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Parents know best: Caregiver perspectives on eating disorder recovery

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Abstract

Objective: This study used mixed methods to evaluate caregiver perspectives on recovery from an eating disorder.

Method: Caregivers ($N=387$) completed an online survey about their child's weight history, treatment history, illness trajectory, and recovery.

Results: Children were predominantly females with adolescent onset anorexia nervosa and currently 18.4 years old on average. Qualitative analysis of caregivers' open-ended definitions of recovery revealed seven distinct recovery domains, including 1) weight (45%); 2) body image, eating disorder cognitions, and related emotions (54%); 3) eating behavior (71%); 4) independence and responsibility in eating disorder management (28%); 5) physical health (21%); 6) psychological well-being (31%); and 7) life worth living (27%). Most (72%) reported that their child had achieved partial or full recovery at some point in their lifetime. Only 20% reported that their child had ever achieved full recovery, but 93% of those had sustained recovery over time (i.e., no relapses since achieving recovery). Physical recovery occurred on average 2.7 years after eating disorder onset, followed shortly by social and emotional recovery (2.9 years), and finally behavioral (3.4 years) and cognitive (3.9 years) recovery, which occurred at weights 6 to 7 pounds higher than those at which physical recovery was achieved.

Conclusion: Findings suggest that caregivers hold a multi-faceted view of recovery that includes not only weight restoration and symptom reduction, but also full engagement in social and occupational activities, establishment of a meaningful life, cognitive flexibility, and emotional well-being. These data support clinical observations that physical and behavioral recovery precede cognitive recovery.

Keywords

recovery; treatment outcome; weight restoration; caregivers; children and adolescents; eating disorders

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Data Availability Statement

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

Introduction

Eating disorders have severe medical (Andersen & Yager, 2009) and psychological consequences (Crow, Swanson, Le Grange, Feig, & Merikangas, 2014) and carry a mortality rate of 4–5% (Arcelus, Mitchell, Wales, & Nielsen, 2011). Some of the resulting changes in health and functioning are easily measured, while other changes (e.g., personality, vitality) may be less discernible. Researchers and clinicians have identified several distinct domains that contribute to recovery (i.e., behavioral, cognitive, and physical) (Bardone-Cone, Hunt, & Watson, 2018; Couturier & Lock, 2006), but there is little agreement about what constitutes recovery in these domains (Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017). Further, there is debate as to whether full recovery is achievable for all patients (Bardone-Cone et al., 2018). The heterogeneous nature of treatments with disparate goals has further complicated reaching consensus on a definition of recovery.

Inconsistent definitions of recovery have made it difficult to compare findings about illness course and treatment outcomes and also resulted in wide variability in treatment outcome estimates, ranging from recovery rates of 57% to 94% for anorexia nervosa (Couturier & Lock, 2006) and 5% to 99% for bulimia nervosa (Steinhausen, 2002). For example, the definition of weight restoration—perhaps one of the most objective recovery domains—has drastic implications for recovery rates. One study found that weight restoration to 85% of median BMI in adolescents with anorexia nervosa yielded a 94% recovery rate, whereas raising the cutoff to 100% of median BMI resulted in a significantly lower recovery rate of 65% (Couturier & Lock, 2006), which correspond approximately to the 9th (85% mBMI) and 35th BMI percentiles (95% mBMI), when averaging values for children ages 12–18 years (CDC, 2009). No consensus currently exists on best practices for calculating expected goal weight, presenting an additional challenge to comparing weight restoration across studies (Lebow, Sim, & Accurso, 2018). Given the practical difficulties of applying an individualized approach, researchers have largely relied on a nomothetic approach to estimating expected body weight (Couturier & Lock, 2006), despite growing clinical support for using personal historical growth curves to estimate goal weight (Golden et al., 2015), thus complicating the translation of research to practice.

There is general agreement that reduction or remission of physical and behavioral symptoms precedes psychological recovery (Khalsa et al., 2017). However, treatment research has struggled to establish a consistent definition of psychological recovery in the context of some body dissatisfaction (Robinson, Chang, Haydel, & Killen, 2001) and dieting behaviors (Neumark-Sztainer, Story, Falkner, Beuhring, & Resnick, 1999) being normative among adolescents. Similar to weight, there is significant variability in how researchers define clinically significant change or the cut-off for normal versus abnormal weight and shape concerns and disordered eating behaviors. Differences in cut-offs significantly influence recovery rates in adolescents with anorexia nervosa, from 57% for Eating Disorder Examination (EDE) scores within 1 standard deviation of community norms to 74% for EDE scores within 2 standard deviations of community norms (Couturier & Lock, 2006). Some research also suggests that overall eating disorder psychopathology improves with weight gain, including eating concerns and dietary restraint but not weight and shape

concerns, which are less amenable to change (Accurso, Ciao, Fitzsimmons-Craft, Lock, & Le Grange, 2014).

