University of Twente
Behavioural, Management and Social Sciences
Department of Positive Psychology & Technology

Subjective Relapses and their Causes according to Patients

STICHTING HUMAN CONCERN

MASTER'S THESIS

Julie Charlotte Müller
s1843907

1st supervisor: Sander de Vos, PhD
2nd supervisor: prof. dr. Gerben J. Westerhof

UNIVERSITY OF TWENTE.

16.08.2020

ABSTRACT

Despite the research effort, the process of healing from an eating disorder is still not sufficiently understood. There are few studies available examining what people with an eating disorder think are warning signs for their worsening in pathology. This study aimed to include a subjective view on the causes of relapse by incorporating the voice of a transdiagnostic sample of patients. ***Methods:*** The total sample of 636 patients contained the diagnoses anorexia nervosa, bulimia nervosa, BED and OSFED. Three follow-up measurements are included at six months, twelve months and 24 months after the treatment at Stichting Human Concern. ***Results:*** Several themes emerged**.** The ones most frequently mentioned were: negative emotional state, external stressors, sense of control, issues in interpersonal relationships, negative view of themselves as well as illnesses, a change in eating pattern and unresolved eating disorder pathology. Moreover, after six months, 46% of the patients, and after twelve months, 48% indicated at least one relapse. ***Discussion***: Relapse was described by the patients as a process being triggered by many different causes. Future research should validate these causes and integrate this knowledge in the development of prevention programmes. Moreover, more qualitative research needs to be done to gain a more subjective view of the warning signs of recovery.

Keywords: eating disorder, relapse, cause, qualitative research, transdiagnostic, anorexia nervosa, bulimia nervosa, binge eating disorder, OSFED, subjective

TABLE OF CONTENTS

INTRODUCTION

According to the Global Burden of Disease Study, 15.8 million people worldwide are affected by an eating disorder (ED) and this number only includes the two common diagnoses anorexia- (AN) and bulimia nervosa (BN) (Our World In Data, 2018). ED is an umbrella term for a mental disorder that is defined by abnormal eating habits, which have a negative influence on a person's physical and mental health (American Psychiatry Association, 2013). The Diagnostic and Statistical Manual of Mental Disorder Five (DSM-5) includes several different ED forms, wherefrom the current study focuses on AN, BN, binge-eating disorder (BED) and Other Specified Feeding-/ Eating Disorders (OSFED) (APA, 2013).

ED's are often resistant and have a chronic course (Löwe et al., 2001). Compared to other psychiatric disorders, ED's have the highest mortality rate resulting from the impact of starvation or by committing suicide (Harris & Barraclough, 1998; Hoek, 2006). The standardised mortality ratio, i.e. the number of the actual death of ED patients divided by the expected number of deaths, is 4.3 for AN and 2.33 for BN (Franko et al., 2002). The death rates of BED patients are significantly less researched and more influenced by the accompanying obesity (Smink, van Hoeken, & Hoek, 2012). Moreover, having an eating pathology leads to a high chance of developing another psychological disorder or vice versa, where major depression and anxiety disorders have the highest chance of co-occurrence (Davey, 2014; Ulfebrand, Birgegard, Norring, Hogdahl, & von Hausswolff-Juhlin, 2015).

Diagnoses

AN often has the most severe course when it comes to ED's (Steinhausen, 2002). AN includes self-starvation or a significantly reduced calorie intake resulting in a minimal bodyweight accompanied by a pathological fear to gain weight as well as a distorted self-perception and body image (APA, 2013). With a gender ratio of 10.1, mainly females and especially adolescent women are affected (Davey, 2014).

BN is characterised by repeated episodes of binge eating, that are followed by inappropriate compensatory behaviours such as self-induced vomiting, fasting, excessive exercise or the misuse of laxatives to prevent weight gain (APA, 2013). Lastly, the included criteria of self-perception, since BN patients often evaluate their identity based on their body shape.

BED is the most common ED (Kessler et al., 2013) and was newly introduced in the DSM-4, mainly including repeated episodes of binge eating. It is associated with eating large quantities of food to the point of high discomfort. Furthermore, they often binge in secret due to feelings of shame together with distress or guilt involved in overeating (APA, 2013). Also, the loss of control that is experienced during a binge is needed to diagnose such a disorder. BED is the only ED with a more equal gender ratio (Grilo, White, & Masheb, 2009).

Lastly, the diagnosis **OSFED**, originally EDNOS, was revised in the DSM-5 and now includes atypical AN, where low weight is not a necessary criterion; bulimia or binge eating disorder with a lower frequency of the pathological behaviour; purging disorder as well as night eating syndrome (APA, 2013).

Prevalences. When looking at the prevalence data of epidemiological studies, it is apparent that the rates for the different ED's vary quite a lot. According to the literature search of Dahlgren, Wisting and Rø (2017), the lifetime prevalence rate in females with AN range from 1.7% to 3.6%, whereas for BN, it revolves around on average 1.0% (Kessler et al., 2013) or 1.5% (Hudson, Hiripi, Pope, & Kessler, 2007). For BED, a lifetime prevalence ranges from on average 1.9% (Kessler et al., 2013) to 3.5% (Hudson et al., 2007) and for OSFED 0.6% (Dahlgren, Wisting, & Rø, 2017).

Treatment

Literature struggles to present a sound evidence base on what treatment options are effective for the majority of patients. Nevertheless, some treatments are considered to be superior to others. The UK'S National Institute for Health and Care Excellence (NICE, 2017) developed guidelines for the treatment of ED's, reviewed by Wilson and Shafran (2005). Most effective for BN is cognitive-behavioural therapy (CBT) but pharmacotherapy, as, for instance, the use of antidepressants, also has some short-term positive effects (Halmi, 2005; Wilson & Shafran, 2005). For AN no clear guidance was given (NICE, 2017), whereas Halmi (2005) suggests a combination of medical management, behavioural as well as cognitive therapy (Steinhausen, 2002). Lastly, for BED patients, CBT, as well as interpersonal therapy, is suggested (Halmi, 2005) while, for OSFED, the NICE (2017) guidelines recommend '*using the treatments for the eating disorder it most closely resembles*' (recommendation 1.6.1).

Recovery and Relapse

As Bardone-Cone, Hunt and Watson (2018) state, "*it [is] almost impossible to integrate this vast body of literature*" (p. 2) to give a good overview regarding the treatment effect for ED patients. Although some forms of treatment show success in battling the tenacity of ED's, the numbers of recovery are somewhat low. Rates of recovery vary across studies, depending on their definition, from 9% to 65% (Carter et al., 2012), with the first year after treatment as the peak period of relapse (Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017).

The DSM-5 defines full remission as the total absence of before present ED criteria for a "*sustained period of time*" (APA, 2013). But this definition does not capture the whole process of battling an ED . The concepts used in research to define recovery are wide-ranging, yet, the review of Khalsa and her colleagues (2017) summed up the three main approaches. Measuring it solely based on weight measurements like BMI or the occurrence of menstruation was one procedure. Other papers exclusively used symptom reports or made use of a combination of both approaches by utilising different nominal margin. Connected to this, Bardone-Cone, Hunt and Watson (2018) highlight in their review the importance of including a wide range of approaches by considering physical, behavioural as well as cognitive and psychological factors.

Depending on remission definition, the rates for AN ranged from 13.2 to 40.5% and for BN from 15 to 47.6% post-treatment (Ackard, Richter, Egan, & Cronemeyer, 2014). For BED as well as OSFED, fewer studies are available. For the first, remission rates range from 19 to 65% (Schmink et al., 2012). For OSFED, Riesco and her colleagues (2018) stated the recovery rates are generally around 40 to 45%.

When looking at long-term effects, Berkman (2007) reported, for studies including a minimum of four years of follow-up, recovery rates ranging from 8 - 88% for AN. For BN, studies including at least one year of follow-up came up with recovery rates from 56 to 99%. The 21-year follow-up study from Löwe and his colleagues (2001) used the Morgan-Russell General Outcomes Categories as definition, including weight and menstrual status as criteria. In their sample, at follow-up, 51% of the 84 patients fully recovered, 21% partially recovered and 10% still had a significant ED.

Although recovering from an ED is often seen as the ideal end of treatment, a lot of patients struggle with it. Relapse is closely related to, yet different from recovery, so how can

one define such a worsening in ED pathology? In the ED field, there are almost as many definitions of relapse as there are different studies, so there is, similarly as with recovery, an evident lack of consensus (Berends, Boonstra & van Elburg, 2018). Relapse can be seen as a natural part of the undertaking of relearning normal eating habits and is a step in the process of recovery. The aforementioned approaches summarised by Khalsa et al. (2017) were also seen in the literature about relapse. Therefore, to comprehensively define relapse, a combination of objective, subjective and standardised measurements needs to be included.

In the transdiagnostic sample of McFarlane, Olmsted and Trotter (2008), 41% of the patients reported a relapse after twelve months. The studies reviewed by Berends, Boonstra and van Elburg (2018) indicated that around 31% of AN relapsed after treatment, using mainly a decrease in weight with a BMI less than 18.5 as criteria. Looking more closely into the underlying process, several causes seem to be associated with relapse. McFarlane, Olsted and Tritter (2008) identified four predictors of relapse, namely: a more severe restriction of calories pre-treatment, slower response to treatment, higher residual symptoms post-treatment and a body-image highly dependent on self-perception. Additional higher vomiting frequencies, motivation to recover as well as comorbidity, are factors repeatedly found in further follow-up studies (Bardone-Cone et al., 2018; Carter, 2012; Keel, Klump, Miller, McGue, & Iacono, 2005; Steinhausen, 2002).

Although a majority of research investigated quantitative predictors, some work was also done on a more patient-oriented perspective. The participants in Wasson's qualitative study (2003) highlighted that the inability to manage one's internal emotional states and interpersonal relationships is a risk factor for relapse. Also, support is not always perceived as supportive by patients, as indicated by Linville, Brown, Sturm & McDougal (2012). Here, it was stated that judgemental support in the form of focusing too much on weight and eating, trivialising the ED and being stereotyped can have a harmful effect on the patient's pathology (Venturo-Conerly et al., 2020).

Moreover, uncertainty, intense negative emotions and the inadequate use of one's ED as coping mechanisms, hesitancy to change or asking for help as well as the omnipresent feeling of worthlessness were named as influencing factors by participants (Federici & Kaplan, 2008). Cockell, Zaitsoff and Geller (2004) identified a loss of structure, dealing with the real-life together with unrealistic expectations about recovery and stress experienced through environmental changes. Lastly, the need to be in control as well as the control the ED

has and its influences on the identity of the patients, self-defeating beliefs, miss of self-worth and feeling not good enough were described as triggers for relapse in qualitative literature (D'Abundo, & Chally, 2004; Lamoureux & Bottorff, 2005).

Another influence on the ability to regain health are significant negative life events. The six-year follow-up study, by Grilo et al. (2012), found out that negative life events can predict ED relapses together with elevated work and social stressors. Supporting, Keel, Dorer, Franko, Jackson & Herzog's (2005) interview study revealed that worse psychosocial functioning predicted relapse and they suggested that ED patients are less able to cope with life stressors.

