EATING DISORDERS AND TREATMENT FROM DIFFERENT PERSPECTIVES

Cover: Eating disorder patients are encouraged to identify and dispute their beliefs about their shape and weight in treatment. One exercise is to estimate how much string it would take to wrap around a part of their body, such as their thigh or waist. When they measure the actual circumference, they realize it is much smaller than imagined.

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Eating Disorders and Treatment from Different Perspectives

Eetstoornissen en behandeling vanuit verschillende perspectieven

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Voor mijn ouders
In herinnering aan mijn vader en grootvader

Contents

Introduction

Eating disorders (EDs) are rare, but very serious psychiatric disorders, with a low recovery rate (1,2). This warrants studies on treatment quality to improve the course and consequences of EDs and enhance recovery rates. Despite the increasing recognition of the value of patient input, few studies address how ED patients evaluate the illness, its consequences and treatment, and how their views are related to scientific evidence and expert opinions.

The most commonly used criteria for the diagnosis of an ED are the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) of the American Psychiatric Association and the International Statistical Classification of Diseases and Related Health Problems (ICD) of the World Health Organisation. Three major types of EDs are differentiated (See appendix 1 for a summary of the diagnostic criteria of the DSM-IV-TR). Anorexia nervosa is characterized by a refusal to maintain a normal weight. Anorexia nervosa patients have a body weight of (less than) 85% of normal, and an intense fear of gaining weight. The non-purging type of anorexia nervosa tries to control body weight with a restrictive eating pattern or excessive exercises whereas the purging type also tries to control the body weight by vomiting, and the use of laxatives, diet pills or diuretics. Bulimia nervosa is characterized by recurrent eating binges at least twice a week over a period of three months. Bulimia nervosa patients engage in compensatory behaviours after binge eating, by non-purging and/or purging means. Non purging behaviour includes excessive exercise and/or fasting. Purging behaviour includes vomiting, the use of laxatives, diet pills, diuretics or other medications. Self-evaluation is strongly influenced by body shape and weight. Furthermore the recurrent binge eating episodes do not occur during episodes of anorexia nervosa. EDs not otherwise specified are characterized by anorectic or bulimic behaviour, but do not meet the threshold criteria for a diagnosis of either anorexia or bulimia nervosa. Binge eating disorder is a specific type of an ED not otherwise specified. It is characterized by recurrent binge eating at least twice a week over a period of three months. Although patients may attempt to diet, they do not engage in compensatory behaviour after binging.

EDs are rare disorders. The incidence of anorexia nervosa is around 8 per 100.000 persons per year. The incidence of anorexia nervosa has increased over the past century. The most substantial increase was among females aged 15-24 years, until the late nineties. The incidence of bulimia nervosa is around 13 per 100.000 persons per year. The average prevalence rates for anorexia nervosa and bulimia nervosa among young females are 0.3 and 1%, respectively (3).

EDs are serious psychiatric disorders. Mortality in anorexia nervosa and bulimia nervosa is higher than in other mental disorders (4). Furthermore the physical, psychological, and social consequences of the disorders are severe (5, 6). The most common physical consequences are due to disturbed eating behaviour and abnormal compensatory behaviours, such as purging. Anorexia nervosa patients are at risk for starvation-induced cardiovascular and renal alterations that may lead to arrhythmias and sudden death. Malnutrition and low body weight causes the bone density of anorexia nervosa patients to decrease. The reproductive functioning of anorexia nervosa patients with severe underweight is also impaired. Bulimia nervosa patients may develop oesophageal and gastric problems and sometimes dental problems, as a result of binges followed by purging. Purging bulimia nervosa patients are also at risk for cardiac arrhythmias. Binge ED patients suffer from overweight-induced physical disorders. The psychological consequences of EDs are also severe. They include preoccupation with food, shape and weight, low self-esteem, body dissatisfaction, depression and (social) anxiety. The social consequences of EDs include occupational and educational impairment, family problems, difficulties in social adjustment and interpersonal problems.

In The Netherlands patients with an ED are offered a wide variety of treatment. The general practitioner plays a central role in the health care system and functions as the “gatekeeper” to specialized treatment. Once an ED is suspected the general practitioner can refer a patient to a general hospital, if the physical condition of the patient requires this, or to a psychologist/psychiatrist in private practice, to a non-specialized outpatient or inpatient unit for mental disorders, or to a specialized centre or unit with a program specifically for EDs.

Because of the low recovery rates, high mortality, and severe consequences of EDs it is important to understand what constitutes optimal treatment of EDs. The application of evidence based treatment methods of EDs is essential. Since the first article published in JAMA by the evidence based medicine (EBM) working Group in 1992, the use of EBM methods has become more and more the standard of care (7). Sackett et al (8) describe EBM as follows: “Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care”.

The development of (multidisciplinary) treatment guidelines should facilitate the application of EBM in clinical practice. In mental health care multidisciplinary guidelines and protocols have been developed for several DSM IV disorders, among which the Dutch multidisciplinary guidelines on Eating Disorders (9). A working group of professional experts and patients’ representatives has studied the evidence on the primary issues relating to EDs. They ordered available evidence on EDs and its treatment hierarchically. The highest (or the best) level of evidence, level A, makes up a body of knowledge based on evidence from systematic reviews or randomised controlled trials (RCTs). The lowest level of evidence is level D and consists of expert opinions. Clinical expertise is thus incorporated into the guidelines and is considered as a body of knowledge, albeit of a lower order. The Dutch multidisciplinary guidelines indicate that level A scientific evidence on the treatment of anorexia nervosa is scarce, and that the findings are inconsistent. There is limited level B and C evidence that inpatient treatment is effective. The scientific level A evidence on the treatment of bulimia nervosa on the other hand is substantial. It indicates that cognitive behavioural treatment (CBT) is effective. The most important component of the effectiveness of CBT is found to be cognitive restructuring. Interpersonal therapy (IPT) is as effective as CBT over the long run, but shows results later in treatment. The Dutch multidisciplinary guidelines therefore recommend CBT as the treatment of first choice for bulimia nervosa. The level A scientific evidence of treatment of binge eating disorder is limited, but it indicates that CBT and IPT are effective for treating binge eating disorder, except in regard to weight loss (9).

A gap between evidence based knowledge and clinical practice has been often described (10, 11). Not much is known about how the ED guidelines are applied in practice. The scarcity of evidence on the treatment of anorexia nervosa affects the possibility to use these guidelines in day-to-day practice. There is also little known about the extent to which the existing evidence-based treatments for bulimia nervosa and binge eating disorder, are implemented. And although the opinions of experienced professionals about best practices are considered a body of knowledge (level D) and are incorporated into the guidelines, there is little information about whether these best practices are actually applied. In day-to-day practice, therapists from a variety of educational backgrounds approach their work from different frames of references or theoretical orientations. They may make use of treatments that are unproven or have not been the subject of academic research. The experience and authority of the therapist may still have more influence than scientific evidence. This is difficult to reconcile with the practice of EBM, where a therapist, when confronted with specific problems, seeks to integrate scientific research with clinical expertise and a patient's preferences.

The notion that patients' preferences are important arises from the changing attitudes towards patients and of patients themselves. In the last decades the patient in mental health care has evolved into a citizen with rights and duties, as recognized in several new laws (12). Today patients are considered to be emancipated citizens and the patient is sometimes referred to as a "client". On a national level patient organisations have begun to defend the interests of different groups of patients. Mental health institutions have installed client councils to provide clients a say in their treatment. Some self-help organisations are even starting to provide care themselves (13). The "empowered patient" no longer accepts the authority of a therapist based on professional prestige alone and wants to have a voice in treatment decisions. Economic developments have also influenced the attitude towards (and of) patients in mental health care. The number of patients in mental health care has increased (14). Although the interpretation of this increase is a matter of debate, mental disorders have become one of the most costly disorders to treat (15). Consequently market-driven policies have been introduced in mental health care. A patient is now also referred to as a "consumer". The government actively promotes improvements in transparency and accountability in mental health care and has taken measures that facilitate the choices a patient can make (16-19). Patients are also active in the development of guidelines. A variety of patient participation is reported. They take part in focus groups or are represented on committees that develop guidelines (20). There are examples of patient participation in the development of guidelines of, for among others, depressive disorders, anxiety disorders and EDs (21, 22). Even though patients are regarded as citizens, clients, or consumers of medical services with specific interests or values to defend, their opinions and experiences are rarely considered as a body of knowledge. Yet their views can express tacit knowledge that complements other bodies of knowledge. Whereas scientific evidence reflects empirical knowledge of treatment trials and experiments, and the therapist's views reflect expert knowledge based on education, training and experience, the patients' perspective reflects experiential knowledge.

The current thesis addresses this issue. It investigates whether and how the patients' perspective contributes to an understanding of EDs, their consequences and best treatment of EDs. It investigates whether and how the patients' experiences and views contribute to the debate on the quality of treatment of EDs. Furthermore it investigates how the patient's perspective is related to other bodies of knowledge, namely the scientific evidence and the therapists' views.

The following central questions are addressed:

1. What are the patients' views on their eating disorder, their consequences and treatment?

2. In what way can the patients' perspective contribute to a better understanding of eating disorders, their consequences and optimal treatment?

3. How is the patients' perspective related to other bodies of knowledge, namely the scientific evidence and the therapists' views?

The thesis is divided into five chapters that address the research questions consecutively. Chapter 1 describes patients' views on their ED. The participants in the study in chapter 1 were ED patients, who were recruited during their treatment at the Centre for Eating Disorders Ursula. Chapter 2 and 3 describe patient views on the consequences of their ED, namely on their quality of life. Chapter 4 describes the patients' evaluation of the treatment for EDs. Chapter 5 compares the patients' and therapists' perspectives on the quality of treatment of EDs. The participants in the study described in chapter 2 to 5 in this thesis, volunteered to take part in the "Quality Project on Eating Disorders", a collaborative project of the patient organisation, The Foundation for Anorexia and Bulimia Nervosa (SABN), the Centre for Eating Disorders Ursula, the University of Leiden and the Erasmus University of Rotterdam. The participants consisted of ED patients and former ED patients recruited from the community in the Netherlands. Participants were included in the study if they met a life time self-reported diagnosis for a DSM-IV ED, assessed with the Eating Disorder Examination Questionnaire (23, 24). The study sample of the therapists described in Chapter 5 consisted of therapists recruited through specialized treatment centres in the Netherlands and at a national teaching day on EDs. Illness models and concepts from health psychology, as described in chapter 1 to 3 (25, 26), are used to gain more insight into the perception of the ED and its consequences. Finally the general discussion addresses the central questions and findings of this research. It describes how different perspectives on EDs and its treatment, namely the scientific evidence, the therapists' and patients' perspective are and can be related.

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Chapter 1

Eating disorders patients' views on illness and recovery

This chapter has been submitted.

Introduction

Eating Disorders (EDs) can have a serious impact on several life domains and may lead to physical, social and mental impairment. Not even half of the patients with an ED fully recovers (1,2). ED patients tend to find it difficult to enter treatment and treatment drop out and relapse are common (3).

It is important to investigate how patients view their illness and (path to) recovery, because this may contribute to an understanding of their illness behaviour: “the varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilise various sources of formal and informal care” (4). This may affect treatment expectations and the ability to enter and remain in treatment.

Leventhal et al. (5) postulated that the attributes of an illness representation shape a patients’ manner of coping with or controlling the illness and play an important role in appraising coping outcomes. They developed a self-regulatory model to conceptualize the treatment adherence process. In this model, health beliefs can be characterized along five dimensions: identity of the illness (its label and symptoms), causal explanations of the illness, perceived controllability of the illness, perceived course of the illness, and the consequences of the illness for the person's life. In their review of the role of illness models in severe mental illness, Lobban, Barrowclough and Jones (6) concluded that the self-regulatory model is a useful framework for understanding beliefs about mental illness. Studies on depression and psychotic illnesses, have shown that health beliefs contribute to treatment seeking, treatment adherence, and clinical outcomes (7-10).

So far only two studies have been carried out on the illness perceptions of ED patients. In a study by Holliday et al. (11) on the illness perceptions of AN patients, it was shown that participants had fairly negative perceptions about controllability and curability of the disorder. Stockford, Turner and Cooper (12) found that 69 ED patients recruited via the Eating Disorders Association research database had a strong illness identity. They found a relationship between illness representations as measured with the IPQ-R and stage of change. Low levels of emotional distress were related to a reluctance to engage in change, whereas high scores on the emotional consequences of the ED were related to contemplation of change.

Although these studies show that illness perceptions as assessed by the IPQ-R reflect relevant aspects of ED patients' views on illness and (the path to) recovery, more disease specific insight on the perception of the course, curability and controllability of the ED may be elicited when also investigating the personal views of ED patients. So far only a few exploratory studies have investigated the personal views of ED patients on their illness and recovery.

Nordbo et al. (13) studied the meaning of self-starvation of 18 anorexia nervosa (AN) patients. They identified eight constructs of meaning: a feeling of security, avoidance of negative emotions, an inner sense of mastery, self-confidence, achieving new identity, eliciting care from others, communicating difficulties and the wish to die. Most patients mentioned more than one aspect of meaning of the ED. Gale et (14) examined the pro's and con's of change perceived by 140 AN and 62 bulimia nervosa (BN) patients, an implicit reflection of their views on their illness. AN patients felt their illness provided safety and structure, demonstrated their specialness and provided a way to communicate emotions. BN patients found the ability to eat and stay slim an advantage.

Dignon, et al. (15) asked 15 AN patients to reflect on what they thought caused their ED. They mentioned unhappiness, control, being in a downward spiral, obsession and perfectionism. Control over food was a strategy to deal with their unhappiness, one which gave them a sense of enjoyment and pride. Tozzi et al. (16) interviewed 69 life time AN patients, almost 90% of whom were recovered at the time of the study, on their perception of the causes of their ED. The most commonly mentioned perceived causes were dysfunctional families, weight loss and dieting, stressful experiences and perceived pressure. Nilsson et al. (17) interviewed 69 AN patients first 8, then 16 years after initial assessment at an adolescent psychiatric clinic to investigate patient perceptions of the causes of their ED. At the first follow up the most commonly mentioned causes were high own demands and perfectionism. At the second follow up there were more mentions of family problems.

Most studies that investigated the personal views of ED patients on the recovery process included patients who had already recovered. Hsu et al. (18)

cite the importance of personal strength, being ready for change, increased self-confidence and feeling understood in the recovery of 6 former AN patients. Marriage, children and psychotherapy were important factors for them in their recovery. In the study by Tozzi, et al. (16) the three most commonly cited factors contributing to recovery were supportive nonfamily relationships, therapy, and maturation. Keski-Rahkonen and Tozzi (19) found that 66 of 158 self-identified ED patients belonging to an internet discussion group used recovery-related words. They found willpower and distancing from the ED important to recovery and that the value of professional help was conditional on the patients' own willingness to change. Nilsson and Hagglof (20) identified turning points in the recovery process of 58 adolescents, that resulted in the recognition of the severity of the illness and acceptance of the illness. They cite friends, making one's own decisions, activities, treatment, family of origin and spouse and children as important factors in the process of recovery. At the beginning of recovery outside influences were important as was the patients' own decisions to continue the process. Pettersen and Rosenvinge (21) described the wish to change as an important factor for recovery for 48 women who were asked about their recovery process. They did not want to be dominated by the ED or wanted to avoid the consequences of the ED. Empathic and caring relationships with therapists, peers or significant others were essential to recovery. The participants stated that recovery included acceptance of oneself, interpersonal relations, problems solving and body satisfaction. Noordenbos and Seubring (22) investigated the criteria for recovery of 41 former ED patients. They identified not just changes in eating behaviour and weight restoration, but also improvement in psychological, emotional and social functioning.

The number of studies on illness perceptions is scarce and the studies investigating the personal views of ED patients on their illness and recovery are limited and vary in their scope, samples and methods. It remains unclear how exactly the self-regulatory model together with the personal views of the ED patients on their illness and recovery, may contribute to understanding ED patients' beliefs about their illness and the ability to remain in treatment, in particular of those patients who are not yet recovered and are still in treatment for their ED. Furthermore whereas Stockford et al

(15) and Cooper et al (23) investigated to what extent illness perceptions as well as self-esteem, locus of control and social support are related to stages of change, they did not examine the interrelationship between illness perceptions, social support and locus of control. It remains unclear in what way illness perceptions are related to the factors that are known – or referred to by former ED patients – to affect coping with illness, including self-esteem, self-efficacy (or a sense of mastery) and social support (16, 18, 20, 21, 24, 25).

This study aims to elaborate the current knowledge on ED patients' views on illness and recovery by investigating both the illness perceptions as assessed with the IPQ-R and the personal views of patients currently in treatment for an ED. It examines in what way illness perceptions are related to self-esteem, mastery, social support and life events, taking into account anxiety and depressive symptoms. Based on prior studies it is hypothesized that perceived causes of the ED are personality features such as perfectionism or familial problems, the burden of the ED (perceived consequences) is severe, but the views on the curability and controllability of the ED are negative, thus explaining the difficulties in treating ED patients and underscoring the need to address the illness perceptions of ED patients.

Methods

Participants

Patients were recruited at the Centre for Eating Disorders Ursula in the Netherlands in August 2007. Patients who were in clinical, day care or group treatment were asked to participate in the study. Informed consent was obtained. Twenty six patients filled out the questionnaire. Seventeen AN patients, 5 BN patients and 4 EDNOS patients participated. Sociodemographic and clinical characteristics are presented in **Table 1.**

Table 1 Sociodemographic and clinical characteristics of the participants

	N = 26
Number of female	26
Mean age (SD)	30.6 (11.6)
Median age	25.5
Diagnosis	
Anorexia Nervosa	17
Bulimia Nervosa	5
Eating disorder Not Otherwise Specified	4
Treatment modality	
Inpatient treatment	15
Day treatment	9
Outpatient treatment	2
Mean duration of current treatment (SD) *(in months)*	3.8 (2.6)
Median duration of current treatment	3.0
Educational attainment	
Primary school	0
Basic high school	4
Advanced high school	14
College/university	8
Current employment status	
Employed	11
In school	6
Both employed and in school	2
No employment or schooling	6

Number of self-reported comorbid diagnoses	
No comorbid diagnosis	11
Depressive disorder	6
Post traumatic stress disorder	3
Obsessive compulsive disorder	3
Anxiety disorder	2
Personality disorder	2
Other	2

Measures

Several questionnaires were administered. The type and content of the questionnaires administered are described below. For a description of the psychometric properties the references can be consulted.

The Illness Perception Questionnaire-R

The IPQ-R is a 70-question self-report inventory designed to assess the five dimensions of the Self-Regulatory Model, namely “control”, “cause”, “identity”, “consequences” and "time-line" of an illness (26). The dimension “identity” assesses the number of symptoms that the patient recognizes as being part of the illness (14 items). The dimension “cause” assesses the appraisal of causal factors of the illness, namely biological, genetic, environmental or psychological causes (18 items). The dimension “control” reflects the patient’s views on his own ability or the possibilities of treatment to bring about recovery or to influence the course of illness. The dimension “consequences” assesses the perceptions about the short and long term physical, social, economic and emotional consequences of the illness. The emotional consequences are also referred to as “emotional representations”. The dimension “timeline” assesses the perceived course of the illness.

The Questionnaire on Illness and Recovery

The Questionnaire on Illness and Recovery is a self-report questionnaire we developed to address the personal views of ED patients on illness and recovery. Patients are asked to reflect on seven aspects of their illness and recovery through open questions: They are asked to describe their eating problems, the meaning of the ED in their life, and why it is so difficult to let go and to name the advantages and the disadvantages of the ED. They are also asked to list the three most important causes of their ED. Finally they are asked how they would decide that they are recovered and what would have changed.

Beck's Depression Inventory II NL

The Beck Depression Inventory (BDI) is a 21-question self-report questionnaire to assess the severity of depressive symptoms. The questionnaire includes items relating to depressive symptoms such as hopelessness and irritability, cognitions such as guilt or feelings of being punished, as well as physical symptoms such as fatigue, weight loss, and lack of interest in sex (27).

The State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory (STAI) is a 40-question self-report questionnaire to assess state and trait anxiety (28). State anxiety reflects a "transitory emotional state or condition of the human organism that is characterized by subjective, consciously perceived feelings of tension and apprehension, and heightened autonomic nervous system activity." State anxiety may fluctuate over time and can vary in intensity. In contrast, trait anxiety denotes "relatively stable individual differences in anxiety proneness" and refers to a general tendency to respond with anxiety to perceived threats in the environment.

The Social Readjustment Rating Scale

The Social Readjustment Rating Scale (SRRS) is a self-report questionnaire that assesses 43 major life events, which have taken place in the previous 12 months (29). According to Holmes and Rahe a “stressor” is any “environmental, social, or internal demand which requires the individual to readjust his or hers usual behavioural pattern”. Additionally patients are asked if they have ever experienced a traumatic life event, such as sexual abuse, physical abuse, emotional neglect or another traumatic life event.

The Pearlin Mastery Scale

The Pearlin Mastery scale is a 5-question self-report questionnaire that assesses mastery (30). Mastery is conceptualized as the extent to which a person perceives himself or herself to be in control of events and ongoing situations and reflects the perception of the ability to manage them.

Rosenberg's Self-esteem

The Rosenberg's Self-Esteem questionnaire (RSE) is a 10-question self-report questionnaire. Self-esteem is defined as self-worth reflected by one's positive or negative orientation towards oneself (31,32).

Social Support Inventory

The Social Support Inventory (SSI) is a self-report questionnaire we developed that assesses both the quantity and the quality of social networks. First it asks how many people one knows, feels related to/acquainted with, or has contact with. It then asks to state the type of relationship (family, friend) and to rate the contact frequency for the first ten network members identified. Then instrumental (i.e. practical) and emotional support is assessed. Feelings of loneliness are also addressed.

Analysis

Both qualitative and quantitative analyses of the patients' views were carried out. The qualitative analysis was carried out by saving and coding every answer on the open questions. Subsequently these coded items were clustered into meaningful categories based on their content. Percentages are described in the results if more than 35% of the participants mentioned a specific aspect. Descriptive analysis was used to investigate the illness perceptions of ED patients. Standardized means were calculated. A Spearman rho test was used to examine intercorrelations on IPQ-R subscales and the correlations of self-esteem, mastery, anxiety and depression, number of comorbid diagnosis, number of life events in the past year, number of traumatic events ever, with the illness perceptions.

Results

The patients' illness perceptions

According to the IPQ-R the ED patients did not identify their illness with a lot of physical symptoms. They mentioned only a few physical complaints as a consequence of the ED. Being tired and weight loss were mentioned most often, namely by approximately 50% of the patients, followed by sleeping problems. On the causal dimension of the IPQ-R, the causes of the ED mentioned by at least two thirds of the patients were psychological causes: distress/worries, their own behaviour, mental attitude (negative thoughts), emotional state, eating habits, growing into maturity and personality. Family problems were mentioned by more than 50% of the patients. Traumatic events were mentioned by more than 46%. The patients were also asked to rank the three most important causes for their ED and- if applicable - to mention other causes not included in the IPQ-R that they felt were important. The causes of the ED they found most important were "low self-esteem" (58%), "personality or character features"(42%), "need for achievement" (38%), such a perfectionism, being overburdened at work and "negative emotions" (31%), such as anxiety, depression. Three patients mentioned severe traumatic events (sexual, physical abuse). Other causes mentioned were being bullied, set backs, feelings of loneliness, family problems, eating habits or hereditary. On the illness coherence subscale of the IPQ- R only a few said that they did not understand their ED or that the ED was a mystery to them. Regarding the consequences of the ED, most patients stated that the ED had major consequences for their life. The majority was not pessimistic about the controllability of their ED. They felt their own behaviour or/and treatment would be helpful in controlling the ED. However they were less optimistic regarding the course of the ED. A substantial number of patients thought the ED to be a long lasting or even chronic condition. The mean scores of the IPQ-R subscales (the mean scores of the subscales divided by the number of items of the subscale) are shown on **Table 2**. A Spearman rho's test was calculated to investigate the correlations among the subscales of the IPQ-R. A lower illness coherence was correlated with a higher perception of a cyclical course of the ED ($\rho = -0.40$, $p = 0.05$), and a higher emotional representation was correlated with a higher perception of a chronic course of the ED ($\rho = 0.46$, $p = 0.05$). No correlations were found among the perception of the course of the ED (cyclical or chronic), controllability, consequences and emotional representation.

Table 2 Mean scores on the illness perception questionnaire (Standardized mean (SD))

IPQ subscales (number of items)	Eating disorder patients N = 26
Timeline: chronic (6)	3.13 (0.84)
Timeline: cyclical (4)	2.83 (0.88)
Personal control (6)	3.92 (0.57)
Treatment control (5)	3.80 (0.57)
Consequences (6)	3.89 (0.53)
Illness coherence (5)	3.56 (0.51)
Emotional representation (6)	3.39 (0.62)

Note: IPQ: illness perception questionnaire, SD; standard deviation

The patients’ views on illness and recovery

The ED patients could articulate the nature of their - disturbed - eating behaviour and were aware of their eating problems. All patients referred to symptoms of their ED, such as restrictive eating pattern, the urge to control their eating habits, losing weight, binging and purging.

The patients were asked to reflect on the meaning of their ED. Fifty percent of the patients mentioned aspects that could be categorized as “identity”. They stated that their ED determined, controlled or affected all areas of their life, day and night. They could not imagine a life without an ED. Some said it kept them going, or that the ED was something that “belonged to them”. Thirty five percent mentioned aspects that could be categorized as “ a sense of safety”: their ED provided security, control or was considered to be a safe haven. Other aspects were mentioned by less than 35% of the patients. Several patients stated that the ED negatively affected their "daily functioning". They were not able to function anymore and had had to quit their studies or jobs or were not able to do "normal things". Others mentioned the "emotional consequences": the ED helped them to avoid feeling bad or was a way to deal with feelings, but on the other hand, also made them feel depressed or sad (for instance after binging). Patients also mentioned severe " social consequences": the ED negatively affected their social interactions, hindered contact, or made them feel isolated. Furthermore patients stated that the ED negatively affected their "self-esteem". One patient said the ED helped her to become invisible.

The patients reflected on why it was so difficult to let go of their ED. Fifty percent mentioned aspects related to core features of the ED, such as the fear of gaining weight, or the loss of appetite and understanding of what could be considered "eating normally". Others (< 35%) mentioned feelings of insecurity, particularly about who they would be without the ED or did not accept themselves or their bodies, the importance of remaining in control, the ED as a way of life, anxiety about making major decisions about study or career, expectations they felt they should be meeting, or being a "grown up" and the need to use their ED to cope with difficult feelings.

