

Self-assessment of eating disorder recovery: Absence of eating disorder psychopathology is not essential

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Abstract

Objective: The definition of recovery in eating disorders (EDs) according to researchers is not necessarily similar to the patient definition. This study aimed to explore the concept of recovery as assessed by those affected by an ED themselves.

Method: Participants from the Netherlands Eating disorder Registry (NER) who reported an (former) ED diagnosis ($n = 814$) assessed their own recovery level: current ED, partial or full recovery. Furthermore, research-based criteria (Bardone-Cone et al., *Behaviour Research and Therapy*, 2010, 48, 194–202) were applied to define recovery. Within the self-assessed full recovery group ($n = 179$), participants who also fulfilled the research-based criteria were compared to those who were only recovered based on self-assessment in the following domains: *ED psychopathology, psychiatric comorbidity, quality of life, and social and societal participation*.

Results: Ninety-six of the participants (54%) who considered themselves recovered did not fulfill the research-based definition. The two recovery groups did not significantly differ in *psychiatric comorbidity, quality of life, and social and societal participation*.

Discussion: Absence of ED characteristics was not essential for individuals to consider themselves recovered. Although the self-assessed recovery status may be subjective, it does advocate the use of additional health indicators besides ED psychopathology when defining recovery.

KEYWORDS

eating disorders, psychopathology, quality of life, self-assessment of recovery, societal participation

1 | INTRODUCTION

Many different recovery definitions in eating disorders (EDs) have been used, resulting in different outcome estimates (Ackard, Richter, Egan, & Cronemeyer, 2014; Dingemans et al., 2016; Vall & Wade, 2015). Bardone-Cone et al. (2010) defined recovery as a healthy weight (BMI > 18.5) combined with absence of binge eating, purging, and fasting in the past 3 months and normative levels of ED cognitions in the past month. A later comparison study recommended the adoption of this definition (Ackard et al., 2014). However, the definition of recovery according

to researchers is not necessarily similar to the patient definition. The agreement between expert-rated and patient-rated outcome for EDs appears to be weak (Bjork, Clinton, & Norring, 2011). Furthermore, both qualitative and quantitative studies investigating patients' perspectives have demonstrated the importance of additional factors for recovery besides remission of ED psychopathology, such as psychological and social well-being, and self-adaptability (de Vos et al., 2017; Emanuelli, Waller, Jones-Chester, & Ostuzzi, 2012; Noordenbos & Seubring, 2006).

The aim of the present study was to explore the concept of recovery. Participants from the Netherlands Eating disorder Registry (NER) assessed

their own recovery level as either fully recovered, partially recovered, or currently suffering from an ED. The first question was whether these three recovery groups could be distinguished based on the four following domains of health indicators: *ED psychopathology*, *psychiatric comorbidity*, *quality of life*, and *social and societal participation*. We expected the self-assessed full recovery group to perform best on these domains and the current ED group to perform worst. Given the different view on recovery between patients and experts, it was expected that part of the participants who considered themselves fully recovered would not be recovered according to research-based criteria (Bardone-Cone et al., 2010). This led to our second research question: How many participants from the self-assessed full recovery group also fulfill the research-based recovery definition, and is there a difference between participants who fulfill this definition and those who do not on the four domains of health indicators? We expected that the latter group considered themselves recovered not based on the domain of *ED psychopathology* but on the three remaining domains (i.e., *psychiatric comorbidity*, *quality of life*, and *social and societal participation*). It was therefore hypothesized that the two groups would be indistinguishable from each other on these three domains.

2 | METHOD

2.1 | Participants

In July 2015, Rivierduinen Eating Disorders Ursula started the NER, in collaboration with the VU University Amsterdam and the Dutch patient and family organization for EDs (Weet). The NER aims to follow the course and outcome of individuals with eating problems or EDs (current or past) via online questionnaires. Individuals of 12 years and older (<16 years with additional parental consent) were eligible to participate. Participants were recruited through websites (Weet and Proud2Bme.nl [a Dutch e-community for individuals with ED symptoms]) and Dutch programs specialized in ED treatment. Data from the baseline survey, which was completed by all participants when they joined the NER, collected between July 2015 and September 2017 were used. The Permanent Committee Science and Ethics (VU University Amsterdam) approved this research project.