In contrast to that, Federici and Kaplan (2008) included in their study what participants name as contributing factors to their process of healing from an ED. Self-initiated belief in the possibility to change, seeing recovery as an ongoing process, satisfaction with treatment, supportive relationships, ability to deal with negative emotions and self-validation played a vital role in decreasing their eating disorder pathology. Moreover, restoration is enhanced by developing an identity independent from the ED.

De Vos and his colleagues (2017) emphasise psychological well-being in their qualitative meta-analysis as fundamental criteria for recovery together with self-adaptability and resilience. A moderate negative correlation between ED psychopathology and general well-being was found, so the absence of well-being could also influence the occurrence of relapse (de Vos, Radstaak, Bohlmeijer & Westerhof, 2018).

Concluding, the majority of the knowledge about relapse was gained through quantitative research and based on more behavioural margins. Qualitative methods, on the other hand, are mostly used in regard to recovery. Since this concept is connected, yet different, it is crucial to gain more insight into the subjective experiences of patients and, therefore, more cognitive and psychological aspects of relapse.

Current Study

Due to the minority of studies using a qualitative approach to understand the patients' perspectives on relapse, the present research means to add knowledge to this. Here, their subjective view is used to achieve an empirical understanding of what the patients consider as causes for their relapse. Moreover, by answering this knowledge gap, aftercare programs can be developed and improved, to work against the chronicity of ED disorders.

A strength of this study is that all ED types are included and not only AN as in the majority of studies. Hereby, a more comprehensive insight into the distinctive ED forms is gained. Moreover, this study aims to investigate if subjective relapses are associated with the ED pathology and if life-events are associated with the occurrence of relapse. By using a psychometric test, a more objective view on the severity of the patients' eating pathology can be compared to their subjective reports.

For the focus on subjective relapse in this study, the following research questions emerged:

RQ 1: *How many patients have experienced a subjective relapse after psychological treatment at six months and twelve months and are there differences between the ED types in the proportions?*

RQ 2: *How many subjective relapses were experienced by the patients after psychological treatment at six months and twelve months and are there differences between the ED types in the proportions?*

RQ 3: *Is there a difference in the severity of the ED pathology (6 months and 12 months post-treatment) between the different ED patients who have and who have not experienced subjective relapse(s) after treatment?*

RQ 4: *Which triggers have caused subjective relapse(s) after treatment according to the patients?*

The following research questions resulted regarding the subject of life events:

RQ 5: *Which events are considered as negative life events according to patients?*

RQ 6: *How many patients have experienced a negative life event during the different follow-up points (6 months and 12 months post-treatment) and are there differences between the ED types?*

RQ 7: *Is there an association between negative life events and relapse for the different follow-up points (6 months and 12 months post-treatment)?*

Based on the aforementioned studies and their outcomes, it is expected that the relapsed patients have more pathological ED symptoms and, therefore, a more severe eating disorder in comparison to the patients who did not indicate a relapse (RQ 3). Moreover, it is expected that there is an association between negative life events and relapse (RQ 7).

METHODS

Design and Participants

Design. A longitudinal research design was used for this follow-up study. This incorporated a follow-up measurement after six-, twelve- and 24 months post-treatment consisting of questionnaires analysed by qualitative as well as quantitative methods.

Setting. The participants were recruited at five locations of Stichting Human Concern, a specialised centre for the treatment of ED's in the Netherlands. The treatment centres are spread across the Netherlands, with locations in Amsterdam, Bilthoven, Den Haag, Tilburg and Zwolle. At Human Concern, patients can receive inpatient- as well as outpatient treatment, usually consisting of weekly sessions. The goals of treatment are, for instance, building up one's self-trust and social skills, learning how to deal with emotions and to have a positive self-image regarding one's body. Lastly, the physical health of the patients is restored and normal eating patterns are taught (Human Concern, n.d.). Stichting Human Concern is unique in their approach since their psychotherapists are recovered ED patients. The experiential knowledge of the therapists gained in their own process of recovery is integrated in their therapeutic approach.

As part of the standard intake procedure of the ED treatment centre, patients were first diagnosed by a psychiatrist in collaboration with an intake team consisting of psychotherapists, family therapists and dietitians. During intake, patients were asked if they would like to participate in the study, including the follow-up research. Moreover, different background characteristics of the patients, like age and gender, were collected during the intake procedure. Many more variables, such as their living situation or treatment duration, were requested which are not used for the current study.

Procedure. The data collection included those patients, who completed at least six months of treatment and left between June 2015 and August 2019. The data gathering at the end of treatment took place by Stichting Human Concern, whereas the follow-up measures were exclusively for research purposes.

Before the start of the study, the participants were informed about the general aim of the research and signed either form of the two versions of the informed consent (available on request via Human Concern). They were informed that they could terminate their participation at any time and their data would then not be used for research purposes. Before starting the

analysis, the collected data was anonymised. This study was approved by the BM Ethics Committee of the University of Twente.

After the end of treatment, the participants received another notification about the follow-up research. A meeting with their clinician was scheduled around the first follow-up measurement to check up on the patients and to speak about the answers to the questionnaire. After October 1st, 2019 these follow-up meetings were cancelled, so after this date, the patients did not receive such a session anymore. Proceeding, all former patients from Human Concern automatically received an email through an online application, named Vital Heath Questmanager, to complete each measurement point questionnaire, so after six-, twelve- and 24 months.

When a participant received a questionnaire but did not respond within seven days, another notification was sent automatically via email (in the time frame of 14 days). Next, two personal emails were sent to the participants, including more detailed information about the procedure of the questionnaires. The first email was sent during the 14 days that the questionnaire was opened but not filled out (see Appendix A1.), followed by the second email (see Appendix A2.) after two weeks when the questionnaire was again opened but not finished (also the total duration of 14 days). Moreover, the emails explained that their participation is rewarded with a voucher to motivate the patients. As compensation for the study, gift vouchers worth 15€ were used. At the end of each measurement point, the participants were able to choose via the website Bol.com, which kind of gift voucher they wanted to receive.

Participants. In total, 826 patients were screened for the research. Inclusion criteria for the treatment at Stichting Human Concern and therefore in the current study were a) the minimum of six months treatment, b) the minimum age of 16, c) a DSM 5 eating disorder diagnosis at intake (APA, 2013) as well as d) a signed informed consent. Overall, 189 patients were excluded from the initial data collection (see Figure 1). After examining the gender of the sample, all men were excluded due to their very low sample size resulting in a final data set of 636 female participants.

Since this study is still ongoing, some participants did not yet receive the questionnaires for all different follow-up points, as shown in Figure 1. Also, some dropout was recorded throughout the study. For the measurement at the end of treatment, 110 patients dropped out due to various reasons (see Figure 1). Forty-five patients did not fill in the

questionnaire for the first follow-up, whereas for the second measurement, 42 patients did not respond.

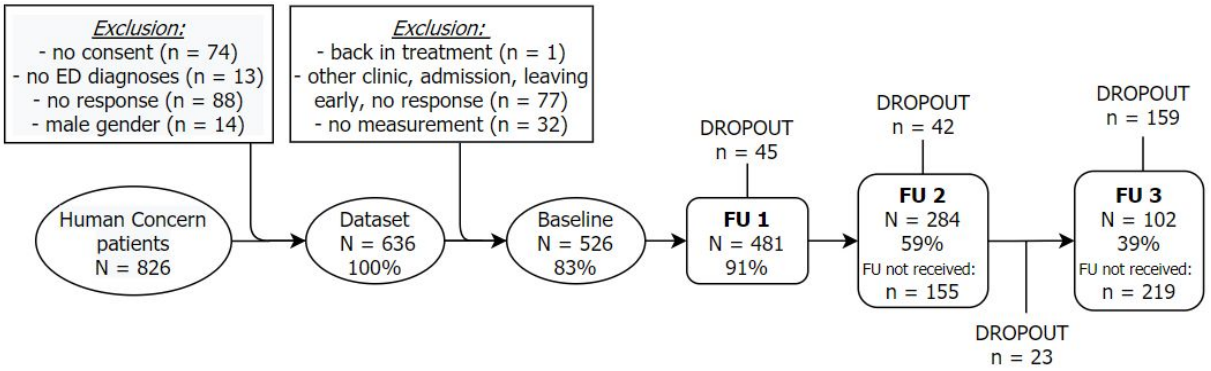

Figure 1. *Flow Chart of Sample for Questionnaire*

Due to the ongoing data collection, fewer answers were recorded for the last follow-up at two years wherefore this data is not included in the quantitative analysis. Still, a response rate of 40% was documented for this time point. For the qualitative analysis, all measurement points were included, resulting in a total of 675 answers. Unfortunately, not enough responses were reported for the BED diagnostic group, since most of the patients only reached the first follow-up. Hence, this diagnosis was excluded ($n = 4$).

Lastly, for the first measurement point, no data on the measurement tool Eating Disorder Examination Questionnaire (RQ 3) was recorded for 75 patients. Nevertheless, the data of 465 patients six months post-treatment, as well as 271 patients for the twelve months post-treatment, were included.

Materials

To gain more insight into the relapse of ED patients, ten open-ended questions were included in each of the three measurement points (see Appendix B.). This questionnaire, designed by Sander de Vos, was provided in Dutch and translated from two native speakers into English for this paper. For the current research purpose, the questions two to four as well as eight and nine from this questionnaire by de Vos were used.

To answer the research questions one, the question: '*Did you have one or more relapses, with regard to your eating disorder, since your treatment at Human Concern?'(Q.2)* was used to explore the occurrence of subjective relapses. To investigate the number of relapses (RQ2) the question: '*How many relapses did you have?'(Q.3*) was applied. To

review the qualitative side of this research, the triggers of relapse according to the patients (RQ 4) were investigated with the question: '*Do you know what caused your relapse?'(Q.4*). Question nine (*'What kind of discomforting or severe events/experiences have you had?'*) was selected to examine how the participants define negative life events (RQ 5). Furthermore, to analyse the occurrence of negative life events (RQ 6), the item: '*Have you gone through any discomforting or severe events/experiences since your treatment at Human Concern?'(Q.8)* was used.

Lastly, in research question three, the severity of the patient's ED was associated with the occurrence of subjective relapses. To objectively measure their pathology, the Dutch version of the Eating Disorder Examination Questionnaire (EDE-Q) was used (Van Furth, 2000). Originally developed as an interview examination by Fairburn and Beglin (1994), the self-report version EDE-Q examines the frequency of pathological ED symptoms in the last 28 days, by asking about eating attitudes and behaviour. This 36-item questionnaire includes four different subscales, namely 'restraint', 'eating-, weight- and shape concern'. Low scores on the 7-point Likert scale (0: not a single day, 1-5 days, 6-12 days, 13-15 days, 16-22 days, 23-27 days and 6: every day) are reflecting a lower ED psychopathology. Research shows that the global score of this questionnaire is a useful tool to assess the ED pathology of patients (Aardoom, Dingemans, Op 't Landt, & Van Furth, 2012). With a high internal consistency ($\alpha = 0.95$), the EDE-Q is considered a valid instrument.

Analysis

Quantitative Analysis. The quantitative data analysis was conducted in the Statistical Package of the Social Sciences (SPSS 26). The data of the descriptive statistics and frequencies of the variables age group, diagnosis category as well as the comorbidity of the patients were imported in SPSS. To determine the occurrence (RQ1) and the number of relapses (RQ 2) as well as the occurrence of life events (RQ 6), the descriptive statistics and frequencies were calculated. All calculated values were rounded to the first number before the decimal point.

