

## **An exploratory study of access to evidence-based therapy for eating disorders**

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### **Abstract**

Eating disorders represent serious, complex, and often ego-syntonic psychological conditions with serious medical complications. While evidence-based psychological and pharmacological treatments have been developed in recent years, not all individuals with eating disorders may be able to access these treatments. This study recruited a large sample of individuals with eating disorders and assessed their experiences in treatment, current level of symptoms, and perceptions of treatment efficacy. Most of the sample was not currently in treatment, and a third of participants reported that they had difficulty finding treatment resources for their eating disorder. Of the participants in treatment, many reported that their therapist utilized cognitive-behavioral interventions, though it is possible this evidence-based modality was not being faithfully followed.

**Keywords:** eating disorders, patient outcomes, evidence-based care

## **Introduction**

Eating disorders (EDs) include a spectrum of conditions that involve insufficient or excessive consumption of food, compensatory techniques, and an obsessive focus on weight (American Psychiatric Association, 2013; DiTomasso, Golden, & Morris, 2010). EDs are among the most deadly psychological disorders (Keel et al., 2003), and include anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), and other diagnoses within the feeding and eating disorders category (American Psychiatric Association, 2013). AN is characterized by a relentless pursuit of thinness which results in becoming significantly underweight. BN is characterized by the same pursuit of thinness, punctuated with cycles of bingeing and compensatory behaviors (such as self-induced vomiting, laxative abuse, abuse of diet pills, and/or over-exercise). Finally, BED is characterized by recurrent binge eating episodes in the absence of any compensatory behaviors.

These disorders are associated with significant mortality risks and medical complications. AN is considered the most deadly psychological disorder, with one in five eventually dying from physiological complications from the disorder (Hoek & van Hoeken, 2003; Keel, Dorer, Franko, Jackson, & Herzog, 2005). On top of these mortality risks, individuals with AN are also 56 times more likely to die by suicide than their healthy peers (Keel et al., 2003). Similar mortality rates and suicide risks exist across ED diagnoses (Crow et al., 2009), with the notable exception of BED. The diagnosis of BED is not associated with elevated mortality rates when compared to other EDs; however, given that individuals with BED are often significantly overweight or obese, they have a higher risk of numerous impairing medical conditions, such as musculoskeletal conditions, chronic pain, diabetes, hypertension, and ulcers (Kessler et al., 2013). Many of the EDs are associated with organ damage as the result of being underweight and/or engaging in compensatory behaviors. Some organ damage, particularly damage to brain matter and bones, may be irreversible (Arkell & Robinson, 2008; Hjern, Lindberg, & Lindblad, 2006). These health consequences are more likely and become potentially life-threatening with a long duration of illness and, in fact, most patients are symptomatic for some time before treatment is attempted (Arkell & Robinson, 2008; Hoek & van Hoeken, 2003; Keel & Brown, 2010; Treasure, Schmidt, & Hugo, 2005). Without a doubt, individuals with EDs represent a high-risk and high-needs population.

## **Efficacy of Psychotropic Medications**

Most psychotropic medications, such as tricyclic antidepressants, selective serotonin reuptake inhibitors (SSRIs), and antipsychotics appear to be ineffective at treating AN (Holtkamp et al., 2005; Kaye, Frank, Bailer, & Henry, 2005). First-generation antipsychotic medications are very effective at promoting rapid weight gain but are associated with tremendous side effects. Because of the weight gain and other side effects, these medications are often refused by individuals with AN. On the other hand, there is promising evidence for the efficacy of atypical antipsychotics in treating AN (Bailer & Kaye, 2011; Tollefson et al., 1997).

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Two recent double-blind, placebo-controlled trials of olanzapine for AN have shown promising findings in terms of facilitating weight gain and reducing obsessive thoughts (Bissada, Tasca, Barber, & Bradwejn, 2008; Brambilla et al., 2007). Despite these findings, in general, pharmacotherapy has only very limited success with individuals with AN, since “medication treatment for AN is associated with high dropout rates, suggesting that the currently available medications are not acceptable to individuals with AN” (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007, p. 317).

