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**Title:** How do *you* define recovery? A qualitative study of patients with eating disorders, their parents, and clinicians

**Running Title:** Patient, parent and clinician definitions of recovery

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**ABSTRACT**

**OBJECTIVE:** Recovery from an eating disorder (ED) may be defined differently by different stakeholders. We set out to understand the definition of ED recovery from the perspective of patients, their parents, and clinicians.

**METHOD:** We recruited patients with EDs (n=24, ages 12-23 years) representing different diagnoses (anorexia nervosa n=17, bulimia nervosa n=4, binge-eating disorder n=2, avoidant/restrictive food intake disorder n=1), along with their parents (n=20), dietitians (n=11), therapists (n=14) and primary care providers (n=9) from three sites: Boston Children's Hospital, University of Michigan C.S. Mott Children's Hospital, and Penn State Hershey Children's Hospital. In-depth, semi-structured, qualitative interviews explored participants' definitions of recovery. Interviews were analyzed using inductive data-driven thematic analysis. Statistical analyses followed to examine the distribution within each theme by respondent type.

**RESULTS:** Qualitative analysis resulted in the emergence of four overarching themes of ED recovery: (1) psychological well-being, (2) eating-related behaviors/attitudes, (3) physical markers, and (4) self-acceptance of body image. Endorsement of themes two and four did not significantly differ between patients, parents, and clinicians. Clinicians were significantly more likely to endorse theme one ( $\chi^2 = 9.90$ ,  $df = 2$ ,  $p = .007$ ,  $\phi_c = .356$ ) and theme three ( $\chi^2 = 6.42$ ,  $df = 2$ ,  $p = .04$ ,  $\phi_c = .287$ ) than patients and parents.

**DISCUSSION:** Our study demonstrates overwhelming support for psychological markers as indicators of ED recovery by all three groups. Clinicians should remain open to additional

markers of recovery such as body acceptance and eating-related behaviors/emotions that may be of critical importance to patients and their caregivers.

**INTRODUCTION:**

Eating disorders (EDs) are common in adolescence (Herpertz-Dahlmann, 2015), associated with significant morbidity and mortality (Crow et al., 2009; Field et al., 2012; Papadopoulos, Ekblom, Brandt, & Ekselius, 2009; Sullivan, 1995), and often have a protracted course with frequent relapses; for many, recovery remains elusive (Keski-Rahkonen et al., 2007). One potential barrier for patients with EDs is the lack of consensus in defining recovery (Bardone-Cone, Hunt, & Watson, 2018). Though there have been numerous studies attempting to define recovery from an ED (Bardone-Cone et al., 2018), there is still no consensus definition that can be operationalized in both clinical and research settings. This makes identifying the optimal treatment approach difficult, as outcomes cannot be compared across studies. To illustrate this confusion, Couturier and Lock applied different definitions of recovery to a treatment cohort and found rates of recovery from anorexia nervosa (AN) varied from 57-94% depending on which definition of recovery was applied (Couturier & Lock, 2006). Similarly, two other reviews found rates of recovery from AN in their respective reviews ranging from 8-88% and 0-92% (Berkman, Lohr, & Bulik, 2007; Steinhausen, 2002). While the variability in recovery rates may be partly attributable to treatment differences, it is also largely related to the definition of recovery used. As a result, patients are left in confusion when trying to identify the best treatment to achieve recovery.

Recognizing the need for a consensus definition of recovery, the ED field has made considerable effort over the last decade to establish one. Several recent reviews have called for operationalizing definitions based on physical, behavioral, and psychological markers of

recovery (Bardone-Cone et al., 2010; Bardone-Cone et al., 2018; Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017). To date, physical (e.g., weight restoration, resumption of menses) and behavioral (e.g., absence of purging or hyper-exercising) markers of recovery have largely been defined by clinicians and researchers. However, over the last decade, researchers and clinicians have increasingly acknowledged the importance of patients' experiences of recovery, as demonstrated primarily in qualitative studies (de Vos et al., 2017). Despite valuable existing research that has shaped current working definitions of ED recovery, knowledge gaps remain. First, extant qualitative studies examining recovery have largely focused on adults, despite adolescence being the typical period for onset of illness. Second, few studies have incorporated the perspectives of parents or other caregivers (Mitrofan et al., 2019), a significant gap as parents play a critical role in evidence-based approaches such as family-based therapy (le Grange, Lock, Loeb, & Nicholls, 2010). Third, studies have rarely included clinicians and patients in the same study. Additionally, studies of clinicians have almost exclusively included mental health providers; studies including dietitians or primary care clinicians are rare. Finally, few studies include a trans-diagnostic cohort, instead typically limiting to patients with restrictive EDs.