The Shapiro-Wilk test was conducted to assess if the variables relapse and EDE-Q (RQ 3) were normally distributed. For this question, the participants with missing EDE-Q scores were neglected. To analyse if there was a difference in ED pathology for relapsed patients, an independent t-test was conducted. The occurrence of relapse was the independent

variable and the global score of the EDE-Q (the participant's ED pathology) the dependent variable for each of the measurement points. The results were analysed separately for each of the different ED's, to see whether there were differences for the diverse diagnostic categories.

Lastly, for the research questions one, six and seven a chi-square test was conducted. It was investigated whether there is an association between relapse and diagnoses (Q1) and if there is an association between life events and diagnoses (Q6) for the first and second follow-ups. For research question seven, it was examined if there is an association between the occurrence of negative life events and having a relapse for both follow-ups. More specifically, it was investigated here how many patients with relapse had a live event and how many patients without a relapse had such an event as well as if there are any differences between both in the proportions.

Qualitative Analysis. For the qualitative part of the study (RQ 4 & 5), the data was analysed in Cleverbridge Atlas.ti 8.4. Differently, here the answers for the last follow-up point were, due to their good quality, included. The answers of the participants were exported from the SPSS file to a Word document. Two separate documents and coding schemes were created for research question four, regarding the relapse triggers, and question five, so the patient's definition of a negative life event and imported to Atlas.ti for the coding process. To ensure inter-rater reliability, the coding process was conducted by two independent researchers.

To evaluate the meaning of the open questions by De Vos, a systematic inductive approach was used to create a coding scheme (Bruce, 2007). This approach consists of grounding conclusions and understandings from a non-evaluative stance. By using this method, the participants' voice is valued, so it fulfils the study's aim of figuring out the subjective experiences of relapse. All the answers of the patients were read and potential themes and emerging ideas were recorded. Ninety-one answers were excluded from the data set since the answers were invalid due to not answering the question or mentioning an ongoing ED pathology after the treatment at Human Concern.

Underlying meanings were deducted and recurring themes were reported and labelled. Attention was paid to formulate the codes as close as possible to the wording used by the participants whereas, for the overarching themes, more theoretical concepts were used. Disagreement regarding the belonging of codes to the themes was resolved through discussion. To ensure intersubjectivity, only similar codes mentioned were used for further analysis and to prevent distortion in the coding process, an independent colleague examined

the themes and compared them to the raw answers. To reach consensus, differences in labels were discussed regarding the meaning as well as the belonging to the themes (Ryan & Bernard, 2003).

After creating a final set of codes for the relapse triggers (see Appendix C1., Table 16) and the negative life event definition (see Appendix C2., Table 17), the whole data set was coded once again. When the participants' answer included a code multiple times, this code was only counted once. This resulted, after independently coding all responses, in a percent agreement of 67% and high inter-rater reliability for the data regarding relapse (Krippendorff's c-Alpha binary 0.731), analysed via Atlas.ti.

RESULTS

Descriptive Statistics

A total of 636 female patients participated in the study. With 33%, the majority of the sample belonged into the age group ranging from 21 to 25, followed by 23 % being between 26 and 30 years (see Table 1). Overall, as shown in Figure 2, most patients (*n* = 247, 39%) were diagnosed with AN, followed by 244 patients (38%) with the diagnosis OSFED. 131 patients (21%) had the diagnosis BN and a minority of two per cent had BED (*n* = 14). The following comorbid disorders were classified: mood or anxiety disorders (*n* = 327, 51%), personality disorders (*n* = 82, 13%) as well as neurobiological brain development disorders (*n* = 41, 6%). Furthermore, comorbidity with a post-traumatic stress disorder (PTSD) (*n* = 36, 5%) and drug or alcohol addictions (*n* =12, 2%) were found together with 3% of the patients that had another psychological disorder (*n* = 18, see Figure 2).

Table 1.
Age groups of the sample (N = 634)

age group	*n*	%
17 - 20	91	14%
21 - 25	210	33%
26 - 30	145	23%
31 - 35	7	12%
36 - 40	47	7%
41 - 51	47	7%
52+	18	3%

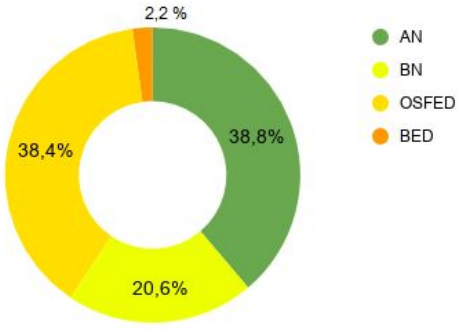

Figure 2. Main ED diagnosis of patients

Relapse of Patients

The Occurrence of Relapse. Research question one dealt with the occurrence of a relapse after the treatment at Stichting Human Concern, with its results displayed in Figure 3. In total, 222 patients (46%) stated that they had experienced a relapse after six months. When looking at the different diagnostic groups for the first follow-up, mostly BED (n = 7, 88%) and bulimia (n = 57, 56%) patients indicated a relapse. Next, 44% of anorectic patients (n = 83) and 41% OSFED patients (n = 75) recorded that they had relapsed.

For the follow-up after 12 months (see Fig. 3), 48% of the participants indicated the occurrence of a relapse (n =137). For the ED category BED, not enough data was calculated to analyse the recorded relapses (n = 1). The percentage for relapses in BN patients was highest (n = 35, 60%), followed by 45% for AN (n = 54) and 45% for OSFED patients (n = 47).

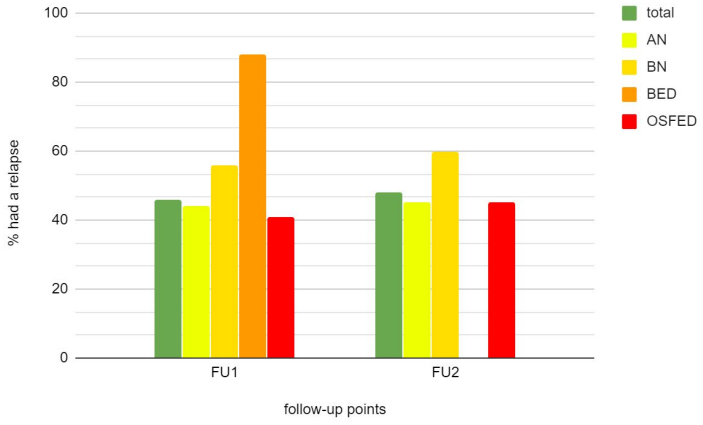

Figure 3. The occurrence of a relapse per follow-up and diagnosis

To analyse if there is an association between the variables relapse and diagnoses, a chi-square test of independence was conducted. For the first follow-up, the association between these variables was significant [X^2 (6) > = 13.895, p = < .05]. For the second

follow-up, the relation between these variables was also significant [X^2 (6) > = 14.872, p = < .05].

The Number of Relapses. For research question two, the number of subjective relapse was researched and reported in Figure 4. After six months, 221 answers were recorded with an average relapse number of 8.73 (*SD* = 23.85), ranging between 1 and 200 (outlier of 1.000.000 excluded). Seventy-six patients reported one relapse (34%), 46 patients reported two relapses (21%), 22 patients reported three relapses (10%), 12 patients reported four relapses (5%) and 16 patients reported five relapses (7%). Twenty-two patients indicated a number from six to ten (10%), eight patients indicated 20 to 30 relapses (4%), 11 patients indicated 50 or more relapses (5%) and lastly, two patients reported 150 and 200 relapses (0.9%).

The numbers regarding each diagnostic group are displayed in Figure 4 below. As the Figure shows, only three responses of BED patients are recorded. The majority of AN and OSFED patients indicated a number of relapses around one till four with a downwards trend. Slight upwards trends are noticed around a total of five and ten relapses. For BN patients, an upward trend is recorded.

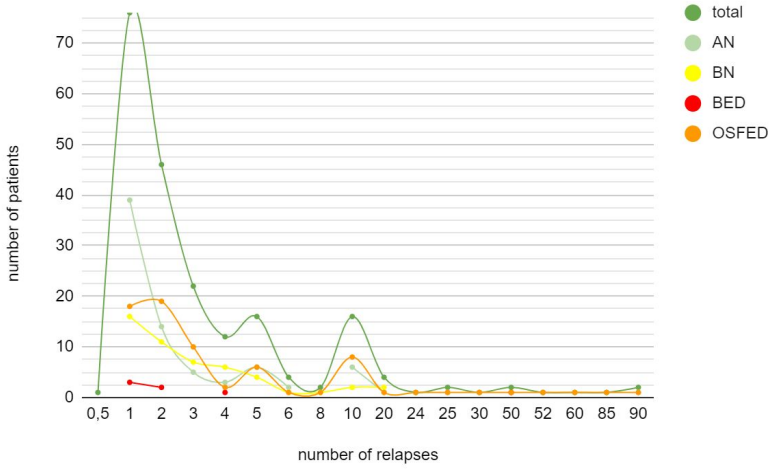

Figure 4. Number of relapses per diagnosis for FU1

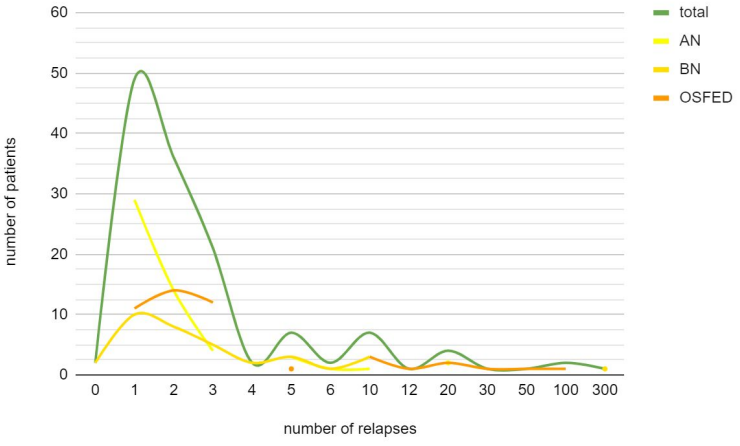

Figure 5. Number of relapses per diagnosis for FU2

Next, the total number of relapses after 12 months was, on average, 7.17 (*SD* = 28.37), including 137 responses ranging from 0 to 300, displayed in Figure 5 above. Fifty patients reported one relapse (36%), 36 patients reported two relapses (26%), 21 patients reported three relapses (15%), two patients reported four relapses (1%), seven people reported five relapses (5%) and two people reported six relapses (1%). Moreover, 14 participants indicated

10 to 50 relapses (10%) next to two people with 100 relapses (1%) and one person indicating the number 300.

Again, the numbers for AN, BN and OSFED at the second follow-up are displayed in Figure 5. For the category BED, only one response with the number 100 was recorded. It can be seen that the majority of the patients experienced one or two relapses. For AN, most patients experienced one or two relapses followed by a sharp decline, whereas the distribution is more evenly for BN patients. OSFED patients recorded either one till three relapses or ten and upwards.

