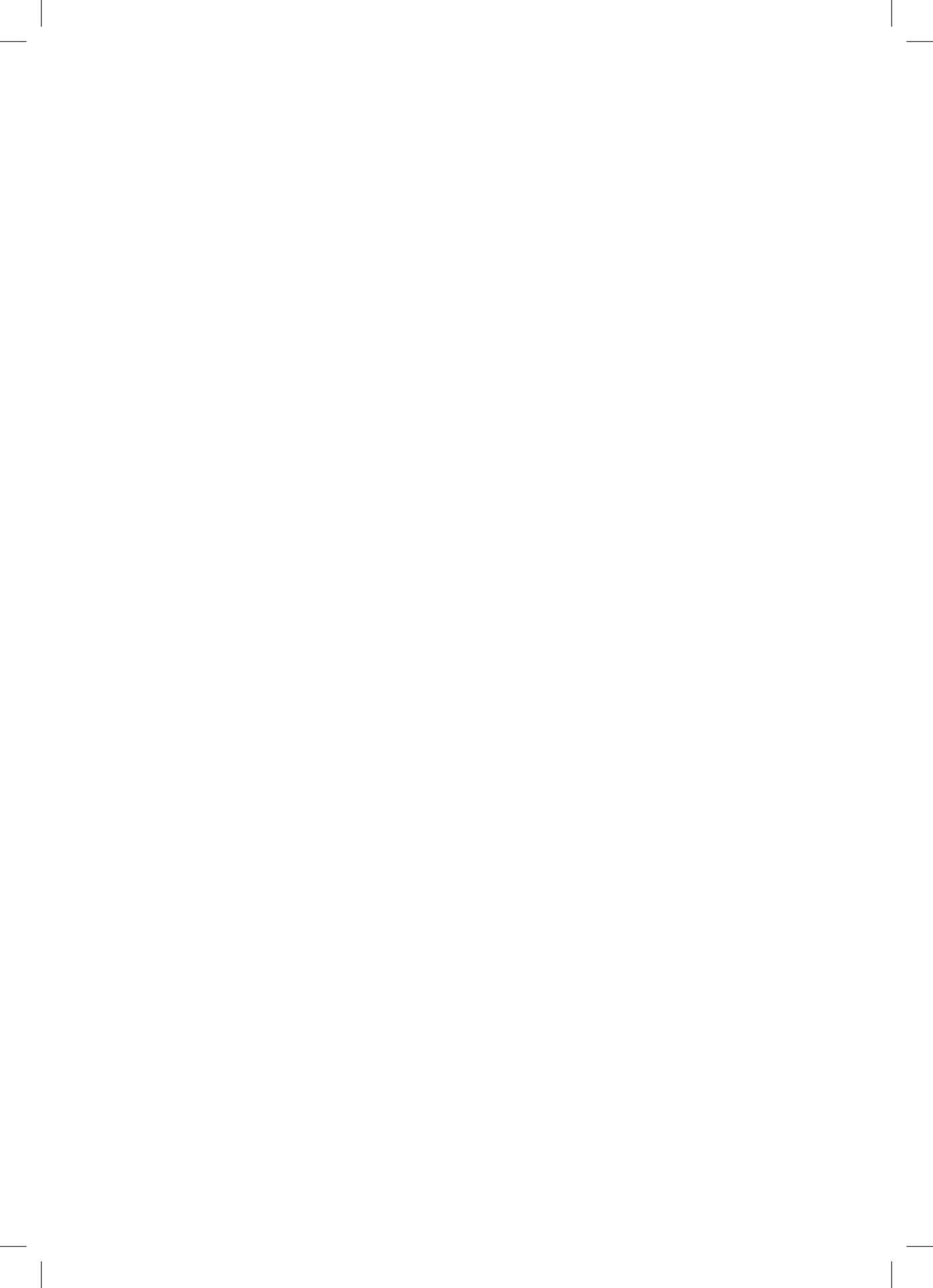
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CHAPTER 1

INTRODUCTION



CASE VIGNETTE

Jane is a 17 year old adolescent when she presents for the first time at our eating disorder center. She lives with her parents and a younger brother. In the past she has suffered from depression. Parents describe Jane as a strong willed, but kind and gentle girl, with few friends. Jane's mother has had anorexia nervosa as an adolescent from the age of 13 to 20. She was admitted and experienced this as an awful time. Her relation to food and weight is still ambivalent. Jane has developed anorexia nervosa in the last year, after her mood dropped again. Jane herself does not want to be treated, she does not see herself as ill and claims her eating pattern is normal. Her BMI is 14.8 and dropping and bradycardia, hypotensia and lanugo are present. Her eating pattern is severely restricted. In her presentation she is remarkably emotionally blunted, not severely depressed. Inpatient treatment was advised (to which she complied) and her parents were involved in the treatment. However, although Jane put on some weight and the severity of her physical condition diminished, she still did not feel something was amiss and left the inpatient unit prematurely. In the next 4 years she is in and out of treatment, her BMI ranging between 18 and 13.5. Her social life is non existent, retaining a job very hard. She strives for an ever lower weight, although she admits that when on the desired weight, she will still think this too much. She understands that others are concerned for her physical well being, she does now admit to having anorexia nervosa, but does not feel her condition is serious enough to warrant the grave concern she encounters from the treatment team and her parents. Weighing of the pros and cons of eating more is hardly done by her and although Jane knows her blood pressure and heart rate are considered very low by us, and understands that this is risky, this does not influence her eating behaviour nor her will to change it. The ultimate consequence of death is not upsetting to her. On the one hand because she does not feel that this is realistic, as she is not that much underweight in her view; on the other hand as she prefers to be thin and at risk rather than healthier and "fat".

This case vignette shows the complexities clinicians face in the day to day reality when treating severely ill patients with anorexia nervosa. How come patients stick to such obviously dangerous behaviour? How is it possible that they disregard the risks they face and do not even seem to care much, as long as they do not put on weight, the consequence most feared? Born out of the deep felt need for more evidence based guidance to aid clinical decision making regarding mental capacity to consent to treatment and the effects of compulsory treatment we decided to study precisely these issues. This thesis aims to explore mental capacity in anorexia nervosa, with an emphasis on finding clinically relevant factors to aid clinicians in their decision making regarding severely ill patients.

ANOREXIA NERVOSA

Anorexia nervosa (AN) is a severe mental illness impacting on all life domains. The onset of the disorder is usually in adolescence but as the mean duration of illness to recovery takes around 7 years^{1,2} transition to adult life is fraught with difficulties. Finishing secondary education is hampered, but also starting higher education or a job, engaging in relationships and generally finding the way into society are life domains severely hindered by this devastating illness. In the global burden of disease study in 2013 it was found that eating disorders were amongst the leading causes of burden in young females in high income countries, with a burden greater than that of alcohol use disorders, gynaecological disorders and interpersonal violence.³ This finding highlights the severe morbidity of AN. The causes of AN are not yet fully elucidated. Multiple factors, including genetic, neurobiological and environmental influences, appear to have an influence in the onset of AN.^{4,5} Recent studies have shown a lifetime prevalence of 1 to 4 % in Europe^{6,7} indicating that AN is not uncommon. Central features of AN are an intense fear of weight gain, body image disturbance and altered cognitive and emotional functioning. A rigid thinking style, a tendency to focus on details at the expense of the bigger picture and intolerance of uncertainty have been shown in patients with AN.⁸⁻¹⁴ Furthermore emotion regulation difficulties and less adequate emotion recognition and processing have been found.¹⁵⁻¹⁹ These features lead to numerous pathological behaviours in order to lose weight, such as severe dietary restriction, purging or excessive physical activity. These behaviours can lead to severe weight loss with physical complications, such as fatigue, loss of menstruation, loss of bone mass and dryness of hair and skin. In extreme cases life threatening bradycardia, hypotension, hypothermia or electrolyte disturbances can occur.⁵ It is therefore not surprising that mortality rates of AN are amongst the highest in psychiatric disorders with a crude mortality rate of 5.1% per decade.^{20,21} Not only are mortality rates high, prognosis is also unfavourable with only 50% of adults recovering completely, 30% reaching partial recovery and 20% remaining severely ill.²² Psychiatric comorbidity is common, with mood disorders (nearly 75% of patients with AN) and a range of anxiety disorders (between 25-75%) most prevalent.^{23,24} Surprisingly, given this unfavourable outcome and the severe consequences, only a minority of patients is treated within the mental health care system.²⁵

Looking at Jane, the patient in our case vignette, numerous features mentioned above are recognizable. Jane's AN started at the age of 16 and she had been troubled before by mood instability and social anxiety. Her functioning on every aspect had deteriorated in the course of her AN and she reached a point where her bodily functions began to fail due to the severe weight loss. Even so, she resisted treatment aimed at weight restoration even though her development was stalled in every aspect of her life.

Treatment guidelines for AN have been published, the most recent of which is the Australian and New Zealand Clinical Practice Guideline of 2014.²⁶ The guideline promotes a comprehensive assessment of the patients and her context with thorough attention to comorbid psychiatric

and medical diagnosis and risks. Predisposing, precipitating and maintaining factors should be included in the case formulation and treatment goals should be set accordingly. It is advised to give great attention to engagement and medical stabilization (if necessary) and not embark directly into psychological treatment as meaningful engagement is a crucial factor in treating AN. Outpatient (or day-patient) treatment is recommended, except for those patients that are medically or psychologically compromised. A range of psychotherapeutic approaches is available for the treatment of AN, but what is indicated for whom is as yet not clear. Cognitive behaviour therapy (CBT) and especially an enhanced form of CBT (CBT-E, Fairburn 2008²⁷) is frequently recommended. Other therapeutic approaches however have been developed which seem to have equal results regarding outcome, such as the Maudsley Anorexia Nervosa Treatment for Adults (MANTRA, Schmidt et al 2012²⁸), Specialist Supportive Clinical Management (SSCM, MacIntosh et al, 2005²⁹) and Focal Psychodynamic Therapy (Zipfel et al, 2014³⁰). However, further research is needed, especially comparing the different treatment strategies and determining what to recommend in which stage of the illness (e.g. recent onset AN vs long standing AN).

COMPULSORY TREATMENT

As AN is such a severe illness with a negative impact on all life domains it is remarkable that patients tend to avoid or resist treatment, especially when this has a clear focus on weight gain. Only a minority of patients is treated within the mental health care system^{25,31}, which means that the majority of patients with AN is not treated for their severe condition.³² Possibly the finding that many patients perceive treatment as coercive is one of the explanations for this.³³ In the group of patients who resist treatment, two issues have been subject of debate in the literature in the last decades. The issues of compulsory treatment (i.e., using formal legal measures to commit or treat patients against their will) and mental capacity to consent to treatment have evoked fierce debates amongst clinicians, philosophers, ethicists and lawyers with opposite views voiced loudly.

Regarding compulsory treatment discussion in the 1980s and early 1990s was based on ethical, philosophical and legal principles rather than on empirical data. AN by some was seen as a lifestyle choice and a sociocultural phenomenon and therefore patients should have full autonomy in refusing treatment, even in life threatening situations^{34,35}. Others however opposed this view and pointed to the fact that AN was not a lifestyle but an illness³⁶ and that compulsory treatment could actually be regarded as compassionate care³⁷ and thus the right course of action for clinicians in severe cases. But as studies regarding the outcome of compulsory treatment were lacking, the debate was stalled due to this lack of data. Only in the second half of the 1990s the first small studies began to appear and around the turn of the millennium two larger studies were published.³⁸⁻⁴² These studies provide a more balanced view in this discussion and suggest that the negative view of the opponents of compulsory treatment is not wholly justified.⁴³

In **Chapter 2** a review of the literature regarding compulsory treatment in AN is presented and the studies that compare compulsory treated patients with AN with those who were treated voluntarily are discussed. At the end of chapter 2 pro's and con's of compulsory treatment are discussed and a recommendation of how to act in clinical practice is given based on the literature.

Non-consensual treatment represents one of the main issues in clinical psychiatry due to practical, juridical, ethical and deontological implications.⁴⁴ In a recent review on the ethics of coercive treatment in psychiatry Steinert⁴⁵ states that coercive treatment can be justified only when a patient's capacity to consent is impaired and severe danger to health or life cannot be prevented by less intrusive means. In this case, withholding treatment can violate the principle of justice. Therefore mental capacity is a central concept in compulsory treatment of anorexia nervosa and in this thesis.

MENTAL CAPACITY

General background

Over the last few decades, ethicists, legal professionals and philosophers but also clinicians have published their views on informed consent, mental capacity and the importance of autonomy.⁴⁵⁻⁵³ Mental capacity is an issue of interest to many of the professionals involved in health care, but empirical research remains scarce. Of all psychiatric disorders, patients with schizophrenia have been studied most frequently regarding mental capacity.⁵⁴ In the meta-analysis of Wang & Shi-Bin, 422 patients with schizophrenia were included and the conclusion was that mental capacity was impaired compared to a control group. Two reviews by Okai et al⁵⁰ and by Candia et al⁵¹ suggest mental capacity problems can be present in people with mood disorders, dementia and mental retardation as well, but this is studied far less intensively than mental capacity in psychotic disorders. Also, Okai et al have shown that mental capacity can be reliably assessed when using an assessment tool. Finally, in general medicine it appears that the frequency of impaired mental capacity (40% in a study by Raymont et al⁵⁵) is no different than in general psychiatry (ranging from 30-50%^{50,56}). To clinicians working in everyday practice the views by ethicists and legal professionals, are not easily applicable in situations where they have to decide regarding mental capacity without the luxury of endless time for deliberation. Notably, recently Steinert⁴⁵ promoted a pragmatic approach to the discussion regarding coercive treatment and mental capacity. Although in other psychiatric disorders studies regarding mental capacity and associated factors have been published to some degree, studies in adults with AN are lacking. In this thesis, explicitly meant to find information to aid the clinician in daily practice, we will therefore focus on identifying clinical parameters associated with diminished mental in patients with severe AN. The ethical discussion will be touched upon but is not the main scope of this thesis.

In medicine the term *mental capacity* is used when referring to whether or not a patient is considered able to decide for herself about the medical treatment that is proposed by the clinician.^{50,51,54,57} The medical treatment regarding which the patients need to decide can vary, e.g. taking medication, undergoing surgery or the decision to agree with hospital admission. Only when a patient has adequate mental capacity can he or she provide informed consent, i.e. agree with the advised treatment or refuse this treatment. As mental capacity deals with the ability to decide, decision making of the patient is a central concept in the assessment of mental capacity by the clinician, reflected by the tendency to use the term *decision making capacity* as a synonym for mental capacity.^{51,54} Four underlying components of this decision making capacity are considered vital to decide if a patient actually has adequate mental capacity. These are understanding, reasoning, appreciation and the ability to choose.^{50,51,54,57} Mental capacity to consent to treatment is presumed and only formally assessed when doubts arise whether or not the patients actually has full mental capacity. Also mental capacity to consent to treatment refers to a *task specific phenomenon*, it is not a general feature of the patient (except of course for comatose patients). A patient can thus have adequate mental capacity to decide about one treatment decision, but perhaps diminished mental capacity to decide on another medical issue. For instance, a patient with Alzheimers' disease could be judged to be able to decide whether or not she would like antibiotics for a urinary tract infection which is causing her pain, but might be judged to lack adequate capacity to decide whether or not to be admitted to a psychogeriatric ward because of her behaviour problems. Obviously, assessment of mental capacity to consent to treatment in daily practice is only done when stakes are high, i.e. when refusal of treatment can have grave consequences and not in situations where treatment refusal hardly has any negative consequences.

Contemporary ideas on informed consent stem from the Nuremberg Code, where it was stated that consent to research should be voluntary, made with free choice, adequate understanding and the capacity to give consent.⁵⁸ The Nuremberg Code came to be against the background of unethical behaviour of (German) health care professionals in the Second World War and the firm resolution that such behaviour should never again occur. In the more liberal view regarding patient rights that emerged after the war, informed consent in the context of medical treatment gained importance. The duty of clinicians to properly inform patients and not override patient autonomy became a central theme in health care legislation. In later years standards conceptualizing mental capacity, without which informed consent could not be validly given, were developed. In 1977, Roth et al⁵⁹ suggested this decisional capacity (i.e. mental capacity) should be assessed by tests regarding reasoning, understanding and the ability to make a choice as these were the elements on which judges based their verdicts in courts. Based on this original work, in 1982 Appelbaum and Roth outlined four legal standards, which from that moment on have come to be used by the majority of the researchers in the field. These so-called standards, which actually are functional abilities, are evidencing a choice, factual

understanding, reasoning and appreciation of the nature of the situation.⁶⁰ Understanding is considered the most basic element of being able to decide regarding medical issues, but not enough. Appreciation is considered essential as well and refers to the idea that certain factual information must mean something to a patient, so this meaning can be integrated into the decision making because the information has personal significance. Reasoning refers to the ability to weigh risks and benefits and evaluate consequences and is therefore considered vital to the decision making ability of a patient as well. Evidencing a choice merely means being able to communicate a choice, be it verbally, or by nodding or blinking the eyes. When applying these standards, the outcome would be dimensional, not dichotomous as the abilities are weighed on a dimensional scale to do justice to the nuance in clinical situations.

Efforts have been made by various researchers to provide clinicians with a tool to assess these standards in clinical practice. As discussed in a review by Sturman et al⁵⁸ eight (semi)structured interviews have been developed, one self report instrument and one questionnaire. Virtually all of these instruments have demonstrated good interrater reliability, the most serious limitation lies in their validity testing. Of these instruments, the MacArthur Competence Assessment Tool for Treatment and for Clinical Research (MacCAT-T and MacCAT-CR to assess mental capacity to consent or treatment or to consent to participating in clinical research respectively) have emerged as the gold standard today. This is due to the more substantial research into reliability, the demonstrated concurrent validity with other measures and the extensive testing in a range of patient populations, medical as well as psychiatric.^{44,50,51,54,55,58,61,62}

The MacCAT-T⁵⁷ is a semi-structured interview to aid clinicians in their assessment of mental capacity to consent to treatment and is one of the most widely used instruments in mental capacity research worldwide. It is a shorter version of the original instrument, the MacArthur Competence Assessment Tool (MacCAT), the development of which is described in a guide by Grisso and Appelbaum in 1998.⁶³ In this semi-structured interview the clinician provides the patient with relevant information regarding disorder and treatment and then in a conversation like manner checks the four abilities mentioned earlier. After the interview, ratings are awarded to each of the abilities. In this way it can become clear whether or not any abilities regarding mental capacity are compromised and if so, how severely. In general psychiatry the MacCAT-T has been used in several populations and has proved to be a reliable instrument. In the review by Okai et al⁵⁰, 37 studies regarding mental capacity to consent to treatment in a diverse range of psychiatric populations (mood disorders, dementia, medical patients) were identified. Okai et al found that lacking capacity was quite common (approximately 29% of inpatients) and psychosis, severity of symptoms, compulsory treatment and treatment refusal were the strongest predictors of lacking mental capacity to consent to treatment. In most of these studies the MacCAT-T was used alongside clinical judgment, however in some studies the MacCAT-T was directly compared to the clinical judgment of mental capacity.^{48,64} In these last studies the proportion of patients judged to have diminished

mental capacity was much higher using the MacCAT-T than using clinical judgment. This is in accordance with the tendency by clinicians to overestimate mental capacity in patients.⁶⁵ Candia & Barba in their review⁵¹ essentially confirm the results reported by Okai et al and point to the finding that a clear pattern between certain cognitive domains and mental capacity is still lacking. Finally, the dominance of the MacCAT instruments is illustrated by a recent meta-analysis by Wang et al⁵⁴, where ten studies in patients with schizophrenia are presented in a meta-analysis showing mental capacity impairment on all four standards of the MacCAT instrument used.

Discussion regarding mental capacity and the MacCAT-T

Clearly the underlying constructs on which mental capacity assessments are based are dimensions. What degree of understanding, reasoning or appreciation is required to be judged to possess adequate mental capacity? This issue is usually resolved by setting “thresholds”; i.e. the more severe the consequences of a certain decision, the more certainty the clinician needs and the higher the threshold would be for the clinician to decide that the patient has adequate mental capacity. Although some have commented on this as being ethically unsatisfactory and paternalistic⁶⁶, from a clinician’s point of view this way of handling seems inevitable.⁶⁷

The ethical question that arises is when mental capacity of a patient is not sufficient anymore to be able to refuse treatment and at what point should society intervene?⁴⁵ Beauchamp & Childress mention guiding principles that need to be taken into account when dealing with ethical problems⁶⁸. These principles are non-maleficence (first do no harm), beneficence (acting to benefit others), autonomy (acknowledging a person’s right to ‘self-government’) and justice (treating people fairly). The principle of autonomy has increasingly dominated discussions about mental capacity and the use of compulsory treatment and this has been criticized by some. The other three principles (non-maleficence, beneficence and justice) should be taken into consideration as well according to these authors.^{45,49,69} A larger role for the ethics of care movement, with more emphasis on empathy and relationships in the decision making regarding ethical dilemma’s, is also advocated by these authors. Others have suggested more emphasis on the narrative of the patient reflecting personal values and (in psychiatric patients) more attention to premorbid values and beliefs.^{47,70-75} According to Lepping the clinician is in danger of paying too little attention to the patient’s relationships, their care needs and long-term social context when focusing mainly on the issue of autonomy.⁶⁹

Another critique regarding the current concept of mental capacity is the proposed lack of attention to the importance of emotions in decision making. By some authors, mental capacity assessments in general and the MacCAT-T in particular are seen as focusing too much on cognitive and rational functioning, whereas decision-making is not wholly rational but rather very much influenced by emotional factors.^{47,70-75} These authors point to the importance of values in the decision making process, i.e. what matters most to patients and is deeply influenced

by the emotional meaning patients give to information provided and the significance of this information for their personal situation. They warn against the following of a decision made by a patient with what is called “pathological values”, i.e. values representing disturbed emotional functioning. For instance, a patient with a severe depression may have little concern for self preservation, and although this patient may understand that he is depressed and that treatment could be helpful, the patient might simply be beyond caring.⁵² These authors fear that in relying too much on the so-called rational abilities such as understanding and reasoning, the patient will be done an injustice as the premorbid values were likely to be different and should be taken into account. Although it can be argued that the standard of appreciation takes these values into account, as Grisso and Appelbaum have replied in relation to this criticism⁷⁶, this does not entirely satisfy concerns voiced by Hindmarch. Appreciation is found to be the one standard to be diminished when patients with a psychiatric disorder are considered to lack mental capacity whereas in medical patients this tends to be reasoning.⁵⁶ But the assessment of appreciation is by far the most normative of the four standards and therefore subject of debate about when appreciation is good enough and not overly influenced by the illness itself, especially in psychiatric disorders.

Mental capacity to consent to treatment in AN

In AN mental capacity to consent to treatment, next to compulsory treatment, has been another issue of debate in the literature. It is a very relevant issue, as only when a patient lacks adequate mental capacity, the clinician may override treatment refusal in order to prevent serious harm to the patient. And as mentioned in the first paragraph of this Introduction, serious harm can certainly be a consequence of AN. When we think of Jane, doubts can arise regarding her mental capacity to refuse the advised treatment. It appears that she does rationally understand that her situation is grave, but that this cognitive knowing has no impact on her decision making, which is puzzling. The discussion regarding mental capacity in AN is intimately intertwined with the discussion regarding compulsory treatment. Although many authors have voiced doubts about the use of compulsory treatment^{36,77-79} most of them felt that one of the key issues was whether or not the patient herself still had adequate mental capacity to refuse treatment. Patients themselves even reported that compulsory treatment in life threatening situations was “self evidently” the right thing to do because (as expressed by these patients) no one was allowed to die from the consequences of having AN.^{80,81} These patients often mentioned that at an extremely low weight they were unable to make their own decisions, suggesting they had diminished mental capacity. They felt that the anorexia nervosa had taken over their thoughts and they speak of valuing the anorexia above all else, rendering all other areas of life meaningless. However, even more so than in the issue of compulsory treatment, studies regarding mental capacity in AN are lacking. Only two small studies have been published, both in adolescents.^{82,83} The discussion in the literature however centered

more around adults with severe AN and on the issue whether or not to withhold treatment in extreme cases, as carrying on with (compulsory) treatment when this had failed for so long was seen by some as inhuman.⁸⁴ The two studies in adolescents had conflicting results. Tan et al did not find any problems in mental capacity to consent to treatment, Turrell et al found subtle difficulties in reasoning.

Also, the discussion regarding the mental capacity assessment focusing too much on cognitive abilities and paying too little attention to the role of emotions is very much alive in the case of AN. The MacCAT-T is criticized by some for having a cognitive bias.^{47,70-75} These authors point to the fact that the MacCAT-T puts too much weight on understanding and rational reasoning, whereas decision making is not wholly rational but very much influenced by emotional factors. Values of patients would not get enough merit in the MacCAT-T. In a reply, Grisso and Appelbaum⁷⁶ remark that in the assessment of appreciation emotion and personal values are captured. Adding to the criticism, Sturman⁵⁸ mentioned that the distorted or false beliefs so commonly encountered in patients with AN might not emerge well enough in the assessment of mental capacity, whilst they have a profound impact on the choice of the patient. This suggests that mental capacity to consent to treatment in AN might be even more complex than in other psychiatric disorders.

So, given this lack of data, we were not helped in the case of Jane what to do. Was her mental capacity good enough to refuse treatment or should we ignore her wishes and commence treatment, even against her will? But would her mental capacity improve when putting on weight, so that this, next to the possible physical danger, would also be an argument to commence compulsory treatment? Could restoration of autonomy be a valid goal of compulsory treatment?

Research questions regarding mental capacity

Many questions still surround the issue of mental capacity in AN. Although a multitude of studies could be designed regarding this complex and fascinating issue, we focused on clinical relevance. Our main aim was to provide clinicians with information regarding when mental capacity might be diminished in patients with AN. To this end we designed a quantitative study. It is for instance not known what proportion of patients display diminished mental capacity or what factors are associated with diminished mental capacity. A clinically obvious associated factor would be body mass index (BMI), with the expectation that a lower BMI means more problems with mental capacity, but this had not yet been studied. Also relevance to course and outcome of the disorder is unknown. Might it be that patients with diminished mental capacity have a poor outcome more often than do patients with full mental capacity? To shed more light on these questions we designed an explorative longitudinal study in 70 adult patients with AN (Chapter 3). As our study was explicitly meant to provide the clinician with information what to take into account when assessing mental capacity, clinical judgment of mental

capacity was the default measure in our study. To be able to report more on what would make a clinician decide a patient would have diminished mental capacity, we also used the MacCAT-T concurrently. Although both measures have limitations (the reliability of the clinical judgment in patients with AN is unclear, the MacCAT-T might focus too much on rationality) as this was an explorative study we decided to take the two most widely used measures as a starting point.

Chapter 3 reports the baseline results of the study into mental capacity to consent to treatment. The study design is presented in more detail in this chapter and the possible connection with emotional dysregulation is discussed. In **Chapter 4** the association of mental capacity to consent to treatment with outcome based on the longitudinal data is presented.

Furthermore, discussion surrounds the use of the MacCAT-T as an instrument to capture mental capacity and this discussion is voiced loudest in AN. As stated before, the MacCAT-T is criticized by some for having a cognitive bias.^{47,70-75} Although the MacCAT-T is criticized, it is the most valid and reliable instrument to date to assess mental capacity to consent to treatment, next to clinical judgment. Therefore in our study we used the MacCAT-T as well as clinical judgment to assess mental capacity to consent to treatment. Using the MacCAT-T alongside clinical judgment we were able to compare these two assessments. This is a particularly relevant question as it is known that clinical assessment has low interrater reliability⁸⁵⁻⁸⁸ and the MacCAT-T has shown to have good interrater reliability in a number of studies.^{57,64} **Chapter 5** discusses the usefulness of the MacCAT-T in the assessment of mental capacity to consent to treatment in AN. Recommendations for the use of the MacCAT-T based on the results of our study are presented in the discussion in this chapter.

DECISION MAKING

When assessing the mental capacity of a patient, the clinician essentially assesses the decision making ability of this patient regarding a certain medical issue. Decision making therefore stands at the core of mental capacity assessments. Clinicians actually assess a patient's ability to decide very regularly by evaluating various abilities (i.e. understanding, reasoning and appreciation) regarding the medical issue at hand. Interest in decision making in patients with AN has risen in the scientific literature in the last decade.^{10,19,89-91}

Looking more fundamentally at decision making, it entails the process of choosing between several options, for instance eating an apple or a candy bar. Choosing between options is a complex (neuro)psychological process and the subjective value that is awarded to each of the alternative options drives the direction of this choice.⁹² In our example, subjective value could include tastiness or healthiness. Decision making is thus influenced by reward and involves several cognitive processes. Each decision making situations consists of a choice between at least two options. The different options are assigned values and probabilities, an option is selected based on this value assignment, behaviour that is expected to lead to

the desired outcome is initiated and executed and the outcome is evaluated and informs and updates the learning process.^{92,93} For instance in the example, a person could value tastiness over healthiness and decide to choose the candy bar. If the outcome is evaluated positively (e.g. the person is satisfied with her choice) chances are higher that the same choice will be made next time.

In studies looking at decision making in AN, reward has long been an area of interest. Remarkably, in AN several studies have found food *restriction* to be experienced as rewarding, causing feelings of success, achievement and self-worth.⁹⁴⁻⁹⁶ These feelings can be regarded as a maintaining factor as they will influence subsequent choices whether or not to restrict food intake. Various neuroimaging studies also show that striatal activation is increased in food restriction in patients with AN, suggesting food restriction to be a behaviour that is highly rewarding to patients with AN.⁹⁷⁻⁹⁹ Furthermore, Decker et al¹⁰⁰ showed recently that it appeared that the excessive control patients with AN display was not associated with more activity in the prefrontal regions (cognitive functioning) but that abnormalities in the regions involved in reward and decision-making regions (striatum and dorsal anterior cingulate) were responsible for this tendency of overcontrol. Importantly, in this latter study it was shown that the tendency to be able to delay gratification seen in currently ill patients with AN disappeared after weight restoration, suggesting this tendency to be state specific. They suggest that where food restriction becomes rewarding initially, this is reinforced by the state dependent abnormalities in reward and decision-making regions. These abnormalities then inform the learning process and food restriction becomes a habitual choice over time.¹⁰⁰ The finding by Foerde et al¹⁰¹ that the dorsal striatum was more active in patients with AN when making choices about what to eat compared to healthy controls adds to this hypothesis. The dorsal striatum is involved in reinforcement learning and action election and thereby habit formation. Furthermore, a recent meta-analysis by Wu et al in 2016⁹¹ supports the importance of deviant habit formation. Disadvantageous reward-related decision making contributing to altered eating behaviour was found in adults, but not in adolescents with AN, suggesting an important role for these learning mechanisms. Wu suggests that maladaptive decision making could be seen as a sustaining factor in patients with AN, which is supported by the results of Cavedini et al in 2006.⁸⁹ Cavedini reports that patients with AN with more maladaptive decision making at the start of treatment gained less weight than patients with adaptive decision making. They therefore suggest that this maladaptive decision making interferes with their ability to profit from treatment and might in this way be responsible for the lesser result of treatment.

