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Eating disorders

Studies of understanding and recovery

Thesis for the degree philosophiae doctor

Trondheim, December 2007

Norwegian University of Science and Technology
Faculty of Social Sciences and Technology Management
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NTNU

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To my family

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Paper 1-5

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List of papers

1. Rosenvinge JH, Pettersen G, Olstad R. The ranking of diseases: a general population survey of status attributed to somatic and mental illnesses. *European Journal of Psychiatry* 2007; submitted.
2. Rosenvinge JH, Pettersen G. Tjenestetilbudet til pasienter med spiseforstyrrelser: En nasjonal kartlegging i primær- og spesialisthelsetjenesten. *Tidsskrift for Norsk Psykologforening* 2006; 41: 1160-8.
3. Pettersen G, Rosenvinge JH. Improvement and recovery from eating disorders: A patient perspective. *Eating Disorders* 2002; 10: 61-71.
4. Pettersen G, Thune-Larsen KB, Rosenvinge JH. Necessary ingredients of the concept of recovery from eating disorders: Comparing clinician and community member perspectives. *Eating Disorders* 2007; submitted.
5. Pettersen G, Rosenvinge JH, Ytterhus B. The “double life” of bulimia: patients’ experiences in daily life interactions. *Eating Disorders* 2008; accepted for publication.

Part I - General overview

Eating disorders - still an enigma

The pioneer in the field of eating disorders (ED) Hilde Bruch named ED as enigmatic illnesses (Bruch, 1978). Despite a substantial development in the understanding of ED during the past 30 years, mysteries, enigmas and paradoxes still persist. How can we understand how and why a person may overeat and vomit several times a day, feel depressed and suicidal, and hiding bulimic symptoms even in close and intimate relations for years and still manage to keep a job and function well in many contexts? Or how is it comprehensible that a person with severe anorexia can express that: "I was nearly dying of anorexia, but it was the anorexia that saved my life. It was my way of surviving"?

ED (anorexia nervosa and bulimia nervosa) do challenge our intuitive conception of a sharp border between normal variations and what we consider as illness or psychopathology. ED are a matter of clearly defined somatic complications, but equally much of cultural ideals, family function, interpersonal relations and subjective experience of well-being. Then, outcome and recovery is not only a matter of objective evaluations, but also a matter of subjective experience and subjective interpretations of one's current condition. As subjective and objective aspects do not necessarily coincide, a paradoxical situation may arise that a patient may have the experience of illness even with a low level of symptoms or being recovered and still presenting with some ED symptoms. Also, a clinical evaluation may depend on how recovery is de-

finied, and whether one uses standardised instruments, the sufferer's subjective experience or both.

The overall motivation for conducting the studies comprising the present thesis is to focus on enigmas and paradoxes associated with understanding of ED and recovery from ED. To accomplish this, qualitative and quantitative methods are used, as well as different kinds of samples and approaches.

Historical and current accounts of ED

Historically, ED have not been eating disorders. Rather, eating behaviours characterised women who departed from social norms, and who actually took advantage of unusual eating behaviours to evade or distance themselves from gender roles and a life agenda defined by men. Ironically, men appointed some of them as saints post mortem, as it was considered miraculous for human beings to live nearly without food. The most famous representative of such holy anorexia was Catharina Benincasa from Siena, who by the age of 12 defied her parents, and left them for a monastery life to oppose their choice of a husband for her. She was canonised in 1461 by Pope Pius II. Other women were, however, demonised and burnt as witches for their food abstinence (Vandereycken & van Deth, 1994), but their names are forgotten today.

Also more or less forgotten are nine doctoral theses about anorexia nervosa from 1668-1762. They may represent the first accounts of anorexia nervosa as

a medical disorder along with the work of Richard Morton (Morton, 1689). Later accounts were provided by Whytt (1767), the French physicians Briquet (1859) and Marce (1860), as notably, by Sir William W. Gull (1868; 1873; 1888) and Charles Lasegue (1873a, b). Morton, describing a male patient who by the age of 16 gradually declined in a state of apathy with a total loss of appetite, outlined the physical manifestations and a possible neurological aetiology. Gull and Lasegue on the other hand, appreciated anorexia nervosa as a mental disorder, and notably, Lasegue proposed a conversion hysteria process at work. In the American medical literature one of the first appearances of ED came with the works of Hammond (1879) and Lloyd (1893), while in the late 18th century a general practitioner from Balsfjord in the Northern Norway (Selmer, 1891) was probably the first one to describe severe eating disturbances in the Norwegian medical literature (Rosenvinge & Vandereycken, 1994). It is noteworthy that in the 1950's influential Norwegian authors (e.g. Eitinger, 1951) still argued against anorexia as a separate entity, and that the illness better could be understood as a psychosomatic disorder, and a variant of female hysteria. This represents a tradition back to Lasegue (1873a, b) and Janet (1903), and a contrast to most other European countries, where one in the 1950's for many years had been running clinical work and research on ED as acknowledged, separate illnesses in their own right.

Historically, anorexia nervosa has been a rare illness both with respect to prevalence and with respect to the many enigmas related to aetiology. Rare cases may be "attractive" and attract professional interest, especially with a certain

risk of fatal consequences. In contrast to most other mental disorders, this is the case for anorexia nervosa. Health professionals often ascribe rare illnesses a high, informal status as "prestigious" (Album, 1991), that can raise the probability of easier access to treatment. This stands in contrast to what may be the case for those who suffer from illnesses understood as trivial, common or at variance with culturally laudable values. Mental illnesses are ranked lower in informal status and prestige compared to somatic diseases with an acute onset where an instrumental treatment may lead to a well-defined successful recovery. In particular, ED are ranked lower than other mental disorders (Album, 1991). Modern times have provided a certain touch of triviality to anorexia nervosa, for instance manifested in the exploding number of features in popular magazines about dieting (Ahrens, Gray & Sypeck, 2004) picturing thin bodies as the manifestation of self-control, beauty and happiness. The revival of bulimia nervosa as a diagnostic entity in the late 1970s (Russell, 1979), highlighted features that in our culture are negatively loaded, and attributed to an "immoral" lifestyle, like loss of control, bingeing, overeating, and vomiting, thus possibly lowering the informal status of ED among health professionals.

Historically, shame, stigmatisation, and guilt due to bingeing and vomiting appear as rather "new" feelings, and closely related to a conception of ED as medical disorders. Ancient physicians recommended vomiting for curative, purification purposes (Nasser, 1997) and in Caesar's Rome, it was one of the signs of a prosperous citizen from the affluent, higher bourgeoisie to have a private "vomitorium", a special room

where one could relax and vomit after excessive meals. No wonder that as late as in the 13th and 14th century bulimia was described as a variant of digestive discomfort (Glanville, 1535). Some 200 years later the conception of bulimia had changed to a medical disorder, and early in the 18th century bulimia was even defined in terms of diagnostic subgroups (Cullen, 1818). While anorexia were to some extent still “admired”, bulimia was considered more shameful and immoral, given the social context of European famine, enlightenment and the secularisation of thoughts and minds (Parry-Jones & Parry-Jones, 1995). Then, there is a short way to internalise social sanctions and develop shame and guilt.

It is only during the past two decades that ED have been made a public issue and have been placed on the official agenda (Skårderud & Rosenvinge, 2001). Media exposure of cases and research findings about ED are disseminated almost every day, the research literature on ED is expanding (Theander, 2002) as well as the number of textbooks, and international and national ED-professional societies. Moreover national treatment guidelines (Statens helsetilsyn, 1992; 2000) and programmes on increasing clinical competence have been designed and implemented (Buhl, 1993; Rosenvinge, Skårderud & Thune-Larsen, 2003) in order to disseminate clinical competence to all treatment service levels. Influential patient organisations have also emerged, strongly advocating the relevance of patient experiences to understand ED as well as opinions about treatment and treatment organisation. In total, ED patients are no longer considered as rare cases in somatic or mental health care, handled by a small handful

of dedicated specialists (Skårderud & Rosenvinge, 2001). Is this reflected in how the treatment is organised? Another question is how ED are understood in the society and how ED are regarded in terms of ranking of prestige related to other mental and somatic diseases. These issues are at focus in papers 1 and 2. One may expect that with a high exposure of ED through many years makes it possible to expect valid responses when also addressing community samples, like in papers 1 and 4.

Treatment organisation and clinical competence

Despite having become a public issue the question still remains about the quality and organisation of health care services for ED. There are many accounts of inadequate treatment- and treatment organisation of ED. There may be several reasons for this situation. First, there may be a poor compliance with clinical guidelines, secondly a low patient volume that makes it difficult to acquire or maintain sufficient clinical experience and competence. Thirdly, clinicians may hold negative attitudes towards ED patients and bulimia nervosa patients in particular because they display a possible chronic disease and that their symptoms make them stand out as immoral, manipulative and clandestine. Hence, patients may be viewed as deserving a lower rank or status than illnesses of a more acute nature, suffered by individuals who are explicitly willing to get well. Finally, therapist gender may affect if and how patients are treated (Noordenbos, 1998). Notably, Feeney, Noble and Waller (2007) found that older, male doctors were less likely to detect and treat patients with bulimia nervosa or pathological overeating.

Here, shame and concealing are often dominant and physical symptoms less visible. Then, a failure to detect and to provide adequate treatment may give rise to more self-stigmatisation. Only a few previous investigations have actually studied the overall organisation of ED treatment (e.g. Rosenvinge & Sundgot-Borgen, 1999). Paper 2 represents a replication and expansion of the previous research.

Aetiology

ED have been understood as pure endocrinological in nature (Bassøe, Stray, Støa & Bassøe, 1972; Simmonds, 1914a, b; 1916; Williams, 1958). Recent studies (Bulik *et al.*, 2006) suggest a substantial heritability of 0.56 for anorexia nervosa. Earlier psychological theories suggested ED as a psychodynamic defence against sexuality (Nævestad, 1969; Waller, Kaufman & Deutch, 1940), proposed constitutional associations with schizophrenia (Brill, 1939; Nicole, 1938; 1939), depression and bipolar disorders (e.g. Cobb, 1943; McElroy *et al.*, 2005; Meyer & Weinroth, 1957; Nemiah, 1950), obsessive-compulsive disorders (e.g. Dubois, 1949; Palmer & Jones, 1939; Rahman, Richardson & Ripley, 1939), or viewing ED as a “compromise with suicide” (Crichton-Miller, 1938).

Bruch (1962; 1969) regarded ED as a result of a developmental deficit due to disturbances of child-parent contact, resulting in a loss of ego functions to buffer normal developmental changes during adolescence. Bruch is also remembered for identifying body image disturbances as an important clinical feature. This feature seems to belong more or less exclusively to ED as they appear in modern times. Recent

psychodynamic theories about the aetiology of ED rely heavily on attachment and relational issues (Fonagy *et al.*, 2002; Perlman, 2005) with a close link to recent advances in developmental psychology, neurobiology and affect-regulation. Here, recovery is not a matter of symptom reduction, but rather to “opening to the joys and frustrations of intimate human relationships” (Perlman, 2005, p. 231). Several studies also supports the notion that development of ED are related to childhood attachment problems (separation-autonomy), parental bonding deficits (Broberg, Hjalms & Nevonen, 2001; Hastings & Kern, 1994; Perry, Silvera, Rosenvinge & Holte, 2002; Salzman, 1997) as well as an identity diffusion development (Akthar, 1984) originated in a failure to reach a mature identity status (Marcia, 1966) in the “Eriksonian” way of thinking about identity development. Another pioneer, Selvini-Palazzoli (1974), departed from psychoanalysis and developed an influential systemic understanding, manifested in family therapy approaches.

During the past decades a cognitive conception of aetiology has also evolved. Here, ED are conceived as a consequence of judging oneself largely, or even exclusively in terms of one’s eating habits, shape and weight, and the ability to control them (Fairburn, Cooper & Zafran, 2003).

While there are advocates for all these models of aetiology, at least in principle however, the aetiology of ED is considered multidimensional in nature, and closely related to knowledge about vulnerability and risk factors. General models of psychopathology (Zubin & Spring, 1977) describing the interplay between (a) genetic and psychological

vulnerability, b) resiliency, c) social reinforcement and modelling, and (d) adverse life events also apply to ED.

Risk factors and epidemiology

Organising risk factors according to aetiological status (Garner, 1993), risk factors for ED comprise dispositional features, *e.g.* premorbid overweight, a negative self-image, perfectionism, as well as adverse life events *e.g.* adult abuse, poor social network, and effects of negative comments on body weight and composition, notably from parents or adults (Fairburn *et al.*, 1997; 1998; 1999). Eliciting risk factors are dieting (Fairburn *et al.*, 2005; Hsu, 1997; Patton *et al.*, 1999), personality (Ghaderi & Scott, 2000), notably neuroticism (Bollen & Wojciechowski, 2004) related to affective dysregulation, and personality disorders (Bulik *et al.*, 2006; Claes *et al.*, 2006) Johnson, Cohen, Kasen & Brook, 2006). Precipitating risk factors comprise dysfunctional cognitive and motivational states as well as interpersonally based resolutions of burdens related to living with or close to a sufferer of ED.

ED are particularly frequent among women aged 15-40 years. During the past decades the female population-based incidence has been rather stable though perhaps moderately increasing for bulimia nervosa (Fombonne, 1995; 1996; Nielsen, 2001). Interestingly the prevalence increased for both genders in the period 1935-1958 (Bulik *et al.*, 2006). Nowadays the prevalence figures for anorexia nervosa and bulimia nervosa range between 0.1-1.0% and 0.5-1.0% respectively. The prevalence of other ED forms like binge eating disorders (BED) and unspecified ED not fitting in existing diagnoses

(EDNOS) is somewhat higher, *i.e.* 1 % for BED (Hay, 1998; Striegel-Moore & Franko, 2003) and 2.4% for EDNOS (Machado, Machado, Goncalves & Hoek, 2007). The standardised mortality rate for anorexia nervosa is raised 4-10 times (Nielsen, 2001). Somatic complications stand for about 60 % of the mortality, while 27 % can be attributed to suicide (Norrington & Sohlberg, 1993; Sullivan, 1995; Theander, 1985). The mortality rate for bulimia nervosa and BED is raised seven and four times, respectively (Nielsen, 2001). Interestingly, a recent Swedish study (Lindblad, Lindberg & Hjern, 2006) reported on a substantial decrease in mortality across decades. This may possibly be related to improved treatment efficacy, as well as treatment organisation in terms of specialized hospital units.

Converting prevalence data from national and international studies, about 50,000 young women may suffer from diagnosable ED in Norway. About 600 of them may need highly specialised treatment (Rosenvinge & Gøtestam, 2002). This calls for studies focusing on the nature and quality of treatment and treatment organisation for ED sufferers. This is an issue discussed in paper 2. An implication of such calculations of patient volumes is that in principle, non-specialists on ED may effectively treat the majority of patients. In order to prompt or optimise the effect of treatment, there is much effort put in identifying early signs of ED. Regrettably and surprisingly, less effort is put in identifying the meaning of recovery, and how recovery may be identified and conceptualised.

Diagnostic crossovers, complications, and comorbidity

Diagnostic criteria for ED according to the DSM-IV (APA, 1994) are provided in the Appendix I. There is a considerable diagnostic overlap between anorexia nervosa and bulimia nervosa (Fairburn & Harrison, 2003), and 30-50% of patients with bulimia have a history of anorexia nervosa (Fairburn & Harrison, 2003; Rosenvinge & Moulund, 1990; Wentz, 2000). Crossover usually occurs by the fifth year of illness. A low level of self-directedness predicts crossover in all directions; high parental criticism predicts crossover from anorexia nervosa to bulimia nervosa, whereas alcohol abuse or dependence and a low level of novelty seeking is associated with crossover from bulimia nervosa to anorexia nervosa (Tozzi *et al.*, 2005). Crossover problems are an important reason for the development of a “transdiagnostic” approach (Fairburn, Cooper & Zafran, 2003), in which even the concept of “crossover” becomes irrelevant. Recent advances in within such an approach thus refer to features of ED which are believed to be common to all the existing ED diagnoses (Fairburn & Bohn, 2005). The transdiagnostic approach is also supported by findings indicating that following recovery a wide range of personality and temperament features as well as symptom diagnoses persist regardless of the actual ED diagnosis (Wagner *et al.*, 2006). Such an approach is adopted also in the present thesis, and the Appendix I provides a brief outline of common features of ED.

Also, psychiatric comorbidity is considerable. Severe depression and dysthymia occur among 50-70% of ED-patients, and the lifetime prevalence of

obsessive-compulsive disorders is about 25% (Braun, Sunday & Halmi, 1994; Halmi *et al.*, 1991). Both obsessiveness and depression stand out as a significant marker of a poor outcome (Berkman, Lohr & Bulik, 2007; Crane, Roberts & Treasure, 2007), and the rate of suicide attempts is significantly higher than in the general population (Corcos *et al.*, 2002). Unique predictors of suicide attempts for anorexia nervosa include the severity of both depressive symptoms and drug use. For bulimia nervosa, a history of addictive problems and current laxative abuse predict suicide attempts (Keel *et al.*, 2003). About 40% of patients with bulimia nervosa also satisfy criteria for an addictive disorder, which is twice as high as for anorexia nervosa. Moreover, that alcohol abuse during follow-up is a significant predictor of mortality in anorexia nervosa (Keel *et al.*, 2003).

However, the comorbidity with anxiety disorders is more uncertain (Godart, Flament, Perderau & Jemmet, 2002; Swinbourne & Touyz, 2007), nevertheless suggesting a higher frequency of anxiety disorders in ED compared with the general population. Also, Halvorsen (2007) found that among those (5%) adolescents who still had ED approximately 10 years after treatment, 56% and 67% had anxiety disorders and depression, respectively. This was significantly higher compared with those 20% who had recovered from the ED. Moreover, 60% of ED patients meet DSM IV criteria for one or more personality disorder diagnoses (Rosenvinge, Martinussen & Østensen, 2000; Skodol *et al.*, 1993), notably unstable personality disorder (bulimia nervosa) and obsessive-compulsive and avoidant disorders (anorexia nervosa) (Råstam, 1992; Wentz, 2000).

For anorexia nervosa malnutrition caused by self-starvation may result in cardiac complications, and a risk of a fatal outcome (Williams, 1958). Especially for bulimia nervosa secret, binge episodes occur frequently, in which patients have less or no control over their eating, and physical exhaustion may be the result of a binge eating episode. Cardiac complications are also associated with bulimia nervosa, while dental erosions and damages from acid attacks are special consequences of bulimic overeating and vomiting.

As pointed out by many authors (*e.g.* Couturier & Lock, 2006b, Noordenbos & Seubring, 2006) recovery depends on the operational definition originated from a certain kind of diagnostic criteria as well as aetiological assumptions on ED. Is for instance recovery in progress if an ED patient is eating regularly and the weight is within a normal range or with no vomiting, bingeing or abuse of laxatives or diuretics? Can we speak of recovery when the patient has a more positive evaluation of herself and her body, and is able to express her emotions and has social contacts, yet still displays some ED symptoms? These issues are discussed in papers 3-5. This is a matter of comorbidity and the nature of such comorbidity in particular, *i.e.* whether ED and other kind of symptoms like depression and anxiety are related or not. They may be causally or casually related to ED, or there may be mediating third factors at work. Also, such conditions may develop as a result of how a long duration of ED affects daily life functioning and quality of life. Moreover, with a long duration of illness, it is difficult to separate ED from identity and way of living, and this may further complicate the recovery assessment. In principle, some

of these issues could be resolved using a prospective or a case-control design; however, this is extremely difficult to conduct.

However, to take the matter a step further, this is also a matter of aetiological assumptions or presuppositions. Indeed, according to a more descriptive and behavioural approach one may regard symptom reduction as a rather good example of recovery from an ED. From a dynamic point of view recovery may be judged as rather poor despite the absence of ED symptoms as long as problems blow up that are conceived as related to ED. Hence, recovery is a matter of recovery “from what”, and “to what”. Technically, an anorexia nervosa patient is recovered from her anorexia even if she develops bulimia nervosa. Similarly, a bulimia patient is recovered from his bulimia even if personality traits associated with affective control or the comorbid personality disorder still persists. However, such conceptions of recovery do not seem very helpful.

Clinical features and ambivalence to treatment and recovery

Sufferers from ED often feel stigmatised. Stigma is here defined according to Goffman (1963) as the experience of possessing undesirable and deeply discrediting personal attributes or traits that disqualify one from social acceptance. Being stigmatised may motivate efforts by the stigmatised individual to hiding the behaviours associated with the stigma.

Feeling stigmatised may not necessarily imply that patients *are* stigmatised. Yet, the feeling arises from shame due to the ED symptoms, and the human need for

consistency may easily lead to a tendency to interpret event as evidence for stigmatisation. As a consequence, a fear of revealing ED symptoms may be strong. Shame may be stronger for patients with ED compared to other clinical groups (Cook, 1994; 1996; Frank, 1991; Sanfther & Crowther, 1998). Shame may even predict a higher symptom severity (Burney & Irwin, 2000) possibly because shame may foster a fear of being stigmatized, a fear that has been identified as a prominent barrier to treatment seeking (Hepworth & Paxton, 2007). An interesting question is whether the feelings of shame is reflected in the objective reality as for instance, manifested in rankings among many kind of disorders, in the quality of treatment services, or in a poor quality of interpersonal relations, or equally much or more, in the subjective experience of shame. This issue is discussed in papers 1, 2 and 5.

Patients with ED also display a profoundly disturbed body attitude (Askevold, 1975; Bruch, 1962; 1969), where self worth and self-esteem are closely linked to body appearance and a feeling of being fat despite a normal or low weight. Hence, a drive for thinness is dominating daily life, and ED becomes often a means of controlling or suppressing emotions, as well as controlling daily life interactions and intimacy with family members or close friends. Thus ED serve as an affect regulation strategy and a means to gain autonomy. In a short time perspective, ED may serve such functions well, and since giving up a “functional” strategy may seem universally contra-intuitive, this is also the case for ED sufferers. However, in a treatment setting this phenomenon is often misinterpreted as negativism (“resistance” to treatment)

or low motivation, and thus rejected from treatment.

Shame may foster ambivalence and a fluctuating motivation to changes and recovery. This may relate not only to fear of new challenges without ED, but also to a resistance to giving up a survival strategy. Some may also resist treatment and fear recovery due to negative cognitive beliefs about being a bad person who actually does not “deserve” to recover. As a consequence of shame, a fear of disclosure, negative self-beliefs and may often result in a considerable time delay from personal recognition of the need for help, and the occurrence of actual help seeking behaviours (Rosenvinge & Klusmeier, 2000). In the long run, however, somatic complications, as well as psychological and social burdens may dominate, thus motivating sufferers to a drive for recovery and to seek help.

To understand more of the recovery process and the elements of recovery may actually help in installing treatment and making treatment more efficient. Moreover, more knowledge about how ED are entangled in daily life and in interpersonal relations may help in identifying and modifying precipitating factors to start a recovery process. Some of these issues are discussed in papers 3 and 5.