The highly focused definition of recovery often employed in research including cut-offs for %mBMI and EDE scores may not represent what patients or caregivers believe is most important. Therefore, it is essential to understand how individuals with eating disorders and their families conceptualize recovery. A recent meta-analysis of 18 qualitative studies found that recovered individuals believe that symptom reduction is insufficient for true recovery and prefer to include additional factors such as psychological well-being, self-acceptance, personal growth, positive relations with others, self-adaptability, and autonomy (de Vos et al., 2017). While identified as essential by individuals with eating disorders, these factors are rarely measured in treatment outcome research.

Because parents and caregivers (herein referred to as caregivers) know their children best, they may be our best resource to establish meaningful patient-centered treatment outcomes. Caregivers are often well-suited to observe change over time that may not be acknowledged by patients in the grips of the disorder or readily detected by others (e.g., clinicians). Although there are some qualitative studies on caregiver experiences of treatment, no studies have systematically examined caregiver perspectives on recovery or how the recovery process unfolds. This study used a mixed methods approach to evaluate caregiver perspectives on recovery from an eating disorder.

Methods

Caregivers of children with an eating disorder completed an online survey about their child's weight history, treatment history, illness trajectory, and their understanding of recovery. Caregivers were recruited through social media (e.g., Facebook, Twitter, YouTube, and Instagram) with help from parent support forums [e.g., Families Empowered and Supporting Treatment of Eating Disorders (F.E.A.S.T.), International Eating Disorder Family Support (IEDFS)], eating disorders organizations [e.g., Eating Disorders Association of New Zealand (EDANZ), Eating Disorders Families Australia (EDFA) National Eating Disorders Association (NEDA)], and eating disorder advocates. A total of 620 caregivers started the survey and provided initial demographic and clinical information on their child's illness; 233 (37.6%) did not complete the remainder of the survey on treatment history and recovery and were therefore excluded. All caregivers provided informed consent to participate, and all study procedures were approved by the Mayo Clinic Institutional Review Board.

Participants

Participants ($N = 387$) were caregivers from 21 countries, including the United States (57.6%, $n = 223$), United Kingdom (15.0%, $n = 58$), Australia (10.3%, $n = 40$), and Canada (7.0%, $n = 27$). Caregiver participants were primarily Caucasian (97.2%, $n = 376$) mothers (94.6%, $n = 366$), as well as fathers (4.7%, $n = 18$), stepmothers (0.5%, $n = 2$), and a foster mother (0.3%, $n = 1$). Other races included Asian (1.8%, $n = 7$), bi or multiracial (0.8%, $n = 3$), and American Indian or Alaska Native (0.2%, $n = 1$); a small minority was of Latino ethnicity (6.2%, $n = 24$). Household income was varied: less than \$50,000 (14.0%, $n = 54$), \$50,000 to less than \$99,999 (24.8%, $n = 96$), \$100,000 to less than \$300,000 (50.3%, $n =$

195), and \$300,000 or more (10.9%, $n = 42$). Caregiver education was relatively high: completed less than college degree (13.7%, $n = 53$), associate degree (7.5%, $n = 29$), bachelor's degree (39.0%, $n = 151$), and masters, doctoral, or professional degree (40.0%, $n = 154$). Survey completers did not differ significantly from non-completers on any of the demographic variables or clinical variables, including age of onset, diagnosis, primary eating disorder symptoms, weight range prior to the eating disorder, or country (United States versus other) ($ps > .05$).

Measures

Caregivers provided basic demographics and reported on their child's eating disorder (e.g., date of onset, formal diagnosis) and treatment history, including the date ranges in which their child participated in each specific type of treatment related to the eating disorder. Caregivers also provided growth history, including weight range prior to the eating disorder, historical weight, height, and body mass index, with the option to report weight and height in the metric or imperial system. Items related to recovery included an open-ended response on how caregivers would define recovery in their own words, as well as additional multiple-choice items asking caregivers to select components of recovery from a predefined list (e.g., ability to maintain weight, ability to eat the range of foods previously eaten, stable vitals), with the option to write in three "other" recovery components. Caregivers were then asked to identify and rank order the top five most important factors in their perception of recovery. The last component of the survey inquired about caregivers' perspective on their child's recovery. First, caregivers were prompted with an initial multiple-choice item on whether their child had *ever* reached a state of recovery (no, somewhat, mostly, or completely). If they responded positively, they were asked to report on the extent to which recovery had been achieved (no, somewhat, mostly, or completely) for each of five distinct domains (i.e., physical health, normal eating, absence of eating disorder cognitions, normal social functioning, and normal mood), as well as the date, weight, and height at which that recovery occurred.

Analysis

For open-ended responses, the first and senior authors used an inductive approach to develop a codebook using thematic analysis to identify common themes. After independent examinations, they reached consensus on themes to be coded. The codebook was then applied to the rest of the transcripts for modifications of both codes and their definitions. Data saturation and inductive thematic saturation were reached for both coders at around 100 participants, at which point no additional codes were identified and the codebook stabilized. Caregiver responses were independently coded for each theme by the two authors. Interrater reliability was examined for each code using Cohen's kappa, where .6 indicated moderate agreement, .8 indicated strong agreement, and $>.9$ indicated almost perfect agreement (McHugh, 2012). All discrepancies between codes were reviewed and reconciled.