In clinical practice it is observed that patients with AN appear to have decision-making problems, specifically related to their food intake. It is highly remarkable that despite the negative consequences of AN described in the beginning of this Introduction, patients with AN are not able to choose to increase their food intake to prevent these severe consequences from occurring. In everyday practice clinicians recognize the positive value patients with AN

assign to being thin, to restrict their food intake or to exercise excessively of which the studies speak. This is one of the most remarkable features of AN and hard to understand for a healthy person. Even more, in discussions with a patient with AN, it appears that they do understand the consequences and seem able to reason, but still choose differently. Clinicians therefore tend to see in clinical practice that values that are assigned to the different options patients have are different from values a healthy person would assign. The studies presented in this thesis stem from the desire to provide clinicians with more information to inform their own decision making in this complex patient group. Not only did we want to provide more clarity on mental capacity and the association with clinical parameters and prognosis, we also wanted to look more fundamentally at the observed deviant decision making ability in patients with AN in relation to mental capacity.

Several neuropsychological tests are available to assess reward-related decision making. These tests usually either assess the preference for immediate rewards versus delayed rewards (Delayed Discounting Task, DDT¹⁰²) or the tolerance of risk in favour of desired rewards (gambling tasks). Two frequently used gambling tasks in reward-related decision-making in eating disorders are the Iowa Gambling Task (IGT¹⁰³) and the Game of Dice Task (GDT¹⁰⁴). In the IGT decision making under uncertainty is assessed (i.e. the probability of a certain outcome of the gamble is unknown), in the GDT decision-making under risk is assessed (i.e. the outcome of the gamble can be estimated to some degree). In the GDT the taking of risk is a more central theme, whilst in the IGT the importance of emotional factors driving decision making is the main issue incorporated in the task.

In our study we have used the IGT as a measure of decision making ability. Some discussion regarding the validity of the IGT exists.^{105,106} Test-retest reliability is questioned as in other populations learning effects have been reported. However, two longitudinal studies on decision making in AN have been done showing no learning effect on the IGT between measurements.^{89,107} Although the ecological validity of the IGT is suggested but not directly tested¹⁰⁵, in AN some evidence exists supporting the ecological validity of the IGT, as Cavedini et al⁸⁹ show. In their study decision making at the start of treatment predicted treatment response. We therefore considered the IGT an appropriate measure for this study. Also, the IGT is the most frequently used task in eating disorders and earlier studies have shown that patients with AN display less adaptive decision making on this task.^{10,12,89,108,109} The IGT has been designed with the *somatic marker* hypothesis of Damasio^{110,111} in mind. The somatic marker hypothesis states that for adaptive decision making in situations where shorter and longer-term consequences of a decision differ (the decision whether to eat or not may be beneficial on the short term as it may reduce anxiety, but will not help to improve one's daily or future life) one has to rely on intuition or "gut feeling" or so called somatic markers, because the complexity of the situation prevents one from relying solely on logical reasoning. Once a person cannot do that, maladaptive decision making occurs as decisions are guided by ratio too much. In the IGT

this is tested by asking the participant to choose between four decks of cards. Each choice is followed by a certain reward (winning money) and sometimes simultaneously by a punishment (loss of money). The decks differ in the magnitude and frequency of gains and losses which is not revealed to the participant. The results of the IGT can be presented in several ways. A total score can be calculated (where gains and losses are taken together) or one can compare the first part and the last part of the task, which is thought to reflect decision making under uncertainty and risky decision making respectively. The most widely used outcome measure is the learning effect (which is not the same learning effect that appears when repeating a task and performing better at it, because the task is already known), where a learning curve is produced (i.e. during the task participants score increasingly advantageous). During the task, participants have to learn, by relying on their gut feeling which decks are advantageous and which are not. It is hypothesized that participants will only be successful in this task if their reward functioning is intact. It has been shown in previous studies that emotional factors, such as high levels of depression, can also disrupt this process.^{10,105,112,113} In AN, comorbidity with mood disorders (75%²³) is the rule rather than the exception. Therefore, when studying decision making in patients with AN, it is essential to take mood symptoms into account.

As decision making is such an essential process in everyday life and when confronted with illness, where the ability to decide regarding treatment (i.e. mental capacity) is so vital, we explore the relationship between mental capacity and decision making in **Chapters 2 and 3**. As a relationship between mental capacity and decision making was expected by us, in **Chapter 6** we report more fundamentally on decision making in patients with AN, as measured with the IGT in relation to symptoms of depression over time. We choose depression as the factor to be studied in conjuncture with decision making as in the literature in AN the role of depression is under debate and a clinically salient relevant factor.

At the end of this thesis a general discussion of the findings presented can be found. Implications for clinical practice are suggested and future research areas touched upon.

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CHAPTER 2

COMPULSORY TREATMENT IN ANOREXIA NERVOSA – A REVIEW

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ABSTRACT

Objective

Compulsory in-patient refeeding of patients with severe anorexia nervosa (AN) has caused considerable controversy. The effects of such treatment on longer-term outcome are not well known. The objective of this paper is to review the evidence on the outcome of compulsory treatment for AN.

Method

Three large databases were searched for studies regarding compulsory treatment in AN.

Results

Detained patients have more severe symptoms and comorbidity and a longer duration of inpatient stay. In the short term compulsory refeeding in AN appears to be beneficial, but the longer term effects remain uncertain. Clinicians report no worsening of the therapeutic relationship after compulsory treatment.

Discussion

In severe cases of AN where the patient refuses life-saving treatment compulsory treatment needs to be considered. Future research should focus on the longer term effects of compulsory treatment and also on questions related to mental capacity in AN.

INTRODUCTION

Anorexia nervosa (AN) is a severe mental disorder with a high mortality rate.¹ The crude mortality rate is 5.1% per decade, the standardized mortality ratio is around 6.² Prognosis is not favourable, with complete recovery rates of only 50% in an adult population; around 30% of patients have a partial recovery and 20% remain severely ill.³ The lifetime prevalence among young females is 2.2%.⁴ AN typically afflicts adolescent women and has a mean duration of illness to recovery of 7 years.⁵ Despite the obvious severity of the disorder many patients are reluctant to engage in treatment, especially if this has a clear focus on increased food intake and weight gain. This ambivalence towards treatment and weight restoration is a typical feature of AN and is reflected by the fact that only a minority of patients with AN in the community are treated within the mental health care system.¹ Refusal of treatment may result in danger to oneself and compulsory treatment can therefore be considered for patients with AN, similar to other mental disorders. Compulsory treatment in AN has been a topic of hot (and also public) debate for many years⁶⁻¹¹ and as recently as in 2012 High Court judges in the UK gave very different rulings in two very severe cases (see <http://www.bbc.co.uk/news/uk-19369239> and <http://www.bbc.co.uk/news/uk-wales-18469963>). Whilst compulsory treatment is seen as an accepted treatment (if necessary) for e.g. psychotic disorders, controversy still surrounds this issue in AN. In earlier publications arguments for or against compulsory treatment were based on ethical, philosophical and legal principles and not on empirical data. Emphasis was laid on AN as a sociocultural phenomenon and on autonomy of patients.¹² Criticism of this point of view was voiced in the same journal by Fost¹³ who stated that AN is not a conscious choice, but a serious illness. Tiller et al⁶ thought that compulsory treatment could sometimes be regarded as compassionate treatment and was therefore justified. In 1989, Goldner¹⁴ concluded that compulsory treatment to save lives was to be recommended as a last resort. However, Rathner¹⁵ claimed that as voluntary treatment in AN already contains many elements that are perceived as coercive, formal compulsory treatment would be “one coercion too many”. A review by Russell in 2001¹⁶ suggested that involuntary admission (not necessarily compulsory feeding by naso-gastric tube) was beneficial in the short term, was of longer duration than voluntary admissions and there seemed to be no evidence for a worsening of the therapeutic relationship. Clearly, different opinions regarding compulsory treatment abound, research is scarce and consensus lacking.

The aim of the present review was to summarize the available literature on compulsory treatment in anorexia nervosa. We aimed to answer the following questions:

- How often is compulsory treatment invoked in the treatment of patients with AN?
- What is the outcome of compulsory treatment in patients with AN?
- What are ‘risk factors’ for the use of compulsory treatment in patients with AN?
- What are the views of patients with AN on compulsory treatment?

METHODS

Relevant articles were identified from a systematic search of electronic databases. These comprised PubMed (1806 to April 2014), Psycinfo (1806 to April 2014) and Scopus (1823 to April 2014). The following search terms were used in combination with each other: anorexia nervosa, eating disorders, compulsory treatment, coercive treatment, involuntary treatment and treatment refusal.

Compulsory treatment was defined as treatment involving a formal legal measure.

Eligible for inclusion in this review were first studies that compared clinical outcome (i.e. BMI at discharge and/or follow up) in groups on the basis of being compulsory treated or not. Furthermore, we included studies on the attitudes of patients with AN regarding compulsory treatment and studies looking at epidemiology of compulsory treatment in AN. Studies that had a primary focus on legal matters, ethical and philosophical discussion, dealt with case reports not related to compulsory treatment, were non-English language, regarded (treatment of) anorexia nervosa in general (including psychotherapeutic interventions) or concerned other eating disorders than AN were not included. We assessed the quality of the studies regarding outcome of treatment by using the checklist designed by Down and Black.¹⁷

RESULTS

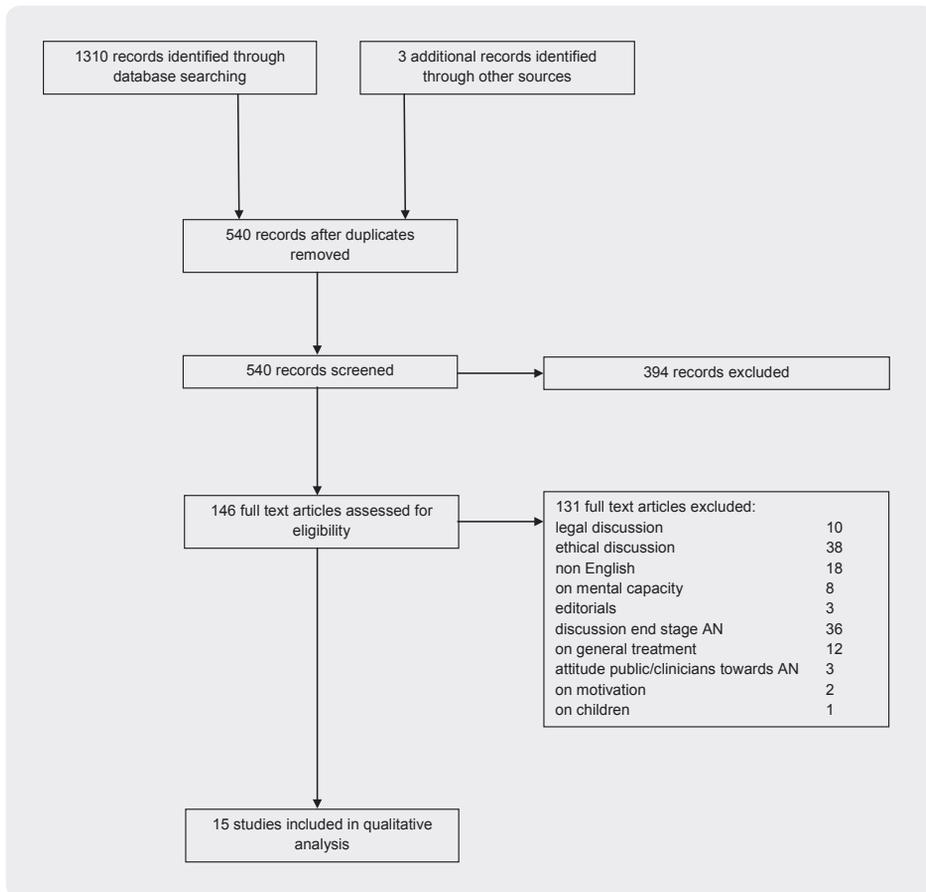
We initially identified 1313 articles using our search terms (see Figure 1). We removed 773 duplicates and screened 540 abstracts. Of these 14 met our full inclusion criteria. We included one additional study (Guarda et al 2007) that did not deal with formal legal measures but with perceived coercion, as it was the only quantitative study on perceptions of patients with AN regarding being coerced into treatment.

Compulsory treatment

Epidemiology

Epidemiological data on compulsory treatment and AN are scarce. We retrieved four papers and one Council Report of the Royal College of Psychiatrists. In two earlier publications rates for compulsory treatment ranged from 1.5%¹⁸ to 11.6 %¹⁹ of inpatients detained under the Mental Health Act for the UK. For the USA we did not find any high quality epidemiological data. In 1998, Appelbaum and Rumpf²⁰ mentioned that according to a major reporting service for court decision regarding mental health only two cases of AN patients had been committed in the USA in the previous 21 years (from 1970-1990). This figure seems extremely low. We did find one other paper from the US on the outcome of compulsory treatment and covering a slightly later period²¹ where 28 patients with AN out of 170 were legally committed over the course of seven years (1991-1998) in just one hospital (University of Iowa Hospital). In one Australian study as much as 28% of admissions were treated compulsorily.²²

Figure 1. Search process



A recent survey of eating disorder services in the UK and Ireland²³ found that around 7.9% of all admissions for eating disorders were under the Mental Health Act. This figure is based on estimates made by lead clinicians from each of the services participating in the survey of the proportion of detained patients in their service. However, large specialised centres where tertiary referrals are treated tend to have higher rates of compulsory admissions, in the range of 20 to 35% (personal communication, Ulrike Schmidt).

Outcome of compulsory treatment

We identified five studies with data on the outcome of compulsory treatment.^{21,24-27} All of these studies compare the outcome of voluntary treatment and compulsory treatment at discharge, with follow up data provided by two (Ramsay et al., 1999; Ayton, 2009). The studies by Ramsay et al and Ayton et al are high quality studies with excellent reporting, good internal validity,

reasonable external validity and sufficient power. Only the study by Ayton et al has good quality follow up data on eating disorder parameters, although Ramsay et al report mortality data, which is also of major importance. The studies by Serfaty and McCluskey and Griffiths et al are very small and descriptive in nature. Reporting is of low quality and validity is low, although in

Table 1. Summary of studies on outcome of compulsory treatment in anorexia nervosa

Author/year	Group + N	Length of illness (yrs)	BMI admission (SD)	BMI discharge (SD)	BMI at follow up
Griffiths et al 1997	Compulsory n=15	8.3	13.4 (1.8)	18.1 (2.1)	-
	Voluntary n=73	unknown	14.3 (2.2)	17.2 (2.9)	-
	AN		ns	ns	
Serfaty & McCluskey 1998	Compulsory N=7	14.3	11.8	17.7	16.4
	Voluntary N=4	11.25	12.0	16.6	17.7
	AN	ns	ns	ns	ns, mean 11 months, range 6-24 months
Ramsay et al 1999	Compulsory N=81	8.2 (6.1)	14.2 (2.7)	18.7 (2.3)	-
	Voluntary N=81	7.6 (6.4)	14.3 (2.4)	18.5 (2.0)	-
	Mainly AN, some BN	ns	ns	ns	
Watson et al 2000	Compulsory N=66	1.9 (1.6)	17.4 (4.7)	20.5 (3.8)	-
	Voluntary N=331	1.6 (1.6)	18.4 (4.7)	20.7 (3.6)	-
	AN, BN, EDNOS	ns	ns	ns	
Ayton et al 2009	Compulsory N=16	3.8 (2.1)	16.6 (2.6)	19.6 (1.5)	-
	Voluntary N=34	1.9 (1.5)	14.2 (1.9)	18.5 (1.6)	-
	Mainly AN, some EDNOS	Sign, p=.001	Sign, p=.001	ns	

Note. BMI=body mass index; Depr=depressive disorder; SA=substance abuse; OCD=obsessive compulsive disorder; ASD=autism spectrum disorder; ns=not significant; sign=significant

the study by Serfaty and McCluskey et al the internal validity is still reasonable and the study by Griffiths et al has sufficient power. The study by Watson et al is of good quality, however the group is very heterogeneous (including also bulimia nervosa patients) and therefore results are less generalisable. All of the available studies are summarised in Table 1. Interestingly,

Comorbidity	Length of stay in wks (SD)	Mortality	Other
60%	14.9 (10.9)	1 of 15	More purging (60 vs 43%)
unknown	8.8 (6.0) Sign, p<.01	unknown 1 year after admission	
-	-	0	3 recovered, 1 partly recovered
-	-	0	1 recovered, 3 partly recovered
44.4%	16.1 (12.9)	12.7%	More previous admissions (p .001); more self harm (p .0035); more history of abuse (p .043); purging ns
30.9%	12.6 (7.6)	2.6%	
ns	Sign, p .03	sign p .04 (5 yr follow up)	
47.8% depr; 29.3% SA	8.2 (6.6)	0	Males and females; AN, BN and EDNOS; IQ 90 vs 100 (p<.001)
41.7% depr; 24.3 SA	5.8 (5.1)	0	
ns	Sign, p<.007		
94% depr*; 12.5% OCD; 19% ASD	60	0%	More self harm (p<.001); more previous admissions (p<.001); trend towards better outcome
59% depr; 14.7% OCD; 11.8% ASD	34.6	6.9%	
* sign, p .01	Sign, p=.006	1 yr follow up	

in the large study by Watson BMI at admission was relatively high in both the voluntary and compulsory group (18.4 kg/m² and 17.4 kg/m² respectively). Most likely the heterogeneity of the group, including also bulimia nervosa patients, contributes to this relatively high BMI. In the study by Ayton et al there is a significant difference between groups in the BMI at admission. According to the authors this is probably due to the fact that the compulsorily treated patients were transferred from another Unit and therefore had received inpatient care already for some time; the mean BMI at the start of inpatient treatment in the other facility is not known (personal communication Dr Ayton). Summarising the findings of these five studies^{21,24-27}, it is found that patients in the compulsory group have more severe symptoms regarding both the AN as well as more severe comorbidity (more previous admissions, more self harm, more common history of abuse, higher levels of depression, longer duration of illness). In all of the studies duration of stay was longer when compulsorily detained. Weight at discharge was similar for both the voluntarily treated and the compulsorily detained groups. Although the question of possible alterations in the strength of the therapeutic relationship when compulsorily treated was not the main aim in these five papers^{21,24-27}, the authors all report there was no worsening of this relationship and patients remained in treatment voluntarily.

Longer term effects of compulsory treatment have not been well studied. In the study by Ramsay et al the mortality rate after 5 year follow up was 12.7% for the detained patients and 2.6% for the voluntary patients. The detained group comprised a more severely ill group which may have influenced their mortality rate. In the most recent study by Ayton in 2009 (in adolescents) outcome at 1 year follow up was comparable for both groups, with a trend for the detained group to do somewhat better, as they had resumed regular menstrual periods more often than the voluntary group, had fewer readmissions and had a better level of functioning overall.

Risk factors for compulsory treatment

Risk factors for compulsory treatment have only been studied in one study by Carney et al^{22,28,29} reported in three separate papers. In a retrospective study 96 admissions were examined, of which 27 were compulsory. The main findings were that risk factors for compulsory treatment were prior AN admissions ($p=0.04$), more comorbidity ($p=0.04$) and a lower BMI ($p=0.06$). In short, a higher illness severity or complexity results in a higher likelihood of compulsory treatment. Interestingly, Carney et al²⁸ found that when clinicians decide on initial admission (as in the UK) more patients are compulsorily detained than when courts have a greater role in the decision to detain compulsorily (as in the USA). Carney et al provide no explanation for this discrepancy, but they wonder about the role of managed care in the USA.

Patient views on compulsory treatment

We retrieved two qualitative studies on patients' opinions on compulsory treatment by Tan et al^{30,31} and one study by Guarda et al.³² Guarda et al describe that nearly half of the patients who denied (the need for) treatment at admission converted to acknowledging the need for

admittance within two weeks of hospitalisation. However, these patients were still voluntary, but experienced high levels of informal coercion. The conversion to acknowledging the need for treatment is similar to the general psychiatric population.³³ Adherence to treatment does not seem to be worsened by the use of compulsion in general psychiatry^{34,35}, which is also described by eating disorder clinicians.^{6,16,21,26}

Tan et al^{30,31} conducted two qualitative studies on the attitudes of patients and parents to compulsory treatment. The main finding from their studies was that most interviewed patients reported that compulsory treatment was “self evidently” the right thing to do because no one was allowed to die from the consequences of having anorexia nervosa. Many patients who themselves had experienced compulsory treatment were grateful in hindsight, in accordance with the findings of Guarda et al.³² Tan et al report that many participating patients also mentioned that at extremely low weights they were unable to make their own decisions. Their perception of coercion was not necessarily related to formal compulsion, but more to the nature of the relationship with the mental health professionals. According to Tan et al, some were in favour of using compulsory treatment at an early stage, as the illness would not have advanced so much and prognosis would be better. Also some patients mentioned that the threat of compulsory treatment alone “kept them going”. Others however were strongly opposed to compulsory treatment when there was no life threatening situation, as patients would shy away from help if they felt under threat.

DISCUSSION

This review summarises the available literature on four aspects of compulsory treatment in AN: epidemiology, outcome, risk factors and patient views of compulsory treatment. Since the last comprehensive review on this topic by Russell in 2001¹⁶ and a more recent review by Touyz & Carney in 2010³⁶ a number of new studies have emerged, especially on epidemiology, risk factors and patient views on compulsory treatment. Below we will discuss the key findings from our review and relate these findings to associated relevant issues (such as timing of detention and mental capacity).

Compulsory treatment

Regarding epidemiology the most detailed data are from the UK, and estimate that 7.9 % of all AN admissions are under the Mental Health Act. However, this figure is a crude estimate and is at variance with studies from other countries. Concerning risk factors for compulsory treatment, a high severity of symptoms results in a higher likelihood of being compulsorily treated. Only one group appears to have systematically studied risk factors.^{22,28,29}

The search regarding outcome of compulsory treatment revealed only five studies of mixed quality. From these one can tentatively conclude that short term outcome of detained patients

is similar to that of patients that are voluntarily treated. This is of clinical importance, as these patients would probably not have been treated at all if not for the availability of legal measures. Obviously, randomized clinical trials are not possible to find out what the outcome would have been if detained patients had not been treated, but from the patient characteristics one can surmise that prognosis would be poor. Also, the fact that the outcome at discharge is similar to that of voluntarily treated patients is the more robust when taking into account the fact that usually the compulsorily treated patients have more severe psychopathology. Based on these findings one can conclude that compulsory treatment can be a beneficial measure in the short term. Thus, especially when a patients' life is at stake, compulsory treatment should be seriously considered. With this in mind, it is remarkable that significant controversy still surrounds the issue of compulsory treatment for AN.

Patients' views on compulsory treatment appear to be similar to those of other psychiatric patients, i.e. after some time half of the compulsorily treated patients agree with the need for compulsory hospitalization. Thus when their life is at stake, patients usually support the need for compulsory treatment. What is also clear is that it is not the use of detention per se, but rather how this is done that matters to patients.^{30,31}

Further issues

Important other issues in the discussion on compulsory treatment are the timing of the compulsory treatment and the role of mental capacity in clinical decision making on compulsory treatment. The timing of compulsory treatment is still a matter of debate^{14,16,37,38}, with as yet no consensus on whether or not compulsory treatment should be utilised early in the course of the illness to prevent deterioration. There is no current evidence comparing earlier and later intervention on outcome, nor is there likely to be, as this would not be ethically feasible. An argument in favour of earlier intervention is that the duration of illness might be shortened in this way and thus the prognosis influenced positively^{39,40} in analogy to schizophrenia where the duration of untreated psychosis is an important prognostic factor. However, patient autonomy must not be overridden lightly and although the short term outcome of compulsory treatment appears favourable, the long term outcome is not well established as yet.

Questions surrounding mental capacity (i.e the ability to adequately make decisions regarding treatment) are also closely linked to the compulsory treatment discussion. Many authors mention that patients' wishes can be overruled in case of danger to themselves and *lack of capacity* to decide on treatment issues. Also legislation in different countries has this option. But what do we know about mental capacity in AN? For psychiatry in general a number of studies have been conducted to assess the proportion of patients that lack mental capacity and to examine how mental capacity can be reliably assessed (for an extensive review see Okai et al, 2007⁴¹). Studies discussed in this review indicated that lack of capacity is common (median 29% of in-patients) and that psychosis, severity of symptoms, compulsory treatment and treatment

refusal were the strongest predictors of lacking capacity. However, no studies in patients with AN were reported in this review. Interestingly, three studies have shown that mental capacity is frequently overestimated by medical staff in general.⁴²⁻⁴⁴ Mental capacity in AN has been subject to much theoretical debate^{6-13,45-53} but few empirical data are available. Only two small studies have looked specifically at the mental capacity of AN patients.^{49,54} Both studies were in an adolescent population and did not include chronic patients with AN. This is unfortunate, as a lot of the discussion focuses on capacity and compulsory treatment in severe and enduring AN. The two studies have conflicting results. In the study by Turrell et al reasoning was found to be impaired in patients with AN as compared to healthy controls, but in the study by Tan et al patients scored highly on the MacCAT-T (a semi structured interview designed to assess mental capacity with good interrater reliability⁵⁵) meaning that they showed good mental capacity. These findings need to be interpreted with caution as the study was small (n= 10 patients), was retrospective and thus mental capacity was not assessed at the clinically relevant 'moment'. The study also found that patients' values regarding life and death differed markedly from those of healthy people. This goes some way to explain that health risks are considered as not very relevant by patients with AN in weighing up arguments for or against treatment. Tan et al conclude that the MacCAT-T is of limited utility in the assessment of mental competency in AN, because of its focus on cognition, leaving aside the importance of emotion in decision making. Others have also criticised the MacCAT-T for not focusing enough on emotional aspects of decision making^{49,50,56-59} and missing more subtle impairments.⁶⁰

In conclusion we can say little is known about mental capacity in AN. The subtleties in the impairment in decision making in AN (as opposed to the more overt impairments in e.g. schizophrenia) are recognized. Thus, it is all the more important to develop ways to assess mental capacity in AN in a reliable and clinically useful manner, as stakes are so high.

Future directions

Reviewing the field of compulsory treatment there are several areas where more research is needed.

First, the main question regarding compulsory treatment in AN is the long term outcome of compulsory treatment in relation to different clinical parameters, such as BMI or comorbidity. As it is not ethically feasible to conduct randomised clinical trials to answer this question, large-scale prospective longitudinal studies with at least 5 years follow up are needed. In practice it is often difficult and costly to set up this kind of study. Also in addition to patient related factors, such studies should make a broad assessment of the nature and quality of care provided to these patients, as for example the attitude of the staff is very important for the experience of patients and their appraisal of the treatment. Ward et al., (personal communication) have recently completed a nearly 20 year follow up of their earlier study²⁵ comparing detained and voluntary patients. Interestingly they conclude that although the mortality in the 5 years

following a compulsory admission was higher than that seen in the voluntary patients, this difference is attenuated over time.

Second, there is a need for studies that can guide clinicians in the often very difficult decisions around whether or not to start compulsory treatment, especially when dealing with patients with severe and enduring AN. Should preservation of life always prevail and if not, what are the circumstances under which we should not intervene? Studies with a qualitative design to unravel the underlying themes would be very useful.

Thirdly, the related issue of mental capacity should be studied in a number of ways. Associations of mental capacity with diverse clinical measures and the level of mental capacity over time should be clarified so as to provide the clinician with risk factors for mental capacity problems in patients with AN and the significance of mental capacity problems with regards to course and outcome of the disorder. Furthermore as generally altered processing of emotions and altered decision making under conditions of risk or uncertainty are commonly found in AN⁶¹⁻⁶⁵ it will be important to study the relationship between these mechanisms and mental capacity. An improved understanding of the more fundamental psychological mechanisms underlying mental capacity might allow tailoring the assessment of mental capacity more specifically to patients with AN. In this way mental capacity could perhaps be better operationalised for the clinicians dealing with complex patients with AN and decision making surrounding compulsory treatment for AN could be more science based in stead of experience based.

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CHAPTER 3

MENTAL CAPACITY TO CONSENT TO TREATMENT IN ANOREXIA NERVOSA – EXPLORATIVE STUDY

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ABSTRACT

Background

Mental capacity to consent to treatment in anorexia nervosa (AN) is a neglected area in clinical decision making.

Aim

To examine clinical and neuropsychological parameters associated with diminished mental capacity in AN.

Method

An explorative study was done in 70 severe adult female patients with AN. Mental capacity to consent to treatment was assessed by experienced psychiatrists. Further measurements included the MacCAT-T (to assess mental capacity status), a range of clinical measures (BMI, comorbidity) and neuropsychological tests assessing decision making, central coherence and set shifting capacity.

Results

Diminished mental capacity occurs in one third of severe patients with AN and is associated with a low BMI, less appreciation of illness and treatment, previous treatment for AN, low social functioning and poor set shifting.

Conclusion

Assessment of diminished mental capacity in AN requires careful evaluation of not only BMI, but also the degree of appreciation of illness and treatment, previous history and the tendency to have a rigid thinking style.

Declaration of interest

None

INTRODUCTION

Anorexia nervosa (AN) is a severe mental disorder with a high mortality rate¹. The crude mortality rate is 5.1% per decade, the standardized mortality ratio is around 6². Prognosis is not favorable, with complete recovery rates of only 50% in an adult population; around 30% of patients have a partial recovery and 20% remain severely ill³. The lifetime prevalence among young females ranges between 0.3 and 2.4%⁴. AN typically afflicts adolescent women and has a mean duration of illness to recovery of 7 years.⁵ The causes of AN are not yet fully elucidated, but appear to be multifactorial, with determinants including genetic and neurobiological influences and pressures in the environment with respect to appearance.^{6,7}

Despite the obvious severity of the disorder, many patients are reluctant to engage in treatment, especially if treatment entails a focus on increased food intake and weight gain. This may partly explain why only a minority of individuals suffering from AN are treated within the mental health care system¹. To patients with AN food does not have the same reward value as it does to healthy people. Various mechanisms have been put forward as potential contributors to this phenomenon.⁷ For example, altered reward processing seems to play a role in the heightened saliency of not eating by modulating emotional distress.⁸ In the later stages this behaviour becomes habitual and thereby refractory to change, a process even further enhanced by the increased compulsivity observed in underweight individuals.⁹ Neuropsychological difficulties like inefficient set-shifting, poor central coherence and impaired decision making¹⁰⁻¹⁵ can complicate treatment because of a difficulty to change set behaviour and a bias toward focusing on details (e.g. the present meal and its dreaded consequences) instead of the future benefits of being able to function again in daily life. Finally the finding by Tan et al¹⁶ that AN becomes part of the personal identity of the patient and that values regarding life and death in the acute phase of the illness differ compared to the remission phase also explain part of the persistence of symptoms in AN. In the light of these clinical and (neuro)psychological findings the question whether or not patients with AN are capable of adequate decision making regarding treatment should be raised. Clinically, this decision making regarding treatment is referred to as mental capacity. Mental capacity is a task specific phenomenon and refers to the ability of a patient to adequately process the information provided by the clinician to arrive at an informed decision regarding the medical issue at hand. These issues generally pertain consent to treatment such as surgery, medication or hospitalisation.