Recognizing the importance of hearing from adolescents/young adult (AYA) and their parents/primary caregivers, as well as their multi-disciplinary clinicians, we set out to: 1) Understand through qualitative interview data the definition of recovery from an ED from the perspective of AYA patients with various ED diagnoses, their parents/caregivers, and clinicians who treat EDs (i.e., registered dietitians (RDs), mental health clinicians (MHs), primary care

providers (PCPs)) and 2) Quantitatively examine the distribution of emergent recovery themes across patients, parents, and treatment providers in defining recovery.

## **METHODS**

### **Study Sample and Procedure**

We recruited a sample of 78 individuals representing AYA patients (aged 12-23) with EDs (n=24), their parents/caregivers (n=20), and clinicians caring for patients with EDs (i.e., RDs (n=11), MHs (n=14), and PCPs (n=9)). Patient participants were recruited at the time they presented for ED-specific care to one of three academic AYA Medicine sites: Boston Children's Hospital (BCH), University of Michigan C.S. Mott Children's Hospital, and Penn State Hershey Children's Hospital. Patients were recruited at various points in their treatment (though none were recruited at their initial visit) and were at various stages of recovery. Our study was approved by the Institutional Review Board at all three sites. Patients were recruited from partial hospitalization as well as multi-disciplinary outpatient ED programs housed within academic AYA Medicine programs and represented restrictive, binge, and binge/purge type ED diagnoses, specifically anorexia nervosa (AN) (n=17), bulimia nervosa (BN) (n=4), binge-eating disorder (BED) (n=1), and avoidant/restrictive food intake disorder (ARFID) (n=2). Parents of participating patients were recruited at roughly the same time; however, not all dyads agreed to participate such that there were some parents without children participating and vice versa. Seven out of 20 parents were male; 75% of parents reported their child requiring partial or residential level of care at some point in their treatment. Clinicians were recruited by email from our network of ED-focused clinicians and had significant experience both in years in practice

(average more than 15 years) and number of patients with EDs treated (average 33 patients/year for MHs, 38 patients/year for RDs, 13 patients/year for PCPs). All clinicians were female with the exception of 3 male PCPs. Non-English speaking was an exclusion criterion. Targeted recruitment of patients was used in an attempt to ensure diverse representation across diagnosis, gender, and age.

We conducted in-depth, semi-structured, qualitative interviews following an interview guide developed in an iterative process by the investigators, all of whom are clinician researchers with expertise in EDs. Uniformly trained research assistants (two per site for a total of six interviewers) conducted comprehensive qualitative interviews using the standardized interview guide. We asked all participants: “Most people look at weight restoration, but we think that recovery is much more complex than that. How would you define recovery?” followed by prompts such as “can you tell me more about that?” or “why?” The question regarding recovery was part of a longer interview that also focused on the feasibility of developing a registry of patients with EDs. Interviews were audio recorded, identified with study-assigned identification numbers, and transcribed verbatim by two research assistants. Transcripts were subsequently de-identified by removing any identifying information shared by participants such as names and identifying places.

Informed consent/assent was obtained from all participants and/or their parents prior to participation. For patients and parents, interviews were conducted at the time of study recruitment when possible; otherwise participants returned at a later time for interviews. Due to



scheduling constraints, clinician interviews were largely conducted by phone; all patient and parent interviews were conducted in person. Overall, the comprehensive interviews focused on recovery and feasibility lasted between 20-60 minutes. Interviews with providers tended to be shorter, while those with patients and parents were longer. The data that support the findings of this study are available from the corresponding author upon reasonable request.

### **Data Analysis**

Overall data analysis followed an exploratory sequential mixed methods design with qualitative analysis preceding quantitative analysis (Creswell & Clark, 2017). For qualitative analysis, we employed an inductive data-driven thematic analysis process, in which themes emerged directly from participants' language. This analysis method was most appropriate due to the exploratory nature of this study's first aim in learning recovery definitions directly from respondents and due to the paucity of existing theoretically or empirically supported coding structures for use with AYA ED patients, their parents, and clinicians. Following transcription, we first extracted raw data specifically related to definitions of recovery from each participant's transcript. We followed the four steps for qualitative research recommended by Braun and Clarke as follows (Braun & Clark, 2006 ). First, the coding team, consisting of two trained research assistants at BCH, familiarized themselves with the corpus of interview data. Second, two transcriptions each of patient, parent, and provider interview data were then randomly selected, and emergent patterns in these interviews allowed each coder to independently develop an initial coding structure. The coding team met iteratively to review the drafted code books and discuss points of discrepancy (e.g. different ways to describe an emerging theme) until they reached consensus on a final code book. Codes that represented the most parsimonious and meaningful

ways to describe patterns observed in the data were included. Third, all interview transcripts were independently coded by each member of the coding team using NVivo software,(Ltd., 2014) such that all interviews were coded by two different people. The coding process demonstrated thematic saturation with no necessity for coding structure revisions emerging as the interviews were coded. Fourth, double coded data were sorted into four naturally occurring overarching themes about ED recovery.