Treatment

For anorexia nervosa, there has only been a few randomised controlled studies (Bulik *et al.*, 2007; Hay *et al.*, 2004) and there is no specific evidence based treatment approach. In contrast, more than 50 randomised controlled treatment trials for bulimia nervosa (Fairburn & Harrison, 2003; Shapiro *et*

al., 2007) show that on average, 30-50% benefit from modifying behaviours and way of thinking through cognitive-behavioural therapy. Interpersonal therapy, which focuses on the patients' current life situation and interpersonal relationships, appears less effective at the end of treatment, but at five years follow-up the effects of both treatments are indistinguishable (Fairburn *et al.*, 1995). Moreover, due to diagnostic crossovers and comorbidity, alternative models based on "transdiagnostics" (Fairburn *et al.*, 2003; Fairburn & Bohn, 2005), or dimensions rather than diagnostic categories (Clinton, Button, Noring & Palmer, 2004; Williamson, Gleaves & Stewart, 2005; Wonderlich *et al.*, 2007) have been developed to improve understanding and treatment. Promising preliminary results have been reported (Fairburn, 2007) designing cognitive-behavioural therapy according along this kind of reasoning. The same is the case for guided self-help (Carter *et al.*, 2003; Cooper, Coker & Fleming, 1996; Ghaderi & Scott, 2003; Dallegrave, 1997; Loeb, Wilson, Gilbert & Labouvie, 2000; Palmer *et al.*, 2002) group therapy combining cognitive-behavioural and interpersonal approaches (Nevonen *et al.*, 1999), and cumulative or stepped care models, starting with self-help and ending with inpatient treatment.

Effect or benefit, however, may be different from recovery. Also, a realistic perspective on the impact of treatment is due, considering the fact that on average it may take 6-8 years before changes take place, despite substantial therapeutic efforts (Keel & Mitchell, 1997; Strober, Freeman & Morrell, 1997).

Even within the realm of a randomised controlled design, effect of treatment may be rather complicated to define. Effects may be intentional or unintentional, immediate and distal, direct and indirect. The impact of events not related to treatment has been underscored in much of the treatment-outcome research. Also, as time passes from the end of treatment, it becomes increasingly difficult to separate indirect or direct long-term treatment effects from the impact of events more remotely related or even unrelated to treatment. Few studies have addressed the impact of non-therapy related events prompting recovery, and how such events may connect with treatment. Some of these issues are discussed in paper 3.

Outcome and recovery

Outcome studies

Outcome studies have mainly adopted a clinician or researcher perspective. Here, patient's experiences are transformed into ordinal or ratio scale scores, and the patient's are classified into predefined outcome categories based on a total clinical evaluation. Hence, the focus is a normative classification, yet however, not necessarily relating to normative comparative data.

A review of the outcome studies from 1953 to 1999 covering nearly 6000 patients (Steinhausen, 2002) showed a crude mortality rate of 5%, a full recovery for 47%, a partial improvement for 34% while 21% developed a chronic course. Interestingly, with increasing duration of follow-up, the percentage who recovered increased from 33% to 73%. Interestingly, a review of adult and adolescent studies (Fisher, 2003) indicates that adolescents fare better

than adults, particularly if treatment is given on an outpatient basis.

Exploring these findings in detail reveals however, a considerable variability, where recovery rates range from 57% to 97% (Couturier & Lock, 2006a). In larger studies 30 -75 % of patients recover from anorexia nervosa (Bassøe & Eskeland, 1982; Fichter & Quadflieg, 1999; Fichter, Quadflieg & Hedlund, 2006; Herzog *et al.*, 1999; Lowe *et al.*, 2001; Nygaard, 1989; Steinhausen, 2002; Strober, Freeman & Morell, 1997; Sullivan, Bulik & Fear, 1998; Zipfel *et al.*, 2000), and between 50% and 70% recover from bulimia nervosa (Ben Tovim *et al.*, 2001; Fairburn *et al.*, 1995; Fichter & Quadflieg, 1997; 2004; Keel & Mitchell, 1997; Keel *et al.*, 1999). This variability across studies are related to 1) sample size and statistical power, 2) patient characteristics (*e.g.* age, and admission status), 3) the duration of follow-up, 4) dropout, attrition, and diagnostic crossovers, 5) methodology (questionnaire vs. interview, telephone vs. in-person, retrospective vs. prospective design), and 6) definitions of outcome and recovery.

To reduce this variability, several authors (*e.g.* Berkman, Lohr & Bulik, 2007; Couturier & Lock, 2006a,b; Hsu, 1980; Schwartz & Thompson, 1981; Seidel, 1991; Steinhausen & Glanville, 1983, Steinhausen, Rauss-Mason & Herzog, Keller & Lavori, 1988;) recommend specific guidelines for conducting follow-up studies. This has resulted in improved reliability. Despite some progress (*e.g.* Couturier & Lock, 2006a, b; Kordy *et al.*, 2002; Olmsted, Kaplan & Rockert, 2005; Rø *et al.*, 2005a,b; Dare *et al.*, 2001), reaching consensus about the construct and external validity of

outcome criteria stands out as a major future challenge. The validity of aspects that may be associated with recovery is the issue of papers 3 and 4.

Selecting outcome assessment tools within the plethora of self-report instruments (for an overview, see Anderson & Paulosky, 2004) may be problematic, as such instruments have been developed for the purpose of screening and clinical evaluations and not for outcome evaluation purposes. In particular, as such instruments mainly measure symptom frequency this may be too restrictive in the sense that positive indicators of recovery are not incorporated. Moreover, self-report items have been generated by expert clinicians, and most of them have been poorly tested on general clinicians and in community samples to ascertain the external validity.

Other instruments evade some of these criticisms. For instance, the Morgan-Russell assessment schedule (Morgan & Russell, 1975) later modified by Morgan & Hayward (1988) is an interview especially designed for outcome assessment. The original version captures strict aspects like weight, food intake, and menstruation. To secure validity and a broad-spectrum picture of outcome, the instrument also covers aspects like family life, occupational status, sexual life and preferences as well as mental and socio-economic status. However, this made the instrument vulnerable to biases from normative factors, related to informal assumptions about "optimal" standards of living and quality of life. Thus, many studies have resorted to narrow or restricted outcome aspects (*e.g.* Eckert *et al.*, 1995) in order to avoid a depletion of reliability. However, outcome stud-

ies have been criticised for not taking into account psychological, emotional and social aspects (Deter, Herzog & Petzold, 1992; Jarman & Walsh, 1999; Noordenbos, 1992). For this reason the narrow or restricted criteria have been regarded as insufficient to account for full recovery (Ratnasurya, Eisler & Szmukler, 1991, Strober *et al.*, 1997). Thus, narrow outcome criteria may be invalid *per se*, while extended criteria may be made invalid with respect to their application or how they operate in practical, clinical evaluations.

Thus, there is a need for validation studies of both narrow and extended criteria, and to develop models on how narrow and extended recovery aspects may be integrated.

Recovery studies

Recovery is a particular aspect of outcome. Recovery has mainly been studied adopting a patient perspective. This perspective means allowing patients to launch their own understanding and experiences, and not confine outcome (or recovery) measures to quantifiable physical and mental determinants. Obviously experiences may be interpreted, but the classification or sorting of experiences in superordinate groups is descriptive and on a nominal level of measurement.

In contrast to outcome studies, recovery as experiences may be reported as citations or classified in ad hoc categories based on analyses of text transcriptions. This approach is highly relevant when the research question is to pursue a certain phenomenon or experience in depth, and not to make an “account” of the fate of a (preferably) large group of former patients. Thus, most of the

studies on recovery from a patient perspective are qualitative in nature. The value of accounts provided by outcome studies aside, in-depth explorations are well suited to catch the complexity of ED and recovery, in particular as recovery from ED is poorly understood. Moreover, a qualitative approach is highly relevant as self-perceptions of for instance, recovery may breed true in its consequences (Leventhal, Meyer & Nerenz, 1980; Marcos *et al.*, 2007).

Apart from recovery, a patient perspective has been applied in studying experiences with ED-symptoms (*e.g.* Abraham & Beumont, 1982), treatment satisfaction (*e.g.* Brink, Isager & Tolstrup, 1988; Clinton, Björk, Sohlberg & Norring, 2004; Noordenbos, Jacobs & Hertenberger, 1998; Rosenvinge & Klusmeier, 2000; Skårderud, 2007; Swain-Campbell, Surgenor & Snell, 2001; Zukcer, Marcus & Bulik, 2006), experiences of causes (Nilsson, Abrahamsson, Torbiörnsson & Hägglöf, 2007) experiences having ED (Freedman *et al.*, 2006), motivation to change (Casanovas *et al.*, 2007).

Though few in total, empirical studies adopting a patient perspective on recovery are increasing in number (*e.g.* Beresin, Gordon & Herzog, 1989; D’Abundo & Chally, 2004; Federeci & Kaplan, 2007, in press; Hsu, Crisp & Callender, 1992; Nilsson & Hägglöf, 2006; Nevenon & Broberg, 2000; Noordenbos, 1989; 1992; Noordenbos, 1998; Rahkonen & Tozzi, 2005; Rorty, Yager & Rossotto, 1993; Tozzi *et al.*, 2003), and many important findings have emerged. Overall, the findings serve to temper conclusions from treatment studies, which may overscore

the impact of therapy in the recovery process.

Exploring this literature in detail, Beresin, Gordon and Herzog (1989) interviewed 13 women who had recovered from anorexia nervosa. In the recovery process life experiences from family, work, school, and meaningful relationships were considered equal in importance as therapy. In a study of six recovered anorexic patients, Hsu *et al.* (1992) reported that psychotherapy, willpower, marriage, children, and increased self-confidence were factors both contributing to and constituting recovery. In addition, Rahkonen and Tozzi (2005) found that ceasing to identify with an ED was important for recovery. In a similar vein, Weaver, Wuest and Ciliska (2005) studied 12 women recovered from anorexia nervosa where they found that “finding me” was regarded as a turning point. These women came to a point where they started to distance themselves from the ED, realising that it no longer helped them to attain life goals and aspirations. They also described a movement from “a victim role” towards being an active participant in the recovery process. A recent study (Federeci & Kaplan, 2007, in press) also reported similar findings, still adding the understanding of recovery as a process as well as the ability to tolerate negative affects as important according to the patient’s experiences.

Despite weight restoration many patients may become depressed and start to loose weight again (Noordenbos, 1989; 1992, Noordenbos *et al.*, 1998). This is also reported in outcome studies (e.g. Deter & Herzog, 1994; Eckert *et al.*, 1995; Herpertz-Dahlmann *et al.*, 2001; Råstam, Gillberg & Wentz,

2003). Moreover, Clinton and McKinley (1986) found that anorexia patients, after normalisation of their weight often had disturbed attitudes towards food and weight, did not have menses, were depressed and continued to be obsessed by food and weight. Bachner-Melman *et al.* (2006) reported a poorer clinical status of patients with no behavioural ED symptoms compared with individuals no behavioural symptoms and additional recovery with respect to cognitive distortions, fear of weight gain, and body image disturbances. This indicates that cognitions and body conceptions should be included in conceptions of recovery. Another implication is that such features are difficult to change. This is also found in controlled treatment and prevention studies (Stice *et al.*, 2000; 2001; Stice, Trost & Chase, 2003; Withers *et al.*, 2002).

Aims of the thesis and research questions

Given the enigmas of ED and the paradoxes of recovery, where ED may have diffuse or unclear starting points and end points, one may suspect that ED have a rather low status compared with other illnesses, and that ED patients are inadequately detected and treated due to poor organisation of treatment services. If this is the case, this represents poor conditions for patients to recover. To study these aspects is a secondary aim of the thesis, manifested in two background papers (papers 1 and 2).

The primary aim of the thesis is to detect aspects of recovery from different perspectives, *i.e.* how patients, clinicians, and representatives from the community select and judge aspects that may be relevant for a valid de-

scription of recovery from ED. May these perspectives be integrated in a model in the prospect of acquiring a comprehensive understanding? The thesis consists of five papers with the following six research questions:

1. How are ED ranked in prestige related to other somatic and mental illnesses? (paper 1)
2. How is treatment for ED organised in the health care system? (paper 2)
3. Which factors do ED sufferers identify as contributing to their recovery? (paper 3)
4. How do sufferers define improvement and recovery from ED, and how may such experiences relate to measures of ED and personal health control? (paper 3)
5. Do clinician's rankings of recovery items differ from those of a community sample controlling for age, clinical experience, and personal eating problems? (paper 4)
6. Which interaction steps are taken to conceal ED symptoms, and what are the consequences of starting a recovery process by symptom unravelling? (paper 5)

Part II - Summary of papers: methods and results

Paper 1: Rosenvinge JH, Pettersen G, Olstad R. The ranking of diseases: a general population survey of status attributed to somatic and mental illnesses. *European Journal Psychiatry* 2007, submitted.

Introduction and research questions

In principle, illnesses are equal in importance in the sense that all kinds of patients should have an equal access to treatment services. Still, the endless stream of patients and the ongoing advances in medical technology create a difference between patient demands, and actual resources or treatment capacity. Thus, some priorities are made. Ideally, these should be based on rational clinical judgments of the need for help, balanced against access to clinical and economical resources.

Medical sociology, however, has revealed that in part, this is an illusion. Hence, one has also identified unspoken irrational norms and values attached to illnesses affecting treatment priorities (Album, 1991). Hence, a “ranking” of diseases is made, where some illnesses are more “prestigious” to treat either because of the complexity, acuteness or technology required. Conversely, it is believed to be less prestigious to treat illnesses, which are chronic in nature and with a poor prospect of recovery, and particularly if symptoms are believed to be self-inflicted or a result of a certain lifestyle (Album, 1991). A question arises then, if access to treatment, for instance of ED, is governed by such unspoken and irrational norms. The previous study (Album, 1991) found a rather low

ranking by medical doctors as far as ED are concerned. Paper 1 addresses the question whether findings can be replicated in a community sample, and in a sub-sample of health professionals. Previous studies (Crisp *et al.*, 2000; Stewart, Keel & Schiavo, 2006) indicate that compared to other somatic and mental conditions ED are related to more negative perceptions among lay people in term of ED as self-inflicted conditions where the individual is to blame. A limitation of the previous research is the failure to test explanatory variables. Such variables were introduced in paper 1.

Subjects and methods

A random sample of 1127 males and females was generated by a national polling agency. The respondents were asked to rank twenty disorders. The disorders were selected in order to cover the five dimensions 1) “illness classification” into the subcategories “somatic”, “psychosomatic”, “addictive”, and “mental”, 2) “gender specificity”, 3) “acute versus a chronic course”, 4) “known versus unknown aetiology”, and 5) “treatment procedures as being highly effective versus unclear or unknown”.

Ranking was specified in terms of “intentions of actions”. Thus, one negative, and two positively formulated

questions measured rank based on economical priorities (*i.e.* “if you had become the minister of health, select three disorders from the above list as your first, second, and third priority for spending a) more money on treatment services, and b) less money on”, and “if 100 mill USD were given to clinical research, select three disorders as your first, second, and third priority to spend this money on”).

Moreover, the respondents were asked to complete 16 statements scaled 1-10 (maximal disagreement) measuring specific attitudes towards health and disorders. The statements covered level of agreement to whether rankings are related to the five dimensions and whether the aetiology is attributed to patient’s life style, gender or social status. As explanatory variables were used age, gender, educational background, health habits (*i.e.* regular smoking and physical activity), and the respondent’s personal experience or experience with family members with severe or chronic disorder. Ranking may also be due to health attributions, and here one used the Health Locus of Control Scale (HLCS) (Levenson, 1973) measuring whether personal health is controlled by internal, external or random factors. The HLCS had reasonable internal consistency (Chronbach’s α), *i.e.* 0.65 (external locus of control), 0.73 (internal locus of control), and 0.65 (random locus of control), respectively. To give a brief account of the content of the HLCS scale, respondents are requested to imagine that if one becomes ill or manage to stay healthy, is this attributed to their own effort (internal), a friend, a

health professional or treatment in the health care services (external), or good or bad luck (random).

Results

In general, high rank was given to acute, somatic diseases with a known aetiology and where high-technology treatment is expected to be effective. Mental disorders and ED in particular were ranked higher (*i.e.* no. 12/20 for ED) than in previous studies among medical doctors (Album, 1991). Women in the study ranked ED higher (*i.e.* no 9) compared to the total material (no. 12). Among mental disorders, only anxiety and mood disorders were ranked higher than ED. Moreover, health professionals in the sample ranked ED in fact higher (11/20) than non-health professionals (12/20) (paper 1, table 1). Still, there was almost a neutral stance (*i.e.* 6.60; SD 2.51) to the statement that “ED have a high status” (paper 1, table 2).

Contrary to expectations few and modest effects were found for explanatory variables like health habits, profession, gender, educational level, age or locus of control. Ranking was influenced by what kind of illnesses that may become personally relevant to the respondents. Notably, subjects with higher education and those who were health professionals tended to rank mental disorders higher within the five illness dimensions outlined above. However, the statistically significant bivariate difference did not stand the test of a multivariate analysis, and overall, the explained variance was rather low.

Paper 2: Rosenvinge, JH. Pettersen G. Tjenestetilbudet til pasienter med spiseforstyrrelser: En nasjonal kartlegging i primær- og spesialisthelsetjenesten. *Tidsskrift for Norsk Psykologforening* 2006; 41: 1160-8.

Introduction and research questions

Another, societal perspective on understanding ED can be taken by studying what kind of treatment sufferers from ED receive within the health care system. How adequate are the health services organised, and what are the reasons why adequate steps to improve quality are not taken? These were the research questions for paper 2. The background for this research relates to the nature of ED in the sense that patients may erroneously be mistaken for being only manipulative and treatment resistant, and unwilling and poorly motivated to receive treatment, and that treatment resources may be better spent on patients who are perceived as actively asking for help. Another background for the study was numerous media portrayals as well as a previous national investigation (Rosenvinge & Sundgot-Borgen, 1999) which revealed shortcomings in the treatment services for ED patients. Secondary to this thesis though, national health authorities funded the study as an attempt to reveal secular changes in the service quality as a result of a national task force through some years attempting to improve clinical competence in treating ED.

Subjects and methods

A questionnaire was distributed to all treatment units in the health care system in Norway, as well as to a sample of general practitioners stratified to rep-

resent general practitioners in Norway. The general practitioner sample was generated by a national polling agency. The agency used the list of members of the Norwegian Medical Association, where over 90% of medical doctors are members. Treatment units were taken from the official register of treatment units in the Norwegian Directorate of Health. In addition to qualitative, open-ended questions, the questionnaire comprised measures of patient volume, clinical experience, and professional collaboration. Building on a previous instrument (Schmidt *et al.*, 1995), a measure of competence and knowledge about ED was used (Rosenvinge *et al.*, 2003), consisting of 31 items ranging from 1-10, with 10 as the maximum score. The internal consistency was acceptable (Cronbach's alpha = 0.58).

A text analysis of the open-ended questions generated general themes according to a detailed categorisation system, adopted from previous studies (Garrett, 1997; Reigstad & Holte, 1995; Rorty *et al.*, 1993). Quantitative data were analysed using bivariate and multivariate methods.

Results

Using interdisciplinary teams organisation, and including the referral agent (a general practitioner) was most often reported (27.4% and 27.8%, respectively). A failure to install treatment when necessary was the case for 79.6%

of the general practitioners, but was significantly lower (51.4%) for the treatment units. A low patient volume was the main reason for not installing treatment, indicated by general practitioners (64.6%) as well as for treatment units in the specialist treatment services (40.1%). This is in accordance with previous findings (Rosenvinge & Sundgot-Borgen, 1999).

A logistic regression analysis showed that young female general practitioners with some clinical experience with ED were more likely to initiate steps to improve the treatment of ED. For treatment units, the probability for installing treatment was related to lower clinical experience and competence, in addition to stating a benefit from national clinical guidelines. Such benefit was not related to being a general practitioner, but on the other hand these guidelines were not originally designed to fit the professional needs of general practitioners. Furthermore, the results indicated interesting discrepancies.

First, there was a discrepancy between how general practitioners and clinicians from treatment units evaluated cooperation with respect to treating ED. The former gave a more favourable evaluation than the general practitioners. However, both judged interdisciplinary cooperation as poorer with respect to ED than other patient groups (Table 5, paper 2). Moreover, there was an incongruence as psychiatric units reported a more favourable cooperation with general practitioners compared

with the judgement from internal medicine units (6.53; SD 1.79 versus 5.57; SD 2.68; $p < 0.03$, effect size = 0.50).

Secondly, satisfaction with treatment services was higher in the specialist units than among the general practitioners (effect size = 0.73) (table 6, paper 2). An attempt to conduct "circular questioning" also revealed discrepancies. Hence, treatment units displayed a higher satisfaction level (5.77; SD 1.95) than the general practitioner's impression about how satisfied patients (4.86; SD 1.80) and relatives (4.49; SD 1.64) were with the same services. On the other hand, general practitioners were less satisfied with their treatment of ED patients (4.46; SD 1.65) compared with how satisfied the specialised treatment units believed that patients (5.41; SD 1.63) and relatives (5.11; SD 1.62) were with the general practitioner's clinical efforts.

Finally exploring therapist satisfaction with treatment and treatment services, a multivariate regression procedure explaining 57% of the variance ($p < 0.0001$) entered "impression of high patient (95% C. I. 0.30-0.61) and relative's (95% C. I. 0.01-0.31) satisfaction with their treatment". Also entered were satisfaction with the cooperation with general practitioners (95% C. I. 0.06-0.23), and between mental and somatic specialised health care (95% C. I. 0.01-0.04). Also interesting was a close relation between satisfaction and self-rated clinical experience (95% C. I. 0.10-0.25).

Paper 3: Pettersen G, Rosenvinge JH. Improvement and recovery from eating disorders: A patient perspective. *Eating Disorders* 2002; 10: 61-71.

Introduction and research questions

The purpose of the study was to explore helping agents and the meaning of recovery from a patient perspective. The study was also conducted to accommodate for some shortcomings in the literature. In previous research, the composing and size of samples may cast doubt about whether this was adequate and sufficient to capture the relevant aspects of the recovery experience. Thus, studies with different kinds of samples may be needed to check this possibility. In addition, the relation between symptom load and recovery experiences has been poorly explored. Specifically, the research questions were (1) to describe factors that are identified by sufferers as contributing to their recovery, (2) to describe how sufferers define recovery, and (3) to relate experiences to measures of ED symptoms and how they attributed their own health status.

Subjects and methods

48 women were recruited to the study, partly through patient organisations on ED, partly from a regional ED treatment unit. Subjects were eligible who were at least 18 years of age, who had ED for at least three years, and who had received treatment for their ED. All subjects had an ED diagnosis. Their age ranged from 20-38 years. Subjects were personally contacted and semi-structurally interviewed by the first author for about 1-3 hours. The framing questions

were “which factors have been helpful to you in your recovery process”, and “what is the meaning of recovery to you”. The Appendix II shows the interview guide in more detail. Each interview was audio taped and transcribed for text analysis. From a random selection of 20 uncoded interviews a blind researcher classified main aspects contributing to recovery to check for reliability. Thus, results are reported in terms of condensates transcripts or direct citations when suitable to describe general tendencies. Aspects which applied to very few participants were eliminated. Due to space limitation requirements, the description of the qualitative analyses had to be highly condensated. A more detailed description is therefore provided here, and appears in the outlines of paper 5.

Furthermore, the participants completed the HLSC (Levenson, 1973) described in paper 1, the Eating Disorder Examination-short form (EDE-Q) (Beglin & Fairburn, 1992) as well as the Eating Disturbance Scale (EDS-5) (Rosenvinge *et al.*, 2001). Both the EDE-Q and the EDS-5 had a good internal consistency 0.89 and 0.83, respectively. While the HLSC measures health attributions the EDE-Q measures the frequency of ED symptoms, and the EDS-5 more disturbed eating patterns and attitudes. In this study the EDE-Q was used for screening purposes. Finally they completed a list of predefined recovery items. Here, recovery items were scored 1-7 (maximum

score) and subjects were asked to rate each item according to their importance for their own recovery process. This list was a first version of the list of recovery items outlined in paper 4. The internal consistency was good, *i.e.* 0.75. A comparison of the preliminary list and the list used in paper 4 is provided in the Appendix III as an illustration.

