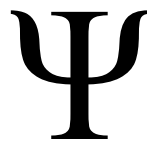




DET PSYKOLOGISKE FAKULTET



«Why do some patients decline eating disorder treatment»?

HOVEDOPPGAVE

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Preface

We want to give a special thanks to our mentors Yngvild Sørebo Danielsen and Guro Årdal Rekkedal for their help and engagement throughout this whole process. We also want to thank our participants for sharing their experiences and being open about this important matter. This thesis would not be possible without them.

Sammendrag

Spiseforstyrrelser er en alvorlig psykisk lidelse med betydelige negative konsekvenser. På tross av dette lar mange være å oppsøke behandling, takker nei til, eller dropper ut av behandling. Kvantitative studier har undersøkt hvilke variabler som kan forklare den høye forekomsten av drop-out, uten konsekvente funn. Vi har derfor valgt et mixed methods design som kombinerer kvantitative og kvalitative data for å undersøke faktorer forbundet med å takke nei til behandling for spiseforstyrrelser. Registerdata fra Avdeling for spiseforstyrrelser ved Haukeland Universitetssykehus ble analysert for å undersøke om alder, BMI, alvorlighetsgrad av spiseforstyrrelsen og komorbide psykiske lidelser var ulik mellom pasienter som takket ja til behandling sammenlignet med de som takket nei. Pasientene som valgte å takke nei til behandling hadde signifikant lavere BMI enn pasientene som takket ja.

Gjennom kvalitative intervjuer med fire av de tidligere pasientene har vi utforsket hvorfor de har valgt å takke nei til behandling og hvordan de opplever behandlingstilbudet. To hovedkategorier ble identifisert: aspekter ved spiseforstyrrelsen og forhold knyttet til behandlingstilbudet. Tema i førstnevnte kategori omhandlet manglende bevissthet rundt lidelsen, trygghet og mestring spiseforstyrrelsen gir, spiseforstyrrelsen som emosjonsregulerende mekanisme, håpløshet og tap, samt eierskap til spiseforstyrrelsen og behandlingen. Aspektene relatert til behandlingstilbudet omhandlet manglende fleksibilitet og et ønske om å jobbe for å finne motivasjon. Resultatene viste at deltakerne opplevde at aspekter ved spiseforstyrrelsen og dens funksjon gjorde det vanskelig å takke ja til behandling.

På bakgrunn av resultatene foreslår vi at behandlere er spesielt oppmerksomme på ambivalens. Spesifikt fremstår det sentralt å validere spiseforstyrrelsens funksjon for den enkelte pasient, samtidig som en hjelper pasienten til å se og formulere tydelig for seg selv hvilke negative konsekvenser det har å leve med spiseforstyrrelsen.

Abstract

Eating disorders are considered a serious mental illness with severe negative consequences. Despite this, many do not seek treatment, decline treatment or drop out of treatment. Quantitative research has not succeeded in finding variables consistently explaining this high prevalence of drop-out before and during treatment. Therefore, we have chosen a mixed methods design combining quantitative and qualitative data to investigate factors associated with declining treatment for eating disorders. Register data from the Department of Eating Disorders at Haukeland University Hospital were analyzed to see if age, BMI, severity of the eating disorder or comorbid mental disorders were different for patients who agreed to treatment compared to those who declined. At a group level, patients who declined treatment had a significantly lower BMI compared to patients who accepted.

Through qualitative in-depth interviews with four of the previous patients, we have explored why they chose to decline treatment and how they experience the current treatment offer. Two main categories of themes were identified, respectively aspects of the eating disorder, and conditions related to the treatment offer. Themes in the former relate to lack of awareness, the coping and security that the eating disorder provides, the eating disorder as a means to regulate emotions, hopelessness and loss, and the need for autonomy and ownership of the eating disorder. The aspects related to the treatment offer dealt with a lack of flexibility and a desire to work to find motivation. The results indicate that the participants experienced that the aspects and function of the eating disorder made it difficult to accept treatment.

Based on the results, we suggest that therapists pay special attention to ambivalence in eating disorder treatment. Specifically, it is important to validate the eating disorder's function for the individual patient while at the same time helping the patient to see and formulate clearly for themselves what negative consequences living with the eating disorder has.

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Background

General overview

An eating disorder (ED) is a mental illness which severely affects a person's eating habits to the extent that it inflicts negative consequences on the person's mental- and/or physical health (American Psychiatric Association, 2013). The term constitutes several different disorders of which anorexia nervosa, bulimia nervosa and binge eating disorder have received the majority of attention in the research literature. On a group level, individuals with eating disorders also display a high rate of comorbid psychiatric disorders and symptoms, with some of the most commonly reported being depression (Martín et al., 2019; Puccio, Fuller-Tyszkiewicz, Ong, & Krug, 2016; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011), anxiety (Martín et al., 2019; Swanson et al., 2011), substance dependence (Bahji et al., 2019) and personality disorders (Martinussen et al., 2017).

Anorexia Nervosa (AN)

AN is a serious psychiatric disorder characterized by severe weight loss, abnormal eating patterns, a disturbed body image and an intense fear of gaining weight or becoming fat (American Psychiatric Association, 2013). The ICD-10 (1992) manual states that anorexia nervosa primarily affects teen girls and young women. It has been reported that 40% of newly diagnosed cases are found within the age group 15-19 years (Jagielska & Kacperska, 2017). A longitudinal study which examined developmental trajectories of disordered eating discovered an increase in cognitive symptoms like body dissatisfaction and weight preoccupation from 11 through 25 years (Slane, Klump, McGue, & Iacono, 2014).

The disorder can be described as a self-starvation syndrome (Holmes, 2021; Keel, 2017) and accounts for the highest rate of mortality amongst psychiatric disorders (Roux, Chapelon, & Godart, 2013; Smink, van Hoeken, & Hoek, 2013). A meta-analysis conducted by Sullivan (1995) illustrated that the mortality rate associated with AN was found to be at

0.56 percent per year. These numbers are more than 12 times the mortality rate among young women in the general population and substantially higher than reported for other female psychiatric inpatients (Sullivan, 1995). The mortality rate has not decreased in recent years. In a meta-analysis conducted by Arcelus, Mitchell, Wales, and Nielsen (2011), the risk of death for people with AN, reported as a weighted annual mortality rate, was found to be 5 per 1000 person-years, with a standardized mortality ratio at 5.86, 95% *CI*, [4.17-8.26]. The numbers were somewhat higher in studies which only included women. Furthermore, the numbers showed that 1 in 5 of the individuals who died with an AN had committed suicide.

In cases where the disorder does not lead to a lethal outcome, the illness is often long lasting and leads to other severe medical conditions such as bone disease, brain impairment, cardiac abnormalities and organ damage (Mitchell & Crow, 2006).

In addition, Olivo, Gaudio, and Schiöth (2019) suggests that AN often delays puberty, and together with being underweight this can affect brain and cognitive development, which in turn can cause impaired cognitive flexibility and executive functions. Moreover, this article reports that adolescents suffering from AN have a more punishment-based learning which can lead to a negative-feedback-based learning which contributes to maintaining the disorder. Additionally, the authors discovered a higher tendency towards social anxiety and emotional reappraisal in adolescents with AN.

AN has been proposed to arise from “a lost sense of emotional self” (Oldershaw, Startup, & Lavender, 2019). The authors argue that AN may be related to emotional difficulties. They propose that people suffering from AN go through overwhelming emotional experiences which is difficult to integrate. According to the authors, this leads to an inadequate development of a coherent self during adolescence. In turn, these emotional difficulties serve as a basis for developing AN as the individual relies upon external signals and validation to get his or her emotional needs met (e.g., weight and shape goals).

Furthermore, once the anorectic identity is established it is validated through others (e.g. when receiving compliments for thinness) and becomes a reinforcing cycle (Oldershaw et al., 2019).

Bulimia nervosa (BN)

This eating disorder is characterized by repeated incidents of binge eating followed by compensatory behavior. The binge eating incidents take place in a limited period of time and is characterized by an abnormally large intake of food as well as experiencing loss of control over the consumption. The binge eating and compensatory behavior both occur, on average, at least once a week for a period of at least three months (American Psychiatric Association, 2013). The disorder is also characterized by an over-evaluation of weight or shape in self-evaluation (Keel, 2017).

BN is further associated with a range of medical complications. These have been described as a direct result of the purging behavior, with the amount and frequency affecting the severity of the complications (Mehler & Rylander, 2015). The complications can include heart problems, dehydration, digestive problems, gum disease, electrolyte imbalances and nutrient deficiencies. One of the possible secondary effects of BN is compromised reproductive health (Mehler & Rylander, 2015).

In the same meta-analysis as mentioned above (Arcelus et al., 2011), the mortality rate for BN was reported. The rates for BN were a bit lower than the rates reported for AN. The weighted annual mortality rate was found to be 1.74 per 1000 person-years, with a relative risk of mortality of 1.93, 95% *CI*, [1.44-2.59]. In female-only studies, the weighted mortality rate was somewhat higher at 2.22, 95% *CI*, [0.73-4.72] per 1000 person-years on follow-up. No male-only studies were identified in their search.

Studies have shown that a person with ED often has different ED diagnoses during the course of the illness, and that diagnostic crossover between the different diagnoses can

occur, for instance between AN and BN (Castellini et al., 2011; Monteleone, Di Genio, Monteleone, Di Filippo, & Maj, 2011).

To summarize, AN and BN can be considered as severe disorders with serious consequences, both in terms of physical, social and psychological effects, such as high comorbidity and increased mortality. In light of the information presented above, and the severe consequences eating disorders can have for affected individuals and their surroundings, it is of great importance to offer these patients the best treatment available.

Alarmingly, a high percentage of people suffering from ED seem to be either ambivalent or reluctant to engage in therapy. Thus, many either fail to seek out treatment, decline the treatment offered or drop out prematurely. Clinical studies have estimated that out of the number of individuals suffering from eating disorders, approximately 20-45% seek treatment (Bohrer, Carroll, Forbush, & Chen, 2017), and as many as 73% drop out of treatment (Fassino, Piero, Tomba, & Abbate-Daga, 2009).

Introduction

Our search

We conducted a literature search prior to the data collection. The aim of this search was to explore relevant literature regarding reasons for dropping out of treatment. The search was conducted in three different databases, namely PsychInfo, Web of Science and PubMed using the words ("eating disorder*" OR "anorexia" OR "bulimia") AND ("drop out" OR "drop-out" OR "dropout" OR "decline" OR "disengage"). No limitations were set for the search in terms of year published or method used. 43 relevant articles were identified after perusal by two independent researchers. Out of all the articles only one of them used a qualitative design (Eivors, Button, Warner, & Turner, 2003). Relevant literature identified while reading articles was also examined. Despite this, no additional qualitative studies were discovered. This finding suggests that there is little qualitative research done within the

subject of this paper. In the following we will elaborate on some of the most prominent findings. A majority of the literature identified concerned anorexia nervosa; this is reflected in the descriptions below.

Drop-out

Although eating disorders are often seen as hard to treat, well documented treatments and reports of relatively good outcomes in a wide range of patients does exist (Christopher G. Fairburn, 2008). However, it should be noted that a large number of patients for different reasons drop out from treatment. For AN patients, a majority of individuals who drop out seem to do this at an early stage of the treatment. This finding has been evident across different types of therapy (DeJong, Broadbent, & Schmidt, 2012). Fassino et al. (2009) conducted a literature review to examine factors associated with drop-out, and stated that predictors identified were inconsistent due to limited sample sizes and methodological flaws. They found that the drop-out rates ranged from 20-51% for inpatients and from 29-73% for outpatients. Among individuals who are undergoing examination for specialized outpatient treatment, the drop-out rate is estimated to be between 13-32%, even before treatment starts (Watson, Fursland, & Byrne, 2013). Geller (2002) found that only 48% of those who were recommended for treatment actually chose to enroll, and out of those who enrolled, 36% subsequently dropped out. There seems to be no evidence that drop-out rates are different between particular eating disorder subtypes, nor is treatment of longer duration associated with lower drop-out rates (Linardon, Hindle, & Brennan, 2018).

Unfortunately, identifying highly predictive drop-out factors across studies seems to be a challenge. Several studies point to methodological limitations, leading to scarce possibilities for comparability. These differences concern both factors examined and the drop-out definitions, which in turn makes them hard to reaffirm (Campbell, 2009; DeJong et al., 2012; Fassino et al., 2009; Gregertsen, Mandy, Kanakam, Armstrong, & Serpell, 2019;

Linardon et al., 2018). The definition of drop-out varies widely in the literature. In some studies, drop-out was defined as patients leaving treatment against professional advice, in some studies the term drop-out was used when the therapist discharged patients for not reaching weight goals or not complying with treatment and some did not explicitly define drop-out. This wide variety of definitions became evident both when reading the literature identified through our search but has also been described in the literature by for instance Gregertsen et al. (2019).