Following qualitative analysis, we investigated how themes were distributed among patient, parent, and clinician respondents. Qualitative data were first dichotomized to represent the presence or absence of each theme from each participant's data. Chi-square tests were then performed with SPSS software to examine distribution of each theme across the three groups of respondents (i.e. patients, parents, and clinicians).

## RESULTS

78 interviews were conducted with 24 patients, 20 parents, and 34 clinicians who treat patients with EDs. Patient participants ages 12-23 years ( $M = 16.7$ ,  $SD = 2.7$ ) were majority female ( $n = 19$ , 79%), and met DSM-5 criteria for one of four ED diagnoses: AN ( $n=17$ , 71%), BN ( $n=4$ , 17%), BED ( $n=1$ , 4%), ARFID ( $n=2$ , 8%) and had been in treatment for an average of 2 years.

Four naturally occurring themes emerged from coded interview data: (1) psychological well-being, (2) eating-related behaviors/attitudes, (3) physical measures, and (4) self-acceptance of body image.

*Insert Table 1 about here*

**Theme 1: Psychological Well-Being**

Among respondents overall, the most prevalent theme used to define ED recovery was psychological well-being ( $N = 67, 86\%$ ); this was also the case among each subgroup (patients  $n = 18, 75\%$ ; parents  $n = 15, 75\%$ ; and clinicians  $n = 34, 100\%$ ). Proportionately more clinicians discussed psychological well-being when defining recovery than patients and parents who were equally likely to discuss psychological well-being when defining recovery. ( $\chi^2 = 9.90, df = 2, p = .007, \phi_c = .356$ ). There was no variability between clinician types within this theme. See Table 2 for exemplar quotes of psychological well-being sub-themes by respondent type.

*Insert Table 2 about here*

**Theme 2: Eating-related Behaviors and Attitudes**

Discussions of eating-related behaviors and attitudes were the second most prevalent theme among participants overall ( $N = 38, 49\%$ ). Among patients ( $n = 12, 50\%$ ) and parents ( $n = 13, 65\%$ ), eating behaviors/attitudes were the second most frequently endorsed aspect of ED recovery. For clinicians, eating behaviors/attitudes were the third most frequently mentioned aspect of ED recovery ( $n = 13, 38\%$ ). Statistical analyses revealed that eating behavior/attitudes discussions were equally distributed across patient, parent, and clinician groups ( $\chi^2 = 3.63, df =$

2,  $p = 0.163$ ,  $\phi_c = .216$ ). See Table 3 for exemplar quotes related to eating behaviors and its sub-themes by respondent type.

*Insert Table 3 about here*

### **Theme 3: Physical Measures**

Discussions of physical measures of ED recovery were the third most prevalent theme among participants overall ( $N = 27$ , 35%). While among patients ( $N = 6$ , 25%) and parents ( $N = 4$ , 20%), physical measures of recovery were the least commonly discussed aspect of ED recovery of the four emergent themes, among clinicians, it was the second most frequently endorsed theme ( $N = 17$  (6 RD, 9 MH, 2 PCP)), 50.0%). Statistical analyses revealed significant between-group differences with more clinicians discussing physical measures of ED recovery compared to both parents and patients and no significant between-group differences between patients and parents ( $\chi^2 = 6.42$ ,  $df = 2$ ,  $p = 0.04$ ,  $\phi_c = .287$ ). It is notable that clinicians other than PCPs made up a large portion of the clinicians indicating physical markers as important. See Table 4 for exemplar quotes related to physical recovery.

*Insert Table 4 about here*

### **Theme 4: Self-acceptance of body image**

Defining ED recovery by self-acceptance of one's body image was the fourth most prevalent theme overall among the four emergent themes ( $N = 24$ , 31%). It was the least prevalent of the

four themes endorsed by clinicians ( $n = 8$ , 24%) and the third most prevalent theme among patients ( $n = 8$ , 33%) and parents ( $n = 8$ , 40%). Statistical analyses revealed that discussions of self-acceptance of body image were in fact equally distributed between respondent groups ( $\chi^2 = 1.71$ ,  $df = 2$ ,  $p = .425$ ,  $\phi_c = .148$ ), meaning that patients, parents, and clinicians were equally likely to describe self-acceptance of body image as an aspect of ED recovery. See Table 5 for exemplar quotes of theme 4 by respondent type.