When reflecting on the advantages of the ED several aspects were mentioned by more than 50% of the patients: "being thin", "being in control"; more than 40% mentioned diminishing negative emotions or "don't have to feel". Some patients (< 35%) also mentioned increasing positive emotions, such as pride, an addictive feeling of emptiness, or being able to go on and on, or even a sense of "self-esteem". The "attention" of others or being freed of obligations because of the ED was also mentioned by a few others.

The perceived disadvantages outnumbered the advantages. More than 80% of the patients mentioned the "physical consequences", such as lack of energy, physical pain, feeling cold, sleeping problems, concentration problems, being physically exhausted. About 70% mentioned negative "social consequences". They felt isolated, lonely, and not able to maintain or engage in social contacts or felt sad about other people worrying about them. Sixty five percent mentioned "emotional consequences", such as feeling depressed, tired of life, ashamed, guilty, and emotionally unstable, being irritable, or not being able to enjoy. Almost half of the patients' sample mentioned "being controlled by the ED", such as always thinking about it, not being able to do anything else. Other aspects mentioned (< 35%) were an impaired "quality of life", such as not being able to do nice or interesting things and "professional consequences", such as losing a job or quitting a study.

When reflecting on recovery (how would they determine that they were recovered and what would have changed) more than 75% mentioned their life would no longer revolve around eating or worrying about food or weight, some thought they then would accept their weight and move on. Sixty five percent stated that they would live a happy life, without worries or anxiety, be more cheerful or relaxed or able to enjoy life. Almost 60% would have a higher self-esteem. More than 40% would have more or better relationships with significant others. Other aspects mentioned (< 35%) were an improved physical health or condition or getting back to work or study.

The relationship of illness perceptions with self image, psychological complaints, perceived social support and life events

A Spearman rho's test was calculated to investigate the relationship between illness perception and self-esteem, sense of mastery, perceived social support, anxiety, depression, number of comorbid diagnoses, age, duration of treatment, life events in the previous year, life time traumatic experiences and duration of current treatment. The results are shown on **Table 3**. A low self-esteem, a low sense of mastery, more depressive symptoms, and an older age were correlated with a high perceived chronicity of the ED. A longer duration of current treatment was correlated with higher treatment control. A high number of traumatic events was correlated with a low perceived personal control. A low satisfaction with social support and shorter duration of current treatment was correlated with a higher perceived cyclical timeline of the ED. A low sense of mastery and more depressive symptoms were correlated with a high emotional representation of the ED.

Table 3 Spearman rho correlations for self-esteem, mastery, psychological complaints, perceived social support, life events, duration of current treatment and the subscales of the illness perception questionnaire

	RSE	Ma	BDI II	Com	Soc	LE	Trauma	Age	Tr
Timeline (chronic)	−0.53**	−0.55*	0.69**					0.52**	
Timeline (cyclical)									−0.40*
Personal control							−0.60**		
Treatment control									0.48*
Consequences									
Illness coherence									
Emotional representation		−0.45*	0.43*						

Note: RSE: Rosenberg's self-esteem; Ma: Pearlin's Mastery; BDI II: Beck depression inventory/depressive symptoms; Com: number of comorbid diagnoses; Soc: perceived social support; LE: number of life events in the past year; Trauma: life time traumatic experiences, TR: duration of current treatment

* Level of significance: two tailed, $p = 0.05$

** Level of significance: two tailed, $p = 0.001$

Discussion

Patients who are in treatment to recover from an ED still tended to have a strong illness identity. The most important causes of the ED they mentioned were low self-esteem, personality, need for achievement, i.e. perfectionism, or emotional state. The perceived consequences of the ED were severe and included physical, social and emotional consequences. Patients were not pessimistic about the controllability of the ED. However this was not associated with the perceived course of the ED. Patients with a low self-esteem, low sense of mastery and more depressive symptoms tended to view the ED as more chronic.

The illness representations of eating disorder patients

The IPQ-R showed to be a useful instrument to gain insight in the illness representations of ED patients, whereas the personal views of ED patients revealed several disease specific aspects of these illness representations.

All ED patients in this study had entered treatment and seemed willing to take action and use the sources of care: The burden of the ED (i.e. the perceived severe consequences) may have persuaded patients to enter treatment. In our sample the perceived disadvantages of the ED mentioned outnumbered the advantages. The ED patients who entered treatment did not or did no longer deny their eating problems as they were able to articulate the nature of their problems. Although the identity dimension of the IPQ-R did not show a strong illness identity, the personal statements of the ED patients showed they still tended to have a strong illness identity: their life revolved around their illness or seemed to be a way to cope with life. Important advantages were directly linked to ED symptoms, such as the wish to be thin. Although there was a lot of agreement on the perceived -severe- consequences of the ED, the meaning the patients attributed to the ED varied. When reflecting on the most important causes of the ED many patients mentioned psychological causes, namely low self-esteem or personality characteristics, as has been found in previous studies (15, 17). While family problems were also mentioned as “cause” of the ED, as was found retrospectively in earlier studies (16, 17), this was not ranked as one of the most important causes of the ED of the patients in our study. The ED patients in our sample were not pessimistic about the controllability of the ED, whether by means of their own behaviour or treatment. A longer duration of current treatment was associated with the belief they could benefit from treatment. The perceived controllability contrasted the findings of Holliday (11) and our own expectations. The patients’ reflections on causes and controllability may reveal an internalizing attribution style. However the perceived controllability of the ED symptoms was not correlated with the perceived course (and thus outcome) of the ED. Their thoughts on recovery showed that they were aware that their ED hinders them from returning to a normal life, and that they hoped their life after recovery would no longer revolve around eating. They strongly felt the need for a greater self-esteem or an alternative way of dealing with difficulties or emotions, in order to be able to live a “happy life”. However the high value most patients placed on “being thin”, and the strong illness identity may explain the lack of correlation between perceived controllability and perceived course of the ED. Those patients who were the most vulnerable, namely those patients with a low self-esteem, low sense of mastery and more depressive symptoms had a higher perceived chronicity of the ED and seemed to have lower expectations or hopes for change. Furthermore the IPQ-R controllability subscales were also not correlated with Pearlin’s Mastery scale. This implies that ED patients may think their behaviour or/and adherence to treatment will contribute to controlling their ED, but this is not associated with a sense of mastery over life’s difficulties in general.

Implications for treatment

The patients of this study who had entered treatment and were in the midst of their treatment process seemed to be confronted with conflicting values, with the perceived burden of the ED on one hand and the strong illness identity on the other hand. It seems important to overcome these conflicting values in treatment. Earlier studies described the wish to change as an important aspect in the recovery process (18- 21). Geller et al. (3, 33) who stress the importance of readiness to change to clinical outcome, found an association between improvement in readiness to change and enhanced insight about the function of the ED, less psychiatric distress, and changes in the self-concept. Those patients assigned higher value to relationships and personal development and lower value to physical appearance. From the start of treatment, throughout the whole treatment trajectory it seems important to address a wide range of problems and not merely the ED symptoms - to outweigh the perceived “advantages” of the ED that contribute to the strong illness identity, including maladaptive beliefs about themselves, their self-esteem and (differentiation of) identity, depressive symptoms, emotion regulation and life skills. Furthermore the ED patients in our study considered the social consequences to be severe, whereas other studies identified patients’ perceptions about social relationships as important for the recovery process (18-21). Therefore it also is important to address the social consequences of the ED in treatment.

Limitations and strengths

A limitation of the current study is the small number of participants. Furthermore the majority of the sample consisted of patients with AN, although patients with BN and EDNOS also participated. The strength of the study is that it is the first study to investigate the views on both illness and recovery of a sample of patients still in treatment of their ED. It clarifies illness behaviour of ED patients and complements the current literature on the patient’s views on illness and recovery. It helps to understand which aspects need to be addressed throughout the treatment trajectory to prevent early treatment drop out or relapse.

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Chapter 2

Quality of life and eating disorders

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Introduction

Eating disorders (EDs) can have a serious impact on various life domains of those inflicted and may lead to physical, mental and social impairment(1). Physical impairment and medical complications are commonly due to disturbed eating behaviour and abnormal compensatory behaviour such as self-induced vomiting or laxative misuse (1). Anorexia nervosa patients are at risk for starvation-induced cardiovascular and renal alterations that may lead to arrhythmias and sudden death, mostly among those with purging behaviour. Due to malnutrition and low body weight the bone density of anorexia nervosa patients will decrease.

Reproductive functioning of anorexia nervosa patients with severe underweight is impaired.

Physical impairment of bulimia nervosa patients, resulting mainly from binges followed by self-induced vomiting or laxative abuse, include oesophageal and gastric problems and sometimes dental problems. Purging bulimia nervosa patients are also at risk for cardiac arrhythmias. Many patients with a binge eating disorder suffer from physical complaints due to overweight. Mental impairment of anorexia nervosa and bulimia nervosa patients varies (2). Comorbidity with affective disorders is found in anorexia nervosa patients. Comorbid affective disorders, anxiety disorders, substance-use disorders and cluster B personality disorders are found in bulimia nervosa patients. Cognitive impairment of patients with EDs includes preoccupation with food, shape and weight, low self-esteem, body dissatisfaction, depression and (social) anxiety (1,2). Social impairment of ED patients includes occupational and educational impairment, disrupted family life, interpersonal problems and difficulties in social adjustment (1,2).

These physical, mental and social impairments can be long-lasting. In a summary of 119 outcome studies on anorexia nervosa, Steinhausen et al. (3) found that 46.9% of anorexia nervosa patients recover from the disorder, 33.5% recover partially, as many as 20.8% will develop a chronic disorder and 5% of anorexia nervosa patients eventually die. In a summary of 24 outcome studies on bulimia nervosa, Steinhausen et al.(4) found that 47.5% of bulimia nervosa patients recover, 26% recover partially and 26% develop a chronic disorder.

When the ED evolves into a chronic disorder the impairments, disabilities and handicaps in several life domains may have a major impact on the course of a patients' life. Therefore it is important to assess the quality of life of ED patients. However, few studies have assessed the quality of life (QOL) of patients with an ED. In a study by Padierna et al. (5) female ED patients recruited at an outpatient clinic for EDs were more dysfunctional than women in the general population in all areas of the SF-36. No differences were found between diagnostic groups. The study showed that more severe EDs were associated with poorer QOL. Even after 2 years of treatment and follow up ED patients were still more dysfunctional in all areas than women of the general population although their perception of the QOL improved (6). In a large community sample Hay (7) found that bulimic eating disorder behaviour was correlated with poor QOL, particularly on the Mental Health scale of the SF-36. In a study by Keilen et al. (8) ED patients had a poorer QOL than controls as measured by the Nottingham Health Profile. In particular psychosocial domains, emotional reactions, social isolation and sleep were reported as impaired. Anorectic patients reported more impairment of mobility, social life and home relationships than did bulimic patients. Danzl et al. (9) examined the QOL of former ED patients of an outpatient clinic using the Lancashire Quality of Life Profile and found that a positive change in eating behaviour was associated with a better QOL. Bijl et al. (10) found EDs to be very debilitating.

Although findings reported in these studies reveal a poor QOL of ED patients, the impact of an ED on patients' lives still remains unclear. In these studies different instruments were used to assess the QOL. Due to a small sample size of some studies analyses were limited. Comparison of the QOL of ED patients with the QOL of a normal reference group has only been carried out once (5). The relative burden of EDs in comparison with other mental disorders has not been thoroughly investigated. Furthermore it is not clear what factors are associated with QOL of ED patients. The severity of the ED pathology can influence the QOL (5,6), but also sociodemographic characteristics such as age, living situation, unemployment, traumatic youth experiences and comorbid psychological complaints may influence the QOL

(10, 11). Based on the transdiagnostic theory of Fairburn et al. (12) in which core low self-esteem is an important underlying maintaining mechanism of EDs, it is presumed that self-esteem may also contribute to the QOL of ED patients. So far these factors have not been investigated in earlier studies.
The present study was intended to fill this gap. The aim of the present study was to examine the QOL of ED patients in a large community sample. The study investigated whether the QOL differs between four diagnostic groups: anorexia nervosa patients, bulimia nervosa patients, eating disorder not otherwise specified patients and former ED patients: patients who met DSM-IV criteria for an ED in the past, but not at present. The study examined whether the QOL differs between ED patients and a normal reference group. The QOL of ED patients was compared with the QOL of patients with mood disorders. Finally this study investigated what factors influence the QOL.

Methods

Participants

The study population consisted of ED patients and former ED patients recruited from the community in the Netherlands; all had participated voluntarily in a large study on the quality of care for EDs. Participants were recruited from all parts of the country by different methods. The majority of the sample was recruited via articles and advertisements in newspapers and a women's magazine and the patient organization for EDs. Another part of the sample was recruited through specialized ED clinics. Participants were included in the study if they met a life time self-reported diagnosis for a DSM-IV ED (13). Life time diagnosis for a DSM-IV ED was based on the diagnostic items of the self-report Eating Disorder Examination Questionnaire, information on body mass index (weight in kilogram/height in metre^2) and menstrual status. Participants filled out the Eating Disorder Examination Questionnaire, and answered questions about weight, height and menstrual status for what they perceived the period they suffered most from their ED (worst period). If they met life time criteria for a DSM-IV ED for that period, they were included in the study.

Instruments

After positive screening for life time diagnosis for a DSM-IV ED, the Eating Disorder Examination Questionnaire was administered again, but now to assess current ED pathology. The Eating Disorder Examination Questionnaire is a self-report questionnaire developed by Fairburn (14). It includes 36 questions on eating behaviour in the past 28 days. The questionnaire consists of diagnostic items and four subscales: Restraint, Eating Concern, Shape Concern and Weight Concern. Diagnostic items include questions based on DSM-IV criteria for EDs relating to feeling of fatness, fear of gaining weight, bulimic episodes, dietary restriction, compensatory behaviour (for instance self-induced vomiting or laxative misuse), importance of shape or weight for self-esteem and abstinence from weight control behaviour. The diagnostic items are rated on a 6 point scale and address the past 28 days. When appropriate respondents are requested to provide a frequency count. So that all criteria for an ED could be assessed according to the DSM-IV, additional questions were asked about weight, height to calculate body mass index and menstrual status. An algorithm reliably assigned DSM-IV diagnosis for an ED or no current diagnosis for an ED. The four subscales contain questions regarding distorted cognitions about eating, dieting, weight or shape or eating behaviour and provide insight into the nature or severity of the ED. In a recent study by Mond et al. (15) the validity of the Eating Disorder Examination Questionnaire in comparison to the Eating Disorder Examination (interview) in screening for EDs in a community sample was investigated. The Eating Disorder Examination Questionnaire has good concurrent validity and acceptable criterion validity and can therefore be used in a community based sample.

The Short Form-36 (SF-36), a generic health related quality of life questionnaire was administered, in order to assess QOL (16,17). The SF-36 incorporates questions about (role) functioning and satisfaction with various life domains. The SF36 consists of 36 questions and evaluates Physical Functioning, Physical Role Functioning, Bodily Pain, General Health Perception, Vitality, Social Functioning, Emotional Role Functioning and Mental Health. SF-36 scales scores range from 0 to 100. A higher score indicates a better QOL.

Self-esteem was assessed by means of Rosenberg’s Self-Esteem questionnaire (18). This consists of 10 questions on self worth and is used to assess one’s positive or negative orientation towards oneself. The scale generally has a high reliability. Test-retest correlations are in the range of 0.82-0.88. Cronbach’s a are in the range of 0.77-0.88. Studies have demonstrated a unidimensional and a two-factor (self-confidence and self-deprecation) structure to the scale (19, 20).

Questions about personal and contextual factors such as sociodemographic characteristics, psychological complaints at present i.e. anxiety, depressive or obsessive compulsive complaints and traumatic history, i.e. sexual or physical abuse or emotional neglect in the past were included.

Analyses

Mean scores on the subscales of the SF-36 were calculated for four groups, namely anorexia nervosa patients, bulimia nervosa patients, eating disorder not otherwise specified patients and former ED patients. One Way Analysis of Variance (ANOVA) with *post hoc* Scheffe was used to compare the QOL of the different diagnostic groups: anorexia nervosa, bulimia nervosa and eating disorder not otherwise specified, and former ED patients. A *t*-test for independent samples was used to compare the ED patients and former ED patients with a normal reference group of Dutch women on QOL (21).

A *t*-test for independent samples was used to compare ED patients both with published data of a group of patients with mood disorders of a Dutch community based sample and with published data of a group of American clinically depressed patients on QOL (10, 16). To investigate which factors are associated with the QOL in our sample a General Linear Model Univariate analysis was performed for each SF-36 subscale (22).

Results

Of the 304 participants, 156 (51.3%) met DSM-IV criteria for an ED in the present: 44 (14.5%) met criteria for anorexia nervosa, 43 (14.1%) for bulimia nervosa and 69 (22.7%) for eating disorder not otherwise specified. Of the eating disorder not otherwise specified patients 10 met criteria for binge eating disorder, others met (sub)threshold criteria for anorexia nervosa or bulimia nervosa. Of the participants who had met criteria for an ED in the past, 148 (48.7%) did not meet criteria for an ED in the present (former ED patients).

Sociodemographic characteristics and clinical data of the various diagnostic groups are presented in **Table 1**. Participants were predominantly women with a mean age of 28.7 years (SD 8.9). The median age was 27.0 years. Mean duration of illness was of 9 years (SD 8.5). The median of the duration of illness was 6.0 years. No significant differences were found on the sociodemographic characteristics between the diagnostic groups.

Table 2 shows the mean scores on SF-36 subscales of the different diagnostic groups and former ED patients in our sample and the results of the ANOVA. ED patients had significantly poorer QOL than the former ED patients on the SF-36 subscales Physical Role Functioning, Emotional Role Functioning, Vitality, General Health Perception, Social Functioning and Mental Health. One-way analysis of variance did not reveal any significant differences between ED diagnostic groups with regard to the QOL, except on General Health Perception. Anorexia nervosa and eating disorder not otherwise specified patients reported poorer QOL than former ED patients on General Health Perception, but not bulimia nervosa patients.

Table 1. Sociodemographic and clinical data of patients with eating disorders by diagnostic group and former eating disorder patients

	AN	BN	EDNOS	Former ED
Female (%)	44 (100)	41 (95.3)	68 (98.6)	145 (96.7)
Age (years)				
Mean (SD)	26.3 (9.1)	29.0 (7.8)	29.4 (9.1)	28.7 (8.9)
Educational level (%)				
Primary school	5 (11.4)	0 (0)	2 (2.9)	7 (4.7)
Basic high school	5 (11.4)	7 (16.3)	8 (11.6)	14 (9.3)
Advanced high school	23 (52.3)	25 (58.1)	37 (53.6)	72 (48.0)
College/University	11 (25.0)	11 (25.6)	22 (31.9)	57 (38.0)
Urbanization (%)				
Very Highly urbanized	7 (15.9)	10 (23.3)	20 (29.0)	51 (34.0)
Highly urbanized	13 (29.5)	13 (30.2)	22 (31.9)	46 (30.7)
Urbanized	10 (22.7)	13 (29.5)	12 (17.4)	29 (19.3)
Rural	5 (11.4)	2 (4.7)	10 (14.5)	11 (7.3)
Very rural	9 (20.5)	4 (9.3)	4 (5.8)	13 (8.7)
Age of onset (years)				
Mean (SD)	16.3 (4.8)	16.3 (4.3)	16.7 (4.5)	16.1 (3.8)
BMI				
Mean (SD)	15.6 (1.5)	21.6 (3.5)	21.0 (5.9)	22.3 (5.0)
Diagnosis at worst period (%) (DSM-IV)				
AN	44 (100)	26 (60.5)	54 (78.3)	98 (66.2)
BN	0 (0)	12 (27.9)	5 (7.2)	24 (16.2)
EDNOS	0 (0)	5 (11.6)	10 (14.5)	26 (17.6)
Duration of illness in years[a]				
Mean (SD)	7.9 (7.2)	11.3(9.7)	10.0 (9.0)	8.5 (8.2)

Note: AN: anorexia nervosa; BN: bulimia nervosa; EDNOS: eating disorder not otherwise specified.
Very highly urbanized: ≥ 2500 addresses per km^2; highly urbanized: 1500-2500 addresses per km^2; urbanized: 1000-1500 addresses per km^2; rural 500-1000 addresses per km^2; very rural: <500 addresses per km^2; BMI: body mass index (kg/m^2).
Due to missing values not all columns add up to N.

[a] N = 280.

Table 2. Distribution of the SF-36 scores of patients with eating disorders by diagnostic group with one way analysis of variance

	AN Mean SD (N = 44)	BN Mean SD (N = 43)	EDNOS Mean SD (N = 69)	Former ED Mean SD (N = 148)	ANOVA		*Post hoc* Scheffe
					F	*p*	
PF	80.2 (18.2)	84.5 (15.4)	81.7 (22.1)	88.3 (18.0)	3.19	0.024	-
RP	42.0 (37.7)	44.6 (39.2)	47.7 (43.6)	65.1 (39.4)	6.37	0.0005	Former ED > AN, BN, EDNOS
BP	65.9 (23.1)	67.8 (19.6)	64.6 (26.3)	71.6 (23.6)	1.64	0.18	-
GHP	48.8 (21.3)	52.5 (17.5)	52.3 (21.5)	61.7 (22.1)	6.29	0.0005	Former ED > AN, EDNOS
VT	39.5 (17.7)	36.2 (15.7)	41.4 (16.1)	53.1 (19.8)	14.87	0.0005	Former ED > AN, BN, EDNOS
SF	46.6 (22.5)	42.2 (26.4)	52.4 (23.7)	65.5 (24.7)	14.77	0.0005	Former ED > AN, BN, EDNOS
RE	29.5 (36.8)	22.2 (32.6)	27.8 (37.2)	49.9 (42.1)	9.00	0.0005	Former ED > AN, BN, EDNOS
MH	41.6 (16.6)	38.3 (16.9)	44.1 (16.3)	59.7 (18.8)	26.42	0.0005	Former ED > AN, BN, EDNOS

Note: AN: anorexia nervosa; BN: bulimia nervosa; EDNOS: eating disorder not otherwise specified; PF: physical functioning; RP: physical role functioning; BP: bodily pain; GHP: general health perception; VT: vitality; SF: social functioning; RE: emotional role functioning; MH: mental health.

ED patients had significantly poorer QOL than a normal reference group of women in the Netherlands on all SF-36 subscales except Physical Functioning (**Tables 3** and **4**). When effect sizes were compared differences were found between subscales of the SF-36. Large effect sizes were found for General Health Perception, Vitality, Social Functioning, Emotional Role Functioning and Mental Health when comparing the two groups. A medium effect size was found for Physical Role Functioning. A small effect size was found for Bodily Pain. The former ED patients had a significantly poorer QOL than women from a normal Dutch reference group on all SF-36 subscales except for Bodily Pain. Medium effect sizes were found for Vitality, Social Functioning, Emotional Role Functioning and Mental Health. Small effect sizes were found for Physical Functioning, Physical Role Functioning and General Health Perception. ED patients reported significantly poorer QOL on al-most all SF-36 subscales when compared to people who met DSM IV criteria for mood disorders in the preceding year, except on Physical Functioning. Large effect sizes were found for Social Functioning and Emotional Role Functioning. Medium effect sizes were found for Physical Role Functioning and Vitality. Small effect sizes were found for Bodily Pain and General Health Perception. However when compared to published data of a group of clinically depressed patients no significant differences were found on Physical Role Functioning, General Health Perception and Vitality. ED patients report significantly poorer QOL on SF-36 subscales Social Functioning, Emotional Role Functioning and Mental Health, although effect sizes are small. ED patients report a significantly better Physical Functioning and Bodily Pain than clinically depressed patients.

Table 3. SF-36 mean scores of patients with eating disorders, normal females and mood disorder patients

SF-36 subscales	ED Mean (SD) (N = 156)	Normal Femalesa Mean (SD) (N = 767)	Mood disorder b Mean (SD) (N = 591)	Clinically depressedc Mean (SD) (N = 502)
PF	82.1 (19.4)	80.4 (24.2)	85.1 (21.9)	71.6 (27.2)
RP	45.2 (40.6)	73.8 (38.5)	69.9 (41.3)	44.4 (40.3)
BP	65.8 (23.6)	71.9 (23.8)	72.7 (26.7)	58.8 (26.7)
GHP	51.4 (20.4)	69.9 (20.6)	61.1 (21.9)	52.9 (23.0)
VT	39.4 (16.5)	64.3 (19.7)	51.3 (21.9)	40.1 (21.1)
SF	47.9 (24.4)	82.0 (23.5)	70.9 (26.7)	57.2 (27.7)
RE	26.8 (35.8)	78.5 (35.7)	62.2 (41.3)	38.9 (39.8)
MH	41.8 (16.6)	73.7 (18.2)	-*	46.3 (20.8)

Note: ED: eating disorder; PF: physical functioning; RP: physical role functioning; BP: bodily pain; GHP: general health perception; VT: vitality; SF: social functioning; RE: emotional role functioning; MH: mental health.

[a] Aaronson NK, Muller M, Cohen PDA, Essink-Bot ML, Fekkes M, Sanderman R, Sprangers MAG, te Velde A, Verrips E. Translation, validation and norming of the dutch language version of the SF-36 health survey in community and chronic disease populations. J Clin Epidemiol 1998; 51(11): 1055-1068.

[b] Bijl RV, Ravelli A. Current and residual functional disability associated with psychopathology: Findings from the Netherlands Mental Health Survey and Incidence Study (NEMESIS). Psychol Med 2000; 30: 657-668.

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* The SF-36 MH score of this sample was not published.

Table 4. Differences of the mean scores on the SF-36 subscales

SF-36 subscales	ED – Normal[a]		Former – Normal[a] ED		ED – Mood disorder[b]		ED – Clinically depressed[c]	
	t-value	ES	*t*-value	ES	*t*-value	ES	*t*-value	ES
PF	0.95 **	0.07	4.56	0.34	1.67 **	0.14	5.32	0.41
RP	8.00	0.74	2.50	0.23	6.60	0.60	0.22 **	0.02
BP	2.87	0.26	0.14 **	0.01	3.11	0.26	3.09	0.27
GHP	10.24	0.90	4.18	0.39	5.20	0.45	0.78 **	0.07
VT	16.47	1.30	6.31	0.57	7.39	0.57	0.43 **	0.03
SF	16.01	1.44	7.50	0.70	10.26	0.88	4.02	0.34
RE	16.30	1.45	7.72	0.78	10.52	0.88	3.55	0.31
MH	21.35	1.78	8.50	0.77	–	–	2.76	0.23

Note: ED: eating disorder; PF: physical functioning; RP: physical role functioning; BP: bodily pain; GHP: general health perception; VT: vitality; SF: social functioning; RE: emotional role functioning; MH: mental health; ES: effect size (Cohen, 1975: small: 0.2-0.5; medium 0.5-0.8; large >0.8).