One prominent feature regarding AN is the variable course and outcome (Wildes, Forbush, & Markon, 2013). The heterogeneity within the group of people suffering from AN may contribute to the major range between the studies in terms of sample size, characteristics, assessment and follow-up procedures. The same challenges seem to be the case for studies conducted on bulimia nervosa (BN). Bell (2001) conducted a review to find which factors predicted failure to engage and drop-out for BN. “Failure to engage” was defined as patients who never show up for their first appointment. Bell (2001) stated that the literature presents multivariate methodology, factors studied, sample size and treatment, which makes it somewhat challenging to compare the results.

It is important to address the problem of drop-out for several reasons. Pike (1998) argues that patients who drop out of treatment are less likely to recover on their own, and it has been argued that this group is more likely to have a poor long-term outcome (Beumont, Arthur, Russell, & Touyz, 1994; Campbell, 2009; Kahn & Pike, 2002). For AN patients, non-completers tend to have poorer long-term outcome, and are often re-referred to treatment when the illness has become more severe and chronic (Fassino et al., 2009).

Variables associated with drop-out

Even though the findings are limited and inconsistent regarding variables associated with, and predictive of drop-out, research has pointed towards some variables. Bell (2001)

found that for drop-out and failure to engage, the only robust factor in patient characteristics was a comorbid borderline personality disorder. Fassino et al. (2009) conducted a literature review concerning factors associated with drop-out from ED treatment. They found that one of the most consistent predictors for drop-out was having the binge-purge subtype of AN. Additionally, their results showed strong evidence that having the traits “high maturity fair” and “impulsivity” increased the risk of drop-out. They also reported a negative correlation between drop-out and “self-directedness” and “cooperativeness”. A range of different variables had been examined in the research reviewed in the article, but they did not show the same consistent link. Some of the more consistent, but rarely examined factors were Borderline Personality Disorder, “higher expectations about treatment”, “poorer anger management”, higher number of previous psychiatric treatments, “higher rate of early life events”, e.g., sexual abuse and “levels of psychopathology in parents”.

In a systematic review and meta-analysis regarding drop-out in AN-treatment by Gregertsen et al. (2019) it was found that lower motivation, lower BMI, and having a binge-purge subtype of AN predicted drop-out. There was a small but significant negative relationship between motivation and drop-out ($r=-0.21$, 95% *CI* [-0.38, 0.01], $p=.042$), a small positive correlation between AN binge-purge subtype and drop-out ($r=0.12$, 95% *CI* [0.04, 0.19], $p<.005$), and lastly a small, negative correlation between admission BMI and drop-out ($r=-0.12$, 95% *CI* [-0.18, 0.06], $p<.005$). Consistent with other reviews, few variables were found to predict drop-out on a reliable basis and the variance explained were scarce.

In sum, the knowledge regarding predictors of treatment drop-out are limited and the predictors identified have small effect sizes. A great number of individuals suffering from eating disorders either fail to seek help, fail to engage in the treatment program offered, or drop out from treatment prematurely. Based on the drop-out numbers combined there seems

to be a great potential for improving the number of individuals receiving adequate treatment for his or her disorder. More knowledge on how to efficiently engage ED patients in treatment and preventing drop-out is highly needed.

Qualitative research

As mentioned earlier only one qualitative study was identified in the search. One of the findings in Eivors et al. (2003) was the description of the eating disorder as a “functional coping strategy” which helped the participants to manage stress and create a sense of achievement. The loss of control was described as a major reason for the participants to leave treatment prematurely. Eivors et al. (2003) suggest that clinicians should work with the patients to gain a shared understanding of the EDs meaning for each individual. Thus, they argue that it is important to understand how the patient is viewing their ED as a way of coping rather than self-destructing actions. In turn, the authors suggest that such an approach can serve as a foundation for a solid working alliance between therapist and patient. Furthermore, they suggest that there is too much focus on EDs as a psychiatric diagnosis and its destructive symptoms. Therefore, the article proposes that having two different therapists, one working with the psychological mechanisms and one working with the physical consequences might be a solution to this issue.

Ambivalence

As previously mentioned, EDs can have severe negative consequences (Arcelus et al., 2011; Mehler & Rylander, 2015; Mitchell & Crow, 2006; Olivo et al., 2019). At the same time EDs can have some perceived positive aspects such as being a coping strategy to manage stress and create a sense of achievement (Eivors et al., 2003), possibly resulting in conflicting feelings towards the disorder. One of the factors thought to contribute to the low numbers in treatment seeking and engagement in therapy amongst eating disorder patients, is ambivalence (DeJong et al., 2012; Feld, Woodside, Kaplan, Olmsted, & Carter, 2001;

Leavey, Vallianatou, Johnson-Sabine, Rae, & Gunpath, 2011). Due to this, we conducted an additional search related to ambivalence in EDs. Interestingly, the number of qualitative studies related to this theme were higher than for drop-out.

People diagnosed with an ED often feel ambivalent about whether they wish to maintain or recover from the illness as they experience both positive and negative aspects of it (Adshead, 2009). Thus, one can say that the individual experience different degrees of motivation and readiness for change. Motivation can be defined as “desire and drive for change”, whereas readiness refers to the “degree an individual is willing to change a behavior” (Algars et al., 2015; Carey, Purnine, Maisto, & Carey, 1999). Furthermore, it appears that individuals with different EDs vary with regards to their readiness for change. Research shows that on a group level, individuals with AN seem less motivated to change compared to individuals with BN (Blake, Turnbull, & Treasure, 1997).

AN is often described as both a friend and a foe by those suffering from the disease (Serpell, Treasure, Teasdale, & Sullivan, 1999; Williams & Reid, 2010). On the one hand AN is seen as an enemy, an uncontrollable disease which negatively affects the personal life and health of the person. On the other hand, it can also be seen as a reliable friend which can be used as a controllable tool, enabling them to take control of their thoughts and behaviors.

Bliss (1982) found that several features of AN were perceived as favorable: 73% cited self-control as an asset, 39% enjoyed being noticed for their thinness, 35% liked their control over others, 31% appreciated relief from sexual concerns, 27% felt morally elevated, and 24% welcomed the cessation of menstruation. For many affected by the illness the anorexic behaviors of food restriction and exercise are consistent with their goals of self-control and thinness (Vitousek, Watson, & Wilson, 1998) Serpell et al. (1999) found that commonly expressed benefits of AN included feeling looked after or protected, gaining a sense of control, and feeling special. At the same time the disorder can have negative effects on the

physical health, psychological well-being and social interaction. Regularly reported adverse aspects of the disease were constant thoughts about food, feeling taken over, and the damage done to personal relationships. The descriptions of positive attributes regarding the ED have also been demonstrated in more recent research (Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006; Skårderud, 2007; Walsh, 2013). Through a qualitative approach conducting semi-structured interviews with 18 participants Nordbø et al. (2006) identified eight recurrent psychological themes. Several of these illustrated positive values for the participants. The themes were labeled avoidance, security, mental strength, identity, care, self-confidence, communication and death (as an expression of a wish to disappear).

Research has also reported that ambivalence is linked to a sense of control. Williams and Reid (2010) reported that participants felt ambivalent as to whether their anorexia gave them control or actually controlled them. Anorexia could be used as a functional and controllable tool, as a way of feeling safe or expressing emotion, as an escape or a focus to avoid negative emotions and situations, a way to disappear, to feel happiness, to feel strong and successful, a way of fighting puberty or punishing themselves or others. Yet, anorexia was described as an uncontrollable disease and negative entity that could take control over the individual and enforce behavior upon it.

It is suggested that the perceived positive attributes to the ED symptoms contribute to the maintenance of the disorder and affects motivation towards treatment (Gagnon-Girouard, Chenel-Beaulieu, Aimé, Ratté, & Bégin, 2019). On the other hand, negative emotions might lead many to consider treatment. It is also possible for individuals to want to do both at the same time: recover and maintain (Williams & Reid, 2010).

Recognizing these conflicting feelings and ambivalence early on in the treatment process might be critical to create a successful therapy program. It has been suggested that the way ambivalence is handled in treatment is critical to the therapeutic alliance and may

affect the client's receptivity to change and ability to recover (Cockell, Geller, & Linden, 2003; Vitousek et al., 1998). Readiness and motivation for change among individuals with EDs has been shown to be predictive for treatment outcome (Gusella, Bird, & Butler, 2003). Understanding ambivalence and identifying ways to strengthen readiness and motivation to change might therefore be an important step in improving today's treatment.

In short, ambivalence and positive cognitions toward the ED seems to be important in relation to the decision regarding therapy, but there is a lack of knowledge and consensus on how this issue should be addressed and managed.

Summary and research gaps

As discussed above, eating disorders constitute a major challenge both for the people suffering from it, but also for their families and friends, the treatment system and individual clinicians. Pike (1998) argues that many individuals refuse to engage in therapy. The existing evidence for treatment outcome appears to be deficient (DeJong et al., 2012; Fassino et al., 2009), and there is a lack of consensus as to what contributes to the large drop-out numbers.

To our knowledge, little research has been conducted with regards to why patients decide to decline the treatment offer after the initial assessment. Due to sparse results in quantitative research, there is reason to believe that there are significant limitations to the quantitative approach as to answering the question of why people choose to decline or drop out of treatment. Qualitative data collected from semi-structured interviews may offer a better insight into these individuals' experience of meeting the treatment apparatus. This information can provide a broader understanding of ambivalence in an early phase of treatment and identifying ways to improve the current treatment offer.

Aims of the study

Since quantitative findings in the literature are inconclusive and scarce, we argue that there is a need for more elaborative examination. The overall aim of this study is to explore

factors related to declining eating disorder treatment at the Department of Eating Disorders at Haukeland University Hospital, and how these patients understand their reasons for declining. These aims will be explored using a mixed methods design, including both a quantitative and a qualitative part. The first part of the study is quantitative and aim to explore potential variables associated with failure to accept treatment, asking the following research question: Do age, BMI, severity of eating disorder symptoms and psychiatric comorbidity differ in patients who choose to engage in treatment versus those who decline treatment at the Department of eating disorders at Haukeland University Hospital?

In the second part of this study, we will conduct semi-structured interviews with former patients who declined treatment after the initial assessment. We aim to explore these patients' experiences of why they chose not to engage in therapy and their thoughts about possible improvements in today's assessment routines. The information collected will represent an idiosyncratic description of each case but can hopefully serve as a generator for formulating some hypotheses suitable for further research.

Method

Design and setting

This study uses a mixed methods design combining data from quantitative and qualitative investigations. The project was performed in cooperation with The Regional Department of Eating Disorders (DED). The department serves as a treatment facility for the most severely ill adult (from age 16) patients with eating disorders in the region. The department offers both inpatient and outpatient treatment. As DED is a third line facility, the patients which receive a treatment offer here have received at least one previous treatment offer in the secondary health service unit, without obtaining the desired results in terms of remission. Additionally, the patients who receive a treatment offer have had a severe and long-lasting eating disorder, based on the ICD-10 (1992) criteria. Since 2007, the department

has collected a wide range of quality improvement data. When patients come to their initial appointment at DED, a standardized clinical assessment is conducted for each patient. The assessment consists of a battery of different acknowledged psychological questionnaires, as well as registration of different sociodemographic variables and clinical characteristics. These include comorbid disorders, age, sex, occupation, relationship status, number of children, current residence, previous treatment, parallel ongoing treatment, background of sexual, physical and/or emotional abuse, background of bullying, history of self-harm and history of suicide attempts. This data is part of the quality register at the department. This study uses data from patients enrolled in the registry between 2018 and 2019 (N=93).

The data in the quantitative part of the study is part of a quality improvement project performed at DED. The quality improvement project was approved by the data protection officer at that hospital (approval no. 2015/12991). The project protocol has been submitted for consideration to the Regional Ethical Committee and deemed exempt from review as it was classified as quality improvement (2018/275/REK vest). Consent to participate is not required for quality improvement projects. Patients referred to treatment at the department from 2018 to 2020 are included in the quantitative part of the paper.

In the qualitative part of the study, participants that had agreed to the quality registry, but declined the recommended treatment offered at DED, were contacted and asked if they would like to participate in a semi-structured interview about their experience of declining treatment. This part of the study was conducted at the University of Bergen and approved by the Regional Ethic Committee of Western Norway (approval no. 2015/00122), see appendix A. Additionally, a separate written consent (appendix B) was obtained for this part of the study.