2.2 | Measures

2.2.1 | Eating disorder psychopathology

All participants ($N = 916$) were asked if they were experiencing eating problems *currently* or *in the past*. Subsequently they were asked to what extent they were experiencing eating problems. In the current eating problems group ($n = 721$), 413 reported an ED diagnosis, 222 reported an ED diagnosis with partial recovery, while the remainder reported a probable ED (no formal diagnosis; $n = 72$) or eating problems, but no ED ($n = 14$). In the past eating problems group ($n = 195$), 179 reported an ED diagnosis with full recovery, while the remainder reported a probable ED ($n = 11$) or eating problems, but no ED ($n = 5$). Only data from the 814 participants with a self-reported ED diagnosis (self-assessed current ED, partial recovery, or full recovery) were used.

The Eating Disorder Examination Questionnaire (EDE-Q) version 6.0 (Fairburn & Beglin, 2008) was used to measure current ED psychopathology and assess ED behavior frequency. An EDE-Q global scale was computed (22 items; range 0–6). Derived from the criteria proposed by Bardone-Cone et al. (2010), the following research-based recovery definition, using the EDE-Q and self-reported height and weight, was applied: (a) absence of underweight (BMI > 18.5 [for participants under 18 an age adjusted cut-off for underweight was used] (Van Buuren, 2004)); (b) abstinence of ED behaviors (no binge eating, self-induced vomiting, laxative use, or fasting in the past month); (c) normative levels of ED cognitions (an EDE-Q global score below the Dutch clinical cut-off [2.17] in the past month). In a large Dutch sample, we previously showed that the EDE-Q global score was highly accurate in discriminating between individuals with an ED and those without (Aardoom, Dingemans, Slof Op't Landt, & Furth, 2012), and a clinical cut-off was calculated (Dingemans et al., 2016). Participants who considered themselves fully recovered were split into self-assessed recovery (only recovered based on self-assessment) and research-based recovery (also fulfilling the research-based recovery definition).

2.2.2 | Psychiatric comorbidity

Participants were asked if they had a current diagnosis for another psychiatric disorder. The number of current comorbid DSM-disorders was assessed and summed. Symptoms of anxiety and depression were assessed by the Patient Health Questionnaire for Depression and Anxiety (Kroenke, Spitzer, Williams, & Lowe, 2009), with higher scores (range 0–6) indicating more symptoms.

2.2.3 | Quality of life

Mental and physical quality of life was assessed by the 12-item Short-Form Health Survey (Ware, Kosinski, & Keller, 1995). Norm-based standardized scores for Physical and Mental Health, based on U.S. general population weights and norms, were computed to have means of 50 and SDs of 10. Higher scores indicate a higher quality of life.

2.2.4 | Social and societal participation

Relationship status was recoded (single/in a relationship). Satisfaction with social contacts was assessed by a single item (satisfied/neutral/unsatisfied). Furthermore, on a 10-point scale, participants could appraise how successful they were in contributing to society, based on (un)paid work or daytime activities (range: 1 “completely unsuccessful”–10 “completely successful”).

2.3 | Statistical analyses

Pearson Chi-square, Kruskal–Wallis, and Mann–Whitney tests were performed to investigate differences between the three self-assessed recovery groups and between self-assessed and research-based recovery in *ED psychopathology* (absence of underweight, binge eating, self-induced vomiting, laxative use and fasting, and a normative

level of ED cognitions), *psychiatric comorbidity* (comorbid psychiatric disorders, anxiety and depression symptoms), *quality of life* (physical and mental health), and *social and societal participation* (relationship, satisfaction social relations, and contribution to society). A per comparison α -level of .0035 (0.05/14 [variables]) was used to control for Type I error. Statistical analyses were performed in SPSS version 22 (IBM Statistics).

3 | RESULTS

In the baseline NER-survey 814 participants reported an (former) ED diagnosis. They were primarily female (98.6%) and their mean age was 26.4 ($SD = 8.7$, range 14–63). Participants listed anorexia nervosa (50%), other specified feeding or ED (32%), bulimia nervosa (14%), and binge-eating disorder (4%) as their current or last diagnosis. Over half (51%; $n = 413$) reported a current ED diagnosis, 27% ($n = 222$)

considered themselves partially recovered, and 22% ($n = 179$) reported full recovery. Age did not differ between the three recovery groups ($F[2,808] = 0.59$, $p = 0.55$). The full recovery group reported the best outcome in ED psychopathology, psychiatric comorbidity, quality of life, and social and societal participation (with exception of physical health; Table 1).