[a] Aaronson, NK, Muller, M, Cohen, PDA, Essink-Bot, ML, Fekkes, M, Sanderman, R, Sprangers, MAG, te Velde A, Verrips, E. Translation, validation and norming of the Dutch language version of the SF-36 health survey in community and chronic disease populations. J Clin Epidemiol 1998; 51(11): 1055-1068.

[b] Bijl RV, Ravelli A. Current and residual functional disability associated with psychopathology: Findings from the Netherlands Mental Health Survey and Incidence Study (NEMESIS). Psychol Med 2000; 30: 657-668.

[c] Ware JEJ, Snow KK, Kosinski MA, Gandek B. SF-36 Health Survey, Manual and Interpretation Guide. Boston: The Health Institute, New England Medical Center, 1993.

All *t*-tests are significant at $p < 0.01$; ** not significant

Using General Linear Model Univariate analysis we investigated the association between each of the SF-36 subscales (dependent variables) and the ED patients and the former ED patients. personal and contextual factors and eating Factors used were educational level, participation pathology (independent variables) for two groups: in a job and/or education at present, current living situation, urbanization level, traumatic history and psychological complaints at present. Covariates used were Eating Disorder Examination Questionnaire subscales at the worst period in the past and at present (Restraint, Eating Concern, Weight Concern, Shape Concern), body mass index at worst period of the ED, current body mass index, age of onset, present age, duration of the ED and Rosenberg Self-esteem. In the analysis variables with the highest *p*-value were excluded in a stepwise fashion until a stable model was found for each SF-36 subscale. **Table 5** shows the results of the General Linear Model analysis for ED patients and former ED patients.

Table 5. Relationships between contextual and personal factors, eating disorder pathology and quality of life of eating disorder patients and former eating disorder patients

		Educational level		Participation in job or education		Urbanization		Psychological complaints	
Factors	Adj R^2	B	*p*-value	B	*p*-value	B	*p*-value	B	*p*-value
PF^{ED}	0.29								
$\text{PF}^{\text{Former ED}}$	0.41					32.52	0.0005^{VHU}		
						30.28	0.0005^{HU}		
						25.76	0.002^{U}		
						32.64	0.0005^{R}		
RP^{ED}	0.18								
$\text{RP}^{\text{Former ED}}$	0.23								
BP^{ED}	0.23								
$\text{BP}^{\text{Former ED}}$	0.22								
RE^{ED}	0.36					26.66	0.053^{R}	31.68	0.001
$\text{RE}^{\text{Former ED}}$	0.34							32.85	0.002
VT^{ED}	0.25								
$\text{VT}^{\text{Former ED}}$	0.53			16.17	0.002^{JOB}				
				11.86	0.042^{EDU}				
				16.71	$0.004^{\text{JOB/EDU}}$				
GHP^{ED}	0.24								
$\text{GHP}^{\text{Former ED}}$	0.32								
SF^{ED}	0.36							15.72	0.011
$\text{SF}^{\text{Former ED}}$	0.61			19.10	0.001^{JOB}				
MH^{ED}	0.53			7.24	0.040^{JOB}			12.77	0.001
				8.24	0.040^{EDU}				
$\text{MH}^{\text{Former ED}}$	0.74	15.08	0.014^{PS}	20.10	0.0005^{JOB}				
		18.49	0.0005^{BHS}	16.83	0.0005^{EDU}				
				12.60	$0.003^{\text{JOB/EDU}}$				

Table 5. Continued

	EDE subscales then		EDE subscales present		BMI at worst period		BMI at present	
Covariates	B	*p*–value	B	*p*–value	B	*p*–value	B	*p*–value
PF^{ED}	0.80	0.003^{SC}	−0.75	0.0005^{SC}	−1.48	0.0005	−1.21	0.013
PF$^{Former\ ED}$								
RP^{ED}			−1.90	0.003^{EC}				
RP$^{Former\ ED}$								
BP^{ED}								
BP$^{Former\ ED}$								
RE^{ED}	1.89	0.001^{SC}						
	−2.64	0.002^{WC}						
RE$^{Former\ ED}$								
VT^{ED}								
VT$^{Former\ ED}$								
GHP^{ED}								
GHP$^{Former\ ED}$			0.92	0.012^{SC}				
SF^{ED}	0.88	0.014^{RS}						
	1.56	0.007^{EC}						
SF$^{Former\ ED}$			−1.42	0.004^{EC}				
MH^{ED}			−0.54	0.006^{EC}				
MH$^{Former\ ED}$			−1.04	0.0005^{EC}				

(continued next page)

Table 5. Continued

	Age of onset		Age		Duration ED		Self-esteem	
Covariates	B	*p*-value	B	*p*-value	B	*p*-value	B	*p*-value
PF^{ED}					−0.001	0.003		
$PF^{Former\ ED}$							1.01	0.001
RP^{ED}								
$RP^{Former\ ED}$							2.52	0.0005
BP^{ED}					−0.003	0.0005		
$BP^{Former\ ED}$					−0.003	0.0005		
RE^{ED}								
$RE^{Former\ ED}$							2.19	0.012
VT^{ED}							1.11	0.001
$VT^{Former\ ED}$	1.48	0.005					2.06	0.0005
GHP^{ED}							1.08	0.003
$GHP^{Former\ ED}$							1.79	0.0005
SF^{ED}	−2.19	0.001	1.73	0.001	−0.005	0.0005	1.58	0.0005
$SF^{Former\ ED}$					0.003	0.006	2.71	0.0005
MH^{ED}	−1.20	0.003	0.97	0.001	−0.003	0.001	1.50	0.0005
$MH^{Former\ ED}$	1.30	0.001			0.002	0.007	2.18	0.0005

Note: ED: eating disorder; PF: physical functioning; RP: physical role functioning; BP: bodily pain; GHP: general health perception; VT: vitality; SF: social functioning; RE: emotional role functioning; MH: mental health; Adj. R^2: adjusted *r* square; VHU: very highly urbanized: 2500 addresses per km^2; HU: highly urbanized: 1500–2500 addresses per km^2; U: urbanized: 1000–1500 addresses per km^2; R: rural 500–1000 addresses per km^2; very rural: <500 addresses per km^2; duration of the ED: in days; SC: shape concern; EC: eating concern; WC: weight concern; RS: restraint; JOB/EDU: job and education; EDU: education; PS: primary school; BHS: basic high school.
B and *p*-values are presented of factors and covariates with an overall significance of $p < 0.01$.

First the results of the General Linear Model analysis for ED patients are described for each SF-36 subscale. The factors or covariates with the largest contribution are mentioned first. Less Shape Concern at present, a lower body mass index at the worst period of the ED, more Shape Concern in the past and a shorter duration of the ED were associated with a higher score on Physical Functioning. A lower score on Eating Concern at present was associated with a higher score on Physical Role Functioning. A shorter duration of the ED was associated with a higher score on Bodily Pain. Living in rural areas, more Shape Concern in the past, no current psychological complaints and less Weight Concern in the past were associated with a higher score on Emotional Role Functioning. A higher self-esteem was associated with a higher score on Vitality. A higher self-esteem was associated with a higher score on General Health Perception. A shorter duration of the ED, a higher self-esteem, an older age, a younger age of onset, more Eating Concern in the past, no current psychological complaints and more Restraint in the past were associated with a higher score on Social Functioning. A higher self-esteem, participation in a job or education, a shorter duration of the ED, no current psychological complaints, an older age, a younger age of onset and less Eating Concern at present were associated with a higher score on Mental Health.

Secondly the results of the General Linear Model analysis are described for former ED patients for each SF-36 subscale. The factors or covariates with the largest contribution are mentioned first. Not living in very rural areas, a higher self-esteem and a lower current body mass index, not lower than 17.5 were associated with a higher score on Physical Functioning. A higher self-esteem was associated with a higher score on Physical Role Functioning. A shorter duration of the ED was associated with a higher score on Bodily Pain. No current psychological complaints and a higher self-esteem were associated with a higher score on Emotional Role Functioning. A higher self-esteem, participation in a job or education or both and an older age of onset of ED were associated with a higher score on Vitality. A higher self-esteem and more Shape Concern at present were associated with a higher score on General Health Perception. A higher self-esteem, participation in a job, less Eating Concern at present and a longer duration of the ED were associated with a higher score on Social Functioning. A higher self-esteem, participation in a job or in education or both, an educational level of primary school or basic high school, less Eating Concern at present, an older age of onset and a longer duration of the ED were associated with a higher score on Mental Health.

Discussion

In this large community based study we found that the QOL of ED patients was substantially worse than the QOL of a normal reference group and was even worse than the QOL of patients with mood disorders. The former ED patients still reported a poorer QOL than a normal reference group. Our findings underscore the impact of EDs on physical, psychological and social well-being, even after recovery of symptoms. The impact of EDs on the QOL was even relatively more severe than the impact of mood disorders. Self-esteem showed the highest association with the QOL of both ED patients and former ED patients.

Severity of the eating disorder, residual effects of psychopathology and quality of life

We found that the SF-36 discriminated between ED patients and former ED patients, but not between diagnostic groups. In keeping with findings of Padierna (5) we found that severe eating disorder pathology was associated with poorer QOL. The QOL of the former ED patients was still worse than that of a normal reference group, although effect sizes were smaller than the effect sizes of the comparison between ED patients and the normal reference group. We assume that although recovery of the symptoms had occurred, residual effects of the disorder may still have been manifest (10). Bijl and Ravelli found that people - with different types of psychiatric disorders - whose last psychiatric episode was more than 12 months earlier still showed diminished functioning at assessment (10).

It is of note that the ED patients reported worse QOL than a Dutch community based sample with mood disorders. The relative burden of EDs may therefore be more severe than that of mood disorders. However diagnosis of an ED in our study was assessed based on the preceding 28 days. In contrast diagnosis for a mood disorder in the study of Bijl and Ravelli was assessed as present if it occurred over the preceding year (10). The difference of QOL of ED patients and mood disorder patients might thus partly be explained by more acute psychopathology of the ED patients in comparison with the mood disorder patients. However when compared to published data of an American sample of clinically depressed patients (16) ED patients in our study still reported significantly worse QOL on the subscales Social Functioning, Emotional Role Functioning and Mental Health.

Personal and contextual factors in relation to quality of life

In both ED patients as well as former ED patients a personal factor, self-esteem contributed most to the QOL. This finding is in line with the transdiagnostic theory of EDs of Fairburn (12). Improving self-esteem seems important for a better QOL for both groups. Of the contextual factors the most important association was found between participation in a job and/or education and QOL. In the study of Bijl and Ravelli (10) a correlation between unemployment and QOL was found as well. They also found a correlation between traumatic youth experiences and QOL. We however did not find an association with traumatic youth experiences. A personal factor, self-esteem, and not a contextual factor was most strongly associated with QOL. A possible explanation is that self-esteem may contribute not only to QOL, but also to the perceived stress due to contextual factors.

The association between various domains of QOL and the independent variables were stronger for the former ED patients than for the ED patients. In the ED patients the domains Emotional Role Functioning, Social Functioning and Mental Health showed the strongest associations ($R^2_{\text{adj.}}$ ranges from 0.36 to 0.53). For the former ED patients the domains Vitality, Social Functioning and Mental Health showed the strongest associations ($R^2_{\text{adj.}}$ ranges from 0.53 to 0.74). A possible explanation is that other independent variables, such as comorbidity and coping with recent negative life events or with illness related needs may also contribute to the QOL of ED patients (11). The model may have been more suitable for former ED patients for whom these other independent variables may be relatively unimportant. Further research is needed to examine what factors contribute to the QOL of ED patients.

Quality of life as outcome measure and implications for treatment

Our findings bring on the need for assessment of QOL as outcome of treatment for EDs and not merely the assessment of the ED symptomatology. Although QOL has become widely used in medical care as an outcome measure of disease and treatment, it is less common in mental health care (11, 23). The use of a generic health related QOL measure helps to provide insight into the QOL of a patient group in comparison to other patient groups or a normal reference group. Whether current generic measures accurately quantify the QOL of patients is a matter for debate (11, 24-26). Several instruments have been developed to measure the QOL of mentally ill patients (11, 27-30). Disease specific or domain specific instruments might be more appropriate for assessing the QOL of mental health patients. The use of both generic and disease or domain specific measures on QOL will provide a better understanding of the dynamics of the QOL of mental health patients.

When outcome criteria for recovery of an ED include improved QOL of ED patients, the focus of treatment of patients with EDs should then be on both symptom reduction and on improving the QOL. By addressing underlying maintaining psychopathological mechanisms such as core low self-esteem in treatment, impairment of various life domains may be reduced besides improvement of ED pathology (12, 31). Consequently treatment and treatment evaluations will focus more on the patient than the disease. This may help improve patient centred care and this may enhance patients' satisfaction with care (32).

Limitations and strengths

A limitation of this study was that participants volunteered to take part in a large study on the quality of care for EDs. The advertisement to participate in this study may have appealed especially to those who have received treatment for EDs. This group may have (had) more severe ED pathology than a randomly selected community based sample. The ED sample included anorexia nervosa, bulimia nervosa and eating disorder not otherwise specified patients, but only ten binge eating disorder patients. Because of the small size of this particular group of EDs, the QOL of binge eating disorder patients could not be compared to the QOL of anorexia nervosa and bulimia nervosa patients. We included the binge eating disorder patients in the eating disorder not otherwise specified group.

Another limitation of our study was that comorbidity of other psychiatric disorders in our sample was not assessed by clinical instruments or a validated self-report questionnaire. Bijl and Ravelli (10) found that comorbidity of psychiatric disorders aggravated the poor functioning on the SF-36 scales. Padierna (5,6) found that ED patients with comorbid depressive symptoms reported the poorest QOL. In our study participants were asked if they had psychological complaints other than the ED in the present, such as anxiety, depressive or obsessive compulsive complaints. This factor was included in the General Linear Model analysis. Although not psychological complaints, but other factors were far more strongly associated with QOL, further research that includes assessment of comorbidity is needed to investigate the relative burden of EDs in comparison to other mental disorders.

The strength of the study was that it was the first large community based sample of ED patients to report on their QOL. Because the sample included both ED patients as well as former ED patients we were also able to assess the impact of the disorder on the QOL even after recovery of symptoms. The results show the severity of EDs and the high impact of EDs in comparison with mood disorders. Furthermore factors associated with QOL were investigated. The results indicate the need to address QOL in mental health care for EDs.

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Chapter 3

The patients’ views on quality of life and eating disorders

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Introduction

The quality of life (QOL) of patients with an eating disorder (ED) was reported to be poor (1-10). Padierna et al. (6) showed that after 2 years of treatment and follow-up, ED patients were still more dysfunctional in all areas of life than women of the general population although their perception of their QOL had improved. De la Rie et al (1) also showed that ED patients, even after symptoms are no longer manifest, still report a poorer QOL than a normal reference group.

The QOL for EDs in most of these studies was assessed using general health-related QOL measures, such as the Short Form-36 (SF-36) (1-8) or the Nottingham Health Profile (9). Although the use of a generic health-related QOL measure helps to provide insight into the QOL of a patient group in comparison to other patient groups or a normal reference group, it has several limitations. In their study on EDs and emotional and physical well-being, Doll et al.(3) found that an ED history of students is accompanied by health-related QOL impairment in emotional well-being. However, anorexia nervosa (AN) participants reported fewer limitations on the SF-36, although they reported several severe comorbid psychiatric symptoms. Doll et al (3) suggest that the SF36 is insensitive to emotional distress, particularly in AN patients. In a study on QOL of inpatients with AN Gonzalez-Pinto et al (4) found global deterioration in the perception of health-related QOL, especially in mental health and vitality of the SF-36. Purging behaviours and comorbidity were found to predict poor QOL of AN patients. Mond et al.(2) found that although ED patients participating in an EDs Day Program reported poorer QOL than normal controls, restrictive AN patients tended to report better QOL than other patient groups, after adjusting for levels of general psychological distress. Mond et al.(2) compared two general health-related QOL-measures, namely the SF-12 and the WHOQOL-BREF. They found differences between the SF-12 and the WHOQOL-BREF. They concluded that using only one instrument can be misleading.

Several more specific instruments have been developed to assess the QOL of patients with a mental disorder (11-13). In a small study of 46 former ED patients from an outpatient clinic, Danzl et al (10) assessed the QOL with one of such instruments, namely the Lancashire Quality of Life Profile. In this study, a positive change in the eating behaviour of former patients from an outpatient clinic was associated with a better QOL on several domains: leisure time, financial situation, and perception of mental health. These changes were associated with changes in family life. The Lancashire Quality of Life Profile includes objective indicators of the QOL (i.e. leisure activities or presence of a significant other) as well as subjective ratings of satisfaction with several life domains, such as work, leisure, financial situation, living conditions, relationships with significant others, health, and general satisfaction with life. Recently, a disease specific health-related QOL instrument has been developed by Engel et al (14). Domains and items of the instrument were elicited by a panel of experts on EDs. Firstly, areas affected by the ED were identified, including the following domains: physical, psychological, financial, social, work/school, and legal. Secondly, the experts listed relevant areas of functioning on these domains. Thirdly, items were elicited. The EDQOL showed to have good psychometric properties.

Whereas objective measures to assess QOL include information on the presence/absence of, for instance, a job or relatives, or information on income and living condition, subjective measures assess the QOL based on personal ratings on several fixed domains. In a disease-specific instrument such as the EDQOL, the fixed domains refer to domains that are known to be affected by the ED. Nonetheless, the relative importance of life domains to the perception of the QOL of ED patients or their personal views on what (domains) they feel to contribute to their QOL are as yet undetermined. Therefore, it seems important to assess the personal views on QOL of ED patients.

The current study explored the personal views of current and former ED patients on their QOL. It examined differences between AN, bulimia nervosa (BN), and ED not otherwise specified (EDNOS) patients as well as between purging and nonpurging ED patients. It aimed to investigate whether the use of an individualized measure- with individually chosen instead of fixed domains-would contribute to the assessment of QOL of ED patients.

Method

Participants

The study sample consisted of current ED patients and former ED patients recruited from the community in the Netherlands. They volunteered to participate in the study. Informed consent was assured. Participants were recruited from different parts of the country using various methods. The majority of the sample was recruited through articles and advertisements in newspapers, and in a women's magazine, leaflets (33%), and the magazine and website of the Dutch patient organization for EDs (27%). A smaller part of the sample was recruited directly at specialized ED centres (10%). The remaining part of the sample (630%) was recruited through diverse channels, for example patients that were in treatment in a specialized ED centre applied to participate in the study when reading about it on the website of the patient organization.

Assignment of Diagnosis

Participants were included in the study upon meeting a life time self-reported diagnosis for a DSM-IV ED (15). Life time diagnosis for a DSM-IV ED was based on the diagnostic items of the self-report Eating Disorder Examination Questionnaire (EDE-Q), information on body mass index (BMI: weight in kilogram/height in meter^2) and menstrual status. Participants filled out the EDE-Q, and answered questions about weight, height, and menstrual status for what they perceived as the period they suffered most from their ED (worst period). If they met the criteria for a DSM-IV ED for that period, they were included in the study. To ensure they did suffer from an ED during that period, participants were asked if a clinician mentioned a diagnosis to them and if so what they were told. If no clinician ever mentioned a diagnosis, the researchers carefully examined all answers on the EDE-Q, especially reported restrictive eating behaviours, binging and purging behaviours, reported weight and height as well a preoccupation with weight or shape, before including the participants in the study.

After positive screening for a life time diagnosis for a DSM-IV ED, the EDE-Q was administered again, but now to assess current ED pathology. The EDE-Q is a self-report questionnaire developed by Fairburn and Wilson (16) It includes 36 questions on eating behaviour in the past 28 days. The questionnaire consists of diagnostic items and four subscales: Restraint, Eating Concern, Shape Concern, and Weight Concern. Diagnostic items include questions based on DSM-IV criteria for EDs relating to feeling of fatness, fear of gaining weight, bulimic episodes, dietary restriction, compensatory behaviour (for instance self-induced vomiting or laxative misuse), importance of shape or weight for self-esteem, and abstinence from weight control behaviour. The diagnostic items are rated on a 6 point scale and address the past 28 days, where appropriate respondents are requested to provide a frequency count. So that all criteria for an ED could be assessed according to the DSM-IV, additional questions were asked about weight, height, to calculate BMI, and menstrual status. An algorithm reliably assigned DSM-IV diagnosis for an ED or no current diagnosis for an ED. The four subscales contain questions regarding distorted cognitions about eating, dieting, weight, shape or eating behaviour, and provide insight into the nature and severity of the ED. In a recent study by Mond et al. (17) the validity of the EDE-Q in comparison to the EDE interview in screening for EDs in a community-based sample was investigated. The EDE-Q has good concurrent validity and acceptable criterion validity and can therefore be used for assessment of EDs in a community-based sample.

Quality of life measure

To assess the patient's view on QOL a procedure derived from the Schedule for the Evaluation of Individual Quality of Life (SEIQOL) was used (18,19). The SEIQOL is a semi-structured interview that assesses an individual's QOL in three steps. In this study, the questions were administered written.

First the participants were asked to nominate the five areas of their life (cues) that are most important to them. These five areas are referred to as domains (and not cues) in this study. Secondly, participants rated their current level of functioning on each domain. They were asked to rate their QOL on a VAS scale from 0 to 100 for all five aspects, subsequently. A higher score indicates a better QOL. The third assessment step of the original SEIQOL procedure involves quantifying the relative importance (weight) of each domain to their perception of the overall QOL. A weighting disk is used, consisting of five disks that are rotated around a central point to form a pie chart. The disks are labeled with the five domains and are adjusted by the participants until the proportion of each domain on the pie chart then accurately reflects the relative importance they attach to these domains. By multiplying each weight with the relevant level of functioning a “SEIQOL Index score” is calculated. These five scores are summed. In our study, the third step was simplified in comparison to the SEIQOL procedure. Participants were asked to rank the five domains from one to five with the most important domain on number one down to the least important domain at five to assess the relative importance of the domains mentioned. An Index score was not calculated.

Analysis

Both quantitative and qualitative analysis were carried out to investigate the patient’s own view on their QOL. Qualitative analysis was carried out by careful examination of all aspects mentioned by the participants. All these aspects were saved and then coded by the researchers. Subsequently, these coded items were clustered into meaningful categories based on their content. This process was facilitated by means of KWALITAN, a software program that enables clustering of relevant items in meaningful categories (20) A χ^2 test was used to investigate the differences between current and former ED patients and between diagnostic subgroups on the frequency of the domains mentioned. A χ^2 test was also used to investigate the differences between current and former ED patients on the ranking of the domains. Some domains were mentioned with a low frequency. Consequently, the ranking of the different diagnostic subgroups was not compared. Mean scores of the ratings on the domains were calculated for current ED patients and former ED patients. *T*-tests were used to investigate the differences between current ED patients and former ED patients on their ratings for the QOL and the differences between purging (use of laxatives, diuretics or vomiting twice a week) and non-purging ED patients (use of laxatives, diuretics or vomiting less than twice a week or no purging behaviour at all). Again because of the low frequency with which several domains were mentioned, the differences between diagnostic subgroups were not analyzed.

Results

Of the 292 participants, 146 (50.0%) met DSM-IV criteria for an ED in the present: 44 (30.1%) met criteria for AN, 43 (29.5%) for BN, and 59 (40.4%) for EDNOS. EDNOS patients met (sub)threshold criteria for AN or BN. The remaining 146 (50.0%) participants did not meet criteria for an ED in the present and were designated as former ED patients. The majority of the sample received a formal diagnosis of an ED by a clinician (81.7%). Only 17.4% did not receive a diagnosis of an ED by a clinician. Twenty four participants did not meet criteria for an ED in the present. Careful examination of their responses on the EDE-Q regarding the worst period they suffered from an ED and information on their weight and height showed they did suffer from ED pathology in the past and they were therefore included in the study.

Participants were predominantly women with a mean age of 28.6 years (SD 8.8). The median age was 27.0 years. The mean duration of illness was 9 years (SD 8.3). The median of the duration of illness was 6.0 years. Sociodemographic characteristics and clinical data of current and former ED patients are presented in **Table 1**. No significant differences were found on the sociodemographic characteristics between the current ED and former ED patients and between diagnostic subgroups.

Table 1. Sociodemographic and clinical data of current eating disorder patients and former eating disorder patients

	Current ED Patients (*N* = 146)	Former ED Patients (*N* = 148)
DSM IV diagnosis		
AN	44	0
BN	43	0
EDNOS	59	0
No ED	0	146
Female (%)	144 (98.7)	141 (96.6)
Age (years)		
Mean (SD)	28.5 (8.9)	28.8 (8.8)
Educational level (%)		
Primary school	7 (4.8)	7 (4.8)
Basic high school	19 (13.0)	14 (9.6)
Advanced high school	81 (55.5)	69 (47.3)
College/University	36 (24.7)	56 (38.4)
Urbanization (%)		
Very highly urbanized	36 (25.0)	50 (34.2)
Highly urbanized	44 (30.6)	44 (30.1)
Urbanized	31 (21.5)	28 (19.2)
Rural	17 (11.8)	11 (7.5)
Very rural	16 (11.1)	13 (8.9)
Age of onset (years)		
Mean (SD)	16.6 (4.5)	16.0 (3.7)
BMI		
Mean (SD)		22.1 (4.6)
AN	15.6 (1.5)	
BN	21.6 (3.5)	
EDNOS	20.3 (5.6)	
Diagnosis at worst period (%) (DSM-IV)		
AN	120	98 (67.1)
BN	14	24 (16.4)
EDNOS	12	24 (16.4)
Duration of illness in years[a]		
Mean (SD)	9.7 (8.4)	8.3 (8.1)

Notes: AN, anorexia nervosa; BN, bulimia nervosa; EDNOS, eating disorder not otherwise specified; very highly urbanized, ≥2500 addresses per km^2; highly urbanized, 1500-2500 addresses per km^2; urbanized, 1000-1500 addresses per km^2; rural 500-1000 addresses per km^2; very rural, <500 addresses per km^2; BMI, body mass index (kg/m^2). Because of missing values not all columns add up to N.

[a] *N* = 280.