Variables for statistical analysis

Variables of interest were selected from the quality register based on results from prior research, as well as talking to clinicians working with EDs. On this basis we wanted to analyze whether BMI, age at referral, levels of anxiety and/or depression, severity of ED-symptoms, intensity of global psychological symptoms or degree of impairment as a result of the ED were any different in the group declining therapy compared to the group who chose to engage in therapy.

Eating Disorder Examination Questionnaire 6.0 (EDE-Q)

EDE-Q is a self-reporting questionnaire which consists of four subscales, namely: restriction, worrying about eating, worrying about figure and worrying about weight (Christopher G Fairburn & Beglin, 2008). The questionnaire summarizes the central symptoms and the severity of the respondents eating disorder. The validity and reliability of the questionnaire is found acceptable (Rose, Vaewsorn, Rosselli-Navarra, Wilson, & Weissman, 2013).

Clinical Impairment Assessment Questionnaire 3.0 (CIA)

CIA is a self-report questionnaire which consists of 16 questions. Measures the degree of psychosocial difficulties which is assumed to be a result of the eating disorder, with focus on the past 28 days (Bohn & Fairburn, 2008). Covers themes which are typically affected by ED psychopathology. These consist of self-perception, mood, interpersonal functioning, cognitive functioning and ability to work. CIA Global score is found to be a reliable and valid measure of impairment secondary to eating disorder symptoms (Maraldo, Fewell, & Vander Wal, 2021; Raykos, Erceg-Hurn, McEvoy, & Byrne, 2019).

Beck Depression Inventory-II (BDI-II)

BDI-II is a 21-item self-report inventory which is designed to measure the presence and degree of depressive symptoms both in psychiatrically diagnosed patients and in normal

populations, both for adolescents and adults. It has been accepted as one of the better self-report measures for this purpose, and it has been administered extensively (Dozois, Dobson, & Ahnberg, 1998).

Beck Anxiety Inventory (BAI)

BAI is a 21-item self-report inventory used to measure level of anxiety (Beck, Epstein, Brown, & Steer, 1988). The inventory measures both cognitive and physiological anxiety symptoms, and the validity and reliability of the questionnaire is found acceptable (Kühner, Bürger, Keller, & Hautzinger, 2007; Storch, Roberti, & Roth, 2004).

Symptom Checklist 90 Revised (SCL-90-R)

SCL-90-R is a self-report questionnaire consisting of 90 questions. Used for mapping of different psychological symptoms in adults both in the normal population as well as individuals with either medical or psychiatric disorders (Derogatis & Unger, 2010). Measures the respondents psychological state the preceding seven days, in terms of nine primary symptom dimensions and three summary scores known as global scores. The Norwegian version of SCL-90-R is found to have acceptable validity and reliability (Siquvelan, Moum, & Leiknes, 2016).

Statistical analysis

Statistical analysis was carried out using IBM SPSS Statistics (SPSS). The “treatment group” consisted of data material from 69 individuals starting treatment at DED, whereas the group consisting of people who declined therapy had a total of 21 individuals. For descriptive data, see appendix C. To test group differences between individuals who declined treatment and those who engaged in treatment, independent sample t-tests were employed. Within the group who engage in therapy, both inpatients and outpatients were included. We made use of baseline data for both groups. For statistical analysis we employed consecutive sampling. We

analyzed the variables age, BMI at referral, BDI total score, BAI total score, EDEQ global score, CIA total score and SCL-90 global score.

Table 1

Overview participants

Group of individuals	N	Percent
Accepting treatment	69	74.2
Declining treatment	21	22.6
Missing	3	3.2
Total	93	100.0

The qualitative interview guide

In developing the interview guide, we made use of information collected in a collaboration with ROS (Rådgivning for spiseforstyrrelser). This is a non-profit organization which offers a wide range of aid to people directly or indirectly affected by ED's. The councilors at ROS also have previous personal experience with ED's.

The employees at ROS had some valuable contributions to the interview guide both based on their own experience and the individuals seeking their help. According to them, a common conception amongst individuals offered treatment at DED is that the CBT-E program is a strict and rigid treatment regime. Some perceive the treatment as harsh, and in some cases impossible to accept. Thus, their experience indicates that the cognitive focus and perception of strictness of the CBT-E does not suit all patients. Due to this, we found it important to include questions in the interview guide related to how the treatment offer was presented and how this information was perceived. In addition, we added questions regarding whether the participants were missing something in today's treatment offer and which alterations would be necessary for them to accept the treatment offer.

Several individuals which the councilors at ROS have met were discouraged by what they believed to be a weight gain focus. Furthermore, a common conception amongst these individuals was that the treatment was too focused on cognitive factors instead of underlying problems which they believed to be the origin and maintenance factors of the ED. Talking about weight and BMI early in the treatment process could present an issue as the idea of gaining weight is a difficult and frightening thought for many patients. As a result of these remarks, we believed that it was crucial to include questions about how the participants experienced their meeting with the department and previous treatment programs.

According to the employees at ROS, several patients had the experience of having to lie about making progress. This came as a result of feeling like progress was a criterion for staying in the CBT-E program. Therefore, the employees at ROS believed that it would be important for the interviewees that the interviewers were not someone not working at the Department of Eating Disorders. See appendix D for interview guide.

Recruitment and procedure for the semi structured interviews

For this part of the study, we wanted to focus on the most commonly known eating disorders, namely anorexia nervosa and bulimia nervosa. We decided to exclude binge eating disorder and eating disorders not otherwise specified. Participants had to be former patients who agreed to be a part of the quality registry, signed a written consent and turned down the recommended treatment offer.

To recruit participants, we made use of the quality register at DED from 2018 to 2020. Eleven former patients who met the inclusion criteria were identified. Relevant candidates were telephoned from the department and asked if they wanted to participate in the study. We were not able to get in touch with three of these. The patients were given information about the purpose of the study, that the interviews would be conducted by a clinical psychologist not affiliated with the treatment unit and that they would be asked about

their experience of their meeting with the department, reasons for turning down the offer and if they have any thoughts on improving the admission process. Additionally, the patients were informed that participation was voluntary. Appointments were made in terms of what suited the participants best. Six patients agreed to participate in the study, but only four met for their appointments. All four participants were female students in their twenties.

The interviews were conducted by clinical psychologist Yngvild Danielsen at the University of Bergen. The interviews took place at an office at the university campus and lasted for approximately 1.5 hours.

Due to the Covid-19 pandemic and the restrictions this has resulted in, one of the interviews were conducted via Microsoft Teams. The interviews were audiotaped using the secure-video solution at the University of Bergen, and the soundtrack were directly transferred via a secure method, based on a wireless transfer to an encrypted server provided by the University of Bergen. The files were stored at a remote desktop via SAFE (Sikker Adgang til Forskningsdata og E-infrastruktur). Informed consent was signed by the participants prior to the interviews.

Qualitative data analysis

Our aim was to explore the individual participants' experiences and why they choose not to engage in therapy, and what they think can be possible improvements in today's assessment routines. For this purpose, we made use of reflexive thematic analysis, as described by (Braun & Clarke, 2006, 2019). We chose this method on the basis of its flexible quality to identify and analyze recurrent themes in the data. In addition, we found the fact that the method can be applied independent of theory and epistemology as a particular strength given our aim to search for the idiosyncratic experience of each participant. We see this as an advantage given the limited research conducted in this field.

We started by separately listening to the interviews to get to know the material, before we individually transcribed two interviews each. Subsequently, we went through each other's transcripts to assure the quality of the written text. We then read and re-read the material several times to familiarize ourselves with the data. Thereafter, we identified and coded the parts of the transcripts that covered our analytic focus. Text was coded and further organized into meaningful groups, before we sat down together to discuss the codes and identify and refine more broad themes from the data material. In line with the principles of reflexive thematic analysis (Braun & Clarke, 2019; Braun, Clarke, Hayfield, & Terry, 2018), we looked for shared meanings across the dataset, between the respondents, when generating the themes.

The themes identified were often redefined as we reread the material, developing a new understanding of the participants while working with the interviews. Thus, making the process of analyzing the data dynamic, reflexive and subjective. We believe that the final themes should not be viewed as fixed categories as it became prominent that several of them were closely related to each other. Still, we consider them to represent somewhat different aspects of the participants' reasons for not engaging in treatment.

Reflexivity

We are both psychology students in our last semester, and we have both been working in an inpatient psychiatric ward for the past years. In our education, clinical training and jobs, we have learned about and worked with people dealing with diverse challenges. Our background as psychology students have provided us with fundamental values and beliefs about how the human psyche works, which in turn may have colored the questions we developed in the interview guide, as well as our interpretation of the interview's answers and narratives as a whole. The same goes for the interviewer. She is a clinical psychologist and a scientist. Some of her clinical experience has been in the ED field. It is probable that her

values and understandings concerning this topic may have had a certain impact on her subtle reactions, the way in which she asked the questions and which follow-up questions and themes she chose to pursue.

We acknowledge the fact that we bring about a certain foundation of knowledge and understanding into our analysis of the interview data. We recognize that we carry with us a culturally conditioned understanding of the concept "eating disorders". Our understanding is first and foremost based on a psychological understanding as well as the time we live in.

Ethics

The participants were asked questions about why they declined treatment and if they have any regrets in doing so. This might evoke negative emotions and cause some to have second thoughts about leaving treatment. All participants therefore went through a short debrief (20-30 min) at the end of the interviews. In this conversation the participants were invited to share thoughts about how they experienced the interview and offered the possibility to discuss e.g., treatment options if this was on their mind. This conversation also served as a place to discuss and follow up on serious topics from the interviews, such as suicidal thoughts. Any participant had the opportunity to be rereferred to DED or other treatment options through a referral from their general practitioner.

The participants were asked questions about factors they might see as possible improvements on today's assessment routines. We argue that giving the participants an opportunity to give their view on how to improve today's treatment might feel rewarding and give a sense of contributing to something important.

It is crucial for the project that the participants feel that they can give honest answers without any possible consequences for future treatment. As mentioned by the employees at ROS, some patients found it difficult to be honest with their therapist. Thus, we argue that it

was critical that someone without treatment responsibilities or someone not employed at the DED conducted the interviews.

Results

Quantitative findings

Levene’s test for equality of variances was found to be violated for the present analysis, hence we computed a t-statistic not assuming homogeneity of variance.

The only variable which had a statistically significant different mean between the two groups was BMI. The group who declined therapy had a significantly ($p=.021$) lower BMI ($M=16.72, SD=2.76$) than the group who started therapy ($M=18.89, SD=5.50$).

Table 2

Results Independent Samples Test

t-test for Equality of Means	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% CI Difference	
						Lower	Upper
Age at referral	-.08	30.22	.94	-.22	2.75	-5.83	5.38
BMI	2.36	60.49	.02	2.18	.92	.34	4.03
BAI Total score	-.82	31.45	.42	-2.97	3.60	-10.30	4.37
BDI Total score	-1.71	28.08	.10	-6.70	3.91	-14.70	1.31
CIA total	-.13	31.35	.90	-.36	2.86	-6.20	5.48
EDEQ Global score	-.50	30.31	.62	-.19	.38	-.96	.59
SCL90 GSI	-1.08	29.77	.29	-2.93	2.72	-8.49	2.63

SCL90	-1.27	34.80	.21	-4.01	3.16	-10.44	2.41
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Qualitative findings

We have organized the themes into two main categories that differ from each other. One mainly deals with internal aspects whilst the other mainly deals with external factors.

The first part of the results concern themes in the interview material that we consider to indirectly answer the research question. These themes primarily concern the respondents' relationship to the eating disorder, their experience of its development and the situation they find themselves in. In our analyzes, these factors emerge as central to the individual's decision regarding treatment, both in contact with The Regional Department of Eating Disorders (DED), as well as other parts of the health care services. The participants highlight experiences and topics which became important in their decision as to whether or not they accepted the current treatment offer at DED. In addition, these were described as being central with regards to previous decisions concerning treatment for their ED in terms of seeking out, accepting or declining, engaging in, dropping out from or carrying out treatment.

The second category of themes which were identified dealt with aspects regarding the treatment offer, thus more structural or external considerations. These were also, but to a lesser extent, experienced as important in the participants decision making process. These themes did not appear as prominent as the previously mentioned category, nor as the most potent motives as to why the women chose to decline the recommended treatment offers.

As mentioned above, DED is a third line treatment offer, and all of the participants have received previous treatment at their local outpatient psychiatric clinic. Naturally, in the interviews these previous experiences were mentioned on several occasions. These were either brought up as a means of elucidating their "treatment narrative", or to exemplify

specific factors they were not particularly fond of. When the quotes are referring to such instances, this will be accounted for. The four respondents will be referred to as R1, R2, R3 and R4.