Difference between Relapse and Eating Pathology. Research question three investigated if there was a difference in the EDE-Q global score between relapsed and non-relapsed patients. The results of the Shapiro-Wilk test implied that the variables were normally distributed ($p < .05$). Thus, an independent t-test was used. Overall, the results showed that for all diagnostic groups (except BED), relapsed patients had a significantly higher EDE-Q score compared to the patients that did not relapse. For the BED patients, no answers or too few answers were recorded to perform the analysis. The results for the measurement point after six months are displayed in Table 2, whereas the results for the second follow-up after twelve months are displayed in Table 3.

Table 2.
Independent t-test results Fu1

	relapse		no relapse		*df*	*t*	Sig. (2-tailed)
	M	*SD*	*M*	*SD*			
AN	2.86	1.59	1.41	1.29	179	6.772	.00
BN	2.45	1.44	0.9	0.83	94	6.252	.00
OSFED	2.33	1.36	0.92	0.96	175	8.086	.00

Table 3.
Independent t-test results Fu2

	relapse		no relapse		*df*	*t*	Sig. (2-tailed)
	M	*SD*	*M*	*SD*			
AN	2.84	1.7	1.26	1.07	111	5.998	.00
BN	2.37	1.44	0.72	0.72	50	4.9236	.00
OSFED	2.47	1.35	0.71	0.8	100	8.174	.00

Causes of Relapse according to Patients. To figure out the patient's view of causes for relapses, research question four addressed the reason for such an occurrence. The following eight overarching themes emerged from the qualitative analysis: negative emotional state, external stressors, sense of control, negative self-perception, problems in interpersonal relationships, illnesses and unresolved ED pathology including a total of 592 applied codes (see Appendix D., Table 18).

"**Negative Emotional State**" was, with a total of 29% of all codes, the theme most often mentioned as a cause of relapse by the patients (see Table 4). Included in this were the participants' descriptions of their emotions and moods, that they used their ED to compensate for such emotional states as well as further mentioned triggers. With a prevalence of 87, the code "***Negative Emotions and Moods***" was the most frequently named cause of relapse in all answers, making up about 14.5%. In this code, statements of the patients regarding their emotional state and how they were able to deal with it were included. This incorporated nearly the whole spectrum of emotions: from "*underlying*" or "*too many emotions*" to "*anxiety*" and "*loneliness*" but also "*isolation*", "*despair*", "*hopelessness*", "*loss of motivation*" to just name a few. As a participant stated: *"Not being able to deal with the emotion, feeling too much pain, too much grief, too much anger."*

Following, several further ***triggers*** were mentioned that did not fit into the other codes (n = 49). The majority of patients indicated for this code "*difficult events of the past coming up*" as well as *"underlying issues and traumas that are not enough under control/worked on*" as the cause. Moreover, specific triggers were stated like a close person developing an ED, advertisement on the radio or the weight scale (see Table 4).

Lastly, 34 of the patients' answers included that using their ***ED*** as a ***compensation*** method, mainly for "*emotion regulation*", functioned as a relapse trigger for them (see Table 4). So, the patients explained that eating functions as "*comfort*", to "*remove emotions*" or "*stress*", that they "*don't want to feel*" the pain or mistreat their ED as an "*avoidance*" mechanism.

Table 4.
Frequencies of theme "Negative Emotional State" regarding relapse

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Neg. Emotions and Mood	87	50%	14.5%
Unspecified Triggers	49	28%	8%
ED as Compensation	34	19.5%	6%
Total	174	29%	*N* = 592

The second most frequent causes of relapse, including 27% of the codes, were incorporated in the theme of **"External Stressors"**, displayed in Table 5. ***Unspecified stress*** and "*tension"* experienced in life (*n* = 72), as well as stress concerning their occupation or study, were labelled most frequently as such stressors (*n* = 50). Here, situations like conflicts at school, in one's current studies or work were named but also the stress experienced through one's occupation. Also, "*rounding up [ones] study*", having chosen the "*wrong occupation*" or "*new working conditions*" were portrayed. Stressful events like ***travelling*** (*n* = 15), with the accompanying changes in daily structure and eating habits, or regarding one's "***Living Situation"*** (*n* = 15), mainly including "*moving*" to another area, were reported. Lastly, ***other*** more short-term ***circumstances*** such as a "*festival*", "*holidays*" or "*a family weekend*" were described (see Table 5).

Table 5.
Frequencies of theme "External Stressors" regarding relapse

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Unspecified Stressors	72	44%	12%
Stress at Occupation	50	31%	8%
Travelling Stress	15	9%	2.5%
Living Situation	15	9%	2.5%
Other Circumstances	10	6%	2%
Total	162	27%	*N* = 592

This was followed by the **sense of control** felt by the patients, that was expressed in 10% of the codes (see Table 6). The causes specified in this theme are connected to the previously mentioned "emotional states", but more in the sense that here these sensations are regarding one's ability of feeling in control. Thus, patients mentioned that they were either searching for control in their ED or were afraid of ***losing*** this sense of ***control*** (*n* = 42). The lack of structure in daily life and "*taking steps in the 'real world*" were further causes for a worsening in ED pathology. "*Change*" was experienced as a trigger, together with the "*anxiety of the future*", "*letting go*" of the ED or changing one's habits. Lastly, the feeling of "***uncertainty***" was named (*n* = 18, see Table 6).

Table 6.
Frequencies of theme "Sense of Control" regarding relapse

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Loss of Control	42	70%	7%
Uncertainty	18	30%	3%
Total	60	10%	*N* = 592

The **"Negative Self-perception"** of the patients also had an influence on relapse (*n* = 51, 8.5%). This theme included their view of their personality as well as their body image (see Table 7). A total of 33 answers announced one's ***negative self-view*** as a cause for relapse, describing "*expecting too much from [oneself]*", "*perfectionism*", "*not feeling comfortable [in their] own skin*", feeling "*uncertain about [oneself]*" or missing "*good self-care*". Eighteen times patients labelled their ***negative body image*** as a trigger, so feeling too thick, wanting to lose weight or general "*uncertainty over [their] own body*" (see Table 7).

Table 7.
Frequencies of theme "Negative Self-perception" regarding relapse

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Neg. View of Self	33	65%	5.5%
Neg. Body Image	18	35%	3%
Total	51	8.5%	*N*= 592

Eight per cent of the codes highlighted that **conflicts** in their **interpersonal relationships** were causing subjective relapse (see Table 8). Here, ***general "problems** in the area of social relations*" were coded most often (*n* = 17). Moreover, this theme can be divided into different social groups, where issues in relation to one's boyfriend are most often expressed. Here, patients announced that being in love or lovesick or contact with boys in general were triggering (*n* = 11). The lack of intimacy in one's ***relationship***, having problems or even the end of such a relation can have, according to the patients, an influence on one's ED pathology. Lastly, conflicts in and with the ***family*** as well as ***friends*** were specified (*n* = 9, see Table 8). Here, patients described, for instance, a difficult relation to one's mother, tension in the family or the death of a friend.

Table 8.
Frequencies of theme "Problems in Interpersonal Relationships" regarding relapse

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Unspecified Social Issues	17	37%	3%
Relationship Issues	11	24%	2%
Family Issues	9	19.5%	1.5%
Friendship Issues	9	19.5%	1.5%
Total	46	8%	*N* = 592

A total of 6% of the codes mentioned the patient's own **illnesses** as a trigger, shown in Table 9. Most of the 34 patients labelled feeling "*fatigued*" as an issue, together with "*sleeping too less*" or changes in their medication. Also, some "*physical complaints*" were

reported, sometimes including surgery. Next, a **change in eating pattern** was outlined as trigger, including "*old eating patterns that are still present"*, "*that I had the feeling that I had eaten too much"*, as well as eating too less or binge eating together with changes in their pattern for special occasions like holidays or eating out (*n* = 29, see Table 9).

Table 9.
Frequencies of single themes regarding relapse

	Frequency of Codes	% of Total
	n	Per cent
Own Illnesses	34	6 %
Change in Eating Pattern	29	5 %
		N = 592

Lastly, the theme "**Unresolved ED Pathology**" emerged, including the ***recovery state*** of the patients as well as other comorbid mental disorders (*N* = 40, 7%, see Table 10). "*They weren't real relapses. It was at points where my ex-eating disorder came out more than usual. And it affected me more.*" is a good example of how the patients described the influence of their ED pathology on relapse. 22 patients stated that some form of the ED was still present, together with the aspect that their ongoing therapy was experienced as challenging. Named ***comorbid mental disorders*** were for instance "*borderline*", "*OCD*" or "*psychosis*", but the majority stated that their "*depression"* was a cause of relapse (*n* = 18, see Table 10).

Table 10.
Frequencies of theme "Unresolved ED Pathology" regarding relapse

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Recovery State	22	55%	4%
Comorbid Mental Disorder	18	45%	3%
Total	40	7%	*N* = 592

Negative Life Events from Patients

Definition of a Negative Life Event according to Patients. Research Question five dealt with the way patients describe their negatively associated life events and what counts, according to them, as such an event. The qualitative analysis resulted in six emerging themes, namely problems in interpersonal relationships, illnesses, unforeseen and sudden life events together with mental issues and suicidality, including a total of 19 codes (*N* = 339, see Appendix D., Table 19).

Problems in Interpersonal Relationships were mentioned most frequently as experienced life events, including social situations and aspects with different groups of people (*N* = 137, 40%, see Table 11). In this theme, the ***death of a relative*** was declared most often as a negative life event (*n* = 43), followed by 32 answers labelling conflicts with or within their ***family***. This included, "*divorce of parents*", "*problems with [...] parents*", "*family hassle and arguments*" as well as "*my sister wants no contact with me anymore*" or more individual problems like: "*I found out that my mother lied about who my real father is*".

Another important event in this theme was a ***break-up*** or "*divorce*" from one's partner (*n* = 23). Furthermore, "*difficult periods*" in one's ***relationship***, in the form of, for instance, "*problems*", "*conflicts*" or "*cheating*" were outlined (*n* = 16). Also ***unspecified social issues,*** like "*happenings in the personal atmosphere*" or statements like: "*Someone I cared about suddenly disappeared from my life*", that did not include a specific social group became apparent (*n* = 14). Lastly, eight answers highlighted that patients had "*conflicts*" with ***friends*** or that close ones had issues that had an influence on themselves (see Table 11).

Table 11.
Frequencies of theme "Problems in Interpersonal Relationships" regarding life events

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Death of Relative	43	31%	12.5%
Family Issues	33	24%	10%
Break-up	23	17%	6.5%
Relationship Issues	16	11.5%	5%
Unspecified Social Issues	14	10%	4%
Friendship Issues	8	6%	2%
Total	137	40%	*N* = 339

The theme "**Illnesses**" was the second most frequently expressed definition of a negative life event through all answers (*N* = 72, 21.5%) displayed in Table 12. A variety of ***own diseases*** (*n* = 32) were named as a life event, ranging from "*jaw problems*", "*dengue fever*" to "*concussion*", "*epileptic seizures*" or a "*tumour*" also including ***surgeries*** or ***hospital stays*** (*n* = 10). Connected, some physical implications of pregnancy were mentioned since "*having a child is quite drastic*", together with the stress experienced when this wish of getting a child is not possible. Lastly, the ***illnesses of relatives*** were described as negative life events (*n* = 30). This includes cancer diagnoses or hospital stays of family members as well as other illnesses, as described, for instance, by this patient: "*That my friend has built up an anxiety disorder and is afraid that he will die*".