Mental capacity is relevant as lacking mental capacity to consent to treatment means that treatment refusal may be overridden when it would lead to danger to oneself, as is so often the case in severe AN seeing its severe physical consequences. Mental capacity assessments generally check four abilities (based on the widely used model by Grisso & Appelbaum¹⁷), namely the ability to **express a choice** about treatment; the ability to **understand** information relevant to the treatment decision; the ability to **appreciate** the significance of that treatment information for one's own situation; and the ability to **reason** with relevant information so as

to engage in a logical process of weighing treatment options. In general psychiatry a number of studies have been conducted to assess the proportion of patients lacking mental capacity to consent to treatment (for a review see Okai et al, 2007¹⁸). These studies indicated that lacking this capacity is common (approximately 29% of in-patients) whereby psychosis, severity of symptoms, compulsory treatment and treatment refusal were the strongest predictors of lacking capacity to consent to treatment. Unfortunately, neither of these papers include any information on AN. Only two small studies examined mental capacity to consent to treatment of patients with AN.^{19,20} Both studies describe an adolescent population and did not include chronic patients with AN, whilst the issue of mental capacity to consent to treatment is fiercely debated in this group in particular. Additionally, results were inconsistent. In the study by Turrell et al²⁰ reasoning was found to be impaired in patients with AN as compared to healthy controls, but in the study by Tan et al¹⁹ patients showed excellent mental capacity to consent to treatment. This latter finding needs to be interpreted with caution as this study was small (n=10) and used a retrospective design, not assessing mental capacity at the clinically relevant ‘moment’.

Mental capacity assessments used in general medicine tend to focus on cognitive abilities as understanding of the information provided and weighing options. Debate exists whether or not this “cognitive” approach is able to accommodate the relevance of emotions and values in decision making.²¹⁻²³ Especially regarding AN, criticism of this “cognitive” approach to mental capacity has been voiced by some authors.²⁴⁻²⁶ Tan has found in previous research^{19,27} that the values regarding life and death of patients who are severely ill change after recovery. Tan refers to the values of the severely ill patients as “pathological” values (i.e. illness driven) and questions whether we should give these pathological values the same weight as we would values regarding life and death of a healthy person. On the other hand it is argued that this concept of values is incorporated in the assessment of the appreciation of the patient regarding disorder and treatment.²⁸ This introduces a subjective and morally complex element into the assessment of mental capacity, for who is to decide whether or not values are pathological? The fact that mental capacity is a concept that cannot be measured objectively complicates research into this area. In conclusion we can say little is known about mental capacity and underlying mechanisms of impairment thereof in AN. The purpose of this study is to examine which clinical parameters are of importance in the assessment of mental capacity to consent to treatment in AN. Providing more objective data to base mental capacity judgments on is important to support clinicians with this difficult task.

METHOD

Study sample

Altrecht Eating Disorders Rintveld is a specialist eating disorder department of the Altrecht Mental Health Institute that offers assessments, consultation and treatment for in- and outpatients. All

consecutive adult female patients who were referred to our center from February 2012 to July 2013 were eligible for inclusion if they had a diagnosis of AN or EDNOS clinically referred to as AN according to DSM-IV.²⁹ The only exclusion criterion for this study was an IQ lower than 70, as we expected neuropsychological difficulties in this group of patients related to cognitive impairments. The presence of AN was established by eating disorder experts (all psychiatrists) and confirmed by the Eating Disorder Examination (EDE).³⁰ A total of 70 patients were included in the study (see Figure 1), 34 patients refused to participate. Patients who refused to participate did not differ on any of the clinical parameters from the study group (see Table 1). The study was conducted in accordance with the ethical standards described by the Medical Research Involving Human Subjects Act (WMO) and was approved by the Institutional Review Board. After complete description of the study to the participants, written informed consent was obtained.

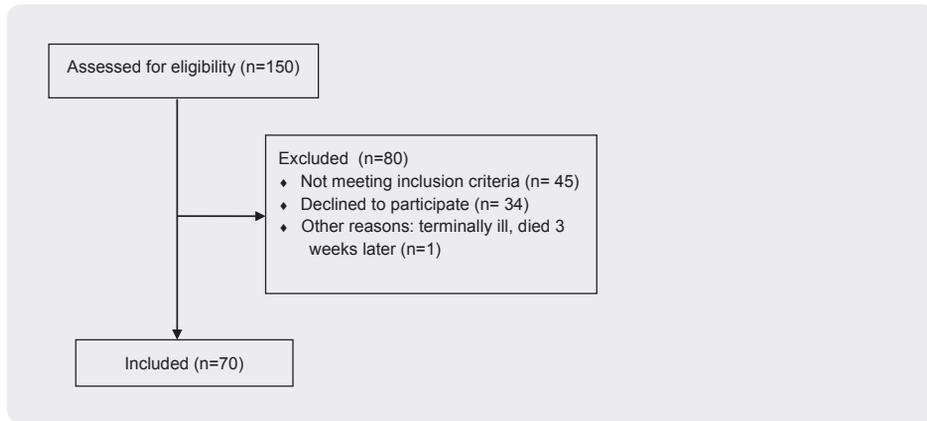
Measures

Mental capacity

During the first meeting the psychiatrist examining the patient also assessed mental capacity of the patient relating to the decision to start treatment. This was done in the manner of a general psychiatric interview by enquiring about patient's beliefs regarding their condition and their ideas about treatment intensity. In this psychiatric assessment attentional function and level of orientation were also routinely assessed to screen for possible delirium. The psychiatrist categorised the outcome of this judgment as full, diminished or lacking mental capacity. The two psychiatrists conducting these examinations were both psychiatrists with several years of experience in specialised eating disorder treatment. They routinely conduct second opinions in complex AN treatments for other centers.

MacCAT-T

Besides clinical judgment, we examined the four abilities underlying mental capacity by using the MacCAT-T³¹, a semi structured interview to assess mental capacity designed by Grisso and Appelbaum. The MacCAT-T generates four scores (Understanding 0-6, Reasoning 0-8, Appreciation 0-4 and Making a Choice 0-2), which should not be combined into a total score. In this way the MacCAT-T provides more insight in particular deficits in a patient's mental capacity. The MacCAT-T was conducted by experienced eating disorder psychiatrists or residents who were trained by the lead investigator and by watching the DVD provided by Grisso & Appelbaum and reading the manual.¹⁷ The interview was done a week after the first interview with the clinician immediately after the second appointment patients had with the clinician to be advised about the treatment plan. The psychiatrist conducting the MacCAT-T was blind to the mental capacity assessment of the patient by the first psychiatrist (the clinical judgment). The MacCAT-T focused on the treatment advice the patient was given, so it was tailored to their specific situation. Patients generally agreed with the advice given; 92% did, 8% did not

Figure 1. Flow diagram inclusion process**Table 1.** Comparison participants and non participants

	Participants n=70 Mean (SD)	Non-participants n=35 Mean (SD)	Sig #
Age (yrs)	27.3 (9.7)	26.7 (7.7)	Ns
Age of onset	17.8 (4.9)	17.0 (3.6)	Ns
Length of illness (yrs)	8.6 (8.1)	10.1 (7.9)	Ns
BMI	15.5 (1.9)	15.4 (2.0)	Ns
EDE	3.6 (1.3)	3.4 (1.2)	Ns
ANR	49 %	40 %	Ns
ANP	51 %	60 %	Ns
Previous ED treatment	74 %	80 %	Ns
Previous hospitalisation	46 %	60 %	Ns
Medication	58 %	46 %	Ns
Hx of abuse	20 %	6 %	p .07

#; all non significance levels have a p value of .20 or above
 Yrs, years; sd, standard deviation; Sig, significance level; Ns, not significant; BMI, body mass index; EDE, Eating Disorder Examination; ANR, anorexia nervosa restrictive type; ANP, anorexia nervosa purging type; ED, eating disorder; Hx, history

and received no further treatment in our center. Recommended treatment could either be inpatient (47% of participants) or outpatient (53%) treatment as our center deals with patients with different levels of severity and comorbidity. As assessing mental capacity to consent to

treatment focusses on the decision making process and not on specific treatment content or modality, we did not feel the different treatment options recommended given would pose a problem to the assessment of mental capacity to consent to treatment.

Interrater reliability testing for the MacCAT-T in this study entailed two independent raters scoring 10 interview forms of the 43 patients who were interviewed by the lead investigator. Intra class coefficients (ICC) were calculated and proved good for two subscales (Understanding Cronbach alpha .77, Appreciation .87), but poor for Reasoning (.30). For Choice we were unable to calculate intra class coefficients due to very little variance of the raters' scores on this subscale (all raters consistently scored a 2, which is the maximum score, but for one rater who in one patient scored a 1 instead of a 2). The agreement on this subscale therefore was exceptionally high. The low ICC for Reasoning is not consistent with other studies. It could be due to the finding that the raters experienced the scoring of Reasoning as more complex than the other subscales. Also, although the ICC is poor, the actual scores on Reasoning of the three raters are consistently high (between 6 and 8, which is the maximum score) so the poor ICC does not reflect large differences in the rating of this subscale.

Clinical measures

Severity of the eating disorder symptoms were rated with the Eating Disorder Examination³⁰ (EDE) and the body mass index (BMI in kg/m²) at the first assessment. To assess psychiatric comorbidity the SCID-I was used³². Earlier eating disorder treatments and admissions were collected from the psychiatric history and social functioning from the social history. Depression and anxiety levels were measured with the Beck Depression Inventory (BDI-II)³³ and Spielberger State Trait Anxiety Inventory (STAI)³⁴. Furthermore, levels of alexithymia were assessed with the Toronto Alexithymia Scale (TAS).^{35,36}

Neuropsychological measures

Three tasks were administered: the Iowa Gambling Task (IGT³⁷) was used to assess decision making ability, the Rey Complex Figure Task (RCFT³⁸) was used to measure strength of central coherence, and the Wisconsin Card Sorting Test (WCST³⁹) was used for determining set shifting ability. All tasks are frequently used to assess neuropsychological functioning in eating disorders.^{11,13,40} These tasks were chosen as in earlier studies^{11,13,40,41} differences were shown between patients with AN and healthy controls and these differences may be underlying neuropsychological markers associated with mental capacity problems.

Statistical analysis

Two groups were created: those with full mental capacity and those with diminished or lacking mental capacity. To determine differences between the two groups (full and diminished mental capacity) independent sample t-test or χ^2 tests were used. To determine inter rater reliability of the four subscales of the MacCAT-T intra class coefficients were calculated. Finally, to examine

the association of the IGT with mental capacity repeated measure ANOVA's were used to test the learning effect between the groups.

RESULTS

Sample characteristics

A total number of 70 patients participated in the study. Characteristics of participants are shown in Table 2, showing a high illness severity with a low mean BMI, a long duration of illness and a high percentage of previous treatment or hospitalization. The majority of the patients (53%) had one comorbid axis I disorder and 31% had 2 or more comorbid axis I disorders. Common comorbid disorders were depressive disorder (48.4%), post traumatic stress disorder (21.7%), social anxiety disorder (18.3%), generalized anxiety disorder (13.3%), obsessive compulsive disorder (6.7%) and panic disorder (6.7%). None of the patients had a delirium.

Mental capacity and associations with clinical parameters

Diminished mental capacity to consent to treatment based on clinical assessment was present in 24 out of 70 patients, i.e. 34.3%. A lower mean BMI, more previous hospitalisations and more previous eating disorder treatments were associated with diminished mental capacity (Table 2).

Patients' scores on the MacCAT-T are also shown in Table 2. Their mean scores are indicative of good mental capacity. However, the group with diminished mental capacity as assessed by the clinician showed significantly lower Appreciation scores on the MacCAT-T. The other three standards did not differ between these two groups. The Appreciation score on the MacCAT-T was correlated with the total score on the TAS ($r = -.35$, $p = .005$) but not with BMI.

There was no difference in the rate of depressive disorder or post traumatic stress disorder (PTSD) between both groups, nor did they differ in EDE score or type of anorexia nervosa (restrictive or binge purge).

Mental capacity and associations with neuropsychological parameters

The IGT was done with 60 patients (10 patients did not manage to finish the neuropsychological testing because of concentration difficulties), 20 having diminished mental capacity and 40 having full mental capacity. Overall, a main effect of block was found, $F(4, 232) = 9.64$, $p < .001$, $\eta_p^2 = .14$, showing a learning effect during the task for all participants (see Figure 2). No block x group interaction was found, $F(4, 232) = 1.56$, $p = .20$. The effect of group showed a trend towards significance, $F(1, 58) = 2.78$, $p = .10$, $\eta_p^2 = .05$. Further exploration indicated that the group with full mental capacity had a better overall IGT performance (choose more advantageously) than the group with diminished mental capacity.

The groups differed significantly on set shifting capacity, with the diminished mental capacity group showing poorer set shifting. Central coherence strength showed a trend for

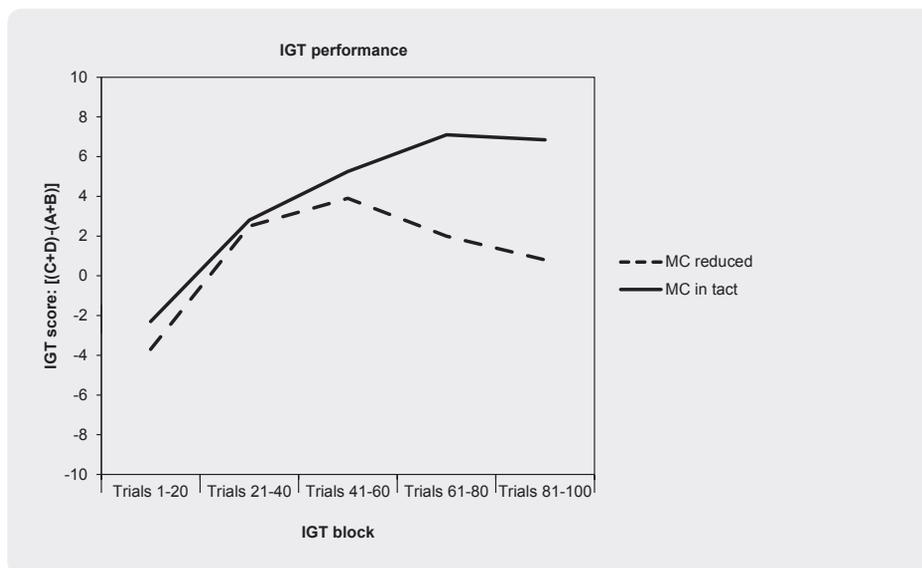
the diminished capacity group performing less, indicating more detail focus as compared to the group with full mental capacity (see Table 2).

None of the neuropsychological parameters (IGT, WCST and RCF) correlated significantly with the variables BMI or the Appreciation subscale of the MacCAT-T.

Table 2. Description participants and differences between full mental capacity and diminished mental capacity group

	Total group (n=70) Mean (SD)	Full MC (n=46) Mean (SD)	Diminished MC (n=24) Mean (SD)	p value
Age	27.3 (9.7)	26.2 (9.3)	29.4 (10.3)	.19
Age of onset	17.8 (4.9)	17.7 (4.6)	18.1 (5.7)	.82
Length of illness (yrs)	8.6 (8.1)	8.5 (8.2)	8.9 (7.9)	.84
BMI	15.5 (1.9)	16.1 (1.6)	14.2 (1.9)	<.001
EDE	3.6 (1.3)	3.7 (1.4)	3.5 (1.2)	.59
ANR vs ANP	49 vs 51 %	47 vs 53 %	55 vs 45 %	.55
Previous ED treatment	74 %	65 %	91 %	.02
Previous hospitalisation	46 %	36 %	65 %	.02
Medication	58 %	52 %	68 %	.22
Relationship	37 %	43 %	24 %	.13
Welfare	25 %	11 %	53 %	.001
Higher education	62 %	70 %	45 %	.06
BDI	29.9 (13.8)	28.8 (13.2)	32.1 (14.9)	.35
STAI trait	59 (10.7)	59.3 (10.7)	58.4 (10.9)	.73
STAI state	56.7 (12.8)	56.6 (12.7)	56.9 (13.3)	.94
TAS	61.3 (9.2)	61.4 (9.2)	61.2 (9.4)	.94
MacCAT-T Understanding	5.74 (.40)	5.78 (.36)	5.65 (.48)	.21
MacCAT-T Appreciation	3.71 (.62)	3.82 (.44)	3.48 (.85)	.03
MacCAT-T Reasoning	7.29 (1.10)	7.39 (.98)	7.11 (1.28)	.32
MacCAT-T Choice	1.94 (.29)	1.96 (.30)	1.91 (.29)	.58
Depressive disorder	48.4 %	45.6 %	55.6 %	.47
PTSD	23.3 %	23.8 %	22.2 %	.89
WCST perseverative errors	7.2 (10.3)	5.9 (7.9)	10.2 (14.4)	.01
RCF recall	18.7 (5.9)	19.3 (6.3)	17.3 (4.7)	.09

MC, mental capacity; SD, standard deviation; BMI, body mass index; EDE, Eating Disorder Examination; ANR, anorexia nervosa restrictive type; ANP, anorexia nervosa purging type; ED, eating disorder; BDI, Beck Depression Inventory; STAI, Spielberger Trait State Anxiety Inventory; TAS, Toronto Alexithymia Scale; PTSD, post traumatic stress disorder; WCST, Wisconsin Card Sorting Test; RCF, Rey Complex Figure Task.

Figure 2. Mean IGT score for two mental capacity groups

DISCUSSION

This is the first study to investigate mental capacity in adults with AN. As shown, diminished mental capacity is a regular feature in patients with AN, occurring in one third of patients with severe AN with an average BMI of 15.5 kg/m². Although a low BMI is highly relevant, still a large proportion (43%) of patients with a BMI lower than 15 kg/m² (in the DSM-5 the cutoff below which the severity of AN is considered to be in the “extreme” range) did have full mental capacity. Moreover, 17% of patients with a BMI of 15 kg/m² or more showed diminished mental capacity. Therefore in our opinion effects malnourishment alone cannot explain the relevance of BMI. None of the patients had a delirium. Also, by using the MacCAT-T we found that abilities involving higher cognitive functioning (reasoning and understanding) were intact in our sample. This is in line with previous research where neurocognitive impairments in AN appear to be subtle and not directly related to BMI⁴². In what way BMI influences mental capacity remains as yet unresolved.

Of interest is that by using the MacCAT-T alongside the clinical assessment of mental capacity we demonstrated that it is important to focus on appreciation of illness and treatment. This is in accordance with previous qualitative work done by Tan et al^{19,27,43}, who found that among patients with AN values regarding life and death differ from healthy people and AN cognitions and behaviour become egosyntonic when severely ill. Also, in a study by Owen et al⁴⁴ appreciation, rather than reasoning, was impaired in psychiatric patients with diminished mental capacity, and reasoning was more impaired in physically ill patients with diminished

mental capacity. In previous studies regarding mental capacity to consent to treatment in depression (for a review see Hindmarch et al, 2013²³) the ability to appreciate is usually found to be diminished and to a lesser degree understanding and reasoning too. In this review the concept of impaired appreciation is discussed in two ways. On the one hand as an inability to appreciate future possibilities by affective symptoms distorting or blinding the individuals' perception of the future and on the other hand as an inability to maintain a minimal concern for the self. These features can be seen in patients with AN as well and may be mediated by overattention to detail (commonly found in AN⁴¹) and the pathological values mentioned earlier¹⁶. As depression rates did not differ between the two mental capacity groups in our study, this suggests that the difference in appreciation must be mediated by an AN specific factor.

The association of appreciation and a high level of alexithymia ($r = -.35, p = .005$) and the lack of correlation between appreciation or alexithymia with BMI is particularly intriguing. Patients often say regarding the consequences of their risky behavior "*I know, but I don't feel it*". Decision making has previously been found to be less advantageous when one's current emotional state is a negative one^{45,46} proposed to be caused by a lesser reliance on somatic or affective markers^{47,48} and a tendency to rely stronger on cognitive reasoning. In the present sample all patients had very high depression and anxiety scores, suggesting that diminished mental capacity in this group of severely ill patients may be a result of their negative emotional state and high alexithymia.

Interestingly, results suggest that patients with diminished mental capacity also show a trend towards impaired decision making. The IGT assesses the degree to which decisions are guided by somatic markers ("gut feelings"). There was no association of decision making performance with BMI, so the poorer performance of the group with diminished capacity cannot be explained by their significantly lower BMI. This is remarkable, as clinically one would expect severely underweight patients to show impaired decision making.

The finding that patients with diminished mental capacity show worse set shifting and a trend towards poorer central coherence is intriguing in the light of decision making processes. Although a relationship between these two neuropsychological abilities and decision making has not been shown so far, it is tempting to presume an association. A rigid thinking style proposedly hampers decision making by not being able to change problem solving strategy or seeing the bigger picture.

Summarising these findings, it appears that several factors are associated with diminished mental capacity. Low BMI seems an important factor, suggesting that clinicians need to be alert to mental capacity issues in these patients. Previous treatment history and poor societal functioning can also point towards diminished mental capacity. The way in which poor societal functioning is related to diminished mental capacity remains uncertain. There may be underlying factors contributing to both diminished mental capacity to consent to treatment and poor societal functioning. Alternatively we cannot exclude the possibility that the clinician might also be influenced in his clinical judgment by the poor societal functioning. More

subtle contributing factors are the inability to change strategies, the slight focus on detail and the combination of negative emotional states. Together with diminished mentalisation these subtle factors might lead to inadventagous decision making on a neuropsychological level and decreased appreciation of the illness and treatment and therefore diminished mental capacity.

Strengths and limitations

Strengths are the relatively large number of patients, the severe psychopathology of the group (as this is the group mental capacity issues are relevant for in clinical practice) and the wide range of assessment measures including a structured clinical interview (SCID-I). Also the combination with neuropsychological parameters regarding decision making is highly innovative and only previously examined in a study in patients with schizophrenia.⁴⁹ A limitation is the subjectivity of the clinical assessment of mental capacity and possibly prejudiced mental capacity judgment by the psychiatrist upon seeing a very underweight patient (*“being so underweight, she must lack capacity”*). As the clinical judgment is inherently subjective we aimed to minimize this limitation by involving highly specialized eating disorder psychiatrists used to working with severely ill patients with AN. The finding that still 43% of patients with AN with a BMI lower than 15 kg/m² was judged to have full mental capacity speaks against prejudiced judgment by the psychiatrists.

Implications for clinical practice

When faced with the task to assess mental capacity in patients with AN, clinicians need to bear in mind that a low BMI is certainly informative, but not exclusively so. All too often mental capacity is said to be adequate because the patient understands her situation. Our results show that although understanding may be adequate, it is the appreciation that is more important in the mental capacity assessments in AN. We urge clinicians not to be mistaken in the idea that a low BMI means lacking mental capacity. In clinical practice we therefore advice the use of so called static markers as BMI and previous history together with more dynamic markers as societal functioning, the emotional state of the patient, the mentalisation ability and the degree of appreciation of illness and treatment. This calls for careful consideration of these factors by the clinician. As far as treatment is concerned, these findings support the importance of incorporating modules to enhance emotion regulation and ameliorate neuropsychological deficiencies. Identifying emotions, recognizing them and learning how to deal with emotions may not only benefit patients because of a higher chance of recovery, also it might improve their decision making abilities and thereby their mental capacity. Interventions such as Cognitive Remediation Therapy,^{50,51} focusing on set shifting difficulties, can be useful to strengthen the neuropsychological functions presumably important in enabling patients to change rigidly set behaviour.

In future research it would be important to have follow up studies to assess the relevance of mental capacity problems on the course of treatment. Do patients with diminished mental capacity do worse? Also in what way mental capacity can be improved would be a relevant line of research. Does it improve with a higher BMI, as would be expected from this study? Or are other factors of more importance in improving mental capacity? Also studies done under more stressful conditions could be relevant, e.g. in emergency situations. We presume mental capacity would be less in stressful circumstances, but no research has been done yet. If this were true, clinicians working in emergency departments would have to be even more alert before discharging patients with severe AN because they seem to “understand” their dire situation.

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CASE VIGNETTE 1

A 21-year old woman with AN for 3 years with a BMI of 13.4 kg/m², bradycardia and hypothermia. Her parents divorced when she was 3 years old and she and her sisters were raised by a mother with schizophrenia, who included her children in her hallucinations and delusions. In the last few years increasing social isolation, gave up her university education and became increasingly anxious. In the first meeting with the clinician she did not speak much, and when she did it was in short sentences and very softly. She could not explain her behaviour, provided no arguments for the restricted eating and could also not reflect on past choices (e.g. study choice) nor on future wishes in life. According to a friend the patient displayed a very high degree of ambivalence in all areas of life and came to decisions only after long periods of doubt. The patient denied the low societal functioning and also the need for treatment, but she accepted the advice to be admitted.

CASE VIGNETTE 2

A 48-year old woman, with AN for 23 years and comorbidly a post traumatic stress disorder (physical and sexual abuse), misuse of alcohol, social phobia and a borderline personality disorder. Her societal functioning was low. She was seeking treatment after deterioration of her eating disorder and body weight after a period of gastrointestinal problems. Although she acknowledged the need for treatment, her reflection on the severity of her present condition and the areas of importance to address in the treatment (such as emotion regulation) was low. Also, the clinician felt that her expectations of the treatment were inappropriately high which made the impression that she did not genuinely grasp the pervasiveness of her condition. She accepted the advice for in patient treatment.

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CHAPTER 4

MENTAL CAPACITY TO CONSENT TO TREATMENT AND THE ASSOCIATION WITH OUTCOME – A LONGITUDINAL STUDY IN PATIENTS WITH ANOREXIA NERVOSA

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The study was conceived, designed and carried out by the first author. Statistical plan was discussed and interpretations of findings were made by the first author. Longitudinal statistics were done with the help of Daniel McNeish. Manuscript was written up with the first author taking the lead and in cooperation with all authors.

ABSTRACT

Background

Relevance of diminished mental capacity in anorexia nervosa (AN) to course of disorder is unknown.

Aims

To examine prognostic relevance of diminished mental capacity in AN.

Method

A longitudinal study was conducted in 70 adult female severe patients with AN. At baseline mental capacity was assessed by psychiatrists and clinical and neuropsychological data (decision making) were collected. After one and two year clinical and neuropsychological assessments were repeated and remission and admission rates were calculated.

Results

Patients with diminished mental capacity had a less favourable outcome with regard to remission and were admitted more frequently. Their appreciation of illness remained hampered. Decision making did not improve, in contrast to patients with full mental capacity.

Conclusions: Patients with diminished mental capacity seem to do less well in treatment and display decision-making deficiencies that do not ameliorate with weight improvement.

Declaration of interest

None

INTRODUCTION

Anorexia nervosa (AN) is a severe psychiatric illness usually beginning in adolescence with a lifetime prevalence among females of 1 to 4% in Europe.^{1,2} Intense fear of weight gain, body image disturbance and disturbed cognitive and emotional functioning are central features of the disorder. These features lead to weight loss behaviours such as dietary restriction, purging or excessive physical activity.³ Acute and chronic effects of starvation complicate treatment of patients with AN and the standardized mortality ratio is around 5.5.^{4,5} In older adolescents and adults AN commonly has a relapsing or protracted course⁶ and only 50% of adults recover completely.⁷ Psychiatric comorbidity is the rule with mood disorders (nearly 75% of patients with AN) and a range of anxiety disorders (between 25-75%) being most common.^{8,9} Mean duration of illness is nearly 7 years^{6,10} and as this disorder usually starts in adolescence transition to adult life is fraught with difficulties finishing education, starting a job or engaging in relationships.

Patients are typically reluctant to engage in treatment, especially when it has a clear focus on weight gain and this tendency to avoid treatment is reflected in the finding that only a minority is treated within the mental health care system.^{11,12} Where onset of the disorder is triggered by genetic, psychosocial and interpersonal factors, changes in neural networks sustain the illness. Altered reward processing to modulate emotional distress^{13,14}, increased compulsivity due to being severely underweight¹⁵ and neuropsychological difficulties¹⁶⁻²¹ might lead to the typical persistence of patients in their self-destructive behaviour. Final factors of importance are the altered values towards life and death in currently ill patients as opposed to recovered patients with AN and the sense that the AN is part of the personal identity instead of an acquired illness.^{22,23}

These findings together with the obvious severity of the disorder lead to doubts regarding decision making abilities or, in other words, mental capacity to consent to treatment. These are relevant doubts, as only a patient with full mental capacity with regards to the medical issue at hand can refuse or consent to necessary treatment according to most international health legislations. Assessment of mental capacity generally considers four abilities²⁴; the ability to **understand** information provided regarding illness and treatment; the ability to **appreciate** this information as relevant to one's own situation; the ability to **reason** with this information, weighing the consequence of either decisions; and the ability to **express a choice** about treatment. A semi-structured interview has been developed to aid clinicians in the assessment of mental capacity to consent to treatment judging these four abilities (MacCAT-T²⁵). Although in general psychiatry a number of studies have been done (for a review see Okai et al²⁶), in AN studies have been scarce. Two small studies have been done in adolescents with inconsistent results^{27,28} In the study by Tan et al, mental capacity of patients with AN was excellent, whereas in the study by Turrell et al impairments in reasoning were shown.

It is tempting to assume that the presence of diminished mental capacity to consent to treatment is relevant to treatment outcome, but this has not yet been studied. Therefore a longitudinal study was conducted in our treatment center. Baseline results from this sample of 70 adult severely ill patients with AN were reported on previously.²⁹ One third of patients had diminished mental capacity at baseline (as assessed by psychiatrists). Diminished mental capacity was associated with a lower BMI, more previous treatment for AN and a lower appreciation of disorder and treatment; duration of illness did not differ between the groups.

Although BMI was significantly different between the two mental capacity groups, still 43% of patients with a BMI below 15 kg/m² was judged to have full mental capacity, highlighting the importance of looking further than BMI alone in the assessment of mental capacity to consent to treatment in AN. The picture that emerged from these baseline data was that a significant group of patients had diminished mental capacity and that not only BMI was of importance (as yet not clear in what way) but also the ability to use one's emotions to come to adaptive decision making. What also became clear was that almost all patients (92%) did follow the treatment advice (whether this was inpatient or outpatient treatment), suggesting that agreement with the treatment advice does not necessarily mean possessing full mental capacity.

More insight in possible differences between the two mental capacity groups in the course of the disorder is relevant to clinical practice as treatment may need to be tailored more to specific needs of the group with diminished mental capacity. The initial group of 70 patients was divided into two groups on the basis of clinical judgment, one with diminished mental capacity and one with full mental capacity to consent to treatment. In this longitudinal part of the study we aim to answer the following questions:

1. Is the course of disorder different between the two mental capacity groups on clinical variables (BMI, percentage of inpatient treatment, duration of inpatient stay, remission rate, eating disorder pathology)?
2. Is the course of disorder different on psychological variables (symptoms of depression, anxiety and alexithymia)?
3. Is the course of disorder different on decision making (appreciation of illness and treatment and more general assessment of decision making ability)?