Results

As a response to the first framing question, three aspects were identified as factors that had contributed to recovery. Thus, 58% mentioned factors related to treatment, 17% mentioned factors related to effects of self-help and non-professional care while life events were mentioned by 25%. Responding to the second framing question, 76% reported that accepting one self and one's body, as well as food not dominating life or as a means to resolve problems were important, while 38% mentioned a feeling that life has a purpose, or that one is able to fulfil one's potentials irrespective of other people's expectations. 13% reported that recovery as more a matter of good social functioning whilst 29% and 33% respectively mentioned being less anxious or depressed, and more contact with, and courage to express feelings.

No overall relation was found between scores on the EDS-5, the HLCS and a grouping of the material based on analysis of interview texts. Moreover, contrary to many theorists and empirical studies proposing for instance, low self-directedness (*e.g.* Fassino *et al.*, 2002), subjects scored rather high on the Internal Locus of Control subscale. This indicates that the subjects were experiencing control over their own health status, and recognising or ac-

knowledging their positive contribution and responsibility for keeping a good health.

Also, the interviews helped to identify two groups of subjects, *i.e.* those with a realistic opinion about recovery and with a functional perfectionism, and those presenting with unrealistic views and presenting with undue perfectionism. The succession of recovery items was in accordance with the succession which appeared when investigating clinicians and a community sample (paper 4). A comparison across samples is provided in the Appendix III. Still, it is noteworthy that subjects in this study differed in the sense that aspects like regular menstruation and normal weight were ranged as one of the most important personal criteria for recovery. It is difficult to explain this result. One explanation may be that recovered patients responding to a list of items would score menstruation and weight highest because this is easier to attain than more complex psychological goals. Another explanation may be that this statistically spurious due to a small within-group range of scores.

Paper 4: Pettersen G, Thune-Larsen KB, Rosenvinge JH. Necessary ingredients of the concept of recovery from eating disorders: Comparing clinician and community member perspectives. *Eating Disorders* 2007, submitted.

Introduction and research questions

Multidimensional recovery criteria have been advocated for years, but what kind of aspects should actually be included? Recovery criteria are developed by researchers and clinicians, but may this introduce a bias? To test this possibility, one may study differences between general clinicians and a community sample with respect to the relevance and importance of recovery aspects. Also, explanatory variables may be introduced, and in paper 4, it was investigated whether group differences were influenced by age, own eating disturbances or acquaintance with ED. The final research question was whether group differences were so marginal that a list of consensus based recovery items might be justified.

Subjects and methods

To address these research questions, a survey was conducted comprising all the 152 women who in 2000 voluntarily signed up for an 18 months national programme to raise clinical competence on ED. In addition, 1152 (76.8%) of the 1500 women randomly selected from the general population participated. On average, clinicians reported working with 4-5 ED patients the past year before signing up, and they scored 4.3 (SD 1.92) on a scale ranging from 1-10 of self reported clinical competence with ED. Sixty-two percent worked in the psychiatric services, 25 worked in

primary health care while 13 percent worked in other professional settings. Half of the sample worked with adult patients, 43 percent worked with children and adolescents while seven percent reported working with both. Hence, the group may seem rather representative of ordinary clinicians working in general mental health care. Being a professional health care worker was an exclusion criterion for the community sample.

All participants completed a 17-items questionnaire to measure recovery and outcome (Rosenvinge *et al.*, 2003). Each item was intended to represent a separate domain of recovery (*e.g.* menstruation, weight and general condition, affects, family and social relations, and coping with socio-cultural pressures to be thin). Each item was scored 1-10, where 10 represented maximal agreement to the item content as important to define recovery. Furthermore, to test covariates, the participants completed the Eating Disturbance Scale (EDS-5) (Rosenvinge *et al.*, 2001), described in the outlines of paper 3. They were also given one 10-point scaled question about their own experience or acquaintance with ED.

The questionnaire forms were distributed personally to all clinicians who participated in the educational programme, and they completed the form at the start of the programme. Subjects in the community sample received the

questionnaire form by mail to be completed at home. Multivariate data analyses were used to compare samples.

Results

Based on the mean score a ranking of the recovery items in descending order yielded almost the same succession of items in both samples. Notably, in both samples, weight and menstruation as one of the core diagnostic features according to the DSM-IV criteria (APA, 1994, see Appendix I), were lower ranked than items covering more general psychological aspects, and was statistically related to the community sample (OR = 0.62; 95% C.I. 0.54-0.72). This trend focusing on psychological issues is also observed in the qualitative analyses of patient experiences (paper 5), yet there were some discrepancies in as much as patients also focused on the importance of weight and menstruation (paper 3).

A logistic regression analysis identified seven items indicating sample differences. Two items significantly raised the odds ratio for belonging to the clinician sample, but introducing covariates only stressing “regular menstruation” remained in the equation (OR = 1.42; 95% C.I. 1.17-1.74). The two other items that “survived” were “body attitude” (OR = 0.72; 95% C.I. 0.57-0.89) and “understanding why one got an ED (OR = 0.54; 95% C.I. 0.42-0.79), but as the figures indicate, the probability was related to belonging to the community sample.

A total sample factor analysis to explore this empirical evidence for sample similarities then, a factor analysis yielded a meaningful data organisation in three factors accounting for 52.9%

and 51.7% of the variance in the clinician sample and the community sample, respectively. The best between-sample match, *i.e.* overlapping items with factor loadings .50 or higher was found for factor 1 (“social aspects”) and 3 (“specific symptoms”). Entering all items from these factors using the total material confirmed the two-factor solution. This solution comprised a psychosocial factor (four items) and a symptom related factor, also with four items. The internal consistency was 0.82 and 0.71 respectively and the cumulated explained variance was 61%. The psychosocial factor comprised items covering relations towards parents and family members, as well as friends and functioning at school or work. The factor loadings ranged from 0.85-0.72. Specific symptom factor comprised weight, no dieting and damaging symptoms, regular menstruation as well as a general good condition, all with factor loadings from 0.79-0.63.

Paper 5: Pettersen G, Rosenvinge, JH, Ytterhus B. The "double life" of bulimia: patients' experiences in daily life interactions. *Eating Disorders* 2008, accepted for publication.

Introduction and research questions

One of the enigmas with ED is the dual motivation. Hence, the disorder may be experienced as a benefit, a benefit in disguise or almost as an adverse life event per se. Moreover, such "pros" and "cons" may shift according to maturity, the impact of other life events, treatment or simply phases of illness. Exploring positive and negative aspects of ED are represented in recent advancements in working towards recovery through enhancing motivation to change (Geller & Drab, 1999).

To reach a more complete understanding of recovery it is also important to know more of the dual motivation through analysing how people function in daily life with their ED. What factors is maintaining the disorders and how is it possible for many to maintain the ED for years even in close relationships without other people knowing about their problem? This is an intriguing issue considering the clinical heuristic and empirical findings that people with ED and bulimia nervosa in particular suffer from a poor impulse control, which predict a difficulty in concealing symptoms like overeating and vomiting. Shame is also a well known affect strongly related to ED (Burney & Irwin, 2000; Cook, 1994; 1996; Frank, 1991; Sanfther & Crowther, 1998) and particularly symptoms such as bingeing and vomiting. In many cases patients are so ashamed, feel so bad, and that they do not to recover, that to disclose

some of the shameful symptoms may block their potentials for recovery. Conversely, what are the consequences of symptom unravelling for starting a recovery process? The purpose of paper 5 was to explore these issues in detail.

Subjects and methods

Subjects and methods were similar to what is outlined in paper 3. However, in paper 5 the focus was on everyday interaction, how and why the subjects concealed bulimic symptoms, and on the consequences of symptom unravelling. Because of space limitation requirement a detailed account of the qualitative analysis, procedure provided here also applies to the outlines of paper 3.

The inclusion criteria for participating were that 1) that subjects were at least 18 years old, had had eating disorders (with bulimic symptoms) for minimum three years and that they had received professional help for their eating disorder. Data collection for the study started in 1999 and included subjects living all over Norway. At the time of study all participants were students or in a stable job, 19 (50%) lived with a partner, and nine (24%) had children. On average they had had eating disorders for 11 years (range 4-23 years). The age range was 20-38 years, and all had received considerable amount of treatment for their eating disorder. The subjects formed a sub-sample of 38 from a previous study (Pettersen & Rosenvinge,

2002). Psychometric data from this study showed that using the Eating Disturbance Scale (EDS-5) (Rosenvinge *et al.*, 2001) the mean score was above the cut of score for disturbed eating. Also, the Eating Disorder Examination short form (EDE-Q) (Beglin & Fairburn, 1992) which was used for screening purposes, showed that 71% (N = 38) reported current bingeing and 42% reported current vomiting. Still, the sample was heterogeneous as some subjects reported current or past experiences of recovery, while others were still struggling with their eating disorders. This heterogeneity was intended in order to reduce possible bias introduced by severity, and restricted information coming from recovered subjects only.

Subject recruitment procedure

A request for participants was distributed to all members of a nationwide patient organisation. Members who wanted to take part in the study then contacted the organisation's head office, and those who were interested were requested to contact the first author by telephone. Participants who were recruited from the health care services were contacted through an information letter. Those who chose to participate also contacted their therapist, from whom the first author received the patient's telephone number. The regional committee for medical and psychological research approved the study, and subjects participated based on an informed consent that was given before the interview started. All subjects were paid approximately USD 20 to participate.

The interview

For practical reasons and for the sake of convenience, the semi-interviews took place either in an office or in the participant's home, and they were conducted by the first author. To avoid bias and complex relations the interviewer had not previously been into a clinical setting with the participants. Each interview lasted from 1 to 3 hours. Apart from collecting personal information as well as information about their eating disorder and history of treatment, the interviews addressed how and why subjects concealed bulimic symptoms in daily life interactions, and the consequences of symptom unravelling. The interview guide was the same as in paper 3, and details are provided in the Appendix II. To detect contrast and variation, and as rich information about the daily life interaction as possible, it was feasible to invite the participants to describe a good and a "bad" day.

In a semi structured interview, the written guidelines are not used rigorously and slavishly. On the contrary, the interviewer may follow-up different themes that appear in the dialogue, thus opening for the possibility of spontaneously provided relevant information. When necessary to reach "communicative validity" (Kvale, 1996), to perform "member checks" (Denzin & Lincoln, 2000), and to ensure optimal saturation of meaning to a given phenomenon according to Glaser's criterion (Glaser, 1978), a constant emphasis was put on clarifying, repeating, confirming and diving deeper into the answers that were provided. Most respondents provided a rich material and spoke openly about their experiences. Some subjects, however, provided more restricted materials.

Data analysis procedure

All the interviews were audio taped, and were subsequently transcribed and coded. The codes were then grouped according to the central topics and the research questions. We used a content analysis according to definitions developed by Kvale (1996). This implies that the transcripts were reviewed several times and according to explicit coding instructions with categories and sub-categories. Using Glaser's criterion for a saturated phenomenological expression (Glaser, 1978) repeated analyses by the first author ensured that no new major themes were ignored. Hence, to ensure validity and reliability, the analyses followed a stepwise procedure of organising data, generating categories by identifying patterns and themes, as well as testing categories against the raw data (Marshall & Rossman, 1995). Thus, first, as the basic data set, all statements in each interview were marked off that were relevant to the research questions. This could be words, phrases or longer paragraphs. In the next step these were extracted, condensed and categorized, and thus the individual expressions now appeared at a higher level of abstraction. The third step involved a further ordering of categories.

The second author, who was blind to the original coding and grouping of the text, then performed an independent re-appraisal of themes and categories against the transcripts. The inter-rater reliability according to Cohen's kappa was 0.85. Results are organized in terms of coding groups and citations suitable to describe general tendencies.

Results

A "double life" was a common description of living with bulimia. Text analyses provided the following grouping of categories:

"Good and bad days"

Defining this was solely dependent on the nature of food intake control, and on bad days even harmless events could be negatively interpreted. Only a new day could alter the interpretation of a day as "bad". Hence, a bad day breeds true in its consequences. By contrast, a "good day" may appear somewhat better, but still not entirely good. Eating regularly took a lot of energy and willpower during work or school, and relapses during the unstructured leisure time often occurred. Also, many reported depressive thoughts about the prospect of having to live on strict diets in the future.

The ability to control food intake and desist from bingeing or vomiting at least during school or work argues against a conception of bulimic behaviors as impulsive in nature. Furthermore, this ability may erroneously be taken as a sign of recovery.

Concealing, shame, and self-depreciation

Shame was related to bingeing and vomiting, but also to appearance and to their self-image as human beings as out of control, having a poor willpower, being self-contemptuous and living a chaotic life.

Suffering aside, many of the women did not really associate their suffering to ED, or that they "deserved" treatment. Some related ED to low weight anorexia nervosa and were ashamed of

their own normal weight. Detachment is then not only a sign of poor insight, but also a sign of low self-image.

Concealing strategies as planned behaviors

Not talking about or belittling the severity of chaotic eating patterns and purging behaviours was the most common hiding strategy. In cases of partly disclosure, this avoiding could also involve other people for the reason of being polite or discrete.

Many active steps were taken to create the appropriate contexts when a binge was planned. This could be to disconnect the phone or cancel appointments to avoid feared unexpected home visits, or to offer a partner the opportunity to go out on leisure activities or work. The double life of bulimia may imply that hiding strategies and the planning and designing of contexts could be presented to others as pure understanding and caring, with the opportunity to binge and vomit as the secret pay-off.

Giving false or skewed information could also take the form of setting up a healthy impression. Actively setting in motion hiding strategies may then appear as manipulative, but they also serve the purpose of preserving at least the illusion of dignity. Moreover planned behaviours to preserve dignity may represent a kind of impression management (Goffman, 1967) depicting a general human trait and not only a malicious sign. Hence, it is a common trait wanting to present oneself in the most favourable way and actually taking active measures to accomplish this. This term may then account for the dichotomous way of functioning equally well or better than psychopathological

terms like poor self-control or dysfunctional affect regulation.

Preserving dignity and avoiding stigmatization

Most women feared that revealing the bulimic behaviors would elicit negative sanctions and stigmatization, and then, to more shame, guilt feelings and lower self-esteem. This fear increased as time passed, and as the need to talk to someone increased. Interestingly, the consequences of unraveling were rather positive. Rather, in most cases others were surprised and astonished for not having realized that something was wrong. Moreover, disclosing reduced the playing of interpersonal hiding games to prevent embarrassing situations. Also, besides showing compassion, other people could share their own problems and thus making interpersonal relationships more intimate and open.

The costs of a double life

Hiding and impression management strategies were time consuming and energy demanding, and they only served to increase self-contempt, shame, and the self-experience of being a failure. Being shameful also created a feeling that others could "see" their shame. Hence, in the long run, attempts to mask problems only served to exacerbate them, and leading to more social isolation. Moreover, overevaluating of the importance of keeping a strict diet and the failure to accomplish this, made them ignore or belittle well functioning domains. This created a general experience of life as chaotic, meaningless or at least fragmented.

Although disclosing problems resulted in compassion, new problems came up. Some reported shame and bad con-

science of having given other people a reason to be concerned and worried. To compensate for this, many created an illusion of being “healthy” or “improved” illusion. Thus, declarations about improvement, admitting previous hiding strategies or a will to reveal the “true self” became second-order hiding strategies in order not to evoke more concern. Hence, disclosure may be a necessary, yet not sufficient step towards recovery.

Shame and self-stigmatisation may be a more realistic consequence of bulimia than sanctions from others. The latter could be subject to validating “behavioural experiments” as in cognitive therapy, yet a therapeutic focus on shame seems necessary to promote recovery. Both approaches may then reduce the impact of symptom on the quality of interpersonal relations.

Part III - General discussion

Discussion related to the research questions

This thesis has proposed that understanding of how ED are regarded by oneself and by others interrelate with conceptions of recovery. Moreover, the thesis has proposed the need for a more comprehensive understanding of ED and of recovery, based on a compound of clinician or expert perspective and a patient experience perspective. Separately, each perspective introduces biases in understanding, albeit for different reasons, and with different kinds of impact. Then, to progress in understanding recovery, a third relevant kind of sample were introduced, *i.e.* individuals from the community. Then it is suggested that despite a slight increase in the “bias factor”, there is more to gain in capturing the complexity of recovery by introducing a panel of samples. Results are discussed in the individual papers, but the main findings will be discussed below.

Research question 1: How are ED ranked in prestige compared with somatic and psychiatric illnesses?

The background papers 1 and 2 narrow the understanding of ED in terms of sketching out how ED are regarded within the health professional community, as well as in the society at large. Relating this kind of knowledge to how patients regard themselves may improve the understanding of recovery.

Paper 1 showed that in general, a high rank was given to acute somatic diseases with a known aetiology. The ranking of mental disorders, and ED in particular, were higher than in a study of

ranking made by health professionals (Album, 1991), and surprisingly, a rather favourable ranking for ED was found. This is interesting comparing to the accounts of shame, guilt, and a lack of deference provided by sufferers from ED (Goss & Gilbert, 2002). Also, paper 5 underlines that self-stigmatisation may be highly predominant. This difference between self and others in attitude may shed light upon why sufferers desist from seeking help. Moreover, the consequences of incongruence between self-perception and the attitudes from others may actually affect treatment and treatment organisation. Thus, postponing help-seeking may result in a higher symptom load, making treatment more difficult, and requiring more resources to organise interdisciplinary cooperation. Moreover, the conditions for recovery may be poorer. Still, the differences between self and others with respect to stigmatisation may relate to other people in close interpersonal relations to the patient (paper 5), and not necessarily to people in general. Despite intermediate rankings of importance and status for ED, other studies still show negative attitudes towards ED patients in the population (Crisp *et al.*, 2000; Stewart *et al.*, 2006). Still, our findings raise some questions which merit further studies. In paper 1 personal experience with severe or chronic illness in the family did not improve the ranking. This is consistent with previous studies on ED (*e.g.* Holliday *et al.*, 2005). Yet, findings from paper 5 show that providing personal experience through disclosure of ED symptoms revealed a rather positive attitude towards ED and the sufferer.

Both paper 1 and Album (1999) suggest that a high rank is related to severity, acuteness, clarity and the possibility of marking off a disease from a particular (immoral or health-threatening) lifestyle. Indeed, given the high mortality risk, and the high risk for a poor outcome of ED, it may be less to gain in ranking or status. In part, the same may be the case with respect to clarity. In early phases ED will always border to fluctuating normal variations of eating behaviours and body preoccupation. Also, judging from the current status of knowledge it is hardly likely that one may be able to pin down the exact nature of the assumed multicomponent aetiology. However, the prospect of improving clarity and hence, some increment in status or rank lies in a more exact understanding of the nature of recovery.

Research question 2: How is treatment for ED organised in the health care system?

Paper 2 showed that the organisation of treatment for ED patients is probably better than the (negative) picture portrayed in the media. Still, there were potentials for improvement, for instance with respect to clinical competence and cooperation across professions and administrative levels. Indeed, cooperation was judged better for other patient groups.

Another trend was that professionals in the primary care services wanted more competence in the specialist psychiatric care, while clinicians in the specialist treatment services wanted more special units for ED patients. This may be interpreted as a reluctance to take responsibility for the treatment and distrust in the adequacy and quality of one's own

clinical competence. Another and more positive data interpretation is that they simply reflect a wish for more cooperation across the administrative levels, or a wish for a continuation of the national task force to increase clinical competence on ED. In general however, both paper 1 and 2 indicate that familiarity and recognition are important for perception of ED as serious illnesses that deserve clinical attention.

Moreover, the probability of illness detection and installing therapy or other clinical steps was related to being a female, younger general practitioner. It is highly human to feel an affinity towards what you recognise as familiar. Thus, understanding and treatment may be easier for younger, female clinicians. On the other hand, it may be problematic to make this a gender therapist issue, as many studies (e.g. Hoek, 1991; King, 1986; 1989) show that a poor detection may be gender unrelated. In fact, detection may be difficult for other reasons, as people with ED often disguise their problems as a general mental disorder or somatic complaints (King, 1986; Mond *et al.*, 2007; Ogg *et al.*, 1997). The reason for this may be shame over bulimic symptoms (Hepworth & Paxton, 2007). On the other hand, clinician's detection competence may be a more salient problem than patient characteristics, as poor detection is a problem in other mental conditions than ED, where shame is not so dominant (Costello & Janiszewski, 1990; Lecrubier & Weiller, 1998; Ormel, Koeter & Brink, 1991; Ormel *et al.*, 1990; Tiemens, Ormel & Simon, 1996; Weiller *et al.* 1996).

Research question 3: Which factors do ED sufferers identify as contributing to their recovery?

The patients reported a balanced experience of helping agents. Non-professional help, treatment, support from other interpersonally important individuals, and life events were reported as important factors contributing to recovery (paper 3). This is in accordance with previous findings (Hsu *et al.*, 1992; Noordenbos, 1989). The patient's motivation to recover, *i.e.* their reporting of a wish to change and a personal commitment to do so was also high. Albeit motivational level was not measured directly, this is suggested from the finding that the desire for a better life without ED was the overall aspect associated with recovery. The finding may cast doubt on clinical heuristics that ED patients are manipulatively reluctant to give up their symptoms. What could be more likely, however, is they might fear the hurdles of improvement in daily life functioning, or that they felt that they simply do not deserve to get better. A related finding is the importance of timing to reach an action stage of change (Geller & Drab, 1999). This is indicating the importance of a combination of a patient who has realised the true dangers of ED and is willing to take the costs of revealing, and a genuinely interested clinician. This finding reiterates a general finding in the psychotherapy research literature (Lambert, 2004) of the relational factors as important to make treatment an agent in the recovery process.

The finding showing that treatment was helpful to recover, is in accordance with many previous studies showing a high overall treatment satisfaction in ED (Brink *et al.*, 1988; Clinton *et al.*, 2004;

Halvorsen, 2007; Newton, Robinson & Hartley, 1993; Rosenvinge & Klusmeier, 2000; Swain-Campbell *et al.*, 2001) as well as for most other patient groups (Seligman, 1995). However, paper 3 showed that treatment satisfaction was conditioned by the experience of an empathic therapeutic relationship, which again, points to the importance of timing.

The effects of guided self-help concur with previous findings. Thus, apart from one study (Walsh *et al.*, 2004) the mainstream of studies show that for subgroups of patients with bulimia nervosa and binge eating this is helpful (Carter *et al.*, 2003; Cooper *et al.*, 1996; Dallegrave, 1997; Ghaderi & Scott, 2003; Loeb *et al.*, 2000; Palmer *et al.*, 2002). Such findings are important, as traditional treatment-outcome studies (*e.g.* Keel & Mitchell, 1999) tend to underestimate the impact of non-therapy related factors contributing to recovery and recovery by spontaneous remission (*e.g.* Woods, 2004). The present findings may also raise the status of self-help in general.

The impact of close relationships and life events was mentioned by one of four individuals. This corresponds to Rorty *et al.* (1993) who also reported on the healing ingredients of an empathic and caring relationship, rather irrespective of the other individual was a therapist or not.

Recognising the impact of important healing processes outside the frame of professional treatment points to the need to maintain a social network and support from family members to promote recovery and life satisfaction (Diener, 1984; Diener & Fujita, 1995). There has been a paucity of research on

general life satisfaction in patients with AN. Participants with a good outcome of ED did not differ significantly from healthy women with respect to self-esteem, but all outcome groups reported a substantially lower level of general life satisfaction (Halvorsen, 2007). The positive effects of disclosure of ED symptoms on recovery are outlined in paper 5. To prompt recovery then, it may be the therapist's task to help patients not only to keep a social network, but also to figure out individuals in the network who one may successfully confide in and who may contribute to the self-esteem and life satisfaction.

