

Exploring the Challenges to Providing Residential Eating Disorder Treatment: A Supervisors' Perspective

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Abstract

Background: Eating disorder (ED) treatments have been widely studied, especially for effectiveness, but there are fewer studies that use qualitative methods to reveal what residential ED supervisors believe are the optimum modalities for treatment and implementation.

Methods: This study elicited eight clinical supervisors' experiences working with residential ED patients. These supervisors were all in charge of the development of their respective programs and were also responsible for training direct care therapists.

Results: Study results reveal the challenges associated with treating EDs, including: the severity of the disorder, the paucity of knowledge, the need for more research on how to effectively treat this psychiatric disorder, and the difficulty of accessing treatment due to financial and cultural pressures.

Conclusion: This study highlights current practices and challenges in the field, such as the need for improved access to residential ED treatment for non-white and low-income individuals; the limitations of insurance policies; and the need for more non-white ED therapists working in residential treatment clinics. Since EDs such as anorexia nervosa can be amongst the most life-threatening mental health disorders, master of social work programs should be encouraged to implement specialized tracks for EDs. The goals of these specialized tracks would be to educate students on current ED research, including the research that shows the prevalence of EDs among male and non-white patients, to promote the ED field to minority students, and to develop incentives for internships in ED clinics for students of color.

Keywords: Eating disorder; residential treatment; clinical supervisors; access; affordability; master of social work

Plain English Summary

Eating disorder (ED) treatment is a complex subject that covers a range of disorders with varying treatment needs and challenges. Starting in the 1990s, inpatient and residential treatment centers began to proliferate in the United States, but few studies have been done on the best treatment practices for residential facilities. In this study, I aimed to investigate the practices and challenges faced by residential ED treatment facilities by interviewing clinical supervisors on their experiences. I found that, in addition to there being no common best practices, residential ED treatment facilities face many challenges, including the high mortality rate for EDs, the lack of research, the barriers to access posed by insurance companies and paucity of trained clinicians especially those practicing from a culturally competent and cultural humility perspective. I conclude that, to improve outcomes, it is important to train social workers on current ED research and to promote specialized tracks for EDs.

Introduction

Eating disorder (ED) treatment is a broad topic with multiple dimensions, and the most predominate foci are anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorder (BED). With complexity, though, comes challenges.

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Do therapists prefer to use evidence-based treatments (EBTs) or an eclectic approach? What does recovery from an ED look like? What is the desired outcome: a certain weight, a return to prior functioning, or symptom reduction? While treatments vary, we risk erasing these differences by generalizing about ED treatment. Currently, there are no consistent outcome measures for inpatient or outpatient ED treatment. Meanwhile, therapists in ED programs continue to use the treatments that they believe are effective (Attia, Marcus, Walsh & Guarda, 2016).

In the past, psychosocial treatments for ED were designed to deal with different elements of the disorder. Behavioral therapy sought to change restricting and binge/purge behaviors, whereas cognitive therapies sought to help patients change their distorted cognitions with regard to body shape and weight (Keel & Haedt, 2008). Severe eating disorders, like AN, were often treated in non-profit, academic hospital settings using a family-based approach, while BN was mainly treated in outpatient settings. In the early 1990s, managed care companies began to reduce hospital stays, and for-profit residential ED treatment centers began to proliferate, with 22 operating in 2006. Currently, 75 nationwide programs are treating patients (Attia, Blackwood, Guarda, Marcus & Rothman, 2016).

Healthcare in general, and the field of EDs in particular, has become a lucrative business and has received much attention from the investment community (Attia et al., 2016). It is a worthy endeavor to shine a light on current residential treatment centers' practices and provide supervisors an opportunity to discuss the implementation of treatment at that level of care, not least of all because Eds have high mortality rates compared with other major psychiatric disorders (Hoang, Goldacre & James, 2014). This study explores the experiences of supervisors of inpatient or residential eating disorder clinics, where patients reside at the treatment facility. While the study initially focused on treatment approaches, interviews with supervisors subsequently revealed the challenges of implementing ED treatment.