METHOD

The study design has been described in detail elsewhere.²⁹ A longitudinal cohort study was conducted in our national specialist center for the treatment of eating disorders and at baseline 70 consecutively referred female adult patients with AN were included. Males (5% of referrals) were excluded to increase homogeneity of the sample. Treatment offered in our center follows guidelines for eating disorders and entails a range of individual and group therapies,

Table 1. Baseline characteristics of participants

	Total group (n=70) Mean (SD)	Full MC (n=46) Mean (SD)	Diminished MC (n=24) Mean (SD)	p value
Age	27.3 (9.7)	26.2 (9.3)	29.4 (10.3)	.19
Age of onset	17.8 (4.9)	17.7 (4.6)	18.1 (5.7)	.82
Length of illness (yrs)	8.6 (8.1)	8.5 (8.2)	8.9 (7.9)	.84
BMI	15.5 (1.9)	16.1 (1.6)	14.2 (1.9)	<.001
EDE	3.6 (1.3)	3.7 (1.4)	3.5 (1.2)	.59
ANR vs ANP	49 vs 51 %	47 vs 53 %	55 vs 45 %	.55
Previous ED treatment	74 %	65 %	91 %	.02
Previous hospitalisation	46 %	36 %	65 %	.02
Medication	58 %	52 %	68 %	.22
Relationship	37 %	43 %	24 %	.13
Welfare	25 %	11 %	53 %	.001
BDI	29.9 (13.8)	28.8 (13.2)	32.1 (14.9)	.35
STAI trait	59 (10.7)	59.3 (10.7)	58.4 (10.9)	.73
STAI state	56.7 (12.8)	56.6 (12.7)	56.9 (13.3)	.94
TAS	61.3 (9.2)	61.4 (9.2)	61.2 (9.4)	.94
MacCAT-T Appreciation	3.71 (.62)	3.82 (.44)	3.48 (.85)	.03
Depressive disorder	48.4 %	45.6 %	55.6 %	.47
PTSD	23.3 %	23.8 %	22.2 %	.89

MC, mental capacity; SD, standard deviation; BMI, body mass index; EDE, Eating Disorder Examination; ANR, anorexia nervosa restrictive type; ANP, anorexia nervosa purging type; ED, eating disorder; BDI, Beck Depression Inventory; STAI, Spielberger Trait State Anxiety Inventory; TAS, Toronto Alexithymia Scale; MacCAT-T, MacArthur Competence Assessment Tool-Treatment; PTSD, post traumatic stress disorder.

psychomotor therapy and attention to rehabilitation on an outpatient, daypatient or inpatient basis. For a description of baseline characteristics see Table 1. The study was conducted in accordance with the ethical standards described by the Medical Research Involving Human Subjects Act (WMO) and was approved by the Institutional Review Board. After complete description of the study to the participants, written informed consent was obtained. One and two years after inclusion participants were contacted by phone and asked for their cooperation with the follow up measurements. Some of the required data were collected from patient files (e.g. current BMI, medication, days of inpatient treatment), other were collected during assessments by psychiatrists and psychologists (e.g. interviews and the decision making task). When patients were no longer in treatment at our center, data on current treatment, BMI and medication was asked from the patient.

Clinical measures

Severity of eating disorder symptoms was rated with the Eating Disorder Examination Questionnaire (EDEQ^{30,31}) and the body mass index (BMI in kg/m²) as measured by the Digital Tanita scale (Tanita Cooperation of America, Inc, Arlington Heights, IL). Eating disorder treatments and admissions were collected from the patients and from their files (when available), social functioning from the social history. Remission rates were assessed. Full remission was defined as having a weight in the normal range (BMI of 18.5-25 kg/m²), having resumed menses (or likely to when contraception was used and weight was in the normal range) and having no more disabling anorectic cognitions (assessed in an interview). Partial remission was defined as having two out of three of these criteria. The presence of legal measures regarding their AN was asked for. Depression and anxiety levels were measured with the Beck Depression Inventory (BDI-II³²) and Spielberger State Trait Anxiety Inventory (STAI³³) respectively. Furthermore, levels of alexithymia were assessed with the Toronto Alexithymia Scale (TAS^{34,35}).

Mental capacity

At baseline mental capacity to consent to treatment was assessed by psychiatrists experienced in the treatment of severe eating disorders. Based on this assessment, two groups were distinguished; a group with full mental capacity to consent to treatment and a group with diminished mental capacity to do so. At baseline the MacCAT-T²⁵) was done. The MacCAT-T is a semi-structured interview designed to aid clinicians in determining the level of mental capacity to consent to treatment. It has good inter rater reliability and construct validity and has been used in mental capacity studies in several psychiatric populations.²⁶ As previously reported²⁹ Appreciation of disorder and treatment was significantly lower in the group with diminished mental capacity. Therefore we repeated this MacCAT-T measurement at follow up. This was done in a face to face interview, when this was not feasible it was done by phone.

Decision making

The Iowa Gambling Task (IGT³⁶) was used to assess decision making ability. The task requires participants to choose a card from four different decks and with each choice they win and sometimes also lose money. Two decks are more advantageous while the other two decks are disadvantageous in the long run and participants have to find this out by relying on their "gut feeling". Decision making is determined by calculating the net score for all 100 trials as the difference in number of choices between the advantageous and disadvantageous decks.

Statistical analysis

A fully direct Bayes approach (FDB) was used to optimally account for the sample size and missing data attributable to attrition.³⁷ Each outcome of interest was fitted as a separate univariate model. There was no a priori hypothesis for the growth trajectory over time, so

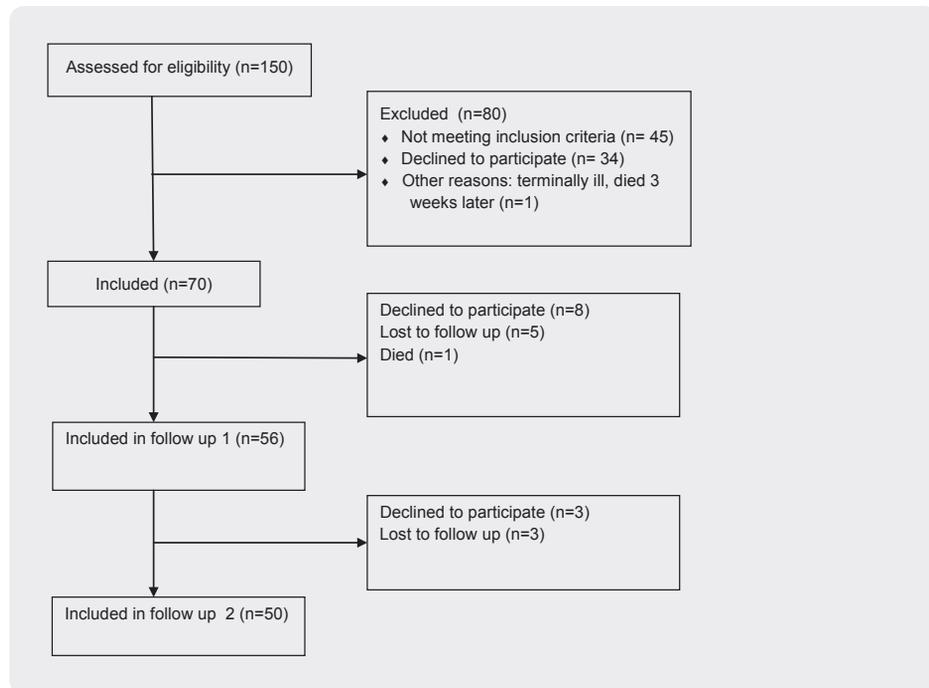
latent basis models were fitted, allowing the data to determine linear or non-linear growth. BMI is included as a control variable in all models to satisfy the assumption that missing values are missing at random. Prior distributions were formed using the method of McNeish³⁸) and models were fit in *Mplus* 7.1 with a Bayesian MCMC algorithm with a Gibbs Sampler and 2 chains with 50,000 MCMC iterations per chain. Bayesian estimation was utilized, so frequentist *p*-values are unavailable. To keep reporting of results succinct and familiar to readers unfamiliar with Bayesian statistics, we report Bayesian *p*-values (p^B). These *p*-values are based on the quantiles of the posterior distribution rather than area beyond a test statistic under a null distribution (as with frequentist *p*-values). Thus, “significance” in our results refers to a value of 0 being highly unlikely in the posterior distribution rather than rejecting the null hypothesis in a frequentist setting, which are conceptual related but not identical.³⁹

RESULTS

Sample characteristics

After 1 year, 56 patients (80%) agreed to cooperate again and after 2 years 50 patients (71%) of the original 70 participants (see Figure 1). After one year 57 of patients (82%) were still in

Figure 1. Flow diagram of inclusion and follow-up process



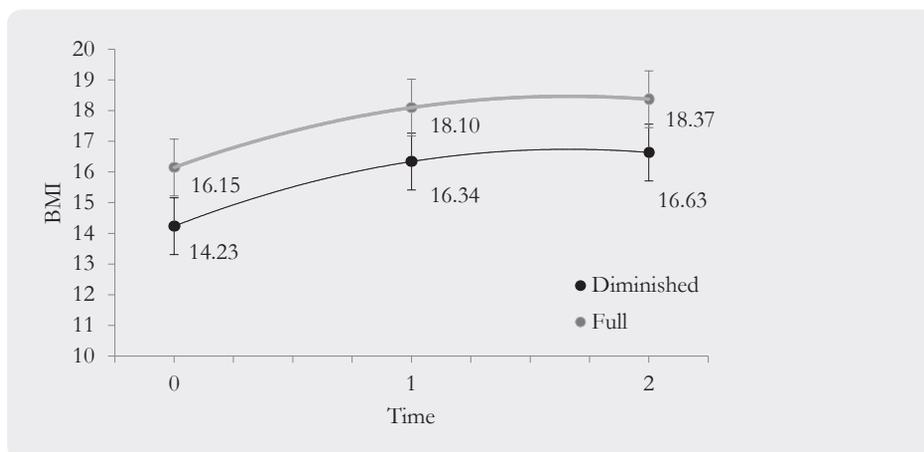
care for their eating disorder and after 2 years 48 (69%), this was not significantly different between the two groups ($p = .39$ and $p = .91$ respectively). Only 1 patient in our study was held under the Mental Health Act (MHA) at baseline, not because of her eating disorder, but because of comorbid alcohol dependence. No one was held under a section of the MHA during follow-up. In the first year of follow up, one patient died of AN related complications. We know that after the end of the study (after the second follow up) another patient died. Both were judged to have diminished mental capacity to consent to treatment at baseline and had a BMI below 15 kg/m^2 .

Is the course of disorder different with respect to clinical variables?

BMI

Figure 2 shows results from an unconditional growth model for BMI. Both groups show a significant increase in BMI from baseline to the year one ($p^B < .001$) but a non-significant change from year one to year two ($p^B = .38$). The growth over time was not significantly different between the groups ($p^B = .70$). The diminished mental capacity group had a significantly lower BMI at baseline than the full mental capacity group (14.2 kg/m^2 , $p^B < .001$) and this significant difference persisted over time. In DSM 5 terminology, this represents on average a change in category from moderate to mild for the group with full mental capacity and from extreme to moderate for the group with diminished mental capacity. The fit of the model was quite good with a *posterior predicted p* (*ppp*) value of 0.542 (*ppp* ranges from 0 to 1 and 0.50 is ideal).

Figure 2. BMI change (in kg/m^2) between baseline, first follow up (after 1 year) and second follow up (after 2 years) between the group with full mental capacity (Full) and the group with diminished mental capacity (Diminished)



Inpatient treatment

Difficulties with sample size and missing data were too great to fit a growth model with this outcome, so we fit models separately at each time-point. At both follow up time points, the group with diminished mental capacity had a borderline significant increase in the probability of having received inpatient treatment after controlling for BMI at baseline (after one year 63% vs. 47%, $p^b = .053$; after two years, 37% vs. 23% $p^b = .057$). However, after controlling for previous admissions, this difference was no longer significant at one year follow up ($p^b = .096$), but the difference became more significant after two years follow up ($p^b = .034$). Patients with previous admissions were more likely to have been admitted in the course of one year ($p^b = .029$) and between the first and second year of follow up ($p^b = .022$), regardless of group. After one year follow up, previous admission is largely responsible for the differences between the groups. Between the first and second year follow up, the difference between the groups was not fully explained by BMI and previous admissions.

Remission rate

Unlike all other models, the remission outcome includes BMI as part of the criteria itself. We considered the conceptual appropriateness of including BMI as a covariate and whether the partial redundancy would hinder interpretation or estimation of the model. We ran the model two different ways, one with BMI as a covariate and one without. The results were quite similar and inferential conclusion did not differ between the models. We therefore report only the model with BMI as a covariate in Table 2. Similar to the model for inpatient treatment, estimation difficulties required that we fit separate model to each time-point rather than

Table 2. Percentage of each mental capacity group in each remission category

		No remission	Partial remission	Full remission
After 1 year	Diminished MC	69.8	16.3	14.0
	Full MC	44.8	40.7	13.7
	p^b	.03	.05	.49
	BMI p^b	.42	.16	.16
After 2 years	Diminished MC	53.9	10.8	35.8
	Full MC	26.6	33.7	38.9
	p^b	.03	.05	.48
	BMI p^b	.45	.32	.27

The p-value is the comparison between the diminished and full groups in each column. For example, the first p^b -value of 0.03 shows that the difference between 69.8% and 44.8% is significant. MC, mental capacity; BMI, body mass index

a single longitudinal model. Remission rate is also a binary variable, so we used logistic models to determine predicted probabilities of remission. As shown in Table 2, after 2 years the group with diminished mental capacity was more likely to show no remission (53.9% compared to 26.6% in the full mental capacity group, $p^B = .026$). Full remission rates were still low (35.8 and 38.9% respectively) in both groups at two year follow-up.

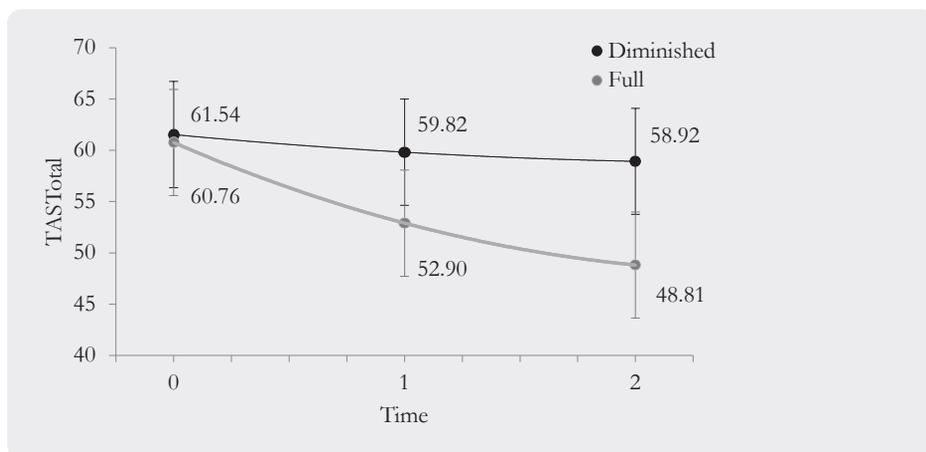
Eating disorder pathology

At the two follow up measurements the EDE-Q was measured. In the analysis BMI was controlled for. The group with full mental capacity went from a EDEQ global score of 3.08 at follow up 1 to 2.76 at follow up 2, which is a non significant change ($p^B = .15$). The group with diminished mental capacity went from 2.59 to 2.27, which is also non significant ($p^B = .27$). Eating disorder pathology as measured by the EDE-Q did not differ between the groups after 1 year or after 2 years ($p^B = .21$).

Is the course of disorder different with respect to psychological variables?

Separate latent growth models were fit to each outcome all controlling for BMI. Both the full and the diminished mental capacity group improve significantly after two years in depression score (BDI improves from both 30 to both 20, $p^B < .001$) and anxiety score (STAI state improves from 57-54 to 44-42 respectively, $p^B < .001$), there are no significant differences between groups at any timepoint (BDI: $p^B = .44$, STAI: $p^B = .42$). As shown in Figure 3, the full mental capacity groups showed a significant improvement in alexithymia score (60.8 to 48.8, $p^B < .001$), which

Figure 3. Alexithymia scores between baseline, first follow up (after 1 year) and second follow up (after 2 years) between the group with full mental capacity (Full) and the group with diminished mental capacity (Diminished), controlled for BMI (in kg/m²)



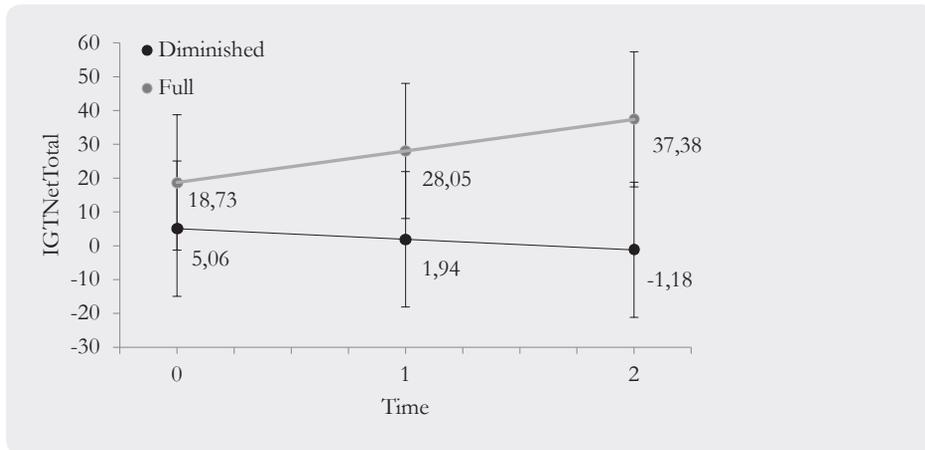
was below the clinical cutoff of 52 for possible alexithymia.^{34,35} The diminished mental capacity group did not improve ($p^B = .10$) and stayed around the clinical cutoff of 61 for alexithymia. The difference over time between groups was significant ($p^B = .006$). The *ppp* values of the alexithymia, depression, and anxiety score models were .41, .48, and .59, respectively, all indicating acceptable fit.

Is the course of disorder different with respect to decision making?

Decision making task

Changes in decision making were modeled with a latent growth model. Because symptoms of depression and alexithymia may theoretically have an influence on decision making ability,^{40,41} a model was tested including BDI and TAS next to BMI as control variables. The group difference at baseline was not significant in this model (19.0 vs 5.9; $p^B = .11$). BMI ($p^B = .43$), TAS ($p^B = .32$) and BDI ($p^B = .30$) were not significant predictors of the IGT score at baseline nor were they significant predictors of the change over time (BMI $p^B = .16$, TAS $p^B = .41$ and BDI $p^B = .38$). The two groups differed in their change over time (see Figure 4), with the full mental capacity group doing better than the diminished mental capacity group ($p^B = .040$). The *ppp*-value for this model was .514.

Figure 4. IGT scores between baseline, first follow up (after 1 year) and second follow up (after 2 years) between the group with full mental capacity (Full) and the group with diminished mental capacity (Diminished), controlled for BMI (in kg/m²), depression and alexithymia scores



Appreciation

The Appreciation scores of the MacCAT-T were difficult to analyse over time as the distribution was highly negatively skewed (most participants scored 3 or higher). Therefore, we conducted

a mean comparison test in the Bayesian framework which allows the normality assumption to be relaxed. The descriptive mean scores, Bayesian p -values, and standardized effect differences are reported at each time-point in Table 3. The group with full mental capacity did well at baseline and kept appreciating well. The group with diminished mental capacity differed noticeably at baseline and after two years.

Table 3. Appreciation scores over time between groups

	Full mental capacity Mean (SD)	Diminished mental capacity Mean (SD)	Group difference p^B	Standardised Effect
Baseline	3.8 (.4)	3.5 (.8)	.02	.25
1 year follow up	3.8 (.5)	3.6 (.5)	.12	.16
2 year follow up	3.8 (.5)	2.9 (1.4)	<.01	.40

DISCUSSION

This is the first large study into mental capacity to consent to treatment in severely ill adult patients with AN using a longitudinal design. The results of this follow up study have two important implications. First, prognosis seems more unfavourable for the group with diminished mental capacity to consent to treatment. Patients with full mental capacity had a mild AN at follow up, whereas the patients with diminished mental capacity still fell within the moderately ill category (DSM-5⁴¹). And as the rise in BMI mainly occurred in the first year after starting treatment and the percentage of no remission is significantly higher in the group with diminished mental capacity, one would not expect the diminished mental capacity group to reach full remission in the near future. In the long run diminished mental capacity to consent to treatment means a higher likelihood of inpatient treatment. These findings suggests a longer duration of care for this particular group. Although the diminished mental capacity group had a lower BMI at baseline, other parameters of prognostic relevance such as duration of illness, percentage of patients with the purging subtype of AN or comorbidity were equal between the groups. Diminished mental capacity therefore seems a factor of relevance to prognosis, next to the more obvious factor of BMI. Both groups improved on BMI at one year follow-up and maintained this improvement one year later at two year follow-up, which is reassuring. Also, anxiety and depression levels lower equally in the course of treatment and remission rates after two years were similar.

A second important finding in this study supports the decision making difficulties clinicians so clearly observe in everyday practice on a more fundamental level. Using the IGT it has become

clear that decision making is more maladaptive in patients with diminished mental capacity, independent of BMI. The IGT is based upon the theoretical model by Damasio (*somatic marker hypothesis*^{42,43}) which states that adaptive decision making is not a merely rational process but relies heavily on emotional factors and “gut feeling”. Emotional dysregulation has been found to be an important maintaining factor in AN before^{23,41,44-46}. In this study, participants also displayed high levels of emotional problems, such as severe depressive symptoms, a high level of anxiety and moderate to high levels of alexithymia. Although depression scores decreased significantly during treatment, levels indicative of moderate depression still existed after two years. Additionally, in the diminished mental capacity group, alexithymia levels remained on a clinical level even after weight improvement. However, even after controlling for BMI, depression and alexithymia the diminished mental capacity group still performed significantly worse on decision making over time. This suggests that the difference between groups cannot be fully explained by the difference in emotional problems as measured in this study (BDI, TAS). Appreciation of the diminished mental capacity group over time remained less than of the full mental capacity group, linking the concept of more fundamental decision making (and “gut feeling”) to the concept of appreciation in AN. Future research should therefore be focused on the interplay between emotional dysregulation (as measured with more direct markers) so often found in AN and the diminished appreciation of illness and treatment.

The high level of emotional problems in our participants support the emphasis laid on emotion recognition and processing in recently developed cognitive-affective treatments for AN, such as the Maudsley Anorexia Nervosa Treatment for Adults (MANTRA⁴⁷) and enhanced form of Cognitive Behavioral Therapy (CBT-E⁴⁸). In recent years several randomized clinical trials have been done that have shown that both MANTRA, CBT-E and Focal Psychodynamic Therapy (FPT) have a positive effect on outcome in AN.⁴⁹⁻⁵¹ It is as yet not clear what works for whom. Perhaps MANTRA is of more value to AN patients with a higher level of affective dysregulation, but this is speculative. Also motivational stage of change might be an important factor, although a recent study could only show a relation between the stage of contemplation and the strength of the therapeutic alliance, but not outcome.^{52,53}

Strengths and limitations

Major strengths in this study are the longitudinal design, the high participation after 1 and 2 year follow-up (80% and 70% respectively) and the generalizability of the results, as this was a naturalistic study. Also the assessment of decision making on a clinical as well as on a more fundamental level provided the opportunity to bring together more basic science and bedside, a strategy very fruitful to move forward in the body of knowledge regarding an issue so complex as decision making.

This study being a naturalistic study with hardly any exclusion criteria, there were missing data in the course of follow up. For a clinical study with patients with AN, who are usually

highly avoidant of treatment^{11,12}, we consider the loss to follow up of 20% and 29% after one and two years as acceptable. Also, in the statistical analyses missing data were accounted for. Nevertheless, outcome might have been influenced by these missing data.

Although clinicians doing the clinical judgment were blind to the outcome of the MacCAT-T, for obvious reasons they could not be blind to their own assessment of mental capacity. We do not think this resulted in treatment bias on the part of the clinicians as this assessment is part of routine clinical practice, especially in complex cases and therefore has not had a major influence on treatment advised.

In our previously reported study²⁹ a substantial group was found to have diminished capacity to consent to treatment. Contrary to what might be expected, follow-up results show that this particular group improves on both weight, eating disorder and more general psychopathology, which is encouraging. On the down side, after two years BMI is still in the moderately severe range and longer duration of care is expected. Decision making on a more fundamental level is maladaptive proposed to be caused by an interaction between emotional dysregulation and lack of appreciation of illness and treatment. Therefore, a key component in treatment should be to improve precisely this hampered emotional functioning, a feature central to more recently developed AN treatments like MANTRA and CBT-E. Whether or not the heightened focus on these emotional difficulties will improve adaptive decision making is an issue that should be assessed in future research.

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CHAPTER 5

ASSESSMENT OF MENTAL CAPACITY TO CONSENT TO TREATMENT IN ANOREXIA NERVOSA: A COMPARISON OF CLINICAL JUDGMENT AND MACCAT-T AND CONSEQUENCES FOR CLINICAL PRACTICE

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ABSTRACT

Informed consent requires adequate mental capacity to consent to treatment. Mental capacity (MC) to consent to treatment refers to the ability to decide regarding medical decisions. MC is assessed in a general psychiatric interview, but this clinical assessment is known to overestimate mental capacity in patients and the interrater reliability is low. The MacArthur Competence Assessment Tool for Treatment (MacCAT-T) has emerged as the gold standard to assess mental capacity to consent to treatment. The MacCAT-T is a semi-structured interview designed to aid clinicians in this assessment and has shown good interrater reliability in patients with schizophrenia and other mental disorders, but has hardly been studied in patients with anorexia nervosa. Patients with anorexia nervosa (AN) regularly avoid treatment, even when severely ill and discussion surrounds their level of MC to consent to treatment.

The aim of this study is to compare clinical judgment and the outcome of the MacCAT-T in patients with AN to inform clinicians regarding the use of the MacCAT-T in daily practice. In a sample of 70 consecutively referred severely ill patients with AN with a mean BMI of 15.5 kg/m² and a mean duration of illness of 8.6 years, clinical assessment of MC by experienced psychiatrists and the outcome of the MacCAT-T interview were compared. Agreement (k-value) was calculated. Agreement between clinical assessment and outcome of the MacCAT-T was questionable (k .23). Unlike in other psychiatric populations, clinicians judged a high proportion of patients with AN as having diminished MC. The MacCAT-T can be useful in assessing MC in AN when used in addition to clinical judgment to aid clinicians in complex cases. Why clinicians judge a relatively high proportion of patients with AN as having diminished MC, in contrast to lower proportions in other psychiatric disorders, is an area in need of further research.

Keywords: mental capacity, anorexia nervosa, MacCAT-T

INTRODUCTION

Informed consent is considered a central theme in health care legislation in Western countries. It refers to the ability of a patient to adequately decide regarding treatment, and without informed consent a clinician cannot commence treatment. In the field of medicine adequate decision making regarding treatment is referred to as mental capacity.

Contemporary ideas on informed consent stem from the Nuremberg Code, where it was stated that consent to research should be voluntary, made with free choice, adequate understanding and the capacity to give consent (Sturman, 2005). The Nuremberg Code was designed with the unethical behaviour of (German) health care professionals in the Second World War in mind and conveyed the firm resolution that such behaviour should never again occur. In the more liberal view regarding patient rights that emerged after the war, informed consent in the context of medical treatment gained importance. The duty of clinicians to properly inform patients and not override patient autonomy became a central theme in health care legislation. In later years mental capacity, without which informed consent could not be validly given, was conceptualized further. In 1977, Roth et al (Roth, Meisel, & Lidz, 1977) suggested this decisional capacity (i.e. mental capacity) should be assessed by tests regarding reasoning, understanding and the ability to make a choice as these were the elements on which judges based their verdicts in courts. Based on this original work, in 1982 Appelbaum and Roth outlined four legal standards, which from that moment on have come to be used by the majority of the researchers in the field. These so-called standards, which actually are functional abilities, generally refer to being able to understand the information provided, engage in reasoning about this information when deciding, appreciate this information as relevant to one's own circumstances and being able to express a choice (Appelbaum & Roth, 1982). An important presumption in clinical practice is that the patient possesses adequate mental capacity to do so. Mental capacity is a task specific phenomenon and in that sense refers to one specific decision patients need to make and is not a general feature of the patient (except for extreme situations e.g. coma). A patient can thus have adequate mental capacity regarding a certain decision, but diminished or absent mental capacity regarding another medical decision (Appelbaum P, 1988; Beauchamp TL, 1994; Wong, J.G., Clare, I.C.H., Gunn, M.J., Holland, A.J., 1999).

When severely ill patients refuse necessary treatment, the issue of mental capacity becomes especially important. In a recent review on the ethics of coercive treatment in psychiatry, Steinert (Steinert, 2017) states that coercive treatment can be justified only when a patient's capacity to consent is impaired and severe danger to health or life cannot be prevented by less intrusive means. In this case, withholding treatment can violate the principle of justice. In most health care legislations clinicians can resort to compulsory treatment when the refusal of the advised medical treatment results in severe danger to the patients' life *and* when this refusal is done without adequate mental capacity. Lacking or diminished mental capacity can

thus provide the clinician with a dilemma, certainly in cases where withholding treatment can harm the patient or others.

In this introduction we will discuss the way mental capacity assessments are done in clinical practice and how clinical researchers have studied the assessment of mental capacity. We will describe legal and ethical considerations regarding the current concept of mental capacity and also pay attention to criticism regarding this concept. Before we come to our research question, we will briefly touch upon anorexia nervosa and the studies regarding mental capacity to consent to treatment done so far in patients with anorexia nervosa.

Assessment of mental capacity to consent to treatment

Assessment of mental capacity to consent to treatment is usually done by the treating clinician, but generally only in situations where the clinician doubts whether or not mental capacity is adequate. This clinical assessment is known to overestimate mental capacity in patients (Lepping, P., Sambhi, R.S., Williams-Jones, K., 2010) and has low interrater reliability (Kitamura, T., Kitamura, F., 2000; Marson, D.C., McInturff, B., Hawkins, L. Bartolucci, A., Harrell, L.E., 1997; Shah & Mukherjee, 2003), i.e. two clinicians have low agreement in their assessment of mental capacity in the same patient. Therefore, efforts have been made by various researchers to provide clinicians with a tool to assess mental capacity in clinical practice. Sturman (Sturman, 2005) discusses in his review eight (semi)structured interviews, one self report instrument and one questionnaire. Virtually all of these instruments demonstrated good interrater reliability, the most serious limitation of these instruments lies in their validity testing. Of these instruments, the MacArthur Competence Assessment Tool for Treatment and for Clinical Research (MacCAT-T and MacCAT-CR to assess mental capacity to consent to treatment or to consent to participating in clinical research respectively) have emerged as the gold standard today. This is due to the more substantial research into reliability, the demonstrated concurrent validity with other measures and the extensive testing in a range of patient populations, medical as well as psychiatric (Candia & Barba, 2011; Dornan, Kennedy, Garland, Rutledge, & Kennedy, 2015; G. Mandarelli et al., 2017; G. Mandarelli et al., 2016; Okai et al., 2007; Raymond et al., 2004; Sturman, 2005; Wang et al., 2016). The MacCAT-T (Grisso, Appelbaum, & Hill-Fotouhi, 1997) is a shorter version adapted from the original mental capacity assessment tool developed by Appelbaum and Grisso in the nineties of the previous century (Appelbaum & Grisso, 1995; Grisso & Appelbaum, 1995; Grisso, Appelbaum, Mulvey, & Fletcher, 1995). As mentioned in the Introduction, four abilities (understanding, appreciation, reasoning and making a choice) were condensed from legal ruling in the United States in the 1980s; these were the abilities that were considered central to mental capacity by court rulings. As these abilities seemed clinically meaningful, they became the four central issues in the research and development of their assessment tools for clinical practice. Using the MacCAT-T the clinician provides patients with adequate information and assesses their degree of understanding, reasoning and appreciation

and ability to make a choice. The MacCAT-T provides ratings for four subscales; Understanding (0-6), Appreciation (0-4), Reasoning (0-8) and Choice (0-2). It has shown good inter-rater reliability in the assessment of mental capacity (Grisso et al., 1997).