Results

Children were predominantly Caucasian (93.8%, $n = 363$) females (90.3%, $n = 346$) with anorexia nervosa or atypical anorexia nervosa (88.8%, $n = 344$) whose age of eating disorder onset was 13.41 years ($SD = 2.06$) and were on average 18.40 years old ($SD = 4.83$) at the time caregivers completed the survey, allowing caregivers to report on 4.96 years ($SD = 4.48$) from onset. Table 1 presents detailed information about demographics, clinical characteristics, and treatment history. Consistent with the diagnostic spread, the primary eating disorder symptoms included weight loss (92.2%, $n = 357$) and/or failure to make expected weight gain (20.4%, $n = 79$), restrictive eating (95.1%, $n = 368$), excessive exercise (62.8%, $n = 243$), purging (16.3%, $n = 63$), and binge eating (8.0%, $n = 31$). Approximately two-thirds of the sample had a history of medical health problems associated with their eating disorder (e.g., bradycardia, dizziness, loss of menses) (66.1%, $n = 256$), and over one-third required at least one inpatient medical hospitalization (37.1%, $n = 139$). Two caregivers noted that their children had died from medical complications related to anorexia nervosa. At first presentation for eating disorders treatment, average duration of illness was 13.21 months ($SD = 22.21$).

Treatment History

The vast majority of children (93.5%, $n = 362$) had received psychological treatment for their eating disorder. The average duration of active treatment was 22.88 months ($SD = 22.75$) over an average total period of 28.91 months ($SD = 31.81$), from initiation to termination of services (or to present, if still in treatment). Approximately two-thirds of the total sample (68.0%, $n = 244$) received three or more types of psychological treatment, and more than half received a higher level of care (57.1%, $n = 221$) (see Table 1 for detailed data on treatment history). Approximately half of the total sample (50.6%, $n = 196$) had engaged in at least one of the following higher levels of care: residential, partial hospitalization program (PHP), or intensive outpatient program (IOP). One fifth of the total sample (20.5%, $n = 77$) were psychiatrically hospitalized on at least one occasion. Of those hospitalized ($n = 77$), a minority ($n = 25$, 6.5%) did not access any additional higher levels of care. About one third of the total sample (36.4%, $n = 141$) received only traditional outpatient psychological treatment. Of these ($n = 141$), most had received a combination of individual and family therapy ($n = 92$, 65.2%) rather than family ($n = 27$, 19.1%) or individual therapy ($n = 22$, 15.6%) alone. The majority reported receiving family-based treatment (FBT) at some point (62.5%, $n = 242$), and another tenth of caregivers who had never received FBT reported engaging in parent-led renourishment (9.8%, $n = 38$). Most caregivers sought out their own support as well (78.9%, $n = 236$), primarily through online support groups (58.2%, $n = 174$), in-person support groups (32.8%, $n = 98$), and individual therapy (42.1%, $n = 126$).

Recovery

Defining Recovery.—Table 2 provides the themes extracted from open-ended responses about how caregivers defined recovery from an eating disorder, which were organized into distinct recovery domains. Kappa values for themes and recovery domains ranged from .66 (moderate) to .95 (almost perfect), with 28 of 30 codes indicating at least strong agreement ($\kappa \geq .80$), and all indicated a statistically significant level of agreement ($ps < .001$). Recovery

domains included 1) weight (45.2%, $n = 155$); 2) body image, eating disorder cognitions, and related emotions (54.2%, $n = 186$); 3) eating behavior (71.4%, $n = 245$); 4) independence and responsibility in eating disorder management (28.6%, $n = 98$); 5) physical health (21.3%, $n = 73$); 6) psychological well-being (31.5%, $n = 108$); and 7) life worth living (27.4%, $n = 94$). The most common themes identified by at least one-third of caregivers included absence of (or decreased) abnormal eating behaviors (46.4%, $n = 159$), flexible eating with no restrictions (37.3%, $n = 128$), weight restoration (i.e., achieving healthy weight) (33.2%, $n = 114$), and absence of (or decreased) eating disorder thoughts (33.2%, $n = 114$).

Table 3 provides the list of predetermined factors endorsed by caregivers as essential to their definition of recovery. Broad recovery factors endorsed by 70% or more of caregivers included weight restoration and maintenance (85.6%, $n = 286$), body image (73.4%, $n = 245$), normal eating (92.2%, $n = 308$), social functioning (73.7%, $n = 246$), cognitive functioning (70.4%, $n = 235$), emotional functioning (79.6%, $n = 266$), and medical markers of health (72.8%, $n = 243$). Specific factors endorsed by more than 70% of caregivers were all related to normal eating behaviors, including the ability to eat range of foods previously eaten (76.3%, $n = 255$), ability to eat in a variety of settings (79.9%, $n = 267$), decreased anxiety at mealtimes (77.2%, $n = 258$), and ability to eat independently without supervision (73.4%, $n = 245$). A minority of caregivers chose to write in one to three “other” factors in the predetermined list, which overlapped almost entirely with the themes pulled out in the qualitative analysis. Because none exceeded 5% consensus, they were not included in this analysis.