3.1 | Research-based recovery

Ninety-six of the 179 participants (54%) who considered themselves fully recovered were not recovered according to the research-based criteria. Table 2 shows that ED psychopathology differed significantly between self-assessed and research-based recovery, except for laxative use. When examining the different criteria of recovery, absence of underweight, abstinence of ED behaviors, and normative levels of ED cognitions were reached by respectively 78.1%, 38.5%, and 34.4% of the participants who were recovered based on self-assessment

TABLE 1 Distribution of means (and standard deviations) of eating disorder psychopathology, psychiatric comorbidity, quality of life and social and societal participation in the three self-assessed recovery groups and statistics

	Current eating disorder ($n = 413$)	Partial recovery ($n = 222$)	Full recovery ($n = 179$)	Statistic ^a	P-value	Effect size ^b	Contrast ^c
<i>Eating disorder psychopathology</i>	Percentage	Percentage	Percentage				
Absence of binge eating	46.2	51.4	79.3	$\chi^2(2) = 56.8$	$\leq .003$	$V = 0.26$	Current < full; partial < full
Absence of self-induced vomiting	58.8	69.8	90.5	$\chi^2(2) = 58.5$	$\leq .003$	$V = 0.27$	Current < partial < full
Absence of laxative use	76.8	89.6	97.8	$\chi^2(2) = 48.3$	$\leq .003$	$V = 0.24$	Current < partial < full
Absence of fasting	45.5	64.9	87.2	$\chi^2(2) = 93.2$	$\leq .003$	$V = 0.34$	Current < partial < full
Normative level of eating disorder cognitions (EDE-Q global score < 2.17)	4.8	19.4	64.8	$\chi^2(2) = 263.0$	$\leq .003$	$V = 0.57$	Current < partial < full
Absence of underweight (body mass index > 18.5)	57.9	75.8	88.1	$\chi^2(2) = 58.8$	$\leq .003$	$V = 0.27$	Current < partial < full
<i>Psychiatric comorbidity</i>	Mean (SD)	Mean (SD)	Mean (SD)				
Comorbid psychiatric disorders	1.2 (1.3)	0.8 (1.0)	0.4 (0.9)	$H(2) = 65.0$	$\leq .003$	$\eta^2 = 0.08$	Current > partial > full
Anxiety symptoms	4.3 (1.6)	3.3 (1.7)	2.2 (1.7)	$H(2) = 155.0$	$\leq .003$	$\eta^2 = 0.19$	Current > partial > full
Depression symptoms	3.8 (1.8)	2.8 (1.7)	1.6 (1.4)	$H(2) = 178.9$	$\leq .003$	$\eta^2 = 0.22$	Current > partial > full
<i>Quality of life</i>							
Physical health	45.2 (10.8)	50.9 (9.2)	52.4 (8.4)	$H(2) = 77.7$	$\leq .003$	$\eta^2 = 0.09$	Current < partial; current < full
Mental health	29.1 (9.3)	34.0 (10.3)	42.6 (11.2)	$H(2) = 160.2$	$\leq .003$	$\eta^2 = 0.19$	Current < partial < full
<i>Social and societal participation</i>	Percentage	Percentage	Percentage				
Relationship	35.6	44.7	60.1	$\chi^2(2) = 30.5$	$\leq .003$	$V = 0.20$	Current < partial < full
Satisfaction social relations satisfied	37.6	57.5	67.4	$\chi^2(4) = 64.3$	$\leq .003$	$V = 0.20$	Current < partial < full
Neutral	33.3	24.4	27.0				Current > partial
Unsatisfied	29.1	18.1	5.6				Current > partial > full
	Mean (SD)	Mean (SD)	Mean (SD)				
Contribution to society	4.5 (2.6)	5.3 (2.5)	6.1 (2.3)	$H(2) = 51.8$	$\leq .003$	$\eta^2 = 0.06$	Current < partial < full

Abbreviation: EDE-Q = Eating Disorder Examination Questionnaire.