The MacCAT-T has since been used in a range of populations, psychiatric and medical, and the high interrater reliability has been replicated a number of times. Two reviews (Candia & Barba, 2011; Okai et al., 2007) and one meta-analysis (Wang et al., 2016) have been published on mental capacity in psychiatric patients. In most studies in these reviews the MacCAT-T was the instrument of choice to assess mental capacity. The interrater reliability again proved to be high, indicating that it was possible to reliably assess mental capacity with the MacCAT-T. Schizophrenia, bipolar disorder and major depressive disorder were the most common diagnoses in the two reviews, in the meta-analysis by Wang et al only patients with schizophrenia were included. Psychosis, symptom severity, involuntary admission and treatment refusal were risk factors for incapacity. Incapacity was found to be present in 29% of patients in the review by Okai et al, in the meta-analysis by Wang et al it was shown that patients with schizophrenia performed worse on all subscales of the MacCAT instrument used compared to healthy controls.

In studies using the MacCAT-T a persistent finding is that the proportion of patients that is judged as having diminished mental capacity is generally much higher when adding the MacCAT-T to the clinical assessment, than when clinicians judge without this tool (Cairns et al., 2005; Vollmann, Bauer, Danker-Hopfe, & Helmchen, 2003). For instance, in the study by Vollmann et al it was found that when the clinician assessed patients with a major depressive disorder the proportion of patients found to lack capacity was substantially lower than when the MacCAT-T was used in this assessment (3 % vs 20%); the same pattern was seen in patients with schizophrenia (18 % vs 53 %). An interesting study by Owen et al (Owen,G.S., Szmukler,G., Richardson,G., David,A.S., Raymont,V., Freyenhagen,F., Martin,W., Hotopf,M., 2013) showed that when physically ill patients have diminished mental capacity it is mainly their reasoning that is deficient, whereas in psychiatrically ill patients appreciation is lower when mental capacity is compromised. This suggests a different pathway to mental capacity problems in medically ill and psychiatrically ill patients.

Legal and ethical considerations in mental capacity to consent to treatment

The MacCAT-T and the focus on the four key abilities have been influential in clinical practice. Clinicians regarded these four abilities as essential, teaching them to new generations. But this translation of legal logic to clinical reality might be inherently problematic. The legal paradigm is much more rational than clinical reality, it is more dichotomous and pays less attention to interpersonal differences. Laws do not leave much room for personalization, whereas in medicine diagnoses, treatments and prognoses are constantly influenced by personal circumstances of the patient.

Another legal matter complicates the assessment of mental capacity in daily practice. Different health care legislation exists for mentally ill and physically ill people with a different weight put on the importance of mental capacity to consent to treatment. There have been some that have argued for the merging of these two different health care legislations as medical law would benefit from one system, with mental capacity as a core feature regardless whether a patient would have a psychiatric disorder or another medical disorder. These authors see no justification for two different legislations and argue that it promotes stigma and enables discriminations against people with a psychiatric disorder (Dawson & Szmukler, 2006; Richardson, 2007; Szmukler & Kelly, 2016). Appealing as this might seem, this has not been the turn society or politicians have taken in designing the health care legislation in recent years.

Besides the difficulty translating legal concepts to the field of psychology and psychiatry, and complex legislation, the question how to optimize ethical decision making regarding patients who might harm themselves or others is an area of continuous discussion. The issue of mental capacity stands at the core of this discussion. Although this is an area of interest for the entire medical field, it is argued by some (Radden, 2002) that psychiatry has ‘a special place in terms of the ethical demands it places on practice’, because of three distinct aspects of psychiatric treatment: the therapeutic alliance, distinct patient features such as impaired reasoning and the goals of treatment which can extend to substantial personality change. The ethical dilemma known to medical practice for a long time is all the more applicable to the field of psychiatry: What degree of paternalism may be adopted to protect a patient’s well-being? Or, in other words, when is the mental capacity of a patient not sufficient anymore to be able to refuse treatment and should society intervene? This issue is usually resolved by setting “thresholds”; i.e. the more severe the consequences of a certain decision, the more certainty the clinician needs and the higher the threshold would be for the clinician to decide that the patient has adequate mental capacity. Although some have commented on this as being ethically unsatisfactory and paternalistic (DeMarco, 2002), from a clinician’s point of view this way of handling seems inevitable (Hotopf, 2005).

Beauchamp and Childress famous work mentions guiding principles that need to be taken into account when dealing with bio-ethical problems (Beauchamp & Childress, 2001). These principles are non-maleficence (first do no harm), beneficence (acting to benefit others), autonomy (acknowledging a persons’s right to ‘self-government’) and justice (treating people fairly). This theoretical framework, also known as principle-based ethics or principlism, is the dominant theoretical framework in medical ethics. A person is autonomous when he or she can make his or her own decisions and choices without constraints by either another person’s action or by psychological limitation. To be autonomous one has to be able to make choices on the basis of deliberation. The principle of autonomy has increasingly dominated discussions about mental capacity and compulsory treatment (in general medicine as well as in psychiatry) and this has been criticized by some. They argue that the importance of the other

three principles (non-maleficence, beneficence and justice) should not be overlooked and that autonomy was always meant to be taken into account together with these other principles. These ethical principles are not meant as rules and one should not have preference over another, but rather should be regarded as concepts that have a different weight in different situations (Berghmans, Dickenson, & Meulen, 2004; P. Lepping & Raveesh, 2014). Also they argue that autonomy of any person can never exist in isolation and therefore other values and social context should always be taken into consideration as well. In that way these authors advocate a larger role for the ethics of care movement, with a larger role for empathy and relationships in the decision making regarding ethical dilemmas.

In an attempt to look for an optimal ethical framework for psychiatry, Bloch and Green have discussed various ethical theories (Bloch, 2006). They too propose a combination of this principle based ethical model (being a pragmatic approach) with the model of care ethics (with a large role for emotions and interpersonal relationships in moral deliberation). In this way they seek to offer a framework that is guided by principles, but takes into account unique personal circumstances as well.

In accordance with the suggestions by researchers from the bio-ethical field, more emphasis on the narrative of the patient reflecting personal values and (in psychiatric patients) more attention to premorbid values and beliefs are advocated by others working in the field of psychiatry and medical ethics (Breden & Vollmann, 2004; Charland, 1998; Charland, 2007; J. Tan, Stewart, Fitzpatrick, & Hope, 2006; J. Tan, 2003; J. Tan, Stewart, & Hope, 2009; Vollmann, 2006).

This dominance of the concept of autonomy over the other ethical principles is at odds with the idea that a human being exists essentially in relation to his or her environment and personal relationships and therefore cannot be seen as separate from this context and these values. Lepping (Lepping & Raveesh, 2014) describes how health care legislation is based on capacity and that when one is found to have adequate capacity, autonomy predominates from that moment on. He warns that overestimation of mental capacity is common and that the degree of capacity may fluctuate. By favoring the principle of autonomy over other ethical principles in the assessment of mental capacity, according to Lepping the clinician is in danger of paying too little attention to the patient's relationships, their care needs and long-term social context. Steinert in a recent paper (Steinert, 2017) therefore promotes a pragmatic approach to the issue of autonomy and mental capacity.

Besides this criticism about the domination of the concept of autonomy and the way this influences the mental capacity assessment from the bio-ethical field, another critique regarding the current concept of mental capacity is the proposed lack of attention to emotions. By some authors, mental capacity assessments in general and the MacCAT-T in particular are seen as focusing too much on cognitive and rational functioning, whereas decision-making is not wholly rational but rather very much influenced by emotional factors (Breden & Vollmann, 2004; Charland, 1998; Charland, 2007; J. Tan et al., 2006; J. Tan, 2003; J. Tan et al., 2009; Vollmann,

2006). Decision making that involves a certain degree of complexity and uncertainty is known to be heavily influenced by emotions (Naqvi, Shiv, & Bechara, 2006). In this type of decision making, people will have to rely on their intuition, because information in these complex situations cannot be processed in a rational and slow fashion since our working memory capacity is limited (Remmers & Michalak, 2016). Adaptive decision making entails that people will rely on their intuition that consists of feelings or bodily signals, also referred to as somatic markers (Damasio, 1994; Damasio, 1996) resulting from the decision making process when receiving evaluative feedback (e.g., reward vs. punishment). This will bias their decision making in an adaptive direction. However, when there are disturbances in the affective system, it will be difficult to rely on these bodily feelings and the decision making process will likely be hampered. How to include emotional functioning in mental capacity assessments however is still not clear.

Anorexia nervosa

Anorexia nervosa (AN) is a disorder, where discussions on mental capacity and consent to treatment often play a major role. Patients with anorexia nervosa usually deny that they are ill, even when they are in a life threatening condition. The mortality rates of AN are among the highest in psychiatric disorders with a crude mortality rate of 5.1% per decade (Arcelus, Mitchell, Wales, & Nielsen, 2011; Fichter, M.M., Quadflieg, N., 2016; F. R. E. Smink, van Hoeken, & Hoek, 2013). Even in cases without a lethal course, anorexia nervosa is a very severe mental illness impacting on all life domains. The onset of the disorder is usually in adolescence but, as the mean duration of illness to recovery takes around 7 years (Herzog, Deter, Fiehn, & Petzold, 1997; Strober, Freeman, & Morrell, 1997), transition to adult life is fraught with difficulties. Finishing secondary education is hampered, but also starting higher education or a job, engaging in relationships and generally finding the way into society are life domains severely hindered by this devastating illness. In the global burden of disease study published in 2016 it was found that eating disorders were among the leading causes of burden in young females in high income countries, with a burden greater than that of alcohol use disorders, gynecological disorders and interpersonal violence (Erskine, Whiteford, & Pike, 2016). This finding highlights the severe morbidity of AN. The causes of AN are not yet clear. Multiple factors, including genetic, social and psychological factors appear to have an influence in the onset of AN (J. Treasure, Claudino, & Zucker, 2010; S. Zipfel, Giel, Bulik, Hay, & Schmidt, 2015). Recent studies have shown a lifetime prevalence of 1 to 4 % in Europe (Keski-Rahkonen A, 2016; F. R. E. Smink et al., 2013) indicating that AN is not uncommon. Central features of AN are restriction of energy intake, an intense fear of weight gain, body image disturbance and altered cognitive and emotional functioning. A rigid thinking style, a tendency to focus on details at the expense of the bigger picture and intolerance of uncertainty have been shown in patients with AN (Chan et al., 2014; U. N. Danner et al., 2012; Galimberti et al., 2012; Lopez, Tchanturia, Stahl, & Treasure, 2008; Sternheim, Startup, & Schmidt, 2011; Tchanturia et al., 2007; Tchanturia et al., 2012). Furthermore, emotion regulation difficulties and less adequate

emotion recognition and processing have been found (U. N. Danner et al., 2016; Fairburn et al., 2009; Harrison, Sullivan, Tchanturia, & Treasure, 2010; J. Treasure & Schmidt, 2013; Wildes, Marcus, Cheng, McCabe, & Gaskill, 2014). These features lead to numerous pathological behaviors in order to lose weight, such as severe dietary restriction, purging or excessive physical activity. These behaviours can lead to severe weight loss with physical complications, such as fatigue, loss of menstruation, loss of bone mass and dryness of hair and skin. In extreme cases life threatening bradycardia, hypotension, hypothermia or electrolyte disturbances can occur (S. Zipfel et al., 2015). Not only are mortality rates high, but prognosis also is unfavorable with only 50% of adults recovering completely, 30% reaching partial recovery and 20% remaining severely ill (Keel & Brown, 2010). Psychiatric comorbidity is common, with mood disorders (nearly 75% of patients with AN) and a range of anxiety disorders (between 25-75%) most prevalent (Fernandez-Aranda et al., 2007; Raney et al., 2008). Remarkably, given this unfavorable outcome and the severe consequences, only a minority of patients is treated within the mental health care system (Hoek, 2006; Keski-Rahkonen, A., Hoek, H.W., Susser, E.S., Linna, M.S., Sihvola, E., Raevuori, A., Bulik, C., Kaprio, J., Rissanen, A., 2007; F. R. Smink, 2012) which is seen by the field as a sign of these patients' well-known resistance to treatment.

The most recent treatment guideline for AN is the Australian and New Zealand Clinical Practice Guideline of 2014 (Hay et al., 2014). This guideline promotes a comprehensive assessment of the patients and her context with thorough attention to comorbid psychiatric and medical diagnosis and risks. Predisposing, precipitating and maintaining factors should be included in the case formulation and treatment goals should be set accordingly. It is advised to give great attention to engagement and medical stabilization (if necessary) and not embark directly into psychological treatment as meaningful engagement is a crucial factor in treating AN. Outpatient (or day-patient) treatment is recommended, except for those patients that are medically or psychologically compromised. A range of psychotherapeutic approaches is available for the treatment of AN, but what is indicated for whom is as yet not clear. Cognitive behaviour therapy (CBT) and especially an enhanced form of CBT (CBT-E, Fairburn 2008) is frequently recommended. Other therapeutic approaches however have been developed which seem to have equal results regarding outcome, such as the Maudsley Anorexia Nervosa Treatment for Adults (MANTRA, Schmidt et al 2012, Schmidt, Wade, & Treasure, 2014), Specialist Supportive Clinical Management (SSCM, MacIntosh et al, 2005 McIntosh et al., 2005) and Focal Psychodynamic Therapy (S. Zipfel et al., 2014). However, further research is needed, especially comparing the different treatment strategies and determining what to recommend in which stage of the illness (e.g. recent onset AN vs long standing AN).

Mental capacity to consent to treatment in anorexia nervosa

Little research has examined mental capacity to consent to treatment in patients with AN, which is surprising given their great resistance to treatment, their seemingly irrational behaviour

and the dire possible consequences of refusing treatment. As mental capacity to consent to treatment in severely ill patients with AN therefore is important to assess, an instrument that might aid the clinician in this judgment could be of great value. Until recently only two small studies had been done in patients with AN, with conflicting results. One small qualitative study (J. Tan, Hope, & Stewart, 2003) using the MacCAT-T did not show any problems in mental capacity, but the interview was done retrospectively, looking back at a period of more severe illness and thus not at the clinically relevant moment for consent to treatment. One quantitative study in 35 adolescents with AN (Turrell, Peterson-Badali, & Katzman, 2011) showed mild problems with reasoning compared to healthy controls. Recently we published the results of a large study into mental capacity to consent to treatment in 70 severely ill patients with AN (Elzakkers, Danner, Hoek, & van Elburg, 2016). It was shown that mental capacity as judged by the clinician was diminished in one-third of the patients and that associated factors of this diminished mental capacity were a lower body mass index (BMI), previous treatment for AN and previous hospitalization. That study used the MacCAT-T as well as clinicians' judgment in the assessment of mental capacity. The results indicated that in AN it was the aspect of appreciation that was driving diminished mental capacity (as determined by the clinician), in line with the findings by Owen et al (Owen, G.S., Szukler, G., Richardson, G., David, A.S., Raymont, V., Freyenhagen, F., Martin, W., Hotopf, M., 2013) in a more general psychiatric population.

In AN the discussion regarding the mental capacity assessment focusing too much on cognitive abilities and paying too little attention to the role of emotions is very much alive (Breden & Vollmann, 2004; Charland, 1998; Charland, 2007; J. Tan et al., 2006; J. Tan, 2003; J. Tan et al., 2009; Vollmann, 2006). That discussion also argues that values of patients do not get enough merit in the MacCAT-T. However, in a reply to this criticism Grisso and Appelbaum (Grisso & Appelbaum, 2006) remark that the assessment of appreciation in the MacCAT-T captures the effects of emotion and personal values. Adding to the criticism, Sturman (Sturman, 2005) mentioned that the distorted or false beliefs so commonly encountered in patients with AN might not emerge well enough in the assessment of mental capacity, whilst they have a profound impact on the choice of the patient. This suggests that mental capacity to consent to treatment in AN might be even more complex than in other psychiatric disorders.

The current study

Many issues are as yet unresolved in assessing mental capacity in AN. As a starting point we therefore conducted a large longitudinal study to find parameters associated with diminished mental capacity in patients with AN, which we reported on previously (Elzakkers et al., 2016). The issue of the mental capacity assessment itself is the focus of the current paper. Using our data from the first large scale study into mental capacity in AN described earlier (Elzakkers et al., 2016) we compare clinical judgment and outcome of the MacCAT-T in patients with AN. The MacCAT-T ratings of severely ill patients with AN will be discussed in comparison to

clinical judgment, and feasibility of the MacCAT-T in daily practice will be addressed. Finally the question will be addressed whether or not the MacCAT-T can be recommended for use in clinical practice in AN.

METHOD

Details of the original study design are described elsewhere (Elzakkers et al., 2016). Briefly, a group of 70 adult women with AN assessed and treated in a specialized center for eating disorders in The Netherlands participated in a study of mental capacity to consent to treatment. Group characteristics are shown in Tables 1 and 2. Altrecht Eating Disorders Rintveld is a specialist eating disorder department of the Altrecht Mental Health Institute that offers assessments, consultation and treatment for in- and outpatients. All consecutive adult female patients who were referred to our center from February 2012 to July 2013 were eligible for inclusion if they had a diagnosis of AN or EDNOS clinically referred to as AN according to DSM-IV (American Psychiatric Association. Task Force on DSM-IV, 2000). The only exclusion criterion for this study was an IQ lower than 70, as we expected neuropsychological difficulties in this group of patients due to their cognitive impairments. The presence of AN was established by eating disorder experts (all psychiatrists) and confirmed by the Eating Disorder Examination (EDE, Cooper & Fairburn, 1987). The study was conducted in accordance with the ethical standards described by the Medical Research Involving Human Subjects Act (WMO) and was approved by the Institutional Review Board. After complete description of the study to the participants, written informed consent was obtained.

Table 1. Characteristics of participants (n=70)

Characteristic	Value (SD)
Age (years)	27.3 (9.7)
Age of onset	17.8 (4.9)
Length of illness (years)	8.6 (8.1)
BMI	15.5 (1.9)
EDE	3.6 (1.3)
ANR	49 %
ANP	51 %
Previous ED treatment	74 %
Previous hospitalisation	46 %
Medication	58 %

SD, standard deviation; BMI, body mass index; EDE, Eating Disorder Examination; ANR, anorexia nervosa restrictive subtype; ANP, anorexia nervosa purging subtype; ED, eating disorder

Table 2. Comorbid axis I disorders of participants (n=62) classified with SCID-I

	N	%
Depressive disorders	30	48.4
Anxiety disorders	42	70.0
PTSD	13	21.7
Social phobia	11	18.3
GAD	8	13.3
OCD	4	6.7
Panic disorder	4	6.7
ADNOS	2	3.3

PTSD, post traumatic stress disorder; GAD, generalized anxiety disorder; OCD, obsessive compulsive disorder; ADNOS, anxiety disorder not otherwise specified

Assessment of mental capacity

Mental capacity to consent to treatment was assessed in two ways. First, the psychiatrist seeing the patient for clinical assessment after referral to our center noted his or her impression of the degree of mental capacity regarding the decision to enter treatment as full or diminished. The psychiatrists were asked specifically to consider this decision in their clinical judgment. Their evaluations were done during the regular psychiatric examination of the patients. These psychiatrists had several years of experience in the field of eating disorders and were thus used to the way patients could present their symptoms (e.g. playing down of severity). Second, the MacCAT-T (Grisso et al., 1997) for every participant was done by another clinician (a total of 7 medical doctors or psychiatrists were involved in the MacCAT-T scoring) who was blind to the judgment by the first psychiatrist (the clinical judgment). In a previous publication (Elzakkars et al., 2016) we reported high intra class coefficients (ICC) for the subscales of the MacCAT-T.

The MacCAT-T is a semi structured interview to assess mental capacity. The MacCAT-T generates four ratings (Understanding 0-6, Reasoning 0-8, Appreciation 0-4 and Making a Choice 0-2), which are not combined into a total score. Clinicians were trained in administering the MacCAT-T by watching the instruction DVD and reading the manual (Grisso & Appelbaum, 1998). The patient's decision whether or not to follow the doctor's treatment advice was used as content for the semi-structured interview, so it was tailored to the specific situation of the patient. The doctor's treatment advice was for either inpatient or outpatient treatment. As the MacCAT-T is about the process of arriving at a choice and explicitly not about the content of the actual choice itself, differences in treatment advice did not hinder this assessment.

Diminished and full mental capacity group formation

Patients were divided into two groups based on psychiatrists' clinical judgments as having either "full mental capacity" or "diminished mental capacity" (for details see Elzakkers et al 2016). The total group was also divided into two groups based on ratings on the four subscales of the MacCAT-T. In a previous study using the MacCAT-T, Owen et al (Owen,G.S., Szmukler,G., Richardson,G., David,A.S., Raymont,V., Freyenhagen,F., Martin,W., Hotopf,M., 2013) used a rating of 50% or less on a subscale to indicate a poor outcome and any rating over 50% as a good outcome. To create two groups (full and diminished mental capacity) based on MacCAT-T scores, this cut off was adapted in the present study. For every subscale a patient could rate poor (50% or less of the maximum rating on that subscale), intermediate (51-75% of the maximum rating) and good (76-100%). If a patient had a poor or intermediate rating on one or more of the four subscales, this patient was regarded as having diminished mental capacity on the MacCAT-T. All others were rated as possessing full mental capacity. A somewhat higher cut off rating than Owen et al was used, as full mental capacity is the preferred situation and anything that impedes on this was presumed to be clinically meaningful in so ill a population with such high stakes surrounding their decision-making regarding treatment.

Statistical analysis

To test for differences on the MacCAT-T subscales between the two mental capacity groups based on clinical judgment, independent t-tests were used. To test agreement between clinical judgments and the MacCAT-T, a kappa coefficient was calculated.

RESULTS

Table 3 shows ratings on the MacCAT-T divided into the two mental capacity groups based on clinical judgment (full and diminished mental capacity). This result has been published before (Elzakkers et al., 2016), but is presented again for the reader's information. Mean ratings overall were above 50% of the maximum rating values on all subscales, but a significant difference was present with regard to the Appreciation subscale. The group with diminished mental capacity (as assessed by the clinician) had a significantly lower appreciation rating than the group with full mental capacity.

Based on clinical judgment, 46 patients had full mental capacity and 24 diminished mental capacity. Based on the MacCAT-T, 43 patients had full mental capacity and 25 diminished capacity (2 participants were not given the MacCAT-T as they only consented to do part of the questionnaires). This means that both clinicians and the MacCAT-T would judge about one-third of the entire group as having either diminished or absent mental capacity. At first this might suggest excellent agreement between the two measurements. However, when the intersection of the two outcomes for each of the measures is examined (see Table 4), it

Table 3. Ratings on subscales of MacCAT-T for groups with full and diminished mental capacity as assessed by clinical judgment

	Full MC	Diminished MC
Understanding 0-6 mean (SD)	5.8 (0.4)	5.7 (0.5)
Understanding min-max	4.5 - 6	4.6 - 6
Appreciation 0-4 mean (SD)	3.8 (0.4)	3.5* (0.9)
Appreciation min-max	2 - 4	1 - 4
Reasoning 0-8 mean (SD)	7.4 (1.0)	7.1 (1.3)
Reasoning min-max	4 - 8	3 - 8
Choice 0-2 mean (SD)	2.0 (0.3)	1.9 (0.3)
Choice min-max	0 - 2	1 - 2

MC, mental capacity; sd, standard deviation; min, minimum rating; max, maximum rating
* p .03 (ratings on other subscales did not differ significantly)

is apparent that the agreement is not so strong. For 32 participants, clinicians and MacCAT-T assessment agreed on full mental capacity, and they agreed for 12 participants on diminished mental capacity. So in 65% of cases the two measures agreed with each other. But 13 patients who were judged to have full mental capacity by the clinicians were assessed as having diminished mental capacity by the MacCAT-T rating, and of the 23 patients the clinicians judged to have diminished mental capacity, nearly one-half (11 patients) showed good MacCAT-T ratings. Kappa value between clinical judgment and MacCAT-T was .23, suggesting questionable agreement (Landis & Koch, 1977).

The experience of the psychiatrists and medical doctors doing the MacCAT-T semi-structured interview was that it was feasible to administer in clinical practice. The preparation of the interview lasted approximately 10 minutes, the interview itself 15-30 minutes (usually 15-20 minutes). Clinicians did not experience difficulties in training nor in executing the interview. Patients felt that the interview gave them another opportunity to think things over and generally were positive about the interview.

DISCUSSION

In this paper the aim was to examine the agreement between clinicians' judgment and the MacCAT-T in the assessment of mental capacity to consent to treatment in severely ill patients with AN. First, we found that clinicians' judgments and MacCAT-T conclusions identified the same proportion of patients with AN as having adequate capacity (about two-thirds). However, we

Table 4. Agreement between clinical judgment and MacCAT-T on mental capacity assessment

		MacCAT-T		
		Full MC	Diminished MC	N
Clinical judgment	Full MC	32	13	45
	Diminished MC	11	12	23
	N	43	25	68

NB; N = 68 and not 70 as two participants did not do the MacCAT-T
MC, mental capacity

found substantial differences between clinicians' judgments and MacCAT-T conclusions, because often they did not identify the same patients as having adequate mental capacity. Second, we found that, using either method, approximately two-thirds of the 68 participants showed no serious deficiencies on any of the MacCAT-T subscales. The finding that clinicians judged one-third of the patients with AN to have diminished mental capacity was strikingly high. Appreciation ratings on the MacCAT-T differed significantly between those whom clinicians perceive as having full and diminished mental capacity. However in comparison to ratings of appreciation in other psychiatric populations (Vollmann et al., 2003), such as among patients with dementia (appreciation rating 2.4) and schizophrenia (appreciation rating 2.8) this difference is subtle.

The poor agreement between clinicians' judgments and the results of the standardized MacCAT-T conclusions presents clinicians treating patients with AN with a complex problem. Interrater reliability between clinicians in the assessment of mental capacity is known to be low (Kitamura, T., Kitamura, F., 2000; Marson, D.C., McInturff, B., Hawkins, L. Bartolucci, A., Harrell, L.E., 1997; Shah & Mukherjee, 2003; Vellinga, Smit, Van Leeuwen, Van Tilburg, & Jonker, 2004), and mental capacity often is overestimated in daily practice (Lepping, P., Sambhi, R.S., Williams-Jones, K., 2010; P. Lepping, 2011). Thus a standardised instrument to raise the reliability of this assessment could be a valuable contribution to daily practice, especially since this instrument, the MacCAT-T, has shown good interrater reliability in other populations before (Cairns et al., 2005; Grisso et al., 1997).

The MacCAT-T has been criticized in the past, mainly for having too much focus on rationality and cognitive abilities (Breden & Vollmann, 2004; Charland, 1998) and this criticism is voiced loudest regarding patients with AN (Charland, 2007; J. Tan et al., 2006; J. Tan, 2003; J. Tan et al., 2009; Vollmann, 2006). Altered values (so called "*pathological*" values) towards life and death have been shown in currently ill patients with AN as opposed to recovered patients (J. Tan, Hope, Stewart, & Fitzpatrick, 2003; J. O. A. Tan, Hope, & Stewart, 2003) and obviously this

complicates treatment in a profound way. When an outcome that is generally feared by many patients in general (“*you might die*”) does not mean the same for the patient as for the clinician, it becomes very hard to motivate the patient to change life threatening behaviour. Also, Tan et al revealed in their qualitative studies (J. Tan, Hope, Stewart, & Fitzpatrick, 2003; J. O. A. Tan et al., 2003) that AN is often seen as part of the personal identity of the patient, in contrast to many other mental disorders, like anxiety or depressive disorders. In the literature, therefore, doubts exist whether or not the MacCAT-T, even though appreciation is also assessed, can grasp the subtleties in mental capacity issues in AN. In a comment by Grisso and Appelbaum (Grisso & Appelbaum, 2006) regarding this criticism, they remark that values actually are an inherent part of the MacCAT-T when assessing appreciation of the disorder. Also, Grisso and Appelbaum warn against complicating the concept of mental capacity by incorporating the element of “*pathological*” values. In their view sensitivity and reliability of the mental capacity assessment might be compromised and patients’ rights might be diminished by using such a moral concept in the assessment.

The finding that clinicians judged one-third of patients with AN as having diminished mental capacity is remarkable in itself. In no other study into mental capacity do clinicians judge so many patients as having problems with their mental capacity, not even in major depression or schizophrenia, although overestimation of mental capacity is acknowledged. (Lepping, P., Sambhi, R.S., Williams-Jones, K., 2010). But of the 23 participants judged by clinicians as having diminished capacity, only 12 were found to have diminished capacity on the MacCAT-T. Could it be that clinicians underestimate mental capacity in AN? This would be an exceptional finding and contrary to what has been found before in other disorders (Cairns et al., 2005; P. Lepping, 2011; Vellinga et al., 2004; Vollmann et al., 2003) Overestimation of mental capacity by the MacCAT-T would also be contrary to the present literature and therefore not likely. On the other hand, of the 45 participants judged by the clinician to have full mental capacity, 13 had diminished mental capacity according to the ratings on the MacCAT-T. Might the MacCAT-T be more sensitive and reveal a blind spot in the judgment of clinicians?

Data of the current study cannot answer these important questions, but it is clear that use of the MacCAT-T in AN encounters specific issues not seen in other psychiatric disorders. The claim that the MacCAT-T emphasizes cognitive abilities and is less sensitive to values or emotions might be part of the explanation for the difference between the two types of judgment. In AN, emotional dysregulation (difficulty in recognizing and processing emotions) is a well-known maintaining factor (U. N. Danner et al., 2016; Fairburn et al., 2009; Harrison et al., 2010; J. Treasure & Schmidt, 2013; Wildes et al., 2014). Being severely underweight can further compromise this ability of recognizing and processing emotions. Possibly clinicians working with patients with AN let themselves be guided by this knowledge and therefore judge other patients to have diminished mental capacity than when a more “neutral” assessment like the MacCAT-T is done. The clinical judgment was done in an interview lasting for about one hour

where other symptoms and personal circumstances were discussed. In the MacCAT-T interview the topic of discussion was much more focused with less contextual information. In that sense, overestimation of mental capacity problems in the clinical judgment or underestimation of mental capacity problems in the MacCAT-T interview might arise, but this is speculative.

Strengths and limitations

A major strength of this study is the size of the group, which is large for the AN field, and the naturalistic design, excluding no patients on the basis of comorbidity. In this way the generalizability of the results is high. Also the fact that the group consists of severely ill patients is a strength, as particularly in this group mental capacity is a relevant issue.