Recovery outcome.—Approximately one quarter of caregivers reported that their child had *never* achieved any state of recovery (27.6%, $n = 107$). For those who had ever achieved lifetime recovery (72.4%, $n = 280$), caregivers endorsed their child having been *somewhat* recovered (23.0%, $n = 89$), *mostly* recovered (28.4%, $n = 110$), or *completely* recovered (20.9%, $n = 81$). Of those who had ever achieved full recovery, the vast majority (93.9%, $n = 62$) had sustained recovery over time (i.e., no relapses since achieving recovery). About three-quarters of caregivers (77.2%, $n = 299$) provided data on current recovery, most of whom (72.6%, $n = 217$) reported that their child was currently recovered (completely: 20.4%, $n = 61$; mostly: 30.1%, $n = 90$; somewhat: 22.1%, $n = 66$). For caregivers whose child was not currently recovered (27.4%, $n = 82$), confidence that their child would eventually achieve recovery was relatively low (not at all confident: 31.7%, $n = 26$; somewhat confident, 41.5%, $n = 34$; mostly confident: 19.5%, $n = 16$; completely confident: 7.3%, $n = 6$).

Recovery pathway.—Caregivers indicated whether their child had ever achieved recovery in the following domains: *physical* (i.e., stable vitals, normal labs, regular menses for females), *behavioral* (i.e., able to eat the same range of foods and with as much flexibility as before the eating disorder, not in need of meal support, not engaging in restriction), *cognitive* (eating disorder thoughts resolved, normal body image concerns), *emotional* (i.e., mood returned to normal), and *social* (i.e., social functioning at work, school, and social activities returned to normal). Table 4 demonstrates that a minority of children ever achieved

complete recovery in any domain. Full recovery was most common for physical health (44.1%, $n = 138$), followed by emotional recovery (24.2%, $n = 74$), social recovery (27.5%, $n = 84$), behavioral recovery (23.9%, $n = 73$), and cognitive recovery (12.1%, $n = 37$). Individuals who achieved full physical recovery did so significantly faster than those who only ever achieved partial recovery ($M = 2.30$ v. 3.36 years, $t = 5.384$, $p = .021$). Length of time to full versus partial recovery did not differ in any other recovery domain ($ps > .10$).

On average, physical recovery of any level (completely, mostly, or somewhat) occurred earliest, 2.76 years ($SD = 3.36$) after the onset of the disorder. Social recovery ($M = 2.92$, $SD = 3.11$) and emotional recovery ($M = 2.95$, $SD = 3.18$) followed shortly thereafter, with a statistically significant delay from achievement of physical recovery (social: $t = 3.745$, $p < .001$; emotional: $t = 3.565$, $p < .001$). Behavioral recovery followed at around three-and-a-half years ($M = 3.42$, $SD = 3.56$) and occurred significantly later than emotional recovery ($t = 2.190$, $p = .030$). Cognitive recovery was the last to be achieved at around four years ($M = 3.96$, $SD = 4.06$) and occurred significantly later than behavioral recovery ($t = 3.611$, $p < .001$).

Since physical recovery occurred first on average, the weight at which physical recovery was achieved was compared to the weight at which recovery was achieved in other domains. On average, social ($M = 3.22$, $SD = 9.78$; $t = -3.216$, $SE = 0.871$, $p < .001$) and emotional recovery ($M = 3.05$, $SD = 9.31$; $t = -3.047$, $SE = 0.799$, $p < .001$) occurred on average three pounds higher than the weight at which physical recovery occurred. Overall recovery ($M = 7.36$, $SD = 10.77$, $t = -8.137$, $SE = 0.904$, $p < .001$), behavioral recovery ($M = 5.54$, $SD = 10.35$; $t = -5.539$, $SE = 1.005$, $p < .001$), and cognitive recovery ($M = 6.92$, $SD = 10.90$; $t = -6.921$, $SE = 1.267$, $p < .001$) occurred about 6 to 7 pounds higher than the weight at which physical recovery occurred. Weight gain for those who achieved full behavioral recovery was greater than those who achieved only partial behavioral recovery ($M = 8.55$ v. 3.48 , $t = 6.458$, $p = .013$). Weight gain for those who achieved full versus partial recovery did not differ across any other domain ($ps > .10$).