***Insert Table 5 about here***

## **DISCUSSION**

In this novel qualitative study examining the definition of recovery as described by three groups—AYA patients, their parents/caregivers, and clinicians--we found considerable overlap yet some divergence in the four themes that emerged: psychological recovery, eating-related behaviors and attitudes, physical measures of recovery, and self-acceptance of body image. All three groups of respondents described psychological well-being most frequently in describing recovery. Patients and parents/caregivers cited eating-related behaviors and attitudes next most commonly, while clinicians cited physical markers of recovery. Overall, our findings uniquely reflect the perspective of *three key stakeholder groups* and validate the need for the definition of recovery to include psychological as well as physical and behavioral markers of recovery. It is important to note that our findings are derived from a treatment seeking population of youth; though their responses may be influenced by both their developmental stage and stage of illness/recovery they were still quite similar to findings in studies of recovered adults.

Our findings are consistent with the longstanding approach of using physical markers to define recovery. Physical improvement, particularly in patients with restrictive EDs, has long been indicative of recovery in both clinical and research settings (Morgan & Russell, 1975). This is understandable given the inherent negative effects observed in malnutrition, including worsening of ED cognitions as well as other associated physical co-morbidities (Herpertz-Dahlmann, Seitz, & Konrad, 2011). Thus, weight restoration has been a benchmark by which recovery has been measured historically. In our study only half of clinicians, a quarter of patients, and a fifth of parents indicated physical markers to be key to recovery. This may have been influenced by our initial question indicating our interest in markers beyond physical ones. Nevertheless, this was still the second most commonly reported theme among clinicians. Of those about two thirds specifically indicated that weight was key to recovery. Resumption of menses has been of particular interest to clinicians for some time as it indicates that weight restoration is adequate for reproductive functioning (Golden et al., 1997). Interestingly, only clinicians suggested that resumption of menses was critical to recovery, likely reflecting their training and biologic focus. In cases in which amenorrhea is an issue, clinicians may need to further educate patients and parents regarding the importance and meaning of regular menstrual periods in recovery.

Our findings also reflect the targeting of ED behaviors in defining recovery. Behavioral change is key to reversal of the physical manifestations of EDs so is logical to include in defining recovery. In our study, the definition of recovery included eating-related behaviors and attitudes for half of

patients, two thirds of their parents, and about one third of clinicians. Many of the subdomains related to eating behaviors also included a related psychological component, e.g., eating without guilt, thereby highlighting the intersection of behavior and associated or precipitating psychological distress. Interestingly, parents and clinicians commonly discussed achieving autonomy in eating as a recovery goal. This may be reflective of increase in the uptake of family-based approaches in which the first stage of recovery involves parents feeding their child (Lock & Le Grange, 2019) but the goal is autonomy for the child over time.

Our findings further emphasize the need to incorporate psychological factors in defining recovery. Respondents from all three groups overwhelmingly cited psychological factors as being key to recovery with 100% of clinicians and 75% of patients and parents including these in their descriptors of recovery. Psychological factors are important to include in defining recovery as they tend to lag behind physical and behavioral markers (Couturier & Lock, 2006). Without psychological recovery, individuals are in a state of 'pseudo recovery' (Bardone-Cone et al., 2018; Keski-Rahkonen & Tozzi, 2005) and are at high risk of relapse (Keel, Dorer, Franko, Jackson, & Herzog, 2005). Despite their importance in predicting relapse and their fundamental place in how patients have defined recovery (de Vos et al., 2017), studies in the ED literature still infrequently include psychological factors in their definitions (Bardone-Cone et al., 2018). Psychological markers of recovery from qualitative studies may suffer from being vague or hard to operationalize (e.g., overall well-being) (de Vos et al., 2017). However, psychological factors proposed by our cohort are largely in keeping with those measured by valid instruments such as the Eating Disorder Examination-Questionnaire (EDE-Q) (e.g., restraint around eating) (Carter,

Stewart, & Fairburn, 2001). The fact that every clinician interviewed endorsed at least one aspect of psychological health or overall well-being as one defining feature of ED recovery aligns with patient and parent descriptions and highlights a clinical understanding of EDs as illnesses that affect more than physical health.

We noted some interesting differences in definitions of recovery by respondent groups that may be particularly relevant for *AYA patients* with EDs. First, patients and parents had the same patterns in the domains they emphasized with psychological recovery being the most frequently cited and physical markers being the least frequently cited of the four themes that emerged. However, the emphases of parents and patients within the domains differed. Within psychological well-being, patients' responses aligned with those of clinicians in that their most frequently cited sub-domains were overall happiness and fewer ED thoughts. In contrast, parents most frequently cited coping skills and reduction in anxiety/fear within the theme of psychological markers. Within the theme of eating-related behaviors/attitudes, patients most commonly indicated eating without guilt as a marker of recovery while parents indicated autonomy in food choices. The responses of patients are in keeping with prior literature in which patients often favor building around feelings rather than behaviors (Bardone-Cone et al., 2010; Bardone-Cone et al., 2018). Parents in our study placed high emphasis on coping and autonomy in defining recovery for their child, potentially reflecting the increased focus on family-based approaches. Thus, clinicians and researchers should recognize that patients and parents may be perceiving recovery differently with each stakeholder's perspective having merit. Further, a marker of age-appropriate autonomy may be particularly salient in establishing



recovery in our teen patients. Recognizing these differences will impact future interventions that build on a comprehensive approach to eating disorder recuperation.