In contrast, medication treatment appears to be very beneficial for individuals with BN and BED. Several studies have found that SSRIs reduce binge frequency in BN in the short-term, with moderate effect sizes (Flament, Bissada, & Spettigue, 2012; McElroy, Guerdjikova, Mori, & O’Mealia, 2012; Romano, Halmi, Sarkar, Koke, & Lee, 2002). In addition to reducing binge frequency in BN, other studies have also noted a reduction in purging and other ED symptoms when patients are randomly assigned to take SSRIs (Fluoxetine Bulimia Nervosa Collaborative Study Group, 1992; Goldstein, Wilson, Ascroft, & Al-Banna, 1999). These benefits are seen across the range of SSRI medications, though it should be noted that the Food and Drug Administration has only indicated fluoxetine for treating BN (Jackson, Cates, & Lorenz, 2010). When comparing dosages of SSRIs, many studies have found that patients with BN benefit from a 60 milligram (mg) dose of an SSRI but typically do not experience a reduction in binge/purge at any lower dosages (Romano et al., 2002; Sundblad, Landen, Eriksson, Bergman, & Eriksson, 2005). SSRI treatment administered continuously for six weeks or more is associated with significant symptom reduction and lower rates of relapse at one-year post-treatment for many patients with BN (Jackson et al., 2010).

Finally, medication treatment also appears to be helpful for individuals with BED, where effective medication treatment would need to accomplish dual goals of binge reduction and weight loss. Again, SSRIs appear to be beneficial with both of these goals at high dosages (40-80 mg/day; Arnold et al., 2002; McElroy et al., 2012), though some studies have suggested that psychotherapy, such as cognitive-behavioral therapy (CBT), is more beneficial than SSRI treatment (Grilo, Masheb, & Wilson, 2005). In addition to SSRIs, tricyclic antidepressants appear to reduce binges, improve mood, and aid with weight loss both in the short- and long-term (Laederach-Hofmann et al., 1999). Appetite suppressants and other weight loss drugs are often prescribed to individuals with BED, and these drugs appear helpful with both binge frequency and weight loss if taken continuously for several months (Appolinario et al., 2003), though other studies have found that, at follow-up, individuals with BED who take appetite suppressants lose no more weight than individuals taking placebos (Grilo, Masheb, & Salant, 2005).

**Psychotherapy Treatment Outcomes**

Of all EDs, AN is, by far, the most resistant to treatment (Strober, 2004). Given the resistance and high mortality rate associated with AN, psychotherapy is recommended for at least a year, and for more than two years with acutely underweight individuals (Wilson, Grilo, & Vitousek,

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2007). The efficacy of outpatient psychotherapy for AN can be difficult to evaluate, though most patients with AN achieve remission within five years (Keel & Brown, 2010). When examining patients across ED diagnostic groups, patients with AN were slowest to achieve symptom remission (Clausen, 2008). Three studies that compared CBT to alternative psycho-therapeutic modalities for individuals with AN found nonsignificant differences between treatment conditions (Ball & Mitchell, 2004; McIntosh et al., 2005). Studies used an abbreviated course of CBT (18-25 sessions), However, these studies used an abbreviated course of CBT (18-25 sessions), which is at odds with standard treatment guidelines for AN (Wilson et al., 2007). The remaining three studies compared CBT to non-therapeutic modalities, such as nutritional counseling, and were unable to draw viable conclusions due to catastrophic rates of dropout (Halmi et al., 2005; Pike, Walsh, Vitousek, Wilson, & Bauer, 2003; Serfaty, Turkington, Heap, Ledsham, & Jolley, 1999). However, other studies found promising evidence in favor of CBT for AN (Bulik et al., 2007; Wilson et al., 2007). CBT would be the expected treatment of choice, given its success in treating other EDs and other psychological disorders that are comorbid with AN (Haby, Donnelly, Corry, & Vos, 2006; Hofmann & Smits, 2008; National Institute for Health and Care Excellence, 2004). When compared to a waiting-list control group, two forms of CBT (one specifically tailored to address eating pathology, while the other also included interventions for mood intolerance, perfectionism, and interpersonal difficulties) were associated with clinically significant improvement in eating pathology (Fairburn et al., 2009).