Given significant variability in recovery trajectories, a subgroup analysis was conducted for participants who achieved recovery in all five domains (30.6%, $n = 79$). Forty-one distinct patterns of recovery were identified, most commonly 1) medical recovery first, followed by recovery in all other domains simultaneously (22.8%, $n = 18$); 2) recovery in all five domains simultaneously (13.9%, $n = 18$); and 3) physical recovery first, followed by simultaneous recovery in social and mood domains, followed by simultaneous recovery in eating and cognitive domains (5.1%, $n = 4$). None of the remaining recovery patterns exceeded a frequency of three. Consistent with the overall analyses, physical recovery in this subgroup predominantly occurred first (82.3%, $n = 68$), either prior to recovery in all other domains (49.4%, $n = 39$) or simultaneous with recovery in at least one other domain (32.9%, $n = 26$). Social recovery occurred simultaneously with eating (50.6%, $n = 40$) and mood recovery (50.6%, $n = 40$) about half of the time. When not occurring simultaneously, eating recovery lagged behind social (29.1%, $n = 23$) and mood recovery (41.8%, $n = 33$) more often than it preceded either (social: 20.3%, $n = 16$; mood: 7.6%, $n = 6$). Mood recovery also occurred simultaneously with cognitive recovery about half of the time (49.4%, $n = 39$) or otherwise primarily preceded cognitive recovery (43.0%, $n = 34$). Cognitive recovery

occurred last most of the time (78.5%, $n = 62$), either simultaneous with recovery in at least one other domain (40.5%, $n = 32$) or following recovery in at least three of the four other domains (38.0%, $n = 30$). Eating and cognitive recovery commonly occurred simultaneously (60.8%, $n = 48$), or cognitive recovery followed eating recovery (32.9%, $n = 26$). Social recovery preceded cognitive recovery (45.6%, $n = 36$) about as often as they occurred simultaneously (44.3%, $n = 35$).

Discussion

Mixed methods findings yielded complementary but distinct results, which highlighted caregivers' multi-faceted view of recovery. Caregivers referenced well-established dimensions of recovery, including weight restoration, reduction in body image disturbance, decreased cognitive and behavioral eating disorder symptoms, and resolution of medical complications. A consistent theme that emerged through both quantitative and qualitative data was the importance of return to flexible eating (including the absence of limits with regard to food type), ability to eat in a range of situations, eating spontaneously, and eating for pleasure. Return to independent eating was also a major theme across methods, which is not surprising with the majority of caregivers having engaged in parent-led renourishment.

However, qualitative data demonstrates that caregivers' definition of recovery is broader than that used in research. In addition to the importance of symptom elimination or reduction, qualitative data yielded several themes that were unique from forced-choice quantitative data. Similar to patients (de Vos et al., 2017), caregivers emphasized returning to functioning and establishing a meaningful life, including engaging fully in social and occupational activities, as well as emotional well-being, including distinct themes such as happiness and joy (e.g., "smiling and laughing freely"), cognitive well-being and flexibility, and the ability to use coping skills to manage emotions, thoughts, and behavior. These themes were distinct from and in addition to the resolution of mood and anxiety symptoms that often accompany eating disorders.

Of note, about 10% of caregivers spontaneously shared the belief that recovery is a lifelong process of symptom management because the "underlying issue" or "genetic predisposition" to engage in eating disorder behavior cannot be "fixed," leaving the individual vulnerable to relapse, particularly during times of high stress. A smaller number (3.5%) defined recovery as implementing rules around eating or exercise (e.g., following a structured meal plan), in contrast to 37% who commented on the importance of flexible eating with no restrictions. In addition to weight restoration (32%), caregivers also mentioned the importance of weight maintenance (21%), sometimes in the absence of mentioning weight restoration, suggesting that stability over time is unique from achievement of a particular weight.

Most caregivers (72%) reported that their child had achieved a state of partial or full recovery at some point in their lifetime, which is roughly comparable to the estimated rates of full and partial recovery in the larger adolescent eating disorder treatment studies (e.g., Lock et al., 2010). However, only 20% had ever achieved full recovery, which is markedly below recovery rates in most treatment studies. These data highlight the shortcomings of available treatments, even if this sample primarily represents a subset of individuals with

more treatment-resistant disorders. In addition, 31% of caregivers whose child was not fully recovered reported that they were not at all confident that their child would ultimately ever recover. In spite of these sobering findings, 93% of caregivers whose child made a full recovery sustained their recovery over time, suggesting that individuals who achieve full recovery largely stay well.

Caregivers also provided novel data on recovery trajectories over time, with physical recovery occurring first (2.7 years after onset), followed shortly by social and emotional recovery (2.9 years after onset) about 3 pounds above the weight at which physical recovery occurred, followed by behavioral (3.4 years after onset) and cognitive recovery (3.9 years after onset) about 6–7 pounds above the weight at physical recovery occurred. Interestingly, the date that caregivers identified for overall recovery was earlier than the date when cognitive recovery was deemed to have occurred, suggesting that caregivers did not incorporate full cognitive recovery in their overall conceptualization of recovery. The patterns of recovery for those who achieved recovery across all domains support clinical observations that physical and behavioral recovery largely precede cognitive recovery, with a high degree of variability in the weight at which recovery in various domains was achieved (i.e., SD of near 10 pounds between weight at physical recovery versus weight at recovery in other domains). Finally, time to recovery as reported by caregivers was significantly longer than the typical follow-up period for most treatment studies, suggesting that longer-term follow-up is essential to better understanding outcomes.