**Limitations** Although our study had many strengths, as with all qualitative work, this may not be representative of the views of all patients with EDs nor their parents or clinicians. However, we achieved a large sample size of individuals representing these three different groups (i.e., patients, parents, and clinicians) from three geographically distinct sites. We had an unusually robust sample size (78 respondents overall) for a qualitative study allowing us to establish thematic saturation with more certainty. Despite this large sample size, sample sizes for each subgroup were smaller and we had very few male participants. We included patients as young as age 12; the perspective of younger patients is valuable and underrepresented in the literature but may have some limitations as they may be less likely to have been in treatment or have ever achieved recovery. Given their developmental stage, the responses of these younger patients likely differ from those who are older. We also included parents of and patients with a variety of ED diagnoses. We felt having representation across diagnostic categories was important as many have called for a trans-diagnostic definition of recovery (Bardone-Cone et al., 2010). Additionally, many individuals have shifting behaviors and diagnoses over time (e.g., going from restrictive to binge/purge disorder) indicating the importance of including more than one type of ED. Though we did have representation across diagnoses, we acknowledge that the majority of our sample was diagnosed with AN, largely reflecting the care-seeking population of patients with EDs. Given that more than 70% of our patient participants were diagnosed with

AN, the themes we present here may be more reflective of individuals with AN or, at minimum, patients with restrictive EDs rather than the general population of individuals with EDs.

There are three additional limitations to acknowledge. Interviews with clinicians were overall shorter and mostly conducted by phone largely due to schedule constraints. This could have constrained the interviews and altered responses. We did not collect information from parents regarding their child's ED diagnosis; parents' comments could certainly be influenced by their child's diagnosis. A final limitation is overlap noted between themes (e.g., the theme of psychological well-being incorporating feelings about food and our eating behavior/attitudes theme including psychological aspects of eating). We believe this is reflective of how EDs manifest as eating behaviors and cognitions are intertwined with overall psychological well-being. We also elected to highlight self-acceptance of body image separately from psychological well-being as it a key feature of most diagnoses of EDs.

**Conclusions and Implications** Our findings are in concert with the recent studies that have called for any definition of recovery to include three domains: psychological recovery, physical improvement including weight restoration, and improvement in ED behaviors (Bachner-Melman, Zohar, & Ebstein, 2006; Bardone-Cone et al., 2010; Couturier & Lock, 2006; Pike, 1998). Patients should partner with their parents and clinicians in defining their path to recovery; while physical markers are the easiest for clinicians to assess, routine assessment of common behaviors and cognitions is equally important. Incorporating markers of autonomy based on the developmental stage of the patient is also key. Future work is needed to develop a brief

assessment tool for ED behaviors and cognitions that could be followed over time similarly to weight trajectories. In the meantime, patients with EDs as well as their caregivers and clinicians should recognize that while there will likely be considerable overlap, the nuances of the outcome they are striving for may differ. Thus communication regarding outcome goals is imperative from the outset of treatment.