Limitations include the lack of interrater reliability measurement of the clinical judgment, which was judged not feasible in daily practice, and possibly the way the groups with full and diminished mental capacity were made based on the MacCAT-T scores. The MacCAT-T has no cut off scores, so our classification was indeed artificial. In adapting previously published cut off scores (Owen,G.S., Szmukler,G., Richardson,G., David,A.S., Raymont,V., Freyenhagen,F., Martin,W., Hotopf,M., 2013) an effort was made at least do this systematically. Regarding the higher cut off ratings than in the study by Owen et al (Owen,G.S., Szmukler,G., Richardson,G., David,A.S., Raymont,V., Freyenhagen,F., Martin,W., Hotopf,M., 2013) false positives were regarded as the lesser problem (this being an explorative study) as future studies would be able to specify in a more detailed way what would constitute diminished mental capacity. The rather low kappa value of .23 is lower than reported in the review by Okai et al (kappa value of .45, Okai et al., 2007), which was also not a high kappa value. Possibly the low to medium kappa values could also be explained by a difference in the concepts that are measured. Perhaps the clinical judgment and the MacCAT-T tap on different underlying concepts of mental capacity which might in part explain the lack of good agreement between the two measurements. Although this is speculative, it would fit the unease clinicians had in this particular study when the MacCAT-T ratings were all adequate but their own clinical intuition told them otherwise.

Suggestions for future research

Summarising the results, it can be said that clinicians and MacCAT-T have questionable agreement in the assessment of mental capacity in patients with AN and that MacCAT-T ratings generally are near maximum values. This suggests subtle difficulties in mental capacity problems in patients with AN, and precisely this subtlety might be a complicating element in the assessment of mental capacity in AN. The most important recommendation is for further research to replicate and explore the finding, because these results stem from the first large scale study into mental capacity to consent to treatment in AN. In future studies the interrater reliability of the clinical judgment regarding mental capacity should be determined by asking two different clinicians to judge the mental capacity of the same patient, as this has not yet

been studied in patients with AN. If this reveals a high interrater reliability, then the question would remain which assessment is more valid. If interrater reliability proves low, this would scientifically speak in favor of a larger role for the MacCAT-T in the assessment of mental capacity in AN. As the MacCAT-T specifically has been designed to aid clinicians in their mental capacity judgment, studies using the MacCAT-T in that way (and not as separate assessment) could provide meaningful information. Qualitative studies investigating clinicians' reasons to say mental capacity is diminished might shed more light on the present difference between the two assessments and might be helpful in bridging that gap. Although not a subject of the present study, future studies in patients and their carers from the legal-ethical field could furthermore be informative in the ongoing discussion regarding the presumed dominance of the concept of autonomy in mental capacity assessments and how to incorporate the concept of care ethics in clinical practice. This discussion touches upon the concept of mental capacity and could potentially influence the way mental capacity is assessed in clinical practice.

Conclusion

As for now, we advise the use of the MacCAT-T in the education of clinicians, especially those in the beginning of training, to familiarize them with abilities relevant to mental capacity in general. Also, when grave decisions regarding treatment of patients with AN have to be made, the MacCAT-T might aid the clinician in the assessment of mental capacity. As can be seen in Table 3, in 44 participants full mental capacity was agreed on by clinician and MacCAT-T. In practice, clinicians could do their own assessment and then (especially in complex cases) do the MacCAT-T. When both measures agree, one could be justifiably confident regarding the assessment. If not, more contextual information and advice from colleagues needs to be sought. In the mental capacity assessment itself, premorbid beliefs and wishes of the patient should be discovered by talking to patients themselves, their families and by involving other team members. In this way the assessment will be done more thoroughly and possible distortions of reality, diminishing appreciation of disorder by the patient, will be better revealed than by just speaking to the patient herself.

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CHAPTER 6

A LONGITUDINAL STUDY ON THE RELATION BETWEEN DECISION MAKING AND SYMPTOMS OF DEPRESSION IN WOMEN WITH ANOREXIA NERVOSA

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Isis Elzakkers designed the study and collected the data for this study and has been a member of the supervising team in writing the paper. Lot Sternheim has had a major contribution in discussing the psychological angle in this paper. Daniel MacNeish carried out the advanced statistical analyses. The manuscript was written in cooperation with all authors.

ABSTRACT

Background and aim

People with anorexia nervosa (AN) are inclined to base their decisions on the short term gains (not eating to reduce anxiety) while longer term consequences seem less relevant (eating to improve daily functioning). Emotional problems such as a depressive state may contribute to this maladaptive decision making. In this longitudinal study, three questions are addressed: 1) to what extent is maladaptive decision making associated with depressive symptoms, 2) are depressive symptoms a predictor for decision making, 3) are changes in depressive symptoms related to changes in decision making?

Method

59 patients with AN and 55 healthy control women participated. Measurements consisted of the Iowa Gambling Task (IGT; decision making) and the Beck Depression Inventory (BDI-II; depressive symptoms). Assessments were repeated after 1 and 2 years for the AN group only.

Results

Patients with AN showed less adaptive decision making in comparison to healthy control women, although both groups learned to avoid the disadvantageous decks. Depressive symptoms were related to decision making performance and at baseline were able to predict decision making performance one and two years later. Depressive symptoms decreased considerably over time, while decision making ability did not change. Changes in depressive symptoms were not related to changes in decision making ability.

Conclusion

People with AN in a more depressed state show less adaptive decision making. Improvement of depressive symptoms however does not coincide with more adaptive decision making. Possibly, other affect-related factors (e.g. emotion regulation) are involved that are more stable over time.

Keywords: decision making; anorexia nervosa; depression; Iowa Gambling Task; eating disorders

General Scientific Summaries: This study suggests that decision making ability of women with anorexia nervosa is less adaptive than of healthy women. This is particularly true when women with anorexia nervosa also suffer from comorbid depressive symptoms. Over time, depressive symptoms decrease, but decision making does not become more adaptive.

INTRODUCTION

Anorexia nervosa (AN) is a devastating disorder affecting primarily young women with a lifetime prevalence in European females of 1 to 4% (Keski-Rahkonen & Mustelin, 2016). A large part of people suffering from AN do not fully recover from the disorder and app. 20% will develop a longstanding eating disorder (Keel & Brown, 2010). Although treatment options for adults with AN are advancing, new interventions are still needed to improve outcome (Zipfel, Giel, Bulik, Hay, & Schmidt, 2015) and it is therefore important to learn about factors affecting the course of the eating disorder. One factor that has been studied rather intensively in the last decade, is the decision making ability of people with AN (e.g., Danner et al., 2016; Danner et al., 2012; Galimberti et al., 2012; Tchanturia et al., 2007). Remarkably, people with AN are often reluctant to engage in treatment despite severe somatic and psychological problems. Their decisions seem to be based on the expected short term outcome (not eating to avoid weight gain or reduce anxious feelings), while longer term consequences seem to be less relevant (improvement of health or functional outcome). In other words, people with AN are inclined to show maladaptive decision making. Decision making is profoundly guided by emotional states (Naqvi, Shiv, & Bechara, 2006) and people with AN are often troubled by severe emotional states such as high levels of depression (Puccio, Fuller-Tyszkiewicz, Ong, & Krug, 2016). The aim of the present study is to examine the relationship of depressive symptoms with decision making ability in people with AN using a longitudinal design.

Emotions and decision making

Decision making that involves a certain degree of complexity and uncertainty is heavily influenced by emotions (Naqvi et al., 2006). This involves both emotions that are part of the decision making context (integral emotions) as well as emotions that are not directly related to the decision making situation at hand (incidental emotions such as mood states) (Andrade & Ariely, 2009). In this type of decision making, people will have to rely on their intuition, because information in these complex situations cannot be processed in a rational and slow fashion since our working memory capacity is limited (Remmers & Michalak, 2016). Adaptive decision making entails that people will rely on their intuition that consists of feelings or bodily signals, also referred to as somatic markers (Damasio, 1996) resulting from the decision making process when receiving evaluative feedback (e.g., reward vs. punishment). This will bias their decision making in an adaptive direction. However, when there are disturbances in the affective system, it will be difficult to rely on these bodily feelings and the decision making process will likely be hampered.

Decision making in anorexia nervosa

Most studies report decision making problems in people currently in treatment for AN (Brogan, Hevey, & Pignatti, 2010; Danner et al., 2012; Matsumoto et al., 2015; Tchanturia et al., 2007). Two

longitudinal studies reported decision making ability to be stable over time (Bodell et al., 2014; Cavedini et al., 2006) and it is therefore plausible that decision making problems represent a trait like phenomenon. These findings also suggest that decision making ability does not become more adaptive as a result of (successful) treatment. Instead, patients displaying maladaptive decision making at admission may benefit less from treatment because they are unable to make decisions in line with their longer term goals (improving health and quality of life). In a first study, decision making ability as measured with the Iowa Gambling Task (IGT; Bechara, Damasio, Damasio, & Anderson, 1994) was found to predict the course of symptoms as expressed in body mass index (BMI; Cavedini et al., 2006). Those with poor performance had a lower BMI at the end of treatment than good performers. The authors argued that poor performers might have been less able to profit from treatment which is reflected in a lack of weight restoration. Although impaired decision making ability is thus suggested to have a negative effect on progress and outcome of therapeutic interventions, except for the study by Cavedini and colleagues (2006) hardly any longitudinal studies have been done in AN.

Emotional states and anorexia nervosa

It is well known that people with AN to suffer from affective disturbances (Oldershaw, Lavender, Sallis, Stahl, & Schmidt, 2015). On a neurobiological level studies revealed altered reward processing and interoceptive dysfunction (e.g., Kaye, Fudge, & Paulus, 2009; Keating, Tilbrook, Rossell, Enticott, & Fitzgerald, 2012) and on a psychological level, this was confirmed by showing difficulties in emotion recognition and regulation (Danner, Sternheim, & Evers, 2014; Harrison, Sullivan, Tchanturia, & Treasure, 2009; Speranza, Loas, Wallier, & Corcos, 2007). Direct confirmation of difficulties using bodily signals to make adaptive decision stems from a study by Tchanturia and colleagues (2007) in which patients with AN showed impaired decision making ability also displayed reduced anticipatory skin conductance responses to all choices as measured with the IGT. The authors reasoned that this may be the result of enhanced levels of depression.

In addition to difficulties with integral emotions, people with AN often experience high levels of negative emotional states such as high depression levels. This is also considered to impact the decision making process (Peters, Västfjäll, Gärling, & Slovic, 2006). For example, in a study among people with different psychiatric disorders, affective instability was directly related to decision making outcomes (Jollant et al., 2007). Raghunathan and Pham (1999) tested the effect of a sadness induction on decision making in a student sample and found that sadness biased preferences towards high-risk/high-reward options. They argued that sadness is thought to trigger the goal of reward seeking. The choice people make will be guided by their intuition telling them which option they will feel better about and sadness will bias one's preference for high reward options independent of the degree of risk involved. The outcome of the decision is therefore used as a way to regulate negative emotions by focusing on the short-term gains. This idea was confirmed by Heilman et al (2010) showing that the use of more

functional emotion regulation strategies resulted in more adaptive decision making with the IGT than the use of less functional strategies. A similar mechanism may also be true for people with AN. Indeed, two experimental studies revealed that inducing sadness resulted in an increase in eating disorder symptoms and a heightened desire to engage in dietary restriction (Naumann, Tuschen-Caffier, Voderholzer, & Svaldi, 2014; Wildes, Marcus, Bright, Dapelo, & Psychol, 2012). So a depressive state may hinder the reliance on intuition contributing to maladaptive decision making (Remmers & Michalak, 2016).

People with AN are thus inclined to show maladaptive decision making, but this may be strengthened in a depressive state. Indeed, two cross-sectional studies showed decision making ability to be worse in those patients with AN reporting more depressive symptoms (Matsumoto et al., 2015; Tchanturia et al., 2007). However, other studies reported a lack of correlation between level of depression and decision making performance (e.g. Abbate-Daga et al., 2011; Garrido & Subira, 2013). The role of depression is much debated in the literature on decision making ability in AN (Danner et al., 2016). For example, two studies reporting no decision making problems in people with AN (Guillaume et al., 2010; Jollant et al., 2007) used exclusion criteria related to emotional problems that potentially may account for their lack of findings: Guillaume et al. (2010) only included patients without comorbid depression and medication and Jollant et al. (2007) included only AN patients who were normothymic (referring to a relative normal emotional state). Because mood disorders are among the most frequent observed co-morbid disorders in AN (up to 54% had a current mood episode, Godart et al., 2007, and up to 75% had a lifetime mood disorder, Zipfel et al., 2015), it is important to learn more about the relationship of depressive symptoms with decision making ability. If decision making is directly influenced by level of depression, one may expect decision making to become more adaptive when the severity of the depressive symptoms is lower. It is as yet unknown whether level of depression is able to predict the course of decision making performance.

The objectives of present study are to test in AN:

1. whether symptoms of depression and decision making performance are related
2. whether symptoms of depression are able to predict decision making performance
3. whether changes in symptoms of depressions are associated to changes in decision making performance

METHOD

To examine the objectives, a naturalistic cohort was used that was part of a larger project into decision making capacity regarding treatment of patients with AN (Elzackers et al., 2016; Elzackers, Danner, Hoek, & van Elburg, 2016). The cohort consisted of 70 patients with AN of whom 59 completed the IGT and a measure of depressive symptoms. After one and two years the measurements were repeated with resp. 52 and 47 patients. Three steps were taken to test

whether symptoms of depression are able to predict decision making outcomes in AN. In step 1 we tested whether decision making performance was impaired in patients with AN compared to a control group without a history of psychiatric illnesses and to what extent this was related to level of depression. In addition we tested whether level of depression and decision making performance were similarly related at baseline, at follow-up 1 (one year later) and at follow-up 2 (two years later). In step 2, it was tested whether level of depression at baseline is able to predict decision making outcomes at follow-up 1 and at follow-up 2. Finally, step 3 tested whether *changes* in depressive symptoms are able to predict changes in decision making performance over time.

Participants

59 people with AN and 55 women without a history of psychiatric disorders participated in the study. All people with AN were recently seen in our national specialized center for eating disorders, Altrecht Eating Disorders Rintveld, in The Netherlands for eating disorder assessment and treatment. Only those participants were included in this study who carried out the IGT (59 of 70 patients included in the larger study). Reasons for not doing the IGT as part of the larger study: refusal to do the task, unable to continue the assessment because of their illness or due to technical problems. The AN diagnosis was determined according to DSM-5 criteria (American Psychiatric Association, 2013, 2013) as established by eating disorder experts (psychologists and psychiatrists with extensive experience in the treatment of patients with AN) and verified using (questions from) the Eating Disorders Examination (Cooper & Fairburn, 1987). Of the 59 patients with AN, 33 met criteria of the restrictive subtype and 26 met criteria of the binge-purge subtype. Their average BMI was in the severe range, the age of onset was 18 years and their mean duration of illness was app. 8.5 years, see also Table 1.

Control participants were age-matched to the patient group and were screened using the Mini International Neuropsychiatric Interview (MINI), an abbreviated psychiatric structured interview (see also van Vliet & de Beurs, 2007) to preclude any psychiatric disorder (such as affective disorders) current or lifetime, and in particular all eating disorders. No control participants were excluded from the analyses.

Ethical and scientific approval was obtained from the Medical Ethical Committee of the University Medical Center Utrecht, protocol number 11-061/C, and from the institutional review board (CWO) of Altrecht Mental Health Institute, number oz-1117.

Procedure and Instruments

Patients were approached to take part in the study upon assessment (i.e., once their ED diagnosis was determined). After written informed consent was obtained, a measurement appointment was scheduled. One year after inclusion, patients were contacted by phone to ask for their participation in the follow-up measurement. In the informed consent at baseline the follow-up measurements were already mentioned and agreed to. Patients were (in addition to other

Table 1. Mean (and SD) of demographic (age) and clinical characteristics (BMI, age of onset, illness duration, eating pathology (EDEQ), depression (BDI-II)) between groups (anorexia nervosa vs. healthy control)

	Anorexia nervosa (n=59)		Healthy control (n=55)		F	p	η_p^2
	Mean	SD	Mean	SD			
Age	27.15	9.96	24.47	8.31	2.41	.12	
BMI (AN n=58)	15.38	1.94	21.74	2.81	191.97	<.001	.64
Age onset	18.02	4.96	na	na			
Illness duration	8.45	8.11	na	na			
EDEQ (AN n=36)	3.72	1.37	0.95	0.78	151.17	<.001	.63
BDI	29.69	14.41	2.60	3.31	185.14	<.001	.62

Note. BMI = body mass index, EDEQ = eating disorders examination questionnaire, BDI-II= Beck depression inventory.

measures, see Elzakkers et al., 2016) asked to repeat the IGT and the depression inventory. Control participants were recruited through advertisement and at Utrecht University. After written informed consent was obtained, the MINI interview was done by phone followed by a measurement appointment. No follow-up measurements were done for the control group.

Decision making ability

To measure decision making ability, the Iowa Gambling Task (IGT; Bechara et al., 1994) was used. The purpose of the IGT is to test participants' ability to resist immediate gains in favor of a longer-term positive outcome (Bechara, Damasio, Tranel, & Damasio, 2005). The task is suggested to capture the inability of people to make adaptive decisions when presented with complex choices (Tchanturia et al., 2007). Participants are asked to choose between four decks of cards and with each choice they can win or lose money. The goal of the task is to win as much money as possible. Each time a card is chosen (100 trials in total), participants win money but on some trials they lose money simultaneously resulting in a net loss. Two decks (A and B) have high gains (100 per trial) but also high losses (-1250 per 10 trials) resulting in a net loss of -250 per 10 trials, these are the disadvantageous decks. Two other decks (C and D) have smaller gains (50 per trial) but also smaller losses (-250 per 10 trials) resulting in a net gain of 250 per 10 trials, these are the advantageous decks. The difference between the two disadvantageous and between the two advantageous decks is the frequency and magnitude of the losses (more frequent but smaller losses in decks A and C, and less frequent but higher losses in decks B and D). Decision making performance is determined by subtracting the number

of cards selected from the disadvantageous decks from the number of cards selected from the advantageous decks: $[(C+D)-(A+B)]$. This is done for the total number of choices resulting in a total IGT score, as well as per block of 20 trials (block 1 to 5) to determine if participants are able to learn to avoid the disadvantageous decks during the task, also referred to as the IGT learning effect or IGT growth trajectory.

Symptoms of depression

Severity of depression symptoms was measured with the Beck Depression Inventory (BDI-II; Beck, Steer, Ball, & Ranieri, 1996) that contains 21 questions, each answer being scored on a scale value of 0 to 3 with higher scores indicating more severe symptoms. Scores can be categorized into the following categories: 0–13: minimal depression, 14–19: mild depression, 20–28: moderate depression, and 29–63: severe depression. Cronbach's alpha in this study was high, .97.

Clinical parameters

Body mass index (BMI) was determined by measuring participants' height and weight using a Tanita body composition analyzer TBF-300 (Tanita Corporation, Tokyo, Japan). The age of onset of the AN and the duration of illness was extracted from the electronic patient files.

Anxiety and alexithymia

To be able to control for anxiety and alexithymia in the analyses, outcomes on the State Trait Anxiety Inventory – state subscale (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) and the Toronto Alexithymia Scale (Bagby, Taylor, & Parker, 1994) were used (see Method section Statistical Analysis),

Statistical Analysis

Analysis of the Iowa Gambling Task

To model changes within blocks of the IGT (i.e., the IGT learning effect) and across administrations of the IGT at baseline, follow-up 1, and follow-up 2, a multiple-group latent basis growth curve model was used. Latent basis growth curve models (Grimm, Ram, & Hamagami, 2011; McArdle & Epstein, 1987; Wu & Lang, 2016) are an extension of the standard latent growth curve model. In the present analyses, we fixed the loading of the first IGT block to 0 and the loading of the fifth IGT block to 1 such that the mean of the growth factor corresponds to the overall amount of growth from Block 1 to Block 5 and the loadings (which are estimated and not fixed in latent basis models) correspond to the percentage of growth that has occurred up to and including the time-point of interest.

Estimation and Software

All models were estimated in *Mplus* version 7.4 using robust full information maximum likelihood which can account for data that are missing at random and that may feature moderate deviations for multivariate normality (Enders & Bandalos, 2001; Raykov, 2005; Yuan & Bentler, 2000). Although the sample size was not overwhelmingly large, McNeish (2016)

showed that maximum likelihood estimation is reasonable with latent basis models with 50 or more individuals. All models used a heterogeneous diagonal residual error structure (i.e., all time-points have a unique error variance estimate but there are no error covariances) and an unstructured growth factor covariance matrix (i.e., the intercept and slope factor have person level variance and these factors are covary).

With robust full information maximum likelihood, chi-square difference tests cannot be computed with simple subtraction because the difference is not sufficiently chi-squared distributed (Asparouhov & Muthen, 2006). We used the method outlined by Satorra and Bentler (2010) and Bryant and Satorra (2012) to compute chi-square difference tests, which is also recommended by the *Mplus* User's Guide (Muthén & Muthén, 2012). In the results section, we also reported the RMSEA and CFI as measures of data-model fit. As output by *Mplus*, the default null model was not nested within a latent growth model (Wu, West, & Taylor, 2009); therefore, we used an alternative null model suggested by Widaman and Thompson (2003) to compute the CFI. Specific methods for each step of the study are discussed in detail next.

Step 1. *Are symptoms of depression and decision making performance related?*

In Step 1, we were first interested in comparing the IGT growth between the control group and the AN group at baseline. Using a multiple group model, a latent basis growth curve model was fit to each group separately and then the fit of the model was inspected. Then, the slope loadings were constrained to be equal between groups to test whether the growth trajectories were equal within each group (via a chi-square difference test). The next step was to test the intercept and slope of the curve between the two groups to determine if the groups' IGT performance was similar at Block 1 (the intercept) and if the growth was similar throughout the IGT. Depression scores were added as predictor of the intercept and slopes values (anxiety and alexithymia scores were included as auxiliary variables to help address the missing at random assumption of FIML; Collins, Schafer, & Kam, 2001). Both linear and quadratic forms of each predictor were considered.

We then proceeded to test the effect of depression on IGT growth in the AN group at follow-up 1 and at follow-up 2 to test whether the effect is approximately equal at each time-point. The control group was only assessed at baseline, so the effect of depression scores on IGT growth was for the control group only possible at baseline. Because it is unlikely that participants will receive a score of 0 on predictor variables, all predictors were grand-mean centered to obtain more substantively interpretable parameter estimates.

Step 2. *Are symptoms of depression at baseline able to predict decision making performance at follow-up 1 and at follow-up 2?*

Step 2 only addresses the AN group who were followed at two additional time-points (follow-up 1, follow-up 2). This creates two possible sources of growth: Between time-point growth (from baseline to follow-up 2) and within time-point growth (IGT Block 1 to Block 5). We first

tested whether the growth trajectories of Block 1 through Block 5 of the IGT were the same across all three time-points, again with a multiple group latent basis model. Then, we tested whether the starting point and total growth was equal across all three time-points to assess whether there is any between time-point differences in the IGT. Depression scores at baseline were used to predict intercept values and total growth at each of the three time-points (with the same controls as Step 1). Similar to Step 1, the predictors were grand-mean centered and different functional forms for the predictors were also tested.

Step 3. *Are changes in symptoms of depression related to changes in decision making performance over time?*

1. Change in decision making performance over time
2. Change in depression symptoms over time
3. Whether depression scores are a significant time-varying covariate of IGT total scores.

As will be shown in the Step 2 results, there was only growth within each time-point (i.e., from Block 1 to Block 5 during the IGT), but not between time-points (IGT performance was stagnant from baseline to follow-up 2), the growth between time-points was essentially zero and there was no variance that can be explained by depression scores. Therefore it was not possible to directly test whether changes in depression scores lead to changes in IGT growth during the task using the five IGT blocks. To overcome this issue, a final analysis was conducted using the IGT total scores at baseline, follow-up 1 and follow-up 2 (which did show some change over time) rather than the growth from Block 1 to Block 5 within each time-point. Directly assessing how depression scores at each time-point predict the growth in total IGT scores would be questionable statistically because, for example, depression scores at follow-up 2 would be predicting the change in IGT scores from baseline to follow-up 1. Instead, depression was treated as a time-varying covariate of total IGT scores which allowed us to test (a) if depression scores affect IGT scores at particular time-points and (b) if those effects are the same across time. Time-varying depression scores were mean centered within time-points and were lagged to account for the fact that depression scores themselves also change over time (e.g., Cole & Maxwell, 2003; Maxwell & Cole, 2007; this will be discussed further in the results section).

RESULTS

Step 1: *Are symptoms of depression related to decision making performance at baseline? Are there differences between patients with anorexia and control participants?*

The first step was to test if the growth trajectories (or IGT learning curves) are similar between the two groups. We freely estimated the curves for each group and then constrained the parameters between groups to test whether the shape of the groups' trajectories is approximately equal (but not whether the groups start at the same point or grow by the same

amount). The fit of each model is shown in Table 2. Both models fitted well in an absolute sense and the shape of the IGT learning curve was approximately equal between the groups (note – this does not mean the trajectories were exactly equal, only that they have the same general shape but could be shifted or stretched along the axes).

Table 2. Model fit of the IGT learning curves between groups (anorexia nervosa versus healthy control) using freely estimated and constrained parameters

Model	χ^2	df	p	RMSEA	CFI
Groups Freely Estimated	18.45	18	0.426	0.021	0.996
Groups Constrained	21.19	21	0.447	0.012	0.998
Satorra-Bentler Difference	2.68	3	0.444		

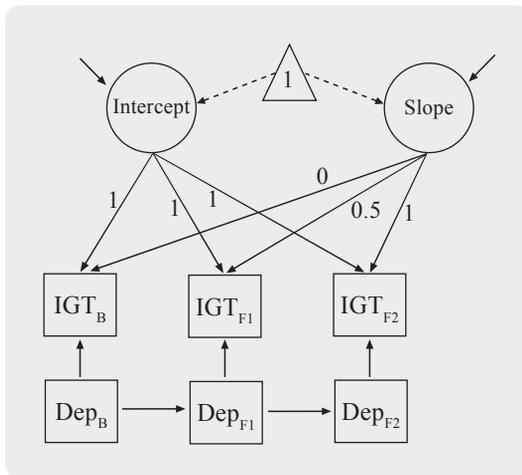
Note: The Satorra-Bentler difference is not equal to the simple difference between the two models.

The average change from Block 1 to 5 in the AN group was 7.56 points ($Z=5.24$, $p<.001$) and the average change from Block 1 to 5 in the control group was 13.86 points ($Z = 8.78$, $p<.001$). The difference between the groups was statistically significant ($Z=6.31$, $p=.003$). The difference in the intercepts (-2.82 for the control group, -5.14 for the AN group) was only marginally significant ($Z=1.80$, $p=.07$). Based on 50:50 mixture chi-square tests that are recommended to test growth factor variances in random effects models (Savalei & Kolenikov, 2008; Stram & Lee, 1994; Verbeke & Molenberghs, 2003), there was significant variation between how much people grew in each group but not significant variation in the intercepts in either group meaning that people within a group started at roughly the same value (which makes theoretical sense because Block 1 responses are essential random guesses so there is little reason why people would systematically vary). Figure 1 shows the estimated IGT learning curves of the AN and control group.

Next, level of depression at baseline was added as a predictor to the model. Results showed that depressive symptoms did have significant effects on the IGT growth, but only for the AN group and not for the control group: fewer depression symptoms were predicted to increase IGT growth ($B=-0.18$, $Z=-2.36$, $p=.018$, $\beta=-0.34$). The difference in the total growth between the AN and control groups from Block 1 to 5 was still significant, ($Z = 3.02$, $p=.003$), even after controlling for depressive symptoms. The final model with depression continued to fit well, $\chi^2(43)=43.57$, $p=0.45$, $RMSEA=0.015$, $CFI=0.996$.

The effect of depression scores on IGT performance was also assessed at follow-up 1 and follow-up 2, testing whether the effect was consistent across time-points. Since only data were collected data on the AN group at these follow-up time-points, no comparison could

Figure 1. Path diagram for time-varying covariate model in Step 3. B= Baseline, F1 = Follow-up 1, F2 = Follow-up 2. Error variances are not shown for simplicity but were constrained to be equivalent across all time-points because a model with constrained error variances did not fit significantly worse than a model with unconstrained error variances. Similarly, the stability paths between the depression scores were constrained to be equal. A path was included from Dep_B to Dep_{F2} but it was not significant and therefore it was removed. The growth factor covariance was tested but was not significant and was therefore removed. A latent basis model where the slope loading at follow-up was freely estimated was also fit, but the estimated loading was 0.53 which was sufficiently close to 0.50 to warrant constraining the growth to linear.



be done with the control group across time-points. Depression scores assessed at follow-up 1 were not a significant predictor of growth in IGT scores at follow-up 1 ($B = 0.03$, $Z = -0.23$, $p = .82$, $\beta = -0.06$). Depression scores at follow-up 2 were a significant predictor of growth in IGT scores at follow-up 2 such that lower depression scores predicted larger amounts of growth. ($B = -0.41$, $Z = -2.22$, $p = .027$, $\beta = -0.81$).

Taken together, patients with AN displayed less adaptive decision making than control participants, albeit that both groups learned to avoid the disadvantageous card decks during the IGT. More depressive symptoms were related to worse decision making performance, but only for women with AN. This was found at baseline and follow-up 2 (so not at follow-up 1), and the effect of depression scores on IGT performance during the task was about equal at each of these time-point.

Step 2: *Are symptoms of depression at assessment related to changes in decision making outcome over time as measured after 1 and 2 years?*

This research question was first addressed by examining the three time points (baseline, follow up 1, follow up 2) with a multiple group model with all parameters unconstrained across group.

Because this step only featured patients with AN, BMI was considered as a relevant control variable. Analyses were run both controlling for BMI and without controlling for BMI. Parameter estimates and inferential conclusions did not change either way and the results without BMI are therefore reported. A multigroup latent basis model without any constraints fitted the data well: $\chi^2(25)=31.36$, $p=0.18$, RMSEA=0.070, CFI=0.959. The RMSEA is a little high when compared to the standard Hu and Bentler (1999) cut-offs, but with a modest sample size, the chi-square test is a more meaningful assessment of data-model fit compared to RMSEA (Kenny, Kaniskan, & McCoach, 2014).

The time-point trajectories were not significantly different from each other $\Delta\chi^2_{SB}(6)=6.34$, $p=.39$ which indicates that the shape of the IGT growth is roughly equal in each of the three time-points. The intercepts and total growth estimates were not significantly different across time-points, $\Delta\chi^2_{SB}(4)=4.58$, $p=.33$, which means that the IGT scores started at about the same value and grew by about the same amount at baseline, follow-up 1, and follow-up 2. The average IGT growth from Block 1 to 5 was 8.63 points, ($Z=8.03$, $p<.001$).

Similar to Step 1, baseline depression scores were included as a predictor as were the aforementioned control variables. Baseline depression was not a significant predictor of intercept values at any time-point, so it was removed as predictor of the intercept at each time-point. Baseline levels of depression predicted the growth in IGT scores at follow-up 1 ($B=-0.30$, $Z=-3.96$, $p<.001$, $\beta=-0.71$), and at follow-up 2 ($B=-0.21$, $Z=-2.07$, $p=.038$, $\beta=-0.35$) such that decreases in depression scores at baseline predicted increases in overall IGT growth. The final model fitted well, $\chi^2(83)=88.91$, $p=0.31$, RMSEA=0.037, CFI=0.973.

To sum up, symptoms of depression at baseline predicted IGT performance one year later and two years later. *Fewer* depression symptoms predicted *more* IGT growth during the task and thus better decision making performance.

Step 3: *Are changes in symptoms of depression related to changes in decision making outcome over time as measured after 1 and 2 years?*

First, changes in the marginal means in both depression levels and IGT scores over time were tested, see Table 2. Descriptive marginal means and standard deviations for both measures are provided in Table 3. To test these means inferentially, we ran separate repeated measures ANOVAs using Proc Mixed in SAS 9.3 with Satterthwaite degrees of freedom. Using restricted maximum likelihood instead of least squares allowed the error variances to be uniquely estimated at each time point, as may be necessary based on the descriptive standard deviations.