This sample was notable for several characteristics. The average age of eating disorder onset was relatively early (13 years), and the vast majority had received treatment that was both intensive and lengthy. The fact that 60% engaged in mental health services beyond traditional outpatient therapy and that 68% had received more than three types of treatment suggests that these respondents struggled to find effective treatment and may have had children with more severe eating disorders, despite getting their children into treatment on average about one year after onset of the disorder. Recruitment from eating disorder forums is a likely source of sampling bias, such that caregivers may have been more likely to be using parent forums due to an ongoing struggle with their child's recovery, more likely to be active advocates in the eating disorders field due to more challenging or negative experiences with treatment, or more cautious in their definition of what constitutes recovery given a lengthy treatment history. As a result, this study may reflect the recovery definitions and outcomes based on a more severe or treatment-resistant sample and may fail to adequately represent the experience of families who only engaged in outpatient treatment or those who distanced themselves from eating disorder advocacy or support groups. Additional limitations include the fact that both caregivers and children were overwhelmingly White females and eating disorder diagnosis was primarily anorexia nervosa or atypical anorexia nervosa.

Despite these limitations, this study represents the most comprehensive effort to understand caregiver beliefs about their child's recovery from an eating disorder in a relatively large and international sample. The use of mixed methods with high interrater agreement allowed for a robust examination of recovery. While most caregivers agreed with the relevance of

researcher-defined domains of recovery, open-ended responses on defining recovery were varied with less than 50% consensus on any of the coded recovery themes.

These findings highlight the shortcomings of currently available treatments, with only 20% having ever achieved full recovery. These results also suggest that measuring a broader range of psychological outcomes over a longer follow-up period is essential to understand recovery trajectories, as it may not be reasonable to expect sufficient improvement in some of these domains by the end of time-limited treatment. Caregivers' perspectives suggest that treatment may need to target overall psychological well-being, including improving overall quality of life by helping patients build a life worth living once eating disorder symptoms have decreased. The desire for a holistic approach to recovery is in contrast to current evidence-based treatments that focus more narrowly on weight restoration and/or behavioral symptom reduction. As a field, we cannot assume that treatments are effective if we fail to incorporate outcomes that caregivers believe to be important or fail to follow participants across their recovery trajectory. Therefore, future efforts should aim to evaluate treatment outcome using a richer set of measures across a longer follow-up period, which may help to inform treatment refinement through the identification of new factors associated with sustained recovery.

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References

- Accurso EC, Ciao AC, Fitzsimmons-Craft EE, Lock JD, & Le Grange D (2014). Is weight gain really a catalyst for broader recovery?: The impact of weight gain on psychological symptoms in the treatment of adolescent anorexia nervosa. *Behaviour Research and Therapy*, 56, 1–6. 10.1016/j.brat.2014.02.006 [PubMed: 24632109]
- Andersen AE, & Yager J (2009). Eating disorders In Sadock BJ, Sadock VA, & Ruiz P (Eds.), Kaplan & Sadock's Comprehensive Textbook of Psychiatry, *Volume I*, Ninth edition (pp. 2128–2149). Philadelphia, PA: Lippincott Williams & Wilkins.
- Arcelus J, Mitchell AJ, Wales J, & Nielsen S (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. *Archives of General Psychiatry*, 68, 724–731. [PubMed: 21727255]
- Bardone-Cone AM, Hunt RA, & Watson HJ (2018). An overview of conceptualizations of eating disorder recovery, recent findings, and future directions. *Current Psychiatry Reports*, 20, 79. 10.1007/s11920-018-0932-9 [PubMed: 30094740]
- Couturier J, & Lock J (2006). What is recovery in adolescent anorexia nervosa? *International Journal of Eating Disorders*, 39, 550–555. 10.1002/eat.20309 [PubMed: 16791851]
- Centers for Disease Control and Prevention (CDC). (2009, 8 4). Percentile data files with LMS values. Retrieved from https://www.cdc.gov/growthcharts/percentile_data_files.htm
- Crow SJ, Swanson SA, Le Grange D, Feig EH, & Merikangas KR (2014). Suicidal behavior in adolescents and adults with bulimia nervosa. *Comprehensive Psychiatry*, 55, 1534–1539. 10.1016/j.comppsy.2014.05.021 [PubMed: 25070478]
- de Vos JA, LaMarre A, Radstaak M, Bijkerk CA, Bohlmeijer ET, & Westerhof GJ (2017). Identifying fundamental criteria for eating disorder recovery: A systematic review and qualitative meta-analysis. *Journal of Eating Disorders*, 5, 34. 10.1186/s40337-017-0164-0 [PubMed: 29118983]