## CITATIONS

- Bachner-Melman, R., Zohar, A. H., & Ebstein, R. P. (2006). An examination of cognitive versus behavioral components of recovery from anorexia nervosa. *J Nerv Ment Dis, 194*(9), 697-703. doi:10.1097/01.nmd.0000235795.51683.99
- Bardone-Cone, A. M., Harney, M. B., Maldonado, C. R., Lawson, M. A., Robinson, D. P., Smith, R., & Tosh, A. (2010). Defining recovery from an eating disorder: Conceptualization, validation, and examination of psychosocial functioning and psychiatric comorbidity. *Behav Res Ther, 48*(3), 194-202. doi:10.1016/j.brat.2009.11.001
- Bardone-Cone, A. M., Hunt, R. A., & Watson, H. J. (2018). An Overview of Conceptualizations of Eating Disorder Recovery, Recent Findings, and Future Directions. *Curr Psychiatry Rep, 20*(9), 79. doi:10.1007/s11920-018-0932-9
- Berkman, N. D., Lohr, K. N., & Bulik, C. M. (2007). Outcomes of eating disorders: a systematic review of the literature. *Int J Eat Disord, 40*(4), 293-309. doi:10.1002/eat.20369
- Braun, V., & Clark, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Carter, J. C., Stewart, D. A., & Fairburn, C. G. (2001). Eating disorder examination questionnaire: norms for young adolescent girls. *Behav Res Ther, 39*(5), 625-632.
- Couturier, J., & Lock, J. (2006). What is recovery in adolescent anorexia nervosa? *Int J Eat Disord, 39*(7), 550-555. doi:10.1002/eat.20309
- Crow, S. J., Peterson, C. B., Swanson, S. A., Raymond, N. C., Specker, S., Eckert, E. D., & Mitchell, J. E. (2009). Increased mortality in bulimia nervosa and other eating disorders. *Am J Psychiatry, 166*(12), 1342-1346. doi:10.1176/appi.ajp.2009.09020247
- 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. *J Eat Disord, 5*, 34. doi:10.1186/s40337-017-0164-0
- Field, A. E., Sonneville, K. R., Micali, N., Crosby, R. D., Swanson, S. A., Laird, N. M., . . . Horton, N. J. (2012). Prospective association of common eating disorders and adverse outcomes. *Pediatrics, 130*(2), e289-295. doi:10.1542/peds.2011-3663
- Golden, N. H., Jacobson, M. S., Schebendach, J., Solanto, M. V., Hertz, S. M., & Shenker, I. R. (1997). Resumption of menses in anorexia nervosa. *Arch Pediatr Adolesc Med, 151*(1), 16-21. doi:10.1001/archpedi.1997.02170380020003
- Herpertz-Dahlmann, B. (2015). Adolescent eating disorders: update on definitions, symptomatology, epidemiology, and comorbidity. *Child Adolesc Psychiatr Clin N Am, 24*(1), 177-196. doi:10.1016/j.chc.2014.08.003
- Herpertz-Dahlmann, B., Seitz, J., & Konrad, K. (2011). Aetiology of anorexia nervosa: from a "psychosomatic family model" to a neuropsychiatric disorder? *Eur Arch Psychiatry Clin Neurosci, 261 Suppl 2*, S177-181. doi:10.1007/s00406-011-0246-y
- 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. *Am J Psychiatry, 162*(12), 2263-2268. doi:10.1176/appi.ajp.162.12.2263

- Keski-Rahkonen, A., Hoek, H. W., Susser, E. S., Linna, M. S., Sihvola, E., Raevuori, A., . . . Rissanen, A. (2007). Epidemiology and course of anorexia nervosa in the community. *Am J Psychiatry*, *164*(8), 1259-1265. doi:10.1176/appi.ajp.2007.06081388
- Keski-Rahkonen, A., & Tozzi, F. (2005). The process of recovery in eating disorder sufferers' own words: an Internet-based study. *Int J Eat Disord*, *37 Suppl*, S80-86; discussion S87-89. doi:10.1002/eat.20123
- 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. *J Eat Disord*, *5*, 20. doi:10.1186/s40337-017-0145-3
- Kraemer HC, Kupfer DJ. Size of treatment effects and their importance to clinical research and practice. *Biol Psychiatry*. 2006; 59:990–996.
- le Grange, D., Lock, J., Loeb, K., & Nicholls, D. (2010). Academy for Eating Disorders position paper: the role of the family in eating disorders. *Int J Eat Disord*, *43*(1), 1-5. doi:10.1002/eat.20751
- Lock, J., & Le Grange, D. (2019). Family-based treatment: Where are we and where should we be going to improve recovery in child and adolescent eating disorders. *Int J Eat Disord*, *52*(4), 481-487. doi:10.1002/eat.22980
- Ltd., Q. I. P. (2014). *NVivo qualitative data analysis software* (Vol. Version 10).
- Mitrofan, O., Petkova, H., Janssens, A., Kelly, J., Edwards, E., Nicholls, D., . . . Byford, S. (2019). Care experiences of young people with eating disorders and their parents: qualitative study. *BJPsych Open*, *5*(1), e6. doi:10.1192/bjo.2018.78
- Morgan, H. G., & Russell, G. F. (1975). Value of family background and clinical features as predictors of long-term outcome in anorexia nervosa: four-year follow-up study of 41 patients. *Psychol Med*, *5*(4), 355-371. doi:10.1017/s0033291700056981
- Papadopoulos, F. C., Ekblom, A., Brandt, L., & Ekselius, L. (2009). Excess mortality, causes of death and prognostic factors in anorexia nervosa. *Br J Psychiatry*, *194*(1), 10-17. doi:10.1192/bjp.bp.108.054742
- Pike, K. M. (1998). Long-term course of anorexia nervosa: response, relapse, remission, and recovery. *Clin Psychol Rev*, *18*(4), 447-475.
- Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the 20th century. *Am J Psychiatry*, *159*(8), 1284-1293. doi:10.1176/appi.ajp.159.8.1284
- Sullivan, P. F. (1995). Mortality in anorexia nervosa. *Am J Psychiatry*, *152*(7), 1073-1074. doi:10.1176/ajp.152.7.1073

Table 1: Distribution of ED Recovery Theme by respondent type.