The repeated measures ANOVA indicated that depression scores changed significantly over time, $F(2,121)=10.30$, $p<.001$. Marginal means from baseline to follow-up 1 changed significantly, $t(108)=-2.90$, $p<.001$, as did scores from baseline to follow-up 2, $t(95.2)=4.33$, $p<.001$, but changes from follow-up 1 to follow-up 2 were not significant, $t(98.9)=1.37$, $p=.17$. These results showed that the marginal (i.e., unconditional) means of depression scores change significantly over time.

Table 3. Mean (and SD) of depression (BDI-II) and decision making (IGT total score) at each timepoint: baseline, one year later (follow-up 1) and two years later (follow-up 2)

	Baseline		Follow-up 1		Follow-up 2	
	Mean	SD	Mean	SD	Mean	SD
Depression	29.87	13.80	22.15	15.31	18.00	15.12
IGT	14.68	31.59	21.65	32.96	26.26	34.74

Note. BDI-II= Beck depression inventory, IGT = Iowa Gambling Task.

A final analysis was done using the IGT total scores at baseline, follow-up1 and follow-up 2. We modeled the growth in IGT total scores over time and included depression scores as a time-varying covariate. To account for the growth in the time-varying covariate, one-lag stability paths were included between the depression predictors. A path diagram for the model is shown in Figure 2. Parameter estimates, standardized coefficients, and model fit are shown in Table 4. As noted previously, the sample size in this study is rather modest, so it may be more useful to inspect effect sizes rather than inferential tests (which may be underpowered, especially for time-varying effects). Based on general recommendations for effect size magnitudes in Cohen (2013) and Keith (2014), the standardized coefficients at baseline and follow-up 2 would be borderline small effects (the lower bound magnitude for

Figure 2. Decision making performance on the Iowa Gambling Task (IGT) as the mean number of cards chosen from the advantageous decks (C+D) minus the mean number of cards chosen from the disadvantageous decks (A + B) per block of 20 trials per group: anorexia nervosa (AN) and control women

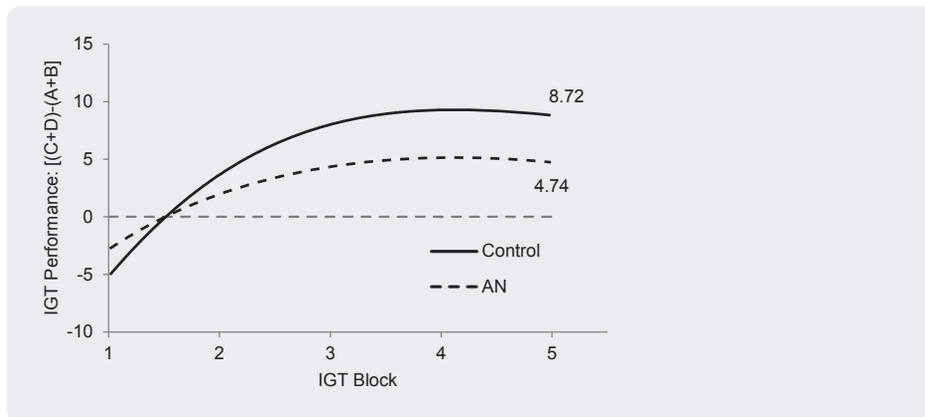


Table 4. Parameter estimates for the model with depression as a time-varying effect

Parameter	B	β
Intercept	14.50	---
Slope	11.38	---
Depression, Baseline	-0.20	-0.08
Depression, Follow-Up 1	-0.44	-0.21
Depression, Follow-Up 2	-0.18	-0.09
Model Fit		
$\chi^2(13)$		8.86
χ^2 p-value		0.78
RMSEA		0.00
CFI		1.00

Note: the slope effect is significant at the .05 level. None of the depression effects are significant at the .05 level.

a small effect is generally between .05 and .10) while the standardized coefficient at follow-up 1 would suggest a small, but noticeable effect (the lower bound magnitude for a medium effect is generally between .25 and .30).

The results for Step 3 showed that level of depression decreased substantially over time (in particular between baseline and follow-up 1) and decision making performance as determined with the total IGT score improved over time. Depression scores showed small, but non-significant, relations with changes in IGT performance on each of the time points.

DISCUSSION

The purpose of this study was to examine the association between level of depression and decision making ability in people with AN. The study included severely ill patients upon clinical assessment at our national specialized center for eating disorders with average depression levels within the severe range. Decision making and levels of depression were compared at baseline assessment to a control group and results showed decision making of patients with AN to be less adaptive. At the same time patients did learn to avoid the disadvantageous decks during the task suggesting that decision making of the patients with AN in this study was not as maladaptive as some of the previous studies on this topic (e.g., Matsumoto et al., 2015; Tchanturia et al., 2007). Patients, but not control participants, with more depressive symptoms displayed worse decision making than those with a less severe level of depression.

Our results further show that decision making performance of patients with AN was stable over time (comparable to Bodell et al., 2014; Cavedini et al., 2006), whilst depression level decreased on average significantly from “severe” at baseline, to “moderate” one year later and “mild” two years later. More importantly, those patients reporting more symptoms of depression at baseline assessment were less able to learn to avoid the disadvantageous decks and thus displayed less adaptive decision making at follow-up. Finally, we were interested to learn whether changes in depressive symptoms would be associated with changes in decision making performance. Our results did not support this idea. Level of depression decreased considerably in a year time (from a severe to a moderate level), while decision making outcome did not change much. The lack of a statistical significant finding may be attributable to the modest sample size (a general issue that effects of time-varying covariates tend to need larger samples to attain similar levels of power as time-invariant covariates; e.g., Muthén & Curran, 1997). Nonetheless, when comparing the effect size measures of depressive symptoms on IGT growth during the task (i.e., IGT learning effects) to the effect size measures of depressive symptoms on total IGT scores between time-points (baseline, follow-up 1 and follow-up 2), it is rather clear that depressive symptoms have a much greater effect on IGT growth *during* the task than IGT scores *between* time-points.

An alternative explanation may be that other factors underlie depressive symptoms and maladaptive decision making in AN, in particular when these factors are less likely to change over time (i.e., reflect more trait-like characteristics). It is for example possible that a reduced ability to learn from affective feedback (Frank, 2013; Kaye et al., 2009) or the tendency to use more dysfunctional emotion regulation strategies (Harrison et al., 2009; Heilman et al., 2010; Racine et al., 2016) are important determinants of maladaptive decision making. For example, people with AN are inclined to suppress their emotions and this tendency is stronger in those reporting more depressive symptoms (Danner et al., 2014). The negative affect that these people experience may increase physiological noise which hinders somatic markers (Heilman et al., 2010), i.e. people are less able to rely on these markers or gut feelings and therefore make less adaptive decisions. An important reason why people in a depressed state may be more inclined to make maladaptive decisions is that they are less able to rely on their intuition to guide their decision making. It is possible that they are less likely to trust their intuition and therefore ignore it (Leykin & DeRubeis, 2010), but it may also be that the depressive symptoms interfere with one’s ability to process information as these people may appraise the affective feedback differently than non-depressed people (Raghunathan & Pham, 1999). Studies indeed confirmed people with mood disorders to show altered reward processing and this may result in assigning different values to the available options during the IGT (Paulus, 2007). Level of depression may improve during treatment, but emotion regulation may not necessarily become more functional. Future research may want to examine how different affect related concepts may influence decision making performance in AN and whether changes in these concepts does influence decision making outcome over time.

In addition, people with AN irrespective of their level of depression may have an insensitivity to somatic signals because of their low weight which may also complicate reliance on their gut feelings (Tchanturia et al., 2007). Although results of the present study do not support this idea directly as controlling for BMI did not change the results, it is possible that having a low weight and at the same time suffering from comorbid depressive symptoms (as the majority of people with AN do), may cause people with AN to suffer from double jeopardy to make maladaptive decisions. These people may benefit from a therapy that addresses emotional problems in addition to their eating pathology (e.g. Cognitive Behavioral Therapy – Enhanced (CBT-E), or Maudsley model of Anorexia Nervosa Treatment for Adults (MANTRA), see Zipfel et al., 2015) and also from a cognitive training such as Cognitive Remediation Therapy (CRT; Danner, Dingemans, & Steinglass, 2015) as decision making problems entails cognitive as well as affective difficulties. This will be a first step, since we do not yet know which specific factors underlie maladaptive decision making that should be targeted in treatment to ensure more adaptive decision making,

There are a few limitations worth mentioning. The sample size in this study was quite small to test research questions as complex as ours (“are changes in symptoms of depression associated to changes in decision making performance?”). On the other hand, many studies on AN use smaller sample sizes and in fact, we included a rather large cohort. Nevertheless, future studies may want to strive for a larger study population. A second limitation might be that mood disorders (as a category) were not taken into account. The present study focused on the extent to which participants experienced depressive symptoms (as a dimensional factor) as this is the rule rather than the exception for people with AN. The average level of depression at baseline assessment was in the severe range as determined with the BDI-II, which is a well-validated and clinically often used instrument to determine level of depression, but at the same time the variation within the group was large. Since our sample size was already small, we decided to test the more subtle relationship between depressive symptoms and decision making performance as this may be more sensitive than examining diagnostic categories.

To conclude, decision making of people with AN is less adaptive when they experience more depressive symptoms in that they are more inclined to rely on the immediate gains (not eating to reduce anxiety) irrespective of the longer-term negative consequences (eating to improve the quality of their daily life). Although depressive symptoms improve as a result of treatment, decision making does not automatically become more adaptive. It is important to consider the role of other emotional problems when studying decision making in anorexia nervosa.

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CHAPTER 7

GENERAL DISCUSSION



THE CASE OF JANE – CONTINUED

After discussing her grave situation with her and her parents, Jane decided not to go forth with inpatient treatment as was advised. We kept in touch with her as an outpatient and one year later, with a BMI of 13.3 and severely weakened, she asked for inpatient treatment. In the meantime we had discussed her wishes for her future and by now she felt that she needed to put on some more weight to achieve her goal (work) however frightening this appeared. She even understood the possible need in the future for legal measures would she (again) decide to leave treatment. She conceded that sometimes her illness would take over her thoughts so much that she was not able to decide for herself and her trust in the treatment team by now had grown. Although she tries hard, and cooperates well with the staff of the inpatient unit, she is too anxious to eat the recommended quantity of food. A legal measure is asked for and just the idea of this measure enables Jane to push through as she does not want to be forced to eat. The working alliance remains good during this difficult time and no forced feeding is needed. With our help she starts working as a volunteer in a restaurant and she moves out of her parents house to sheltered living. Her parents ask for help in their process of having a severely ill daughter, this relaxes the relationship between Jane and her parents somewhat. In the years that follow Jane is able to manage her disease, sometimes asking for a short period of inpatient treatment when her dietary restrictions run out of control. Her BMI is just over 15. She succeeds in living apart from her parents in the sheltered home and expands her work. She engages in a training to think more flexible (Cognitive Remediation Therapy) and receives (off label) antipsychotic medication with the same goal, both have a positive effect on her cognitive flexibility and she decides that she wants to put the anorexia nervosa behind her. She engages in treatment in a unit in our center with higher goals (and more pressure) and profits from this approach now (unlike at the start of her illness). The legal measure is reinstated every year and to Jane this is a motivation to keep things into her own hands (a minimum weight limit is set together with her below which admission is required). At the age of 25 she has a paid job, has a partner, has resumed her hobby (dancing) and her BMI is around 19. Her legal measure has been stopped. She still has disabling anorectic thoughts and tends to be obsessive compulsive in daily life, but cognitive behaviour therapy nor medication have relieved this tendency. At the age of 26 she decides to stop treatment in our center and engages in further treatment elsewhere. One year later she reports that she is feeling better and more relaxed and says she can finally say she has recovered from her anorexia nervosa after 10 years.

The project presented in this thesis originated in the bewilderment how it could be that despite such severe and possibly lethal consequences, patients with AN regularly decide against treatment in which weight restoration or improvement plays a role. Designing this scientific project proved to be a challenge, as hardly any previous studies regarding the mental capacity to consent to treatment in AN existed. We therefore realised that a first step would be to explore this complex and clinically relevant issue. As our goal was to provide clinicians with scientific data to aid them in the complex task to assess mental capacity in patients with AN we focused on clinically relevant themes such as prevalence and associated factors of diminished mental capacity in AN. The results of this study have been presented in Chapters 3, 4, 5 and 6 of this thesis. As mentioned in the Introduction the discussion regarding mental capacity to consent to treatment in AN is intimately intertwined with the discussion on the effectiveness of compulsory treatment. Therefore as a starting point we published a review of the literature on compulsory treatment in AN, which is presented in Chapter 2.

MAIN FINDINGS

A review of the literature regarding compulsory treatment in AN (Chapter 2¹) revealed a paucity of empirical research in this area. Epidemiological data on the prevalence of compulsory treatment were scarce. The only crude estimate was a figure from the UK, suggesting that 7.9% of all AN admissions were under the Mental Health Act.² Only five studies were identified with data on outcome of compulsory treatment in AN compared to outcome of voluntary treatment of which only three studies were of high quality and only two provided follow up data.³⁻⁷ In these five studies the outcome regarding weight gain at the end of inpatient treatment was equal between compulsory and voluntary treatment. This was an encouraging outcome as patients who were compulsorily treated tended to have more severe psychopathology. Self harm and previous admissions were more likely in the compulsory treated group. Longer term effects of compulsory treatment have not been well studied. In an adolescent population outcome after 1 year follow up was still comparable for both groups, with a trend for the compulsorily treated group to do slightly better regarding level of functioning, readmissions and resumption of menstruation.⁷ In a large adult population mortality after 5 years follow up was higher for the compulsorily treated group, although this difference was attenuated after 20 year follow up.⁴ Patient's views on compulsory treatment did not much differ from patient views on compulsory treatment in general psychiatry. After some time half of the patients with AN who were compulsorily treated agreed with the need for hospitalization⁸ and in a qualitative study it was found that patients with AN supported compulsory treatment in a life threatening situation. Views on compulsory treatment in other stages of the illness varied amongst patients with AN.^{9,10}

When experienced eating disorder psychiatrists assessed 70 consecutively referred adult patients with AN regarding their mental capacity to consent to treatment, it was found that

in one third of cases this capacity was judged to be diminished (Chapter 3¹¹). In this group BMI was significantly lower, patients had had more previous admissions and had been treated more often before for their eating disorder. By using the MacCAT-T¹², a semi-structured interview for the assessment of mental capacity to consent to treatment, it was shown that it was the aspect of appreciation of illness and treatment that was mainly responsible for the diminished mental capacity. This is in line with previous findings in other psychiatric populations, where it was also the aspect of appreciation that was found to be hampered in diminished mental capacity.¹³ This meant that one third of patients with AN in the study did not appreciate fully that they actually were severely ill and that treatment might be of use. The diminished mental capacity found by the clinicians could not be explained by a lack of understanding or reasoning, as these areas of interest in the MacCAT-T were not different between the two groups. Comorbid depressive disorders or PTSD did not differ between the group with full mental capacity and the group with diminished mental capacity (as judged by the clinician).

Although a low BMI was associated with diminished mental capacity, still a large proportion (43%) of patients with a BMI below 15 kg/m² (severely ill range) did have full mental capacity, indicating that BMI was not the only factor of importance in mental capacity issues. The study revealed other, more subtle, contributing factors such as difficulty to change problem solving strategies, a slight focus on detail and a trend towards less adaptive decision making on a more fundamental level.

In Chapter 4 the results of the longitudinal part of our mental capacity study were presented. The original patient groups (one with full mental capacity and one with diminished mental capacity as judged by the clinician) were followed over the course of 2 years. After 1 year 80% of the original 70 patients cooperated again and after 2 years 71%. Both groups showed a significant increase in BMI in the first year of follow up, but not in the second year. The difference in BMI at baseline persisted over time. In DSM 5 terminology¹⁴ the group with full mental capacity improved from a moderate AN to a mild AN (BMI ≥ 17 kg/m²) over time whereas the group with diminished mental capacity changed from extreme (BMI ≤ 15 kg/m²) to moderate AN. The group with diminished mental capacity was more likely to receive inpatient treatment at both follow up time points after controlling for BMI at baseline. However, when also controlling for previous admissions, this significant difference in the likelihood of inpatient treatment held only for the second time point, (i.e. between the first and the second year of follow up) and became a trend like difference after one year follow up. This means that although previous admissions were largely responsible for the differences in admissions between the groups after one year, the difference between the two groups could not be fully explained by BMI or previous admissions between the first and second year of follow up. Full remission rates were equal in both groups at follow up (around 37%), but the group with diminished mental capacity was more likely to show no remission after two years. Eating disorder pathology controlling for BMI did not differ between the two groups at any time

point. Depression and anxiety scores improved in both groups in a similar manner. However, alexithymia scores did improve in the full mental capacity group, but not in the diminished mental capacity group. Decision making on a more fundamental level as measured with the IGT differed in the two groups. The diminished mental capacity group did not improve over time, the full mental capacity group did.

In our study patients were divided into two mental capacity groups based on clinical judgment. Although admittedly arbitrary and subjective, clinical judgment still is the only instrument professionals in the field have to assess mental capacity to consent to treatment. The MacCAT-T¹² was developed 20 years ago in an attempt to aid clinicians in this complex task, but has not yet found its way into general practice. In research however it has been used in a variety of populations and consistently has been found to be very reliable.^{15,16} This in contrast to clinical judgment which is known, not only in matters of mental capacity, for a relatively poor reliability.¹⁷⁻²⁰ In Chapter 5 the results were reported on the agreement between the MacCAT-T and clinical judgment in the assessment of mental capacity to consent to treatment in our patients with AN. The agreement between the two methods was questionable ($K = .23$). As mental capacity is not a concept easily quantifiable, questions of validity surround both methods. This result did not provide clear guidance on which method to favour. However, use of the MacCAT-T can aid the clinician in the assessment of complex cases by confirming or contradict clinical judgment. In this way, the assessment gains methodological quality.

In Chapter 6 the relationship of decision making on a more fundamental level as measured with the Iowa Gambling Task (IGT²¹) and depression was explored in the entire group of patients participating in the mental capacity study and their results were compared to a healthy control group at baseline. As expected, patients with AN showed less adaptive decision making compared to control participants. For the patient group more symptoms of depression were related to worse decision making performance at all three time points (baseline, follow-up 1 and follow-up 2). Moreover, symptoms of depression at baseline predicted decision making performance one and two years later. Patients with fewer depression symptoms at baseline did better at the IGT at follow up, i.e. they displayed better decision making performance. A clear relationship of the observed improvement in depression scores and improvement on the IGT performance over time could not be shown, possibly due to lack of power. A tentative conclusion from this part of the study was that a high level of depression may hinder adaptive decision making, although improvement of depressive symptoms over time did not lead to more adaptive decision making. This might have been due to sample size considerations. It could also be because a reduced ability to learn from affective feedback²²⁻²⁴ or the tendency to use more dysfunctional emotion regulation strategies²⁵⁻²⁷, next to depressive symptoms, are important determinants of maladaptive decision making.

DISCUSSION

Compulsory treatment in anorexia nervosa

Although as described in Chapter 2 of this thesis empirical studies are scarce, the available evidence regarding compulsory treatment in AN calls for the realisation that compulsory treatment can be an option in severe cases. Short term outcome is similar for voluntary and compulsory treatment. Regarding long term outcome few studies^{4,7} have been done, but what has been done does not support abolishment of compulsory treatment. This is all the more encouraging, as it is very questionable whether the group who was compulsorily treated would have received treatment if not for the compulsory treatment. And as this was a severely ill group, chances are that outcome might have been worse. Patients tend to support the use of compulsory treatment in case of life threatening situations, which is also an important voice to hear. None of the studies³⁻⁷ revealed a worsening in the therapeutic relationship and patients generally remained in care voluntarily after compulsory treatment was stopped, indicating no severe damage done in the working alliance between patient and clinician. The qualitative work done by Tan et al^{9,10} provided the field with valuable insight into the thoughts and feelings patients have regarding compulsory treatment. One of the most important themes was that it was not the compulsory treatment as such, but rather how this was conducted that mattered most to the patients. The importance of this theme is reflected in daily practice by identical comments by patients and by patient and carer organisations.

A definite answer to the question of the benefits and setbacks of compulsory treatment will be hard to get. A randomized clinical trial is not feasible due to ethical considerations. Therefore the eating disorder field has to base their treatment guidelines on retrospective or prospective studies following groups of patients and comparing them to voluntarily treated patients. Compulsory treatment of patients with AN requires a highly specialized staff so presumably not many centers will have the possibility to start such studies. And as legislation differs across countries combined efforts of specialized centers across the globe to set up a comparison between compulsory and voluntary treatment in a larger sample is virtually impossible. However, effort should be done to study a number of issues regarding compulsory treatment. First replication is needed and new studies should encompass follow up measurements of at least one year but preferably longer. AN is an illness with a mean duration of seven years²⁸⁻³⁰ and illness durations of over 10 years are no exception in specialized treatment centers. Therefore follow up should be sufficiently long, however time consuming and costly.

Also efforts should be made to study whether duration of illness has an influence on the outcome of compulsory treatment. Is compulsory treatment equally effective in patients with an illness duration of less than three years as in patients with an illness duration of over ten years? For clinicians this would be highly relevant information to base their decisions on. As a large number of patients are needed to answer these questions, it would be necessary to pool data from more centers.

Thirdly qualitative studies could shed more light on the underlying arguments for clinicians to ensue compulsory treatment. The Australian group of Carney et al³¹⁻³³ has identified risk factors for compulsory treatment (prior AN admissions, more comorbidity, lower BMI) but more insight into the considerations of the responsible clinicians might be useful to identify relevant themes that push the balance towards engaging in compulsory treatment. Is it illness severity alone, or are other factors also relevant in this clinical decision making? Issues such as countertransference, experience in working with AN, the importance that is being given to shared decision making (with patient or family) might also influence the use of compulsory treatment and might be important to address. Qualitative studies in patients who have experienced compulsory treatment could reveal what kind of interventions were particularly helpful or particularly traumatic, and this information could then be used to diminish possible negative effects of compulsory treatment.

Furthermore, it would be informative to know which proportion of compulsory treated patients has insufficient mental capacity to be granted the right to refuse treatment. In other psychiatric populations (such as mood disorders and psychotic disorders^{15,16}) treatment refusal has been found to be associated with problems in mental capacity but in AN this has not yet been studied. It is an important point as withholding treatment from a person who is in danger because of her psychiatric disorder and has diminished mental capacity to decide regarding this treatment is legally complex. This is not to say that in all patients with AN that refuse treatment compulsory treatment should be advised. In the literature there are some^{34,35} that voice doubts regarding whether or not there is a time when the treatment team should conclude there is nothing to be done anymore, whether continuing of (compulsory) treatment produces more harm than good and whether or not to comply with the patients' wishes to let her be, even when this request is made with insufficient mental capacity.

In the case of Jane her mental capacity to refuse inpatient treatment was certainly questionable, but still no compulsory treatment was begun. Instead, a focus was put on exploring her future perspective and improving her social functioning, however low her weight was. Whether or not this was the right course to follow is unknown, but after some time Jane herself decided that it would simply not do to stay on her very low weight if she wanted to move ahead in society and develop herself. After this decision, made by her without external pressure by the treatment team, the way towards recovery began. In the course of this recovery path, compulsory treatment was commenced. No forced feeding was done, but Jane decided that she might benefit from more pressure when she would not comply with the treatment goals (that were set in a discussion with her and the treatment team). So, the term "compulsory treatment" might not do justice to the particular treatment that Jane has gotten, but a legal measure was invoked and repeated for some time. In the literature some patients have mentioned that the fact that a legal measure more or less "forced" them to reach a certain weight, somehow made it less difficult to decide to eat as they could sooth their conscience by saying it was not their own choice, but they were

forced to (by a judge) to comply with the treatment.^{37,10} In this way, compulsory treatment might indeed be an “act of compassion” so eloquently worded by Tiller et al in 1993.³⁶

Mental capacity to consent to treatment in anorexia nervosa

The case of Jane demonstrates the complexities surrounding the issue of mental capacity to consent to treatment. Mental capacity to consent to treatment obviously is a concept not easily quantified. The four abilities usually assessed (Understanding, Appreciation, Reasoning and Choice) stem from work by Grisso and Appelbaum.³⁷⁻³⁹ These abilities were condensed from legal ruling in the United States in the 1980s; and were considered central to mental capacity by court rulings. As these abilities seemed clinically meaningful, they became the four central issues in mental capacity assessments. The MacCAT-T¹² was based upon this influential research and in clinical practice clinicians regarded these four abilities as essential, teaching them to new generations. But this translation of legal logic to clinical reality might be inherently problematic. The legal paradigm is much more rational than clinical reality, it is more dichotomous and pays less attention to interpersonal differences. Laws do not leave much room for personalisation, whereas in medicine diagnoses, treatments and prognoses are constantly influenced by personal circumstances of the patient. This difference in thinking between clinicians and legal professionals has become more apparent in recent years. Clough (from the School of Law in Leeds, United Kingdom) reports in a commentary in 2016 that in her view from a uniquely legal perspective “the narrow, bio-medical view” of clinicians influences the courts too much and that “value judgments” still persist next to “an insensitivity to the social and political context of anorexia”.⁴⁰ Other authors have tempted to bridge this gap and have argued that laws might need to be changed.⁴¹ It is clear that the discussion regarding the legislation on mental capacity is still very much alive today. Besides this discussion from a more legal point of view, from a more ethical point of view criticism continued too. The main point that is put forward is that the dominance of the concept of autonomy and the decline in paternalism might not do justice to the needs of severely ill patients.⁴¹ Unfortunately, no studies regarding mental capacity to consent to treatment in patients with AN have been published since the study presented in this thesis began. It seems that the field is moving slowly and that from a theoretical point of view papers are being published, but from a clinical point of view these are lacking.

However important and interesting theoretical reflections might be, the clinician practicing medicine needs to decide and generally does not have the luxury of theoretical discussion or unlimited time. With this clinician in mind the study presented in this thesis was designed and the findings are of importance to clinical practice. BMI matters, as many would think, but other issues such as previous history as well. Appreciation is less when mental capacity is diminished, as many clinicians will no doubt recognize and prognosis is also less, although improvement is the rule rather than the exception. The correlation that was found at baseline between appreciation and a high level of alexithymia was particularly intriguing as it is thought that a well

functioning emotional system is a prerequisite for adaptive decision making and thus also for adequately deciding regarding treatment (i.e. mental capacity). When a patient would not be able to rely on her gut feeling to guide her decisions, as this gut feeling is blunted, inaccessible or perhaps overridden by a low BMI, intense anxiety or depressive symptoms, these decisions (as measured with the IGT) become less adaptive. The data revealed that the diminished mental capacity group did show a trend towards less adaptive decision making on the IGT (controlling for BMI), however alexithymia nor appreciation was directly related to the outcome of the IGT.

Our findings tentatively point towards the importance of emotional factors in mental capacity and, as the diminished mental capacity group showed less adaptive decision making in our study as well, also supports the notion that emotional factors are important in more fundamental decision making. Although no studies have yet been published studying the role of emotional factors in mental capacity, very recently Ayre et al⁴² have suggested that the intense emotional dysregulation of patients with borderline personality disorder might impact on their decision making abilities regarding medical treatment (i.e. their mental capacity). In AN emotion dysregulation is also recognized and is considered to be an important underlying problem.⁴³⁻⁴⁷ Earlier, Hindmarch⁴⁸ had already suggested in a review of mental capacity in people with depression that affective symptoms might minimize the concern for one self and in that way minimize appreciation, subsequently influencing decision making. However, our study was limited in that only a few markers of emotional functioning were measured. Very likely other emotional factors (on a psychological as well as on a neurobiological level) besides alexithymia and depressive symptoms, are of relevance to decision making. These might also explain why decision making does not become more adaptive with improvement of depression, alexithymia or anxiety or with improvement in BMI. Heilman²⁶ suggests that it is emotion regulation that needs to be targeted, and not emotions, to improve adaptive decision making. Further research therefore is needed in this complex matter.

In the assessment of mental capacity to consent to treatment in AN the present study provides the clinician with parameters with special significance for the risk of diminished mental capacity. But as mentioned in Chapter 5, interrater reliability of clinical assessment is rather poor.^{17,18,20} The more robust reliability of the MacCAT-T speaks in favour of using this more regularly besides the clinical judgment, but our results point towards a typical particularity in patients with AN. In other psychiatric populations (major depression, schizophrenia), clinicians consequently judged a relatively low proportion of patients as having diminished mental capacity.^{19,49-51} Use of the MacCAT-T in those populations consistently showed that the proportion of patients with diminished mental capacity was much higher than when clinicians judged these patients. In AN however, we did not find this large difference between the two methods (see Chapter 5). One third of patients was judged to have diminished mental capacity by the clinicians, a proportion much higher than when clinicians assess patients with schizophrenia.⁴⁹ This finding is remarkable in itself for it appeals to the intuition many

clinicians have that something must be terribly wrong with the ability to adequately decide regarding treatment in patients with AN. To complicate matters further, agreement between the MacCAT-T and clinical judgment was rather low. With these results, clinicians might be inclined to thus agree with the criticism that the MacCAT-T does not take into account more emotional factors important in decision making. But as appealing as this might be, scientifically a method is not more valid because it *feels* right. In practice, the scientifically correct course of action would be to rely on two judgments (clinical assessment and MacCAT-T) instead of just one (be it clinical judgment or MacCAT-T) as validity of both methods is unknown. If both point towards a certain direction, chances are that this is the right direction. But this still leaves us with the remarkable and unprecedented tendency of clinicians to judge so many patients with AN as having diminished capacity. How might this be explained? Part of the explanation might be that even experienced eating disorder psychiatrists may be influenced by the sight of emaciation more visible in extremely low weight patients. Although this may in part be true, still four out of ten patients with AN with a BMI below 15 kg/m² were judged to actually have full mental capacity, so this cannot explain everything. Possibly clinicians took previous history into account, as clinicians usually do, to get a picture of the present state of motivation and feasibility of treatment goals. They might have judged that when previous treatment had not helped this was meaningful for the present decision making ability (i.e. mental capacity) of the patient, but this remains speculative and another argument in favour of conducting qualitative studies regarding the reasons why clinicians judge someone with AN as having diminished mental capacity. The criticism that the MacCAT-T does not sufficiently take into account emotional factors due to a focus on more cognitive abilities⁵²⁻⁵⁸, might be appealing, but cannot be proven with the data of the present study. On the contrary, the fact that a high level of alexithymia was correlated with low appreciation on the MacCAT-T, but was not associated with diminished mental capacity as judged by the clinician¹¹, speaks against this idea. Apparently to clinicians it is not alexithymia that determines capacity status, but to the MacCAT-T it does seem more relevant. In the scientific literature regarding mental capacity to consent to treatment, the MacCAT-T remains the most widely used instrument due to the reliability, construct validity and face validity. In an assessment that can at times be so complex as the mental capacity assessment, a tool that has these advantages should be valued.