Aspects related to the ED

“I did not feel I had a problem” - Lack of awareness

Several participants described that they initially (at the start of the ED development) did not understand their symptoms as an eating disorder. Some described signs of something being wrong, but the citations below suggest that they were seemingly unable to take the symptoms seriously or in some way denied the symptoms as being part of an eating disorder.

R3 state:

When it first started, I didn't realize that it had begun. It was a bit like, it went a couple of months before I realized that this isn't normal, and this is a sign that something's wrong, but I didn't react to it at all.

In a similar fashion, R1 recounted:

It was ... I did not feel like I had a problem (...) In a way I did realize that I... I acknowledged that I was struggling, and things were difficult, but I don't think I grasped how serious it was.

The fact that the women did not recognize the seriousness of the situation made it difficult for them to both understand that they were in need of help, and also to utilize the help they were offered. Three of the women sought help through the traditional health services because they experienced somatic challenges such as low blood pressure and what they experienced to be heart problems. R2 narrates:

(...) then I was referred to a somatic examination for some somatic stuff and ...

wondered if I could have some diabetes or something, and ... yes. But they all found

the same. And then I went in for my heart, but they realized that the reason behind was restrictive eating and exercise.

In addition, all of the women initially report abdominal pain and dyspepsia. Two of the participants describe the fact that their symptoms were characterized as secondary to an ED as a shock. R1 states "(...) so it was at the end of January, I think, when they wanted me to be hospitalized and be an inpatient there. The fact that they saw this as necessary was a shock to me".

None of the women initially regarded their eating problems in a serious matter, but several state in hindsight that they should have grasped it earlier. R2 stated that "I did not understand how serious it was... I did not feel that I had a problem at the time".

A couple of the participants stated that despite inquiries from friends, family and health professionals who encouraged them to seek help for their eating problems, they were not able to see the severity of their problems. R1 said the following about her first meeting with therapy: "(...) I wasn't very motivated to do it... It was... I did not feel that I had a problem".

R2 describes how she thought that she could not be severely ill since she still was able to maintain her excessive walking:

I was able to be active. I wasn't bedridden ... so I thought that this couldn't be that bad, as long as I was able to walk all of my steps. I did that even when I was hospitalized at Haukeland on the somatic ward. I walked around in the hallways there and visited all the wards (laughter).

The laughter seems to demonstrate that she in retrospect finds this way of thinking illogical and that she is now able to acknowledge this as a symptom of the ED.

R4 explains her restrictive eating as a result of different types of abdominal pain instead of viewing her symptoms as an ongoing ED.

(...) it hasn't been for example that I wanted to become thin. The last few years it's been more like I had a stomach ache so I controlled the food intake to avoid this pain, so I can be able to run...

Furthermore, she states: “My main problem has not been the thought of gaining weight, but it's the fact that I get stomach ache”. Based on these utterances, it seems like this participant at this point does not view her restrictive eating as a symptom of an ED. This is despite the fact that she had been diagnosed with, offered and recommended therapy for Anorexia Nervosa. Earlier in the interview she explains that she has suffered from the eating disorder for seven years, and also that she would have wanted early interventions. Thus, she seems to have a conflicted cognition regarding her ED symptoms, now attributing it more as secondary to stomach ache. This may be an expression of the ambivalence commonly experienced by individuals suffering from ED.

“To take control” - Coping and creating security

All participants mention aspects of coping, security and control in relation to the eating disorder. These factors were described as particularly important, which in turn made it difficult to “let go” and to accept treatment in the health care system. R3 recount: “(...) to take control has always been important to me because my family and parents have always been unpredictable, very often being angry for no reason. Yes, in some way it made sense in the meaninglessness”. This woman describes her eating disorder as a way of taking control in a life that felt unpredictable and unsafe.

R1 reports that the ED symptoms became more prominent when other safe structures “vanished” (e.g., leaving studies, moving away from parents, Covid-pandemic). She states:

It was the corona pandemic, really. That I became so isolated... I have always experienced that during vacations (...) when I am alone over a longer period of time, then it becomes very... it's hard... (sobs, sounding sad) eh ... and that's what I

became at that point... and I usually use school as a way of distracting myself and digital lessons at home became too little in a way, it was too little to do (...) and so it became a very tough semester.

It seems evident that this participant makes use of external structures in her life to create predictability and safety. When these for some reason are limited, it seems like the eating disorder strategies, in the form of rules and restrictions, are familiar and easy at hand.

All of the women describe having had an ED for many years, and all of them describe the ED rules as their go to coping strategy, the “safe” option when faced with a demanding situation. As the development of the ED started at such an early age for all participants, one can speculate if the widespread use of these strategies has led to an insufficient development of alternative coping strategies. This can be interpreted as one important factor as to why the thought of letting the rules and restrictions go appears frightening to the women. If the familiar strategies are prohibited, the feeling of unpredictability and loss of control appears. As R3 puts it:

Eh, well, back then I didn't realize it. I didn't realize why it was so important really, before maybe last year, especially that summer. Eh, it was as if it gave me such an enormous feeling of security really. It was a bit like ... this summer I felt that it [the ED] was like a friend I have hated for many years, but at the same time it gave me a feeling of security which nothing else can match.

It becomes apparent how the aspects of loss of control and lack of predictability made it extremely difficult for her to make the decision of letting go of the eating disorder as it made her feel secure. All the women state that the eating disorder works or has worked as a coping strategy in various ways. As R2 recounted: “(...) well again it feels like something I can master and ... it's a bit like the more I gain weight the more I feel like I am just fat and can't accomplish anything”. This is similar to how R3 describes it “(...) when I don't eat, I feel like

I am accomplishing something. In a way it becomes a consolation for all the other things I am failing”.

Two of the participants cite eating restrictions as explicit coping arenas as a substitute for a lack of experience of mastering other areas, such as sports and school. R2 illustrates this mechanism through this statement:

(...) I had a period when I was a bit younger, and then I kind of felt like I managed it, but... well, yes. Or, at that time I put it [ED] aside, lived a normal life and tried out several different sports and such, and I feel like I've always been “so so”. Then... when I lost more and more weight, I kind of felt like “yes, I know how to do this” (...) it was a bit like I mastered it.

This statement illustrates how the ED mechanisms like restrictive eating in some sense is replacing participation in other important social arenas. When she experiences a lack of achievement in other arenas she seems to turn to the ED, as she experiences self-efficacy in relation to this.

Furthermore, two of them describe that this experience felt most prominent in the beginning of the ED-development. R4 went on describing that the restrictions offered mastery in the beginning. “(...) If you get into an eating disorder and stay there, or at least with anorexia, then you're likely to experience mastery and such, at least in the beginning”.

Over time, three of the participants experienced that their eating behavior has been a way to create security, control and predictability in a more explicit manner. The fact that the ED has been seen as a coping strategy has made the thought of letting it go difficult. When the interviewer asks R1 what is holding her back from accepting treatment she states: “That ... that I kind of want the control over my life that I have now”.

R3 describes that when she was offered treatment, she felt the decision process as an inner battle:

At the same time, it was a bit like “why should I do this?” because then I am going to lose the only thing that gives me meaning and security, and achievement. Because that’s also something that’s very important to me: achievement.

All participants state that having to undergo treatment to change behavioral patterns associated with the eating disorder, hence giving up control, will be experienced as anxiety provoking, as well as leading to restlessness and discomfort. R1 describes how breaking the routines associated with her eating disorder will create uneasiness and distress: “The feeling of, as you said anxiety and uneasiness, occurs when others are going to intervene and make changes”. Furthermore, she states:

Breaking routines is more uncomfortable to me, for example to eat something or not go exercising, than just exercise or just skip the food, in a way it’s ... it costs me nothing to do so [maintain routines], but to me it will be so extremely more costly to do it [breaking routines]. It will bother me for a whole day and affect my mood, and it will affect school, my concentration (...) uneasiness. It’s like, I usually say it’s like forgetting to close the garage door. That’s there just something there ...

This also goes for weight gain. Specifically, three of the participants mention that gaining weight will represent "the definition of losing all control" or "completely losing control", which in turn will lead to "fear, anxiety, restlessness" and "losing all security". R1 describes how the thought of engaging in therapy and thus having to gain weight makes her afraid: “It is all in a way related to me being afraid of gaining weight ... so if someone would change something that resulted in me gaining weight that is what would make me ... extra scared”.

“Liberating not to have emotions” - A means to regulate emotions

Several of the participants describe how they in different ways use their ED as a way of regulating emotions. For some, the somatic symptoms of the ED became a way of

repressing difficult psychological reactions and managing stressful life events. Yet others used restrictive eating to control physical pain such as stomach ache.

R4 reported that she occasionally used running as a means to wear out her body. She goes on describing this as a strategy to avoid feeling emotions:

The point is that there is a lot of anxiety and restlessness in the body. Or I have a lot of restlessness. You can say that if exercise has been a part of the illness then it was a way of ... I wanted to exercise in a way that made me exhausted. It wasn't about burning calories or something like that, I just wanted to be so tired that I was able to relax.

Thus, she does not describe the excessive physical activity as a symptom of the ED per se, but as a way of alleviating a bodily sensation of stress.

R2 reported using walking and working out to reduce restlessness, and to "shut everything out". She goes on explaining that she regulates anxiety through physical activity. She portrays it like this:

(...) I know now, when I go on long hikes, I only do it for that reason [avoid panic attacks which can come as a result of breaking her "ED rules"] but now I know. Back then it was more like I didn't know, I just walked and walked and walked and walked.

And later on: "I was very scared when I got there, I... But then I kind of found soothing through the steps. So, I just walked back and forth, back and forth, back and forth...". It becomes evident that this participant is using her excessive pacing as a means of keeping difficult feelings and uncomfortable bodily reactions at a distance. Although this seems to alleviate her distress in the short-term, it becomes evident for her that it is part of maintaining the ED symptomatology, as it serves as a positive reinforcement.

Furthermore, two of the women stated that they explicitly appreciate the somatic symptoms caused by being underweight. R3 state that she actually enjoys dizziness, low blood pressure and "a body that does not work", because this causes poor memory and less emotion, and furthermore that it feels "liberating not to have emotions". She describes it like this:

(...) I didn't want to lose any components of the eating disorder because I wanted to have a bad memory, and to have no feelings and I wanted a body that didn't work.
 (...) another big driving force was how liberating it was not to have emotions as a consequence of the eating disorder.

This participant describes how she is using the ED-symptoms in an explicit matter as a means for avoiding or distracting difficult emotions. The eating disorder might be a way of escaping conflicting feelings, difficult life situations or painful memories as the symptoms of being underweight makes the mind numb. Furthermore, she states:

I thought it was difficult to go to a therapist that I couldn't stand. And, eh, I was struggling socially with friends and family and it was getting close to Christmas when I was going to spend time with my family which was hard. (...) And then it was a lot of things that I dreaded (...) and then I did what I knew best, which was to not eat. And in a way I let myself get very ill from doing so... then I started getting stomach ache, like severe abdominal pain, especially at night time (...) and then it was like "am I supposed to eat when I have this much pain?" and then I felt like it helped to not eat during the evening.

After a period of this eating pattern, she developed an ulcer, which made her throw up because of the pain. She puts it like this:

(...) this created a nausea reaction in the stomach which made me throw up. It was kind of liberating as well, because it felt so good to be able to throw up without

having to put an effort in it, because I knew it didn't do my body good and that was actually kind of nice.

At the same time, she describes that the ache works as a maintaining factor, as she eats less when in pain. She also states the stomach ache as a possible effect of her restricted food consumption. In this way, the stomach ache functions both as a consequence as well as a maintaining factor, which becomes a reinforcing cycle.

“I lost a part of myself” - Hopelessness and loss

In addition to the participants viewing certain aspects of the ED as positive, in the form of keeping anxiety and discomfort at bay, three of the participants also state disbelief to the fact that a life without the eating disorder can render a better alternative. Several expressed feelings of hopelessness and loss. As a result, they have neglected to seek out the treatment apparatus explicitly, and furthermore to accept recommended treatment when offered. Several describe a feeling of hopelessness, and thoughts like "one can never get completely well" as R1 states. R2 narrates: “I think he [boyfriend] wants me to get completely well, but then you always read that it’s impossible to get completely well from it ... and well, what does “well” mean ...?”.

Three of the women also express a lack of motivation to change due to the loss of positive life aspects, which they possessed prior to the development of the ED. For example, both R2 and R4 stated that they no longer have friends who are “waiting”. R2 speaks about a lack of motivation to start treatment because she has already lost what seems important in life, her friends. She puts it like this: “Yes. And especially regarding social life. Cause it's not like they [friends] are sitting there waiting for me, it's like ... or, I don't really have a network any longer ...”.