- Golden NH, D M, Katzman DK, Sawyer SM, Ornstein RM, D M, ... D M. (2015). Update on the medical management of eating disorders in adolescents. *Journal of Adolescent Health*, 56, 370–375. 10.1016/j.jadohealth.2014.11.020 [PubMed: 25659201]
- Khalsa SS, Portnoff LC, McCurdy-McKinnon D, & Feusner JD (2017). What happens after treatment? A systematic review of relapse, remission, and recovery in anorexia nervosa. *Journal of Eating Disorders*, 5, 20. 10.1186/s40337-017-0145-3 [PubMed: 28630708]
- Lebow J, Sim LA, & Accurso EC (2018). Is there clinical consensus in defining weight restoration for adolescents with anorexia nervosa? *Eating Disorders*, 26, 270–277. 10.1080/10640266.2017.1388664 [PubMed: 29087249]
- Lock J, Le Grange D, Agras WS, Moye A, Bryson SW, & Jo B (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry*, 67, 1025–1032. 10.1001/archgenpsychiatry.2010.128 [PubMed: 20921118]
- McHugh ML (2012). Interrater reliability: the kappa statistic. *Biochemia Medica*.
- Neumark-Sztainer D, Story M, Falkner NH, Beuhring T, & Resnick MD (1999). Sociodemographic and personal characteristics of adolescents engaged in weight loss and weight/muscle gain behaviors: Who is doing what? *Preventive Medicine*, 28, 40–50. 10.1006/pmed.1998.0373 [PubMed: 9973587]
- Robinson TN, Chang JY, Haydel KF, & Killen JD (2001). Overweight concerns and body dissatisfaction among third-grade children: the impacts of ethnicity and socioeconomic status. *The Journal of Pediatrics*, 138, 181–187. 10.1067/mpd.2001.110526 [PubMed: 11174614]
- Steinhausen HC (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry*, 159, 1284–1293. 10.1176/appi.ajp.159.8.1284 [PubMed: 12153817]

Table 1.

Characteristics of children affected by an eating disorder.

	<i>M (SD), or n (%)</i>	Range
<i>Current age (years)</i>	18.40 (4.83)	[7,43]
<i>Age of onset (years)</i>	13.41 (3.06)	[1,31]
<i>Gender</i>		
Female	346 (90.3%)	
Male	31 (8.1%)	
Transgender female	4 (1.0%)	
Transgender male	1 (0.3%)	
Gender fluid	1 (0.3%)	
<i>Ethnicity (Latino)</i>	27 (7.0%)	
<i>Race</i>		
White	363 (93.8%)	
Asian	6 (1.6%)	
Bi or multiracial	18 (4.7%)	
<i>Diagnosis</i>		
Anorexia nervosa	321 (82.9%)	
Atypical anorexia nervosa	23 (5.9%)	
Bulimia nervosa	6 (1.6%)	
ARFID	16 (4.1%)	
Other eating disorder	11 (2.9%)	
Not formally diagnosed	10 (2.6%)	
<i>Weight range prior to eating disorder</i>		
Underweight	16 (4.1%)	
Normal	286 (73.9%)	
5th to 25th	46 (11.9%)	
25th to 50th	46 (11.9%)	
50th to 75th	76 (19.6%)	
Unsure (within normal)	125 (32.3%)	
Overweight	54 (14.0%)	
Obese	31 (8.0%)	
<i>Psychological Treatment</i>		
Inpatient psychiatric hospitalization	77 (20.5%)	
Residential treatment	109 (29.1%)	
Partial hospitalization program (PHP)	104 (26.9%)	
Intensive outpatient program (IOP)	112 (29.9%)	
Outpatient therapy		
Family-based treatment (FBT)	242 (62.5%)	
Family therapy (not FBT)	58 (15.5%)	
Individual therapy with ED specialist	241 (62.3%)	
Individual therapy with non-specialist	207 (55.2%)	

	<i>M (SD), or n (%)</i>	Range
Group therapy	74 (19.7%)	
<i>Medical/Dietary Treatment</i>		
Inpatient medical hospitalization	139 (37.1%)	
Outpatient medical monitoring	203 (54.1%)	
Nutrition counseling	232 (61.9%)	

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Table 2.

Factors identified in caregivers' open-text definition of recovery.