Table 12.
Frequencies of theme "Illnesses" regarding life events

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Own Illnesses	32	44.5%	9%
Relatives with Illnesses	30	41.5%	9%
Hospital Stay	10	14%	3%
	72	21.5%	*N* = 339

Another theme that emerged consisted of events categorised into unforeseen and sudden life events, outlined in 20% of the codes (*n* = 69, see Table 13). Here, **unforeseen life events** included a longer period of stress like happenings in one's job environment as well as one's living situation whereas a car accident was counted to more **sudden events**. It was mentioned four times that the patients were, mostly as the victim, involved in a ***car accident***. "*Conflict in [one's] job situation*", "*difficult periods at work and study*" as well as losing or ending one's ***occupation*** were labelled most often when it comes to unforeseen events (*n* = 33).

The code "***Other Circumstances***" was applied 23 times. A variety of different aspects were named, shifting from travelling, issues around one's pets, "*overriding sexual behaviour from others*" and "*emotional abuse*", or even that one patient "*had to reanimate someone that unfortunately didn't make it*". Lastly, a change in their ***living situation*** was stated nine times, entailing either moving in general or "*going back to [their] parents*" place (see Table 13).

Table 13.
Frequencies of theme "Unforeseen and Sudden Life Events" regarding life events

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Unforeseen Life Events			
Occupation	33	48%	10%
Other Circumstances	23	33%	7%
Living Situation	9	13%	2.5%
Sudden Life Events			
Car Accident	4	6%	1%
Total	69	20%	*N* = 339

Lastly, the topic of the mental state of the patients was developed as a theme for the question regarding negative life events (*n* = 47, 14%, see Table 14). This included negative emotions and moods as well as mental disorders but also negative experiences in therapy. **Mental issues**, as for example: "*I have been very depressed for a while*" were stated 21 times, specificing ***diagnoses*** such as "*depression*", "*postnatal depression*", "*borderline*", "*burn out*",

"*relapse in eating disorder*", "*social phobia*". Moreover, a "*difficult start [in a] new* ***therapy***" was often indicated as a negative life event, together with answers like: "*Not a good click with the practitioners at the treatment centre and I felt insufficiently understood...*".

With a frequency of twenty, a variety of ***emotional states*** were named by the patients (see Table 14). These ranged from "*isolation*", feeling "*lonely*", "*loss of life purpose*", "*personal struggles*", "*much more suppression and negative thoughts*" to statements like: "*I don't know what to do with myself[..]. Self-hate is getting larger.*".

Connected to the mental state of the patients, the theme "**Suicidality**" (*N* = 18, 5%) became apparent (see Tables 15). Codes regarding suicidality are displayed in Table 13 and were divided between either a ***relative*** that ***died through suicide*** (*n* = 8) or if the patient ***him-/herself attempted suicide*** (*n* = 6) or had "*suicidal thoughts and thoughts of self-harming*" (*n* = 4).

Table 14.
Frequencies of theme "Mental Issues" regarding life events

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Mental Disorder	21	44.5%	6%
Emotional States	20	42.5%	6%
Therapy Issues	6	13%	2%
Total	47	14%	*N* = 339

Table 15.
Frequencies of theme "Suicidality" regarding life events

	Frequency of Codes	% in Theme	% of Total
	n	Per cent	Per cent
Suicide by Relatives	8	44%	2%
Own Suicide Attempts	6	33%	2%
Suicidal Thoughts/Self-harm	4	22%	1%
Total	18	5%	*N* = 339

The Occurrence of Negative Life Events. For research question six, the occurrence of live events was researched displayed in Figure 6. Overall, 155 patients, so 32%, indicated at the follow-up point after six months, that they have experienced such an event. The results were highest for the ED category OSFED (*n* = 65, 36%), followed by BN (*n* = 37, 37%) and AN patients (*n* = 51, 27%) as well as BED patients (*n* = 2, 25%).

The number of recorded life events was lower for the measurement point of 12 months (see Fig. 6), including a total of 37% (*n* = 106). Results showed that 25 BN (43%), 48 AN

patients (40%) and 32 OSFED patients (31%) indicated a life event. Lastly, only one answer was recorded for the group of BED patients (n = 1).

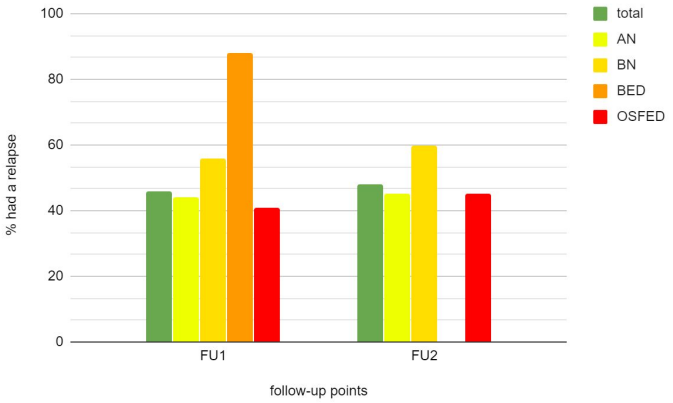

Figure 6. The occurrence of a negative life event per measurement and ED

Moreover, a chi-square test of independence was executed, to investigate if there is an association between the variable life events and diagnoses. For the first follow-up, the association between these variables was not significant [X^2 (6) > = 7.431, p = > .05]. Contrasting, for the second follow-up, the relation between these variables was significant (X^2 (6) > = 13.488, p = < .05). Hence, only for the measurement point after twelve months, a significant association was found between negative life events and the different ED diagnoses.

Association between Relapse and Negative Life Events. Research Question seven asked for an association between subjective relapses and the occurrence of negative life events, so a chi-square test of independence was performed to examine the relation between the concepts life event and relapse. For the first follow-up, the relation between these variables was not significant [X^2 (1) > = 0.10, p = > .05]. Seventy-one patients indicated to have experienced both, a relapse and a life event, whereas 174 had experienced neither one. 150 patients experienced only a life event and 84 experienced only relapsing.

For the second follow-up, the relation between these variables was significant [X^2 (1) > = 5.868, p = < .05]. So here, experiencing a negative life event is associated with having a relapse for the time after 12 months. Sixty-one patients indicated that they had such a life event as well as a relapse, 76 only had a relapse. 45 patients indicated only negative life events, whereas 102 recorded that they had neither.

DISCUSSION

Main findings

This study is one of the few including the view of a mixed diagnostic sample of ED patients when it comes to gaining insight into the process of relapsing. The occurrence as well as the number of subjective relapses were investigated together with the causes of relapsing according to patients. Moreover, it was analysed what patients define as a negative life event, how many patients experienced such an event and whether there is an association between live events and relapse.

Relapse. The ***first research question*** was regarding how many patients experienced a relapse. At six months follow-up, 46% of the patients had one or more relapses and at twelve months follow-up 48% relapsed. Moreover, after six months, OSFED patients relapsed more often, whereas, after twelve months, BN patients had the highest numbers of relapse in comparison. When looking at the number of relapses asked for in ***research question two***, the majority of the patients indicated one to two relapses. An interesting finding for future research was that for both measurement points a significant association was found between relapse and diagnoses. By figuring out what differences there are for the various ED diagnoses in the proportion of relapse, prevention methods can be tailored to the specific needs of each patient.

Moreover, these outcomes are in line with the findings of the literature review of Khalsa et al. (2017), who report that, on average, 35 to 50% of the patients experience one or more relapses. Furthermore, they report that the risk of relapsing is highest during the first year of treatment but persists up until two years. Unfortunately, not enough data was collected at the follow-up at two years, to see whether the occurrence of relapses diminishes within two years. Since the data collection at Human Concern is still in progress, this could be a topic of interest for future research.

Research question three investigated the difference in the EDE-Q score for relapsed and non-relapsed patients. Results showed that for all time points as well as diagnostic groups, relapsed patients had a significantly higher global score on the EDE-Q and, therefore, a more severe eating pathology. This validates the subjective view of the patients regarding their relapse, which highlights the importance of including their experiences.

In support of these results, Carter et al. (2012) showed that higher scores on the EDE-Q scales Weight, Shape and Eating Concern are associated with experiencing a relapse

(Carter et al., 2012). Nevertheless, the current results should be treated with caution since it was not analysed if the patient's EDE-Q global score actually reaches the cut-off score for clinical significance. There is some discussion in the field about which score is most accurate, including numbers ranging from 0.96 to 2.5 (Rø, Reas, & Stedall, 2015). When looking at the results of the current paper, only the relapsed AN patients for both follow-up moments fall in this significant clinical range.

The main interest of this paper was to identify the causes of subjective relapse according to patients, included in ***research question four***. Eight main themes emerged during the analysis, namely: negative emotional state, external stressors, sense of control, negative self-perception as well as problems in interpersonal relationships, illnesses and, lastly, an unresolved ED pathology.

The theme regarding the patients' emotional state was described most often as a cause for relapsing by the patients, specifying a broad range of negative emotions and moods together with underlying traumas triggering their ED. Also, it was indicated that they misused their ED as compensation to regulate their negative emotions. Federici and Kaplan (2008) emphasise the importance of the ability to process and regulate one's emotions for recovery. When this is not possible, as indicated by the patients of this study, the chance of relapsing is higher, suggesting that it might be important to focus on including education on appropriate coping skills as a prevention method.

The second cause of relapse according to the patients were external stressors, including general stressors as well as stressors in specific areas, like one's occupation, living situation or during travelling. Occupational stress was also mentioned by Grilo et al. (2012), named as elevated work stressors. This trigger was followed by the explanation of the patients that they need to have control, in the sense that their relapse was either caused by the loss of control or that their ED was used to gain control. Moreover, a lot of uncertainty triggered a worsening in the pathology of the patients.

Participants in the qualitative study of Lamoureux and Bottorff (2005) stated a similar loss of control in the process of finding an identity apart from one's ED. Fogarty and Ramjan's (2016) findings indicate that empowerment is an essential coping mechanism for this loss. Connecting, it is an important step of recovery to "hand over" the control and regain a health level of it (Smith et al., 2014). Moreover, research confirms that intolerance of

uncertainty was found to be correlated with an ED symptomatology for AN patients (Kesby, Maguire, Vartanian, & Griham, 2019).

A lot of patients described their negative view of themselves and their bodies as a cause for relapsing. In line with this negative self-view, a lack of self-validation was also mentioned in other studies (D'Abundo, & Chally, 2004; Federici & Kaplan, 2008). Furthermore, perfectionism is a well-known risk factor for relapse as, for instance, setting high standards for oneself which were frequently mentioned by the patients (Fairburn & Beglin, 1994). The meta-analysis of Duncan, Sebar and Lee (2014) highlights the importance of finding a new perspective on one's personality and accepting oneself in order to be able to recover.

Another emerging theme was interpersonal relationships with a problematic nature. According to the patients, conflicts with family, friends or one's boyfriend influenced relapsing. However, social functioning is known to be affected by an ED resulting in a decreased feeling of connectedness (Patel, Tchanturia, & Harrison, 2016). Thus, research highlights the importance of adequate social support to counter the feeling of loneliness, which was often named as an accompanying factor by the participants (Pettersen, Thune-Larsen, Wynn, & Rosenvinge, 2012).