Table 2. The domains mentioned by the participants to contribute to the quality of life

	Frequency (*N* = 286)	%
Sense of belonging	266	93.0
Family	127	44.4
Partner	142	53.4
Children	33	11.5
Friends/other	219	76.6
Work/education	184	64.3
Health	114	39.9
Well-being	109	38.1
Sense of self	92	32.2
Self-image	63	22.0
Self-efficacy	38	13.3
Disease-specific psychopathology	84	29.4
Leisure activities	84	29.4
Life skills	63	22.0
Sense of purpose or meaning	37	12.9
Financial situation/living condition	31	10.8
Pets	11	3.8

The patient's views on quality of life and eating disorders

Table 2 shows the results of the qualitative analysis by means of KWALITAN. The domains that both current and former ED patients view as contributing to their QOL are ranked by frequency. Domains mentioned were relationships with others, which were grouped under a sense of belonging, health, work, education, self-image or self-efficacy, which we grouped under a sense of self, well-being, disease specific psychopathology, leisure activities, life skills, a sense of purpose or meaning, financial situation, housing, and pets. A sense of belonging was cited by 93% of the participants as important and refers mainly to having friends or relatives (i.e. sources of social support). However the ability to communicate with others or feeling regarded (perceived social support) is also included under a sense of belonging. Work or education refers to participating in a job or education or working as a volunteer. Health refers to physical as well as mental health. A sense of self refers to self-esteem, but also to self-efficacy, such as the ability to set goals for oneself in life and to take responsibility for one's own life. Well being refers to feeling happy, feeling relaxed or being able to enjoy life. Psychopathology refers to disease specific ED symptoms or coping (or learning how to cope) with the pathology, such as a disturbed eating pattern, being preoccupied with food, weight, body shape, or other comorbid psychological problems such as feeling anxious or depressed. Leisure activities vary and include for instance listening to music or playing an instrument, driving a car, travelling, playing sports, reading, and hiking in nature. Life skills touches on social skills as follows: being able to express oneself, feeling a harmony between thoughts and feeling, and being able to control or let go, being able to do the things that are important. A sense of purpose or meaning alludes to religion, spirituality, personal growth, creativity, making plans for the future, and living a conscious life. The financial situation, housing and pets were mentioned less frequently than other categories. Housing refers to having a place of your own, living condition or feeling at home. Pets refers to having a dog or a cat or a horse to care for.

Table 3 shows the results of the ranking of the domains contributing to the QOL by the participants. A sense of belonging is considered most frequently as the most important life domain in particularly relationships with a partner, children and family. The second most important domain is self image, followed by well being and health. Work or education are frequently mentioned, but are relatively less frequently considered the most important life domain. Leisure activities and financial situation or living condition are consistently considered as the relatively least important domains.

Table 3. The ranking of the domains mentioned by the participants to contribute to the quality of life

Ranking (%)	First Place	Second Place	Third Place	Fourth Place	Fifth Place
Sense of belonging					
Family	31.5	26.0	18.9	15.0	8.7
Partner	45.8	20.4	11.3	12.0	10.6
Children	45.5	42.4	6.1	0.0	6.1
Friends/other	20.1	25.1	24.2	19.2	11.4
Work/education	8.7	17.4	25.5	27.7	20.7
Health	27.2	23.7	14.0	18.4	16.7
Well-being	32.1	14.7	21.1	12.8	19.3
Sense of self					
Self-image	36.5	25.4	12.7	12.7	12.7
Self-efficacy	15.8	18.4	28.9	21.1	15.8
Disease-specific psychopathology	21.4	19.0	20.2	21.4	17.9
Leisure activities	6.0	16.7	20.2	25.0	32.1
Life skills	19.0	23.8	25.4	11.1	20.6
Sense of purpose or meaning	5.4	24.3	21.6	24.3	24.3
Financial situation/living condition	3.2	6.5	9.7	32.3	48.4
Pets	9.1	36.4	45.5	0.0	9.1

A comparison of different groups of patients on the perception of the quality of life

First of all, differences between current ED patients and former ED patients were analyzed. Current ED patients mentioned disease specific psychopathology to be important for the perception of their QOL significantly more often than did former ED patients ($X^2 = 7.1$, $p = 0.008$). Former ED patients mentioned a partner to be important for the perception of their QOL significantly more than did current ED patients ($X^2 = 11.8$, p 0.001). A χ^2 test performed on the ranking of family, partner, friends, work, education, health, well being, life skills, leisure activities, and disease specific psychopathology revealed no significant differences between current ED patients and former ED patients. **Table 4** displays the distribution of the mean ratings of current ED patients and former ED patients on the QOL domains. Mean scores were calculated based on the rating on the VAS-scales and could range from 0 to 100. A higher score indicates a better QOL. Current ED patients report poor QOL on all life domains, particularly on well being and self-image. Former ED patients report a better QOL than current ED patients on all but two domains (children, self-efficacy), but their ratings were just above average.

Table 4. Distribution of the mean scores of patient's quality of life domains of current eating disorder patients and former eating disorder patients and the comparison of their mean scores by means of *t* tests

	ED Patients Mean (SD)	Former ED Mean (SD)	*t* value	*p*
Sense of belonging				
Family	58.0 (25.8)	70.1 (24.9)	−2.7	0.008
Partner	51.8 (29.7)	66.1 (29.5)	−2.8	0.005
Children	65.8 (22.3)	66.0 (25.6)	−0.02	n.s.
Friends/other	53.9 (25.1)	68.6 (23.1)	−4.5	0.0005
Work/education	48.1 (25.3)	60.1 (29.6)	−2.9	0.004
Health	42.6 (21.6)	59.5 (24.1)	−3.9	0.0005
Well-being	34.3 (23.2)	54.8 (29.0)	−4.0	0.0005
Sense of self				
Self-image	32.8 (20.7)	51.9 (28.8)	−3.0	0.004
Self-efficacy	54.8 (24.9)	59.3 (26.4)	−0.5	n.s.
Psychopathology	33.5 (23.5)	48.3 (29.3)	−2.5	0.01
Leisure activities	45.7 (28.2)	61.2 (26.9)	−2.6	0.01
Life skills	35.5 (26.1)	57.6 (28.1)	−3.1	0.003
Sense of purpose or meaning	39.4 (18.8)	60.2 (21.0)	−3.1	0.004

Notes: ED, eating disorder; SD, standard deviation; n.s., not significant.

Secondly, differences between AN, BN, and EDNOS patients on the frequency of the domains mentioned were analyzed. Significantly more AN patients mentioned leisure activities as important in the perception of their QOL than did BN or EDNOS patients (X^2 = 8.4, p = 0.02). Significantly more EDNOS patients mentioned life skills to be important for the perception of their QOL than did BN and AN patients (X^2 = 10.3, p = 0.006). Significantly more EDNOS patients mentioned children to be important for the perception of their QOL than did BN and AN patients (X^2 = 6.8, p = 0.034).

Thirdly, when comparing purging and non-purging ED patients, no differences were found regarding which domains were mentioned. However, purging ED patients found work or education more often a very important life domain than did non-purging ED patients (X^2 = 9.8, p = 0.04). When comparing purging and non-purging patients on their mean scores of the domains, purging ED patients reported a significantly poorer mean score on disease specific psychopathology (t = 1.55, p = 0.05).

Conclusion

A sense of belonging was the domain that was mentioned most often (93.0%) by both current ED patients as well as former ED patients as important for their QOL. Furthermore, a sense of belonging was most often ranked as the most important life domain. Other domains that were alluded to contributing to the QOL, include health, well being, work, education, disease specific psychopathology, a sense of self, life skills and a sense of purpose or meaning. Current ED patients more often mentioned disease specific psychopathology to contribute to their QOL than former ED patients. Current ED patients reported poor QOL on most domains, particularly on self-image and well being. Former ED patients reported better QOL than current ED patients, but ratings were just above average. Purging ED patients reported poorer QOL on disease specific psychopathology than non-purging ED patients.

Quality of life and social support

In this study 93.0% of the participants mentioned a sense of belonging as important to their QOL. This study shows that having a family, partner or friends seems to be of particular importance in the perception of the QOL of both current ED patients and former ED patients. Furthermore a sense of belonging was most often mentioned as the most important life domain.

Several studies show that ED patients generally report poor social networks. Tiller et al. (21) found that ED patients had smaller social networks than students. AN patients were significantly less likely than BN patients to have a partner. Although AN patients perceived their social support to be adequate, BN patients were dissatisfied. In a study of Karwautz et al. (22) on the perception of family relationships, AN patients perceived lower individual autonomy and higher perceived cohesion in their family relationships compared to their sisters, but no difference in perceived emotional connectedness. Furthermore in a study on coping strategies and recovery Bloks et al. (23) show that recovery in ED patients is associated with seeking social support. To enhance the QOL of ED patients it seems important to address the quality of the patient's social relationships when treating EDs.

It may be important to involve relatives of ED patients in treatment. ED treatment programs ideally provide family treatment that includes family caregivers of ED patients, such as family based treatment for adolescents. In a study by De la Rie et al. (24) on the QOL of family caregivers, professional support is welcomed by 75% percent. They found that the QOL of family caregivers of ED patients, namely parents, partner or siblings, was reported to be worse than the QOL of a normal reference group. Family caregivers mentioned that the ED substantially affected family life. In response to the ED, family caregivers felt anxious, powerless, sad, or desperate. The relationship of the caregiver with the ED patient changed. Family caregivers were more worried, lost their trust, and reported more conflicts. Participants of the study of de la Rie et al. mentioned specific needs regarding professional support, such as practical advice, information and emotional support, as well as the effects on daily life and the relationship with the ED patient, that may need to be addressed.

The scope of domains of the quality of life of eating disorder patients

The wide range of domains mentioned in this study appears to complement current knowledge on the QOL of ED patients. It broadens the scope of relevant domains of the QOL of ED patients. It showed a wide variety in domains mentioned and differences in the relative importance of these domains. To our knowledge no prior study on ED patients has been conducted using (a procedure derived from) the SEIQOL. A few studies have been conducted with other mental health patients. In a sample of 35 patients with a serious mental disorder, the most important domains identified were children, family, health, social support, financial, work/job, love/relationship, friends, creativity, home, and pets (25). In a study with 18 depressed patients the most important domains mentioned were: mental health, family of origin, work, marriage/relationship, friends, and leisure. Patients reported poor QOL on these domains (26). Because of the small sample size of both studies it is difficult to compare the results. However the findings of our study concur with these studies findings and suggest that a wide variety of domains are important to the QOL of mental health patients. This needs to be taken into account to be able to accurately assess the QOL of an individual patient.

Quality of life and illness related needs

In this study current ED patients found disease specific psychopathology more often important in the perception of the QOL than former ED patients. Current ED patients reported a poorer QOL than former ED patients. Furthermore purging ED patients reported poorer QOL on disease specific psychopathology than non-purging ED patients. Katschnig et al. (11) refers to QOL as an ongoing process of adaptation with the environment as a driving mechanism. Adaptation includes the satisfaction of specific needs, namely physiological needs, the need for a relationship with a significant other, the need for acceptance by others, the need for achievement and a sense of meaning. Furthermore mental health patients have to fulfil illness-related needs as well. This includes the resources to manage symptoms, the need to enter psychiatric care or obtain help, to adapt to treatment programs and maintain relationships with mental health professionals. The more severely affected mental health patients are, the more difficult they may find it to fulfil these illness related needs. We hypothesize that the impact of disease specific psychopathology on the QOL of the most severely affected ED patients; namely the purging ED patients, may reflect the inability to fulfil these illness-related needs.

The assessment of quality of life of eating disorder patients

When assessing the QOL of ED patients, several measures can be used to determine the QOL. General health related QOL measures with subjective ratings on fixed life domains provide information on perceived QOL. Different individuals rate themselves on the same life domains. This will enable the comparison of the QOL of ED patients and other patient groups. A disease-specific QOL instrument provides more specific information on the QOL of a particular ED patient (14). Subjective ratings on domains known to be affected by the ED, will be helpful in formulating treatment goals. A disease specific instrument will be particularly helpful in comparing the QOL of diagnostic subgroups of ED patients. Nevertheless, a disease-specific instrument does not fully grasp the wide variety of life domains that are important to individual patients. An individualized measure provides personal ratings of individually chosen life domains that are relatively important to a particular patient. Our findings suggest that the use of an individualized measure will enable clinicians to better understand the perception of the QOL of an individual ED patient. This will be helpful in formulating treatment goals. When an individualized measure is used as an adjunct to standardized QOL measures to formulate treatment goals, treatment will become more patient centreed (27-29).

Limitations and strengths

A limitation of this study was that participants volunteered to take part in a large study on the quality of treatment for EDs. The advertisement to participate in this study may have especially appealed to those who have received treatment for EDs. This group may have or have had more severe ED symptoms than a randomly selected community-based sample. Other limitations of this study are the assessment of EDs with a self-report measure and the lack of a control group. The strength of the study is that it was the first large community-based sample of ED patients to report on their personal views on the QOL.

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Chapter 4

Evaluating the treatment of eating disorders from the patients' perspective

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Introduction

Evidence based clinical practice regarding treatment for any disorder should be founded on research of the efficacy, effectiveness, and efficiency of different treatment options as well as the clinical and physical circumstances and the patient's preferences (1,2). By incorporating these factors the clinician is more likely to recommend a treatment the patient is willing to accept. When patient values are integrated with the best research evidence and clinical expertise, clinicians and patients will form a therapeutic alliance that optimizes clinical outcomes and quality of life (3). Therefore it is of great importance to investigate the views of patients on treatment of eating disorders (EDs).

Since the 1980s the patient's perspective on treatment of EDs has received growing attention. Most studies were case studies or small samples. In her review, Bell (4) mentioned many methodological weaknesses, such as low response rate or poorly defined treatment categories, of a number of these studies. During the last 15 years the evaluation of treatment of EDs from the patient's perspective has been a topic of only four studies with a sample size greater than 100. Two studies considered treatment seeking behaviour and the evaluation of different types of treatment. Newton et al. (5,6) conducted a survey of members of the ED Association, a patient organization in the United Kingdom. ED patients did not seek help until, on average, 5 years after the onset of the ED. Counseling and self-help groups were regarded as beneficial by a large majority, whereas behaviour therapy was not regarded as helpful. This study was replicated in Norway by Rosenvinge and Klusmeier (7). They found a similar patient delay in seeking treatment as Newton et al. (5,6) did. Outpatient individual or group therapy and self-help groups were reported as most useful by the participants. More than 50% of the patients were dissatisfied with family therapy. Subjects were more content with therapists who were more knowledgeable about EDs. Two studies explored the evaluation of treatment of EDs in a specialized centre. In a study by Swain-Campbell et al. (8) the greater part of the 120 ED patients who received treatment in a specialized ED centre as well as participated in a survey reported to be satisfied with treatment. In this study the largest source of patient discontent was directed at the focus on weight gain and the cessation of bingeing and purging and the perceived pressure to change. Patients most often mentioned the therapeutic alliance as an important aspect of treatment, such as bonding and trust, collaboration, and shared commitment. In a study by Clinton, and Clinton et al. (9, 10) the majority of the 469 ED patients were satisfied with treatment in specialized ED centres 36 months after initial assessment. They found that focusing on active control of eating habits and support were important predictors for satisfaction with treatment.

Although these studies described the patient's view on the helpfulness of different treatments, the results are difficult to interpret and it remains unclear what exactly contributed to the perceived helpfulness of these treatments. It is therefore difficult to draw conclusions from these studies.

The current study intended to gain a more in-depth view on the evaluation of treatment of EDs from the patient's perspective. It investigated the treatment history of ED patients and former ED patients in the Netherlands. The patient's evaluation of different types of treatment as well as those aspects that contributed to this evaluation were addressed. Differences between ED patients and former ED patients were examined. Furthermore it examined the factors that contribute to the evaluation of treatment of EDs.

Method

Participants

The study sample consisted of ED patients and former ED patients recruited from the community in the Netherlands. They volunteered to participate in the study. Informed consent was assured. Participants were recruited from different parts of the country by various methods. The majority of the sample was recruited through articles and advertisements in newspapers, a women's magazine and leaflets (33.3%), and the magazine and website of the Dutch patient organization for EDs (27.3%). A smaller part of the sample was recruited directly at specialized ED centres (10.5%). The remaining part of the sample (28.9%) was recruited through various channels, for example patients were under treatment in a specialized ED centre, but applied to participate in the study when reading about it on the website of the patient organization. Participants were included in the study if they met a life time self-reported diagnosis for a DSM-IV ED (11). Life time diagnosis for a DSM-IV ED was based on the diagnostic items of the self-report Eating Disorder Examination questionnaire (EDE-Q), information on body weight and height to calculate body mass index (BMI: weight in kilogram/height in square meter), and menstrual status. Participants filled out the EDE-Q and answered questions about weight, height, and menstrual status for what they perceived to be the period they suffered most from their ED (worst period). The content of the EDE-Q was not modified for this purpose, but participants were asked to consider the 28 days period they suffered most from the ED and not the past 28 days. If they met the criteria for a DSM-IV ED for the period they suffered most from the ED they were included in the study. To ensure they did suffer from an ED during that period, participants were asked if a clinician mentioned a diagnosis to them and if so what they were told. If no clinician ever mentioned a diagnosis, the researchers carefully examined all answers on the EDE-Q, especially reported restrictive eating behaviours, binging and purging behaviours, reported weight and height as well a preoccupation with weight or shape, before including the participants in the study.

Instruments

Patient Characteristics.

Eating psychopathology. After a positive screening for a life time DSM-IV ED diagnosis, the EDE-Q was administered again, but now to assess the current ED psychopathology. The EDE-Q is a self-report questionnaire developed by Fairburn and Wilson. (12) It includes 36 questions on eating behaviour. The questionnaire contains diagnostic items and four subscales: restraint, eating concern, shape concern, and weight concern. Diagnostic items include questions based on DSM-IV criteria for EDs relating to feeling of fatness, fear of gaining weight, bulimic episodes, dietary restriction, compensatory behaviour (e.g. self-induced vomiting or laxative misuse), importance of shape or weight for self-esteem, and abstinence from weight control behaviour. The diagnostic items are rated on a 6-point scale and address the patient's last 28 days. When appropriate respondents are requested to provide a frequency count. To assess all criteria for an ED according to the DSM-IV, additional questions were asked about body weight, height, and menstrual status. The four subscales contain questions regarding distorted cognitions about eating, dieting, weight or shape, or eating behaviour and provide insight into the nature or severity of the ED. An algorithm reliably assigned either DSM-IV or no diagnosis for the worst period and at present (the last 28 days). In a recent study by Mond et al. (13) the validity of the EDE-Q was investigated and compared with the EDE interview in screening for EDs in a community sample. The authors concluded that the EDE-Q has good concurrent validity and acceptable criterion validity and can therefore be used for assessment of EDs in a community based sample.

Self-esteem. Self-esteem was assessed by means of Rosenberg's Self-Esteem (RSE) questionnaire (14,15). The RSE questionnaire consists of 10 questions on self worth, which is used to assess one's positive or negative orientation towards oneself. The scale generally has a high reliability. Test-retest correlations are in the range of .82-.88. Cronbach's α are in the range of 0.77-0.88. Studies have demonstrated a unidimensional and a two-factor (selfconfidence and self-deprecation) structure to the scale (16).

Quality of life. The Short Form-36 (SF-36) (17,18) a generic health-related quality of life questionnaire was administered in order to assess the quality of life. The SF36 incorporates questions about (role) functioning and satisfaction with various life domains. The SF-36 consists of 36 questions and evaluates physical functioning, physical role functioning, bodily pain, general health perception, vitality, social functioning, emotional role functioning and mental health. SF-36 scale's scores range from 0 to 100. A higher score is indicative for a better quality of life.

Further patient characteristics. Additional questions assessed sociodemographic characteristics, psychological complaints at present, i.e. anxiety, depressive or obsessive compulsive complaints, and traumatic history, i.e. sexual or physical abuse or emotional neglect in the past.

Treatment Characteristics. A questionnaire specifically designed for the purpose of this study, the "Questionnaire for Eating Problems and

Treatment," addressing treatment history and the patient's evaluation of their treatment, was administered. This questionnaire was developed by the authors. A panel of experts including three researchers, three therapists, and seven patients of the day treatment program at the Centre for Eating Disorders Ursula was consulted to provide items. The final version of the questionnaire was divided in three parts. The first part consisted of questions about treatment seeking behaviours. It included closed questions on seeking treatment as well as open questions to provide additional information on treatment seeking history. The second part contained questions about treatment history and experiences with treatment. For each type of treatment participants were asked to evaluate their experiences. Types of treatment to evaluate included general health care, namely treatment of the general health practitioner, general hospital, or dietician, and mental health care, namely a psychiatrist or psychologist in private practice, a general outpatient clinic, a psychiatric hospital, and specialized ED centres. A differentiation was made between institutions with a specialized treatment program specifically for ED patients, usually the specialized ED centres to which we refer patients for specialized treatment, and institutions without such a program, to which the patients are referred for non specialized treatment. In these latter institutions ED patients are usually treated together with other mental health patients (i.e. patients with depressive disorders and anxiety disorders). Furthermore, involvement of partner or parents in treatment, the use of psychotropic drugs, and non professional treatments were included. For each type of treatment, participants were asked to rate three questions on a 5-point Likert scale, namely to what extent treatment was perceived as helpful regarding the ED, how satisfied they were with treatment, and to what extent treatment contributed to improve their quality of life. Taken together these questions assessed the evaluation of treatment. Furthermore, participants were asked to list all positive and negative experiences with treatment and mental health professionals and to provide additional comments on their ratings if they felt this to be necessary. The third part of the questionnaire consisted of questions on expectations of, and opinions on, the quality of treatment. Open questions referred to expectations of, and opinions on, the quality of treatment as regards the content of treatment, the mental health professionals involved, and the organization of treatment. Furthermore, participants were asked to rate 70 items on a 5point Likert scale to assess the extent of importance for a specific item or criterion for the quality of treatment of EDs. Lastly, patients were asked to rank the 10 most important criteria of the list. The current paper describes the results of the first and second part of the questionnaire. The results of the third part of the questionnaire will be described elsewhere (19).

Analyses

Both quantitative and qualitative analysis were carried out investigating the evaluation of treatment of EDs from the patient's view. Descriptive analyses were used to review treatment history and perceived helpfulness of different types of treatments. Differences between ED patients and former ED patients were analyzed by means of χ^2-or *t*-tests. χ^2 and *t* values are mentioned in the results only when significant differences were found. A sum score of the ratings of perceived helpfulness of treatment, satisfaction with treatment, and contribution to the quality of life of treatment was calculated to compare the evaluation of treatment of ED patients and former ED patients by means of *t*-tests. Values of the *t*-tests are mentioned in the results only when significant differences were found. To understand which aspects contributed to the evaluation of treatment, a qualitative analysis was conducted. The answers on the open questions regarding the evaluation of treatment were analyzed by means of KWALITAN, a software program which clusters relevant items in meaningful categories based on content analysis (20). Finally a stepwise multiple regression analysis was used to investigate the factors that contribute to the evaluation of treatment of EDs (sum score). For each type of treatment a separate univariate regression analysis was carried out with patient and treatment characteristics as independent variables and the evaluation of treatment as a dependent variable. Then a multiple regression analysis with the most relevant independent variables was carried out. Patient characteristics entered into the analysis as independent variables were sociodemographic characteristics (age, urbanization, participation in a job or education, educational level), disease characteristics (ED pathology in the past and in the present, duration of the ED, recovery, comorbid complaints), and other factors (self-esteem, traumatic history, patient delay, and quality of life). Treatment characteristics entered into the analysis as independent variables were treatment history or number of treatments, drop out of treatment at least once in treatment history, refusal of treatment at least once in treatment history, different types of treatment received, doctor delay, and negative experiences with treatment. Dependent variables were the sum scores of the evaluation of treatment of psychologists or psychiatrists, outpatient clinics, psychiatric hospitals, and specialized ED centres.

Results

Participants

Three hundred and sixty-four persons applied to take part in the study. Three hundred and four participants completed the study. Of the 60 applicants who did not complete the study, 27 did not return the screening questionnaire, mainly because they felt the questions did not apply to them. Three were excluded because they did not meet the criteria for a DSM IV ED. Thirty did not finish the study because they found the questions regarding their treatment history and evaluation to be too long, too confronting, or felt their current symptoms of the ED were too overwhelming. The overall response rate was 83.3%.

Of the 304 participants, 156 (51.3%) met the DSM-IV criteria for an ED in the present: 44 (14.5%) met the criteria for anorexia nervosa (AN), 43 (14.1%) for bulimia nervosa (BN), and 69 (22.7%) for an ED not otherwise specified (EDNOS). Of the participants classifying as having an EDNOS 10 met the criteria for a binge ED, others met the (sub)threshold criteria for AN or BN. Of the participants who had the met criteria for an ED in the past, 148 (48.7%) did not meet the criteria for an ED in the present (former ED patients). Within this group of former ED patients, 98 (66.2%) met the criteria for AN in the past, 24 (16.2%) met the criteria for BN, and 26 (17.6%) met the criteria for an EDNOS. The majority of the sample received a formal diagnosis of an ED by a clinician (81.7%). Only 18.3% did not receive a diagnosis of an ED by a clinician. Half of these 18.3% (26 participants) did not meet the criteria for an ED in the present.

Table 1. Sociodemographic characteristics of eating disorder patients by diagnostic group and former eating disorder patients

Present Diagnosis	AN	BN	EDNOS	Former ED
Female (%)	44 (100)	41 (95.3)	68 (98.6)	143 (96.6)
Age (years)				
Mean (SD)	26.3 (9.1)	29.0 (7.8)	29.4 (9.1)	29.3 (8.9)
Median age	23.0	27.0	28.0	27.0
Educational level (%)				
Primary school	5 (11.4)	0 (0)	2 (2.9)	7 (4.7)
Basic high school	5 (11.4)	7 (16.3)	8 (11.6)	14 (9.3)
Advanced high school	23 (52.3)	25 (58.1)	37 (53.6)	71 (48.0)
College/University	11 (25.0)	11 (25.6)	22 (31.9)	56 (37.8)
Current participation in a job or education (%)				
Job	17 (38.6)	15 (34.9)	24 (34.8)	57 (38.5)
Education	13 (29.5)	8 (18.6)	12 (17.4)	32 (21.6)
Job and education	6 (13.6)	11 (25.6)	15 (21.7)	29 (19.6)
No job, no education	8 (18.2)	9 (20.9)	18 (26.0)	30 (20.3)
Urbanization (%)				
Very highly urbanized	7 (15.9)	10 (23.8)	20 (29.4)	51 (34.4)
Highly urbanized	13 (29.5)	13 (31.0)	22 (32.4)	45 (31.1)
Urbanized	10 (22.7)	13 (31.0)	12 (17.6)	28 (18.9)
Rural	5 (11.4)	2 (4.8)	10 (14.7)	11 (7.4)
Very rural	9 (20.5)	4 (9.5)	4 (5.9)	13 (8.8)
Living situation (%)				
With parents	13 (29.5)	5 (11.6)	11(15.9)	20 (13.5)
Independent	22 (50.0)	29 (67.4)	33 (47.8)	70 (47.3)
With partner	9 (20.5)	9 (20.9)	25 (36.2)	58 (39.1)
Living with children (%)				
Yes	4 (9.1)	5 (11.6)	14 (20.3)	18 (12.1)

AN, anorexia nervosa; BN, bulimia nervosa; EDNOS, eating disorder not otherwise specified.
Very highly urbanized: 2,500 addresses per km^2; highly urbanized: 1,500–2,500 addresses per km^2; urbanized: 1,000–1,500 addresses per km^2; rural 500–1,000 addresses per km^2; very rural: <500 addresses per km^2; BMI: body mass index (kg/m^2).
Owing to missing values not all columns add up to N.