Moreover, the importance of maintaining a social network to promote recovery may to some extent serve as an argument against inpatient treatment for ED, thus supporting some findings (*e.g.* Gowers *et al.*, 2000) indicating that inpatient treatment may delay improvement and recovery. Other studies however (Rø *et al.*, 2005a, b), lend indirect support to the positive impact of hospitalisation on recovery, yet the issue of efficacy of inpatient hospitalisation remains a controversial one (Vandereycken, 2003). Many factors may influence whether hospitalisation promotes recovery, among how ED are conceived, as well as the nature of organisation of health care services for ED patients, as discussed in papers 1 and 2.

The patient experiences of recovery indicate two rather different groups of patients. The first one is those who just had started the recovery process, and those who considered themselves as almost or fully recovered. The second group displayed more frequently unrealistic perfectionism and high expectations of themselves and of life in gen-

eral. Hence, they had to some extent lost contact with "normal" challenges and expectations. In contrast, the latter group had realised that life without ED does not imply a life without problems and challenges. Also, they had managed to change negative experiences and a grief of having "lost" many years living with ED into positive cognitions. This division resembles the differences in recovery experiences reported by patients with a good versus poor outcome (Federici & Kaplan, 2007, *in press*). The question for future research remains then, why do some manage to change cognition and negative experiences and others do not?

Moreover, in cases where the therapist was part of such a relationship, the therapist's need for a high clinical competence on ED was not mentioned in the interviews as important to establish or maintain a good working alliance. This finding stands somewhat in contrast to mainstream viewpoints emphasising the need for specific competence on ED, in order to provide treatment that contributes to recovery. To some extent, this finding may reflect the needs specific to a particular illness phase or stage in the recovery process. Hence, specific competence may be especially relevant in the acute phase of the illness (in which the subjects from paper 3 were not), while general clinical experience and competence may be more relevant in later phases of the illness, where existential issues may be more prominent. On the other hand, this finding may represent a time effect. The interviews were conducted almost ten years ago, and the treatment the subjects refer to, took place long before that. At that time one has reason to believe that few therapists had specialized competence on ED. Today the situation

is changed. The dissemination of competence through several educational programs, and the increased professional attention and focus on ED would have made it more likely to see a therapist with specialised competence today.

Research question 4: How do sufferers define improvement and recovery from ED? How may such experiences of recovery relate to measures of ED and personal health control?

Accepting one self and one's body, and not using food as a problem solving strategy stand out as important to consider oneself as recovered from ED. This in accordance with Silvera *et al.* (1998), who found that accepting and liking oneself, without having to be "perfect" is a more important aspect of self-esteem in ED-patients than feeling competent and efficient (as the other aspect of self-esteem). Indeed, however, for the subjects in paper 3 self-liking referring to oneself and one's body is more than just a superfluous acceptance. Rather, it touches on more fundamental and positive core beliefs and illness perceptions. Moreover, the findings of self-acceptance and self-liking are examples of psychological aspects associated with the experience of recovery. Such aspects are also found in paper 4. Here, clinicians and a community sample endorsed similar, psychological aspects as important for recovery.

In general, the findings concur with previous studies (Beresin *et al.*, 1989; Federici & Kaplan, 2007 in press; Hsu *et al.*, 1992; Nilsson & Hägglöf, 2006) describing recovery as "turning points" related to motivation or a will to change, social support, detachment from ED as the frame of identity,

treatment impact as well as positive life events.

At the time when the interviews were conducted, most of the subjects had been in a recovery process for a long time. This may explain why many of them did not stress the importance of symptom frequency reduction as particularly important to recovery. This corresponds to the argument related to the failure to stress the importance of clinical competence on ED, as discussed above. Hence, a time effect may occur, pointing to phase specific needs ranging from life saving to a reflection on living. Hence, had the patients been in a life saving situation when they were interviewed, symptom reduction might have been endorsed more frequently, at least if they had been experienced as alien to them, *i.e.* "ego-dystonic".

Moreover, according to previous outcome research (Deter & Herzog, 1994; Eckert *et al.*, 1995; Herpertz-Dahlmann *et al.*, 2001; Råstam, Gillberg & Wentz, 2003) depression and other symptom disorders emerge parallel to a reduction of ED-symptom frequency and a relief of ED symptom load. Similar findings have been reported in recovery studies (*e.g.* Noordenbos, 1989; 1992; 1998). Hence, from a clinical and experiential point of view, a reduction of ED symptom frequency may not necessarily stand out as optimal. In some cases, ED symptoms may represent a buffer against other psychological and existential problems or have a function in daily life, and in affect regulation. Thus new problems may arise if one manages to reduce the frequency of ED symptoms before addressing problems the ED symptoms serve to cover or buffer. Thus, frequency of ED symptoms

seems insufficient, and functional issues should be included in judging the current state of recovery. On the other hand, there is a general consensus that a critically low body weight precludes working with psychological and existential issues. The same may be true for other kinds of ED symptoms. Hence, completely disregarding the frequency aspect of symptoms in treatment and in recovery evaluation seems meaningless. Analysing and categorisation of patient experiences on a more abstract level (paper 5) indicate the importance of symptom load and symptom frequency as an indicator of the level of severity or conversely, the level of recovery. This may be so because symptoms with a high frequency and intensity may result in or exacerbate problems in other areas, like interpersonal relations as well as feelings of shame and guilt. Hence, in judging recovery one should consider the interaction between symptom reduction, and social, interactional, psychological and existential issues. This interaction represents a challenge with respect to the operationalisation and measurement of recovery.

Paper 5 also indicates that improvement with respect to the extent one spend time hiding symptoms and the extent that food and eating govern daily life open for working with psychological and existential issues to reach a new level of recovery. This concurs with previous studies (*e.g.* Federeci & Kaplan, 2007, in press) in reporting patient's experiences of recovery when they explore and manage affect tolerance and negative emotions. In sum, there is less empirical support to a restrictive conception of recovery focusing on the frequency of ED symptoms only. Moreover Paper 3 shows that consistent with a self-representation model

of illness (Leventhal *et al.*, 1980) the coping and meaning related to symptoms are decisive for considering one self as recovered. Hence, even if dieting and food preoccupation may be present, one still would count oneself as recovered provided an experience of coping, meaning, coherence of life, self-esteem, a reasonable body experience and a generally fair life satisfaction, and that symptoms are not used as a problem solving strategy. Thus, symptom frequency as well as symptom impact should be included in a conception of recovery. This is illustrated more comprehensively in the recovery model presented elsewhere in this thesis.

There is a clinical heuristic that patients with ED are reluctant or resistant to giving up their ED-symptoms. In this respect, one could say that they are not able to take responsibility for their own health. At least for patients with some years of suffering, this heuristic may not be true. Indeed, the wish to improve the quality of life was an important issue among the women in the study (paper 3), where subjects had been struggling with ED for on average 11 years. This is consistent with the high scores on the internal locus of control scale, indicating a high level of personal control and responsibility for one's own health.

However, like recovery, this may also be related to phases of illness: High internal locus of control may be "negative" in the beginning of a recovery process in the sense that it may lead to self-blame and taking responsibility for the development of ED. Later in the recovery process, however, internal locus of control may act more positively and constructively towards recovery. In this view, and considering the fact that pa-

tients in the sample had been living with ED for years, a high internal health locus of control could be expected.

Scores on the HLCS were unrelated to the nature of the helping or recovery agent (*i.e.* a therapist, a non-professional, a friend or relative or a positive life event). However, to our knowledge no previous ED-study has used locus of control as a parameter, and hence, the present finding needs replications in patient samples preferably varying in duration of illness. Also, the findings may stand in contrast to previous findings (Fassino *et al.*, 2002) that ED patients display low self-directedness.

The same pattern was found with respect to the EDS-5. Thus, there was no relation between the EDS-5 and the nature of the recovery agent. Also, the findings showed that there is possible to display ED symptoms and still experience recovery. Feeling recovered despite symptom scores may, of course, exemplify the contrary (*e.g.* denial) or a rather static professional conception of recovery, but this is refuted by the patient experiences of recovery as a continuous process. Paper 5 also introduces meaning and interpretation of symptoms as equally important as symptom frequency. This aspect is not included in the EDS-5.

Research question 5: Do clinician's ratings of recovery items differ from a community sample controlling for age, clinical experience, and personal eating problems?

Overall, general clinicians and women randomly selected from the community do judge recovery from ED rather similarly. The importance of psycho-

logical and personal and emotional outcome aspects were rated higher than aspects directly linked to a formal DSM-IV diagnosis. Hence, when the subjects were presented with a multi-component list of items relevant for recovery, and with the option to select weight restoration and regular menstruation as indicators of recovery, they actually selected more general aspects of recovery, like body attitude, insight, life quality and emotional regulation (paper 4). Moreover, modest group differences and impact of covariates indicate that the recovery aspects had a good convergent and ecological validity. This is shown by an almost similar succession of recovery items in both samples. Empirically this is linked then to previous findings (Vanderlinden, Buis, Pieters & Probst, 2007), but also to theoretical frameworks like, for instance subjective well being (Diener, 1984; Diener & Fujita, 1995) or coping, representing areas offering models to explain the relation between symptoms and meaning.

The recovery criteria from paper 3 and 4 are not fully comparable with respect to scoring and content. Still some reformulations to ease comparisons (Appendix III) are justified for illustrative purposes. Then, with a possibly spurious exception (*i.e.* that patients tend to focus on regular menstruation as important for recovery), the overall trend was that universal psychological factors (*i.e.* well-being and quality of life), or general factors (*i.e.* a positive body attitude and an understanding of why ED developed) were more important than resuming a normal weight or the absence of symptoms (*e.g.* vomiting or dieting). This is confirmed in the total sample factor analysis (Paper 4) yielding eight items, a psychological factor and a symptom related factor with four

items, respectively that may constitute a basis for future development and research on understanding and conceptualising recovery from ED.

Research question 6: Which interaction steps are taken to conceal ED symptoms, and what are the consequences of starting a recovery process by symptom unravelling?

A “double life” was described as a dichotomy between being active and outgoing with good functioning, and a high symptom load, shame, and fear of stigmatisation. Concealing was well planned in the purpose of impression management (Goffman, 1967) and a need to preserve dignity. This stands in contrast to a notion of ED patients as exhibiting behaviours more or less out of their self control, and thus, that they are victims of their impulses.

Still, the term ‘double-life’ may have a double meaning. Thus, the designing, concealing and planning may in some respect portray an illusion of activity, and being in an offensive interpersonal position, yet this is also a trap, as the patient more or less becomes a victim of her own planning and activity.

An important finding from paper 5 was that the level of symptoms was a good indicator of the illness severity in the sense that more symptoms, increased shame and guilt and feeling of being a “looser” and a bad person. Still, subjective experience and interpretation of symptoms may override their frequency in determining severity and recovery. This points to the complex relation between symptoms and meaning attached to the symptoms.

Apart from symptom frequency and symptom interpretation, an equally important recovery index may then be “time spent on planning and hiding the ED symptoms” and to create a well functioning facade.

When the mental distance between well functioning social appearances and feelings and behaviours related to shame that need to be concealed becomes too pervasive, much planning and designing of daily life are needed, and this is experienced as time consuming and exhausting. The need to preserve or uphold a certain level of dignity (Goffman, 1978) may also account for such consequences of concealing. In some way shame and dignity are interrelated, and may even occur simultaneously (Skårderud, 2007). The interrelation between shame and dignity needs further research. For instance, it may be the case that in the early phase of the illness, a potential and motivation to start recovery lies in a high level of shame and a low level of dignity, in the sense that ED-symptoms are not “integrated” in the individual’s way of living. In the later phase of the illness, on the other hand, potentials and motivation for recovery may rely on a low level of dignity and a low level of shame, as well as a readiness to explore the reality behind the fear of being stigmatised.

Expected negative sanctions in terms of stigmatisation may lead to self-stigmatisation and negative self-concepts of having poor self-control, self-discipline or violating moral or ethical “standards” related to overeating and bingeing. This again increases hiding strategies and time spent during the day on lies, charades, manipulating information to seal off an increasingly larger

part of one's personal life. When symptoms actually increase in number or frequency, a typical vicious circle is set in motion. Also, fear of stigma is a major barrier to treatment seeking (Hepworth & Paxton, 2007).

The self-stigmatisation effect is also diffusing (Goffman, 1963), where all kinds of actions and feelings will be related to ED, particularly since food and eating are overvalued indices of self-esteem. An intriguing side effect of self-stigmatisation, shame and hiding is that in order to preserve pride or dignity, behaviours in the "frontstage domains of life" may utterly conform in nature. For clinicians, this represents a challenge in judgment of recovery, notably in the risk for false positive cases of recovery.

To summarise, and relate the findings to recovery, there may be several ways to start a recovery process. One example is "less time spent on hiding ED symptoms", leading to the reporting of less interpersonal problems and a stronger experience of recovery. This may be a combination of new cognitions as well as new behaviours. Another example from paper 5 is a more existential one, depicted in the wish to have a better life, and realising that the current way of life is meaningless and chaotic. This may elicit the courage to disclose ED symptoms, thus giving one self the possibility of new experiences in the encounter with others.

Strengths and limitations

An overall limitation of the present thesis is that the studies comprising it, were not planned, designed and conducted according to a "master plan". Rather, it is a result of a professional

development throughout many years. This generates some of the limitations that are discussed below.

The usefulness of a transdiagnostic approach (Fairburn *et al.*, 2003; Fairburn & Bohn, 2005) adopted in this thesis aside, specifying the type of ED in paper 1 would still have been helpful to identify possible differences between ED subgroups with respect to ranking of prestige.

A low response rate was a problem in paper 1, but the failure-to respond rate was still comparable to the mainstream of community surveys. This was also a problem in paper 2, obviously limiting the external validity of the findings.

Moreover, in paper 1 the subgroup of health professionals could have been larger to increase the reliability of within-group comparisons. On the other hand, strength of this study compared to previous research (Album, 1990) was the use of explanatory variables although they did not explain much of the variance. Replicating the study in a repeated measurement design may test secular changes. Using the findings from paper 1 (and partly from paper 2) to state that there is no "objective" parallel to patient's self-stigmatisation may seem a little pretentious. On the other hand, there may be huge problems in asking directly about possible prejudices, unless data can be validated through personal interviews.

Strength of the papers 3 and 5 is that most of the women had received many kinds of treatment (and some of them had in various degrees participated in activities run by the patient organisation as well). Thus, they had a comprehensive experience of treatments and

therapists as background for their opinions about how this related to recovery experiences. The finding that specific competence on ED was judged as marginally important for experiencing a benefit from treatment is interesting. However, it is a limitation of the study that no objective investigation of competence was conducted.

Moreover, in paper 3 a measure of motivation stages (*e.g.* Geller & Drab, 1999) would have represented an asset. However, at the time of investigation no suitable instrument had been developed. On the other hand, measures of perfectionism were available at this time, and could have been useful to include considering the psychology of ED where perfectionism is a prominent feature (Fairburn *et al.*, 2003), and the findings from paper 3 (*i.e.* the grouping of patients into healthy and unhealthy perfectionism). Moreover to complement the collected information about ED, quality of life represents an important dimension. However, there may be several problems using standard quality of life measures (Rie *et al.*, 2007), and only recently (Engel *et al.*, 2006) has a measure adapted to ED been published.

Furthermore, paper 3 represents an interesting combination of interview data and self-report data collected through standardised instrument. To some extent, though, this also represents a compromise with respect to sample size. To reach adequate statistical power and still preserve the quality of interview data, another strategy could have been to increase the sample size and interviewed only a smaller sub-sample. Moreover, the results viewed in retrospect, the adding of a measure of subjective well-being (*i.e.* Diener *et al.*,

1985) would have further improved the study.

Retrospective interviews may cause biases in as much as selective memory, current states or conditions of life may colour the subjective reports (Friedman, 1993). Viewing this as a limitation rests, however on the epistemological assumption of an objective reality, only distorted by human error factors. On the other hand, from a more constructivist viewpoint, the fact that subjective reports are coloured by memory or current conditions adds an important quality to the data collected (Widerberg, 1995). Resting the epistemological issues aside, the thorough and systematic questioning of the qualitative interviews performed may help patients retrieve and interpret their personal history, thus serving to increase rather than decrease the validity. Hence, the remaining possible limitation may be an active, deliberate, repressing of information. In this investigation this stands out as a theoretical limitation, yet the respondent's privilege. Moreover, some findings of changes in patient experiences of cause and onset of ED (Nilsson *et al.*, 2007) indicate that although experiences and interpretations of the past do change over time, the changes are towards more complexity and richness, and not towards dissociation and decay in memory. This may be explained by maturation, and imply that it may actually be advantageous to collect information of past events after some years.

Strength of paper 4 is the large number of subjects assuring an adequate external validity. However, due to the overall limitation mentioned above, no patient sample was included. This would have increased the possibility of com-

paring results from paper 3. However, the participants in paper 3 also completed a rudimentary list of fixed recovery items, which to some extent was comparable to the items completed by participants in paper 4. This is illustrated in the Appendix III. It is noteworthy that in paper 4, the explained variance indicates that the list of recovery items may be far from complete. This may stimulate future research to identify new recovery aspects. With reference to a possible time effect, new studies should direct attention to patients with a shorter duration of illness, and those who are in a more acute phase of the illness.

An empirical model of understanding and recovery

Using a variety of samples and methodological approaches several aspects have been identified as relevant for recovery. Figures 1 and 2 illustrate how these aspects may be grouped in domains, and put together in a comprehensive model. Figure 1 illustrates a state where recovery has not commenced, while figure 2 shows a state where recovery is present. The Appendix IV shows how the model relates to findings in the thesis, and how one in clinical work may approach the various aspects in terms of suggested way of posing questions to the patients.

The model contains psychological, social, existential and interpersonal aspects of recovery as basic functional domains. Psychological and existential issues related to recovery from ED refer to self-esteem, accepting oneself and the body, not to use food to resolve problems or not to let food dominate life, a feeling that life has a purpose, to have contact with emotions and the

courage to express them, and to fulfil own potential and not just to conform to expectations from others. Interpersonal and social issues, on the other hand, include family relations affected or disrupted due to symptom frequency or symptom concealing through impression management, symptoms interfering contact with friends or with school or work. Figure 1 below illustrates the model.

Centred in the model are core ED beliefs about self-concepts due to shame, and self-stigmatisation, frequency of core symptoms, *i.e.* overeating, vomiting, dieting, excessive exercising or laxative abuse, as well as weight status, general condition, and somatic complications. Highly interrelated with behavioural symptoms are cognitive schemas, beliefs and illness perceptions that the ED patient may hold. These schemas, beliefs or thoughts are often very rigid and resistant to the change needed in order to recover.

In contrast to the basic elements, as the dotted arrows serve to indicate, the core symptoms element may in principle disappear, but the model also takes into account that symptoms may still occur at a low frequency or intensity provided a good level of functioning according to the basic four domains.

Referring to the patient experiences (papers 3 and 5) this may be described as some kind of a malicious “carpet” flooding into the four basic domains. This carpet is illustrated by the dotted circle in the model (Figure 1). Hence, all kinds of daily activity and daily functioning may then be affected. In various phases of the illness, the four basic domains of the model may be differently affected according to personal

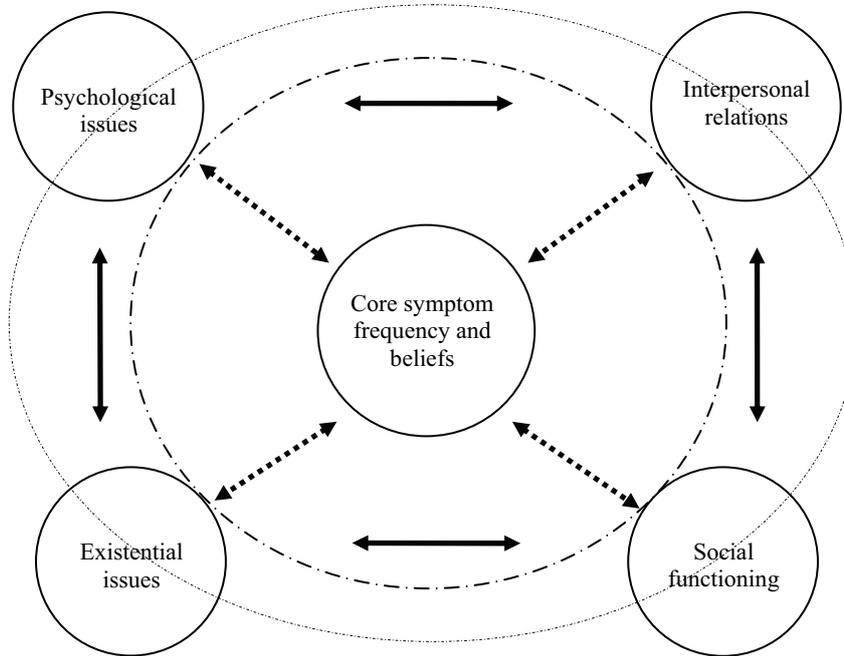


Figure 1: An interaction model showing psychological issues, interpersonal relations, existential issues and social functioning as four basic domains of functioning. The model illustrates a scenario with a poor recovery from ED. Solid arrows indicate stable associations, and dotted arrows indicate weighted associations, dependent on the level of recovery. Dotted circles indicate diffusions of core symptoms and beliefs.

experiences and clinical status. For instance, in the acute phase of ED symptom frequency may exert a strong influence on the basic elements in terms of social functioning, as well as interpretation of personal and interpersonal actions, and existential issues.

To make the carpet becoming less dominating, or even almost disappearing, thus gradually moving on the track towards recovery one needs to reduce frequency of dieting, bingeing and compensatory behaviours, as well as cognitive beliefs as origins of or perpetuating the frequency. It is this dialectic between cognitive beliefs and symptoms that may foster recovery, and

reducing the impact on the basic domains of functioning is breaking up.

A life without an ED still implies the need to confront challenges in the different aspects. However, if the confronting strategy no longer comprises food, eating, shape and weight and believing in the need to control them, general challenges and problems may be more or less detached from the personal history suffering from ED. Such detachment is important for experiencing recovery (Federeci & Kaplan, 2007, in press). Rather, they may be better accounted for as challenges of life. Figure 2 below illustrates a situation of recovery along this way of reasoning.

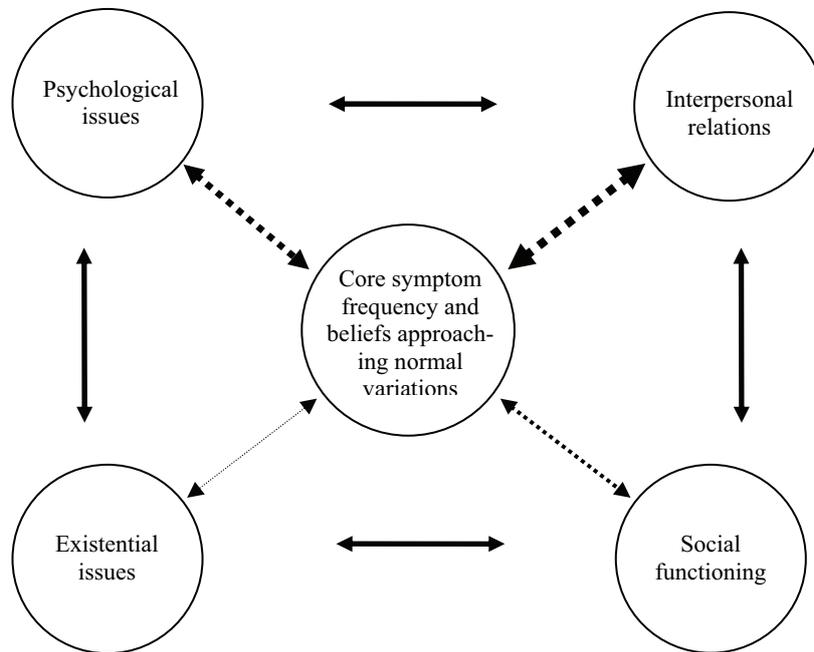


Figure 2: The interaction model of understanding of ED showing the relationship between the elements in a state of recovery. Arrows of different shapes illustrate different level of influence.