Lastly, illnesses, mostly including feeling fatigued, as well as a change in eating pattern and an unresolved ED pathology or comorbid disorders influenced a relapse according to the patients. In connection to the triggering effect of eating pattern change, McFarlane, Olmsted and Trottier (2008) concluded that to avoid relapse, the adherence to a healthy meal plan is important in the phase of treatment. So, when comparing the causes expressed by the patients to the found predictors in the ED field, it is highlighted that the majority is validated by prior research.

Negative Life Events. ***Research question five*** included: "*Which events are considered as live events according to the patients?*". In total, six themes emerged, where interpersonal conflicts including also break-up and the death of relatives together with physical issues of oneself and others were named as negative life events. Moreover, events in the domain of one's occupation or living situation were indicated, together with sudden life events like a car accident. Lastly, comorbid disorders, disturbing emotional states and suicidality were experienced as such events by the patients. The majority of the defined life events in this study are also included in the Oxford Risk Factor Interview by Fairburn et al.

(1999) as well as the Social Readjustment Rating Scale by Holmes and Rahe (1967), which are both valid assessments of life events.

The occurrence of negative life events during the different measurement points was included in ***research question six***. After six months, 24% indicated a negative life event, whereas after one year only 17% recorded such an event. This indicates that with time, fewer patients experienced negative life events. At the first follow-up, similar results were seen for OSFED- and BN patients and somewhat lower numbers for AN- and BED patients. For the second follow-up, only persons with a diagnosed OSFED had somewhat lower results. Most literature incorporates the amount of negative life events occurring before the onset of an ED, which makes it difficult to compare the current results.

Research question seven dealt with the association between life events and relapse. The analysis revealed no significant association for the first follow-up but a significant association for the second time point. So, after 12 months there was proof that experiencing a life event has an influence on relapsing and vice versa. Similarly, Sohlberg (2008) found a significant association between stressful life events and a poorer outcome in ED pathology for the diagnoses AN and BN. Moreover, Grilo et al.'s (2012) study showed that negative life events are significant warning signs for relapse, so the current findings are partly contrasting. Nevertheless, it has to be mentioned that the first follow-up included a higher number of responses which enhances the validity of these results. Further research is needed to gain a clearer picture of the relation between both variables.

In general, most ED literature focuses on the influences negative life events have on the onset and not the worsening of this disorder. Since the results show that around one third of the patients have experienced such an event, it is important to further investigate into this direction. Since some of the mentioned life events correspond with the reported causes of relapsing by the patients and a relation was found with ED pathology, it could be that these experiences have a negative influence on the ability to recover from an ED. The role of life events here is still relatively unresearched, yet important to be included in prevention methods, so it is suggested to conduct further research to fill this knowledge gap.

Strength and Limitations

The strengths of this study include the large sample size, the inclusion of a transdiagnostic sample as well as the design of a long-term follow-up. Limitations are the lack

of a common definition of a relapse for the patients, the specific clinical setting and the low participation rate for the follow-up after 24 months.

The measures used in this study capture a subjective estimation of the causes that could have influenced relapse. Hence, the question one needs to keep in mind when evaluating the results is: what is seen as relapse by the patients? Since the study did not ask for a definition of relapse, it is not clear if, for instance, a period of binging or only a single binge was counted as such a worsening. To rule out this lack of understanding, future research could focus on the subjective definition of relapse according to patients.

When speaking about applying the findings for other samples, it is important to highlight that all patients were collected through a speciality treatment service. This selection effect could as well have an influence. Due to the unique inclusion of the experiential knowledge of therapists recovered from ED, this treatment can not be compared to the normal clinical population of ED patients. Additionally, one has to keep in mind that it could be, that the same causes or life events are mentioned for the different measurement points by the same patients. This may have led to an overrating of subthemes, although the questions asked explicitly only for the time frame of the last six months.

A strong side of the study is that it was aimed to include a broad spectrum of ED diagnoses, also to gain insight in the differences across all ED's. As already mentioned, most studies regarding relapse are done solely with anorexic or bulimic participants (Ackard, Richter, Egan & Cronemeyer, 2013). Therefore, the integration of diversity is important, especially since BED and OSFED are relatively unresearched.

Moreover, the long duration of the follow-up can be highlighted as a strength. According to Bardone-Cone, Hunt and Watson (2018), studies with this interest range from one month to 12 months whereas Khalsa et al. (2017) found studies ranging from four weeks to 18 months post-treatment. Research shows that lower remission rates are associated with a shorter follow-up duration (Berends et al., 2018; Keel & Brown, 2010; Khalsa et al., 2017). With the used time frame of 24 months, a long period is included to get a good and reliable overview of the changes over time.

Nevertheless, it has to be said that a lot of data from this last measurement point could not be used in the quantitative analysis due to the low participation numbers. This is a limitation that could be ruled out by including a larger sample here and, therefore, ensuring

the validity of the interpretations. Still, enough data was collected to make some qualitative statements from the follow-up measure after two years.

Lastly, the sample size of 636 increases the reliability and validity of the presented results. Most qualitative studies include, often due to their interview design, much lower sample sizes as Khalsa et al. (2017) shows. In their literature review, the included 27 studies had a sample size ranging from 21 to 233. Nevertheless, in the current study, the number of BED was often not large enough, wherefore this group had to be excluded for most of the analysis. An improvement for this limitation would be to adapt the research design accordingly or focus more on this specific ED diagnosis to be able to draw more valid conclusions.

Conclusion and Future Suggestions

The current study showed that, although receiving treatment, around half of the patients experienced a relapse in the period of six- and twelve months post-treatment. This highlights the lack of appropriate coping techniques taught in therapy as well as the work that still needs to be done in order to prevent such a worsening in the patient's ED pathology. The ED research field needs to focus more on the individual needs of the patients to gain a deeper understanding of warning signs for relapse that go beyond symptom checklists.

The next steps in this type of research is to use more qualitative methods and utilise the found relapse triggers as guidance to create specific prevention techniques. As already mentioned in the beginning of this paper, first steps are done to not only focus on pathology but also incorporate well-being into the treatment of EDs. Positive psychology focuses on a lot of the aspects that the patients mentioned are missing on their way to recover. Strengthening one's relations, having a purpose in life and accepting oneself are just a few concepts of this approach that suit the specified relapse causes. Therefore, to empower and motivate patients to lead a life apart from their ED, it might be helpful to integrate this theoretical stance.

For further research, it is also suggested to conduct more research including a diverse sampling method by incorporating also the diagnosis BED and OSFED for further knowledge gathering. Regarding negative life events, it is advised to conduct more research on the relationship of these events with relapse, to either confirm or disagree with the current results. Lastly, more replications need to be done of studies including a longer follow-up duration and

other clinical settings to compare the results found in the current research. This would improve the ability to help patients dealing with the chronicity accompanying eating disorders.

Concluding, the results of the present study make clear that a complex system of factors impacts the process of relapsing. Learning more about such warning signs is essential for recovering patients as well as clinicians to avoid a worsening in pathology. The ED field needs to focus on the use of qualitative methods to gain a more in-depth and richer understanding as close as possible to the patients and their experiences. This study aimed to contribute it's part, but more is needed to fight the chronicity of ED's.

REFERENCE LIST

Aardoom, J.J., Dingemans, A.E., Op 't Landt, M.C.S., & Van Furth, E.F. (2012). Norms and discriminative validity of the Eating Disorder Examination Questionnaire (EDE-Q). *Eating behaviors*, *13*(4), 305-309. doi: 10.1016/j.eatbeh.2012.09.002

Ackard, D.M., Richter, S.A., Egan, A.M., & Cronemeyer, C.L. (2014). What does remission tell us about women with eating disorders? Investigating applications of various remission definitions and their associations with quality of life. *Journal of a Psychosomatic Research*, *76*(1), 12–18. doi:10.1016/j.jpsychores.2013.10.002

American Psychiatry Association (APA) (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington: American Psychiatric Publishing.

Bardone, A.M., Hunt, R.A., & Watson, H.J. (2018). An overview of conceptualizations of eating disorder recovery, recent findings, and future directions. *Current Psychiatry Reports, 20*(9), 79. doi:10.1007/s11920-018-0932-9

Berends, T., Boonstra, N., & van Elburg, A. (2018). Relapse in Anorexia Nervosa. *Current Opinion in Psychiatry, 31*(6)*,* 445-455. doi:10.1097/yco.0000000000000453

Bruce, C.D. (2007). Questions arising about emergence, data collection, and its interaction with analysis in grounded theory study. *International Journal of Qualitative Methods*, *6*(1), 51-68. doi: 10.1177/160940690700600105

Cockell, S. J., Zaitsoff, S. L., & Geller, J. (2004). Maintaining change following eating disorder treatment. *Professional Psychology: Research and Practice*, *35*(5), 527–534. doi:10.1037/0735-7028.35.5.527

D'Abundo, M., & Chally, P. (2004). Struggling with recovery: Participant perspectives on battling an eating disorder. *Qualitative Health Research, 14*(8), 1094–1106. doi:10.1177/1049732304267753

Davey, G. (2014). *Psychopathology: Research, Assessment and Treatment in Clinical Psychology* (2nd ed.).[UK]: The British Psychological Society, Chichester, West Sussex: Wiley

Dahlgren, L.D., Wisting, L., & Rø, Ø. (2017). Feeding and eating disorders in the DSM-5 era: asystematic review of prevalence rates in non-clinical male and female samples. *Journal of Eating Disorders, 5*(56). doi: 10.1186/s40337-017-0186-7

de Vos, J.A., LaMarre, A., Radstaak, M., Bijkerk, C.A., Bohlmeijer, E.T., & Westerhof, G.J. (2017). Identifying fundamental criteria for eating disorder recovery: A systematic review and qualitative meta-analysis. *Journal of Eating Disorders, 5*, 34. doi: 10.1186/s40337-017-0164-0

de Vos, J.A., Radstaak, M., Bohlmeijer, E.T., & Westerhof, G.J. (2018). Having an eating disorder and still being able to flourish? Examination of pathological symptoms and well-being as two continua of mental health in a clinical sample? *Frontiers in Psychology*, *9*, 2145. doi: 10.3389/fpsyg.2018.02145

Duncan, T.K., Sebar, B., & Lee, J. (2014). Reclamation of power and self: a meta-synthesis exploring the process of recovery from anorexia nervosa. *Advances in Eating Disorders, 3*(2)*,* 177–190. doi: 10.1080/21662630.2014.978804

Fairburn, C.G., & Beglin, S.J. (1994). Assessment of eating disorders: Interview or self-report *International Journal of Eating Disorders, 16*(4), 363-370. doi: 10.1002/1098-108X(199412)16:4<363::AID-EAT2260160405>3.0.CO;2-#

Fairburn, C. G., Cooper, Z., Doll, H. A. & Welch, S. L. (1999). Risk factors for Anorexia Nervosa: Three integrated case–control comparisons. *Archives of General Psychiatry, 56*, 468–476. doi: 10.1001/archpsyc.56.5.468

Federici, A., & Kaplan, A.S. (2008). The patient's account of relapse and recovery in Anorexia Nervosa: A qualitative study. *European Eating Disorder Reviews, 16*(1), 1 -10. doi: 10.1002/erv.813

Fogarty, S., & Ramjan, L.M. (2016). Factors impacting treatment and recovery in Anorexia Nervosa: Qualitative findings from an online questionnaire. *Journal of Eating Disorders, 4*, 18. doi: 10.1186/s40337-016-0107-1