Residential ED patients are complicated both medically and psychiatrically and have many barriers to treatment including the disorder's symptoms (Eating Disorder Review, 2017). Recovery from an ED is a long process and requires a tremendous amount of effort, especially when the disorder has been present for a long time. This can be daunting for patients trying to get a foothold on recovery. When asked what they believed is the best treatment, all of the supervisors felt that there was not one best treatment. Each patient's symptom presentation was particular to their case, with AN presenting very differently than BN and BED, and BED presenting very differently than AN but having similar symptoms to BN. However, looking at all of these distinct disorders through a dimensional lens, they may all share similar features such as an obsession with food and a negative body image. For individuals and their families seeking residential treatment, having good commercial insurance, having the financial means to afford the time away from their responsibilities, and advocates supporting their need for residential treatment, are all essential to ensuring they can get the treatment they need to recover.

State of Knowledge

There are a few gaps in the current literature. The first gap centers on the lack of in-depth qualitative studies that describe the experiences of residential ED therapists. The second centers on the question of which treatment programs are implemented in residential ED treatment facilities. The third is the lack of consensus of what constitutes "recovery" from an ED. A novel approach to filling in these gaps requires exploring what clinical supervisors in well-known residential ED clinics believe is the most effective treatment for EDs, how therapists define recovery from an ED, whether there are alternate modalities of treatment, and how therapists implement that treatment in their clinics.

Past research has surveyed ED therapists working predominately in outpatient treatment programs and has focused on the rationale for choosing a particular EBT, based on a given population and on the experiences of the therapists working in the field (Couturier et al., 2013; Jarman, Smith & Walsh, 1997; Kinnaird, Norton & Tchanturia, 2017; Mussell et al., 2000; von Ranson & Robinson, 2006; Wallace & von Ranson, 2012). Currently, only four studies have been conducted (2 quantitative and 2 qualitative) to examine ED treatment from the therapist's perspective (Couturier et al., 2013; Mussell et al., 2000; von Ranson et al., 2006; Wallace & von Ranson, 2012). Past research has focused on empirical support for EBTs, the selection of an EBT for a given ED, and the level of training that therapists receive in EBT. When examining the type of EBT that therapists provide to ED patients, a common barrier is the lack of adequate training. Interviewing supervisors from residential treatment programs will provide more insight into whether EBTs are being utilized, the extent to which they are utilized, and any barriers clinicians experience utilizing the EBTs.

Methodology

This qualitative interview research design elicited clinical supervisors' experiences working with ED patients in residential clinics. Ethics approval was obtained from XX Institutional Review Board [blinded for review]. Intensity sampling, a type of purposive sampling, was utilized (Padgett, 2017). Interest in this research study developed while working as a med-psych social worker in a hospital setting and observing the many treatment failures of ED patients. In order to be included in the study, participants needed to be supervisors of inpatient or residential ED clinics, possess a clinical license, and be involved in program development and implementation. Participants were recruited through a working contact list of residential ED clinical supervisors in the United States, which was developed through internet searches, cold calls to residential clinics, and professional contacts. Next, potential participants were sent an email with the study recruitment flyer attached or they were contacted by phone using a prewritten script. One participant was interviewed in person after an informed consent and site letter was executed. Five participants were interviewed via Face Time, after verbal consent was given by participant. Interviews were audio taped and transcribed verbatim.

There were eight participants. Of those eight participants, seven were female and one male. There was a similar race breakdown: seven were white, while only one was biracial, mixed African American and white. The breakdown of clinical licenses was: four licensed clinical social workers (LCSW), two psychologists, one licensed professional counselor (LPC) and one psychiatrist, all with between six-month and 33 years of supervisory experience. The supervisors had clinical experience prior to becoming supervisors of between four years and 35 years. Seven clinical supervisors were either in the final stages of completing requirements for a certified eating disorder specialist (CEDS) credential or already possessed the CEDS designation. All supervisors worked in residential facilities treating adults, four of whom worked exclusively with women while the other four worked with both women and men. Only one supervisor reported being in recovery from an ED.