R1 appeared sad and shed some tears as she stated that she does not believe that treatment can work for her. She went on saying that she considered the treatment offer she

has now been presented with at DED as "one last chance", which in turn leads to a fear of wasting her last opportunity to get better:

(...) it's a bit that this is in a way the last... for my part I think that this is the last, in a way... the last treatment I will try... with the admission... that I have somehow done, I feel, everything else. Ehm, that's also a part of the reason why I have been a bit reluctant to enter the treatment, and, because... I do not want to spend it [her last chance] in a way ...

Being ill for a long time and at a critical stage of development, many of the participants may have lost important life experiences which are crucial for developing adequate life skills across different social and practical areas. R1 describes how having an ED took such a huge part of her life that she had to "relearn" how to "be social" again. She explains:

(...) I was isolated all of high school (...) and because I was so ill [the ED] I could not be social and such, so to a great extent I lost that part of myself (...) we [her mother and the participant] decided I should attend to "folkehøyskole" (...) it would be a nice way to learn how to be social again in a way.

She speaks about her social skills as something which prior to the development of the ED was an important part of her identity, but in a way were replaced as her life got consumed by rules and restrictions. This in turn made her feel lonely and sad, and at this point she started to realize what the ED actually took from her.

Some of the participants describe how they want to get better but at the same time fails to carry out treatment. R1 expresses hopelessness and a feeling of failure as she's not able to do what she thinks the therapist or treatment program (from earlier experiences) is demanding of her. She puts it like this:

I did want to, but then I'm not able to, and I'm kind of not able to always admit the fact that I'm not able to accomplish it (on the verge of tears). So, in a way I just stay passive. Suddenly half a year has gone by without having carried out what I was supposed to.

When she speaks about this it becomes apparent that she does not want this to happen again, thus it represents a barrier for her. She is afraid of "failing" treatment, "failing" her therapist, and "failing" herself. It's as if she needs assurance of achievement to be willing to try again, one last time. The phenomenon regarding not being able to be honest in therapy also becomes apparent for R2:

But at the same time ..., yes, cause even though I'm motivated for treatment, it's also so ambivalent, and in a way, it becomes, yes ... to just spend an hour there and just sitting there telling lies about ... yes ...

A feeling of hopelessness and loss became prominent in several of the interviews, albeit in different ways. For R3 the ED has become an important part of her identity, which makes the process of letting go dramatic and painful. She describes it like this:

Yes, I kind of went through a very heavy process of grief this summer, it was a sincere process of grief where it felt like ehh, not as if something had died, but as if something was dying and I killed it. But I knew it had to die and it kind of ... and the fact that it was me who took the responsibility of killing it, that meant so much to me, it was completely awful and ehh... If I were to say goodbye to the eating disorder, I had to say goodbye to it (...).

This participant speaks about the ED as an important part of herself, as if it is an integral part which can only be separated and destroyed through a personal process where she takes a stand and says goodbye once and for all. To her, it's crucial that she is the one executing this process.

In addition, some of the ED characteristics appear to have become important aspects of the women's identities. Several of the participants describe the eating disorder and aspects of it as an integral part of themselves, thus making a decision to let go of these attributes is partly associated with a great experience of loss. R3 describes how the ED became something very personal and dear to her:

(...) the eating disorder, it was so painful to me and so close to my heart and so personal (...) with the eating disorder I just wanted to, hold it tight, keep it to myself. Eh, and in a way... it is much more vulnerable to acknowledge to others that it exists when I just wanted to keep it close and dear to myself.

Losing other important life experiences because the ED takes so much time and effort making the ED an integrated part of their life might be a reason as to why it is so hard to let go of the ED.

“I had to make the choice for myself” - Ownership to the Eating Disorder

The participants expressed that it was important for them to make the choice to accept treatment themselves. Several say that they opposed or reacted passively to previous treatment if they had not made the decision to seek help on their own. Some participants have negative experiences from previous treatments where they have felt pressured to accept a treatment offer, especially if they did not agree with the decision regarding whether they needed help or not. R2 describes that she went to treatment because she felt pressured by her mother and boyfriend, but that she did not herself feel the need for help. According to her, this meant that she was able to maintain eating in line with the ward's recommendations when she was hospitalized, but that as soon as she was on leave, she "snuck away" and stopped following the treatment plan. She describes that she was “cheeky enough to skip a few meals” and that she dropped more and more meals when she did not have staff around who monitored what she ate.

R1 says that she previously went into treatment because her parents wanted it, that she "remained passive, and let them take control", but that it slipped as soon as she was on her own and had to take responsibility herself. She describes it like this:

(...) I was very tired and fed up, but that in a way I just let my parents run the show.

They were the ones who gave me food, and they were the ones who controlled what I eventually got. And when I gained weight and became healthier physically so that I was allowed to start exercising, they were in control of that as well (...) so we found out I was going to "folkehøyskole" (...) but I also quickly realized that I had been very dependent on my parents because the food and exercise part slipped out completely.

All participants emphasized that it was important for them to feel ownership of the decision. To achieve the desired result, all of them stressed the importance of making the decision to go into treatment themselves, as well as actively taking part in the treatment. R3 puts it like this: "Well I, I kind of... ehh, it's me that has to do the job and that's why it's so important that it came from me. That it kind of, that it was me that had to feel it (...)". R4 puts it like this: "(...) maybe it [decision regarding treatment] has to grow a bit and such, but it's... but it can't feel like it's forced upon you".

In general, these women all feel like this autonomy and agency are inevitable factors to be able to engage in treatment and get well from the eating disorder. This is reinforced by experiences where this has not been the case. R3 describes one particular instance:

Yes, it was completely horrible to sit there and, in a way, let them feed me four times a day, I just had to follow their way of doing it, which in no respect created a feeling of coping within me.

Despite the fact that several of the women describes a desire to make a decision to engage in therapy, it's not quite that simple, as described by R1:

(...) it's not only because I am sick that I choose to not engage in treatment (...) it's thought through, it's not only because the sick part of me don't want to, it's also in a way the rational part of me thinking: don't use your last chance [to undergo therapy] only to please family and friends...

And furthermore:

Mm, I don't know exactly... it's a bit like what we have talked about earlier, it has to feel like its one's own choice, but ... still, it's really difficult because the sick part of me will always decline treatment. It's hard to tell if it's the sick part saying no or like we talked about earlier regarding motivation, and the fact that it has to be convenient timing (...) I don't think anyone (...) is able to carry out treatment or actually get well if they're not on it themselves (...) so it's not helpful when parents or friends or people around enforce it on you.

Although several of the participants express a wish for wanting to engage in therapy, it becomes clear that it's a double-edged sword. As the last quote illustrates, the decision-process is a battle between the “rational part” and the “sick part” of the self. On the one hand, recovery will entail a lot of positive effects, whereas the participants on the other hand are scared to see what might get lost in the process. This includes an uncertainty about “who am I without the eating disorder?”. This corresponds to the outspoken feeling of ambivalence the majority of people diagnosed with an ED experiences, as described in the introduction.

The above-mentioned themes regarding the ED seem to be central to the participants' decision-making process as they make up large parts of the interviews. The women also point to some aspects regarding the treatment offer itself which influenced their decision about whether or not to accept treatment. These themes are organized under the next category.

Aspects regarding the treatment offer

“Your terrain does not match” - Lack of flexibility

Three of the participants spoke of different aspects of the treatment that could possibly be improved. Higher flexibility and having the opportunity to choose a less manual based treatment program, as well as working with underlying issues were mentioned by the participants.

R4 expresses that the treatment program did not address the underlying reasons for her ED-symptoms: “It was also the fact that there was only focus on the food (...). They did not work with any of the underlying things in a way, or how I really felt”. She later goes on stating that she in previous treatment has experienced exclusively working with reaching a certain weight. To her this became problematic, as she did not feel like the therapist and her had a mutual understanding of her symptoms and the recovery process.

All but one of the participants describe that they perceived the treatment as too rigid and manual-based, with no room for individual adaptations. R2 states that she has been in inpatient treatment as a weight stabilizing measure, after which she was recommended further outpatient-based treatment with CBT-E. She was prepared and willing to say yes to this treatment before she came to the preliminary interview. In the first meeting with the therapist, this participant felt that accepting the treatment offered would be a step backwards, as this involved keeping diet lists. She states that before she was admitted she had been very busy weighing food and counting calories, something she had now managed to stop doing. She conveyed her concern to the therapist. Furthermore, she says:

In a way she [the therapist] to a great extent read from the book, and would absolutely not budge, and I could use the treatment, and I think there should be an arrangement where it was not necessary to keep track of what I was eating.

She reports that she as a result of this "did not feel heard", and that she would have agreed to the treatment if keeping diet lists had not been a requirement. In hindsight, she thinks the

therapy could have worked after some time, but states that her anger in the situation led to her spontaneous declining the treatment.

R4 also describes that she experienced the treatment as rigid, and that she "felt she needed to focus on other things than what the model facilitated". She describes that she was familiar with this model from earlier encounters and did not experience that this offer would suit her without making adjustments. She describes it like this:

In a way it was an OK meeting with the department, but it was, I guess I felt like ...
ok ... we have made a pre-designed map, and your terrain does not match, so you will
have to change the terrain instead of us changing the map.

R1 explains that she chose to decline the treatment offer due to practical considerations and difficulties in adapting the treatment offer to her life situation. Her specific offer entailed inpatient treatment, as opposed to outpatient treatment. She explains that she was shocked when she was told that inpatient treatment was recommended, as she herself had envisioned an outpatient service. According to her, one of the reasons why she declined this offer had to do with practical considerations. Being admitted to inpatient treatment would mean that she would have to take leave from her studies. In addition, she describes feeling that having to leave home for a longer period of time would be a major intervention in her everyday life and would cause her to lose flexibility and freedom. She goes on telling:

(...) I kind of want to maintain the control I have over my life now ... I don't want to
get locked up in a ward. I mean, I know I can have visitors and stuff, but ... I want to
be able to hang out with friends and live by myself.

Two of the women pointed to what they saw as specific shortcomings in the treatment offer. According to them, they may have come to a different decision regarding treatment if these wishes were fulfilled. R4 missed an interdisciplinary offer at the department. She had been actively involved in sports her entire life and described running as her most important hobby

and interest. She describes running as part of her healthy self, and not as a symptom of the eating disorder. Accordingly, she missed that the department could offer treatment which also focused on sports, and healthy physical exercise, and pointed to examples of such treatment options at other treatment facilities. She also describes that her wish would have been to work with a physiotherapist and a nutritionist combined with the psychotherapy offered at the clinic. She went on stating that being able to pursue her passion in a healthy and responsible way would be decisive in her treatment decision. She states that “(...) I think that would be a lot smarter. It would probably be, how should I put it, a bit pricier, but then it could actually be the case that one got well ...”.

R2 misses some kind of availability outside the outpatient follow-up hours. She says that in the long run, CBT-E might have given her tools that she herself could use in demanding situations, but that this would have been challenging to put to use by oneself in the beginning. Specifically, she points to meal situations as the most prominent. She states that the need for guidance is most potent in the real-life meal situations, not during the consultations at the psychologist's office. In this context, she proposes a treatment offer where the therapist could have been available by telephone.

“Grab a hold of it and motivate” - Finding motivation

The women describe various factors as prerequisites for accepting the treatment. These dealt with both aspects of the treatment itself, but also personal processes such as acceptance and motivation.

Three of the participants states that they perceived the treatment offer as a good offer despite the above-mentioned shortcomings. R3 describes her experience with the department like this:

In a way, I have no objections to the department. That it's kind of, yes, they... have made the right assessments all the way... and they have let me proceed at my pace.

That it has been very important really.

Three describe that they felt taken care of and safe in meeting with the department, but one describes an experienced lack of understanding of her individual situation. R4 expresses how she in previous meetings with the department felt unsafe to share openly with the therapist as she was afraid, she would lose her autonomy:

(...) when I got there, the communication with the therapist was not great... or somehow, I didn't open up. I kind of didn't feel safe... ehm... or safe was maybe a bit wrong, but in a way, I want to be good I think (...) I was probably a little scared too. Also possibly say [the therapist] that even if you say things, it does not mean that we have to change it...

She furthermore describes a fear of opening up to the therapist because she was afraid this would mean that she had to change, that everything she spoke about would be interpreted as a sign of the AN. In relation to this, she states that she would have liked the therapist to be more explicit about the fact that her opening up about her difficulties would not lead to any enforced changes. These negative experiences seem to undermine the respondent's motivation to accept treatment.