^aFor categorical variables (eating disorder psychopathology, relationship and satisfaction social relations) Pearson Chi-square test statistics are presented; for continuous variables Kruskal-Wallis tests are shown.

^bEffect size Cramer's V: 0.1~small, 0.3~medium, 0.5~large. η^2 : 0.02~small, 0.13~medium, 0.26~large.

^cOnly contrasts (Mann-Whitney tests) significant at the $\alpha = .0035$ level are depicted.

TABLE 2 Distribution of means (and standard deviations) of ED psychopathology, psychiatric comorbidity, quality of life, and social and societal participation in participants recovered based on self-assessment alone and those also fulfilling the research-based criteria

	Self-assessed recovery (n = 96)	Research-based recovery (n = 83)	Statistic ^a	p-value	Effect size ^b
<i>Eating disorder psychopathology (research-based criteria)</i>					
	Percentage/mean (SD)	Percentage/mean (SD)			
Absence of underweight (body mass index >18.5)	78.1	100	$\chi^2(1) = 20.6$	$\leq .003^*$	$V = 0.34$
Absence of binge eating	61.5	100	$\chi^2(1) = 40.3$	$\leq .003^*$	$V = 0.48$
Absence of self-induced vomiting	82.3	100	$\chi^2(1) = 16.2$	$\leq .003^*$	$V = 0.30$
Absence of laxative use	95.8	100	$\chi^2(1) = 3.5$.06	$V = 0.14$
Absence of fasting	76.0	100	$\chi^2(2) = 22.8$	$\leq .003^*$	$V = 0.35$
Normative level of eating disorder cognitions (EDE-Q global score < 2.17)	34.4	100	$\chi^2(1) = 84.1$	$\leq .003^*$	$V = 0.68$
<i>Eating disorder psychopathology (dimensional)</i>					
Body mass index	22.3 (5.0)	21.7 (2.6)	$U = 3,805.5$.8	$r = 0.02$
Binge eating	2.3 (4.2)	0 (0)	$U = 2,448.5$	$\leq .003^*$	$r = 0.47$
Self-induced vomiting	0.7 (2.2)	0 (0)	$U = 3,278.5$	$\leq .003^*$	$r = 0.30$
Laxative use	0.2 (1.4)	0 (0)	$U = 3,818$.06	$r = 0.14$
Frequency of fasting absent	76.0	100	$\chi^2(4) = 22.8$	$\leq .003^*$	$V = 0.36$
1–5 days	16.7	0			
6–12 days	4.2	0			
13–15 days	2.1	0			
16–22 days	1.0	0			
Eating disorder cognitions (EDE-Q global score)	2.5 (1.3)	0.8 (0.6)	$U = 1,238.5$	$\leq .003^*$	$r = 0.59$
<i>Psychiatric comorbidity</i>					
Comorbid psychiatric disorders	0.5 (1.1)	0.4 (0.7)	$U = 3,962.5$.94	$r = 0.01$
Anxiety symptoms	2.5 (1.7)	1.9 (1.6)	$U = 3,067.5$.009	$r = 0.19$
Depression symptoms	1.8 (1.2)	1.4 (1.5)	$U = 3,097.0$.01	$r = 0.19$
<i>Quality of life</i>					
Physical health	51.4 (8.6)	53.4 (8.0)	$U = 3,342.5$.08	$r = 0.13$
Mental health	40.9 (10.9)	44.6 (11.2)	$U = 3,100.5$.01	$r = 0.18$
<i>Social and societal participation</i>					
Relationship	56.8	63.9	$\chi^2(1) = 0.91$.34	$V = 0.07$
Satisfaction social relations satisfied	65.6	69.5	$\chi^2(2) = 1.69$.43	$V = 0.1$
Neutral	30.2	23.2			
Unsatisfied	4.2	7.3			
Contribution to society	5.8 (2.2)	6.5 (2.3)	$U = 2,979$.005	$r = 0.21$

^aFor categorical variables (underweight, eating disorder behaviors, eating disorder cognitions, relationship and satisfaction social relations), chi-square test statistics are presented; for continuous variables, Mann–Whitney tests are shown.