Careful examination of their responses to the EDE-Q regarding the worst period they suffered from an ED and information on their weight and height showed that they did suffer from ED pathology in the past and they were therefore included in the study.

Sociodemographic characteristics of the various diagnostic groups are presented in **Table 1**. Participants were predominantly women with a mean age of 28.7 ± 8.9 years. The median age was 27.0 years. No significant differences were found on the sociodemographic characteristics between the diagnostic groups, except for living situation. AN patients were more likely to be living with their parents; BN patients were more likely to be living independently; EDNOS and former ED patients were more likely to be living with a partner ($\chi^2 = 15.063$, $p = .020$).

Table 2. Clinical data of eating disorder patients by diagnostic group and former eating disorder patients

Present Diagnosis	AN	BN	EDNOS	Former ED
Age of onset (years)				
Mean ± SD	16.3 ± 4.8	16.3 ± 4.3	16.7 ± 4.5	16.1 ± 3.7
Median age of onset	15.0	17.0	16.0	16.0
BMI				
Mean ± SD	15.6 ± 1.5	21.6 ± 3.5	21.0 ± 5.9	22.3 ± 5.0
Median BMI	15.9	21.2	19.0	21.1
Diagnosis at worst period (%) (DSM-IV)				
AN	44 (100)	26 (60.5)	54 (78.3)	98 (66.2)
BN	0 (0)	12 (27.9)	5 (7.2)	24 (16.2)
EDNOS	0 (0)	5 (11.6)	10 (14.5)	26 (17.6)
Duration of illness in years (*N = 280*)				
Mean ± SD	7.9 ± 7.2	11.3 ± 9.7	10.1 ± 9.0	8.5 ± 8.3
Median duration of illness	6.0	8.0	6.0	6.0

AN, anorexia nervosa; BN, bulimia nervosa; EDNOS, eating disorder not otherwise specified. Owing to missing values not all columns add up to *N*.

Clinical data of the participants are presented in **Table 2**. The mean duration of illness was of 9 ± 8.5 years. The median duration of illness was 6.0 years. Ninety patients (29.6%) met the criteria for another ED diagnosis in the past compared to their current ED diagnosis. In comparison with women of the general population with an age between 15 and 44, the average BMI of the former ED patients was slightly lower (23.5 vs. 22.3). Sociodemographic and clinical characteristics of our sample are comparable to findings in the literature on patients with EDs.(21, 22).

Treatment history

Participants realized they were suffering from an ED on average 3.6 years after the onset of the ED (median 1.5 years). The mean age of onset was 16.3 ± 4.2 years. They reported a substantial patient delay in seeking treatment for their ED. Patients sought treatment on average 4.2 ± 6.3 years after the onset of the ED (median 2.0 years). Twenty-two percent sought treatment within half a year after the onset of the ED, 14.2% within a half year to 1 year after the onset of the ED, and 20.3% sought treatment within 1-2 years after the onset of the ED; however, as much as 22.4% did not seek treatment until 5 years or more after the onset of the ED. No differences were found between ED and former ED patients. Seventy-two percent of the participants first visited their general practitioner. In the Netherlands the general practitioner plays a central role in the health care system and functions as the "gatekeeper" to specialized care. More than 50% of the sample reported an average doctor delay of 1.1 ± 2.2 years (median 0.4 years). 59.3% started treatment for the ED within half a year after seeking treatment and 10.7% started treatment for the ED within half a year to 1 year after seeking treatment. However, as much as 20.7% reported they had not started treatment for the ED within 3 years after seeking treatment. Again no differences were found between ED and former ED patients. Participants described different paths of treatment after referral. Only a few participants reported being referred immediately to a specialized ED centre. The majority underwent several types of treatment before being referred to a specialized ED centre. Over 50% did not receive treatment in a specialized ED centre at all. 21.4% of the participants had experienced one type of treatment, 23.1%

two types of treatment, 19.4% three types of treatment, and 33.3% four or more types of treatment. Patients who had received treatment in a specialized centre had received significantly more types of treatment than did patients not treated in a specialized centre (*t* = 6.20, *p* = .0005). Former ED patients received less treatment than did current ED patients (*t* = 3.34, *p* = .001). Fifty-six percent of the participants reported to have dropped out of treatment at least once during their treatment history. Forty percent of the participants refused treatment at some point in their treatment history. There was a significant difference between former ED patients and ED patients in that fewer former ED patients refused treatment ($\chi^2 = 10.46$; *p* = .001).

Treatment evaluation

Table 3 summarizes the participant's ratings of perceived helpfulness of different types of treatment. A majority of the participants found consultation with the general practitioner and treatment in a general hospital unhelpful. Of the patients admitted to a general hospital, ~75% was hospitalized on a child or adolescent ward or an internal medicine unit because of extreme weight loss or physical complications due to the ED. Treatment in specialized ED centres, self-help groups, and involvement of a partner in therapy were reported as most helpful. The only difference between ED and former ED patients was the treatment in a specialized ED centre. Although a majority of both ED patients and former ED patients regarded treatment in a specialized ED centre as helpful, former ED patients were more positive (*t* = -4.52, *p* = .0005). In general, specialized treatment was more often mentioned to be helpful than non-specialized treatment. No significant differences were found between outpatient or inpatient treatment of both specialized and non-specialized treatment. Sixty three percent of the participants reported negative experiences with treatment or mental health professionals during their treatment history. No significant differences were found between ED patients and former ED patients.

Table 3. Evaluation of treatment of eating disorders from the patients' perspective

	N	Unhelpful (%)	Somewhat Helpful (%)	Helpful (%)
General health care				
General practitioner	239	68.2	15.9	15.9
Dietician	35	40.0	20.0	40.0
General hospital	69	72.5	15.9	11.6
Mental health care				
Private psychiatrist or psychologist	126	53.2	22.2	24.6
Non specialized	149	59.7	13.4	26.8
Outpatient clinic				
Non specialized	105	47.6	20.0	32.4
Psychiatric hospital				
Specialized ED centre	136	14.7	22.1	63.2
Involvement of parents or partner in treatment				
Parents	83	42.2	24.1	33.7
Partner	25	28.0	20.0	52.0
Psychotropic drugs	161	42.2	16.8	41.0
Non professional treatment				
Self help groups	53	22.6	24.5	52.8

N, number of participants who rated this form of treatment. Perceived helpfulness was rated on a 5 point likert scale: unhelpful: 1 and 2 on the likert scale; somewhat helpful: 3 on the likert scale; helpful: 4 and 5 on the likert scale.

The patient's views on treatment of eating disorders

Qualitative analysis was conducted on treatment seeking history and on the experiences with treatment. The answers of the participants regarding their positive and negative experiences with different types of treatment as well as the additional comments on their ratings were clustered into relevant categories. The patient's views are illustrated by quotations of one of the participants.

Participants mentioned several reasons for the delay in starting treatment, such as delay of referral, waiting lists, or being sent from one institution to the other. When participants refused treatment, they felt that treatment did not meet their preferences or needs. When participants dropped out of treatment they mentioned lack of perceived helpfulness (i.e. no trust, no change of their symptoms, or not feeling understood), lack of motivation, not meeting weight demands, or feeling homesick as reasons for dropping out. Similar experiences were reported for both ED and former ED patients.

> *I found it difficult to be referred from one institution to another and discuss my problems over and over again.*

> *When you finally decide to seek treatment, you feel ready to engage in treatment. Then it is very hard to have to wait on a waiting list before you can enter treatment.*

> *I was being offered inpatient treatment, but I did not want to be hospitalized, so I refused treatment.*

When seeking help from a general practitioner, participants felt a lack of knowledge on EDs (in the general practitioner) and lack of empathy, understanding, or delay of referral as important causes of dissatisfaction. Those who found treatment in a general hospital unhelpful mentioned problems with tube feeding and difficulty with the focus on weight restoration by means of classical behavioural strategies, feeling isolated, and a lack of understanding from the nurses.

> *I felt very lonely, miserable and angry.*

> *I was forced to tube feeding. It felt like a punishment.*

Positive experiences with non-specialized treatment, such as treatment of a psychologist/psychiatrist with a private practice, an outpatient clinic, or psychiatric hospital, revealed helpful components of treatment. Helpful components of non-specialized treatment mentioned by the participants were non-specific factors such as a good working alliance, being able to tell their story, feeling understood, feeling supported, and gaining insight into one's problems. Negative aspects of non-specialized treatment mentioned were lack of understanding or empathy due, in part, to a lack of knowledge of EDs, lack of focus of treatment on ED pathology, and lack of support.

> *It is nice when someone really listens to you and tries to understand you instead of judging you.*

Positive experiences with specialized ED centres concerned the understanding and specific knowledge of EDs of the professionals of the centre and the focus on both the ED symptoms as well as underlying problems.

These were most frequently mentioned as helpful components of treatment. The support from other ED patients was also mentioned as valuable. When specialized treatment was found to be unhelpful, participants most frequently stated feeling that the rules governing treatment or on the ward were too strict, there was rivalry with other ED patients on the ward, or that there was too much focus on ED pathology instead of on the underlying psychological issues.

> *I started to eat again. I gained insight in the underlying mechanisms of the eating problems. I felt supported by the other eating disorder patients.*

> *It is important that a mental health professional knows a lot about eating disorders.*

When a partner was involved in treatment, this was evaluated positively when psycho-education and marriage counselling or family therapy were conducted.

> *We are able to communicate more openly. He understands me better than before. It is a relief.*

Negative experiences with treatment overall varied from being refused entrance to a treatment program, perceived pressure to gain weight, or patronizing or intrusive remarks by a mental health professional.

Patient and treatment characteristics, and the evaluation of treatment for eating disorders

To investigate which patient and treatment characteristics contributed to the patient's evaluation of treatment, stepwise multiple regression analyses were conducted. **Table 4** shows the results of the multiple regression analysis.

Table 4. Patient and treatment characteristics and the evaluation of treatment

	Psychologist/ Psychiatrist (Adj R^2 1/4 0.11)		Outpatient Clinic (Adj R^2 1/4 0.08)		Psychiatric Hospital (Adj R^2 1/4 0.19)		Specialized Eating Disorder Centre (Adj R^2 1/4 0.25)	
	B	*p*-Value	B	*p*-Value	B	*p*-Value	B	*p*-Value
Patient characteristics								
Participation in job or education								
Job							0.25	0.029
Education								
Job and education	0.21	0.018						
No job or education								
Urbanization								
Very highly urbanized								
Highly urbanized								
Urbanized								
Rural					0.24	0.007		
Very rural								
EDE subscales worst period								

	Psychologist/ Psychiatrist (Adj R^2 1/4 0.11)		Outpatient Clinic (Adj R^2 1/4 0.08)		Psychiatric Hospital (Adj R^2 1/4 0.19)		Specialized Eating Disorder Centre (Adj R^2 1/4 0.25)	
	B	*p*-Value	B	*p*-Value	B	*p*-Value	B	*p*-Value
Eating concern					−0.20	0.027		
Recovery							−0.32	0.008
Treatment characteristics								
Number of treatments					−0.29	0.001		
Drop out	−0.28	0.002	−0.29	0.0005				
Partner involved							0.30	0.011

Adj. R^2: adjusted r square; very highly urbanized: 2,500 addresses per km^2; highly urbanized: 1,500–2,500 addresses per km^2; urbanized: 1,000–1,500 addresses per km^2; rural 500–1,000 addresses per km^2; very rural: <500 addresses per km^2. Variables are presented if they were included in the regression model.

Evaluation of treatment by a psychologist or psychiatrist in a private practice was predicted by drop-out of treatment and participation in a job and an education. Not having dropped out of treatment at least once in treatment history, and having both a job and participating in education predicted a more positive evaluation of treatment of a psychologist or psychiatrist. Evaluation of treatment in an outpatient clinic was predicted by drop out of treatment. Not having dropped out of treatment at least once in treatment history predicted a more positive evaluation of treatment in an outpatient clinic. Evaluation of treatment in a psychiatric hospital was predicted by the number of treatments, urbanization, and EDE-Q subscale eating concern at the worst period of the ED. Fewer treatments, living in a rural area, and less eating concern at the worst period of the ED predicted a more positive evaluation of treatment in a psychiatric hospital. Evaluation of treatment in a specialized ED centre was predicted by recovery, having the partner involved in therapy, and participating in a job. No ED at present, having the partner involved in therapy, and having a job predicted a more positive evaluation of treatment in a specialized ED centre.

Conclusion

In this study a substantial patient delay before seeking treatment for EDs was found. Twenty-two percent did not seek treatment until 5 years after the onset of treatment. More than 50% of the sample also mentioned a doctor delay. Although two-thirds started treatment for the ED within half a year after seeking treatment, a worrying 20.7% did not start treatment for the ED within 3 years. Treatment in a specialized ED centre was perceived as most helpful. Participants indicated the focus on ED symptoms as well as underlying issues and the perceived support from other ED patients as helpful components. Furthermore, self-help groups and involvement of a partner in treatment were viewed as valuable by more than 50% of the sample who received this type of treatment. No strong predictors for the evaluation of treatment were found.

Limitations and strengths

A limitation of this study was that participants volunteered to take part in a large study on the quality of treatment of EDs. More than 98% of the participants did seek professional treatment. In a large longitudinal study on the prevalence of mental disorders and psychosocial impairments in adolescents and young adults only 26.4% of the 3% suffering from an ED sought professional treatment (23) The advertisement to participate in this study may have appealed especially to those who have a history of different treatments for EDs. This group may have (had) more severe ED pathology than did a randomly selected community based sample. However the current study provides valuable information on the evaluation of treatment of EDs, particularly of those ED patients who need this treatment the most.

The strength of the study is that it is the first large sample of ED patients to report on both their treatment history and treatment evaluation as well as their views on helpful components for the quality of treatment. In contrast to earlier studies, comparison was possible between the evaluation of general health care treatment, non specialized mental health treatment, and specialized treatment for EDs. Because the sample included both ED patients as well as former ED patients, assessment was also feasible for the differences and similarities between those groups. Furthermore, this was the first study to investigate patient characteristics and treatment characteristics that were associated with the patient's treatment evaluation.

The improvement of readiness to seek and engage in treatment: addressing patient and doctor delay

Although the average reported patient delay in seeking treatment in our study is less than the average patient delay (~5 years) reported by Rosenvinge and Klusmeier (7) and Newton et al. (5,6), 22% of our sample did not seek treatment until after 5 years after the onset of the ED. Denial of the illness and shame may prevent the identification and acknowledgment of the ED, which hinder treatment seeking behaviour soon after the illness develops. Interventions to increase the knowledge about EDs in the general public may help raise awareness of the nature of EDs and enhance early detection by family members and friends. These interventions need to address public beliefs regarding treatment of EDs. In a study by Mond et al. (24) on the public beliefs regarding the helpfulness of treatment interventions for bulimic patients, respondents indicated that seeing a general practitioner, counselor, or dietician was more likely to be helpful than seeing either a psychologist or a psychiatrist. Self-help groups were also regarded as helpful. When family members and friends learn more about the perceived helpfulness of treatment of EDs from the patient's perspective, it will enable them to support their relatives to seek treatment. Almost three-quarters of our sample first visited their general practitioner, who acts as the gatekeeper of specialized treatment, and increasing the knowledge and diagnostic and motivational skills of EDs for general practitioners is also warranted. This will enable general practitioners to help patients acknowledge their ED and increase readiness for treatment. It may also assist in decreasing doctor delay and targeted referral. However, even after referral patients can find it difficult to engage in treatment. In our study 14% of those patients who reported to have dropped out of treatment at least once mentioned lack of motivation or readiness to engage in treatment as the main reason to quit treatment prematurely.

Moving towards stepped care for eating disorders

Based on the gathered information on the patient's perspective, referral to a specialized ED centre should be considered first. In line with Swain-Campbell et al. (8) and Clinton et al. (9,10), treatment in a specialized centre was evaluated most often as helpful. Especially important is addressing both ED symptoms as well as underlying issues. It is recommended that self-help groups be offered when waiting lists or anxiety to enter treatment is hampering entering into specialized care. A positive evaluation of self-help groups was found concurrent to the study of Newton et al. (5,6) and Rosenvinge and Klusmeier (7). When self-help groups are offered as pre-treatment, patients will be encouraged to engage in treatment and stepped care will be promoted.

Involvement of relatives in treatment of eating disorders

In contrast to the findings by Rosenvinge and Klusmeier (7), involving a partner in treatment was perceived as helpful by many of the participants, especially when psycho-education and marriage counselling or family therapy was offered. It is difficult to compare these results, because in the study of Rosenvinge and Klusmeier family therapy is unclear defined. Although involvement of a partner in treatment was perceived as valuable in our study by more than 50% of the patients who received this type of treatment, involving parents or caregivers was generally perceived less as helpful, namely by more than 30%. However, the importance of involving relatives in treatment when a patient lives together with her or his family or a partner is underscored by findings of a study on the quality of life of family caregivers of ED patients by de la Rie et al.(25) The quality of life of parents, partner, or siblings was reported to be worse than the quality of life of a normal reference group. Caregivers stated that the ED affected family life substantially. Seventy-five percent welcomed professional support and mentioned the need for practical advice, information on EDs, and emotional support.

The individual encounter with the therapist

In the individual encounter with a therapist a collaborative approach is welcomed by patients. Helpful components are proper communication skills of mental health professionals, a good therapeutic alliance, and the focus of treatment. Patients find a focus of treatment on both the ED symptoms as well as underlying issues helpful, but some patients mentioned that too much emphasis on either ED symptoms or underlying issues was less constructive. To establish a good therapeutic alliance, it is important to negotiate treatment goals with an individual patient at different moments during the process of change. The extent to which treatment goals are negotiated may explain differences in satisfaction with interventions focusing on control over eating problems as found in earlier studies (8-10).

Patient and treatment characteristics and the evaluation of treatment

Investigating similarities and differences between patients in their evaluation of treatment can help to predict the type of patient who will perceive to benefit most from a particular type of treatment. In this study the evaluation of treatment was predicted only partially by the independent variables. Not dropping out of treatment partly predicted a more positive evaluation of nonspecialized treatment, which may be associated with the readiness to engage in treatment. Participation in a job or in an education predicted a more positive evaluation of treatment of a psychologist or psychiatrist in a private practice and treatment in a specialized centre. Recovery predicted a more positive evaluation of treatment in a specialized centre. However, the percentage explained variance ranged from 8% for the evaluation of outpatient treatment to 25% for treatment in a specialized ED centre. This finding suggests that other factors are important in explaining the evaluation of treatment. We presume that the illness perception of ED patients at different stages of the illness trajectory may affect the evaluation of treatment. Leventhal et al.(26) postulated that individuals create mental representations of illness based on five key dimensions: illness identity, timeline, consequences, causes, and controllability/curability. In a study by

Holliday et al. (27) on the illness perception of AN patients, participants had fairly negative perceptions about controllability and curability of the disorder. Views of illness controllability and curability may affect expectations of treatment. Furthermore, these perceptions may vary at different stages of the illness trajectory and consequently the expectations of treatment may change as well. Specific treatment experiences during the course of illness may contribute positively or negatively to the sense of controllability and curability. This in turn may affect expectations of future treatment. It is to be considered that illness perceptions may affect the evaluation of treatment as a mediating variable in this study. Further research is needed to investigate this hypothesis and to examine further the factors that contribute to the evaluation of treatment.

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Chapter 5

The quality of treatment of eating disorders: a comparison of the therapists' and patients' perspective.

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Introduction

Eating disorders (EDs) are severe mental disorders with a poor prognosis (1,2). Treatment quality needs to be investigated to improve the course and consequences of EDs and enhance recovery rates. Our current state of scientific knowledge on the effectiveness and quality of the treatments for EDs is limited, specifically for anorexia nervosa (3). Guidelines of EDs summarize the state of the art of treatment of EDs (4-7). These guidelines show that knowledge on the quality of treatment of EDs is primarily based on clinical trials or follow-up studies in a naturalistic setting, assessing the quality of treatment in terms of outcome. Donabedian (8) suggested to take into account other aspects of care, besides the outcome of care or effectiveness, when the quality of care is assessed. He advised to include structure (attributes of the setting in which care occurs) and process (actual activities when providing care) in the concept of treatment quality. Current guidelines show that those aspects are hardly taken into account when evaluating the quality of treatment of EDs. Other bodies of knowledge may supplement the information on the quality of treatment of EDs; namely, the views of therapists and patients.

Although some of the current guidelines on treatment of EDs incorporate expert opinions and the views of patient organizations on specific topics, little is known about the views of therapists working in the field of EDs on what contributes to the quality of treatment in their day-to-day practice. Ranson and Robinson (9) reported that therapists tended to tailor treatment to the individual's needs, rather than apply the available evidence. Pederson-Mussell et al. (10) showed that the use of empirically supported psychotherapy for EDs was limited. This suggests a gap between evidence-based knowledge and clinical practice. It therefore seems important to get more insight into the views of therapists working in the field of EDs. Furthermore, little is known about the patients' views on the quality of treatment of EDs. A growing number of studies have been investigating the patients' treatment evaluation and satisfaction (11-16), but no prior study has systematically investigated the views of patients with ED on what contributes to the quality of treatment of EDs. The current study aimed to investigate the quality of treatment of EDs from the therapists' and patients' perspective and compares their views. Differences between patients with current ED and former ED were also investigated.

Method

Participants

The therapists' sample consisted of therapists recruited through specialized treatment centres in the Netherlands and at a national teaching day on EDs.

The patients' sample consisted of patients with current and former ED recruited from the community in the Netherlands by various methods, namely via the website of the patient organization, advertisements in a magazine and newspapers, and via specialized ED centres. After a screening questionnaire was filled out to assess life time DSM IV diagnosis of EDs (17), participants could enter the study. Study sample, recruitment method, and diagnostic criteria are described in detail elsewhere (16).

Quality of treatment

We developed the "Questionnaire for Eating Problems and Treatment" to assess the quality of treatment from the patients' and therapists' perspective. Questions and items take into account several aspects of quality: structure, process, and outcome.[8] First, a patient version of the questionnaire was developed. After consulting an expert panel of four researchers, three therapists, and seven patients of the day treatment program at the Centre for Eating Disorders Ursula, the final version of the questionnaire was divided into three parts. The first and second part on treatment trajectories and the evaluation of the treatment received are described elsewhere (16). The third part of the questionnaire consists of questions on expectations of and opinions on the quality of treatment (Appendix A1). Open questions referred to treatment content (process and outcome), the mental health professionals involved (process), and the organization that provides treatment (process and structure). Furthermore, participants were asked to rate 70 items on a 5-point Likert scale to assess their importance (Appendix A2). The 70 items reflect all aspects of quality: process, structure, and outcome. Lastly, participants were asked to rank the 10 most important items of the list. Therapists were asked to fill out the similar questions- with the exception of the questions 8-11. They were asked to rate four additional items (Appendix A3).

Analysis

For the quantitative analysis of the answers of both therapists and patients on the list of 70 items (Appendix A2), we counted how many participants rated “important” (“4” on the Likert scales) and “very important” (“5” on the Likert scales) on each item. The ratings “important” (“4” on the Likert scales) and “very important” (“5” on the Likert scales) of the four additional items of the therapists were counted as well (Appendix A3). Then the ranking of the 10 most important items of both therapists and patients regarding treatment quality was analyzed by frequency analysis. A weight was assigned in line with the order in which items were ranked, from 10 for the highest ranking (the first place of the “top 10”) down to 1 for the lowest ranking (the 10th place of the “top 10”) to assess the relative importance of the mentioned criteria.

An exploratory principal component analysis (PCA) with varimax rotation was carried out to identify relevant factors of the 70 items regarding treatment quality of the patients with current and former ED (Appendix A2). Participants who answered “very important” on more than 50 items were excluded from the analysis. Cronbach’s alphas were calculated to determine the reliability of the relevant factors. Standardized mean scores were calculated for all factors. A one-way analysis of variance was used to examine differences between patients with anorexia nervosa (AN), bulimia nervosa (BN), ED not otherwise specified (EDNOS), former ED, and therapists on the standardized mean scores on the identified relevant factors of the patient sample.

For qualitative analysis, all the answers on the open questions of both therapists and patients were saved and then coded by the researchers (Appendix A1). Subsequently, these coded items were clustered into meaningful categories based on their content. This process was facilitated by means of KWALITAN, a software program that enables clustering of relevant items in meaningful categories (18).

Results

Participants

Seventy-three therapists volunteered to fill out the questionnaire on the quality of treatment of EDs. Sociodemographic and professional characteristics of the therapists are presented in **Table 1**. Two thirds of the sample were women therapists with a mean age of 42 (SD, 9.9). The sample consisted of both senior as well as junior therapists, with an average of more than 15 years (SD, 9.4) of experience as a therapist. All therapists were currently working with patients with ED. The number of patients with ED was more than 50% of their case load for over 75% of the therapists. Their theoretical orientation regarding their work varied. Sixty-one percent of the therapists mentioned more than one theoretical orientation. Seventy-five percent mentioned a cognitive behavioural theoretical orientation. Therapists were asked their first choice of treatment for AN, BN, and binge eating disorder (BED). Of the 69 therapists who answered this question, cognitive behavioural therapy (CBT) was mentioned by ~78% of the therapists for AN, by 75.8% of the therapists for BN, and 71.8% of the therapists for BED. Of those who mentioned CBT as their first choice of treatment, 70.4% applied this form of treatment with patients with AN, 78% with patients with BN, and 56.5% with patients with BED. Of those who mentioned CBT as their first choice of treatment, 70.4% received training in this form of treatment regarding patients with AN, 68.6% regarding patients with BN, and 60% regarding patients with BED.