Several point out that it could have been positive if the therapist to a greater extent was involved in conveying hope and tried to address what the individual envisioned as their motivation for change, so that this could be used in the treatment process. R4 talks about the therapist being able to spend more time finding out what engages the patient and thus finding motivation to take part in treatment and work with the eating disorder. She describes it as follows:

(...) at the same time you must in a way be able to find out what interests you and engages you. And grab a hold on it and motivate (...). Also, in a way think about how it was before the disorder, what was it that made you happy then? And if you [the therapist] motivate in a way, try to grab a hold on it.

The participants also conveyed some thoughts about factors which influence the motivation to overcome their eating disorder, and moreover accept treatment. In this context, several of the participants described a desire to become less rigid, and to be able to regain flexibility in everyday life. Two of the participants talked about flexibility in relation to social factors, as they described a desire to be able to be with family and friends in contexts which included food and socializing. In their current situation, these participants saw their participation as impossible if food was involved, e.g., having dinner at a restaurant. R1 states:

Then I could go home more often, for example. I avoid going home so that I can avoid eating, or the fact that I don't eat with my friends, I can't eat out. I wish that I can be a little more normal, and in a way take part in fun things [with friends and family]. I'm pretty tired all the time.

R2 says that she has a strong desire to be able to eat or drink wine with her boyfriend, but this factor is currently not a big enough motivation in terms of accepting treatment.

You get tired of having to walk so much... so I wish I could have a normal meal with my boyfriend, and like being able to drink wine... now [due to Covid-19] it's not possible to go out partying, but somehow... I wish I could have gone out to take a drink with him, and stuff, and yes...

Furthermore, she describes a feeling of unrest in the mind and body just at the thought of having to go outside of her food restrictions. This feeling becomes so strong and uncomfortable that even trying does not seem worth it. R1 states a wish to be more flexible in

terms of working out, so that she can take part in vacations without getting up early to do so, which in turn will make it easier to relax.

Also, exercising, that it should not, in a way... that I do not have to plan my whole day around exercise or when I'm on holiday for example, don't have to get up super early to exercise or, yes, being able to skip it, and... yes.

The other two women convey that the motivation for change is to a greater extent linked to function and performance related to doing well in a school context and sports. R3 explains how she realized that she had to eat to function and perform in her studies: "Yes, it has also been like: I actually have to eat to function in school (...) it is extremely stupid to take these exams if the brain does not work". Furthermore, she describes a kind of maturation process where she previously lived in a kind of denial and thought that she did not need food, but that she has now come to a place where she realizes and accepts that she is dependent on food to be able to do well in her studies. She expresses that this realization made her more ready and motivated to receive treatment. She puts this in context with the fact that over time she has realized that she actually needs to eat.

Yes, sometimes I have to in a way just remind myself of the purely physiological and completely distance myself from my feelings, just think like, I do not know, just accept that I am like that like all other people. One is dependent on certain things such as food for example. Because most of the time I am convinced that I am the exception to all rules.

Discussion and conclusion

Reasons for declining therapy

The quantitative part of this study found that 22.6 % of referred patients declined treatment. These numbers are in line with numbers previously reported in the literature (Watson et al., 2013). This indicates that a large proportion of patients drop out even before

treatment starts. Combined with the large number of drop-outs reported in ED-treatment, one can debate if the available treatment offers are good or even adequate. It may be argued that the existing treatment offers may not be good enough. Even though outcomes for completers in some cases leads to remission, it can be argued that the existing treatment is insufficient and to some extent failing in its mission to successfully treat this severe disorder.

Our quantitative results are similar to previous findings, identifying few variables associated with drop-out (Gregertsen et al., 2019). In our analysis neither psychiatric comorbidity nor severity of eating disorder symptoms differed between the two groups of patients declining treatment and engaging in treatment. However, the group declining treatment had significantly lower BMI. This could indicate that patients with severe anorexia more often decline treatment than patients with other eating disorders. The quantitative analysis was conducted after the interviews. Thus, the interview guide was developed previous to these findings. Otherwise, it would have been interesting to explore this link in the interviews.

Based on the interviews we conducted, there seems to be complex reasons as to why the participants decline the recommended treatment. Two main categories were identified, respectively aspects related to the ED and aspects concerning the treatment offer. The themes within the first categories were related to lack of awareness of having an ED, coping and creating security, a means to regulate emotion, hopelessness and loss, and ownership to the ED. The aspects concerning the treatment offer were related to lack of flexibility and finding motivation. None of the aspects regarding the treatment offer were unanimous between the interviewees, as each of the themes were only mentioned by one or two participants. Thus, aspects regarding the treatment offer seem less prominent in the decision about whether or not to accept treatment.

Not being aware of the disorder made it difficult to seek out and accept treatment. The participants did not recognize their symptoms as being part of an eating disorder despite having friends and professionals express concern regarding their weight, eating habits and work out routines. Several explain that insight was absent even though the somatic condition was so serious they were in need of hospitalization. One can speculate if this lack of awareness can be a way of denying the disorder. The participants describe a shift towards acknowledging treatment as an option when they are aware and recognize their symptoms as an ED.

The respondents described how aspects and functions of the ED that were perceived as positive made it difficult to accept treatment. Several describe a sense of security, predictability and mastery, as weighing heavier than the possible positive aspects of getting well. Our results are similar to other qualitative findings in the literature e.g., viewing the ED as a coping mechanism (Nordbø et al., 2006; Skårderud, 2007). One of the respondents describes how the ED became worse during Covid-19. It seems like the ED symptoms give her some sort of predictability and security in a difficult and unpredictable time, hence using the ED as a coping mechanism. It is possible to speculate if this could be the case for others as well. This might explain why we have seen a rising number of ED-cases in Norway during the pandemic (Befring, 2021; Sundquist, 2021). Naturally, our sample is too small to draw any conclusions regarding this topic.

Three of the participants speak about a limited social network, and how this will not automatically improve through undergoing treatment, making them less motivated to accept treatment. It may seem like several of the women are not able to see the benefits of recovery because they have lost a lot along the way when living with an eating disorder for many years. The loss appears to primarily concern social networks and friends, but our interpretation is also that lack of time spent with peers in an important developmental period

has led to less opportunities for social and emotional learning. All of our participants describe that the symptom development started at a young age, although this was not obvious to them at first. One can speculate that time and energy consumed by the ED symptoms in this time period may have led to missing out on valuable moments regarding bonding with friends, experiencing disagreements and disappointments. Missing out on such moments could have led to less opportunities to develop both social, emotional and functional coping skills. This becomes apparent in statements concerning how the ED is seen as the most potent coping skill for several of the participants. Lacking more functional coping strategies might make it even harder to seek treatment. Furthermore, several of the participants state that low calorie intake has led to lower cognitive functioning and reduced energy level. It is conceivable that the calorie deficit has meant that these women have not had the surplus to participate fully socially. In turn, this may have contributed to reduced active involvement on these arenas. Additionally, the decreased energy and cognitive functioning might have contributed to a reduced ability to perceive, process and learn from social experiences.

Another consequence of restrictive eating and excessive exercising can be impaired ability to experience emotions, a kind of numbness which for some of our participants was described as liberating. Using this aspect of the ED as a way of regulating and handling both emotional and physical pain might be one of the reasons as to why it is so hard to let go of the ED. Keeping difficult emotions at bay might be an important factor when considering whether or not to accept treatment. This might especially be the case for those who are vulnerable to developing emotional dysregulation, e.g., individuals who have experienced childhood trauma. Interestingly, this coincides with research linking increased drop-out numbers with higher rates of early life events such as sexual abuse or parental break up.

Although the emotional numbness is described as liberating, several express a wish for working with underlying issues which in turn can make them deal with emotional distress

in a more functional manner. Distancing oneself from the emotional experiences in life might result in lacking experiences with emotional pain, and how to overcome and grow from these incidents. Thus, developing adequate emotional coping skills entails facing the situation and one's own reactions, and learning from these. In this way emotional difficulties can be viewed both as a risk factor and maintaining mechanism for the ED. These assumptions are in line with Oldershaw et al. (2019), describing AN as arising from a "lost sense of emotional self".

Some studies cite ambivalence as a possible factor in drop-out (DeJong et al., 2012; Leavey et al., 2011). The ED is described as both positive and negative which in some ways acts as a safe friend, but which at the same time acts as an enemy who gets in the way of social life and unfoldment in other arenas (Serpell et al., 1999; Williams & Reid, 2010). This seems to be the case for our participants as well, though only one participant actually mentions the word ambivalence. In several of the participants, ambivalence seems to emerge as a theme in the interviews, though not necessarily in an explicit matter. The women seem to be torn between, on the one hand, wanting to get well and participate in a normal social life on an equal footing with others. Each and all describe that they would like to get treatment, and that they wish to get well. Two of the participants states that there is nothing to complain about regarding the treatment offer, and have some difficulty pointing out explicitly how DED could improve its treatment. While at the same time they do not want to let go of the eating disorder which in many ways has become part of their identity and security in life, thus entails positive aspects which they do not want to lose such as the feeling of control, security and achievement.

It seems that aspects regarding the eating disorder itself contribute to the women not wanting to undergo treatment. Several of them want to postpone the decision and do not appear ready to let go of the ED yet. At the same time, they present difficulties explaining

when and where would be the right time, and what the optimal treatment offer should consist of. This coincides with the clinical experience described by the therapists at DED, with the experiences described by ROS employees and the descriptions of the various participants. This raises the question of whether ambivalence might be best understood as a part of the eating disorder itself, which in turn means that the person with the eating disorder will hardly experience feeling ready as long as he or she is actually ill.

An interesting finding is that several of the participants mention abdominal pain in connection with the ED. In which direction this relationship is explained varies somewhat between the participants, but also within the interviews. A couple of the participants explicitly say that their gastro-intestinal problems are caused by the restrictive food intake, while they later describe the gastro-intestinal problems as a result of and a maintaining factor for low food intake. In one of the participants, these descriptions occasionally sound like denial of the underlying problem. She initially describes that she has an eating problem, after which she states that the restrictive eating is solely a result of abdominal pain. Whether this is an expression for the EDs dynamic character, or actual denial is not clear, but the shifts in descriptions are interesting. Nevertheless, it is remarkable as all, but one respondent highlights abdominal pain as important in the development and maintenance of their ED.

Several pointed to the fact that they perceived the main focus in treatment to be aimed at increasing food-intake and weight, with a lack of working with underlying emotional suffering, and the basis for the ED development. This indicates that the informants consider working therapeutically with emotions as central to eating disorder treatment and essential for long term recovery or being able to stay in treatment.

Based on the participants' answers, it became evident that some of the factors they missed (e.g., working with underlying causes) in the treatment offer are actually part of the current treatment offer. However, these apply later in the treatment course. The aim of our

interviews was to look at the participants' *experience* of the meeting with the department and the reasons for their rejections, not to evaluate the actual treatment offer. Nevertheless, this raises the question of how one can best describe treatment to new patients. What are the most essential aspects or goals to agree upon and how is user involvement practiced? It is problematic if patients decline treatment on the basis of perceived shortcomings in the treatment, if these are not actually present. This shortcoming constitutes an important aspect listed by more than one of the women. It seems evident that this calls for a more explicit formulation of what the treatment offers entail, especially concerning topics addressed in therapy.

All of the participants mainly spoke about factors related to the eating disorder itself as important in their decision, rather than quantifiable and demographic variables. As a consequence, using quantitative research in the search of reasons for drop-out might be complicated. Research questions regarding reasons for not engaging in ED treatment may better be explored using other methods or that other variables need to be included.

The research conducted on the ED field has to a great extent been within the quantitative tradition. In studies examining aspects of the ED, the focus has also to a great extent been on symptoms (DeJong et al., 2012; Fassino et al., 2009; Gregertsen et al., 2019; Linardon et al., 2018), rather than the functions of the ED. In the qualitative part of this study, the functions of the ED were listed as important for each and all.

As mentioned, there are many examples of studies examining drop-out from treatment. Despite the fact that a lot of research has been conducted regarding which variables can explain drop-out, differences in the methodology create challenges in viewing the results as a whole. Several problems with these studies have already been presented. First and foremost, the definition of drop-out varies widely between studies, which has led to challenges associated with summarizing the findings in meta-analyzes (DeJong et al., 2012;

Fassino et al., 2009; Gregertsen et al., 2019; Linardon et al., 2018). Some of the drop-out studies also include early drop-out, and in a few cases drop-out is defined as declining treatment directly after initial assessment conversations. A more precise term for this phenomenon might be "failure to engage" (FTE). This term has been referred to in a few studies (e.g., Bell, 2001), but the literature seems to be scarce on this specific topic. This group is roughly defined by Bell (2001) as people who are referred to a service, but who do not show up for their initial appointment.