Different shapes of the dotted lines intend to illustrate that the impact of the inner circle aspects may be different on each of the four basic domains.

The model (Figures 1 & 2) illustrates recovery from a descriptive point of view. This is a limitation related to the cross-sectional designs of the papers on which the model was constructed. Further development of the model may include process oriented elements, specifying start- and end points. Such points are difficult to identify, yet important to comprise the course of ED from activating a risk factor to full recovery. Integrating elements from risk factor research, and for instance, the Self Regulation Model [SRM] (Leventhal *et al.*, 1980) may represent a progress in this respect. The SRM suggests that

positive or negative illness perceptions impact the probability of starting a recovery process as well as the success or failure to recover. Illness perceptions are centred on cause, consequences, illness identity, timeline, and control/cure. For instance considering the latter, if the patient believes that ED can be cured raises the probability of a rapid recovery.

A limitation of the present model as well as the SRM is that they do not specifically address the impact of medical complications and comorbid psychological conditions like addiction, mood disturbances, self-mutilations or personality disorders commonly observed in ED.

A provisional listing of recovery features

There has been some progress (*e.g.* Couturier & Lock, 2006a, b; Dare *et al.*, 2001; Kordy *et al.*, 2002; Olmsted *et al.*, 2005; Rø *et al.*, 2005a,b), in defining operational criteria for recovery and outcome. However, one is far from reaching some kind of consensus. Using an integration of findings from many kinds of samples and using mixed methodological approaches, the findings from this thesis and the model presented above may result in the provisional account of the following features relevant for defining and evaluating outcome of ED. These features are highly interrelated. The succession of features does not indicate a ranking of importance.

- Less negative perfectionism
- When appropriate, being comfortable with talking to friends or relatives about previous or current ED problems.
- A BMI within a range, which do not creates or maintain serious health problems.
- Concerns about weight and shape is less, or not decisive for self-esteem.
- ED do not longer diffuse into daily life functioning, or block the natural flow of everyday interpersonal and social functioning.
- Bingeing, compensatory behaviours or self-mutilations are absent, or at least infrequently, and do not act as affect modulations or means to resolve real or imagined psychological issues.
- When using assessment schedules containing normative population data, changes should be clinically and not only statistically signifi-

cant. Hence scores should fall within the normal population range.

- Experiencing a life without ED symptoms as attractive or gratifying.
- Coping with new challenges in life which does not include ED symptoms as a strategy.
- Addressing existential issues and engage in future planning, and not confining meaning of life to maintaining unrealistic weight or shape goals, or to hiding ED symptoms.
- No remaining or appearing of clinically significant anxiety or depression.

Implications for clinical work and future research

Papers 1 and 5 have shown that the empirical basis for stigmatisation is poor. Hence, self-stigmatisation is an obvious example of a core belief that should be challenged in order to promote recovery. Consistent with previous findings (Gowers & Shore, 1999) the present thesis (papers 3 and 5) indicate that treatment approaches aiming to reduce shame and self-stigmatisation may be beneficial.

Although most of the subjects (paper 3) had experienced recovery, many of them also experienced some kind of grief over the loss of life quality due to the ED. This serves as another example of an appropriate focus in therapy. Particularly, recovery may be prompted by reconciliation and acceptance, as well as reframing the interpretation and understanding of past events.

Moreover, a rigid way of life with a lot of planning of daily activities in order to hide symptoms, as well as dietary rules may also be confronted. Cognitive

therapy may be well suited particularly in as much as psychoeducative approaches are integrated in this kind of approach. Psychoeducation may be effective in terms of providing an understanding of the relation between food, eating and emotions or emotional regulation and nutritional needs. Interpersonal therapy may be suitable to address how symptoms diffuse into daily life interaction and colouring the relations to other people. Both these kinds of therapies represent evidence based treatments for bulimia nervosa (Fairburn *et al.*, 1995) although their effect slope is rather different.

The model (Figure 1) illustrated four important basic elements of human functioning. Helping people with problems related to these elements obviously require a general clinical competence. The inner circle, on the other hand, relates specifically to ED, and to work with this needs more specialised competence. As the model is interactive, this implies a dialectic relation. Hence, treating ED would require both general and specialist competence. Moreover, the model may indicate the nature of interdisciplinary work, and what kind of professionals that may comprise an interdisciplinary treatment team. Paper 2 has shown that this is rather commonly used. However, considering the dialectic relation between general and specialist competence, an interdisciplinary team may be composed according to stages in the recovery process. For instance while specialist competence may be highly needed in the primary health care services, this may not necessarily be required for patients with a longstanding ED. Thus, judgment or evaluation of recovery may have directly consequences for how treatment services are

organised. Also, the recovery model (Figure 1) may serve as a chart for composing interdisciplinary treatment teams. Thus, the model may serve as a chart for structuring the course of treatment, and how focus in therapy may shift according to the clinical status of the patient and the speed of recovery.

The thesis has pointed out important ingredients of recovery. Future research may, clarify more of how the model domains interact with ED, as well as how they operate through mediating factors. Thus, factors that may slow down or speed up the recovery process may be resilience (Friborg *et al.*, 2003; Werner & Smith, 2001), personality and affect regulation (Fonagy *et al.*, 2002; McCrae & Costa, 1997), illness perceptions and attributions (Leventhal *et al.*, 1980), quality of life experiences (Rie *et al.*, 2007), and subjective well-being (Diener *et al.*, 1985; Diener, 1994; 2006). Recent development within the latter suggests that apart from cognitive aspects subjective well-being also consists of an emotional domain containing positive affects (joy, pride, enthusiasm, etc.) as well as negative affects like shame, guilt, sadness, anger, and anxiety (Diener, 2000; Diener & Lucas, 2000). These are emotions that may be closely linked to recovery and the recovery process. Also, the nature and functionality of coping strategies (*i.e.* emotion focused versus task oriented strategies) may be linked to outcome and recovery (*e.g.* Troop *et al.*, 1994).

Moreover, motivation and self-determination theory (Deci & Ryan, 2002) as well as self efficacy (Bandura, 1977) are constructs related to recovery (Pinto *et al.*, 2006; Vansteenkiste,

Soenens & Wandereycken, 2005). Recently, several instruments have been developed to measure stages of motivation and readiness to change (e.g. Martinez *et al.*, 2007; Rieger *et al.*, 2000; Serpell *et al.*, 2004) that may be used in future research. The thesis has shown that shame and dignity may block motivation to disclosure and to consider change. Another interesting direction for future research then, is to study the stages of the motivation to change (Geller & Drab, 1999), the relationship between the intrinsic and extrinsic motives for change, and the impact of treatment focusing on motivational processes.

Also, representing a prospect for future research is the extending of possible recovery items to encompass cognitive schema distortions related to overvaluation of body shape and weight as well as undue perfectionism (Fairburn *et al.*, 2003; Fairburn & Bohn, 2005) and overvalued ideas of the nature of recovery and the glorious life without an ED. Including these features may then help in understanding why some patients (by way of treatment or not) manage to change dysfunctional cognitions and beliefs, while others do not. Here, one may also control or the impact measures of personality and motivation to change.

Finally, recovery processes may be related to comorbidity issues and recent developments in the classification of various forms of ED. For instance, the relation between self-stigmatisation and depression should be explored, and recovery processes may be related to class analyses of the ED spectrum (Clinton *et al.*, 2004; Williamson *et al.*, 2005; Wonderlich *et al.*, 2007). This implies that recovery and recovery

processes may not necessarily be specific to the ED diagnoses, *i.e.* that recovery processes follow different tracks according to content and progress.

A final note on the listing of features relevant for recovery deserves to be mentioned. This concerns how this may be used in research and clinical work. Future research is needed to decide whether the list should be further developed as a scale, or whether each of the features (minus the one referring to clinical significant changes) could be used as a starting point for more global clinical judgements.

Conclusions

This thesis shows a fairly positive picture of ED with respect to attitudes among health care professionals, the community as well as of how treatment is organised. This is incongruent with the patient's expectations, fear of stigmatisation, and a negative view on ED, indicating the self-stigmatisation as an essential issue or belief. This belief may be modified in treatment.

From a patient perspective, treatment was highly valued as contributing to recovery. However, the impact of self-help (paper 3) points to the need for a closer cooperation between therapists and non-professionals agents, like patient organisations. Life events and important relations were essential to recovery in addition with the patient's own resources, efforts and motivation to disclose.

There is a considerable consensus across patients, professionals, and lay people about a multidimensional conception of understanding and recovery, and about the aspects that are relevant.

A list of relevant recovery aspects is suggested in the thesis.

Integrating the qualitative and quantitative empirical findings, a model is developed for understanding and recovery. Yet it may also be helpful as a guide to compose interdisciplinary teams, as well as in planning treatment focus as the process of recovery may proceed.

Albeit some limitations with respect to comorbidity analyses, the model may generate future research into how recovery processes interact with stages of motivation, coping, well-being, resilience, and personality in the prospect of future entangling the enigmas of ED.

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Appendix I

Diagnostic criteria for anorexia nervosa and bulimia nervosa according to DSM-IV (American Psychiatric Association, 1994) and for a proposed transdiagnostic category "eating disorders" (Fairburn et al., 2003; Fairburn & Bohn, 2005):

Anorexia nervosa

- A. Refusal to maintain body weight at or above a minimally normal weight for age and height, *i.e.* weight loss leading to maintenance of body weight less than 85%.
- B. Intense fear of gaining weight or becoming fat, even though underweight.
- C. Disturbance in the way 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, *i.e.* the absence of at least three consecutive menstrual cycles.

Bulimia nervosa

- A. Recurrent episodes of binge eating characterized by both (1) eating, in a discrete period of time (*e.g.* within any 2-hour period) an amount of food that is definitively larger than most people would eat during a similar period of time and under similar circumstances, and (2) a sense of lack of control over eating during the episode.
- 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 behaviors 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.

The transdiagnostic category "Eating disorders"

- Restrictive eating.
- Overeating.
- Vomiting and the abuse of laxantia or physical activity.
- Compulsive, and "automatic" checking of one's own or others body composition or physical appearance.
- Overevaluation of the importance of controlling food, weight and body shape.

Appendix II

Interview guide used in the data collection in papers 3 and 5.

- Demographic information.
- Can you describe a good and a bad day as it appears to you?
- How long time did it take before you realised that you had an eating problem?
- What were your motives or reasons for seeking professional help?
- Imagine that eating disorders follow a certain course towards recovery: How would you place yourself in this course?
- Have you experienced recovery? In what way and in which domains of life?
- Who has contributed most in your recovery process?
- According to your personal experiences, how would you define “recovery”?
- Have you to some degree revealed your eating problems to someone close to you? If so, what responses did you get?
- If you have mostly been hiding your eating problems to people close to you, how have you managed to do this in everyday interactions?
- Why did you choose to hide your eating problems?

Appendix III

Comparisons of recovery items across three samples (paper 3 and 4) when arranged in descending order of reported importance scoring (1-7 and 1-10, respectively).

ED patients (N = 48)	Normal population (N = 1152)	Clinicians (N = 152)
Regular menstruation	Body and self-acceptance	Confident about feelings
Quality of life	Understand why ED developed	Quality of life
Recognize feelings eliciting symptoms	Confident about feelings	Body and self-acceptance
Resume previous activities or initiate new ones	Recognize feelings eliciting symptoms	Recognize feelings eliciting symptoms
Understand why ED developed	Social activities	Functioning at school/job
No negative perfectionism	Quality of life	Social activities
Normal weight	Social network	Social network
Contact with feelings	No symptoms in case of stress	Understand why ED developed
Body and self-acceptance	General condition	No symptoms in case of stress
No dieting	No dieting	General condition
No symptoms in case of stress	Recognise pressure to diet	Better family life
-	No negative perfectionism	Recognise pressure to diet
-	Better family life	Regular menstruation
-	Functioning at school/job	No dieting
-	Normal weight	No negative perfectionism
-	Regular menstruation	Normal weight

Appendix IV

Developmental steps of the interactive model of recovery with suggestions of possible questioning.

Model elements	Data and source (papers 3-5)	Suggested questions
Psychological	Challenging the belief in stigmatisation ⁵	Do you fear criticism if you disclose ED symptoms?
	Accepting oneself and one's body ³	How satisfied are you with your body, appearance and with yourself in general?
	Recognise feelings ^{3,4}	In general, are you able to identify your feelings?
	Understand why one got an ED ^{3,4}	Do you know the reasons why you developed an ED?
Interpersonal	Positive life events involving close relations ³	Have you experienced positive life events in your close relations?
	Interpersonal improvement as a result of disclosure ⁵	Have your personal relations improved after you disclosed your ED?
	Improved family relations * ⁴	Have your family relations improved after you disclosed your ED?
Existential	Life has a purpose ³	Do you experience your life as having a purpose?
	Experiencing meaning in life ³	To what extent do you experience life as meaningful?
	A wish for a better life ³	Have you given consideration to the wish for a better life without ED?
Social issues	Functioning at school or work * ⁴	Are you frequently unable to go to school or work due to ED?
	Social network * ⁴	Do you have close friends?
Core symptom frequency and beliefs	Low frequency of damaging symptoms (dieting, vomiting or bingeing, or laxative abuse) * ⁴	How often during the past 4 weeks have you been restricting food intake, bingeing, vomiting or abused laxatives?
	Good general condition * ^{3,4}	What is your current weight?
	Time not spent on symptoms in daily life functioning, and symptoms not diffusing into other domains of life ^{3,5}	How much during the day are you preoccupied with ED symptoms and by strategies to conceal them?

* items appearing in the final factor analysis solution in paper 4.

Paper 1

Rosenvinge JH, Pettersen G, Olstad R. The ranking of diseases: a general population survey of status attributed to somatic and mental illnesses. *European Journal of Psychiatry* 2007; submitted.

The ranking of diseases: a general population survey of status attributed to somatic and mental illnesses

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ABSTRACT - *Background and objectives:* Previous studies show a huge difference in how medical doctors and other health professionals rank various diseases according to importance. Such differences have been ascribed to whether a disease is somatic or psychiatric in nature, whether the aetiology is known or unclear, whether treatment is definitively curative or not, and whether the course of illness is acute or more long-standing. The purpose of the present work is to study illness ranking in the general population, and what may explain the rankings.

Methods The sample consisted of 1127 adults randomly selected from the Norwegian National Population Register, who completed a questionnaire.

Results Somatic diseases were given the highest rank, but mental disorders were ranked higher than in previous studies. Modest effects were found for explaining variables.

Conclusions The results indicate that general population rankings do not differ greatly from rankings made by professionals.

Introduction

Previous studies (1-3) show a huge difference in how medical doctors and

other groups of health professionals classify or rank various diseases, as well as medical specialities as more or less prestigious. Such rankings seem to be

informal in nature, and may reflect social norms, expectations related to the patient and professional roles as well as subjective concepts of illness. On the one hand, it may be reasonable to expect that some diseases should be ranked higher in priority according to objective needs for instant treatment. On the other hand, rankings may violate ideals of equal opportunity to treatment, professional attention and care. Informal rankings by medical doctors and other health professionals may thus create unwanted differences in the quality of clinical work, in the attention given to the particular patients as well as in the priority given to research on the aetiology and treatment of certain diseases. To counteract unwanted differences related to treatment and research, it is important to know more about how diseases are ranked in different subgroups of the population and what kind of explaining factors that can be identified. Such knowledge may be important for the general population, health professionals as well as for health policy audiences.

A ranking of diseases has been ascribed to whether a disease is somatic or psychiatric in nature, whether the aetiology is known or unclear, whether treatment is definitively curative or not, and whether the course of illness is acute or more long-standing (1). Moreover, Album (1) found that acute medical diseases affecting a distinct, vital organ like the heart or brain were ranked higher than long-standing mental disorders that mainly affect women. Similarly, in this study (1) diseases were ranked lower if the aetiology was attributed to the patient's "immoral" or unhealthy way of life (e.g. addictive disorders and lung cancer), and where the symptoms (e.g. certain skin dis-

eases) might make the patients appear ugly or disgusting to the professional.

However, to our knowledge, possible explanatory factors for a ranking of diseases have not been put to systematic empirical testing. Moreover, no previous studies have investigated illness rankings in the general population and whether rankings correspond to those found within professional subpopulations. Previous studies among health professionals indicate that norms resulting in a ranking of diseases according to perceived ranking reflect a professional culture that focuses on instrumentality and the instrumental professional role as an ideal (1). For this reason, diseases that require a lot of advanced technical equipment for their treatment may be viewed as more "important" than, for instance, mental disorders where psychotherapy is required. An alternative explanation is that such professional norm systems merely reflect general norms and attitudes towards illnesses and diseases in the society. Then, it is important to include a general population sample to establish reference findings.

Alternatively, the ranking of disorders might be attributed to more personal or individual factors. Given that such factors are evenly distributed among people one may expect that rankings are only marginally related to whether a sample consists of people from the general population sample or health professionals. For instance, norms or ideals for a professional role may be overridden by personal acquaintance or experience with a particular disorder or by the perceived risk of oneself being affected by a gender or age related disease. If such personal factors play a part, one may then predict

that a disease that does not require high-technology treatment, that may be chronic, or with unclear aetiology will be highly ranked as prestigious and worthy of attention. Ranking may also be influenced by factors related to personality. If so, lower ranking related to disorders being attributed to an “immoral” or a self-inflicted unhealthy way of life may be explained by an experience of being in control over one’s own health. It may be the case that disorders attributed as self-inflicted may be ranked lower in importance by people with a high sense of personal control compared with people with a more external health locus of control. One may expect that people, who tend to believe that their own health depends on random factors that they cannot influence, will rank higher those disorders that are perceived as striking anyone.

The purpose of the present study is then to analyse how somatic, mental, psychosomatic, and addictive disorders are ranked in the general population according to importance, and to study a set of explanatory variables. In particular, it is expected that the ranking of disorders depend on age, gender, being a health professional or not, health habits, and perceived health locus of control.

Methods

Design, subjects and procedure

Using a cross-sectional design, a questionnaire was distributed to 1000 males and 1000 females from 18 years and above in the Northern part of Norway. The sample was randomly se-

lected from the national population register. A professional polling agency (“Norsk Gallup”) was responsible for the sample selection and the distribution and collection of the questionnaires. To increase response rate all subjects took part in a lottery for five rewards of USD 100 each. In total, 1127 individuals returned the questionnaire. No gender difference in response rate was found (men 57 %, N = 572, women 55 %, N = 550). In the active sample 38 percent had a higher education (college or university degree), 40 percent had completed high school, while 22 percent had a lower level of education. Moreover, 22 percent reported being health professionals while the remaining (78 %) had other professions. The mean age was 44.2 years (SD 11.0, range 19-87). Men were somewhat older (45.4 years, SD 11.2) than females (42.9, SD 10.6) ($t(1097) = 3.94, p < 0.001$).

Instrument

Twenty disorders (Table 1) were selected in order to cover the dimensions “somatic/psychosomatic/addictive/mental”, “male/female dominated”, “acute/chronic course”, “known/unknown aetiology”, and treatment as being “highly effective/unclear or unknown”. To reduce response bias and response sets, the diseases were listed in a random order according to these dimensions. Another step to reduce response bias was to use the questionnaire format to separate attitudes related to the disorders from the ranking. In one part of the questionnaire then, one negative, and two positively formulated questions measured rank based on economical priorities, and not on attitudes (i.e. “if you had become the minister of health, select three disorders from the above list as your first, second, and

third priority for spending a) more money on treatment services, and b) less money on”, and “if 100 mill USD were given to clinical research, select three disorders as your first, second, and third priority”). In another part of the questionnaire, 16 statements measured specific attitudes towards health and disorders. Each statement was scaled 1 (maximal agreement) to 10 (maximal disagreement), and covered issues like agreement to whether prestige is related to the dimensions acute/chronic, clear/unclear aetiology, effective/uncertain cure, and whether the aetiology is attributed to patient’s life style, gender or social status.

Furthermore, in order to explain rankings, respondents provided information about their age, gender, educational background, health habits (i.e. regular smoking and physical activity), and whether they had a personal experience with family members with severe acute or chronic disorder. To study whether a ranking of disorders depends on whether individuals perceive an internal, external or random control over their own health, the “Health Locus of Control” scale (4) was used. In the present study Chronbach’s α for internal consistency showed acceptable values, i.e. 0.65 (external locus of control), 0.73 (internal locus of control), and 0.65 (random locus of control), respectively.

Ranking of disorders

In the first step, the first, second, and third priority were summed up for each of the three ranking variables (i.e. “would give more money to treatment services”, “would spend less money on” and “would give more money to fund research”) for each of the 20 disorders. In the second step, a sum score was

computed by adding the score for “would give more money to” and “would give more money for funding research”, and subtracting the score for “would spend less money on”. Based on this sum score, each disease was given a total rank. In addition, they were classified as psychiatric (i.e. depression, eating disorders, anxiety disorders, and schizophrenia), psychosomatic (asthma, ulcer, and fibromyalgia) or addictive disorders (alcoholism and drug addiction). All other diseases were considered as somatic in nature. A sum score was computed for each of these four categories.

Statistical analyses

The ranks of the 20 selected disorders were analysed separately for men and women, for three different age groups (<29 years, 30-59 years, 60 + years), for smokers versus non-smokers, for health professionals versus non-health professionals and finally for those with and without a personal experience of serious illness in their close family. Factors, which influenced the ranking of diseases in the bivariate analyses, were used in stepwise linear regression analyses.

Results

Table 1 shows the ranking of diseases for the total material. Here, typical acute and life threatening diseases (i.e. breast cancer, aids, cardiac infarction, brain tumor, and brain stroke) were ranked highest, while diseases like sciatica, ulcer, alcoholism, appendicitis, and ankle fracture were ranked lowest. Interestingly, mental disorders were ranked rather high, with anxiety –and

Table I

Diseases listed according to sum scores and ranks for subgroups, using the ranking in the total material for reference. A sum score was computed by adding the score for "would give more money to treatment services" and "would give more money for funding research", and subtracting the score for "would spend less money on". A negative value indicates that more individuals voted for saving money than those giving priority to the disease.