	%	n	κ
Weight			
Weight restoration (achieving healthy weight)	45.2%	155	.91
Weight maintenance (maintaining weight over time)	32.9%	113	.90
	21.9%	75	.91
Body image, eating disorder cognitions, and related emotions	54.2%	186	.86
Body image not a primary concern; body acceptance	19.8%	68	.82
Absence of eating disorder thoughts	31.8%	109	.87
Absence of anxiety around food/eating	12.8%	44	.83
Enjoyment of food and exercise	10.2%	35	.82
Eating behavior	71.4%	245	.90
Absence of abnormal eating behaviors	45.2%	155	.89
Absence of compensatory behaviors	17.8%	61	.88
Intuitive eating	10.2%	35	.95
Flexible eating with no restrictions	37.6%	129	.84
Follows rules around eating or exercise	3.5%	12	.87
Independence and responsibility in eating disorder management	28.6%	98	.90
Independence in eating	20.7%	71	.89
Accepting responsibility for eating disorder behaviors, prioritizing recovery	6.1%	21	.89
Awareness and acceptance of eating disorder	3.8%	13	.66
Asking for help when needed	3.2%	11	.90
Physical well-being	21.3%	73	.87
Physical health	18.4%	63	.89
Hunger cues return	4.4%	15	.80
Psychological well-being	31.5%	108	.86
Emotionally stable, able to manage emotions/thoughts/behaviors	23.6%	81	.87
Decreased depression and anxiety	8.2%	28	.86
Cognitive well-being and flexibility	4.7%	16	.89
Life worth living	27.4%	94	.91
Normal functioning (social and professional engagement, travel, etc)	20.1%	69	.92
Happiness, joy, and meaning in life	13.1%	45	.87

<i>κ</i>	.70
<i>n</i>	35
%	10.2%

Belief that recovery is a continual process of managing symptoms

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Table 3.

Predetermined factors endorsed as relevant to their child's recovery.

	All Factors		Top 5 Factors	
	%	n	%	n
<i>Weight restoration and maintenance</i>	85.6%	286	91.9%	294
Ability to maintain weight	64.1%	214	60.0%	192
Higher than predicted weight	25.4%	85	49.4%	158
85% of EBW (based on BMI at 50th percentile)	25.7%	86	40.9%	131
Historical BMI growth percentile	25.1%	84	18.4%	59
BMI in the normal range	21.3%	71	20.3%	65
Historical weight	16.2%	54	15.0%	48
BMI at 50th percentile	12.3%	41	16.3%	52
<i>Body image</i>	73.4%	245	2.8%	9
Decreased body image concerns	65.0%	217	2.5%	8
Able to wear clothing appropriate for the situation	46.1%	154	0.6%	2
<i>Normal eating</i>	92.2%	308	20.3%	65
Able to eat range of foods previously eaten	76.3%	255	5.3%	17
Able to eat in a variety of settings	79.9%	267	4.4%	14
Cessation of restriction and abnormal eating behavior	56.0%	187	12.5%	40
Decreased anxiety at mealtimes	77.2%	258	0.0%	0
Able to eat independently, without supervision	73.4%	245	0.9%	3
Expression of hunger	63.2%	211	1.9%	6
<i>Absence of binge and compensatory behaviors</i>	57.8%	193	39.4%	126
Cessation of binge eating	9.6%	32	29.4%	94
Cessation of purging	15.0%	50	17.5%	56
Cessation of excessive exercise	47.3%	158	8.4%	27
Cessation of low-level movements	30.2%	101	5.3%	17
<i>Medical markers</i>	72.8%	243	54.7%	175
Stable vitals	45.8%	153	4.4%	14
Regular menses	53.0%	177	5.0%	16
Resumption of height growth	24.6%	82	46.9%	150
Normal bone density	11.1%	37	4.1%	13
<i>Functioning</i>	73.7%	246	2.2%	7
Cognitive (able to think/reason clearly)	70.4%	235	3.8%	12
Emotional (improved mood)	79.6%	266	2.8%	9
Social (decreased withdrawal/isolation)	66.2%	221	1.6%	5
Social (able to socialize with peers)	57.5%	192	0.6%	2
<i>Treatment-related</i>	16.5%	55	69.7%	223
Completed treatment	16.2%	54	58.8%	188
Exhausted insurance benefits	2.1%	7	60.6%	194

Table 4. Achievement of recovery overall and by domain, including time from age of onset to achievement (years).

	Yes					n/a	Unsure	Time
	Completely	Mostly	Somewhat	No				
Overall recovery	63 (16.3%)	102 (26.4%)	93 (24.0%)	129 (33.3%)	---	---	3.34 (3.26)	
Physical recovery	138 (44.1%)	70 (22.4%)	46 (14.7%)	37 (11.8%)	22 (7.0%)	---	2.76 (3.36)	
Behavioral recovery	73 (23.9%)	73 (23.9%)	44 (7.1%)	116 (37.9%)	---	---	3.42 (3.56)	
Cognitive recovery	37 (12.1%)	69 (22.5%)	48 (15.7%)	131 (42.8%)	---	21 (6.9%)	3.96 (4.06)	
Social recovery	84 (27.5%)	78 (25.5%)	68 (22.2%)	66 (21.6%)	10 (3.3%)	---	2.92 (3.11)	
Emotional recovery	74 (24.2%)	85 (27.8%)	71 (23.2%)	72 (23.5%)	4 (1.3%)	---	2.95 (3.18)	