^bEffect size Cramer's V : 0.1~small, 0.3~medium, 0.5~large; r : 0.02~small, 0.3~medium, 0.5~large.

^cSignificant after correction for multiple testing $p < .0035$.

alone. None of the comparisons in the domains of *psychiatric comorbidity*, *quality of life*, and *social and societal participation* reached significance after correction for multiple testing.

4 | DISCUSSION

The aim of this study was to explore the concept of recovery. As expected, participants who considered themselves fully recovered had the best outcomes on the health indicators compared to the

self-assessed partial recovery and current ED group. Within the self-assessed full recovery group, more than half of the participants (54%) were not recovered according to research-based criteria. Consistent with our hypothesis, these participants did not significantly differ from those with research-based recovery on any of the health indicators from the domains of *psychiatric comorbidity*, *quality of life* and *social and societal participation*.

In line with our results, Noordenbos and Seubring (2006) demonstrated that although the absence of multiple ED symptoms and attitudes were evaluated as important for recovery by patients with

self-perceived recovery, not all patients reported absence of these symptoms following treatment (41–80%) or 2 years later (49–97%). Bjork et al. (2011) found that there was only weak agreement between remission rates in EDs based on a self-report questionnaire (78%) and expert-rated outcomes (24–55%). Patients seem to use different criteria for recovery than experts. Furthermore, Pettersen and Rosenvinge (2002) concluded that patients can experience recovery and control over their own health, despite a level of ED psychopathology. Possibly an improvement of ED symptomatology is sufficient for individuals to consider themselves recovered.

On the other hand, because self-assessed recovery is more subjective it is possibly less valid. Patients with EDs tend to deny or underestimate the severity of their eating problems (Vandereycken & Van Humbeeck, 2008). Given the egosyntonic nature of EDs, especially anorexia nervosa (Gregertsen, Mandy, & Serpell, 2017), individuals might also be more inclined to consider themselves recovered, while still experiencing these symptoms. A majority of the self-assessed recovered participants who did not fulfill the research-based definition reported ED cognitions (66%). The presence of these cognitions after recovery increases the chance of relapse in EDs (Keel, Dorer, Franko, Jackson, & Herzog, 2005). Therefore these participants could be the ones with a higher risk of relapse. An interesting next step in future NER waves would be to examine whether self-assessed recovery is also a prerequisite for sustained recovery later in life.

The current study has several limitations. First, to allow for the assessment of a large sample, the NER data collection was exclusively based on self-report, which presents certain constraints in regards to the level and detail of information that is collected. A possible consequence could be that part of the 814 participants who reported an ED diagnosis did not actually receive one. Furthermore, the distribution of the ED diagnoses within our sample differed from lifetime prevalence estimates in the general population (Smink, van Hoeken, & Hoek, 2012) and those seen in specialist ED units (Dingemans et al., 2016). Anorexia nervosa was overrepresented while binge-eating disorder was underrepresented. Therefore, it is uncertain if our results can be generalized to the general ED population. Third, the health indicators assessed in the NER survey were not extensive. Some indicators were only measured with a single item, whereas other features and recovery themes (e.g., spiritual/existential dimension, self-adaptability, acceptance) were missing (de Vos et al., 2017; Huber et al., 2016; Stuart, Tansey, & Quayle, 2017). Future waves of the NER data collection should include these aspects. Finally, the research-based definition of recovery was derived from the criteria proposed by Bardone-Cone et al. (2010), but was not the same. ED behaviors were assessed for the past month instead of 3 months. Furthermore, we used a clinical cut-off based on the global score of the EDE-Q for ED cognitions instead of cut-offs for the four subscales. Our criteria were less strict, therefore it is possible that even fewer participants would have fulfilled the Bardone-Cone criteria. In these participants, some of the other health indicators might have reached a significant difference.

This study showed that absence of ED characteristics was not essential for individuals to consider themselves recovered. Moreover, the presence or absence of ED psychopathology, in individuals who

considered themselves recovered, was not associated with other important health indicators (psychiatric comorbidity, quality of life, social and societal participation). Although the self-assessed recovery status may be subjective, it does advocate the use of additional health indicators besides ED psychopathology when defining recovery.

DATA ACCESSIBILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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