Diseases	Sum scores and ranks											
	Total N = 1127		Men N = 572		Women N = 550		Health workers N = 220		Others N = 880		Severe illness experience N = 318	
1. Breast cancer	729	1	314	2	416	1	120	1	595	1	207	1
2. Aids	572	2	290	4	284	2	106	2	445	2	147	4
3. Cardiac infarction	533	3	333	1	191	6	67	7	443	3	168	2
4. Brain tumour	511	4	269	5	243	4	105	3	410	4	156	3
5. Brain stroke	466	5	220	6	247	3	102	4	356	6	133	5
6. Lung cancer	456	6	299	3	148	10	57	10	380	5	132	6
7. Anxiety disorder	346	7	164	9	166	8	65	8	285	7	93	8
8. Mood disorder	310	8	175	7	167	7	88	5	252	8	110	7
9. Ovarian cancer	282	9	95	10	204	5	64	9	232	9	90	9
10. Fibromyalgia	230	10	83	11	143	11	34	13	189	10	58	12
11. Testicular cancer	228	11	167	8	62	13	72	6	133	12	28	13
12. Eating disorder	206	12	46	13	160	9	38	11	187	11	70	10
13. Asthma	138	13	48	12	83	12	22	14	116	13	66	11
14. Schizophrenia	59	14	-1	14	61	14	38	11	19	14	22	14
15. Drug addiction	-125	15	-84	17	-29	15	-2	15	-117	15	-52	17
16. Sciatica	-173	16	-52	15	-115	17	-41	17	-120	16	-38	15
17. Ulcer	-179	17	-82	16	-108	16	-52	18	-134	17	-46	16
18. Alcoholism	-295	18	-158	19	-136	18	-26	16	-268	18	-96	18
19. Appendicitis	-352	19	-149	18	-205	19	-79	19	-269	19	-112	19
20. Ankle fracture	-130	20	-268	20	-330	20	-120	20	-468	20	-183	20

mood disorders being ranked higher than somatic disorders like ovarian cancer and testicular cancer.

Ranking within the various subgroups of the total sample showed a tendency towards a high ranking of diseases that potentially might be or become somewhat personally relevant. Thus, women tended to rank ovarian cancer and eating disorders higher than men, while men ranked lung cancer and testicular cancer higher than women. Also, smokers gave higher priority to lung cancer compared to non-smokers, and while breast cancer was given top

rankings among those between 18-59 years as well as in other subgroups (Table 1), participants over 60 years gave this disease a much lower ranking. Moreover, aids, was given a substantial lower ranking among participants over 60 years. What mostly differentiated health professionals in the sample was that this subgroup ranked lung cancer and cardiac infarction substantially lower.

Table I
Continued

Diseases	Sum scores and ranks											
	No severe illness experience		Smokers		Non-smokers		18-29 years		30-59 years		60+ years	
	N = 809		N = 393		N = 734		N=103		N= 936		N= 61	
1. Breast cancer	523	1	244	2	486	1	40	1	599	1	13	8
2. Aids	428	2	257	1	318	4	21	5	455	2	-1	17
3. Cardiac infarction	358	4	204	4	322	3	20	7	434	4	33	1
4. Brain tumour	364	3	192	5	328	2	15	11	439	3	5	15
5. Brain stroke	333	5	162	6	306	5	26	2	404	5	18	3
6. Lung cancer	315	6	206	3	241	7	21	6	367	6	30	2
7. Anxiety disorder	240	7	100	7	223	8	19	9	293	7	15	5
8. Mood disorder	231	8	91	9	264	6	19	8	292	8	9	12
9. Ovarian cancer	209	9	93	8	206	9	22	4	240	9	17	4
10. Fibromyalgia	172	11	76	12	153	11	23	3	188	10	10	10
11. Testicular cancer	178	10	76	11	154	10	15	12	172	12	14	6
12. Eating disorder	159	12	67	10	139	12	19	10	182	11	9	13
13. Asthma	75	13	30	13	111	13	8	13	122	13	13	9
14. Schizophrenia	38	14	18	14	42	14	-4	16	56	14	14	7
15. Drug addiction	-63	15	-32	15	-83	15	1	14	-102	15	2	16
16. Sciatica	-130	17	-78	17	-88	16	-2	15	-135	16	-2	18
17. Ulcer	-144	18	-76	16	-114	17	-9	17	-156	17	9	14
18. Alcoholism	-117	16	-96	18	-200	18	-17	18	-241	18	-10	20
19. Appendicitis	-243	19	-123	19	-233	19	-31	19	-299	19	10	10
20. Ankle fracture	-416	20	-242	20	-357	20	-56	20	-520	20	-3	19

Impact of explaining variables on the ranking of "somatic", "psychosomatic", "psychiatric", and addictive disorders

Using bivariate statistical analyses, substantial differences were found. Women gave higher priority to psychiatric disorders (4.00 SD 1.52) than men (3.67 SD 1.58) and this difference was statistically significant ($F(1) = 13.18, p < 0.0001$). The opposite was the case with respect to giving priority to somatic disorders. Here, men scored higher than women (5.66 SD 2.09 versus 5.10 SD 2.13, $F(1) = 20.61, p < 0.0001$). No gender differences in priority were found, however, on the group-

ing variables "psychosomatic disorders", and "addictive disorders".

Furthermore, the higher educational level, the higher priority was given to psychiatric disorders (3.62 SD 1.26, 3.74 SD 1.54, and 4.28 SD 1.62 for low, medium and high level, respectively, ($F(2) = 36.10, p < 0.0001$)). Again, the opposite pattern was found with respect to the priority of somatic disorders (6.09 SD 1.79, 5.51 SD 2.10, and 4.80 SD 2.20 for low, medium and high level, respectively ($F(2) = 31.89, p < 0.0001$)). No gender differences were found in giving priority to psychosomatic and addictive disorders within the various educational level groups.

Table II

Means and SD for 16 fixed statements about illness rankings for the total material and by subgroups. 1 = maximal agreement, 10 = maximal disagreement.

	Total N = 1127 M (SD)	Men N = 572 M (SD)	Women N = 550 M (SD)	Health workers N = 220 M (SD)	Others N = 880 M (SD)
Illnesses caused by a poor way of life are less prestigious.....	3.42 (2.56)	3.44 (2.61)	3.38 (2.45)	3.45 (2.58)	3.40 (2.51)
Illnesses that can be cured are less prestigious than chronic illnesses.....	5.68 (3.02)	5.57 (2.98)	5.78 (3.03)	6.46 (3.12)	5.47 (2.95)***
Using technological equipment in treatment is highly prestigious.....	4.30 (2.92)	4.44 (2.89)	4.13 (2.90)	4.23 (3.19)	4.30 (2.82)
Illnesses that a subject to much research gives them high prestige.....	3.94 (2.93)	4.02 (2.91)	3.83 (2.91)	4.05 (3.08)	3.88 (2.86)
The patient's social status impact how illnesses are given priority.....	4.74 (3.13)	4.72 (3.13)	4.74 (3.10)	4.83 (3.08)	4.68 (3.11)
"Female" illnesses rank lower in prestige than "male" illnesses.....	4.78 (3.23)	5.55 (3.12)	3.94 (3.10)***	4.51 (3.26)	4.81 (3.20)
Rare diseases rank low in prestige.....	5.58 (2.88)	5.61 (2.93)	5.52 (2.81)	6.01 (2.81)	5.43 (2.87)**
Sports related illnesses and injuries rank low in prestige.....	6.89 (2.73)	6.81 (2.78)	6.95 (2.68)	7.11 (2.64)	6.82 (2.74)
The prestige of illnesses depends on whether the cause is clearly defined ..	4.76 (2.47)	4.73 (2.45)	4.76 (2.46)	4.94 (2.72)	4.69 (2.37)
Somatic diseases have a higher status than mental illnesses.....	3.18 (2.66)	3.33 (2.65)	3.00 (2.62)*	3.13 (2.78)	3.16 (2.58)
Cardiac infarction is the most important disease in the health services	4.19 (2.57)	4.29 (2.54)	4.07 (2.57)	4.20 (2.70)	4.20 (2.51)
Eating disorders have a high status	6.60 (2.51)	6.48 (2.48)	6.71 (2.53)	6.95 (2.46)	6.50 (2.49)**
Easily cured mental illnesses have a higher status than those that are difficult to treat.....	4.26 (2.49)	4.26 (2.47)	4.24 (2.48)	4.11 (2.69)	4.26 (2.40)
Lung cancer has a high status even if the cause is smoking.....	4.42 (2.72)	4.40 (2.72)	4.43 (2.70)	5.00 (2.91)	4.25 (2.61)***
Fibromyalgia has a high status	7.18 (2.62)	6.73 (2.53)	7.63 (2.62)***	7.55 (2.65)	7.09 (2.57)**
Diseases among elderly have a higher status than those affecting younger.....	7.75 (2.49)	7.68 (2.46)	7.81 (2.51)	7.86 (2.53)	7.71 (2.48)

Note. * = p < 0.04; ** = p < 0.01; *** = p > 0.000 compared with total.

Table II
Continued

	Severe illness experience N = 318 M (SD)	Others N = 809 M (SD)	Smokers N = 393 M (SD)	Others N = 734 M (SD)
Illnesses caused by a poor way of life are less prestigious.....	3.54 (2.64)	3.25 (2.47)	3.65 (2.66)	3.30 (2.55)*
Illnesses that can be cured are less prestigious than chronic illnesses.....	5.54 (3.09)	5.73 (2.98)	5.79 (3.02)	5.62 (3.01)
Using technological equipment in treatment is highly prestigious.....	4.25 (2.97)	4.28 (2.90)	4.26 (2.87)	4.32 (2.94)
Illnesses that a subject to much research gives them high prestige.....	3.73 (2.86)	4.04 (3.05)	3.98 (2.98)	3.92 (2.90)
The patient's social status impact how illnesses are given priority.....	4.71 (3.08)	4.86 (3.18)	4.88 (3.29)	4.67 (3.04)
"Female" illnesses rank lower in prestige than "male" illnesses.....	4.61 (3.23)	4.81 (3.22)	4.79 (3.23)	4.77 (3.23)
Rare diseases rank low in prestige.....	5.55 (2.82)	6.94 (2.70)	5.76 (2.94)	6.48 (2.85)
Sports related illnesses and injuries rank low in prestige.....	6.70 (2.82)	6.94 (2.70)	6.97 (2.81)	6.90 (2.69)
The prestige of illnesses depends on whether the cause is clearly defined.....	4.59 (2.51)	4.79 (2.44)	4.67 (2.51)	4.80 (2.55)
Somatic diseases have a higher status than mental illnesses.....	3.00 (2.57)	3.24 (2.69)	3.04 (2.82)	3.25 (2.74)
Cardiac infarction is the most important disease in the health services.....	4.13 (2.59)	4.22 (2.63)	4.41 (2.66)	4.07 (2.51)*
Eating disorders have a high status.....	6.49 (2.42)	6.51 (2.49)	6.58 (2.52)	6.61 (2.51)
Easily cured mental illnesses have a higher status than those that are difficult to treat.....	3.97 (2.36)	4.36 (2.54)*	4.44 (2.66)	4.16 (2.39)
Lung cancer has a high status even if the cause is smoking.....	4.21 (2.71)	4.33 (2.62)	4.50 (2.86)	4.37 (2.65)
Fibromyalgia has a high status.....	7.04 (2.74)	7.13 (2.55)	7.18 (2.68)	7.18 (2.58)
Diseases among elderly have a higher status than those affecting younger.....	7.63 (2.55)	7.65 (2.49)	7.65 (2.67)	7.80 (2.39)

Note. * p < 0.04; ** p < 0.01; *** p > 0.000 compared with total.

Table III
 Stepwise regression coefficients for the 16 statements about illnesses using age, external, internal and random health locus of control as the independent variables

	Gender male = 1 female = 2	Age	External	Internal	Random	Adj. R ²
Illnesses caused by a poor way of life are less prestigious.....	-	-	-	0.12***	-	0.01
Illnesses that can be cured are less prestigious than chronic illnesses.	-	-	-	-	0.10x	0.01
Using technological equipment in treatment is highly prestigious.....	-	-	0.08**	0.07*	-	0.01
Illnesses that a subject to much research gives them high prestige.....	-	-	0.11***	-	-	0.01
The patient's social status impact how illnesses are given priority.....	-	-	-	-	0.07++	0.01
"Female" illnesses rank lower in prestige than "male" illnesses.....	0.23***	-	-	-	-	0.05
Rare diseases rank low in prestige.....	-	-	0.07+	-	0.08*	0.01
Sports related illnesses and injuries rank low in prestige.....	-	-	0.11x	-	0.11***	0.04
The prestige of illnesses depends on whether the cause is clearly defined.....	-	-	0.09**	0.06+	0.11***	0.03
Somatic diseases have a higher status than mental illnesses.....	-	-	-	0.06+	0.06+	0.01
Cardiac infarction is the most important disease in the health services.....	-0.06+	-0.13***	0.10**	0.11***	-	0.04
Eating disorders have a high status.....	-	-	0.10+++	0.12***	0.10**	0.04
Easily treated mental illnesses have a higher status than those that are difficult to treat.....	-	-	-	0.08**	0.07*	0.01
Lung cancer has a high status even if the cause is smoking.....	-	-	0.09+++	0.06++	-	0.01
Fibromyalgia has a high status.....	0.15***	0.08**	0.12***	0.07+++	0.09+++	0.07
Diseases among elderly have a higher status than those affecting younger.....	-	-0.12***	0.12***	0.07*	0.13***	0.06

Note. - Excluded from the final model, *** = p < 0.0001 ** = p < 0.01; * = p < 0.02; + = p < 0.04; ++ = p < 0.03; +++ p < 0.002; x p < 0.001.

Moreover, health professionals gave higher priority to psychiatric disorders than those with other professional backgrounds (4.20 SD 1.63 versus 3.76 SD 1.52, $F(1) = 13.96$, $p < 0.0001$). Also, health professionals ranked addictive disorder higher than non-health professionals (2.87 SD 1.16 versus 2.56 SD 1.10, $F(1) = 13.67$, $p < 0.0001$).

No differences were found for giving priority to psychosomatic disorders, while non-health professionals ranked somatic diseases higher than health professionals (5.49 SD 2.09 versus 4.89 SD 2.18, $F(1) = 14.54$, $p < 0.0001$).

Among health habits, smokers and non-smokers did not give different priorities to the disease groups, while those who were physically active on a regular basis tended to give higher priority to psychiatric disorders than those who were not physically active (4.04 SD 1.62 versus 3.69 SD 1.50, $F(1) = 14.05$, $p < 0.000$). However, no statistically significant differences were found with respect to somatic, psychosomatic, and addictive disorders. No differences were found among age groups or between those with and without a personal experience of serious illness in the family.

However, bivariate analyses may be deceptive in the sense that they do not permit control for the impact of several variables at the same time. Hence, the grouping variable "somatic disorders", "psychiatric disorders", "psychosomatic disorders", and "addictive disorders" were used as dependent variables in separate stepwise regression analyses. In general, low beta values throughout indicated poor predictive power for age, gender, educational level, being a health professional or not, health habits, and perceived health locus of control.

Moreover, the regression models explained a rather low proportion of the variances, ranging from 0.02- 0.07 (adjusted R^2).

Impact of explaining variables on fixed attitudinal statements about illnesses

Table 2 show the impact of explaining variables on the fixed statements about illnesses. In the total material, the highest agreement score (i.e. the value closest to 1) was obtained on the statement that diseases caused by a poor way of living are perceived as less prestigious. The highest disagreement score was found on the statement that geriatric diseases have a higher status than diseases affecting younger age groups. These findings were reiterated for all subgroups except for smokers, who mostly agreed to the statement that somatic diseases rank higher in status than mental disorders. In general, few gender differences were found. However, where male respondents took a neutral stance, females tended to agree significantly more to the statement that "female" disorders rank lower in prestige than "male" diseases, and to disagree to the statement that fibromyalgia has a high status. These gender differences are also shown in the regression analyses (table 3). Moreover, the regression analyses showed a low and inconsistent impact of the health locus of control variables. Also, the impact of age was minimal, except that older respondents tended to state that cardiac infarction is the most important disease in the health care services. Nevertheless, the regression models again explained a rather low proportion of the variances, ranging from 0.01- 0.07 (adjusted R^2).

Discussion

The purpose of the present paper was to study how somatic, mental, psychosomatic, and addictive disorders are ranked in the general population, and to study the impact of the explanatory variables age, gender, educational level, being a health professional or not, health habits, and perceived health locus of control.

The main finding from this study was that in general, high rank was given to acute diseases with a known etiology and where high-technology treatment is expected to be effective. Another finding was that mental disorders were given a high rank. The ranking of mental disorders was higher than in a study among health professionals (1) conducted more than ten years ago. Although not directly comparable, this difference may possibly be attributed to a change towards more openness and less negativism and prejudice towards mental disorders in the society. On the other hand, this kind of open mind towards a higher understanding of the importance of giving priority to mental disorders were mostly attributed to having a higher education, and being a woman, and hence, a somewhat restricted population segment.

It is noteworthy that few and modest effects were found for explanatory variables like health habits, profession, gender, educational level, age or locus of control. This was contrary to our expectations, and the results rather, indicated that ranking is made based on what kind of illnesses that may become personally relevant to the respondents. This was, however, not a universal trend. For instance, apart from the oldest respondents, AIDS was ranked very

high despite the fact that this disease is not expected to be especially personally relevant in this general population sample. A finding to note was also that male respondents tended to agree more to statements that diseases affecting women are underrated in importance. This may point to important gender differences in opinions about illness priorities.

The present study was comparable to a previous one among medical doctors (1) in the sense that although not using the same list of diseases, the same dimensions were used, i.e. acute-chronic, somatic-mental-psychosomatic-addictive, male/female dominated, known/unknown aetiology, and treatment as being "highly effective/unclear or unknown". Thus, apart from some rather positive differences, the present study indicates that rankings in the general population do not differ much from those made within health professions. Thus, priorities made in the health care system seem to reflect a universal consensus, and in fact, rather reasonable opinions that acute illnesses should be given priority where immediate as well as effective treatment can be given. Hence, no indirect support was found for the possibility that priorities made in the health care system reflect unwanted professional cultures in terms of prejudices towards an unwillingness to treat particular diseases. Such consensus is important given the fact that with limited resources in the health care system, priorities must always be made, and decisions have to be taken as to what kind of illnesses that should be treated. On the other hand, some general prejudices may be detected in the sense that irrespective of subgroups, the respondents tended to support the idea that illnesses attributed to a poor or negative life style

are less prestigious. This kind of opinion was also, though moderately, linked to an internal health locus of control, i.e. an idea of being personally responsible to one's own health. However, this raises the issue of self-infliction, and general opinions about what kind of diseases that are caused by immoral or harmful lifestyles and what kind of diseases which are not. Balanced against this is the finding that only health workers tended to be less favourable to the general notion that lung cancer caused by smoking is important. Also, when asked to rank individual diseases by their personal priorities life style dependent diseases like AIDS and cardiac infarctions still are ranked high not only in the total material, but also in most subgroups.

Although acceptable, the response rate still represents a limitation to this study. Thus, the moderate inflation of the external validity of the findings highlights the need for replications. Another limitation is that the group of respondents with a health professional background was small, and could not be differentiated according to various health professions. Then, it was impossible to test within-group differences with respect to ranking and explanatory factors. Finally, the cross sectional design was obviously unsuited to test secular changes. Again, this calls for a replication to test the hypothesis generated from this study that there may be a trend towards more favourable attitudes of mental disorders.

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Paper 2

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Tjenestetilbudet til pasienter med spiseforstyrrelser – en nasjonal kartlegging i primær- og spesialisthelsetjenesten

ABSTRACT

The present study reports on the results of a nationwide survey in the primary and secondary health care system targeting cooperation, satisfaction, the usefulness of clinical guidelines, and other steps to improve treatment quality. 212 heads in the psychiatric and somatic specialist health care, and 294 GP's responded to questions about treatment organisation, number of treated patients with eating disorders, and whether steps to improve treatment quality had been taken. Clinical guidelines had been useful mainly in the psychiatric specialist care, and predicted establishing interdisciplinary inpatient treatment teams. Steps to improve quality of treatment between GP's were related to being a female, somewhat younger, and having clinical experience in treating eating disorders. Few patients with eating disorders was the main reason for not having considered steps to improve the treatment quality. Interdisciplinary cooperation was judged more positively by the psychiatric specialist health care than by the GP's. Between the GP's as well as within the specialist health care interdisciplinary cooperation in treating patients with eating disorders was judged poorer compared with patients in general. Being content with one's treatment services was related to good cooperation with colleagues, good clinical competence as well as believing that patients, and relatives also were content with treatment. A low response rate tempers the external validity of the results.

Key words: eating disorders, health care services, treatment organisation, clinical guidelines, quality of care.

Spiseforstyrrelser omfatter diagnosene anorexia nervosa og bulimia nervosa, med undergrupper basert på subkliniske og atypiske varianter av disse diagnosene. Spiseforstyrrelser kjennetegnes av symptomer som selvpåført vekttap, overspising, oppkast eller andre vektkontrollstrategier. Mange

Forfatterne har utført undersøkelsen på oppdrag fra Sosial- og helsedirektoratet, Avdeling for psykisk helse. Den foreligger som rapport til direktoratet per april 2005, og publiseres med oppdragsgiverens tillatelse.

pasienter med spiseforstyrrelser har problemer med adekvat affektregulering, mellommenneskelige relasjoner og sosial fungering. I mange tilfeller ser man komorbide psykiske lidelser som angst, depresjon og personlighetsforstyrrelser (Braun, Sunday & Halmi, 1994; O'Brien & Vincent, 2003; Rosenvinge, Martinussen & Østensen, 2000; Skårderud, Rosenvinge & Göttestam, 2004). Etiologien er ukjent, men regnes for å være multifaktoriell knyttet til

biologi, psykologi og kultur (Skårderud et al., 2004). Sykdomsforløpet kan variere fra noen måneder til flere år, og om lag 20-25% har et dårlig sykdomsforløp (Keel & Mitchell, 1997; Strober, Freeman & Morrell, 1997).

Prevalensen av spiseforstyrrelser i den generelle befolkningen er lavere enn ved mange andre psykiske lidelser. Både prevalens og insidens er relativt stabil (Fombonne, 1995; 1996) og er mest konsentrert til unge kvinner. Et

nøkternt estimat tilsier at om lag 50 000 norske kvinner fra 15-45 år har en behandlingstrengende spiseforstyrrelse (Rosenvinge & Götestam, 2002). Sammenliknet med andre psykiske lidelser kan somatiske komplikasjoner være omfattende og bidra til en høy standardisert mortalitetsrate (Nielsen, 2001; Sullivan, 1995).

Mange med spiseforstyrrelser utsetter eller kommer ikke til behandling. Dette kan skyldes skam og skyldfølelse knyttet til overspising og oppkast. Andre har svak erkjennelse av sykdom og greier ikke å fastholde en opplevelse av subjektiv lidelse og dermed et konsistent opplevd behandlingsbehov. Utsettelse eller uteblivelse fra behandling bidrar til en betydelig differanse mellom prevalens i befolkningen og antall pasienter i helsevesenet. Differansen reduseres ved større grad av åpenhet omkring spiseforstyrrelser, økt bevissthet i befolkningen om rett til helsehjelp, noe som nå også er lovfestet, samt tiltak for å øke kvaliteten i tjenestetilbudet.

Særtrekk ved spiseforstyrrelser som skissert ovenfor representerer utfordringer for den enkelte helsearbeider i å gi hver pasient med en alvorlig spiseforstyrrelse kompetent og evidensbasert behandling. Helsevesenet stilles imidlertid også overfor organisatoriske utfordringer. Behandlingen må som regel omfatte sosiale, psykologiske og somatiske aspekter. Dette krever tverrfaglig samarbeid og et samarbeid mellom psykisk helsevern og somatisk medisin. Mange pasienter med spiseforstyrrelser debutterer i ungdomstiden, men

kan være behandlingstrengende langt ut i voksenalderen. Dette innebærer ofte behov for samarbeid mellom barnemedisin/psykisk helsevern for barn og ungdom og spesialisthelsetjenesten for voksne. I mange sykehusavdelinger kan det gå lang tid mellom hver pasient med spiseforstyrrelser man ser. Når en pasient først er henvist, kan den kliniske tilstanden imidlertid være både akutt og alvorlig. En god løsning er gjerne å ha etablert "systemkompetanse", i betydningen formaliserte, og gjerne skriftlige utrednings- og behandlingsprosedyrer. Imidlertid er det i en presset klinisk hverdag, og med få pasienter med spiseforstyrrelser, lett å nedprioritere etableringen av slike prosedyrer. Med lite pasientvolum er det heller ikke lett å opparbeide og vedlikeholde individuelle kliniske ferdigheter, og man kommer fort inn i en negativ kompetanseutvikling.