The nature of the ED is dynamic, and patients may choose to decline treatment at different points in the assessment. It might be better to use FTE as a description of the group of people who choose to decline treatment after initial assessment, but before they have started the actual treatment program. Additionally, it could be interesting to single out the no-shows in a subgroup or different definition. In this way, the literature will be able to differentiate between people who do not show up for their first appointment, people who decline treatment after receiving an offer, and people who drop-out during different stages of treatment. It is plausible that the group of people who choose to decline treatment after initial assessment may have other reasons as to why they do not wish to proceed with the recommended treatment, compared to other drop-out groups. Further research on this particular group is needed to investigate these assumptions.

Valuable corporation

An interesting discovery in our work is that the user organization ROS had almost exactly the same hypotheses about the participants' experiences, as the participants actually communicated. This should not be a surprise as ROS has been in contact with numerous people who have been in contact with DED. In addition, several of the employees we spoke to have personal experiences with ED. This illustrates how important user involvement is,

and to which great extent someone with personal experience can illuminate both positive aspects and shortcomings.

Implications and further research

Based on the information presented in the results and discussion above, some clinical implications will be suggested in the following section.

Our findings suggest that the patients referred to DED could benefit from being better informed about what treatment entails, before assessment. It can be argued that socialization to the treatment should start already at the second-line level. This could contribute to a process in which one starts working with ambivalence earlier. In turn, this can help the patient understand the symptomatology beforehand. In this process it could be beneficial to examine the functional aspects of the ED in cooperation with the patient. We base this suggestion on the fact that two of the participants did not recognize themselves in the description of the symptom severity at the initial meeting with the department. Such a process may contribute to reducing resistance, which is a natural result when caught off guard in this kind of situation. Additionally, a greater focus on this process can contribute to the patients feeling met and understood by the therapist.

A direct implication of the findings could be that DED creates a standardized informational source which can be made available for the public, but especially distributed to all first- and second-line treatment facilities, as well as user organizations. This should entail information about the different treatment offers, and thematize important issues like how it is normal to feel ambivalent, acknowledging that the decision process is challenging, validating the EDs perceived functional aspects and stressing that underlying issues will be worked with. Through a collaboration with ROS, one could adapt the initial information in such a way that the patients get a clear picture of what treatment entails.

An ED can originate conflicting emotions, as described both in the previous literature and by all our respondents. Thus, one of the core features with having an ED seems to be ambivalence. This raises the question if it is even possible to feel *completely* ready to undergo treatment in an initial phase. One major dilemma that arises for the clinicians is the balance between pushing and keeping the patient's autonomy. Open dialog and validation of the perceived positive functions of the ED is of great importance when dealing with ambivalence.

Based on the participants' experiences, it could be beneficial if treatment at DED to a greater extent focus on conveying hope regarding developing more functional coping strategies to handle emotional reactions. We acknowledge that working with this is part of the treatment, but our findings suggest that this is under-communicated to the patients. One way to address this challenge could be to have greater focus on conveying this message, which in turn can contribute to developing hope, motivation and self-efficacy in the patients.

In further research, it would be useful to have a more standardized and transparent terminology in the ED-field regarding the definitions of drop-out used. As mentioned earlier, we advocate for a more elaborative use of the term “failure to engage” instead of the, in our opinion, too broad use of *drop-out*.

In addition to the aforementioned, it is proposed that the link between EDs and abdominal pain should be examined further. It would be interesting to explore how these two are related, and how this can be taken into consideration in a treatment setting. In relation to this, it would be interesting to look at possible causal links, as well as exploring the theme further through qualitative design.

Lastly, our findings suggest that the perceived positive aspects of the ED and their functions should raise greater attention as our findings suggest that these might be especially important factors in the decision-making process. Using both qualitative and quantitative to

examine the function of the ED in relation to failure to engage and drop-out could give a broader understanding of this topic.

Strengths and limitations

There are several shortcomings regarding our study. First and foremost, the quantitative dataset consisted of a scarce sample size, N=90 (3 missing). The “treatment group” consisted of data material from 69 individuals, whereas the group consisting of people not engaging in therapy had a total of 21 individuals. This small sample size makes it difficult to carry out statistical analysis, and its ability to generalize is limited. In addition to this, the groups were only broadly defined. The group of individuals who did not start therapy consists both of people who decline treatment because they do not want the recommended offer, but it also includes individuals who actually for different reasons do not receive a treatment offer after an initial assessment round. This made it difficult to single out the individuals which actually declined treatment from those who were not offered one after initial assessment. Thus, we face some of the same challenges as has been described in the literature, as well as our aforementioned critique of the definitions in the research field.

In the process where we found participants for the interviews, it proved challenging in several cases to separate the different groups. A large proportion of the individuals which are referred to the department may in an initial phase say no, before they on a later occasion choose to accept treatment, or where the person starts treatment and later drops out, subsequently returning after a period of time. The same applies to the definitions in the quality registry, where no distinction is made between the reasons as to why someone does not start treatment.

Additionally, the qualitative sample was small, which leads to scarce opportunities with regards to generalizing our findings, or other additional themes might have emerged if we had more informants. On the other hand, this study may contribute to valuable insight to

the therapists at DED, both in their assessment routines, but also as hypothesis-generating information in further research. Our aim for this study was to catch the individual participants' idiosyncratic experience, which is valuable information itself, and to our knowledge, largely missing in this area.

Another possible shortcoming is the fact that due to the Covid-19 pandemic; it was not possible to arrange physical meetings for all the interviews. One of the participants had to be interviewed through video. This may function as a barrier in the interview setting with regards to opening up and being vulnerable when speaking about such personal and important themes. On the other hand, this may have served as a safe solution for the participant as the screen can function as a barrier which creates a perceived safe distance. In this case it may be easier to share inner thoughts. On the interviewer's hand, not sitting in the same room as the participant makes it more difficult to read body language and atmosphere. In turn, this may reduce the interviewer's possibility to ask the best follow-up questions and tune in emotionally adequately based on the appearance of the participant.

Our participants were all women, of almost the same age and similar living and working situations. In addition, we only interviewed participants who have been in contact with one specialized department, making it difficult to generalize findings. This is a regional department which works according to evidence-based methods, so there is no obvious reason why large differences had been found in people who have met with similar departments, but it would have been interesting to do a larger-scale study with participants from all parts of the country.

Being students, our knowledge and experience about thematic analysis is limited. This might be a limitation, especially as we are fresh learners of interpretation of qualitative interviews. Yet at the same time viewing the data material as students with sparse research knowledge and clinical experience might be an advantage as we are less affected by specific

treatment directions or scientific perspectives. However, being fully open minded will never be possible. As mentioned earlier our background in psychology is an important part of our understanding of the participants.

Based on our findings and previous literature we argue that using a mixed method design is an advantage in this field since there seems to be complex reasons as to why some fail to engage in therapy. To our knowledge there exists a limited number of qualitative studies exploring drop-out and failure to engage, making it especially important to include a qualitative approach in the understanding of this subject. We suggest that using a mixed method design gives us a broader understanding of the topic, as well as the opportunity to illuminate some of the perceptions from people with personal experience with ED.

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Appendix A



Region: REK vest Saksbehandler: Camilla Gjerstad Telefon: Vår dato: 18.06.2020 Vår referanse: 55304
Deres referanse:

Guro Årdal

55304 Faktorer som påvirker behandling og frafall fra spiseforstyrrelsesbehandling i spesialisthelsetjenesten.

Forskningsansvarlig: Helse Bergen HF - Haukeland universitetssykehus

Søker: Guro Årdal

Søkers beskrivelse av formål:

Hovedformålet med studien er å produsere kunnskap som kan hjelpe oss å forstå mer om vansker med å engasjere seg i og frafall fra behandling for spiseforstyrrelser. Studien består av flere deler, for å få utforske perspektivet til de sentrale aktørene i behandling av spiseforstyrrelser – pasient og behandler. Det vil derfor gjennomføres fokusgruppeintervju med behandlere og individuelle intervju med personer som har valgt å avslutte behandling for spiseforstyrrelse før denne var fullført, samt personer med spiseforstyrrelse som har valgt å takke nei til behandlingstilbud. I tillegg vil vi gjøre en registerundersøkelse ved hjelp av data fra "Lokalt register for spiseforstyrrelser" ved Avdeling for spiseforstyrrelser ved Haukeland Universitetssykehus, for å se hvilke faktorer som predikerer drop out fra og effekt av spiseforstyrrelsesbehandling.

REKs vurdering

Vi viser til din tilbakemelding mottatt 11.06.20 for ovennevnte forskningsprosjekt. Tilbakemeldingen er behandlet av komiteleder for REK vest på delegert fullmakt fra komiteen, med hjemmel i forskningsetikkforskriften § 7, første ledd, tredje punktum. Søknaden er vurdert med hjemmel i helseforskningsloven § 10.

REK vest ba om tilbakemelding (vedtak 26.05.20)

REK vest ønsket tilbakemelding på følgende:

- REK vest vil anta at de pasientene som dropper ut, men som er i kontakt med ROS vil være en litt annen gruppe enn de som dropper ut og som ikke har kontakt med ROS. Komiteen vektlegger at også disse pasientene bør bli representert. Finnes det andre måter å komme i kontakt med dem som har droppet ut av behandlingsapparatet og som heller ikke er i kontakt med det frivillige støtte/hjelpeapparatet? Vil det være mulig å legge til en anonym spørreundersøkelse på nett for å sørge for å få med perspektivene til denne gruppen? REK vest ber om tilbakemelding.
- Det bør legges opp til at det er erfarne psykologer som gjennomfører pasientintervjuene.
- Informasjonsskrivet må revideres og sendes til REK vest.

REK vest

Besøksadresse: Armauer Hansens Hus, nordre floy, 2. etasje,
Haukelandsveien 28, Bergen

Telefon: 55 97 50 00 | E-post: rek-vest@uib.no
Web: <https://rekportalen.no>

- Stipendiaten og masterstudentene er ikke oppgitt som medarbeidere i søknadsskjemaet. Vi ber om at alle medarbeidere (navn, grad, institusjon, rolle) oppgis.
- Data skal ikke sendes til utlandet, men det opplyses om at det er samarbeid med Italia. Hva består samarbeidet i?

Tilbakemelding fra prosjektleder

- *Vi er enig i at det er en risiko for at pasientene vil kunne tilhøre to ulike grupper. Vi har nå utarbeidet et informasjonsbrev med informasjon om studien samt med informasjon om anonym spørreundersøkelse. Vi ønsker å invitere ulike DPS i Helse Bergen, samt Avdeling for spiseforstyrrelser ved HUS, om å sende ut informasjonsbrev om studien til alle pasienter som avslutter eller takker nei til spiseforstyrrelsesbehandling fra prosjektstart og ett år frem i tid. Se vedlegg for informasjonsbrev samt vedlegg for anonym spørreundersøkelse. Pasientene får i informasjonsbrevet opplysninger om hvem de kan kontakte om de ønsker å delta i intervjudel av studien, samt informasjon om at de kan logge seg inn anonymt på nett og fullføre kort spørreundersøkelse i SurveyXact dersom de ønsker å delta.*
- *DPSer vil få tilbud om å bidra i studien. For å øke sannsynlighet for deltagelse fra DPS sin side ønsker vi å tilby to timer internundervisning av psykolog fra avdeling spiseforstyrrelser. En før oppstart hvor en gjennomgår status spiseforstyrrelsesbehandling og sentrale utfordringer samt en etter deltagelse hvor data blir presentert. Dette vil også falle inn under oppdrag som Regional avdeling spiseforstyrrelser har i forhold til opplæring og formidling av kunnskap opp mot DPS. Deltagende DPSer vil bli fulgt opp av medarbeider i prosjektet underveis for å øke forpliktelse til utsendelse av brev til aktuelle.*
- *Dette er nå endret slik at psykolog eller psykologspesialist tilknyttet prosjektet vil gjennomføre pasientintervjuene. Vi vil sørge for at intervjuet gjennomføres av psykolog som ikke tidligere har vært pasientens behandler.*
- *Skrivene er oppdatert*
- *Stipendiat kandidat: Cathrine Nitter, mastergrad, ansatt ved ROS (Som stipendiat vil hun være tilknyttet Institutt for Klinisk Psykologi, UiB. Rolle i prosjektet: medarbeider. Psykologstudent Oda Dybvik Dahlsveen, UIB, Rolle i prosjektet: medarbeider. Skriver hovedoppgave på dataene. Psykologstudent Maren Erstad, UIB, Rolle i prosjektet: medarbeider. Skriver hovedoppgave på dataene. Psykologstudent Katharina Stoll, UIB, Rolle i prosjektet: medarbeider. Skriver hovedoppgave på dataene. Psykologstudent Caroline Emilie Tellefsen, UIB, Rolle i prosjektet: medarbeider. Skriver hovedoppgave på dataene*
- *Det skal ikke utleveres data til utlandet. Samarbeidet med Italia består i klinisk veiledning samt samarbeid rundt forskning på feltet. Konkret kan være aktuelt å samarbeide om publikasjoner på prosjektet der dette treffer ifht klinisk og forskningskompetanse.*
- *Oppsummert og tilleggsopplysning: Vi har nå gjennomgått tilbakemelding fra REK Vest og gjort endringer ihht denne. Under gjennomgangen oppdaga vi at 3 av spørreskjemaene som er en del av kvalitetssikringsarbeidet og beskrevet i DPLA (sendt personvernombudet) ikke er kommet med i søknaden. Disse spørreskjemaene er ikke beskrevet i protollen som REK først fikk tilsent men er beskrevet nå. Dette gjelder: ROMA III/IV, The irritable bowel severity scoring system (IBS-SSS), Gastrointestinal symptom rating scale (GSRS).*

Vurdering av tilbakemeldingen

REK vest ved komitéleder har vurdert tilbakemeldingen. REK vest finner at prosjektleder

har besvart komiteens spørsmål på en tilfredsstillende måte. REK vest minner om at prosjektittitelen bør være den samme i informasjonsskrivene som i REK-søknaden. Det må fremgå av informasjonsskrivet at REKnr er 55304. Vi har ingen ytterligere merknader.