Table 1. Sociodemographic and professional characteristics of the therapists

Sex (%)		
Male	26	(35.6)
Female	47	(64.4)
Age		
Mean ± SD	42.0	± 9.9
Median	43.0	
Profession		
Psychiatrist	3	(4.2)
Head of staff	5	(6.9)
Clinical psychologist/Psychotherapist	15	(20.8)
Health psychologist	3	(4.2)
Resident in psychiatry	3	(4.2)
Health psychologist in training	2	(2.8)
Nurse	28	(38.8)
Social worker	2	(2.8)
Art or psychomotor	6	(8.3)
Therapist Other	5	(6.9)
Field of employment[a]		
General hospital	4	(5.6)
Private practice	1	(1.4)
Nonspecialized outpatient clinic	22	(30.6)
Nonspecialized psychiatric hospital	10	(13.6)
Specialized ED centre	44	(60.3)
Theoretical orientation[b]		
Biomedical	11	(15.2)
Psychoanalytic	16	(22.2)
Client-centreed	23	(31.9)
Behavioural	22	(30.6)
Cognitive behavioural	54	(75.0)
System	27	(37.5)
Transactional	4	(5.6)
Other	16	(22.2)
Years of experience as a therapist \		
Mean ± SD	15.6	± 9.4
Median	16.0	
Minimum	0.25	
Maximum	34.0	

Number of patients with ED in caseload	
More than 50%	55 (75.3)
25–50%	10 (13.7)
5–25%	5 (6.8)
1–5%	3 (4.1)

Notes: SD, standard deviation; ED, eating disorder.

[a] *N* 5 81, because some therapists worked at two different institutions at the time of the study.

[b] More than one answer was possible.

Sociodemographic characteristics and clinical data of patients with current and former ED are presented in **Table 2**. Of the 304 participants of the patients' sample, 156 (51.3%) met DSM-IV criteria for an ED in the present: 44 (14.5%) met criteria for AN, 43 (14.1%) for BN, and 69 (22.7%) for EDNOS. Of the patients with EDNOS, 10 met criteria for BED, others met (sub)threshold criteria for AN or BN. Of the participants who had met criteria for an ED in the past, 148 (48.7%) did not meet criteria for an ED in the present (patients with former ED). Patients with current and former ED had significantly poorer quality of life (QOL) than a normal reference group of women in the Netherlands (19). Participants were predominantly women with a mean age of 28.7 years (SD, 8.9). The mean duration of illness was 9 years (SD, 8.5). No significant differences were found on the sociodemographic characteristics among the diagnostic groups.

Table 2. Sociodemographic and clinical data of patients with current eating disorder and former eating disorder

	Current Patients with ED *N* = 156	Former Patients with ED *N* = 148
DSM IV diagnosis		
AN	44 0	
BN	43 0	
EDNOS	69 0	
No ED	0 148	
Female (%)	153 (98.1)	143 (96.6)
Age (years)		
Mean ± SD	28.2 (8.7)	29.3 (8.9)
Median	26.0	27.0

Educational level (%)		
Primary school	7 (4.5)	7 (4.7)
Basic high school	20 (12.8)	14 (9.3)
Advanced high school	85 (54.5)	71 (48.0)
College/University	44 (28.2)	56 (37.8)
Urbanization (%)		
Very highly urbanized	37 (23.7)	51 (34.4)
Highly urbanized	48 (30.8)	45 (31.1)
Urbanized	35 (22.4)	28 (18.9)
Rural	17 (10.9)	11 (7.4)
Very rural	17 (10.9)	13 (8.8)
Age of onset (years)		
Mean ± SD	16.4 (4.5)	16.1 (3.7)
BMI		
Mean ± SD		23.3 (5.0)
AN	15.6 (1.5)	
BN	21.6 (3.5)	
EDNOS	21.0 (5.9)	
Duration of illness in years[a]		
Mean ±SD	9.8 (8.6)	8.5 (8.3)
Median	6.7 6.0	

Notes: AN, anorexia nervosa; BN, bulimia nervosa; EDNOS, eating disorder not otherwise specified; BMI, body mass index (kg/m^2). Very highly urbanized: ≥2,500 addresses per km^2; highly urbanized: 1,500–2,500 addresses per km^2; urbanized: 1,000–1,500 addresses per km^2; rural 5001,000 addresses per km^2; very rural: <500 addresses per km^2. Owing to missing values not all columns add up to N.

[a] *N* = 280.

The therapists' views on the quality of treatment of eating disorders

First, the rating of the items on the list were analyzed. Fifty-four of 74 items (73%) were found to be important to very important by at least two-third of the therapists. Ten items were found important by less than 50% of the therapist. The three least important criteria were as follows: "mental health professional who shares personal experiences" (9.6%), "receiving standardized treatment" (12.4%), and "single person bedroom when admitted" (28.6%). Furthermore, it is noteworthy that "evidence-based treatment" was considered to be important by 71.0% of the therapists, whereas “protocol-based treatment” was found to be important by 34.3% of the therapists.

Second, the ranking of the 10 most important items was analyzed. **Table 3** shows the ranking of the weighed top 10 criteria by the therapists. A great variety was found in the ranking of items. The criterion that was mentioned most often was “learning to take your own responsibility.” This was mentioned by 33 of the 73 participants (45%). When weighing, the criteria “being respected” was found the most important criterion. The following criteria were not mentioned at all: “being able to talk about suicidal thoughts,” “therapist who shares personal experiences,” “the location of treatment should be easily reachable,” “knowing how long treatment will take,” “learning how to cook as part of treatment,” “liberal visiting hours (when admitted),” and “ good quality of food (when admitted or in day treatment)”. Of the four additional criteria “evidence-based treatment” was mentioned only four times as a “top 10” criterion. “Protocol-based treatment” was mentioned only twice as a “top 10” criterion. The four additional criteria did not affect the weighed ranking of the criteria.

Third, the therapists personal views on the mental health professional, treatment, and institution were analyzed qualitatively. Their views can be summarized as follows: the mental health professional needs to have good communication skills (such as being respectful), needs to be able to establish a good therapeutic alliance by showing empathy, being committed and supportive, to have therapeutic skills such as expertise on EDs, guard the boundaries of the relationship, be patient and introspective. A few remarks were made regarding the therapeutic style, such as being directive and providing clarity. Treatment should focus on learning how to eat normally, weight regain, and being able to handle symptoms. However, treatment should also focus on problems underlying the ED, such as self-esteem, body image, dysfunctional cognitions, social emotional development, and quality of life. Therapists also mentioned treatment conditions, such as treatment planning and formulating attainable goals, safety and support. More than half of the therapists mentioned CBT, but psychoeducation, psychomotor therapy, group therapy, or specialized multidisciplinary treatment were also found to be important to the quality of treatment. Furthermore, some therapists mentioned enhancement of motivation, learning to take one's own responsibility, and gaining insight or autonomy as important aspects of the quality of treatment. Only a few therapists mentioned specific aspects of the institution they found important. When they did, they mentioned that the institution should offer different types of treatment, both outpatient, day treatment as well as residential treatment, good treatment conditions, expertise on EDs, and continuity of care.

Table 3. The ranking of the weighed criteria on the quality of treatment of eating disorders of therapists

	Weighed Criterion
1	Being respected
2	Learning to take your own responsibility
3	Learning how to eat normally
4	Focus on recovering weight
5	Focus on improving your body image
6	Being taken seriously
7	Trust in therapist
8	Explanation or information on EDs
9	Keeping a(n) (eating) diary
10	Being able to talk about eating behaviours

Table 4 The ranking of the weighed criteria on the quality of treatment of eating disorders of current and former eating disorder patients

	Weighed Criterion
1	Trust in therapist
2	Being taken seriously
3	Treatment that addresses the person
4	Being able to talk about feelings
5	Focus on self-esteem
6	Being respected
7	Being able to talk about thoughts
8	Addressing underlying problems
9	Being able to talk about eating behaviours
10	Being accepted as you are

The patients' views on the quality of treatment of eating disorders

First, the rating of the items on the list was analyzed. Fifty of 70 criteria (71%) was found important to be very important by at least two-third of the patients with current and former ED. Twelve items (17%) were found important to be very important by less than 50% of the patients. The three least important criteria were "receiving standardized treatment," (5.9%) "gain weight first before focusing on other problems," (13.6%) and "companion as tutor/counselor" (34.2%).

Second, the ranking of the 10 most important items was analyzed. **Table 4** shows the ranking of the weighed criteria regarding the quality of treatment. A great variety was found in the ranking of items. The most often mentioned criterion was "trust in therapist". This was mentioned by 138 of the 304 participants (45%). When weighing the criteria, "trust in therapist" was also found the most important criterion. The least often mentioned criteria were "knowing how long treatment will take" (0), "receiving standardized treatment" (0), "participating in compulsory components of treatment," (2) "role playing as part of treatment," (4) and "being able to talk about religion." (5) Only small differences were found between patients with current and former ED when looking at the weighed criteria. They ranked similar items, but in a slightly different order. Patients with current ED valued "being accepted as you are" more highly than patients with former ED. "Being accepted as you are" was not part of the 10 most important criteria of the patients with former ED. Patients with former ED valued "learning to take your own responsibility" more highly than patients with current ED. "Learning to take your own responsibility" was not part of the top 10 criteria of the patients with current ED.

Third, the patients' personal views on the mental health professional, treatment, and institution were analyzed qualitatively. Their views can be summarized as follows: the mental health professional needs to have good communication skills (such as taking someone seriously), to have knowledge of and experience with EDs, to facilitate engaging in a relationship with the therapist, to listen to the patient, to stand beside the patient and work together, and to focus on the person and not the disorder. Patients stressed the importance of focusing on problems underlying the ED, such as selfesteem, but most of them also felt the need to address the eating pattern or behaviours. They often mentioned that treatment should focus on both symptoms of the ED as well as problems underlying the ED. Treatment conditions need to include goals and rules, but also give the patient a say in the matter. Patients less often mentioned specific aspects of the institution they found important. When they did, they mentioned the importance of after care or the continuity of care, diminishing waiting lists, accessibility of the institution, a proper location, and offering different forms of treatment.

A comparison of therapists and patients on the quality of treatment of eating disorders

Table 5 shows the results of the exploratory PCA with varimax rotation of the patients' sample. Participants who did not differentiate between the items and rated more than 50 items with "5" on the Likert scales were excluded from the analysis. The N of the PCA was 258 participants. The analysis revealed seven interpretable factors with a cumulative explained variance of 33.0%. Cronbach's as vary from 0.68 to 0.84. **Table 5** shows the seven factors, respectively "mastery," "treatment modalities,", "information," "focus on underlying problems," "bond with therapist," "acceptance," and "focus on eating behaviour" and their items.

Table 6 shows the standardized mean scores of all factors by diagnostic group (both patients with current and former ED). All factors were found to contribute to the quality of treatment, having high mean scores. "Acceptance" had the highest mean scores. Furthermore, **Table 6** shows the standardized mean scores of the therapists on the factors. Five therapists who rated more than 50 items of the 70 items "5"on the Likert scales were excluded from the analysis. Therapists found all factors to contribute to the quality of treatment. Standardized mean scores of the therapists on all seven factors were above average. Only few differences were found between therapists. Junior therapists and social workers/nurses found "treatment modalities" more important than senior therapists. "Acceptance" had the highest mean score.

Table 5. The items of the factors of the principal component analysis with varimax rotation of the patients' sample

Factors	Mastery	Treatment Modalities	Information	Focus on Underlying Problems	Bond with therapist	Acceptance	Focus on eating behaviours
Items	Focus on self-esteem	Participating in compulsory components of treatment	Explanation or information about eating disorders	Being able to talk about thoughts	Therapist who truly listens	Being respected	Being able to talk about eating behaviours
	Focus on social contacts	Role-playing as part of treatment	Explanation about somatic complaints and consequences of the eating disorders	Being able to talk about feelings	Therapist who is interested	Being able to tell your story	Focus on recovering weight
	Focus on quality of life	Music, drawing or drama as part of treatment	Explanation and information about treatment	Being able to talk about the past	Trust from you therapist	Being taken seriously	Learning how to eat normally
	Focus on the future	Sport and exercising as part of treatment		Being able to talk about suicidal thoughts	Feeling supported	Being accepted as you are	Keeping a(n) (eating) diary
	Focus on the transition back to normal life	Learning how to cook as part of treatment		Addressing underlying problems	Being put at ease		
	Learning how to express oneself	Talking in groups					
	Learning to be assertive						
	Learning to take your own responsibility						

Table 6. The factors of the principal component analysis and the distribution of standardized mean scores by subgroup with one-way analysis of variance

						Mean (SD)					ANOVA		
Factors	Nr	C's *a*	VAR Σ 33.2%	Min	Max	AN, $N = 38$	BN, $N = 38$	EDNOS, $N = 63$	No ED, $N = 119$	Th, $N = 68$	f	*p*	Post hoc Sheffe
Mastery	8	0.84	6.6	18.8	50.0	42.2 (6.5)	41.4 (6.3)	44.4 (3.8)	44.1 (5.6)	43.1 (5.2)	2.6	0.04	n.s.
Treatment Modalities	6	0.78	5.1	10.0	50.0	31.8 (6.5)	30.7 (8.3)	32.2 (9.9)	31.6 (8.3)	37.5 (5.4)	7.5	0.0005	T >AN,BN, EDNOS, No ED
Information	3	0.80	4.9	16.7	50.0	40.5 (7.1)	41.9 (6.8)	42.7 (6.9)	41.6 (7.5)	44.7 (5.9)	3.0	0.02	T >AN
Focus on underlying problems	5	0.75	4.5	24.0	50.0	42.1 (6.1)	44.6 (5.0)	43.9 (5.6)	45.1 (4.9)	39.6 (5.6)	12.9	0.0005	BN, EDNOS, No ED > T
Bond with therapist	5	0.77	4.1	32.0	50.0	47.3 (3.2)	46.3 (4.8)	47.0 (4.0)	47.1 (3.8)	44.6 (4.4)	4.9	0.001	AN, EDNOS, No ED > T
Acceptance	4	0.75	4.1	30.0	50.0	49.1 (2.0)	48.7 (2.5)	48.2 (3.4)	48.5 (3.3)	46.6 (4.0)	4.9	0.001	AN, BN > T
Focus on eating behaviours	4	0.68	4.0	10.0	50.0	38.4 (6.1)	36.3 (7.5)	38.9 (7.0)	38.9 (7.5)	43.7 (5.6)	8.7	0.0005	T > AN, BN, EDNOS, No ED

Notes: Nr, number of items; C's *a*, Cronbach's alpha; VAR, rotated sum of squared loadings; Min, miminum; max, maximum; AN, anorexia nervosa; BN, bulimia nervosa; EDNOS, eating disorder not otherwisespecified; No ED, no eating disorder; Th, therapists; Σ , sum; SD, standard deviation.

A one-way analysis of variance to compare therapists and patients with AN, BN, EDNOS, and former ED was conducted with all seven factors (**Table 6**). Therapists found “treatment modalities” and “ focus on eating behaviours” to be significantly more important than patients with AN, BN, EDNOS, and former ED. Therapists found “information” more important than patients with AN. Therapists found “focus on underlying problems” less important than patients with BN, EDNOS, and former ED. Therapists found “bond with therapist” less important than patients with AN, EDNOS, and former ED. Therapists found “acceptance” less important than patients with AN and BN. No significant differences were found on “mastery”.

Conclusion

Both therapists and patients most often mentioned treatment focus, therapeutic alliance, and communicational skills as important aspects of the quality of treatment. However, they valued similar topics differently. Therapists valued the focus on ED symptoms and behavioural change more highly, whereas patients underscored the importance of the relationship with the therapist and addressing underlying problems. Most therapists work from a cognitive behavioural theoretical orientation, but protocol-based treatment was not found important.

A comparison of therapists and patients on the quality of treatment of eating disorders

In this study, therapists and patients agreed on most aspects of the quality of treatment, in particular, regarding the process and structure of care. However, therapists and patients valued similar topics differently as was found with both quantitative and qualitative analysis. Therapists most often stressed the focus on ED symptoms and behavioural change, whereas patients with (current and former) ED most often stressed the importance of the therapeutic relationship and the need to address problems underlying the ED. Of the seven interpretable factors that explained more than 30% of the variance, the therapists more highly valued “focus on eating behaviours” and "treatment modalities", whereas patients with (current and former) ED more highly valued "addressing underlying problems" and the "bond with therapist." Nevertheless, these differences seem to be subtle. Careful analysis of the significant differences found with the one-way analysis of variance shows that the standard deviation of the mean scores within the groups was higher than the difference of the means of the highest and lowest mean between the groups. This suggests that in most cases the therapist and patient will be able to work together on mutual goals, because their shared values may outweigh the differences. However, the match between therapist and patient needs to be carefully monitored. If not, any differences in values that appear can have several implications. They may affect the role expectations of both the therapist and the patient. To a therapist, a "motivated" or "progressing" patient will be a patient who is willing to work on (eating) behavioural change, whereas to a patient, a "helpful" therapist will be a therapist who is understanding and willing to focus on the patient as a person and not merely on behavioural symptoms. When treatment goals need to be negotiated at different stages of the therapeutic process, the therapist and patient may interpret each other's behaviour based on these different role expectations and consequently have different views of the therapeutic alliance. Differences in the views of the therapeutic alliance may negatively affect the alliance itself and in turn hinder treatment progress. Current guidelines mainly focus on the effectiveness of treatment methods or techniques, although several studies show that the therapeutic alliance-defined as the collaborative and affective bond between therapist and patient (20) is crucial to psychotherapeutic success in treatment of mental disorders. In their meta-analysis Martin et al. (20) show that the therapeutic alliance has a moderate, but consistent effect on outcome of psychotherapeutic treatment. In their summary of research on the therapeutic relationship and psychotherapy outcome, Lambert and Barley (21) estimated that client therapist relationship factors account for ~30% of the variance in outcome. Since then other studies consistently underscored the importance of therapeutic alliance (22-26). A good therapeutic alliance seems to be a necessary, but not a sufficient, condition for the success of treatment.

The patients’ views: the importance of the therapeutic alliance

The importance of acceptance and the bond with the therapist, key features of the therapeutic alliance, as felt by patients with current and former ED of our study is supported by research on the therapeutic alliance as mentioned earlier. Only a few studies on EDs reflect on the therapeutic alliance in relation to outcome. In a study of Zeeck and Hartmann (27) on the therapeutic process and outcome, experiences of negative emotions between sessions in patients with AN, which may be linked to failure to build a good therapeutic alliance, was associated with bad outcome. A frequent and intense process of “recreating the therapeutic dialogue,” i.e. frequent or intense remembering of therapy between the sessions, was found to be associated with good outcome. In a study by Loeb et al. (28), early establishment of the alliance of patients with BN and their therapists predicted post treatment purging frequency. Pereira et al. (29) found the therapeutic alliance to be important in family therapy of adolescent AN.

Patients with ED may stress the importance of acceptance and a good therapeutic alliance, because they find it particularly challenging to engage in a relationship with a therapist. This may be due to early life experiences, when mental representations about self and others, and oneself in relationship with others are formed (30). Attachment styles may affect relationships later in life, as well as the therapeutic alliance. Several studies suggest a relationship between attachment styles or interpersonal problems and engaging in a therapeutic alliance in EDs (23, 31-37). Presumably, difficulties to enter treatment of some patients with ED may in fact reflect the difficulties to engage in a relationship with the therapist or a psychiatric key worker.

The therapists’ views: theoretical orientation and day-to-day practice

The majority of the therapists of our study mentioned they endorse a cognitive behavioural orientation. More than 70% mentioned evidence-based treatment to be important, whereas protocol-based treatment was not found important. Furthermore, 49 therapists mentioned to work eclectic or integrative in their day-to-day practice (more than one theoretical orientation). Not all of the therapists who mentioned CBT as their first choice of treatment applied this form of treatment or received training in this form of treatment. Wilson and Shafran (38) stress the importance of the dissemination of the available evidence and guidelines in order to improve the clinical practice. The therapists may be afraid protocol-based treatment will restrict their possibilities to attune therapy to an individual patients' needs. Earlier studies seem to suggest this (9,10). The guidelines describe that the available evidence, particularly on treatment of BN and BED, shows the effectiveness of CBT on eating behaviours as well as on self-esteem and social functioning. However, therapists who are trained to work from other theoretical orientations, for instance, a psychodynamic or client-centred orientation, in which the alliance as a vehicle for change is a core feature of therapy may find working from a manual alienating. This may be an obstacle of the dissemination of the evidence.

However, in a study by Loeb et al.(28) of patients with BN on the therapeutic alliance and therapist adherence to a treatment protocol, better adherence of the therapists was associated with a better therapeutic alliance. Goldfried and Davila (39) have described how both technique and therapeutic relationship can serve to facilitate general principles that are the keys to the change process. On the basis of their findings in the study on treatment of borderline personality disorders, Spinhoven et al. (24) suggested that the therapeutic relationship and specific techniques interact with and influence one another and may facilitate processes of change underlying clinical improvement. When taking this into account, dissemination of available evidence may be facilitated.

Limitations and strengths

A limitation of this study was that therapists who participated in this study were mainly recruited at specialized ED centres. Therefore, they are more experienced with EDs and its treatment than a randomly selected group of therapists of different psychiatric centres. Another limitation of the study is that the patients with current and former ED volunteered to take part in a large study on the quality of treatment of EDs. More than 98% of the participants did seek professional treatment. The advertisement to participate in this study may have appealed especially to those who have a history of different treatments for EDs. This group may have (had) more severe ED pathology than a randomly selected community-based sample. However, the current study provides valuable information on both the therapists' and the patients' views on the quality of treatment of EDs, perhaps, particularly of those patients with ED who need this treatment the most. The strength of the study is that it is the first large sample of patients with ED to report on their views on the quality of treatment of EDs. It is also the first study in which the patients' views are compared directly with the therapists' views on similar topics regarding the quality of treatment.

Towards converging evidence-based knowledge, clinical practice, and patients' views

When the best research evidence, clinical expertise, and patient values are integrated, clinical outcomes and quality of life will be optimized (40). However, the therapists' and patients' views need to be integrated in treatment trials and outcome research by assessing process variables such as the focus of treatment and the therapeutic alliance, as well as structure variables (such as to which extent the program or institute guarantees continuity of care). This will enhance insight in the working mechanisms of particular forms of treatment. Research will then correspond more with the day-to-day experience of both therapists and patients, which may facilitate implementation of the results. Furthermore, when the evaluation of treatment by patients will be a standard outcome measure, service acceptability will be enhanced, which in turn may affect compliance and the progress of treatment (41). Accessibility of treatment may be enhanced through implementation of the Worldwide Charter for Action on Eating Disorders (42). In the individual encounter of a therapist and patient, therapists should be aware of the importance of acceptance and the therapeutic alliance when negotiating treatment goals. Therapists need to be attuned to the perception of the therapeutic alliance by the patient, to be aware of differences in role expectations and discuss the patients' expectations to enhance the therapeutic alliance and facilitate treatment progress. Patients need to be invited to share their needs and preferences. All in all, converging three bodies of knowledge–namely the available evidence and the therapists' and patients' views–will contribute to optimizing treatment of EDs.

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Appendix A

Table A1. Questionnaire on the quality of treatment for eating disorders

The following questions address the quality of treatment for eating disorders in general. The most important aspect of treatment is that it helps you to recover. We want to learn about your expectations about treatment and why you think some treatments are more helpful for recovery than others, i.e. what determines quality of treatment for you. Even if you have little or no experiences with treatment, we would like to know your opinion.

1 What do you find important regarding treatment for eating disorders and why?
2 What should definitely get attention in the treatment of eating disorders and why?
3 What do you expect of treatment?
4 What do you consider good treatment?
5 What do you consider bad treatment?
6 How would you describe a good therapist?
7 How would you describe a bad therapist?
8 Do you have a preference for a male or female therapist?
  - Yes, I prefer a male therapist
  - Yes, I prefer a female therapist
  - No, I do not have a preference

9 Can you expand on your answer to question 8?
10 Do you have a preference for individual or group therapy?
  - Yes, I prefer individual therapy
  - Yes, I prefer group therapy
  - No, I do not have a preference

11 Can you expand on your answer to question 10?
12 What should a good institution offer people with eating disorders?
13 How do you picture a good institution?
14 What suggestions or advice do you have to improve treatment for people with eating disorders?

Table A2. The questionnaire for eating problems and treatment-Rating list

The following list is a list of “criteria” for treatment. On a scale from 1 to 5 to what extent do you find this criterion important for the quality of treatment for eating disorders? Please circle the relevant number.

	Criteria	Not Importa				Very
			At		Important	
1.	Being able to talk about eating behaviours	1	2	3	4	5
2.	Being able to talk about thoughts	1	2	3	4	5
3.	Being able to talk about feelings	1	2	3	4	5
4.	Being able to talk with companions	1	2	3	4	5
5.	Being able to talk about the past	1	2	3	4	5
6.	Being able to talk about suicidal thoughts	1	2	3	4	5
7.	Being able to talk about religion	1	2	3	4	5
8.	Being confronted with your problems	1	2	3	4	5
9.	Being respected	1	2	3	4	5
10.	Being able to tell your story	1	2	3	4	5
11.	Being taken seriously	1	2	3	4	5
12.	Being able to say anything	1	2	3	4	5
13.	Being accepted as you are	1	2	3	4	5
14.	Therapist who truly listens	1	2	3	4	5
15.	Therapist who is interested	1	2	3	4	5
16.	Trust in therapist	1	2	3	4	5
17.	Therapist who is honest	1	2	3	4	5
18.	Trust from your therapist	1	2	3	4	5
19.	Therapist who respects your privacy	1	2	3	4	5
20.	Therapist who shares personal experiences	1	2	3	4	5
21.	Therapist with enough time	1	2	3	4	5
22.	Therapist with a sense of humor	1	2	3	4	5
23.	Feeling supported	1	2	3	4	5
24.	Being put at ease	1	2	3	4	5
25.	Therapist who gives you hope	1	2	3	4	5
26.	Treatment that addresses the person	1	2	3	4	5
27.	Focus on recovering weight	1	2	3	4	5
28.	Focus on improving your body image	1	2	3	4	5
29.	Focus on self-esteem	1	2	3	4	5
30.	Focus on social contacts	1	2	3	4	5
31.	Focus on quality of life	1	2	3	4	5
32.	Focus on somatic complaints	1	2	3	4	5
33.	Focus on the future	1	2	3	4	5

Criteria	Not Importa At /			Very Important	
34. Focus on the transition back to normal life	1	2	3	4	5
35. Learning how to express yourself	1	2	3	4	5
36. Learning to be assertive	1	2	3	4	5
37. Learning to understand you have a problem	1	2	3	4	5
38. Learning to take your own responsibility	1	2	3	4	5
39. Knowing where or who you can turn to for help	1	2	3	4	5
40. Short waiting lists	1	2	3	4	5
41. The location for treatment should be easily reached	1	2	3	4	5
42. Explanation or information about eating disorders	1	2	3	4	5
43. Explanation about somatic complaints and consequences of the eating disorder	1	2	3	4	5
44. Explanation and information about treatment	1	2	3	4	5
45. Clear structure in treatment	1	2	3	4	5
46. Setting achievable targets	1	2	3	4	5
47. Focus on targets step by step	1	2	3	4	5
48. Knowing how long treatment will take	1	2	3	4	5
49. Receiving standardized treatment	1	2	3	4	5
50. Learning how to eat normally	1	2	3	4	5
51. Gain weight first before focusing on other problems	1	2	3	4	5
52. Focus on the here and now	1	2	3	4	5
53. Addressing underlying problems	1	2	3	4	5
54. Clear rules during treatment	1	2	3	4	5
55. Getting/doing homework assignments	1	2	3	4	5
56. Participating in compulsory components of treatment	1	2	3	4	5
57. Companion as tutor/counselor	1	2	3	4	5
58. Keeping a(n) (eating) diary	1	2	3	4	5
59. Participating in decisions of the treatment plan	1	2	3	4	5
60. Role-playing as part of treatment	1	2	3	4	5
61. Music, drawing, or drama as part of treatment	1	2	3	4	5
62. Sport and exercising as part of treatment	1	2	3	4	5
63. Learning how to cook as part of treatment	1	2	3	4	5
64. Talking in groups	1	2	3	4	5
65. Treatment for my parents/partner	1	2	3	4	5
66. Liberal visiting hours (*when admitted*)	1	2	3	4	5
67. Bedroom for one person (*when admitted*)	1	2	3	4	5
68. Safe environment (*when admitted*)	1	2	3	4	5
69. Good quality of food (*when admitted or in day treatment*)	1	2	3	4	5
70. Aftercare when treatment has ended	1	2	3	4	5

Table A3. Additional items rated by the therapists

1. Gaining insight	1	2	3	4	5
2. Therapist that provides a proper diagnosis	1	2	3	4	5
3. Evidence-based treatment	1	2	3	4	5
4. Protocolized treatment	1	2	3	4	5

Conclusions and general discussion

The aim of this thesis was to answer three central questions:

1. What are the patients' views on eating disorders, their consequences and treatment?

2. In what ways can the patients' perspective contribute to a better understanding of eating disorders, their consequences and optimal treatment?