CBT is also the gold standard of treatment for other EDs and is generally well-tolerated by patients (National Institute for Health and Care Excellence, 2004). In a 20-week trial of CBT among patients with BN, the treatment lead to a substantial change in symptoms that was maintained at follow-up (Fairburn et al., 2009). Compared to underweight individuals with AN, therapeutic change appears to happen more quickly among patients with BN (who are at a healthy weight), perhaps suggesting that they are better able to tolerate the meta-cognitive process of challenging disordered thoughts and beliefs. Still, the remission rates for patients with BN are less than 30% at one-year follow-up in some trials, though that remission rates increases to 70% by the 10-year follow-up (Keel & Brown, 2010). There is a consensus in the research literature about the treatment of BN with CBT, which “continues to be the best empirically supported therapy” (Hay, 2013, p. 467).

The research on treatment efficacy for individuals with BED is similar to the literature on BN, in that individual CBT, internet-delivered CBT, and CBT-based structured self-help were all found to be beneficial in reducing binge eating in patients with BED, with large effect sizes shown (Mitchell et al., 2008; Vocks et al., 2010). Across all ED diagnoses, there is evidence supporting the use of CBT as a first-line treatment.

**Access to appropriate care**

Though evidence-based treatments have been developed for EDs in recent decades, this does not mean these treatments are widely available and easily accessed by individuals with EDs. One possible barrier to treatment is the often ego-syntonic nature of EDs, with some

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patients going to great lengths to avoid treatment (Wein & Foord-May, 2009). However, other barriers to receiving evidence-based treatments are systemic, including “lack of insurance, coverage with inadequate scope of benefits, low reimbursement rates, and limited access to health care specialists and appropriate interdisciplinary teams with expertise in eating disorders, which may be owing either to geography or insurance limitations” (Golden et al., 2003, p. 499). Lack of insurance coverage (or limits to mental health coverage) could lead to patients being discharged before they have fully recovered; this places patients at risk for decompensation and potentially life-threatening medical complications. Lack of insurance coverage (or inadequate insurance coverage) contributes to startling findings such as those from a 2003 epidemiological study of more than 2,000 women, where only one in three White/Caucasian women and one in 20 African American women received any form of treatment for their ED (Striegel-Moore et al., 2003). Geography is also related to these issues of access, with specialist treatment often being concentrated in large cities and limited/non-existent in more rural areas (National Eating Disorders Coalition, 2016).

When treatment resources are available and can be paid for with insurance coverage, another remaining issue is the potential long wait for treatment (Ljotsson et al., 2007). In the United Kingdom, it was reported that some patients were waiting more than a year in some areas to receive an appointment, and that, overall, there had been a 36% reduction in hospital appointments for patients with EDs (Donnelly, 2017). The difficulty in accessing an ED provider/treatment facility may lead to patients seeking treatment that is not specifically for their ED. For instance, a recent survey of over 10,000 adolescents in the United States found that, of the 90% of patients who attempted to find specialized ED treatment, only 3-28% of patients with EDs were able to access such services (Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). Similarly, in a small sample of patients seeking treatment for their ED, only 36.5% were appropriately diagnosed and only 46.2% had received treatment specifically for an ED (Cachelin & Striegel-Moore, 2006).

## **Summary**

Patients with EDs represent a population with high treatment needs, though recent studies suggest that a number of barriers prevent access to needed specialty treatment. Given the medical sequelae associated with EDs and the high mortality rates associated with these disorders, delays in treatment should be avoided wherever possible. Identifying specific barriers to access represent an important next step in evaluating the standard of care provided to patients with EDs. Unfortunately, few studies have examined the kind of care patients with EDs are able to access.

## **Methods**

### **Participants**

Individuals who self-reported being diagnosed with an ED were recruited as participants ( $N = 259$ ) for this research through social media platforms such as Facebook. Most of the participants were not currently in treatment ( $n = 150, 57.90\%$ ). The average age of the sample

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was 34.74 years ( $SD = 12.45$ ). The racial/ethnic composition of the sample was largely White/Caucasian, and the majority of the participants were female. Participant demographics are outlined in Table 1.