Helsemyndighetene har i flere år satt søkelys på kvaliteten av tjenestetilbudet til pasienter med spiseforstyrrelser. Gjennom Opptappingsplanen for psykisk helse har Regjeringen utgitt en særskilt strategiplan mot spiseforstyrrelser (Sosial- og helsedepartementet, 2000), og Statens helsetilsyn har gitt ut retningslinjer for behandling i spesialisthelsetjenesten (Statens helsetilsyn, 2000) som er mer omfattende enn de som ble laget i 1992 (Statens helsetilsyn, 1992). Hensikten med disse retningslinjene er å presentere konsensusbasert og evidensbasert behandling, mens strategiplanen peker på hvordan tjenestetilbudet bør organiseres.

I tilslutning til en markert oppmerksomhet omkring tjenestetilbudet til pasienter med spiseforstyrrelser, kartla man i 1997 på landsbasis hvilke tiltak som var gjennomført i spesialisthelsetjenesten, eventuelt hvorfor man ikke hadde gjennomført slike tiltak (Rosenvinge & Sundgot-Borgen, 1999). Resultatene viste at helsemyndighetenes daværende kliniske retningslinjer (Statens helsetilsyn, 1992) var lite allment kjent og brukt, med unntak av i psykisk helsevern for barn og ungdom. Det viste seg at jo flere pasienter man så, jo mer økte sannsynligheten for om tiltak var realisert. Det mest vanlige var individorienterte tiltak, der en bestemt behandler var "øremerket" til å ta seg av pasientgruppen. Systemorienterte og personuavhengige rutiner og tiltak som eksempelvis behandlingsteam, var sjeldnere angitt.

Svakheter i denne kartleggingen var at man undersøkte få forklaringsvariabler og kun henvendte seg til spesialisthelsetjenesten. De som gjør bruk av tjenestetilbudet i spesialisthelsetjenesten var ikke representert slik at man kunne ha kontrollert resultatenes validitet og reliabilitet. En svært høy svarprosent gav imidlertid grunnlag for å anta at resultatene var representative for spesialisthelsetjenesten.

Siden 1997 er helsevesenet betydelig omstrukturert. Staten har overtatt eieransvaret for spesialisthelsetjenesten, og styrer denne gjennom fem regionale helseforetak (RHF). Staten har gitt RHF-ene både pålegg og stimuleringsiltak for å øke kvaliteten på organisering og innhold i tjenestetil-

budet til pasienter med spiseforstyrrelser. I den forbindelse ønsket sentrale helsemyndigheter å kartlegge tjenestetilbudet til pasientgruppen på nytt for å undersøke om pålegg og stimuleringstiltak har blitt fulgt opp av de enkelte RHF-ene.

Negative erfaringer i møtet med helsevesenet kan dominere mediebildet, mens gode erfaringer sjelden gis den samme oppmerksomhet. I media og i annen offentlig debatt hevdes det derfor ofte at tjenestetilbudet til pasienter med spiseforstyrrelser er dårlig eller mangelfullt. En nasjonal kartlegging kan bidra til en mer nyansert debatt og danne et faktagrunnlag for en mer målrettet innsats for forbedringer. Dette gjelder de pågående revisjoner av henholdsvis Regjeringens strategiplan og de nasjonale retningslinjer for behandling av spiseforstyrrelser, samt mer konkrete forbedringer i helseforetak og avdelinger.

Hensikten med denne artikkelen er å presentere resultatene fra denne nye, nasjonale kartleggingen av tjenestetilbudet til pasienter med spiseforstyrrelser. Ved siden av å beskrive behandlingsformer, herunder tvunget psykisk helsevern, antall pasienter samt klinisk erfaring og kompetanse, blir følgende problemstillinger belyst:

- 1) I hvilken grad er Helsetilsynets nyeste retningslinjer for behandling av spiseforstyrrelser kjent og anvendt i den kliniske hverdagen?
- 2) Hvilke tiltak er realisert i helsevesenet, og hvilke begrunnelser gis for eventuelt ikke å realisere tiltak?
- 3) Hva predikerer om tiltak er realisert?

- 4) Hvordan vurderes samarbeidsforholdene knyttet til behandling av pasientgruppen sammenliknet med behandling av pasienter generelt?
- 5) Hvor tilfreds er man med eget behandlingstilbud, og hvor tilfreds har man inntrykk av at pasienter, pårørende og samarbeidsinstanser er?
- 6) Hva forklarer variansen i grad av tilfredshet med eget behandlingstilbud? Der det er mulig, blir resultater sammenliknet med data fra kartleggingen i 1997.

Metode

På oppdrag fra Sosial- og helsedirektoratet distribuerte Statistisk sentralbyrå i 2004 et spørreskjema til fastleger og faglige ledere i spesialisthelsetjenesten. Skjemaet inneholdt spørsmål om pasientgrunnlag, klinisk erfaring, om tjenestetilbudet til pasienter med spiseforstyrrelser, samarbeidsforhold, kompetanse- og behandlingstiltak. Skjemaet inneholdt også et standardisert mål på klinisk kompetanse ved spiseforstyrrelser (Rosenvinge, Skårderud & Thune-Larsen, 2003). Det var også anledning til å gi skriftlige kommentarer. Skjemaet ble sendt til alle 588

faglige ledere ved landets poliklinikker/enheter i psykisk helsevern for barn og ungdom, poliklinikker og sykehusavdelinger i psykisk helsevern for voksne, samt barneavdelinger og medisinske avdelinger. Fra det totale antall fastleger (N = 3713) ble det trukket et representativt utvalg på 1003 med hensyn til kjønn, alder og fylke. Faglige ledere og fastleger fikk spørreskjemaet tilsendt personlig til sitt arbeidssted.

I alt 306 faglige ledere besvarte ikke skjemaet. Ytterligere 21 fikk ikke skjemaet på grunn av feil adresse, og 49 returnerte skjemaer helt eller delvis ubesvart. Det endelige materialet av faglige ledere var således 212, noe som gir en svarprosent på 36,1 (N = 588). Totalt 661 fastleger besvarte ikke skjemaet. Nitten fastleger mottok aldri skjemaet på grunn av feil adresse, og 29 returnerte skjemaet ubesvart eller mangelfullt. Totalt omfattet det endelige materialet 294 fastleger. Dette gir en svarprosent på 29,3% (N = 1003). Alle fem regionale helseforetak (RHF) var representert. Fordelingen av svar fra spesialisthelsetjenesten på de ulike typer avdelinger (Tabell 1) viser at poliklinikker i psykisk helsevern for voksne var best represen-

Tabell 1. Antall og prosentandel av besvarte skjemaer fra poliklinikk og avdeling i psykisk helsevern for barn, ungdom og voksne, barneavdeling og medisinsk avdeling med sammenlikningstall fra tilsvarende kartlegging i 1997 (Rosenvinge & Sundgot-Borgen, 1999).

	Kartlegging 1997 (N = 269)		Kartlegging 2004 (N = 212)	
	Antall	%	Antall	%
Poliklinikk/avdeling i psykisk helsevern for barn og unge	68	26,1	50	23,6
Poliklinikk i psykisk helsevern for voksne	76	27,6	86	40,6
Avdeling i psykisk helsevern for voksne	36	12,3	42	19,8
Barneavdeling	23	8,8	3	1,4
Medisinsk avdeling	63	24,1	23	10,8
Ubesvart	3	1,1	8	3,8

tert, og i større grad enn ved kartleggingen i 1997.

Databearbeidelse

For å kondensere overordnede temaer ble skriftlige kommentarer analysert med bruk av kvalitativ metodikk. Kvantitative data ble analysert med univariate og multivariate metoder ved bruk av statistikkpakken SPSS, versjon 12,0. Effekttørrelse i forhold til statistisk signifikante ($p < 0,05$) gruppeforskjeller ble estimert ved bruk av Hedge's g , der verdier fra 0,0-0,5 konvensjonelt betegnes som en liten effekt, 0,6-0,8 som en moderat effekt og verdier større enn 0,8 som en betydelig effekt.

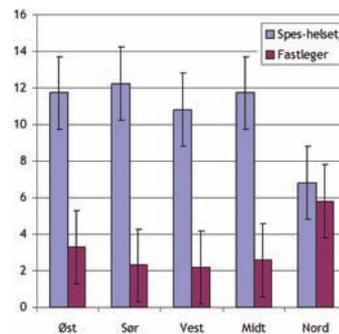
Resultater

Av 191 respondenter oppgav 79,6% individualterapi som den vanligste behandlingsformen. Individualterapi var vanligst både i spesialisthelsetjenesten for voksne og for barn. Totalt rapporterte 7,3% ($N = 191$) familieterapi som hovedfokus i behandlingen, og alle som oppgav dette var respondenter fra spesialisthelsetjenesten for barn. Kognitiv terapi var den vanligste type behandling (51,1%, $N = 180$). Det var ingen systematiske forskjeller mellom spesialisthelsetjenesten for barn og voksne med hensyn til hvorvidt kognitiv terapi, miljøterapi eller psykodynamisk behandling var hovedfokus.

Figur 1 fremstiller gjennomsnitt og spredning i antall behandlede pasienter fordelt på forvaltningsområde og regionale helseforetak. Antall pasienter som i 2003 fikk en spiseforstyrrelse som hoveddiagnose var høyere i spesialisthelsetjenesten (11,03, $SD 25,69$)

enn blant fastlegene (2,95, $SD 4,56$) ($t(452) = -8,01$, $p < 0,0001$), men effekttørrelsen var moderat ($g = 0,47$). Mens det for fastleger var ingen signifikante regionale forskjeller i antall pasienter ($F(4) = 0,65$, n.s.), var det signifikante forskjeller i spesialisthelsetjenesten ($F(4) = 3,20$, $p > 0,01$). Det var ingen statistisk interaksjon mellom "gruppe" (fastlege versus spesialisthelsetjeneste) og "helseforetak" i forhold til antall pasienter ($F(4) = 1,74$, n.s.). Nord-Norge skiller seg ut fra de øvrige regionene i totalt færre pasienter hos fastleger og i spesialisthelsetjenesten, og liten forskjell i antall pasienter i begge disse forvaltningsområdene (Figur 1). Bivariate forskjellsberegninger viser statistisk signifikant høyere antall pasienter i spesialisthelsetjenesten enn hos fastlegene i helseregionene Øst, Sør, Vest og Midt ($p > 0,001-0,01$; $g 0,67-1,37$) til forskjell fra i helseregion Nord (n.s., $g = 0,11$).

Det var ingen forskjeller i antall behandlede pasienter i somatisk spesialisthelsetjeneste (10,30, $SD 26,33$) og i spesialisthelsetjenesten i psykisk helsevern (11,25, $SD 13,89$, $t(175) = 0,26$, n.s., $g = 0,04$). 33 avdelinger (15,6%, $N = 212$) jevnt ($\chi^2(4) = 8,29$, n.s.) fordelt over helseregionene oppgav at de i 2003 hadde tatt i bruk tvunget psykisk helsevern (tvangsinnleggelse), mens sju avdelinger (3,3%, $N = 212$) oppgav at de hadde iverksatt tvangsbehandling. Sondeforing ut fra nødrett ble angitt av åtte avdelinger (3,8%, $N = 212$). På en tidelt skala med 10 som kategorien "svært tilfreds" med gjeldende lovverk for tvangsbehandling



Figur 1. Gjennomsnittlig antall pasienter i 2003 med spiseforstyrrelse som hoveddiagnose blant fastleger og i spesialisthelsetjenesten fordelt etter regionale helseforetak. Spredning (SD) er angitt for hver søyle.

av pasienter med spiseforstyrrelser var spredningen 1-10. Gjennomsnitt og standardavvik på hhv. 5,24 og 1,99 viser verken høy tilfredshet eller utilfredshet med den aktuelle rettstilstanden.

Kompetansedeltagelse og kompetansenivå

Færre fastleger (31,9 %, $N = 294$) enn fagfolk i spesialisthelsetjenesten (70,3, $N = 212$) angav at de noen gang hadde deltatt i kompetansetiltak om spiseforstyrrelser i form av kurs, konferanser eller undervisning ($\chi^2(1) = 80,40$, $p < 0,0001$, Cramer's $V = 0,41$, $p < 0,0001$). På en tidelt skala for subjektivt vurdert klinisk erfaring der 10 angav "betydelig klinisk erfaring", var gjennomsnittet for hele materialet 4,23 ($SD 2,09$). Fastlegene angav en mindre grad av klinisk erfaring enn ledere i spesialisthelsetjenesten (3,53, $SD 1,68$ versus 5,22, $SD 0,64$, $t(484) = -9,51$, $p < 0,0001$, $g = 1,26$). Ved bruk av et mer objektivt mål på kompetanse (Rosenvinge, Skårderud & Thune-Larsen, 2003), med 10 som optimal skåre, var gjen-

Tabell 2. Nyttan av helsemyndighetenes retningslinjer for behandling av spiseforstyrrelser. Resultatene sammenliknes med funn fra tilsvarende kartlegging i 1997 (Rosenvinge & Sundgot-Borgen, 1999).

	1997		2004		2004	
	Spesialisthelsetjeneste (N = 261)		Spesialisthelsetjeneste (N = 212)		Fastleger (N = 283)	
	Antall	%	Antall	%	Antall	%
Nytte av Helsetilsynets retningslinjer for behandling						
Ja	77	29,5	90	42,5	37	12,6
Nei	31	11,9	23	10,8	57	19,4
Usikker	81	31,0	59	27,8	66	22,4
Kjenner ikke til retningslinjene	53	20,3	24	11,4	126	42,9
Ubesvart	19	7,3	16	7,5	8	2,7

nomnsnittet for hele materialet 5,78 (*SD* 0,71). Fastlegene hadde klart lavere kompetanse (5,58, *SD* 0,64) enn i spesialisthelsetjenesten (6,08, *SD* 0,69, $t(452) = -7,85$, $p < 0,0001$, $g = 0,76$). Det var ingen regionale forskjeller i kompetanseskårer verken for fastleger ($F(4) = 1,15$, n.s.) eller i spesialisthelsetjenesten ($F(4) = 1,19$, n.s.). Det samme var tilfelle for grad av klinisk

erfaring (hhv. $F(4) = 1,39$, n.s. og $F(4) = 1,23$, n.s.)).

Råd og kommentarer fra respondentene

I alt 29 av fastlegene (12%, $N = 294$) benyttet muligheten til å gi råd og kommentarer. Kondenserte temaer dreide seg om "å bedre behandlingstilbudet i spesialisthelsetjenesten" (kortere ventetid, bedre henvisningsrutiner og kompe-

tanse), samt "å bedre faglig samarbeid mellom forvaltningsnivåene".

Kondenserte temaer fra 53 av 212 faglige ledere i spesialisthelsetjenesten (25%) omfattet det "å etablere regionale kompetansesentre", "å bedre samarbeid på alle forvaltningsområder" og "tiltak for å bedre klinisk kompetanse" (retningslinjer for tvangsbehandling, veiledning, videreutdanning, behandlingsmodeller).

Nyttan av helsetilsynets retningslinjer for behandling

Tabell 2 viser at flest (42,5%, $N = 212$) av de faglige lederne i spesialisthelsetjenesten oppgav at retningslinjene hadde vært til hjelp i behandlingen. Blant fastlegene var det flest (42,9%, $N = 294$) som ikke kjente til at de eksisterte ($\chi^2(3)$

Tabell 3. Behandlingstiltak for pasienter med spiseforstyrrelser som er realisert, grunner til at tiltak ikke er realisert samt hva fastleger tror er realisert i spesialisthelsetjenesten. Totalprosent avviker fra 100 fordi enkelte gav flere svar.

Type tiltak	1997		2004		2004		2004	
	Spesialisthelsetjeneste*		Spesialisthelsetjeneste		Fastleger		Fastleger tror iverksatt i spesialisthelsetjeneste	
	Antall	%	Antall	%	Antall	%	Antall	%
Bestemt behandler tar seg av pasienter med spiseforstyrrelser	88	33,7	48	22,6	-	-	37	12,6
Spesifikk samarbeidsrelasjon mellom avdelinger	71	27,2	30	14,2	-	-	19	6,5
Henvissende lege informeres om behandling og deltar i ettervern	71	27,2	59	27,8	31	10,5	11	3,7
Fast, tverrfaglig team i avdelingen	25	9,6	58	27,4	-	-	37	12,6
Fastleger i opptaksområdet tilbys klinisk veiledning	11	4,2	13	6,1	29	9,9	9	3,1
Ettervern koordinert med tiltak i regi av pasientorganisasjoner	9	3,4	3	1,4	7	2,4	3	1,0
Prosedyrebok i utredning/behandling	-	-	40	18,9	15	5,1	2	0,7
Rutinemessig oppfølging av pårørende	-	-	56	26,4	15	5,1	6	2,0
Bruk av tester/vurderingsinstrumenter	-	-	39	18,4	5	1,7	5	1,7
Brukererfaringer integrert i behandling	-	-	29	13,7	12	4,1	4	1,4
Grunner til at tiltak ikke var planlagt/realisert								
Ser få pasienter med spiseforstyrrelser	74	28,4	85	40,1	190	64,6	-	-
Mangler tilstrekkelig kompetanse	27	10,3	33	15,6	115	39,1	-	-
Mangler økonomiske ressurser	26	10,0	36	17,0	32	10,9	-	-
Spørsmålet er irrelevant ut fra avdelingens faglige profil	12	4,6	17	8,0	12	4,1	-	-
Diagnoser er uviktige	5	1,9	7	3,3	1	0,3	-	-

* Rosenvinge & Sundgot-Borgen, 1999

Tabell 4. Forhold som er knyttet til sannsynligheten for realisering av kompetansetiltak

Prediktorer	Fastleger			Spesialisthelsetjenesten			Totalt		
	B	OR	95% C.I	B	OR	95% C.I	B	OR	95% C.I
Klinisk erfaring ¹⁾	0,48	1,62	(1,32-1,99)	-0,25	0,78	(0,63-0,95)	-0,35	0,71	(0,61-0,81)
Alder	0,05	0,95	(0,91-0,99)	-	-		-	-	
Kjønn (1=mann, 2=kvinne)	0,86	2,36	(1,19-4,69)	-	-		-	-	
Nytte av retningslinjer ¹⁾	-	-		0,67	1,96	(1,31-2,93)	0,42	1,51	(1,20-1,92)
Klinisk kompetanse ¹⁾	-	-		-0,74	0,48	(0,27-0,85)	-0,65	0,52	(0,35-0,77)
	40,48			37,08			82,98		
Modell (χ^2)	$p < 0,0001$			$p < 0,0001$			$p < 0,0001$		
Cox & Snell R ²	0,15			0,25			0,22		

¹⁾ angitt på skala 1-10 (optimal skåre)

= 92,74, $p < 0,0001$, Cramer's $V = 0,44$, $p < 0,002$). Av de 90 faglige ledere som angav at retningslinjer for behandling hadde vært til hjelp i den kliniske hverdagen, kom flertallet (93,3%) fra spesialisthelsetjeneste i psykisk helsevern. Av de 22 faglige ledere som ikke kjente til at retningslinjene eksisterte, var det også flest fra spesialisthelsetjenesten i psykisk helsevern (65,2%), (χ^2 (3) = 15,00, $p < 0,002$, Cramer's $V = 0,28$, $p < 0,002$). Inndeling av svar fra spesialisthelsetjenesten i enheter for barn respektive voksne gav ingen statistisk signifikante forskjeller i kjennskap eller bruk av retningslinjene.

Som primær målgruppe for retningslinjene er det viktig å vite hvordan spesialisthelsetjenesten vurderer deres nytte. I alt 113 avgav svar, fordelt som at disse hadde vært til hjelp i behandling (20,4%), internundervisning (15,9%), etablering av behandlingsrutiner (8,8%), samt kombinasjoner av disse alternativene (54,9%).

Tabell 2 viser en høyere prosentandel nå (42,5%) enn ved forrige kartlegging i 1997 (29,5%) som angav nytte av helsemyndighetenes faglige retningslinjer for behandling (χ^2 (3) = 11,88, $p < 0,008$, Cramer's $V = 0,16$, $p < 0,008$).

Hvilke tiltak er realisert i spesialisthelsetjenesten og av fastlegene og hvilke grunner anføres for manglende tiltak?

Bruk av tverrfaglige team i avdelingene, samt å inkludere henvisende instans i behandling og oppfølging, var de hyppigste angitte tiltak i spesialisthelsetjenesten (hhv. 27,4% og 27,8%). Det var 12,6% av fastlegene som også oppfattet at tverrfaglige team var etablert (Tabell 3).

Lite pasientgrunnlag var den viktigste grunnen til manglende planlagte eller realiserte tiltak både for fastlegene (64,6%) og for spesialisthelsetjenesten (40,1%). Dette er sammenfallende med funn fra kartleggingen fra 1997 (Rosenvinge & Sundgot-Borgen, 1999) (Tabell 3).

Det å legge behandlingsoppgaver til fagteam i avdelingen er betydelig sjeldnere angitt i 1997 (9,6%) enn i dag (27,4%). I 1997 var det å legge behandlingsoppgaver til en bestemt person det vanligste (33,7%), men er nå sjeldnere angitt (22,6%) (Tabell 3). Tabell 3 viser også at et spesifikt samarbeid mellom avdelinger er sjeldnere angitt i 2004 (14,2%) enn i 1997 (27,2%).

Hva predikerer iverksetting av tiltak?

Flertallet av fastlegene (79,6%, $N = 234$) og omtrent halvparten av de faglige lederne (51,4%, $N = 109$) hadde ikke iverksatt spesielle behandlingstiltak for pasientgruppen. Av alle ($N = 509$) som besvarte spørsmålet, angav 31,8% ($N = 160$) at de hadde realisert eller konkret planlagt spesielle tiltak. En trinnsvis logistisk regresjonsanalyse for fastleger gav en statistisk signifikant modell der sannsynligheten for å realisere tiltak økte med høyere skårer på subjektivt angitt klinisk erfaring, om fastlegen var yngre, og kvinne (Tabell 4). I spesialisthelsetjenesten så vel som for hele materialet økte sannsynligheten for tiltak dersom man hadde hatt nytte av kliniske retningslinjer og om man angav mindre klinisk erfaring og lavere klinisk kompetanse (Tabell 4). Forhold som ikke påvirket sannsynligheten for tiltak var regiontilhørighet samt tilfredshet med tjenestetilbud og samarbeidsforhold.

Samarbeidsforhold mellom primær- og spesialisthelsetjenesten i behandling av spiseforstyrrelser

Faglige ledere vurderte samarbeidsrelasjoner innad og mellom forvaltningsnivåene mer

Tabell 5. Fastleger og spesialisthelsetjenestens vurdering av samarbeidsrelasjoner når det gjelder pasienter med spiseforstyrrelser og pasienter generelt på tidelt skala der 10 er "svært godt".