Tillatelsen gjelder frem til prosjektslutt 01.07.2025. Opplysningene kan oppbevares i fem år etter prosjektslutt av etterkontrollhensyn. Deretter skal data slettes eller anonymiseres.

Vedtak

Godkjent

REK vest har gjort en helhetlig forskningsetisk vurdering av alle prosjektets sider. Prosjektet godkjennes med hjemmel i helseforskningsloven § 10.

Med vennlig hilsen

Marit Grønning
Professor dr.med.
komiteleder REK vest

Camilla Gjerstad
rådgiver

Sluttmelding

Søker skal sende sluttmelding til REK vest på eget skjema senest seks måneder etter godkjenningsperioden er utløpt, jf. hfl. § 12.

Søknad om å foreta vesentlige endringer

Dersom man ønsker å foreta vesentlige endringer i forhold til formål, metode, tidsløp eller organisering, skal søknad sendes til den regionale komiteen for medisinsk og helsefaglig forskningsetikk som har gitt forhåndsgodkjenning. Søknaden skal beskrive hvilke endringer som ønskes foretatt og begrunnelsen for disse, jf. hfl. § 11.

Appendix B

Forespørsel om å delta i forskningsprosjekt

«Hvorfor velger noen pasienter å takke nei til tilbud om behandling ved avdeling for spiseforstyrrelser?»

Formål

Prosjektet gjennomføres i regi av Institutt for Klinisk Psykologi ved Universitetet i Bergen. Formålet med studien er å undersøke hvilke årsaker som bidrar til at pasienter som har fått et tilbud om behandling ved Avdeling for Spiseforstyrrelser ved Haukeland Universitetssykehus velger å takke nei til behandling på tross av at behandler ved avdelingen anbefaler å igangsette et behandlingsforløp. Vi ønsker å undersøke deltakernes idiosynkratiske opplevelse av møtet med avdelingen, samt få å få innblikk i årsakene til at vedkommende takket nei, og eventuelt om han eller hun har tanker om hvilke forhold som kunne vært forbedret for å øke sannsynligheten for igangsetting av behandling.

Resultatet fra forskningsprosjektet kan bidra til økt forståelse for hvordan pasienter opplever møtet med Avdeling for Spiseforstyrrelser, og potensielt til forbedring av behandlingstilbudet for personer med spiseforstyrrelser. Resultater fra studien vil formidles i en hovedoppgave ved profesjonsstudiet i psykologi, samt i forskningsartikler. Informasjonen som presenteres i intervjuene skal ikke kunne knyttes til personidentifiserbare opplysninger om deg.

Hvem er ansvarlig for forskningsprosjektet?

Prosjektet utføres i regi av Institutt for Klinisk Psykologi (IKP) ved Universitetet i Bergen. Prosjektleder er Førsteamanuensis/psykologspesialist Yngvild Sørebo Danielsen. Profesjonsstudenter i psykologi, Oda Dahlsveen Dybvik og Maren Cecilie Erstad vil intervju, transkribere og analysere intervjuer fra prosjektet til sin hovedoppgave under veiledning av Yngvild Sørebo Danielsen og Guro Årdal Rekkedal, psykolog ved Avdeling for Spiseforstyrrelser.

Hvorfor får du spørsmål om å delta?

Vi søker deltakere som har vært på inntakssamtale på Avdeling for Spiseforstyrrelser, men som selv har takket nei til tilbud om behandling. Vi søker personer som ønsker å dele sine tanker og erfaringer rundt denne prosessen med oss.

Hva innebærer det for deg å delta?

Dersom du ønsker å delta innebærer dette at du deltar i et forskningsintervju ved Universitetet i Bergen. Intervjuet vil ta 2-3 timer og gjennomføres av en av psykologstudentene tilknyttet prosjektet. Intervjuet inneholder spørsmål om din opplevelse

av møtet med Avdeling for Spiseforstyrrelser, hvorfor du valgte å takke nei til behandling, og eventuelt informasjon om forslag til forbedringer ved tilbudet. Intervjuet har ikke en terapeutisk hensikt. Dine svar vil bli tatt opp på lydbånd og lagret i henhold til personvernloven. Lydopptakene vil bli behandlet konfidensielt. Lydopptakene vil så snart som mulig bli omgjort til skriftlig form, som vil lagres uten navn eller personidentifiserbare opplysninger. Vi vil deretter undersøke innholdet og se etter tema som går igjen i svarene fra de som har blitt intervjuet.

Mulige fordeler og ulemper

Prosjektet gir deg som deltaker mulighet til å dele dine erfaringer, og til å bidra til kunnskapsutvikling. Mulige ulemper er at intervjuet tar tid å gjennomføre, og at noen av temaene som kommer opp potensielt kan oppleves vanskelige å snakke om.

Det er frivillig å delta

Deltakelse i prosjektet er frivillig. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Hvis du i løpet av intervjuet eller etter intervjuet finner ut at du ikke lengre ønsker å delta, kan du til enhver tid trekke samtykket tilbake uten å oppgi grunnen for dette. Dersom du trekker deltakelsen, kan du be om å få slettet de innsamlede opplysningene, med mindre opplysningene allerede har inngått i analyser eller har blitt anvendt i vitenskapelige publikasjoner. Alle opplysninger om deg vil bli anonymisert i publikasjoner og formidling av resultater. Det vil ikke ha noen negative konsekvenser for deg dersom du velger å ikke delta, eller dersom du trekker deg på et senere tidspunkt. Dersom du ønsker å trekke deg eller ønsker mer informasjon om prosjektet, kan du kontakte Yngvild Sørebo Danielsen, tlf. 48117634, e-post: yngvild.danielsen@uib.no.

Personvern – oppbevaring og bruk av dine opplysninger

Opplysningene vi samler inn om deg skal kun brukes slik vi har beskrevet under «hensikten med prosjektet». Du har rett på innsyn i opplysningene som er registrert om deg, og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene. Alle opplysninger vil bli behandlet uten navn og fødselsnummer, eller andre direkte gjenkjenner opplysninger. En kode vil bli knyttet mellom deg og dine opplysninger gjennom en navneliste. Det er utelukkende prosjektleder Yngvild Sørebo Danielsen som har tilgang til denne listen som lagres på et eget område på forskningsserveren. Opplysningene vil bli oppbevart i inntil 5 år av dokumentasjonshensyn eller vilkår fra Regionale komiteer for medisinsk og helsefaglig forskningsetikk. Datamaterialet vil lagres ved bruk av SAFE- Sikker Adgang til Forskningsdata og E-infrastruktur. SAFE bygger på Norm for informasjonssikkerhet i helse- og omsorgstjenestene og sikrer at informasjonssikkerheten med hensyn til konfidensialitet, integritet og tilgjengelighet blir ivaretatt ved behandling av sensitive personopplysninger. Deltakerne vil ikke kunne gjenkjennes i den skriftlige formidlingen av resultater fra prosjektet, alle svar vil være anonymisert.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

Godkjenning

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har gitt forhåndsgodkjenning saksnummer REK 2015/00122.

Etter ny personvernlov har behandlingsansvarlig Universitetet i Bergen og prosjektleder Yngvild Sørebo Danielsen et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6 nr. 1a og artikkel 9 nr. 2a. På oppdrag fra Universitetet i Bergen har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

Hvor kan jeg finne ut mer?

Dersom du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Institutt for Klinisk Psykologi, Universitetet i Bergen ved Yngvild Sørebo Danielsen. E-post: yngvild.danielsen@uib.no
- Avdeling for spiseforstyrrelser, Haukeland Universitetssykehus ved Guro Årdal Rekkedal. E-post: guro.ardal.rekkedal@helse-bergen.no
- Personvernombud ved Universitet i Bergen, ved Janecke Veim. E-post: janecke.veim@uib.no
- NSD – Norsk senter for forskningsdata AS, e-post: personverntjenester@nsd.no, eller telefon: 55582117

Med vennlig hilsen

Yngvild Sørebo Danielsen
Prosjektansvarlig
(Forsker/veileder)

Oda Dybvik Dahlsveen,
Maren Cecilie Erstad,
(Psykologistudenter)

Samtykkeerklæring

Jeg har mottatt og forstått informasjonen om prosjektet «Hvorfor velger noen pasienter å takke nei til tilbud om behandling ved Avdeling for Spiseforstyrrelser?», og jeg har fått anledning til å stille spørsmål. Jeg samtykker til:

- Å delta i intervju på ca. 2-4 timer.

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 31.12.2020.

Sted og dato _____ Deltakers signatur _____

Deltakers navn med trykte bokstaver

Appendix C

Table 3

Descriptive data

		N	Percent
Gender	Man	3	3.2
	Woman	85	91.4
	Missing	5	5.4
Relationship status	Single	56	60.2
	Co-habitant	10	10.8
	Married	3	3.2
	Partner	11	11.8
	Other	4	4.3
	Missing	9	9.7
Main occupation	Full Time work	8	8.6
	Part Time work	8	8.6
	Qualification Program	2	2.2
	Primary/ High school student	15	16.1
	College/ University student	16	17.2
	On sick leave	18	19.4
	Working disabled	5	5.4
	Other	13	14
	Missing	8	8.6

Highest commenced education	Primary school	3	3.2
	High School	43	46.2
	College/ university 1-3 years	25	26.9
	College / university 4+ years	12	12.9
	Missing	9	9.7

Appendix D

Intervjuguide

Forholdet til spiseforstyrrelsen

Kan du fortelle litt om spiseforstyrrelsen?

Hvilket forhold har du til din spiseforstyrrelse?

(Hvis du skulle beskrevet spiseforstyrrelsen din som en venn, hvordan ville du beskrevet den? Hvis du skulle beskrevet spiseforstyrrelsen som en fiende, hvordan ville du beskrevet den?)

Motivasjon

Hvordan kom du i kontakt med helsevesenet? Hva var det som gjorde at du valgte å oppsøke avdelingen for spiseforstyrrelser? Hvem tok initiativ til å oppsøke behandling?

Hva ønsket du å få ut av behandlingen?

Møte med behandlingsapparatet

Kan du fortelle om ditt møte med helsevesenet? (Hva tenkte du og følte i møte med behandlingsapparatet?) Hvordan opplevde du å bli møtt på avdelingen for spiseforstyrrelser på Haukeland? Hvordan opplevde du den første samtalen?

Hvordan fikk du presentert behandlingen?

Hvordan opplevde du presentasjonen av behandlingen?

Opplevde årsaker til å ikke starte behandling

Kan du fortelle hvorfor du valgte å ikke starte behandling? Kan du fortelle litt om hvordan valget ditt påvirket deg emosjonelt? (Underveis i prosessen og etterpå?) Var det noen praktiske hindringer som påvirket valget ditt?

Opplevde du at det var vanskelig å ta en avgjørelse og i så fall hvorfor?

Hva har du tenkt om valget i ettertid? Hva føler du om valget du tok nå i ettertid?

Har du søkt hjelp i ettertid? Hva gjorde at du valgte å oppsøke/ikke oppsøke behandling i etterkant?

Forbedringspunkter

Hva tenker du kunne vært gjort annerledes?

Hva skal til for at du skulle valgt å starte behandling?