Table 1: *Demographic Statistics*

Demographic	Frequency	Percent
<b>Gender</b>		
Female	255	98.50
Male	2	0.80
Transgender/non-binary/other	2	0.80
<b>Age</b>		
Less than 20 years old	19	7.30
20-29	80	30.90
30-39	77	29.70
40-49	43	16.60
50-59	31	12.00
60 years and older	9	3.50
<b>Race/Ethnicity</b>		
White/Caucasian	238	91.90
African American	1	0.40
Hispanic	6	2.30
Asian American/Pacific Islander	5	1.90
Middle Eastern	6	2.30
Prefer not to say	3	1.20

### **Procedure**

All study procedures were conducted online, and were approved by the Research Ethics Review Board at Immaculata University prior to the start of data collection. Participants were asked several questions about their ED diagnosis and their current or most recent treatment experience. No standardized inventories were utilized because such measures have not been developed for these purposes.

## Results

### Diagnosis and Treatment

The vast majority of the participants had been diagnosed with an ED by a healthcare professional (91.50%,  $n = 237$ ). The remaining participants were unsure about their diagnosis, were self-diagnosed with an ED, or were awaiting diagnostic information from their current providers. Of the participants who were diagnosed with an ED by a healthcare professional, 45.1% were diagnosed with anorexia nervosa ( $n = 107$ ), 15.6% were diagnosed with bulimia nervosa ( $n = 37$ ), 10.5% were diagnosed with binge eating disorder ( $n = 25$ ), 5.1% were diagnosed with ED not otherwise specified ( $n = 12$ ), 3.4% were diagnosed with another feeding or ED ( $n = 8$ ), and 20.3% were diagnosed with multiple EDs at different times during their recovery ( $n = 48$ ).

In this sample, 109 participants (42.10%) were currently in treatment while 150 participants (57.90%) were not. There was a significant relationship between current level of symptoms and whether the participants were currently in treatment. While participants with no symptoms or infrequent symptoms were more often not currently in treatment, participants experiencing frequent and even daily symptoms were in or not in treatment in relatively equal proportions,  $\chi^2(5) = 23.31, p < .001$ . Current symptoms and current treatment attendance are outlined in Table 2.

Table 2: *Current symptoms and treatment*

Current level of symptoms	In treatment, $n$ (%)	Not in treatment, $n$ (%)
No symptoms	5 (4.60)	27 (18.00)
Very occasional symptoms (e.g., bingeing once every few months)	9 (8.30)	31 (20.70)
Occasional symptoms (e.g., purging once a month)	12 (11.00)	17 (11.30)
Frequent symptoms (e.g., restricting once a week)	27 (24.80)	20 (13.30)
Daily or almost daily symptoms	34 (31.20)	32 (21.30)
Symptoms multiple times a day	22 (20.20)	23 (15.30)

Participants were asked to identify which kinds of providers they sought during their current or most recent treatment experience. Participants could identify up to six different kinds of healthcare providers, and most participants reported working with more than one type of

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provider during their current/most recent treatment experience ( $M = 2.14$ ,  $SD = 1.21$ ). The most frequently selected type of provider selected by participants was counselors/therapists ( $n = 149$ , 57.50%), followed by psychologists ( $n = 100$ , 38.60%), family doctors/primary care physicians ( $n = 98$ , 37.80%), psychiatrists ( $n = 97$ , 37.50%), and urgent care/emergency room physicians ( $n = 25$ , 9.70%). In addition, nearly a third of the sample identified working with a provider not mentioned above ( $n = 84$ , 32.40%). Nearly 20% of the sample reported that their current or most recent treatment experience did not include working with a psychologist or a therapist/counselor ( $n=48$ ). Many participants indicated that it was difficult or very difficult to schedule an appointment for ED treatment ( $n = 93$ , 35.9%) and/or that they were placed on a waitlist for treatment ( $n = 107$ , 41.30%). When asked about their satisfaction with their current or most recent treatment, nearly half of the sample reported being satisfied or very satisfied ( $n = 125$ , 48.30%). Participants were also asked to describe the length of the current or most recent treatment, and this information is outlined in Table 3. The average length of treatment was 15 months in the full sample ( $M = 15.22$ ,  $SD = 17.66$ ), though treatment length varied from one week to eight years; in the full sample, this would include some individuals who were still in ongoing therapy. The average length of treatment for those not currently in treatment was similar at 13 months ( $M = 13.39$ ,  $SD = 18.35$ ).