Franko, D.L., Keshaviah, A., Eddy, K.T., Krishna, M., Davis, M.C., Keel, P.K., & Herzog, D. B. (2013). A longitudinal investigation of mortality in Anorexia Nervosa and Bulimia Nervosa. *American Journal of Psychiatry*, *170*(8), 917-925. doi: 10.1176/appi.ajp.2013.1708issue

Grilo, C.M., et al. (2012). Stressful life events predict eating disorder relapse following remission: Six-year prospective outcomes. *International Journal of Eating Disorders, 45*(2), 185-192. doi: 10.1002/eat.20909

Grilo, C.M., White, M.A., & Masheb, R.M. (2009). DSM-IV psychiatric disorder comorbidity and its correlates in Binge Eating Disorder. *International Journal of Eating Disorders, 42*(3), 228-234. doi: 10.1002/eat.20599

Harris, E.C., & Barraclough, B. (1998). Excess mortality of mental disorder. *The British Journal of Psychiatry, 173*, 11–53. doi: 10.1192/bjp.173.1.11

Hudson, J.I., Hiripi, E., Pope, H.G., & Kessler, R.C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological Psychiatry, 61*(3), 348-358. doi: 10.1016/j.biopsych.2006.03.040

Hoek, H.W. (2006). Incidence, prevalence and mortality of Anorexia Nervosa and other eating disorders. *Current Opinion in Psychiatry, 19*(4), 389-94. doi: 10.1097/01.yco.0000228759.95237.78

Human Concern (n.d.). Retrieved on May 15, 2020, from https://humanconcern.nl/

Khalsa, S.S., Portnoff, L.C., McCurdy-McKinnon, D., & Feusner, J.D. (2017). What happens after treatment? A systematic review of relapse, remission, and recovery in Anorexia Nervosa. *Journal Eating Disorder, 5*(20). doi: 10.1186/s40337-017-0145-3

Keel, P.K., & Brown, T.A. (2010). Update on course and outcome in eating disorders. *International Journal of Eating Disorders. 43*(3), 195-204. doi:10.1002/eat.20810

Keel, P.K., Dorer, D.J., Franko, D.L., Jackson, S.C., & Herzog, D.B. (2005) Postremission predictors of relapse in women with eating disorders. *American Journal of Psychiatry, 162*, 2263-2268. doi: 10.1176/appi.ajp.162.12.2263

Keel, P.K., Klump, K.L., Miller, K.B., McGue, M., & Iacono, W.G. (2005). Shared transmission of eating disorders and anxiety disorders. *International Journal of Eating Disorders, 38*(2), 99-105. doi: 10.1002/eat.20168.

Kesby, A., Maguire, S., Vartanian, L.R., & Grisham, J.R. (2019). Intolerance of uncertainty and eating disorder behaviour: Piloting a consumption task in a non-clinical sample. *Journal of Behavior Therapy and Experimental Psychiatry*, *65*, 101492. doi:10.1016/j.jbtep.2019.101492

Kessler, R.C., et al. (2013). The prevalence and correlates of Binge Eating Disorder in the World Health Organization World Mental Health Surveys. *Biological Psychiatry*, *73*(9), 904-914. doi: 10.1016/j.biopsych.2012.11.020

Lamoureux, M.M.H, & Bottorff, J.L. (2005). "Becoming the real me": Recovering from Anorexia Nervosa. *Health Care for Women International, 16*(2), 170-188. doi: 10.1080/07399330590905602

Linville, D., Brown, T., Sturm, K., & McDougal, T. (2012). Eating disorders and social support: Perspectives of recovered individuals. *Eating Disorders, 20*(3), 216–231. doi:10.1080/10640266.2012.668480

Löwe, B., Zipfel, S., Buchholz, C., Dupont, Y., Reas, D.L., & Herzog, W. (2001). Long-term outcome of anorexia nervosa in a prospective 21-year follow-up study. *Psychological Medicine*, *31*(5), 881-90. doi: 10.1017/s003329170100407x

McFarlane, T., Olmsted, M.P., & Trotter, K. (2008). Timing and prediction of relapse in transdiagnostic eating disorder sample. *Eating Disorders*, *41*(7), 587-593. doi: 10.1002/eat.20550

National Institute of Health and Care Excellence (NICE) (May 23th, 2017). *Eating Disorders: recognition and treatment, NICE guideline [NG69]*. Retrieved from: https://www.nice.org.uk/guidance/ng69

Our World In Data (2018). *Number of people with an eating disorder, World 1990 to 2017.* Retrieved on February 29, 2020, from https://ourworldindata.org/grapher/number-with-an-eating-disorder

Patel, K., Tchanturia, K., & Harrison, A. (2016). An exploration of social functioning in young people with eating disorders: A qualitative study. *PLOS One, 11*(7). doi: 10.1371/journal.pone.0159910

Pettersen, G., Thune-Larsen, K.B., Wynn, R., & Rosenvinge, J.H. (2012). Eating disorders: challenges in the later phases of the recovery process. *Scandinavian Journal of Caring Sciences*, *27*(1), 92–98. doi:10.1111/j.1471-6712.2012.01006.x

Riesco, N., Agüera, Z., Granero, R., Jiménez-Murcia, S., Menchón, J.M., & Fernández-Aranda, F. (2018). Other Specified Feeding or Eating Disorders (OSFED): Clinical heterogeneity and cognitive-behavioral therapy outcome. *European Psychiatry, 54*, 109–116. doi:10.1016/j.eurpsy.2018.08.001

Ryan, G., & Bernard, H.R. (2003). Techniques to identify themes. *Field Methods, 15*(1), 85-109. doi: 10.1177/1525822X02239569

Steinhausen, H.C. (2002). The outcome of Anorexia Nervosa in the 20th century. *American Journal of Psychiatry*, *159*, 1284-1293. doi: 10.1176/appi.ajp.159.8.1284

Smink, F.R., van Hoeken, D., & Hoek, H.W. (2012). Epidemiology, course, and outcome of eating disorders. *Current Opinion in Psychiatry. 26*(6), 543–548. doi: 10.1097/YCO.0b013e328365a24f

Smith, V. et al. (2014). The experience of specialist inpatient treatment for Anorexia Nervosa: A qualitative study from adult patients' perspectives. *Journal of Health Psychology, 21*(1), 16–27. doi:10.1177/1359105313520336

Ulfvebrand, S., Birgegard, A., Norring, C., Hogdahl, L., & von Hausswolff-Juhlin, Y. (2015). Psychiatric comorbidity in women and men with eating disorders results from a large clinical database. *Psychiatry Research*, *230*(2), 294-299. doi: 10.1016/j.psychres.2015.09.008.

Van Furth, E.F. (2000). *Nederlandse vertaling van de EDE-Q*. Leidschendam, NL: Robert-Fleury Stichting.

Venturo‐Conerly, K.E., Wasil, A.R., Dreier, M.J., Lipson, S.M., Shingleton, R.M., & Weisz, J.R. (2020). Why I recovered: A qualitative investigation of factors promoting motivation for eating disorder recovery. *International Journal of Eating Disorders. 53*(8), 1244-1251. doi: 10.1002/eat.23331

Wasson, D.H. (2003). A qualitative investigation of the relapse experiences of women with Bulimia Nervosa. *Eating Disorders, 11*(2), 73–88. doi:10.1080/10640260390199271

Wilson, G.T., & Shafran, R. (2005). Eating disorder guidelines from NICE. *The Lancet*, *365*, 79-81. doi: 10.1016/S0140-6736(04)17669-1

APPENDIX

Appendix A. Notification Emails

1. Herinneringsmail Nr. 1

Beste [name of participant],

Je bent bij Human Concern in behandeling geweest. Wij nemen standaard een half jaar, één jaar en twee jaar na beëindiging van de behandeling contact met je op.

Dit doen we om te kijken naar het effect van onze behandeling, zodat we onszelf waar nodig kunnen verbeteren en om te weten hoe het nu met je gaat.

Hiervoor sturen wij je een zogeheten 'follow-up' vragenlijst via het programma Vital Health Questmanager. Als het goed is heb je in het verleden al met dit programma gewerkt en de vragenlijst zal je dan ook bekend voorkomen.

Onlangs heb je een mail ontvangen van dit programma, met een link naar de follow-up vragenlijst. Middels deze mail wil ik je hieraan herinneren en je verzoeken deze in te vullen. Voor de zekerheid heb ik je ook nog een mail met nieuwe inloggegevens gestuurd.

Om je te bedanken voor het invullen van de vragenlijst mag ik je een cadeaubon t.w.v. €15,- aanbieden. Je mag kiezen voor een VVV-bon of een bon bij Bol.com (dit wordt gevraagd in de vragenlijst). Nadat je de vragenlijsten hebt ingevuld stuur ik je de bon per post toe.

Ik zie graag je reactie tegemoet en wens je nog een fijne dag!

2. Herinneringsmail Nr. 2

Beste [name of participant],

Zie de mail hieronder verstuurd op [date of last email]

Volgens onze gegevens is deze follow-up vragenlijst nog niet ingevuld. Wellicht heb je hierover nog vragen en zijn er onduidelijkheden?

Door het invullen van follow-up vragenlijsten kunnen we zien hoe het nu met je gaat en kunnen we (anoniem) onderzoek doen naar onze behandeling op lange termijn.

Hiermee kunnen we de behandelingen bij Human Concern dus blijven verbeteren!

Als bedankje voor het invullen van de follow-up vragenlijst willen we je graag een cadeaubon opsturen. Ik hoop dat je in de gelegenheid bent om de lijsten voor ons in te vullen.

Mocht je nog vragen hebben neem dan gerust contact met me op.

Appendix B. Questionnaire by Sander De Vos (translated into English)

- *1: Hoe is het het afgelopen (half) jaar met je gegaan?*
- *2: Heb je sinds je behandeling bij Human Concern nog één of meerdere terugvallen gehad met betrekking tot je eetstoornis?*
    - Did you have one or more relapses, with regard to your eating disorder, since your treatment at Human Concern?
- *3: Hoeveel terugvallen heb je gehad?*
    - How many relapses did you have?
- *4: Weet je wat de reden was van het ontstaan van je terugvallen?*
    - Do you know what caused your relapse? (causal relation interesting)
- *5: Ben je sinds je behandeling bij Human Concern nog ergens in behandeling gegaan of ben je op dit moment nog ergens in behandeling (voor de klachten waar je eerder bij Human Concern voor in behandeling bent geweest)?*
- *6: Bij welke instantie of praktijk ben je in behandeling (of was je in behandeling) na je behandeling bij Human Concern?*
- *7: Om wat voor soort behandeling gaat het?*
- *8: Heb je sinds je behandeling bij Human Concern nog vervelende of ernstige dingen meegemaakt?*
    - Have you gone through any discomforting or severe events/experiences since your treatment at Human Concern?
- *9: Welke vervelende of ernstige dingen heb je meegemaakt?*
    - What kind of discomforting or severe events/experiences have you had?
- *10: Opmerkingen?*
    - Comments?