Samarbeid mellom	Fastleger		Spesialisthelsetjenesten		g ^x
	M	SD	M	SD	
Primær- og spesialisthelsetjeneste					
- pasienter med spiseforstyrrelser	4,87	2,08	6,41	1,92***	0,14
- pasienter generelt	6,67	1,63	7,06	1,74**	0,16
p-verdi og effektstyrke (g)	0,000	(0,09)	0,000	(0,33)	
Spesialisthelsetjeneste i psykisk helsevern og somatisk spesialisthelsetjeneste					
- pasienter med spiseforstyrrelser	4,41	1,90	5,93	2,35***	0,07
- pasienter generelt	5,08	1,94	6,18	2,04***	0,09
p-verdi og effektstyrke (g)	0,000	(0,35)	0,000	(0,40)	
Spesialisthelsetjeneste for barn/ungdom og voksne					
- pasienter med spiseforstyrrelser	4,20	1,89	5,23	2,13***	0,07
- pasienter generelt	5,04	1,90	5,44	1,84*	0,03
p-verdi og effektstyrke (g)	0,000	(0,34)	0,000	(0,54)	

*** $p < 0,0001$; ** $p < 0,01$; * $p < 0,02$; ^x Hedge's

positivt enn fastlegene (Tabell 5). Både fastleger og faglige ledere i spesialisthelsetjenesten vurderte samarbeidsforholdene som dårligere for pasienter med spiseforstyrrelser enn for pasienter generelt (Tabell 5).

I behandling av pasienter med spiseforstyrrelser vurderte imidlertid faglige ledere i spesialisthelsetjenesten i psykisk helsevern samarbeidet med primærhelsetjenesten bedre (M 6,53, SD 1,79) sammenliknet med hvordan faglige ledere i somatisk spesialisthelsetjeneste vurderte sitt samarbeid med primærhelsetjenesten (M 5,57, SD 2,68, $t(186) = 2,18$, $p < 0,03$, $g = 0,50$).

Spesialisthelsetjenesten i psykisk helsevern vurderte samarbeid til somatisk spesialisthelsetjeneste i behandling av spiseforstyrrelser som noe bedre enn respondentene i somatisk spesialisthelsetjeneste gjorde, men forskjellen var ikke statistisk signifikant. For behandling av pasienter generelt var forskjellene imidlertid statistisk signifikante (M 6,34, SD 1,94 versus M 4,95, SD 2,46, $t(191) = 3,06$, $p < 0,003$, $g = 0,69$).

Tilfredshet med eget behandlingstilbud samt inntrykk av tilfredshet hos pasienter, pårørende og samarbeidsinstanser

Tilfredshet med eget behandlingstilbud var høyere i spesialisthelsetjenesten enn blant fastlegene, og effektstyr-

ken var høy ($g = 0,73$) (tabell 6). I spesialisthelsetjenesten var tilfredsheten med eget behandlingstilbud høyere (5,77, SD 1,95) enn det inntrykk fastlegene hadde av pasientenes (4,86, SD 1,80) og de pårørendes (4,49, SD 1,64) tilfredshet med det tilbud de fikk i spesialisthelsetjenesten. Fastlegenes tilfredshet med eget behandlingstilbud var derimot lavere (4,46, SD 1,65) enn spesialisthelsetjenestens inntrykk av henholdsvis pasienttilfredshet (5,41, SD 1,63) og pårørendes tilfredshet med tjenestetilbudet hos fastlegen (5,11, SD 1,62) (Tabell 6). Det var imidlertid god overensstemmelse mellom tilfredshetsnivå i spesialisthelsetjenesten (5,77, SD 1,95) og hvor tilfreds man trodde fastlegene var (5,67, SD 1,76) med spesialisthelsetjenestens tilbud til pasientgruppen.

Tabell 6. Fastleger og spesialisthelsetjenestens tilfredshet med eget behandlingstilbud til pasienter med spiseforstyrrelser samt inntrykk av tilfredshet med tjenestetilbudet til pasientgruppen hos pasienter, pårørende og samarbeidspartnere. 10 angir "svært tilfreds".

	Fastleger		Spesialisthelsetjenesten		g ^x
	M	SD	M	SD	
Tilfredshet med eget behandlingstilbud	4,46	1,65	5,77	1,95*	0,73
<u>Inntrykk av tilfredshet hos</u>					
- dine pasienter med behandlingstilbudet du/din avdeling gir	5,14	1,65	5,84	1,64*	0,43
- pårørende med ditt/din avdelings behandlingstilbud	4,84	1,67	5,68	1,73*	0,50
- pårørende med din/din avdelings oppfølging	4,90	1,69	5,58	1,86*	0,39
- dine pasienter med behandlingstilbudet i spesialisthelsetjenesten	4,86	1,80	-	-	-
- dine pasienter med oppfølgingen hos fastlegen	-	-	5,41	1,63	-
- pårørende med oppfølging i spesialisthelsetjenesten	4,49	1,64	-	-	-
- pårørende med oppfølging hos fastlegen	-	-	5,11	1,62	-
- spesialisthelsetjenesten med din oppfølging som fastlege	5,13	1,49	-	-	-
- fastleger med behandlingstilbudet i spesialisthelsetjenesten	-	-	5,67	1,76	-

* $p < 0,0001$; ^x Hedge's g

Tabell 7. Sammenlikning av somatisk spesialisthelsetjeneste og spesialisthelsetjeneste i psykisk helsevern med hensyn til tilfredshet med eget behandlingstilbud til pasienter med spiseforstyrrelser samt inntrykk av tilfredshet med tjenestetilbudet til pasientgruppen hos pasienter, pårørende og samarbeidspartnere. 10 angir "svært tilfreds".

	Somatisk spesialisthelsetjeneste		Spesialisthelsetjeneste i psykisk helsevern		g ^x
	M	SD	M	SD	
- Tilfredshet med eget behandlingstilbud	4,20	2,59	5,98	1,74**	0,71
Inntrykk av tilfredshet hos					
- pasienter med behandlingstilbudet i din avdeling	3,95	2,06	6,05	1,42**	1,66
- pasienter med oppfølging hos fastlegen	4,06	2,18	5,54	1,51*	0,77
- pårørende med oppfølging i spesialisthelsetjenesten	3,80	2,48	5,80	1,65*	0,92
- fastleger med behandlingstilbudet i spesialisthelsetjenesten	3,84	2,63	5,92	1,46**	0,94
- pårørende med behandlingstilbudet	3,45	1,79	5,94	1,52**	1,48
- pårørende med oppfølging	3,80	2,48	5,89	1,65**	0,97

* $p < 0,01$; ** $p < 0,0001$; ^x Hedge's g

Tabell 7 viser for øvrig et stabilt mønster der man i somatisk spesialisthelsetjeneste skåret klart lavere enn i psykisk helsevern på alle tilfredshetsindikatorer.

Hva predikerer tilfredshet med eget behandlingstilbud?

Ved en trinnsvis regresjonsprosedyre undersøkte man hva som forklarte variansen i målet på tilfredshet med eget behandlingstilbud. Regresjonsmodellen forklarte 57% av denne variansen og var statistisk signifikant ($F(4) = 74,96$, $p < 0,0001$). Det som bidro til forklart varians var inntrykk av høy grad av pasienttilfredshet ($\beta = 0,40$, 95% C. I. 0,30-0,61) og pårørendes tilfredshet med tjenestetilbudet ($\beta = 0,14$, 95% C. I. 0,01-0,31). Tilfredshet med samarbeidet mellom primær- og spesialisthelsetjenesten ($\beta = 0,16$, 95% C. I. 0,06-0,23), samt tilfredshet med samarbeidet mellom somatisk

spesialisthelsetjeneste og spesialisthelsetjenesten i psykisk helsevern ($\beta = 0,14$, 95% C. I. 0,01-0,04). Jo mer tilfreds man var med eget behandlingstilbud, desto høyere vurderte man også sin egen kliniske erfaring i behandling av pasientgruppen ($\beta = 0,18$, 95% C. I. 0,10-0,25). Forhold som statistisk sett ble ekskludert fra regresjonslikningen var opplysninger om antall pasienter, nytten av kliniske retningslinjer for behandling, objektivt kompetansemål, om man arbeidet som fastlege eller i spesialisthelsetjenesten, hvorvidt man hadde iverksatt spesifikke tiltak knyttet til pasientgruppen, samt inntrykk av pårørendes tilfredshet med oppfølgingen i spesialisthelsetjenesten.

Diskusjon

Undersøkelsen viser at enheter i spesialisthelsetjenesten behandler om lag ti pasienter med spiseforstyrrelser i løpet

av ett år, men spredningen er betydelig. Antallet er lavere for fastleger, og med lavere pasientvolum følger også en forventet lavere klinisk erfaring og kompetanse i behandling av spiseforstyrrelser sammenliknet med spesialisthelsetjenesten. I Nord-Norge er imidlertid antall pasienter i forvaltningsnivåene omtrent like stort. En forklaring kan være at geografiske avstander i landsdelen kan gjøre henvisning til spesialisthelsetjenesten lite hensiktsmessig slik at fastlegene i større grad må håndtere denne pasientgruppen på egen hånd. Ut fra resonnetet om at pasientvolum fremmer kompetanse, er det overraskende at kompetanse og klinisk erfaring av den grunn ikke er høyere hos fastlegene i denne helseregionen sammenliknet med de øvrige regionene.

Ikke-signifikante regionale forskjeller i kompetanse og klinisk erfaring både blant fastleger og i spesialisthelsetjenesten gir liten støtte til antagelser om uheldige geografiske forskjeller i tjenestetilbudets kvalitet. Resultatene viser også at tvang er relativt lite i bruk for denne pasientgruppen, og at den utilfredshet med lovverk og rettstilstand som fremmes i enkelte fagmiljøer ikke gjenspeiles i denne studien.

Ett hovedfunn er at helsemyndighetenes retningslinjer for behandling av spiseforstyrrelser i spesialisthelsetjenesten (Sosial- og helsedirektoratet, 2000) angis som nyttige av om lag 40% av respondentene fra spesialisthelsetjenesten, og hovedsakelig i psykisk helsevern. Denne prosentandelen er høyere enn i en tidligere nasjonal

kartlegging (Rosenvinge & Sundgot-Borgen, 1999). En forklaring på denne forskjellen kan være at helsemyndigheter og andre har markedsført de nye retningslinjene i fagmiljøene på en mer systematisk måte enn hva tilfellet var med retningslinjene fra 1992. Andelen som ikke kjenner retningslinjene er også halvvert siden kartleggingen i 1997 (Rosenvinge & Sundgot-Borgen, 1999). Likevel er det tankevekkende at til tross for spesifikke implementeringstiltak, er det et flertall som ikke eksplisitt finner retningslinjene særlig nyttige, og at de ser ut til å ha vært til mindre hjelp i etablering av behandlingsrutiner enn hva man håpet på da de ble utformet. Grunnen til dette er uvisst, men det er grunn til å peke på at på den ene siden kan nasjonalt utsendte retningslinjer vanskelig tilpasses alle slags lokale forhold og dermed oppleves som lite nyttige. På den andre siden kan lokalt utformede behandlingstilbud komme i utakt med en alminnelig konsensus vedrørende kvalitetsnivå når ikke nasjonale retningslinjer danner det nødvendige bakteppet. Endelig er det grunn til å fremheve at man i enkelte fagmiljøer ser en forestilling om at retningslinjer er standardiserte behandlingsopplegg, som ikke ivaretar individuelle behandlingsbehov, og som gjør at man enten ikke leser retningslinjer eller ikke finner dem relevante. Standardisering har imidlertid aldri vært intensjonen, og tvert i mot understrekes det i retningslinjene at behandling alltid må tilpasses lokale og individuelle forhold.

Et annet hovedfunn er at tverrfaglige team fremstår som

et viktig behandlingstiltak overfor pasienter med spiseforstyrrelser. Dette er en markert endring i forhold til den nasjonale kartleggingen fra 1997 (Tabell 3). Den gang var det ikke slike systemorienterte, men mer individorienterte tiltak som dominerte, i den forstand at en bestemt behandler enten ble bedt om, eller selv påtok seg behandlingsoppgavene. Individorienterte tiltak er viktige fordi krevende terapeutiske utfordringer nødvendiggjør fagfolk med spesifikk interesse og kompetanse på spiseforstyrrelser. Individorienterte tiltak er imidlertid også sårbare og ustabile i form av risiko for faglig utbrenning og det faktum at "øremerkede" fagfolk også flytter på seg, slik at behandlingstilbudet kan forsvinne. Trass i at om lag en av fem ledere stadig angir slike individorienterte tiltak, representerer dreiningen mot tverrfaglige team i avdelingene en positiv utvikling mot mer stabile og optimale tiltak. En slik utvikling er også i tråd med anbefalinger fra helsemyndigheter og sentrale fagmiljøer (Rosenvinge & Gøtestam, 2002; Rosenvinge et al., 2003; Sosial- og helsedirektoratet, 2000; Statens helsetilsyn, 1992; 2000). På den annen side er det overraskende, og ikke i tråd med faglige råd, når utbredelsen av formalisert samarbeid mellom enheter er redusert sammenliknet med den tidligere kartleggingen (Rosenvinge & Sundgot-Borgen, 1999). Det kan imidlertid tenkes at faste, tverrfaglige team mellom avdelinger er mer påkrevd når man i avdelingene kun har en "øremerket" behandler eller med andre ord, at når tverrfaglige team er

opprettet i en avdeling, er dette tilstrekkelig med det pasientgrunnlaget man forholder seg til. En annen forklaring på at færre nå benytter tverrfaglige team fra flere avdelinger kan være at enhetene selv etablerer den nødvendige tverrfaglige kompetanse. Dermed reduseres behovet for å etablere formalisert samarbeid med andre. I så fall kan det representere en ønsket utvikling dersom det innebærer at pasientene i mindre grad transporteres mellom avdelinger og enheter, med den risiko dette gir for at behandlingstilbudet fragmenteres.

Det at yngre, kvinnelige fastleger med klinisk erfaring med pasientgruppen også med større sannsynlighet realiserer behandlingstiltak, er i tråd med allmenne erfaringer fra fagfeltet. Litteraturen (for eksempel Noordenbos, 2003) omtaler dessuten hvordan holdninger og kommunikasjonsferdigheter hos mannlige fastleger kan skape uheldige terapeutiske relasjoner, som bidrar til å forsinke tidlig oppdagelse og dermed redusere sannsynligheten for tiltak overfor unge kvinner med spiseforstyrrelser. Man skal imidlertid være svært tilbakeholden både med å stemple mannlige leger som mindre egnet til å ta seg av denne pasientgruppen, og i det hele tatt å tillegge behandlerens kjønn betydning for adekvat behandling av selv tilstander med skjev kjønnsfordeling. På den annen side kan man tenke seg at når pasient og terapeut har samme kjønn og heller ikke er så forskjellige i alder, kan det bidra til å fremme den gjenkjennelsesprosessen og identifikasjon som er nødvendig for empati og etablering av

terapeutisk relasjon, som igjen gjør at legen treffer spesifikke tiltak i utrednings- og behandlingsøyemed. Det er også vist at selv om menn ikke nødvendigvis er uegnet, kan kvinner være å foretrekke som terapeuter for kvinner med spiseforstyrrelser, og særlig dersom overgrep, kroppsmisnøye og overbeskyttende mødre er en sentral del av problemkomplekset (Waller & Katzman, 1997).

I spesialisthelsetjenesten var nytte av retningslinjene den sterkeste prediktoren for å realisere tiltak. Dette er en klar endring fra forrige kartlegging (Rosenvinge & Sundgot-Borgen, 1999), hvor de daværende retningslinjene var uten betydning for om man hadde truffet tiltak. Odds ratio var imidlertid moderat (1,96, 95% C.I. 1,31-2,93) og støtter opp under øvrige resultater som indikerer at det gjenstår en del før målet og hensikten med retningslinjene er oppnådd. I den grad odds ratio kan oppfattes dit hen at retningslinjene kan inspirere, og fungere som pådriver for å realisere behandlingstiltak, blir det en utfordring å gjøre dem bedre kjent. Ikke minst gjelder dette for somatisk spesialisthelsetjeneste og blant fastlegene. Blant sistnevnte er det tross alt over 40% som ikke kjenner til at slike retningslinjer eksisterer (Tabell 2). Retningslinjene omtaler både diagnostiske kjennetegn og medisinske forhold. Både fastleger og indremedisinere/pediatere kan ha nytte av å sette seg inn i retningslinjene for å sikre et kvalitetsmessig mest mulig likeverdig tjenestetilbud til pasientgruppen. Man vet at tidlig oppdagelse øker sannsynlig-

heten for en god prognose (Keel & Mitchell, 1997; Strober et al., 1997), og mange pasienter med alvorlige spiseforstyrrelser trenger også medisinsk utredning og behandling (Strober et al., 1997).

I kartleggingen fra 1997 (Rosenvinge & Sundgot-Borgen, 1999) predikerte antall pasienter om tiltak var iverksatt. Pasientgrunnlaget hadde i nåværende kartlegging ingen prediktiv verdi. Som i forrige kartlegging (Rosenvinge & Sundgot-Borgen, 1999) var likevel få pasienter med spiseforstyrrelser den viktigste grunn til at verken fastleger eller spesialisthelsetjenesten fant grunn til å etablere tiltak, eksempelvis rutiner for utredning og behandling. Dette er forståelig, men er like fullt uheldig. Det aktuelle pasientvolum er trolig lavere enn det potensielle (Rosenvinge & Gøtestam, 2002). Det er flere grunner til å forvente økt antall pasienter med spiseforstyrrelser, og bedre kjennskap til kliniske retningslinjer kan bidra til å gi fagfolk det kompetansegrunnlag som gir dem interesse og mot til å ta på seg flere behandlingsoppgaver. Et tilgrensende funn er at tiltak og forhold som predikerer realiseringen av disse ikke er knyttet til regiontilhørighet. På samme måte som for klinisk erfaring og kompetanse gis med dette liten empirisk støtte til påstander i den offentlige debatt om uheldige geografiske forskjeller i kvaliteten på tjenestetilbudet.

Et tredje hovedfunn var at samarbeidsrelasjoner i organisering av tjenestetilbudet for pasientgruppen ble vurdert rimelig bra. Alle skåreverdier på den tidelte skalaen for tilfreds-

het med samarbeidsrelasjonene var jevnt over middels og med lave standardavvik. Imidlertid vurderte man i spesialisthelsetjenesten alle samarbeidsrelasjoner innad og mellom forvaltningsnivåene som klart bedre enn hva fastlegene gjorde. Samarbeidet med primærhelsetjenesten i behandling av pasienter med spiseforstyrrelser ble vurdert som dårligere på medisinske avdelinger og barneavdelinger enn i det psykiske helsevernet. Både faglige ledere og fastleger vurderte dessuten samarbeidsrelasjoner som dårligere for pasienter med spiseforstyrrelser enn for pasienter generelt. Etiologien er multifaktoriell, slik at flere profesjoner og tjenesteytere må involveres. Over tid kan den kliniske tilstanden variere i alvorlighet for den enkelte pasient. Derfor ligger det en utfordring i å skape samarbeidsrelasjoner som fremmer en felles, faglig forståelse, slik at pasienten både unngår å bli unødig kasteball i systemet og selv ikke opplever et fragmentert tjenestetilbud. Slik systemkompetanse blir i økende grad vektlagt i helsevesenet generelt (NOU, 2005).

Det fjerde hovedfunnet gjaldt tilfredshetsvurderinger knyttet til tjenestetilbudet. Her var også skåreverdiene jevnt over middels langs en tidelt skala. Fastleger hadde et noe dårligere innrykk av pasienter og pårørendes tilfredshet med tjenestetilbudet i spesialisthelsetjenesten enn spesialisthelsetjenestens egen tilfredshetsvurdering av sitt tjenestetilbud. I så måte kan man tolke forskjellen slik at faglige ledere i spesialisthelsetjenesten overvurderte sin innsats overfor pasientgruppen i forhold til

brukerne selv. På den annen side kan det tenkes at fastlegene undervurderte sin innsats i den forstand at spesialisthelsetjenesten hadde inntrykk av at så vel pasienter som pårørende var mer tilfredse med fastlegenes tjenestetilbud enn hva fastlegene selv var.

Lav svarprosent, med opplysninger fra kun om lag en tredel av originalmaterialet, svekker gyldigheten av å generalisere resultatene til populasjonen av alle fastleger og alle avdelinger i spesialisthelsetjenesten. Privatpraktiserende psykologer og psykiatere er en viktig del av spesialisthelsetjenesten, og det er en svakhet ved studien at disse ikke kunne inkluderes. Styrken i spørreskjema som kartleggingsmetode ligger i at man får en generell oversikt. Andre kvalitetsindikatorer som eksempelvis ventetid på behandling, behandlingstid, kost-nytteanalyser samt tilfredshetsmål fra pasienter og pårørende kunne imidlertid ha gitt et mer nyanansert bilde av tjenestetilbudet.

Med slike forbehold, kan resultatene likevel tegne et bilde som positivt bilde av tjenestetilbudet, spesielt i spesialisthelsetjenesten. Dette er viktig å få frem i lys av et negativt bilde som ofte tegnes i den offentlige debatt og i media av tjenestetilbudet som totalt utilstrekkelig og nærmest på grensen til det uforsvarlige. Slike bilder drives frem av overgeneraliseringer ut fra uheldige enkeltsaker, som i seg selv sikkert er sanne nok. På den annen side er selvopplevd tilfredshet en upålitelig markør for god behandling av spiseforstyrrelser. Ikke minst i lys av den nye pasientrettighetsloven understreker dette behovet

for nye studier med flere kvalitetsindikatorer, som nevnt ovenfor.

Det finnes således forbedringspotensial, eksempelvis knyttet til fastlegers kompetanse og til samarbeidsrelasjoner. En grunn til at resultatene kan tolkes dit hen at fastleger undervurderer sin innsats overfor denne pasientgruppen kan være at de både mangler tid og kompetanse til å få en opplevelse av å lykkes. Langt på vei kan man si at det er uklare forventninger til fastleger kompetanse og hva slags tiltak de skal treffe for denne pasientgruppen. Fagmiljøene og helsemyndighetene bør samarbeide om å utarbeide minimumskrav med hensyn til utredning og behandling, samt retningslinjer for henvisning til spesialisthelsetjenesten.

De kvalitative kommentarer i form av råd til helsemyndighetene dreier seg om at fastleger ønsker bedre tilbud i spesialisthelsetjenesten og spesialisthelsetjenesten ønsker seg regionale kompetansesentre. Dette kan gjenspeile en ansvarsfraskrivning eller en manglende tro på egen kompetanse, i den forstand at man vil at "andre" enn en selv skal eller bør behandle pasienter med spiseforstyrrelser. Rådene kan imidlertid også gjenspeile et ønske om fortsatt satsning på kompetansetiltak, opplæring i evidensbasert behandling samt tiltak for å bedre organiseringen av tjenestetilbudet. Dette er viktig for å møte en forventet økning i antall pasienter med spiseforstyrrelser i årene som kommer (Rosenvinge & Gøttestam 2002), pasienter som med pasientrettighetsloven i den ene hånden og kunnskap om evi-

densbasert behandling hentet fra Internett og andre kilder i den andre, vil stille helt andre kvalitetskrav til helsevesenet enn hva vi nok hittil har sett.

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Paper 3

Pettersen G, Rosenvinge JH. Improvement and recovery from eating disorders: A patient perspective. *Eating Disorders* 2002; 10: 61-71.

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Paper 4

Pettersen G, Thune-Larsen KB, Rosenvinge JH. Necessary ingredients of the concept of recovery from eating disorders: Comparing clinician and community member perspectives. *Eating Disorders* 2007; submitted.

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Paper 5

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