Table 3: *Length of treatment*

Length of treatment	Current treatment, $n$ (%)	Most recent treatment, $n$ (%)	Full sample, $n$ (%)
Less than 1 month	1 (0.90)	7 (4.70)	8 (3.10)
1-5 months	24 (22.00)	50 (33.30)	74 (28.60)
6-11 months	17 (15.60)	27 (18.00)	44 (17.00)
12-23 months	25 (22.90)	28 (18.70)	53 (20.50)
24-35 months	10 (9.20)	12 (8.00)	22 (8.50)
36-47 months	13 (11.90)	7 (4.70)	20 (7.70)
48-59 months	3 (2.80)	2 (1.30)	5 (1.90)
5 years or more	6 (5.50)	8 (5.30)	14 (5.40)
Unsure	10 (9.20)	9 (6.00)	19 (7.30)

Many participants were prescribed medication as part of their ED treatment ( $n = 119$ , 45.90%); in addition, some participants were prescribed medication but were unsure if it was specifically for their ED, ( $n = 28$ , 10.80%). Of the participants who reported being prescribed medication for their ED ( $n = 119$ ), SSRIs were most frequently prescribed ( $n = 59$ , 49.60%), followed by a combination of medications of different drug classes ( $n = 30$ , 25.20%), mood

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stabilizers/antipsychotics ( $n = 8$ , 6.70%), psychostimulants ( $n = 6$ , 5.00%), non-SSRI antidepressants ( $n = 4$ , 3.40%), benzodiazepines ( $n = 1$ , 0.80%), and prescription weight loss aids ( $n = 1$ , 0.80%). In addition, some participants could not recall what they had been prescribed as part of their ED treatment ( $n = 10$ , 8.40%).

Participants were asked a series of questions specifically about their mental health treatment provided by a therapist, counselor, or psychologist, if they indicated that they worked with one during their current/most recent treatment for their ED ( $n = 211$ , 81.47%). In terms of session frequency at the beginning of their treatment, most participants indicated that they received therapy on a weekly basis ( $n = 116$ , 55.00%), though others were seen more than once a week in the beginning of their treatment ( $n = 51$ , 24.20%). Other participants indicated that they saw their therapist/ counselor/ psychologist less frequently at the start of treatment, such as having sessions every other week ( $n = 31$ , 14.70%) or once a month ( $n = 9$ , 4.30%). In addition, some participants could not recall the session frequency ( $n = 4$ , 1.90%). When queried about the therapeutic modality utilized by their clinician (participants could select more than one option), cognitive-behavioral therapy was selected most frequently ( $n = 124$ , 58.80%), followed by mindfulness-based stress reduction ( $n = 51$ , 24.20%), dialectical behavior therapy ( $n = 40$ , 19.00%), client-centered therapy ( $n = 34$ , 16.10%), psychoanalysis/psychodynamic therapy ( $n = 28$ , 13.30%), art therapy ( $n = 25$ , 11.80%), interpersonal therapy ( $n = 19$ , 9.00%), and existential therapy ( $n = 1$ , 0.50%). Some participants indicated that their clinician practiced an eclectic mix of therapeutic modalities ( $n = 46$ , 21.80%), while others were unaware of the therapeutic modality provided ( $n = 40$ , 19.00%). In addition to therapeutic modality, participants were queried as to whether they received group therapy, family therapy, and/or couples therapy as part of their ED treatment, and several participants indicated receiving these services (group therapy  $n = 50$ , 23.70%; family therapy  $n = 27$ , 12.80%; couples therapy  $n = 10$ , 4.70%).

Finally, participants who indicated that their clinician utilized a cognitive-behavioral approach were asked a series of questions to assess faithful delivery of the model, based on how consistent their treatment was to the recommendations provided by Fairburn (2008). The recommendation for session frequency in cognitive-behavioral therapy for eating disorders is twice-weekly for the first few weeks of treatment. Of the participants who indicated that their clinician was utilizing cognitive-behavioral therapy in their treatment ( $n = 124$ ), 23.80% of participants indicated that they were seen twice-weekly during early stages of treatment ( $n = 34$ ). In addition, key interventions of CBT for EDs include collaborative weighing, self-monitoring, psychoeducation, and between-session homework. In this sample, 44.10% of participants ( $n = 63$ ) indicated that they were weighed as part of their therapy session. Approximately half of participants were asked to engage in self-monitoring ( $n = 83$ , 58.00%). 44.80% of participants were provided with guided reading or other psychoeducational materials recommended in cognitive-behavioral treatment of EDs ( $n = 64$ ). Finally, 69.90% of participants were asked to complete between-session homework ( $n = 100$ ).