Appendix C. Coding Schemes

1. Coding Scheme regarding Relapse

Table 16. *Coding Scheme Relapse*

Themes	Subcodes	Explanation	Variation within Codes	Example
change in eating pattern	*change in eating pattern*	change in eating pattern/habits	- binge eating - eating unhealthy - eating too much - old eating pattern - going out for dinner	- *"te veel ongezonde dingen gegeten en toen zag ik op dat moment maar 1 manier",* - *"Dan had ik het gevoel dat ik te veel had gegeten of gedronken "* - *"gebrek aan ritme in mijn eetpatroon"* - *"ik dan vaker uit eten ga"*
unresolved ED pathology	*recovery state*	state of the eating pathology	- ED still present - never fully recovered - only small setbacks - in therapy	- *"ruimte geven aan de eetstoornis die nog aanwezig was"; "Ik zal de terugval niet zozeer bestempelen als een grote, heftige terugval, maar wel een moment waarop ik weer veel houvast zocht in eten."* - *"moeizame start nieuwe therapie"*
	comorbid mental disorder	other mental disorder diagnoses mentioned than ED		*"depressieve klachten", "borderline" "ik zat bijna tegen een burn out aan", "OCD"*
illnesses	*illnesses*	illnesses the patients mention	- feeling tired/fatigue - surgery - pregnancy - medication	*"kaakblessure", "Door de gastric bypass operatie moest ik mijn hele eetpatroon opnieuw uitvogelen"* *"vaak vermoeidheid."*
negative self-perception	*negative view of self*	relation to oneself, emotions regarding oneselfs personality or behaviour	- self image - not feeling comfortable in own skin - miss of self care	- *"mijn lage zelfbeeld", "negatieve zelfevaluatie","Mijn identiteit nog niet hervonden. Heb een hekel aan mezelf.", "onzekerheid over mezelf"* - *"mijn eigen criticus was not te sterk. De lat had ik te hoog liggen"* - *"niet lekker in mijn vel zitten"*
	negative body image	image patients has of own body		*"Het stuk lichaamsbeeld/lichaamsbeleving verdiend nog altijd aandacht"*
emotional state	*neg. emotions and moods*	the patients emotions and how they handle it	- specific emotions - specific moods - not able to deal adequately with - unhealthy thoughts	*"Het gevoel het zelf te moeten oplossen en me eenzaam gevoeld te hebben.", "Angst, heledіepgewortelde angst", "achterliggende gevoelens", "teveel emoties", "eenzaam gevoel", "gewoon een rot gevoel"*
	ED as compen-sation	behaviours that are used as compensation for something (mostly neg. emotions)	- for feelings - coping mechanism	*"heel gezond eten en 2x per dag sporten me beter laat voelen.", "Gebruik voeding om die emoties te verdoven."* *"voelde het toen alsof ik niet anders kon dan mijn ES inzetten als verdoving/vlucht."*
	unspecified triggers	further triggers described that do not fit into the other codes	- specific mentioned triggers - traumas	- *"iemand in mijn nabije omgeving heeft afgelopen jaar anorexia ontwikkeld en dit triggerde me enorm"*

			- a lot of things going on	- *"Te veel gebeurtenissen achter elkaar (volle emmer)"*
sense of control	*loss of control*	searching for control in ED or being afraid of loss of control	- loss of structure - searching for safety - change - powerlessness - making choices purpose in life	*" Ik wist niet wat ik met mezelf aan moest"* *"Mijn neiging tot ergens controle over willen hebben.""verandering"* *"ik voelde me niet veilig in mezelf"* *"Ik denk dat het gebeurd is na een periode waar ik geen grip op had. Het zijn in de wat onstabielere periodes geweest."*
	uncertainty	uncertainty mentioned by patients		*"onzekerheid", "Onzekerheid over de keuzes die ik wil maken", "ik geen onzekerheid mag voelen"*
external stressors	*unspecified stress*	general stress experienced in life		*"spannende dinge", "spanning/stress", "drukte"* *"opeenstapeling van gebeurtenissen die voor extreem veel spanning zorgden."*
	stress at occupation	stress experienced in their occupation (job, school, studies)		*"een baan heb die me vrij veel stress oplevert"* *"door mijn studie in combinatie met mijn baan"*
	travelling	longer periods of being away from home	- vacation & trips	*"reisde ook flink", "Ja, ik was in een nieuwe omgeving in Zuid-Afrika en had daar wat moeit…"*
	living situation	moving to another place	the process of moving somewhere else, stress through living again with their parents	*"een verhuizing naar een nieuw dorp", "Verhuist wat ik heel lastig vind", "Terug wonend bij ouders wat niet goed verloopt"*
	other circum-stances	stressful circumstances mentioned <u>except</u> other external stressors		*"festival", "getting a mortgage","bijv. logees heb die meerdere dagen blijven, "een familie weekend"*
problems in interpersonal relationships	*unspecified social issues*	aspects related to interpersonal relations in general	no specific person addressed	*"Het abrupte einde van een dierbaar, emotioneel contact."*
	family issues	issues mentioned regarding family	- conflicts - death/illnesses in family	*"ziekte in familie", "Veel problemen in de familiare sfeer.", "Dood van onze zoon"*
	relation-ship issues	" regarding their relationship or sexual relations	- conflicts - break-up	*"relatieproblemen", "jongens",* *"problemen met vriend*
	friendship issues	" regarding friends	- conflicts - circumstances surrounding friends	*"Met het verhuizen van mijn vriend naar Amerika", "goede vriendin die op sterven ligt"*

2. Coding Scheme regarding Life Events

Table 17. *Coding Scheme Negative Life Events*

Themes	Subcodes	Explanation	Example
problems in interpersonal relationships	*unspecified social issues*	circumstances that happen in the interpersonal context without specific reference	*"persoonlijke problemen van iemand in mijn omgeving die mij ook raken.", "omgang met anderen", "Gebeurtenissen in de persoonlijke sfeer"*
	death of close one	decrease of a person in one's personal environment except for death by suicide	*"overlijden van mijn tante", "doodgeboren prematuur kindje", "Mijn tweelingbroer is om het leven gekomen"*
	family issues	circumstances that happen in the family context	*"familie perikelen", "zusje miskraam", "rondom mijn zoon", "verder heeft mijn zus het contact met mijn moeder verbroken"*
	friendship issues	circumstances that happen in the context of friendships	*"vriend naar het buitenland", "priveomstandigheden van een vriendin", "waar helemaal geen vrienden in de buurt wonen"*
	relationship issues	circumstances that happen in the context of intimate relationships	*"Een relatie pauze", "Mn partner is vreemdgegaan", "relatie moeilijkheden", "scheiden"*
	break-up	break-up of a intimate relationship with partner	*"Ik heb mijn relatie van bijna 10 jaar beëindigd", "Mijn relatie met mijn partner is sinds juni 2018 voorbij."*
illnesses	*own illnesses*	having issues with your physical health + pregnancy & not being able to get a child	*"Tijdens een paniekaanval te hard met mijn hoofd tegen de muur gebonkt waardoor ik een hersenschudding heb opgelopen", "kaakproblemen", "en teleurstellingen rondom ons ivf/icsi traject (hormoongebruik, verlies)."*
	hospital stay	stay in the hospital/surgery/treatment of oneself	*"2 weken in het ziekenhuis verbleven op Lombok, door heftige vorm van knokkelkoorts", "Hier uiteindelijk voor geopereerd.",*
	relatives with illnesses	someone else with physical issues/ diagnosis serious illness	*"Oma opname ziekenhuis", "moeder gediagnosticeerd met kanker"*
mental issues	*emotional states*	feelings expressed by the participants	*"Ik weet niet zo goed hoe ik mijn leven in moet vullen", "faalangst", "crisis", "Ik weet niet wat ik met mezelf aan moet"*
	mental disorders	mental disorders expressed by patients	*"paniekaanvallen", "terugval in alcohol", "burnout, angsten en depressie", "eetstoornis"*
	therapy issues	issues with the therapy or treatment of mental issues	*"moeizame start nieuwe therapie", "Geen goede klik met behandelaren op Rintveld"*
suicidality	*own suicide attempts*	(attempted) suicide by self	*"Ik stond op het punt om mijn polsen door te snijden"*

	own suicidal thoughts & self-harming	having suicidal thoughts or self-harming oneself	*"Laatst een keer zelfmoord gedachte", "Mezelf weer 2x geschlagen in mijn gezicht"*
	suicide by relatives	(attempted) suicide by others	*"Bekenden die zelfmoord plegen", "Een vriendin heeft 2 zelfmoordpogingen gedaan"*
sudden life events	*car accident*	being victim or cause of a car accident	*"ik ben aangereden", "auto ongeluk waarbij ik geen schuld had", "een van mijn beste vriendinnen heeft een auto-ongeluk gehad"*
unforseen life events	*occupation*	circumstances in the field of one's work, studies	*"werkstress","Daarnaast werk en collegialiteit die ver te zoeken is binnen het concern.", "hele vervelende werkbegleider op eindstage"*
	living situation	moving, going back to parents	*"Ik verloor mijn huis", "Paar keer verhuisd", "Ook mijn eigen plekje opzeggen en Amsterdam verlaten vond ik erg moeil…"*
	other circum-stances	additional events mentioned by the participants that do not belong in the other categories	*"Emotioneel misbruik en dreiging tot seksueel misbruik", "ik ben gestalkt", "Ik had einde augustus een rechtzaak van mijn verkrachting"*

Appendix D. Frequencies of Codes

1. Frequencies for Coding Scheme regarding Relapse

Table 18.
Frequencies of Codes regarding Relapse

Themes	**Subcodes**	Responses	
		N	Per cent
Negative Emotional State		174	29%
	Neg. Emotions and Mood	87	14.5%
	Unspecified Triggers	49	8%
	ED as Compensation	34	6%
External Stressors		162	27%
	Unspecified Stressors	71	12%
	Stress at Occupation	50	8%
	Travelling Stress	15	2.5%
	Living Situation	15	2.5%
	Other Circumstances	10	2%
Sense of Control		51	8.5%
	Loss of Control	42	7%
	Uncertainty	18	3%
Problems in Interpersonal Relationships		46	8%
	Unspecified Social Issues	17	3%
	Relationship Issues	11	2%
	Family Issues	9	1.5%
	Friendship Issues	9	1.5%
Own Illnesses			6%
Change in Eating Pattern			5%
Unresolved ED Pathology		40	7%
	Recovery State	22	4%
	Comorbid Mental Disorder	18	3%
		592	100%

2. Frequencies for Coding Scheme regarding Life Events

Table 19.
Frequencies of Codes regarding Life Events

Themes	**Subcodes**	Responses	
		N	Per cent
Problems in Interpersonal Relationships		137	40%
	Death of Relative	43	12.5%
	Family Issues	33	10%
	Breakup	23	6.5%
	Relationship Issues	16	5%
	Unspecified Social Issues	14	4%
	Friendship Issues	8	2%
Illnesses	Own Illnesses	32	9%
	Relatives with Illnesses	30	9%
	Hospital Stay	10	3%
Unforeseen Life Events			
	Occupation	33	10%
	Other Circumstances	23	7%
	Living Situation	9	2.5%
Sudden Life Events	Car Accident	4	1%
Mental Issues		47	14%
	Mental Disorder	21	6%

	Emotional States	20	6%
	Therapy Issues	6	2%
Suicidality		18	5%
	Suicide by Relatives	8	2%
	Own Suicide Attempts	6	2%
	Suicidal Thoughts/Self-harm	4	1%
		592	100%