3. How is the patients' perspective related to other bodies of knowledge, namely the scientific evidence and from the therapists' perspective?

These questions will be addressed consecutively.

The patients' views of eating disorders, their consequences and optimal treatment of eating disorders – a summary of the findings

The personal views on illness and recovery of eating disorders (ED) patients who were currently in treatment are described in *Chapter one*. These patients had a strong illness identity. They felt that the ED determined, controlled, or affected all areas of their life, or they could not imagine a life without the ED. The most important causes of the ED they identified were low self-esteem, personality characteristics, need for achievement, and emotional state. These characteristics reflect an internalizing attribution style. The perceived consequences of the ED were severe. The patients stressed the fact that the ED affected daily life, as well as emotional and social functioning. Patients were not pessimistic about the controllability of the ED. However their views on controllability were not related to the perceived course of the ED. Patients with a low self-esteem, low sense of mastery and more depressive symptoms tended to view the ED as more chronic.

The perceived consequences of the ED are also reflected in the subjective quality of life as is described in *Chapter 2 and 3*. The quality of life of current and former ED patients as described in *Chapter 2* was substantially worse than the quality of life of a normal reference group and was even worse than the quality of life of a reference group of patients with mood disorders. More severe ED pathology was associated with poorer quality of life. The former ED patients still reported a poorer quality of life than a normal reference group. Self-esteem showed the highest association with the quality of life in the case of both current and former ED patients.

Chapter 3 describes the patients' personal views on quality of life. Both current and former ED patients listed a wide variety of domains as well as large differences in perceived relative importance of these domains. A sense of belonging (social relationships) was the domain mentioned most often by both current and former ED patients as important for their quality of life. Furthermore, it was most often ranked as the most important life domain. Other domains that were listed as contributing to the quality of life, included health, well-being, work, education, ED pathology, a sense of self, life skills and a sense of purpose or meaning. Current ED patients mentioned ED pathology more often as contributing to their quality of life than former ED patients. Current ED patients reported poor quality of life in most domains, particularly in regard to self-image and well-being. The impact of ED pathology on the quality of life was highest for the purging ED patients.

The patients' perspective on the treatment of EDs is described in *Chapter 4 and 5*. *Chapter 4* indicates that the treatment histories of the participants varied greatly. A substantial patient delay before seeking treatment was found. Patients sought treatment on average 4.2 years after the onset of the ED (SD ± 6.3; median 2.0 years). Although 22% sought treatment within half a year after the onset of the ED, as much as 22.4% did not seek treatment until 5 years or more after the onset of the ED. A doctor delay was also found of on average 1.1 years (SD ± 2.2 years; median 0.4 years). Although approximately 60% started treatment for the ED within half a year after seeking treatment, as much as 21% reported they had not started treatment for the ED within three years after seeking treatment. Several reasons for the delay in starting treatment were mentioned, including referral delays, waiting lists, or being sent from one clinic to another. Participants also described different paths of treatment after referral. Almost 80% received more than one type of treatment. The majority underwent several types of treatment before being referred to a specialized ED centre. Over 50% received no treatment in a specialized ED centre at all. Forty percent of the current and former patients refused treatment once. The reasons they gave were that they felt that treatment did not meet their preferences or needs. Fifty-six percent of the current and former ED patients dropped out of treatment at least once. The reasons they mentioned were lack of perceived helpfulness (i.e. lack of trust, no change in their symptoms or not feeling understood), lack of motivation, not meeting weight requirements or feeling homesick. A majority of the participants found consultation with the general practitioner and treatment in a general hospital unhelpful. The evaluation of non-specialized treatment varied substantially. Treatment in a specialized ED centre was most often perceived as helpful. Patients indicated the focus on ED symptoms as well as on underlying issues and the perceived support from other ED patients as helpful. Furthermore self-help groups were viewed as valuable by more than fifty percent of the patients who had received this type of treatment.

Chapters 4 and *5* conclude that in their one-on-one encounter with a therapist, patients welcomed a collaborative approach. Helpful components were proper communication skills, a good therapeutic alliance and focus in treatment sessions on both ED symptoms and on underlying issues. Both current and former ED patients stressed the importance of addressing the person, not merely the ED.

The contribution of the patients' perspective to an understanding of eating disorders, their consequences and optimal treatment of eating disorders

The patients' perspective contributes to an understanding of EDs and the consequences of the EDs in several ways. It provides starting points on how to optimise treatment for EDs throughout the treatment trajectory.

Whereas mental health professionals tend to focus on an ED as a categorical disorder and define recovery as the ability to control the symptoms of an ED, the patients' views on their ED and on recovery as described above, indicate that several aspects beyond specific ED symptoms affect the patient's experience of the illness. The perceived causes of the ED, the perceived probability of recovering from an ED, and the experience of a sufficient quality of life, seem to depend largely on self-esteem and the perceived quality of interpersonal relationships. It is noteworthy that the internalizing attribution style of ED patients regarding the most important causes of their disorder is different from that of patients suffering from anxiety or depressive disorders (1,2). Furthermore although these studies show that the perceived consequences of anxiety and depressive disorders are also severe, the study on the quality of life of ED patients indicates that their quality of life is worse than that of mood disorder patients, confirming the impact of the ED on all areas of life. This indicates the importance of a broad approach to the treatment of EDs, with a focus on the person, not merely on the symptoms of the ED.

Several recommendations on how to optimise treatment for EDs throughout the treatment trajectory can be elicited from the findings of this study. First it shows a substantial patient delay in seeking treatment, leaving a number of ED patients untreated for a substantial period of time. This is not uncommon. Studies report that a proportion of people with various mental disorders are untreated in several countries, although the reasons for these unmet needs are not clear and may vary (3, 4). Other studies also report a patient delay in seeking and finding treatment for different mental disorders (1, 5, 6). One study shows that seeking treatment for the first time is not so much related to the psychiatric disorder, as to the burden of the disorder on daily life (7). Patient delay in EDs is a serious problem that needs to be targeted. In *Chapter 4* the importance of interventions to increase the knowledge of the general public was described. This will help to raise awareness of the nature of EDs and may enhance early detection by family members and friends. Further, based on the information gathered on the patients' perspective, a decision tool has been developed to help reduce patient delay (8). This booklet summarizes information on EDs and treatment possibilities. The experiences of the participants in this study are described and a questionnaire is included to facilitate thinking about one's own priorities. The booklet may raise awareness of the nature and severity of the ED and present a (rough) idea of the different treatment options. Furthermore by reading about the experiences and opinions of others in similar situations, it encourages thinking about treatment preferences. By helping patients make choices and enhancing their self-regulation abilities, it may be even therapeutic in itself.

The information gathered on the patients' perspective, as described in *Chapter 4 and 5*, indicates that when an ED patient seeks treatment, referral to a specialized ED centre should be considered first. The phenomenon of a hampering referral system has been found in earlier studies and needs to be targeted (1, 2, 9). Doctor delay can be primarily diminished by increasing general practitioners knowledge of EDs, and making them aware of the need to refer their patients promptly. Specialized ED centres can facilitate this process by taking the initiative by offering themselves as consultants to the general practitioners in their region.

Once referred, patients welcome services that treat patients respectfully, provide sufficient information and short or no waiting lists.
Referral to self help groups is recommended, when waiting lists or anxiety to engage in treatment inhibit entering specialized care, because self-help groups were positively evaluated by many patients who had participated in such a group (see *Chapter 4*). The Dutch multidisciplinary guidelines show that there is some (level A) evidence that self help groups based on cognitive

behavioural frame of reference, but without a qualified therapist, can be effective (10). Several studies (level C) show that the most important contribution of self-help groups are related to perceived recognition, support, understanding and equality (10). It still needs to be investigated whether self-help groups, when offered as pre-treatment, actually contribute to optimal care and to what extent they encourage patients to enter treatment.

At the start of treatment it is important that patients be encouraged to express their views on their illness and the (road to) recovery and how treatment may contribute to recovery. Studies on depression, anxiety and psychotic illnesses, have shown that health beliefs or illness representations contribute to treatment seeking, perceived needs of treatment, treatment adherence, and clinical outcomes (11-15). Studies on EDs stress the importance of motivation to change as important in treatment seeking and adherence (16, 17). ED patients are found to be ambivalent in their motivation to change and are reluctant to actually engage in treatment or they drop out of treatment when they are in a pre contemplation stage of change. However the process of moving from a pre contemplation stage of change to actual change may be affected by the health beliefs of the ED patients. Further, while the burden of the ED (perceived consequences) may be an important factor in deciding to seek treatment for the ED, as is suggested in *Chapter 1* of this thesis, perceived conflicting values and not necessarily a lack of motivation per se may negatively affect the illness behaviour of current ED patients. This may hinder patients from actually engaging or staying in treatment.

The substantial percentage of current and former ED patients in this study who mentioned having refused treatment or dropping out of treatment at least once, and the reasons for refusing treatment or drop out of treatment, as described in *Chapter 4,* also reflect the importance of addressing the patients' views. Although treatment drop out has been reported for other mental disorders, a study on drop out in cognitive behavioural therapy shows that those who dropped out more often received a diagnosis of an ED than those who continued (18). The findings of self-reported treatment drop out in this study are consistent with other reports on ED treatment drop out. The factors associated with treatment drop out remain unclear, due to the variety of factors that are assessed in studies on drop out in EDs, and a lack of consistency in the findings (19-36). In the current study, a minority mentioned a lack of motivation as a reason for dropping out. Other reasons for drop out given by the current and former ED patients of this study, as described in *Chapter 4,* were a lack of trust or not feeling understood. It is especially important to establish a good therapeutic alliance from the start of treatment. As described in *Chapter 5*, ED patients stress the importance of a good therapeutic alliance. It was hypothesized that entering treatment or engaging in a relationship with a therapist is particularly challenging for some ED patients, due to early life experiences and interpersonal difficulties.

Another reason mentioned for treatment refusal or drop out was that treatment did not meet the patient's needs and preferences. The current and former ED patients in this study, as described in *Chapter 5* stated they wanted to have a say in their treatment. Patients need to be invited to share their views, so that patient and therapist can negotiate the treatment goals. This is of particular importance, because in comparing the therapists' and patients' views, as described in *Chapter 5,* patients and therapists find similar aspects important to the quality of treatment, but may value these aspects differently. Addressing the issues relevant to patients may prevent drop out. Similar to patients with anxiety or depressive disorders, both current and former ED patients state firmly that not the disorder, but the person with the disorder needs to be the focus of treatment and treatment outcome (1,2). Addressing both ED symptoms and the underlying issues throughout the treatment trajectory is necessary. It is important to stress that many patients do not deny the importance of addressing the ED symptoms. However they prefer a focus on ED pathology as long as other issues are addressed simultaneously. The importance of self-esteem and interpersonal relationships for ED patients as described in *Chapter 1 to 3* shows that treatment goals from the patients' perspective are not limited to recovering from ED symptoms. The views of current ED patients on recovery, as described in *chapter one,* reflect that in the treatment of EDs it is important to address the patients' maladaptive core assumptions about themselves, their self-esteem and (differentiation of) identity, depressive symptoms, emotion regulation, life skills, and their quality of life. The importance of social relationships for the quality of life of ED patients, as described in *Chapter 3,* warrants addressing social functioning and the involvement of relatives in treatment.

Continuity of care needs to be assured. The importance of the continuity of care has also been expressed by anxiety or depressive disorder patients (1,2). The findings of the current study underscore the need to target a hampering referral system by improving the communication between primary, secondary and tertiary care, as well as between departments and clinics and by enhancing the knowledge on referral possibilities. To regulate the continuity of care in EDs, specialised ED centres need to develop a program for disease management. Furthermore it needs to be investigated whether and to what extent self-help groups can contribute to the continuity of care for recovered ED patients, after regular treatment has ended.

Based on the findings of this study the patients' views can be translated into general criteria as well as disease specific criteria for the quality of care. The evaluation of the quality of treatment by current and former ED patients depends on the perceived quality in three domains: the service, the therapeutic process and the organisation of care. On the broadest level these aspects can be a useful contribution to the formulation of performance indicators for mental health care. Nowadays insurance companies are key players in (mental) health care, with a great influence on the quality of treatment by virtue of the contracts they make with (mental) health care services for their clients. It is recommended that in choosing providers with whom to contract, insurers use performance indicators that include those aspects that are important to patients, regarding the quality of treatment. Mental health care providers can also include these criteria regarding the three domains in their own Quality Management Models to assess the conditions necessary to the quality of care they themselves provide. An example may illustrate this. The current study indicates that during the therapeutic process self-esteem needs to be improved (a general criterion of the second domain). Treatment planning should specify how often and in what way self-esteem is to be addressed. It can then be investigated whether the changes in ED patient's self-esteem are correlated with specific treatment interventions. To monitor changes, patients can be asked to fill out an instrument to assess their self-esteem prior to and after treatment, as well as monthly over the course of treatment. The same criteria regarding the three domains can also be used to evaluate treatment on an individual level.

Strengths and limitations

A strength of the study described in *Chapter 1* is that it is the first study to investigate the views on both illness and recovery of a mixed sample of patients still in treatment for an ED. It clarifies illness behaviour of ED patients and complements the current literature on the patients' views on illness and recovery. It helps to understand which aspects need to be addressed throughout the treatment trajectory to prevent early treatment drop out or relapse. A strength of the study in the respective sections in *Chapters 2 to 5* is that this is the first study with a large sample of current and former ED patients to report on both their treatment history and treatment evaluation as well as their views on what components they perceived helpful for the quality of treatment. In contrast to earlier studies, it was possible to compare evaluations of general health care treatment, non-specialized mental health treatment, and specialized ED treatment. Because the sample included both current and former ED patients, it was also possible to assess differences and similarities between the two groups. Furthermore, this was the first study to investigate whether and if so, which patient characteristics and treatment characteristics were associated with the patients' evaluation of treatment. The current study provides valuable information on both the therapists' and the patients' view on the quality of treatment of EDs, perhaps particularly of those ED patients who need this treatment the most. It is also the first study to compare directly the patients' views with the therapists' views about the quality of treatment.

A limitation of the study on the views of ED patients on their illness and recovery, as described in *Chapter 1*, is the small number of participants. Furthermore the majority of the sample consisted of anorexia nervosa patients, although patients with bulimia nervosa and ED not otherwise specified also participated. A limitation of the study is that the current and former ED patients, described in *Chapter 2 to 5*, were volunteers for a large study on the quality of treatment of EDs. More than 98% of the participants did seek professional treatment. The advertisement to participate in this study may have appealed especially to those who had a history of different treatments for EDs. This group may have had more severe ED pathology than a randomly selected community based sample. Another limitation of this study was the assessment of the ED with a self report measure. Nevertheless the majority of the sample also received a formal diagnosis of an ED by a clinician (81.7%). Careful examination of the responses on the self report measure was carried out of those who did not receive a formal diagnosis of a clinician. The limitation of the therapists' sample described in *Chapter 5* is that therapists who participated in this study were mainly recruited at specialized ED centres. Therefore they are more experienced with EDs and their treatment than a randomly selected group of therapists in non-specialized psychiatric centres.

Towards converging three bodies of knowledge: scientific evidence, therapists' views and the patients' perspective

Three bodies of knowledge, namely scientific evidence, therapists' views and the patients' perspective affect the understanding of EDs and their treatment in their own way. Scientific evidence reflects empirical knowledge of treatment trials and experiments, as is summarized in several guidelines on EDs (10, 37-39). The therapists' views reflect expert knowledge based on education, training and experiences that enables therapists to understand individual experiences within a specific frame of reference. The patients' perspective reflects experiential knowledge. The results of this thesis provide new insight into what the patients' perspective as well as the therapists' perspective contribute to the understanding of EDs and their treatment. It shows how the patients' and therapists' perspectives can complement scientific research as bodies of knowledge, in particular regarding the improvement of the external validity of scientific research. It is discussed how these three bodies of knowledge are and can be related.

Scientific evidence and the patients' views

In this thesis several methods were chosen, quantitative as well as qualitative, to investigate the patients' perspective on their ED, road to recovery, quality of life and treatment. Both standardized instruments (questionnaires) and open questions were used. The loss of qualitative information inherent in the use of standardized questionnaires was thus compensated for to do justice to individual experiences and diversity. By systematic analysis of the individual views and experiences described throughout this thesis, more insight has been gained into the patients' tacit knowledge. The scientific evidence as summarized in the Dutch multidisciplinary guidelines could therefore be complemented by the findings of the current thesis, as evidence at level C.

Furthermore studies on the effectiveness of the treatment of EDs - evidence at level A and B - can be refined if research planning takes into account aspects that are brought forward by patients. The use of the patients' experiential knowledge to support research planning is in line with several initiatives, such as that of the James Lind Alliance who "aims to identify the most important gaps in knowledge about the effects of treatments, and has been established to bring patients and clinicians together in 'Working Partnerships' to identify and prioritise the unanswered questions that they agree are most important. This information will help ensure that those who fund health research are aware of what matters to patients and clinicians." (40)

Based on the findings of the current thesis, the questions that are important to address in research include the *outcome*, *structure* and *process* of treatment (41). The *outcome* criteria used in research need to be more person- rather than symptom-oriented, including for example self-esteem, comorbid conditions and quality of life. The *structure* of treatment, such as the way treatment is organized needs to be included as a covariate, for instance the time between seeking treatment, referral and start of treatment.

To date, it is unknown if and how delayed referral, treatment allocation processes (who decides which patient gets what type/modality of treatment, and why), lack of services and information, and waiting lists, have an impact on the process of treatment or even outcome. The *process* of treatment needs to be investigated not by focussing on one particular therapeutic method, but by including therapeutic methods from different frames of references, the assessment of the therapeutic alliance and content analysis of therapy sessions. Treatment modality (i.e. group vs. individual treatment) needs to be included as a covariate. All this will enhance insight into the working mechanisms of particular forms of treatment.

Scientific evidence and the therapists' views

The therapists' perspective as described in *Chapter 5* of this thesis shows a gap that has been often described between evidence-based knowledge and clinical practice (42-44).

In this thesis it was found that the majority of the sample of therapists endorses a cognitive behavioural orientation, currently regarded as the best available evidence-based treatment, in particular in bulimia nervosa. Nevertheless it is questionable whether this approach is implemented in actual day-to-day practice: a substantial number of therapists indicated that use eclectic or integrative methods in their day-to-day practice (more than one theoretical orientation). Furthermore therapists who participated in this study were mainly recruited at specialized ED centres. Therefore they are more experienced with EDs and its treatment than a randomly selected group of therapists in non-specialized psychiatric centres. This raises the question to what extent evidence-based knowledge is known and used by therapists in non-specialized treatment centres.

Over 70% of the therapists in our study considered evidence- based treatment to be important. On the other hand they did not consider protocol-based treatment important. The evidence of the effectiveness of CBT (level A) is accumulating, in particularly in treating bulimia nervosa. Although over the long run IPT is also found to be effective, CBT seems to be effective over a shorter period. The Dutch multidisciplinary guidelines therefore recommend

CBT as a first choice of treatment for bulimia nervosa and recommend the use of the protocol developed by Fairburn. As we stated in *Chapter 5*, it can be assumed that senior therapists who are trained to work from other theoretical orientations, for instance, a psychodynamic or client centred orientation may find working from a manual alienating. Clinical heuristics with long standing reputations are not easily debated, let alone changed, in particularly where therapists work in multidisciplinary teams with entrenched traditions and ways of working. Education targeted at senior therapists may be helpful to facilitate the dissemination of scientific results.

Dissemination of scientific evidence is the first step of implementation of these results, but it is not enough. In day-to-day practice therapists are confronted with patients with anorexia nervosa for which little empirically validated treatment exists They are confronted with bulimia nervosa and ED not otherwise specified patients with multiple problems and with patients who do not respond to CBT. Scientific research available today does not provide starting points for how to treat those patients. Furthermore, the merits of different theoretical orientations, perceived by experienced therapists, are not reflected in the topics of research projects. This may hinder implementation of the available evidence. If research planning takes into account the therapists' different theoretical orientations and views and research thus corresponds more with the day-to-day experience of therapists, implementation of scientific evidence will be facilitated.

The therapists' views and the patients' views

Therapists tend to feel committed to their individual patients and the process of their treatment. They try to understand the experiences of their patients within their frame of reference. They provide meaningful comments on the sometimes overwhelming problems of daily reality of their patients. In our study therapists and patients agreed on several aspects of the quality of treatment, in particular regarding the *process* and *structure* of treatment. Both therapists and patients most often mentioned treatment focus, therapeutic alliance and communicational skills as important aspects of the quality of treatment. Nevertheless therapists valued the focus on ED symptoms and behavioural change more highly, whereas patients stressed the importance of the relationship with the therapist and of addressing underlying problems. In most cases the therapist and patient are able to work together on mutual goals, because their shared values outweigh the differences. However differences in values that do surface can have several implications. They may affect the role expectations of both the therapist and the patient. To a therapist a “motivated” or “progressing” patient is a patient who is willing to work on (eating) behavioural change, whereas to a patient a “helpful” therapist is a therapist who is understanding and willing to focus on the patient as a person and not merely on behavioural symptoms. When treatment goals need to be negotiated at different stages of the therapeutic process, the therapist and patient may interpret each other’s behaviour on the basis of these different role expectations and consequently have different views of the therapeutic alliance.

When negotiating treatment goals with individual patients, therapists should be aware of the importance of acceptance and the therapeutic alliance. Therapists need to be attuned to the perception of the therapeutic alliance by the patient, to be aware of differences in role expectations and to discuss the patient’s expectations, in order to enhance the therapeutic alliance and facilitate treatment progress. Patients need to be invited to share their needs and preferences.

Therapists tend to focus on the individual encounter with the patient. However this study shows that the experiences of ED patients with treatment are also determined by the rendering of service and the organisation of care. Therapists need to be aware that a patient’s evaluation of treatment largely depends on adequate and prompt referral to start treatment, pre-treatment, waiting lists, and most important the continuity of treatment.

Converging three bodies of knowledge

The findings of this study provide starting points for converging three bodies of knowledge. The three bodies of knowledge are shown to be complementary. By taking the experiential knowledge of patients and the expert knowledge of therapists into account in research planning, scientific research will take a step forward. Dissemination of scientific results to therapists will further contribute to optimising the treatment of EDs. And if therapists are also aware of the patients’ personal views, EBM as it is defined will be approximated (45).

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Summary

This thesis investigates eating disorders (EDs) and treatment from the patients' perspective and compares the patients' perspective as a body of knowledge with the scientific evidence and the therapists' perspective.

EDs, namely anorexia nervosa, bulimia nervosa, and the EDs not otherwise specified, are rare, but very serious psychiatric disorders, with a low recovery rate. Mortality in anorexia nervosa and bulimia nervosa is high in comparison to other mental disorders. The physical, psychological and social consequences are also severe. Optimal treatment is imperative.

Evidence-based medicine (EBM) has increasingly become the accepted means to offering optimal treatment of EDs, although the evidence on treatment of EDs, as described in the Dutch multidisciplinary guidelines on EDs, is limited. In EBM, a therapist, when confronted with specific problems, seeks to integrate scientific research with clinical expertise and a patient's preferences.

The growing importance of the patients' preferences arises from the changing attitudes towards (and of) patients. Today patients are considered to be emancipated citizens or consumers, who want to have a say in their treatment. Although a patient's preferences are considered important in an individual's encounter with a clinician, the patients' views are rarely considered to be a body of knowledge.

This thesis investigates if and how the patients' perspective - as a body of knowledge - contributes to an understanding of EDs, the consequences of EDs and what should be regarded optimal treatment of EDs and how the patients' perspective is related to other bodies of knowledge. The following questions are addressed:

1. What are the patients' views on eating disorders, their consequences and treatment?

2. In what ways can the patients' perspective contribute to a better understanding of eating disorders, their consequences and optimal treatment?
3. How is the patients' perspective related to other bodies of knowledge, namely the scientific evidence and the therapists' perspective?

Chapter 1 examines the views of patients, currently in treatment, on their illness and recovery. The participants were ED patients, who were recruited during their treatment for their ED at the Centre for Eating Disorders Ursula. Twenty six patients filled out a questionnaire – which included open questions addressing their views regarding the ED and recovery and the Illness Perception Questionnaire (IPQ-R). They had a strong illness identity. They felt the ED determined, controlled or affected all areas of their life, or they could not imagine a life without the ED. The most important causes of the ED they mentioned were low self-esteem, personality, need for achievement, i.e. perfectionism, or emotional state, revealing an internalizing attribution style. The perceived consequences of the ED were severe. The patients emphasized that the ED affected everyday life, as well as their emotional and social functioning. They were not pessimistic about the controllability of the ED. However this was not related to the perceived course of the ED. Patients with a low self-esteem, low sense of mastery and more depressive symptoms tended to view the ED as more chronic.

The participants of the study described in *Chapter 2 to 5* in this thesis volunteered to take part in the "Quality Project for Eating Disorders", a collaborative project of the patient organisation, The Foundation for Anorexia and Bulimia Nervosa (SABN), the Centre for Eating Disorders Ursula, the University of Leiden and the Erasmus University of Rotterdam. The participants consisted of current ED patients and former ED patients recruited from the Dutch community.