ED Recovery Theme	Patients (n=24)	Parents (n=20)	Clinicians (n=34)	Chi-square values						Overall (N=78)
	(n, %)	(n, %)	(n, %)	value	d.f.	p-value	$\phi_c$	NNT* clinician v. patients	NNT* parent v. patients	(n, %)
1: Psychological well-being	18 (75%)	15 (75%)	34 (100%)	9.90	2	0.007	0.36	4	$\infty$	67 (86%)
2: Eating-related behaviors/attitudes	12 (50%)	13 (65%)	13 (38%)	3.63	2	0.16	0.22	8	7	38 (49%)
3: Physical measures	6 (25%)	4 (20%)	17 (50%)	6.42	2	0.04	0.29	4	20	27 (35%)
4: Self-acceptance of body image	8 (33%)	8 (40%)	8 (24%)	1.71	2	0.43	0.15	11	14	24 (31%)

\*NNT: Number needed to take (Kraemer and Kupfer, 2006)

Table 2. Exemplar interview excerpts related to psychological well-being (Theme 1)

Sub-themes of psychological well-being	Patients		Parents		Clinicians	
	n	Excerpt	n	Excerpt	n	Excerpt
Overall Happiness (N=16)	n=5	<i>"I'd say it's when you're content and happy with the majority of your life and satisfied"</i> (19 y/o F w/ AN)	n=1	<i>"I think that looking at her being happy"</i> (Mother)	n=10	<i>"Moving through the steps and stages of physical, mental, emotional healing enough to experience some freedom in the way they live."</i> (MH)
Fewer ED Thoughts (N=15)	n=4	<i>"Not thinking about eating or thoughts around eating / exercise frequently"</i> (youth* w/ BN)	n=2	<i>"When thoughts about food are no longer functionally impacting your life. When they are no longer an inhibiting issue"</i> (Mother)	n=9	<i>"How much is the person still being tormented by eating disorder thoughts, by that eating disorder voice"</i> (MH)
Coping Skills (N=12)	n=2	<i>"..really important for recovery and being able to handle stressful situations without having food as a coping mechanism"</i> (19 y/o F w/ AN)	n=4	<i>"Dealing with stress in a positive way, have they developed some positive coping mechanisms?"</i> (Mother)	n=6	<i>"Being able to fluidly and flexibly utilize non-self-destructive coping strategies, to get through your day to day life and not having to resort to manipulating weight shape or appearance to navigate your world."</i> (MH)
Mental Recovery (N=9)	n=2	<i>"It's one thing to say 'I'm physically recovered,' but it's a whole other thing to say 'I'm mentally recovered,' and I think that that's the hardest part, because you could look totally fine, but you could mentally be at your worst"</i> (youth* w/ BN)	n=2	<i>"I think recovery is both mental and physical. Mental is a huge part of that, recovery"</i> (Mother)	n=5	<i>"Of course, yeah weight restoration is an important part but I think that really recovering mentally is huge, probably the hardest part to overcome I think."</i> (PCP)
Less Anxiety/ Fear (N=7)	n=2	<i>"Probably just being able to participate in normal activities without a fear of anything that a normal person wouldn't be scared of"</i> (16 y/o F w/ AN)	n=3	<i>"It's reducing anxiety to be able to handle new foods"</i> (Mother)  <i>"watching him be less agitated if he's not able to exercise"</i> (Mother)	n=2	<i>"..is there, is there anxiety and stress around food and food situations?"</i> (RD)  <i>"Not having any fear of weight gain or how their food is impacting what they eat... overall lack of fear"</i> (MH)

Social Belonging (N=7)	n=1	<i>"I would say their social life, is it the same as it was before? Has it increased?" (18 y/o F w/ AN)</i>	n=2	<i>"Fitting into the group and having a sense of belonging" (Mother)</i>	n=4	<i>"Developing relationships, and maintaining relationships" (RD)</i>
Mental Stability/ Wellness (N=3)	n=2	<i>"...general mood, like 'have you experienced recent mood swings?" (18 y/o M w/ AN)</i>	n=1	<i>"I would like my daughter's brain health to catch up to her body health...her mind is not where it needs to be. And that's a daily struggle." (Mother)</i>	n=0	

MH: Mental health clinician, PCP: primary care provider, RD: registered dietitian

AN: Anorexia nervosa, BN: Bulimia nervosa

\*because there were so few individuals with ARFID, BN and BED, we have eliminated demographic characteristics that might identify them



Table 3: Exemplar interview excerpts related to eating behaviors/attitudes (Theme 2)