### **Discussion**

This study sought to better understand the treatment experiences of individuals with EDs. While effective treatments have been developed for EDs, it was unknown if these therapies are widely practiced and easily accessed by individuals who need them. More than half of this sample was not currently in treatment, though this does not indicate symptom remission; in fact, many of the participants who were not currently in treatment were actively symptomatic, with some experiencing daily ED symptoms. It is unclear why these individuals are not in treatment despite being actively symptomatic. It is possible that issues of access interfered with receiving treatment, as a third of the sample reported having difficulty obtaining appointments for ED treatment and even more reported being placed on a waitlist. Given the secrecy and, at times, ego-syntonic nature of EDs, treatment should be delivered as soon as the individual is willing to seek treatment; having to navigate hurdles to get an initial appointment may be tiresome enough that individuals willing to seek treatment may give up and remain symptomatic.

Most participants reported working with an interdisciplinary team of providers as part of their recovery, which is consistent with treatment guidelines. However, it should be noted as alarming that nearly 20% of the sample was not working with a mental health professional as part of their current or most recent treatment experience. Successful treatment of an ED requires mental health services that often need to be delivered for a year or more (Wilson et al., 2007). While most of the participants were in services for more than a year, the quality of those services is difficult to evaluate, though it is promising that most participants reported being satisfied with their services.

Many of the participants reported that their therapist was providing CBT. When asked more specifically about the frequency of therapy sessions at the beginning of treatment, nearly half the sample was not attending weekly sessions. While infrequent sessions may be a necessity due to insurance coverage and scheduling conflicts, this is not consistent with evidence-based treatment guidelines. Key interventions of this modality include in-session weighing, self-monitoring of food intake and related thoughts and feelings, psychoeducation about weight, and the use of between-session homework assignments to challenge the overevaluation of shape and weight which defines EDs. The findings of this study are similar to Shafran and colleagues (2009) and Waller and Turner (2016), who concluded that many providers who claim to be utilizing a cognitive-behavioral approach are not faithfully practicing this modality. This could suggest that clinicians lack the training to faithfully implement cognitive-behavioral therapy for EDs or may struggle to follow the tenants of this approach.

### **Limitations**

The primary limitation of this study is common to most research studies conducted online, in that it is difficult to know how representative this sample is of individuals in ED recovery. There is good reason to suspect that this sample may not be particularly representative,

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in that our sample was overwhelmingly female and Caucasian. Future research should endeavor to recruit a more representative sample of individuals in recovery.

Another limitation of this research study is the reliance on descriptive data. While no standardized inventories have been developed for the purposes of this research, the data obtained in this study are exploratory, and it is difficult to draw conclusions from data that is limited by the use of author-created questions and also by the use of self-report data from patients, who may not be able to accurately recall their treatment experiences or may not have been told the type of treatment they were receiving.

### **Future Research**

Future research on access to treatment for EDs remains direly needed. This study was able to collect descriptive data on certain aspects of treatment for individuals with diagnosed EDs. The results of this study suggest that many individuals with EDs are not in treatment and that, in addition to the ego-syntonic features of EDs that may delay treatment, it appears that individuals with EDs may struggle to find adequate services. Future research could focus on patient interviews about their treatment and their ability to access treatment when needed. In addition to qualitative interviews, future research could develop standardized inventories to assess treatment success and faithfulness to an evidence-based modality, such as CBT. At this time, much about ED treatment remains poorly understood and future research could endeavor to identify current obstacles to treatment and how to best disseminate evidence-based care to this population. Finally, given that the results of this study suggest that clinicians who implement cognitive-behavioral therapy may not be faithfully following the model, future research should identify reasons for therapeutic drift away from this model of therapy and ascertain why clinicians are veering away from this approach.

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