Chapter 2 investigated the quality of life (QOL) of current and former ED patients. The QOL of current ED patients, as assessed with the Short Form-36 (SF-36), was found to be substantially worse than the QOL of a normal reference group and was even worse than the QOL of patients with mood disorders. The former ED patients still reported a poorer QOL than a normal reference group. We found that the SF-36 discriminated between ED patients and former ED patients, but not between ED diagnostic groups. Severe ED pathology was associated with a poorer QOL. Self-esteem (Rosenberg) showed the highest association with the QOL of both ED patients and former ED patients. The findings underscore the impact of EDs on physical, psychological, and social well-being, even after remission of symptoms. The impact of EDs on the QOL was even relatively more severe than the impact of mood disorders. Our findings reveal the need to assess ED treatment outcome in terms of QOL and not only the ED symptoms. The use of a generic health related QOL instrument helps to provide insight into the QOL of a patient group in relation to other patient groups or a normal reference group.

In *Chapter 3* the current and former ED patients' personal views on QOL were assessed. They were asked to list the five most important aspects of their life and rate themselves on these aspects. The wide range of domains cited seems to complement current knowledge on the QOL of ED patients. It broadens the scope of relevant domains of the QOL of ED patients. It showed a wide variety in domains mentioned and differences in the relative importance of these domains. A sense of belonging (social relationships) was the domain mentioned most often (93%) as important for their QOL by both current ED as well as former ED patients. Furthermore, a sense of belonging was most often ranked as the most important life domain. Other domains patients listed as contributing to the QOL, included health, well-being, work, education, disease specific pathology, a sense of self, life skills and a sense of purpose or meaning. Current ED patients mentioned ED pathology as contributing to their QOL more often than former ED patients. Current ED patients reported poor QOL in most domains, particularly in regard to self-image and well-being. Former ED patients reported better QOL than current ED patients, but ratings were just above average. Purging ED patients reported poorer QOL on ED pathology than non-purging ED patients. We hypothesized that the impact of ED pathology on the QOL of the most severely affected ED patients; namely the purging ED patients, may reflect their inability to fulfil illness-related needs. Our findings suggest that the use of an individualized instrument should enable clinicians to better understand the QOL perception of an individual ED patient. This is helpful in formulating treatment goals. When an individualized measure is used as an adjunct to standardized QOL measures to formulate treatment goals, treatment becomes more patient centred.

Chapter 4 describes the treatment history and treatment evaluation of current and former ED patients. A questionnaire was specifically designed for the purpose of this study, the "Questionnaire for Eating Problems and Treatment", addressing treatment history and the patients' evaluation of their treatment. The final version of the questionnaire was divided into three parts. The first part consisted of questions about treatment-seeking behaviours. It included closed questions on seeking treatment as well as open questions to provide additional information on treatment-seeking history. The second part consisted of questions about treatment history and experiences with treatment. Participants were asked to evaluate their experiences for each type of treatment. The third part of the questionnaire consisted of questions about expectations of and opinions on the quality of treatment, including open questions and a list of 70 criteria to be rated on a 5-point Likert scale.

A substantial patient delay before seeking treatment for EDs was found. Twenty-two percent of the participants did not seek treatment until five years after the onset of the ED. We believe that denial of the illness and shame may inhibit recognition and acknowledgement of the illness and hinder treatment-seeking behaviour soon after the illness develops.

More than half of the sample also mentioned a doctor delay. Although two-thirds began treatment for the ED within half a year after seeking treatment, an alarming more than 20% did not start treatment for the ED within three years. Almost three-quarters of our sample first visited their general practitioner, who acts as the "gatekeeper" to specialized treatment. Improving general practitioner's knowledge and diagnostic and motivational skills regarding EDs, is warranted. Participants described different paths of treatment after referral. Only a few participants reported being referred immediately to a specialized ED centre. The majority underwent several types of treatment before being referred to a specialized ED centre. Over 50% received no treatment in a specialized ED centre at all. Twenty-one percent of the participants had experienced one type of treatment, 23% two types of treatment, more than 19% three types of treatment and 33% four or more types of treatment. Patients who had received treatment in a specialized centre had received significantly more types of treatment than patients who had not. Former ED patients received less treatment than current ED patients. Forty percent of the current and former patients refused treatment once. Fewer former ED patients refused treatment. The reasons for refusing treatment current and former ED patients mentioned were that they felt that treatment did not meet their preferences or needs. Fifty-six percent of the current and former ED patients dropped out of treatment at least once. The reasons cited were lack of perceived helpfulness (i.e. no trust, no change in their symptoms or not feeling understood), lack of motivation, not meeting weight demands, or feeling homesick.

A majority of the participants found consultation with the general practitioner and treatment in a general hospital unhelpful. The evaluation of non-specialized treatment varied substantially. Treatment in a specialized ED centre was most often perceived as helpful by both current ED patients and former ED patients. Former ED patients were the most positive. Participants indicated that the focus on ED symptoms as well as underlying issues and the perceived support from other ED patients was helpful. Some patients mentioned that too much emphasis on either ED symptoms or underlying issues was less constructive.

In the individual encounters with a therapist patients welcome a collaborative approach. Helpful components are proper communication skills of mental health professionals, a good therapeutic alliance, and the focus of treatment sessions. Both current and former ED patients underscored the importance of addressing the person, not merely the ED. Self-help groups and involvement of a partner in treatment were viewed as valuable by more than half of those who received these types of treatment. No strong predictors for the evaluation of treatment were found.

Chapter 5 compared the therapists' and patients' perspectives on the quality of treatment. The therapist sample consisted of 73 therapists recruited through specialized treatment centres in The Netherlands and at a national teaching day on EDs. Therapists were asked to answer similar questions, on an adapted version of the patients' "Questionnaire for Eating Problems and Treatment". Therapists and patients agreed on most aspects of the quality of treatment, in particular regarding the process and structure of treatment. Both therapists and patients most often mentioned treatment focus, therapeutic alliance and therapist communicational skills as important components of the quality of treatment. However they valued similar topics differently, as was found with both quantitative and qualitative analysis. Therapists valued the focus on ED symptoms and behavioural change more highly, whereas patients underscored the importance of the relationship with the therapist and addressing underlying problems. In most cases therapist and patient are able to work together on mutual goals, because their shared values outweigh the differences. However, the match between therapist and patient needs to be carefully monitored. Differences in values that arise can have several implications. They may affect the role expectations of both the therapist and the patient. To a therapist a "motivated" or "progressing" patient is a patient who is willing to work on (eating) behavioural change, whereas to a patient a "helpful" therapist is a therapist who is understanding and willing to focus on the patient as a person and not merely on behavioural symptoms. When treatment goals need to be negotiated at different stages of the therapeutic process, therapist and patient may interpret each other's behaviour based on such different role expectations and consequently have different views of the therapeutic alliance.

In the *general discussion* it is concluded that the patients' perspective, as a body of knowledge, contributes to an understanding of EDs and the consequences of the EDs in several ways. Recommendations are made on how to optimise treatment for EDs throughout the treatment trajectory and how to diminish patient delay and doctor delay, how to improve the referral process, and to ensure the continuity of care. The evaluation of the quality of treatment by current and former ED patients depends on the perceived quality of three domains: the service, the therapeutic process and the organisation of care. We recommended to translate these three domains into criteria for the quality of care. It is concluded that to advance scientific research a step forward, it is important to take into account the patients' perspective, as well as the therapists' perspective. Converging three bodies of knowledge, namely the available evidence, the therapists' views and patients' views will then further contribute to optimising the treatment of EDs.

Samenvatting

In dit proefschrift worden eetstoornissen en de behandeling van eetstoornissen vanuit het patiëntenperspectief onderzocht. Vervolgens wordt nagegaan hoe het patiëntenperspectief, als kennisbron, zich verhoudt tot de wetenschappelijke kennis en het perspectief van hulpverleners.

Eetstoornissen, te weten anorexia nervosa, boulimia nervosa, en de eetstoornis niet anders omschreven, zijn zeldzame, maar zeer ernstige psychiatrische aandoeningen met een gering herstelpercentage. De mortaliteit van anorexia nervosa en boulimia nervosa is hoog in vergelijking met andere psychiatrische ziektebeelden. De lichamelijke, psychologische en sociale gevolgen zijn eveneens ernstig. Optimale behandeling is noodzakelijk.

Evidence-based medicine (EBM) is in toenemende mate de standaard geworden voor optimale behandeling, hoewel de wetenschappelijke evidentie voor de behandeling van eetstoornissen, zoals beschreven in de Nederlandse multidisciplinaire richtlijnen beperkt is. Bij EBM, zal een hulpverlener, als hij wordt geconfronteerd met specifieke problemen, de wetenschappelijke evidentie proberen te integreren met zijn klinische expertise en de voorkeur van de individuele patiënt.

Het belang dat wordt gehecht aan de voorkeuren van individuele patiënten hangt samen met de veranderde houding ten aanzien van patiënten en van de patiënten zelf. Momenteel worden patiënten gezien als geëmancipeerde burgers of consumenten, die willen meebeslissen over hun behandeling. Hoewel de voorkeuren van patiënten belangrijk worden geacht in een individueel consult met een hulpverlener, worden de opvattingen en ervaringen van patiënten nauwelijks als een bron van kennis beschouwd.

Dit proefschrift onderzoekt of en hoe het patiëntenperspectief, als kennisbron, kan bijdragen aan een beter begrip van eetstoornissen, de gevolgen van eetstoornissen en optimale behandeling. Vervolgens wordt het patiëntenperspectief, als kennisbron, vergeleken met andere kennisbronnen. De volgende vragen zijn het uitgangspunt van deze dissertatie:

1. Wat zijn de opvattingen en ervaringen van patiënten betreffende hun eetstoornis, de gevolgen van hun eetstoornis en de behandeling?
2. Op welke manier kan het patiëntenperspectief bijdragen aan een beter begrip van eetstoornissen, de gevolgen van eetstoornissen en optimale behandeling?
3. Hoe verhoudt het patiëntenperspectief zich tot twee andere kennisbronnen, namelijk de wetenschappelijke stand van zaken en het perspectief van hulpverleners?

In *Hoofdstuk 1* zijn de opvattingen van patiënten over hun ziekte en herstel onderzocht. De deelnemers waren patiënten met een eetstoornis die gevraagd werden om mee te doen met het onderzoek, terwijl zij in behandeling waren bij het Centrum Eetstoornissen Ursula. Zesentwintig patiënten hebben een vragenlijst ingevuld met open vragen die betrekking hadden op hun opvattingen over hun ziekte en herstel. Ook vulden zij de Illness Perception Questionnaire (IPQ-R) in. Uit hun antwoorden kwam naar voren dat patiënten met een eetstoornis een sterke ziekte-identiteit hebben. Zij gaven aan dat de eetstoornis hun leven op veel levensdomeinen beheerste of dat zij zich geen leven zonder eetstoornis konden voorstellen. Als belangrijkste oorzaken voor de eetstoornis noemden zij een lage zelfwaardering, persoonlijkheid, prestatiedrang, perfectionisme, of emotionele toestand. Dit wijst op een internaliserende attributiestijl. De ervaren gevolgen van de eetstoornis waren ernstig. De patiënten benadrukten dat de eetstoornis hun alledaagse leven beïnvloedde, evenals hun emotionele en sociale functioneren. Zij waren niet pessimistisch over de controleerbaarheid van de eetstoornis, maar dit was niet gecorreleerd met het verwachte beloop van de eetstoornis. Patiënten met een lage zelfwaardering, een gering gevoel het leven te kunnen sturen en meer depressieve klachten zagen de eetstoornis vaker als chronisch.

De deelnemers aan de onderzoeken beschreven in *hoofdstukken 2 tot 5* van dit proefschrift namen vrijwillig deel aan het "Kwaliteitsproject Eetstoornissen", een samenwerking tussen de patiëntenorganisatie, De Stichting Anorexia en Boulimia Nervosa (SABN), het Centrum Eetstoornissen Ursula, de Universiteit Leiden en de Erasmus Universiteit Rotterdam. De deelnemers kwamen uit het hele land en waren zowel patiënten met een eetstoornis als patiënten die ooit een eetstoornis hadden gehad, maar op het moment van het onderzoek geen symptomen meer rapporteerden (voormalige patiënten).

In *hoofdstuk 2* is de kwaliteit van leven van (voormalige) patiënten met een eetstoornis onderzocht. De kwaliteit van leven werd gemeten met de Short Form-36 (SF-36). De kwaliteit van leven van patiënten met een eetstoornis was duidelijk slechter dan de kwaliteit van leven van een normale referentiegroep en zelfs slechter dan de kwaliteit van leven van patiënten met een depressieve stoornis. De voormalige patiënten rapporteerden nog steeds een slechtere kwaliteit van leven dan een normale referentiegroep. Er was een verschil tussen patiënten en voormalige patiënten, maar niet tussen de diagnostische subgroepen. Ernstige eetstoornis pathologie was geassocieerd met een slechtere kwaliteit van leven. Zelfwaardering was het meest geassocieerd met de kwaliteit van leven van patiënten en voormalige patiënten. De bevindingen laten eens te meer zien hoe veel invloed een eetstoornis heeft op het lichamelijke, psychologische en sociale welzijn van patiënten, zelfs als de symptomen niet langer manifest zijn. De impact van de psychiatrische aandoening was zelfs groter dan bij depressieve patiënten. De bevindingen tonen aan dat kwaliteit van leven een belangrijke uitkomstmaat van de behandeling van eetstoornissen moet zijn, en dat niet alleen het herstel van symptomen van de eetstoornis moet worden gemeten. Het gebruik van een algemene kwaliteit van leven vragenlijst geeft bovendien inzicht in de kwaliteit van leven van een groep patiënten in vergelijking met andere groepen patiënten of een normale populatie.

In *hoofdstuk 3* zijn de persoonlijke opvattingen over kwaliteit van leven van de deelnemers onderzocht. Patiënten en voormalige patiënten zijn gevraagd om met betrekking tot hun kwaliteit van leven, de vijf belangrijkste aspecten van hun leven te noemen. Vervolgens konden zij aangeven hoe zij zelf vonden dat het met hen ging wat betreft deze aspecten. Er werden veel verschillende aspecten genoemd, die zijn geclusterd in domeinen op grond van de inhoud. Er werd een grote verscheidenheid aan domeinen vastgesteld. Er bleek een verschil te zijn in het relatieve belang dat aan deze domeinen werd gehecht. Het domein "sociale relaties" werd door zowel patiënten als voormalige patiënten het meest genoemd (93%). Ook werd dit domein het vaakst als belangrijkste domein genoemd. Andere domeinen die de kwaliteit van leven bepaalden waren gezondheid, welzijn, werk, opleiding, ziektespecifieke pathologie, zelfbeeld, levensvaardigheden en zin- of betekenisgeving. Patiënten noemden vaker ziektespecifieke pathologie dan voormalige patiënten. Patiënten rapporteerden een slechtere kwaliteit van leven op de meeste domeinen dan voormalige patiënten, in het bijzonder betreffende zelfbeeld en welzijn. Hoewel voormalige patiënten een betere kwaliteit van leven rapporteerden dan patiënten, waren hun scores net boven het gemiddelde. Purgerende patiënten rapporteerden slechtere kwaliteit van leven betreffende ziektespecifieke pathologie dan niet purgerende patiënten. De invloed van ziektespecifieke pathologie op de kwaliteit van leven is het grootst bij de patiënten met de meest ernstige eetstoornissen, namelijk de purgerende patiënten. De bevindingen complementeren de huidige kennis over kwaliteit van leven van patiënten met een eetstoornis. Zij laten zien dat een geïndividualiseerd instrument om kwaliteit van leven te meten hulpverleners kan ondersteunen om beter inzicht te krijgen in de perceptie van kwaliteit van leven van een individuele patiënt. Dit kan bijdragen aan het formuleren van relevante behandeldoelen. Als naast een gestandaardiseerde vragenlijst om kwaliteit van leven te meten een geïndividualiseerd instrument wordt gebruikt om behandeldoelen op te stellen, wordt de behandeling meer patiëntgericht.

Hoofdstuk 4 beschrijft de ervaringen met behandeling van patiënten en voormalige patiënten. Voor dit doel is een vragenlijst ontwikkeld, te weten de "Vragenlijst Eetproblemen en Behandeling", waarin vragen zijn opgenomen over het traject van de behandeling, alsmede de ervaringen met en opvattingen over behandeling. De uiteindelijke versie van de vragenlijst bestaat uit drie delen. In het eerste deel zijn open en gesloten vragen opgenomen over het zoeken naar en vinden van hulp. Het tweede gedeelte bevat open en gesloten vragen over de ervaringen die mensen met verschillende vormen van behandeling (kunnen) hebben gehad. Deelnemers is gevraagd voor elke vorm van behandeling hun ervaringen te evalueren. Het derde gedeelte van de vragenlijst bevat vragen over verwachtingen en opvattingen over de kwaliteit van de behandeling. In dit gedeelte is een lijst met 70 criteria opgenomen die gescoord kunnen worden op een 5-punts Likert schaal.

Er kon een aanzienlijke vertraging worden vastgesteld in het zoeken naar hulp na het begin van de eetstoornis. Tweeëntwintig procent van de deelnemers heeft geen hulp gezocht binnen vijf jaar na het begin van de eetstoornis. Ontkenning en schaamte kan herkenning en onderkenning van de eetstoornis in de weg staan en een barrière vormen voor het tijdig zoeken naar hulp.

Meer dan de helft van de deelnemers noemde een aanzienlijke vertraging in het vinden van hulp. Hoewel twee derde startte met een behandeling binnen een half jaar nadat er hulp werd gezocht, startte twintig procent niet binnen drie jaar met behandeling voor een eetstoornis. Bijna drie kwart van de deelnemers bezocht eerst de huisarts, de “poortwachter” naar gespecialiseerde behandeling, met klachten. De eetstoornis werd vaak niet onderkend en patiënten werden laat of niet adequaat doorverwezen. Het blijkt noodzakelijk om de kennis van huisartsen te vergroten zodat zij beter in staat zijn om te kunnen screenen op een eetstoornis en patiënten kunnen motiveren de stap naar de hulpverlening te zetten. Deelnemers beschreven verschillende trajecten nadat zij werden doorverwezen. Slechts een kleine groep werd meteen verwezen naar een gespecialiseerde instelling. De meerderheid had verschillende vormen van behandeling achter de rug, voordat zij terecht kwam bij een gespecialiseerde instelling. Meer dan vijftig procent heeft geen behandeling gehad in een gespecialiseerde instelling. Eenentwintig procent heeft één vorm van behandeling gehad, drieëntwintig procent twee vormen van behandeling, meer dan negentien procent drie vormen van behandeling en drieëndertig procent meer dan drie vormen van behandeling. Patiënten die behandeld zijn in een gespecialiseerde instelling hebben in totaal meer behandelingen gehad dan degenen die niet in een gespecialiseerde instelling behandeld zijn. Voormalige patiënten hebben minder behandelingen gehad dan patiënten. Veertig procent heeft wel eens behandeling geweigerd. Minder voormalige patiënten hebben wel eens behandeling geweigerd. De belangrijkste reden om behandeling te weigeren was dat de aangeboden behandeling niet aansloot bij de voorkeuren of behoeften van de patiënten. Zesenvijftig procent van de patiënten en de voormalige patiënten is wel eens voortijdig gestopt met behandeling. De redenen die hiervoor werden genoemd liepen uiteen: de behandeling hielp niet (geen verandering in symptomen, zich niet begrepen voelen), patiënten waren niet gemotiveerd, zij haalden de gewichtseisen niet of zij hadden heimwee.

De meerderheid van de deelnemers heeft de hulp van de huisarts en de behandeling in een algemeen ziekenhuis als negatief ervaren. De evaluatie van de niet-gespecialiseerde vormen van behandeling liep uiteen. De behandeling in een gespecialiseerde instelling werd het vaakst als positief ervaren door zowel patiënten als voormalige patiënten. Voormalige patiënten waren het meest positief. Deelnemers noemden dan vooral de aandacht voor de eetproblemen, naast de aandacht voor achterliggende problemen en de ervaren steun van lotgenoten. Sommige patiënten vonden het nadelig als er te veel nadruk werd gelegd op de symptomen van de eetstoornis ten koste van de aandacht voor de achterliggende problemen.

In het individuele contact met een hulpverlener gaven de patiënten de voorkeur aan een gelijkwaardige samenwerking. Goede communicatieve vaardigheden van de therapeut, een goede werkrelatie en de focus van de zittingen waren van belang voor een goed contact met de hulpverlener. Zowel patiënten als voormalige patiënten benadrukten het belang om hen als persoon te benaderen en niet als “geval”. Zelfhulpgroepen en betrokkenheid van de partner werden waardevol gevonden door meer dan de helft van degenen die deze behandeling hadden gekregen. Er werden geen sterke voorspellers gevonden voor de manier waarop de behandeling werd geëvalueerd.

In *Hoofdstuk 5* is het perspectief van therapeuten en patiënten betreffende de kwaliteit van de behandeling vergeleken. De werving van de therapeuten heeft plaats gevonden in gespecialiseerde centra en op een landelijke onderwijsdag van het Kenniscentrum Eetstoornissen Nederland. Uiteindelijk hebben drieënzeventig therapeuten deel genomen aan het onderzoek. De therapeuten hebben overeenkomstige vragen beantwoord als de patiënten in een aangepaste versie van de "Vragenlijst voor Eetproblemen en Behandeling". Therapeuten en patiënten hadden dezelfde opvattingen over de meeste aspecten van de kwaliteit van de behandeling, in het bijzonder als ging om het proces van de behandeling en de organisatie van de zorg. Als belangrijke componenten voor de kwaliteit van de behandeling noemden zowel de patiënten als de therapeuten de focus van de behandeling, de werkrelatie en de communicatieve vaardigheden van de therapeut. Zij gaven echter een ander gewicht aan overeenkomstige onderwerpen, zoals bleek uit zowel de kwantitatieve als de kwalitatieve analyses van hun antwoorden. De therapeuten hechtten meer waarde aan de focus op het normaliseren van het eetpatroon en gedragsverandering, terwijl de patiënten het belang van de relatie met de therapeut en de aandacht voor achterliggende problemen benadrukten. In de meeste gevallen zullen therapeuten en patiënten gezamenlijk aan de behandeldoelen kunnen werken, omdat hun overeenkomstige opvattingen zwaarder wegen dan de verschillen. Echter, een goede "match" tussen therapeut en patiënt is erg belangrijk. Verschil in waardering die therapeut en patiënt hechten aan aspecten in de behandeling kan de nodige implicaties hebben. Zo kan het de rolverwachtingen beïnvloeden. Voor een therapeut is een "gemotiveerde" of zich ontwikkelende patiënt, iemand die bereid is om haar of zijn eetgedrag te veranderen, terwijl voor een patiënt een "goede" therapeut iemand is, die haar of hem begrijpt, en aandacht heeft voor de patiënt als een persoon en niet alleen voor het gedrag en de symptomen. Bij de onderhandeling over behandeldoelen op verschillende momenten van het therapeutische proces, kunnen de therapeut en de patiënt het gedrag van elkaar interpreteren overeenkomstig hun rolverwachtingen met als gevolg dat zij verschillende opvattingen hebben over de therapeutische relatie en deze verschillend zullen ervaren.

In de conclusie en discussie van het proefschrift wordt vastgesteld dat het patiëntenperspectief, als kennisbron, bijdraagt aan een beter begrip van eetstoornissen en de gevolgen van eetstoornissen. Er worden aanbevelingen gedaan hoe de behandeling voor eetstoornissen geoptimaliseerd kan worden gedurende het hele behandeltraject, hoe het zoeken naar behandeling bespoedigd kan worden, hoe het vinden, verwijzen naar en starten van behandeling verbeterd kan worden en hoe de continuïteit van zorg kan worden gegarandeerd. De evaluatie van de kwaliteit van de behandeling door patiënten wordt bepaald door de ervaren kwaliteit van drie domeinen: dienstverlening, het therapeutisch proces en de organisatie van de zorg. Het wordt aanbevolen om deze drie domeinen te vertalen naar kwaliteitscriteria voor de zorg. Er is vastgesteld dat wetenschappelijk onderzoek een stap vooruit kan zetten, indien de aspecten die de patiënten – alsmede de therapeuten – hebben aangedragen, opgenomen worden in het opzetten van nieuw onderzoek. Door drie kennisbronnen met elkaar te verbinden, namelijk de wetenschappelijke kennis, de opvattingen van de therapeuten en de opvattingen en ervaringen van patiënten, wordt optimale behandeling van eetstoornissen bevorderd.

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Appendix 1

Diagnostic criteria: Anorexia Nervosa
(American Psychiatric Association, DSM-IV-TR, 1994)

A. Refusal to maintain body weight at or above a minimally normal weight for age and height (eg, weight loss leading to maintenance of body weight less than 85% of that expected or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
B. Intense fear of gaining weight or becoming fat, even though underweight.
C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
D. In postmenarchal females, amenorrhea ie, the absence of at least three consecutive cycles.

Specify type:

- **Restricting Type**: During the current episode of anorexia nervosa, the person has not regularly engaged in binge-eating or purging behaviour (ie, self-induced vomiting or the misuse of laxatives, diuretics, or enemas).
- **Binge-Eating/Purging Type**: During the current episode of anorexia nervosa, the person has regularly engaged in binge-eating or purging behaviour (ie, self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

Diagnostic Criteria: Bulimia Nervosa
(American Psychiatric Association, DSM-IV-TR, 1994)

A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:

   (1) Eating, in a discrete period of time (eg, within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.

   (2) A sense of lack of control over eating during the episode (eg, a feeling that one cannot stop eating or control what or how much one is eating).

B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas or other medications; fasting or excessive exercise.
C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for 3 months.
D. Self-evaluation is unduly influenced by body shape and weight.
E. The disturbance does not occur exclusively during episodes of anorexia nervosa.

Specify type:

- **Purging type**: During the current episode of bulimia nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics or enemas.
- **Nonpurging type**: During the current episode of bulimia nervosa, the person has used inappropriate compensatory behaviours, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics or enemas

Diagnostic Criteria: Eating Disorder Not Otherwise Specified
(American Psychiatric Association, DSM-IV TR, 1994)

The Eating Disorder Not Otherwise Specified category is for disorders of eating that do not meet the criteria for any specific Eating Disorder. Examples include

1. For females, all of the criteria for Anorexia Nervosa are met except that the individual has regular menses.
2. All of the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.
4. The regular use of inappropriate compensatory behaviour by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two cookies).
5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.
6. Binge-eating disorder: recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviours characteristic of Bulimia Nervosa.