Sub-Themes of eating behaviors/attitudes	Patients		Parents		Clinicians	
Eating with satisfaction and without guilt (N=10)	n=6	<i>"I could just go to a restaurant and order different things, and I could eat anything at my friend's house. And I wouldn't feel like...grossed [out] by those foods"</i> (youth* w/ ARFID)	n=2	<i>"If they want to go to McDonalds and buy a Big Mac and French fries and a milkshake- and that's what they really want- they can go do it and not feel guilty"</i> (Father)	n=2	<i>"I am able to eat things I want to and I don't feel the guilt or anxiety afterwards."</i> (MH)
Eliminating ED eating behaviors (N=9)	n=2	<i>"Not using ED behaviors. I think that is the most important. And being okay, and not having urges to use behaviors—or not having a lot of urges to do anything bad"</i> (20 y/o F w/ AN)	n=1	<i>"You are never sure when the recovery is complete, you can only tell from [eating disorder] behavior."</i> (Father)	n=6	<i>"somebody who has not exhibited eating disorder behaviors for one year"</i> (PCP)
Increasing autonomy in eating choices (N=7)	n=0		n=4	<i>"I think getting the individual to become fully independent again in making good food choices"</i> (Mother)	n=3	<i>"Being able to feed themselves in a way that supports a healthy body and healthy mind"</i> (MH)
Increasing dietary variety and flexibility (N=4)	n=1	<i>"...they'd be flexible about their food and what they'd eat. So they'd be willing to eat something unhealthy if they were at a party or something"</i> (youth* w/ BN)	n=2	<i>"recovery would be that she got to the point where she was eating food that everyone else eats—fruits and vegetables and a variety of food"</i> (Mother)	n=1	<i>"Are they able to increase the variety of their foods?"</i> (RD)
Comfort eating in social settings (N=4)	n=2	<i>"Social aspects of eating and food-- that was important to me in recovery, that took me the longest to be more comfortable with again"</i> (18 y/o F w/ AN)	n=1	<i>"Sometimes they won't eat in front of people because they're concerned with what it's going to look like"</i> (Father)	n=1	<i>"Able to go out with friends and eat with their friends and eat with their families? Are they able to eat at school without supervision?"</i> (MH)
Being honest with others about eating (N=3)	n=1	<i>"It's so tricky because if the eating disorder is still there, you'll just lie about everything, and there's really no way for any type of doctor to know if it's really gone because it"</i>	n=2	<i>"Recovery comes when she's being honest about what her feelings are around food, because if she's honest, I can handle it, the ups the downs"</i>	n=0	

		<i>could be there, whispering to you, just like, you're fine, say that you'll eat, and once you're on your own, old habits die hard"</i> (16 y/o F w/ AN)		(Father)		
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Table 4: Exemplar interview excerpts related to physical measures (Theme 3)

Sub-themes related to physical measures	Patients		Parents		Clinicians	
Weight Restoration (N=18)	n=5	<i>“Probably being at a healthy weight that I kind of imagine it would be, and just kind of staying there for a while”</i> (youth* w/ BED)	n=3	<i>“Well certainly the weight. That I think—I think that’s number 1.”</i> (Father)	n=10	<i>“Weight restored or weight stable within a healthy target weight range”</i> (MH)
Other improved measures of physical health (e.g. heart rate, blood pressure) (N=6)	n=1	<i>“There’s major side effects to all of this like osteoporosis, and a slow heart rate, low blood pressure, and having your weight gain back it helps even everything out and it makes...I don’t know it just makes the body easier to function.”</i> (16 y/o F w/ AN)	n=1	<i>“I would rather have some other biometrics that, your heart rate has improved, your blood work is on target”</i> (Father)	n=4	<i>“The whole worry about heart and bones”</i> (MD)  <i>“Health signs and labs are ok”</i> (MH)
Menses resumption (N=3)	n=0		n=0		n=3	<i>“menstrual period”</i> (PCP)

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Table 5: Exemplar interview excerpts related to self-acceptance of body image (Theme 4)

	Patients		Parents		Clinicians		
<b>Self-Acceptance of Body Image (N = 24)</b>	n=8	<i>"I struggle with the body image and self-image and esteem. And so I think it would be feeling comfortable with myself and accepting and being like okay this is how my body is. Other people are different and...I just have to live with the thing that I have. And I just have to appreciate it. Because we only...have one chance and so...I guess just like love it and enjoy it."</i>	n=8	<i>"Yeah I guess the majority of what I consider recovered is just a realistic view of their body image is the only word I can think of right now, that it's not distorted in one direction or the other. I think that would show that they are more recovered than just a certain weight, just that they are happy with who they are."</i> (Father)	n=8	<i>"Accepting their bodies—that is a big one. I'm not saying loving your body because I think that is a really hard goal to achieve. But accepting your body and accepting your body size....Accepting one's perceived imperfections"</i> (MH)	

MH: Mental health clinician

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