Decision making

In our study, 1) patients with AN showed less adaptive decision making on the IGT than healthy control participants and 2) patients with AN that were judged to have diminished mental capacity did worse on the IGT than patients that were judged to have adequate mental capacity. For the entire patient group (and not the two mental capacity groups separately) a relationship between depressive symptoms and performance on the IGT was shown at all time points and more depression at baseline was related to worse IGT performance at follow up. The group with

diminished mental capacity had lower appreciation scores and this was correlated to a higher level of alexithymia. Over time we could not show a relationship of the observed improvement in depression scores and the observed improvement in the IGT performance, nor could we show a relationship between the improvement of alexithymia in the full mental capacity group and their improvement on the IGT over time. Although clinically salient, apparently the fact that the diminished mental capacity group did not improve in alexithymia over time at all was not related to their worse performance on the IGT and therefore their less adaptive decision making. As mentioned before, possibly this is due to the fact that we focused on two very specific factors, i.e. depression and alexithymia which are very relevant to AN. However, other emotional concepts are also very relevant to AN and may influence the decision making process, such as emotion dysregulation.

Keeping in mind that to award value to a range of options is essential in decision making and that the IGT²¹ was designed to assess decision making in complex and/or uncertain situations in which one cannot rely (solely) on rational processes and therefore has to rely on bodily or “gut” feelings and will decide less adaptively when emotional functioning is problematic, our results support the existence of decision making difficulties in AN, possibly due to a relative inability to rely on emotional factors or altered reward processing. These difficulties appear to exist in an even greater degree in those that have diminished mental capacity. This is emphasized by Tan et al, although by no means fundamental neuropsychological research, when they stated from a more philosophical perspective the same conclusion; values, distorted by the illness, are of utmost importance in the decision making abilities and thus mental capacity of the patient with AN.^{9,10,52,53}

Although we attempted to gain more insight in the role of emotional factors in decision making, our choice of assessment measures was limited. We assessed specific emotional states, but not more emotion processing related factors with the exception of alexithymia. Next to the importance of reward and value assignment to decision making, emotional functioning in a broader sense is relevant in decision making as has been shown in earlier studies.^{43-47,59,60} Although the IGT as a measure for decision making is widely used, and certainly in the field of eating disorders, outcome on the IGT is also influenced by other factors (such as working memory and learning processes⁶¹⁻⁶³) and might (partially) explain outcome on the IGT in patients with AN. Other cognitive factors that might influence decision making are executive functioning problems, such as a relatively weak central coherence and less adequate set shifting that have both been found previously in patients with AN.⁶⁴⁻⁶⁶ Although intelligence (IQ) might also influence outcome on the IGT, patients with AN generally have a normal to above normal IQ. Specifically, in a recent paper⁶⁷ based on data from over 700 patients with AN from our own center it was found that the mean IQ in this large group was slightly above average (103 vs 100). This suggests that in future studies into decision making in AN, researchers should focus more on other cognitive factors possibly influencing outcome on decision making tasks (such as the ones mentioned above) than on IQ.

STRENGTHS AND LIMITATIONS

The study presented in this thesis has several strengths. It represents the first study worldwide to assess mental capacity in adults with severe AN in a quantitative fashion, the longitudinal design being an added strength. We had hardly any exclusion criteria and therefore consider the results to be fairly generalizable. We included a relatively large group for a clinical study, with a wide range of assessment measures including assessment of comorbidity with the SCID-I.⁶⁸ There was acceptable loss to follow up, this being a clinical study. By comparing the clinical judgment to the outcome of the MacCAT-T we presented the first evidence that indeed this agreement is only moderate, as was suggested but never shown. To associate mental capacity with more fundamental decision making measurements has not been done before in any study in any psychiatric population and is therefore innovative. Our results indeed suggest a relation between more fundamental decision making problems and diminished mental capacity and can therefore be a starting point for new translational research in this area.

Limitations are also present. In the course of follow up there were missing data. Although the loss to follow up of 20% resp. 29% is considered acceptable according to the literature, and in the statistical analyses missing data were accounted for, outcome might have been influenced by these missing data. A further limitation is the lack of interrater reliability measurement of the clinical judgment, combined with the sorting of the patients based on this criterion. In the complexities of this already logistically challenging study in clinical practice it was not feasible to do an inter-rater reliability study. However, this is an important point for future studies to consider. In general psychiatry inter-rater reliability of clinical assessment of mental capacity to consent to treatment is rather low^{17,18,20} and there is a tendency to underestimate mental capacity problems.⁵¹ Whether or not this is also true for patients with AN is still unknown. Given the finding that clinicians judged a third of the patients with AN to have diminished mental capacity where usually clinicians (in other psychiatric disorders) judge a far lower proportion of patients to lack capacity is remarkable and difficult to explain. It is by no means clear cut that the inter-rater reliability of this assessment in patients with AN is just as low. Or, for that matter, that clinicians working with patients with AN underestimate possible mental capacity problems. Further research should address these issues. Regarding the IGT more attention to working memory, the influence of problems with executive functions and emotion processing factors might be advisable in future studies, although it is a well recognized measure for assessing decision making in patients with AN. By taking these factors into account, decision making problems in patients with AN might be studied in a more detailed way.

CONCLUSION

The study presented in this thesis has provided some important answers regarding compulsory treatment in AN and decision making abilities of people with AN but has raised even more questions. The clinician needs to bear in mind clinical factors such as BMI and previous history,

but also has to pay close attention to appreciation of illness, emotional functioning and personal circumstances (such as previous history, stage of the disorder and personal values) when assessing mental capacity to consent to treatment or deciding on compulsory treatment. Further research is needed, especially regarding the decision making process of the clinician herself. What thoughts, ideas, values and feelings are of importance for the clinicians to decide as they do? Involvement of patients themselves in qualitative studies is warranted, especially regarding compulsory treatment. If the decision by the treatment team is that compulsory treatment should be commenced, how can this be done in such a way that negative consequences or traumatization of the patient are prevented?

Decision making regarding health issues, certainly when stakes are high such as in severe AN, is something influenced deeply by personal views and also an act not undertaken in isolation. The patient with AN is a person that interacts with her environment, just as any other human being. This environment is the outside world, but also the inside world of emotions, hopes and dreams. Perfect autonomy is not the human condition, but rather people are intimately connected to each other, to their culture, to their emotional and cognitive status and to expectations laid upon them by society. Therefore, the decision to refuse treatment cannot solely be seen as an independent act, but as something meaningful in interaction with the treatment team, the family, their emotions and perhaps other actors as well. With this in mind, a mental capacity assessment should not be a standard procedure, but rather a process commenced upon with a keen eye for the particular circumstances of the patient. Decision making regarding compulsory treatment should bear in mind the same issues and keep in mind effectiveness of compulsory treatment but also previous history and the duty not to harm patients with unhelpful interventions.

Returning to Jane we see numerous factors associated with diminished mental capacity. A very low BMI, previous eating disorder treatment, hampered emotional functioning, a diminished appreciation and treatment refusal. Jane was definitely in dire straits, was judged by us to have diminished mental capacity to refuse the treatment offered, but still we did not go forth with compulsory treatment at first. Was this the right course of action? At the time we felt that we would demoralize her more by forcing our best intentions upon her than by supporting her in her wish to be left at peace, but not losing touch. By staying available to her, we hoped that eventually she would trust us enough to begin treatment. In the end, this is what happened, but things could easily have turned out the other way. She could have gone the way of losing even more weight, going into hospital or perhaps retreating in isolation and she even could have died as a consequence of her severe anorexia nervosa. We like to believe that our attitude fitted her needs at the time, but cannot say for sure. Jane is doing very well now and when approaching her to ask for permission to use her story in this thesis, her response was quick and kind. This reaction shows that the relationship between her and the treatment team has remained good throughout the entire process and perhaps, in line with what former patients say, it is exactly this attitude that in the end has helped her most.

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A D D E N D U M

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ACHTERGROND EN VRAAGSTELLING

Wat is wilsbekwaamheid?

Het begrip 'wilsbekwaamheid' betekent in de geneeskunde: het vermogen van patiënten om adequaat te kunnen besluiten over de eigen behandeling. Patiënten kunnen instemmen met een behandeling, maar zij kunnen een bepaalde behandeling ook weigeren. Als de gevolgen van de weigering van een behandeling niet ernstig zijn, zal een arts na verdere uitleg aan de patiënt deze weigering respecteren. Als de gevolgen wel ernstig kunnen zijn, is het belangrijker dat de besluitvorming van de patiënt adequaat is. Is de patiënt wel wilsbekwaam om de behandeling te kunnen weigeren? Artsen moeten de wilsbekwaamheid toetsen als zij vermoeden dat die weleens verminderd zou kunnen zijn en de consequenties van de weigering van de behandeling ernstig zijn voor de patiënt.

Wilsbekwaamheid is niet iets wat duidelijk meetbaar is, zoals temperatuur, maar een concept. In de loop der jaren zijn er enkele vaardigheden voorgesteld die de mate van wilsbekwaamheid zouden bepalen. Die vaardigheden zijn het *begrip* van de informatie, de *waardering* van die informatie (dat wil zeggen, het op jezelf betrekken), het kunnen *redeneren* met die informatie (dat wil zeggen verschillende opties kunnen afwegen) en in staat zijn om een *keuze* te maken. Artsen die een wilsbekwaamheidsbeoordeling doen, toetsen in een gesprek met de patiënt deze vaardigheden. Ze wegen dan af of zij de patiënt voldoende in staat vinden om een beslissing over zijn behandeling te kunnen nemen. Schatten artsen de wilsbekwaamheid laag in en zijn de gevolgen voor de patiënt ernstig als hij de behandeling weigert? Dan mogen de artsen, tegen de wil van de patiënt in, toch die behandeling starten. Wilsbekwaamheid is dan ook een belangrijk begrip in de medische wereld en in de wetten die de arts-patiënt relatie regelen.

Wat is anorexia nervosa?

Anorexia nervosa (AN) is een ernstig ziektebeeld met zowel psychiatrische als lichamelijke symptomen. Mensen met AN hebben devaste overtuiging te dik te zijn (vertekend lichaamsbeeld) en doen veel moeite om gewicht te verliezen, zoals beperkt eten en overmatig bewegen. Deze overtuiging is vaak waanachtig van karakter: de patiënt beschouwt de overtuiging bijna als werkelijkheid, waardoor die nauwelijks bespreekbaar is. Des te lager het gewicht, des te sterker is deze overtuiging. Andere symptomen van AN zijn rigiditeit, afgevlakte emoties en veel angst voor verandering. De effecten van gewichtsverlies zijn velerlei. Een verlaging van de lichaamstemperatuur, bloeddruk en pols, vertraging van het denken en problemen met de menstruatie worden vaak gezien. Op de langere termijn treedt botontkalking op. Bij jonge mensen wordt de botopbouw en de lengtegroei bedreigd. Het honger- en verzadigingssysteem raakt ernstig ontregeld: er treedt een verkeerde inschatting van de verzadiging op en men heeft al heel snel het gevoel "vol" te zitten. Hoe meer gewichtsverlies, hoe meer rigide en dwangmatig een patiënt wordt. Dat bemoeilijkt gedragsverandering weer verder.

Slechts 50% van de volwassenen met AN herstelt volledig, 30% herstelt enigszins en 20% herstelt niet. Ongeveer 10% van de patiënten overlijdt uiteindelijk. Een patiënt met AN lijdt dikwijls aan een gestoorde realiteitstoetsing. Hij werkt daarom vaak niet mee aan de behandeling of volgt de adviezen niet op. Dit maakt de omgeving, inclusief de hulpverleners, vaak erg machteloos en gefrustreerd.

Onderzoeksvragen

Wilsbekwaamheid bij AN is nog nauwelijks onderzocht, terwijl er zeker vraagtekens te plaatsen zijn bij de wilsbekwaamheid van deze ernstig zieke patiënten. Het is nog niet duidelijk hoe vaak problemen met de wilsbekwaamheid bij deze patiëntengroep voorkomen en waar eventuele problemen met de wilsbekwaamheid mee te maken hebben. Ook is het nog niet duidelijk of een verminderde wilsbekwaamheid betekenis heeft voor de prognose. Daarnaast is er onduidelijkheid of een instrument dat in de literatuur gebruikt wordt om wilsbekwaamheid te beoordelen (een interview genaamd de MacCAT-T) ook te gebruiken is bij anorexia nervosa. Verder is het niet duidelijk of eventuele problemen met wilsbekwaamheid te maken hebben met meer fundamentele beslisgedragproblemen. Naast deze vragen over wilsbekwaamheid speelt al lang een discussie of het onder dwang behandelen van patiënten met AN zinvol is. Het onderzoek dat in dit proefschrift beschreven wordt, probeert deze vragen te beantwoorden.

Methode

In dit onderzoek hebben we 70 volwassen vrouwen met anorexia nervosa onderzocht aan het begin van hun behandeling bij Altrecht Eetstoornissen Rintveld. Op twee manieren werd de wilsbekwaamheid onderzocht wat betreft het besluit om het advies voor behandeling al dan niet op te volgen. Na zijn intake vulde de psychiater op een formulier in of hij de patiënte wel, niet of verminderd wilsbekwaam achtte. Hiernaast werd de patiënte gezien door een andere arts/psychiater die het interview (de MacCAT-T) gebruikte om de mate van wilsbekwaamheid te scoren. Diverse andere maten werden bij de start van de behandeling gemeten, zoals BMI, aanwezigheid van andere psychiatrische stoornissen, mate van somberheid, angst en alexithymie (moeite met ervaren van emoties) en verschillende neuropsychologische taken omtrent beslisgedrag, de mate waarin patiënten van strategie konden wisselen en de mate van detailfocus. Hierna hebben we hen na 1 en na 2 jaar weer benaderd om enkele van de onderzoeken te herhalen en ook om het beloop van hun ziekte te beschrijven.

Naast dit onderzoek hebben we een literatuuronderzoek gedaan naar wat er bekend is over de effecten van gedwongen behandeling bij anorexia nervosa.

Onderzoekresultaten

In **hoofdstuk 2** wordt beschreven dat het onder dwang behandelen van patiënten met anorexia nervosa voor wat betreft effect op gewichtsstijging niet onderdoet voor een vrijwillige

behandeling. In beide groepen neemt het gewicht evenveel toe gedurende de opname, al doen de patiënten die gedwongen zijn opgenomen hier wel veel langer over. Het lijkt erop dat patiënten die onder dwang worden opgenomen meer andere psychiatrische problemen hebben dan de vrijwillige groep. Na ontslag blijven beide groepen in gelijke mate vrijwillig in behandeling, wat impliceert dat de behandeling onder dwang de relatie met de hulpverlener niet ernstig heeft geschaad. Hoewel de resultaten op korte termijn gelijk lijken, zijn de resultaten op langere termijn minder duidelijk. De resultaten die er zijn, wijzen niet op een negatief effect van een behandeling onder dwang op de langere termijn.

Hoofdstuk 3 toont aan dat in de onderzochte groep van 70 vrouwen met anorexia nervosa één derde volgens de psychiater verminderd wilsbekwaam was bij de start van de behandeling. Het meest aangetast is de waardering van de stoornis: deze patiënten vinden dat ze ofwel niet, ofwel niet zo ernstig, ziek zijn als de psychiater vindt. Patiënten die verminderd wilsbekwaam zijn, hebben vaker eerdere behandeling voor hun eetstoornis gehad, hebben een minder goed maatschappelijk functioneren en zijn wat meer rigide dan patiënten die volledig wilsbekwaam worden geacht door de psychiater. Er is een trend richting onvoordeliger beslisgedrag bij de verminderd wilsbekwame patiënten. De mate van depressie of angst noch de aanwezigheid van andere psychiatrische stoornissen verschillen tussen deze twee groepen.

De patiënten met verminderde wilsbekwaamheid in het begin van de behandeling werden in de loop van de twee jaar iets vaker opgenomen en hadden een wat slechtere uitkomst van de behandeling dan de patiënten die wel volledig wilsbekwaam werden geacht, zoals wij laten zien in **hoofdstuk 4**. De waardering van de stoornis verbeterde niet in deze groep en ook het beslisgedrag verbeterde niet, hoewel ook zij aankwamen in gewicht. De groep met adequate wilsbekwaamheid bij de start van de behandeling verbeterde wel in beslisgedrag in de loop van de tijd.

In **hoofdstuk 5** wordt beschreven dat het oordeel van de psychiater en de uitkomst van het interview, de MacCAT-T, niet erg overeen komen. Opvallend is dat een vrij groot deel van de patiëntengroep als verminderd wilsbekwaam wordt beoordeeld door de psychiater, namelijk één derde, terwijl dit in andere patiëntenpopulaties vaak veel minder is.

Als laatste kijken we in **hoofdstuk 6** naar de invloed van depressieve symptomen op het beslisgedrag. We laten zien dat patiënten met meer depressieve symptomen minder adaptief beslisgedrag vertonen. We konden echter niet aantonen dat het verbeteren van deze depressieve klachten het beslisgedrag ook verbeterde over de tijd.

Discussie

Dit onderzoek is één van de eerste onderzoeken wereldwijd dat op kwantitatieve wijze naar wilsbekwaamheid bij een grote groep volwassenen met anorexia nervosa kijkt. In die zin is het een belangrijk onderzoek, maar ook noodzakelijkerwijs beperkt. Het was immers nog niet mogelijk om hypothesen te toetsen vanwege de vele hiaten in onze kennis van dit onderwerp tot nu toe.

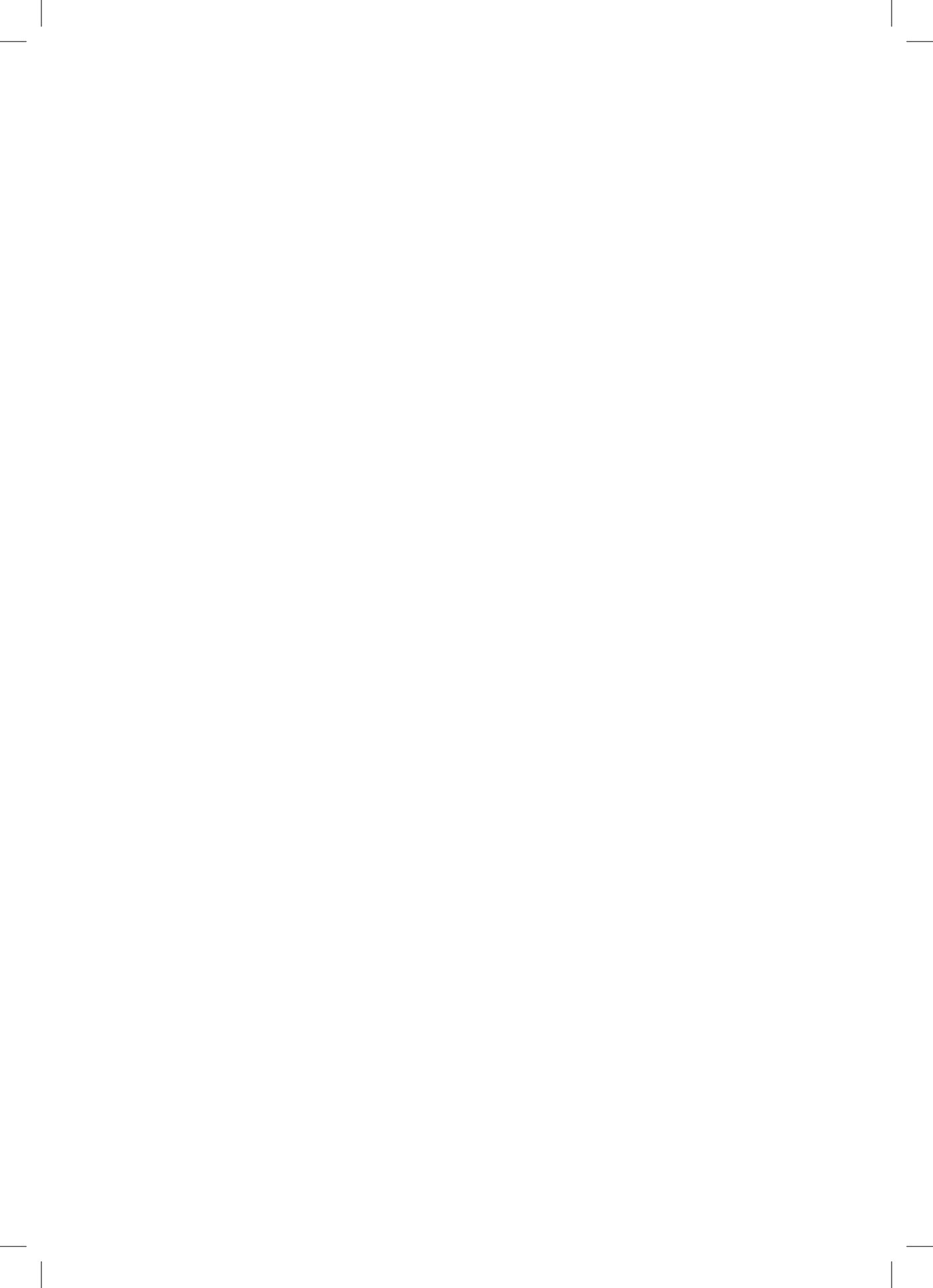
Voor wat betreft dwangbehandeling kunnen we op grond van de literatuur concluderen dat de resultaten van een behandeling onder dwang op korte termijn niet onder doen voor die van een vrijwillige behandeling. Dat is bemoedigend. De verwachting is immers dat een groot deel van de patiënten die onder dwang zijn behandeld, anders geen behandeling hadden gekregen. Dan was het vermoedelijk slechter met hen gegaan dan met de ingezette behandeling onder dwang. De resultaten op langere termijn zijn minder goed onderzocht, maar wat er is onderzocht geeft geen aanleiding tot pessimisme. Patiënten zelf wijzen erop dat het niet zozeer gaat om het element van dwang an sich, maar meer om hoe die behandeling uitgevoerd wordt. Het is belangrijk om altijd in contact te blijven met de patiënt en zoveel mogelijk in overleg te gaan, ook in een situatie waarin dwang wordt toegepast. Op die manier hoeft dwangbehandeling geen traumatische ervaring te zijn. Het lijkt daarom belangrijk dat dwangbehandeling slechts wordt uitgevoerd door gespecialiseerde teams.

Er is discussie in de literatuur of er ook een moment is waarop de behandeling gestaakt zou moeten worden vanwege gebrek aan effect, zelfs als dat het overlijden van de patiënt zou betekenen. In diverse landen wordt op verschillende wijze met deze complexe discussie omgegaan. Wanneer is het moment daar dat besloten kan worden dat verder doorgaan met een (dwang)behandeling zinloos medisch handelen wordt? Op deze vraag is het antwoord nog niet goed te formuleren, behalve dan dat voors en tegens in een dergelijke casus zorgvuldig moeten worden afgewogen, met inachtneming van de visie van de familie, collega's en gebruik makend van morele beraden.

Verder onderzoek dient zich onder andere te richten op de achterliggende factoren waarom clinici overgaan tot het toepassen van dwang. Zijn er factoren te ontdekken bij de clinici zelf en zo ja, welke dan? Zijn er gedachten, emoties of normen en waarden te ontdekken die de geneigdheid tot dwangbehandeling doen toenemen en zo ja, hoe hiermee om te gaan in de praktijk? Verder is het belangrijk om meer kwalitatief onderzoek te doen bij patiënten, om zo beter zicht te krijgen op wanneer een dwangbehandeling nu wel en wanneer niet als traumatiserend wordt ervaren. Dit om een nodeloos negatieve uitkomst van de dwangbehandeling te voorkomen.

Uit ons onderzoek blijkt dat één derde van de patiënten bij intake verminderd wilsbekwaam is, althans volgens de psychiater die de intake doet. Hoe dunner, hoe groter die kans. Uit ons longitudinale onderzoek valt op te maken dat er ook op meer fundamenteel niveau problemen zijn in het beslisgedrag in deze groep. Dat wordt ook gereflecteerd in de uitkomst dat de waardering van deze verminderd wilsbekwame patiënten minder goed is en blijft gedurende twee jaar, ondanks dat zij wel aankomen in gewicht. Er is een vermoeden dat dit te maken heeft met het emotioneel functioneren van deze patiënten. Dat is echter nog niet goed hard te maken op grond van ons onderzoek. Het instrument dat deze beoordeling kan ondersteunen heeft voor- en nadelen. Het is betrouwbaarder dan een klinische beoordeling, maar de vraag blijft of dit instrument niet teveel leunt op cognitieve vaardigheden. Vanuit ons eigen onderzoek en

de literatuur overziend is de aanbeveling dat bij een beoordeling van de wilsbekwaamheid niet alleen de cognitieve capaciteiten omtrent besluitvorming in acht moeten worden genomen. De context van de patiënt wat betreft voorgeschiedenis, levensloop, levensbeschouwing en relaties zijn zeker ook relevant. Een wilsbekwaamheidsbeoordeling is niet een objectieve test, maar blijft een subjectieve waardering door de clinicus. Het is van groot belang om je daar als clinicus bewust van te zijn.



DANKWOORD

Het dankwoord is meestal het enige onderdeel van het proefschrift dat wordt gelezen. Aangezien ik mij daar zeer van bewust ben, volgt hier voor al die mensen die niet verder komen dan dit stukje van het proefschrift de ultrakorte samenvatting van wat ik de afgelopen 6 jaar heb onderzocht.

Anorexia nervosa is een heel ernstige ziekte, je kunt eraan overlijden doordat je te weinig eet. Patienten zijn geneigd hulp af te wijzen en dat is eigenlijk vreemd, want de gevolgen van anorexia nervosa kunnen zo ernstig zijn. Ik vroeg me dus af of patienten met anorexia nervosa wel goed kunnen besluiten, of dat misschien door het ondergewicht ze niet meer zo goed konden nadenken. Of je wel goed kunt besluiten over een behandeling heet in de geneeskunde wilsbekwaamheid. Nadat we een groot onderzoek hadden opgezet en 70 patienten met anorexia nervosa hadden onderzocht en 2 jaar gevolgd kunnen we enkele dingen zeggen. Een derde van die patienten lijkt inderdaad minder goed te kunnen beslissen. Hoe dunner hoe erger dit is. Vooral lijken ze te vinden dat ze ofwel niet ziek zijn, ofwel niet zo ziek als anderen zeggen. We vermoeden dat de manier waarop ze met hun emoties omgaan (niet goed emoties voelen of niet adequaat kunnen verwerken) ook belangrijk is in de verminderde wilsbekwaamheid. Gelukkig komen ze in de loop van 2 jaar nog wel aan, maar niet zo goed als patienten die in het begin wel goed konden beslissen. Verder onderzoek is nodig.

Zo. Toch nog aan verspreiding van wetenschappelijke kennis gedaan.

En dan nu het echte dankwoord!

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heb ik het idee dat we over en weer elkaar positief hebben kunnen beïnvloeden en heb ik ook veel van jullie kunnen leren.

De groep zonder wie dit allemaal überhaupt niet mogelijk was geweest, is natuurlijk de groep van patiënten die hebben meegewerkt. Velen niet maar een keer, maar twee of zelfs drie keer. Ik en de anderen die mij hebben geholpen met de dataverzameling zijn door het hele land gereden, maar vaak namen jullie ook de moeite naar Rintveld te komen voor de afspraken voor het onderzoek. Er zijn zelfs mensen die mij op de hoogte hielden wanneer ze vanuit Groningen of Assen in de buurt waren, zodat wij niet zo ver hoefden te reizen. Allemaal heel veel dank voor jullie openheid, moeite en inzet. Ik wens jullie het allerbeste!

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Binnen Rintveld bestaat er een groep van patienten die gevraagd en ongevraagd onder leiding van de ervaringsdeskundige het management van commentaar en advies voorziet, de klankbordgroep. Jaren heb ik er deel van uitgemaakt en ik heb jullie ook regelmatig zaken voorgelegd uit het onderzoek en gevraagd wat jullie daarvan dachten. Jullie suggesties en interesse hebben mij ook zeer gesteund, dank daarvoor.

Beste teamleden van lijn 3, wat hebben we het toch goed met elkaar! Klein maar fijn zijn we, maar aan alles komt een eind. Ons team wordt wat groter met de veranderingen in het behandelaanbod, maar behoud met elkaar het goede. De eerlijkheid naar elkaar, de moed, het wederzijdse respect en vooral, de humor. Een dag niet gelachen is een dag niet geleefd! Een bijzondere vermelding verdient natuurlijk Dagmar Hendriks. Lieve Dagmar, onze kennismaking blijft een bron van hilariteit. Ik heb het erg gewaardeerd om met je te mogen werken, leven en lachen en hoop je in de toekomst nog regelmatig tegen te mogen komen.

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Lieve mensen van mijn intervisiegroepje. We kennen elkaar al lang, nog vanuit de opleiding in Ermelo. Hoewel we soms wat verzaken in onze bijeenkomsten, waardeer ik de aanwezigheid van onze groep zeker. Het brengt wat continuïteit in mijn leven, wat rust en een plek waar mensen mijn twijfels kennen en waar die er mogen zijn. Nu bijna iedereen gepromoveerd, leidinggevende, superspecialist of eerste geneeskundige is, kunnen we misschien weer even wat relaxen en beschouwen. Dank voor jullie aanwezigheid en steun.

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CURRICULUM VITAE

Isis Elzackers werd geboren in 1972 in Bergen op Zoom. Na het gymnasium studeerde zij Geneeskunde aan de Vrije Universiteit in Amsterdam alwaar zij in 1999 cum laude haar arts examen behaalde. Nadat zij een jaar had gewerkt als arts assistent Interne Geneeskunde, ging zij werken als arts assistent Psychiatrie. Vanaf 2002 deed zij de opleiding tot psychiater bij GGZ Meerkanten (nu GGZ Centraal) in Ermelo. Gedurende de opleiding werkte zij op diverse afdelingen en ontwikkelde zij een interesse voor thema's rondom wilsbekwaamheid in de psychiatrie. In de laatste stage van haar opleiding, ziekenhuispsychiatrie aan de Vrije Universiteit in Amsterdam, werd de interesse in het thema wilsbekwaamheid verder bestendigd. Na aanvankelijk twee jaar te hebben gewerkt op een rehabilitatie afdeling van Altrecht in Nieuwegein, startte zij in 2009 bij Altrecht Eetstoornissen Rintveld, een topGGZ afdeling voor de diagnostiek en behandeling van eetstoornissen. Met haar ervaring in de langdurige zorg en rehabilitatie zette zij daar samen met haar collega's de zorg op voor mensen met een langdurige eetstoornis. Methodisch werken met rehabilitatie is nu beschikbaar voor de patienten bij Rintveld en er is een samenwerking opgezet met de regionale organisatie voor begeleid wonen om jong volwassenen met een eetstoornis te ondersteunen in het (begeleid) zelfstandig wonen in de regio. Hiernaast heeft zij Hans van Delden, hoogleraar Medische Ethiek aan de Universiteit Utrecht, betrokken bij het leiden van morele beraden op de afdeling.

Na de toekenning van een subsidie van Fonds Nuts Ohra eind 2011 startte zij haar onderzoek naar de wilsbekwaamheid bij volwassenen met anorexia nervosa vanaf 2012, waarvan in dit proefschrift de resultaten beschreven worden.

Vanwege haar onderzoek bij een complexe patiëntengroep wordt zij regelmatig gevraagd voor consultatie rondom thema's als dwangbehandeling, wilsbekwaamheid en dilemma's omtrent het staken van de behandeling bij mensen met ernstige en langdurige anorexia nervosa.