Intensive interviews (from 35–105 minutes) were conducted. The interview was structured to start with open-ended questions followed by prompting questions. Participants were asked questions about their supervisory experience, their treatment modalities, and their sense of what challenges face ED treatment. In addition, they were asked whether therapists under their supervision had any formal training or certificates in the various treatment modalities they had used in their clinics, which treatment approach they thought was most effective, and whether they had thoughts on models of treatments other than those used in their clinics. Finally, to gauge the complexity of ED treatment, supervisors were asked about whether they felt economic forces played a role in how treatment was implemented, about the business aspects of ED treatment, and how their clinics address issues of culture, ethnicity, and race.

Thematic analysis is an ideal choice for the study of a supervisor's knowledge of ED treatment because it "is a method for identifying, analyzing, and reporting patterns within data" (Braun & Clark, 2016, p. 8). Themes were coded using an inductive approach and using a semantic design to identify conceptual patterns in the data that cohered into themes (Braun & Clark, 2006, pp. 12–13). In order to ensure rigor during the qualitative study, dialogue with academic advisors and mentors was utilized following the recommendations of Padgett (2017). Peer debriefing and support, which was conducted among DSW graduate students and faculty members, facilitated feedback to avoid bias, and also helped to shield the qualitative study from the effects of researcher bias, which may have emerged through immersion in the study (Padgett, 2017, pp. 216–217).

Results

As a result of analysis, four themes emerged: the severity of EDs, the lack of a panacea for ED treatment, the influence of economic factors on residential ED treatment and the need for more research. Quotations from supervisors noting their years of supervisory experience, absent identifying information, are interspersed throughout to highlight each theme.

Severity of Eating Disorders

The experts interviewed all posit that an ED is a relationship with food that affects biopsychosocial functioning, and all agreed that ED patients who enter residential treatment are very sick by the time of their admission, requiring constant supervision.

Sickest psychiatric patients. Respondents reported that adult ED patients are not only complicated psychiatric patients but also, by the time they enter residential treatment, have a level of acuity that cannot be addressed on an outpatient basis. A supervisor stated that “[w]hen you’re doing residential and higher-level care, you’ve got people who are ... more fragile, more acutely ill” (Psychologist, 20 years). Another supervisor said that EDs “have the highest mortality rate out of any other psychiatric illness. Part of that is due to the medical complications and part of that is due to the high rate of suicide that folks who struggle with eating disorders commit” (LPC, 5 years).

The residential level of care is appropriate when a patient’s ED is severe enough that supervisors need a) to ensure the patient’s safety and b) to give them the highest dose of treatment and, therefore, the best chance for recovery.

What does it mean to be cured?

In “Identifying fundamental criteria for eating disorder recovery: A systematic review and qualitative meta-analysis, “the recovered patients surveyed felt that “self-acceptance, positive relationships, personal growth, decrease in eating disorder behavior/cognitions, self-adaptability/resilience and autonomy” defined what it meant to be recovered (de Vos, et al., 2017, p. 1). According to all supervisors interviewed, a cure for EDs would include no longer reaching the criteria for the respective disorder in the DSM-5. Some believed the timeframe outlined in the DSM-5 for each disorder needed to be adhered to, others felt that a longer period of time was needed such as 3 years. A supervisor felt that “sustainable recovery ... is more like a three-year benchmark (Psychologist, 11 years).

One supervisor mentioned the debate in the field about there being a “lack of uniform definition of what cured is” and there is a debate over the difference between being in “recovery” and being “recovered.” They saw a year as a good benchmark for being “recovered” if the patient was symptom free, even if they still obsessed about body image and weight (LCSW, 6 months). Another supervisor discussed the “recovery vs recovered” issue but felt a “harm reduction model was more apropos (LCSW, 6 years). One supervisor believed that there was a “continuum of recovery” where “thoughts about weight and food, if present, were not impacting a person’s life (LCSW, 5 years). A supervisor felt that if a person was not engaging in ED behaviors, did not have “hungry brain syndrome,” and looked for support from the clinical team prior to relapsing, they were in the “spectrum of recovery” (Psychiatrist, 33 years). A supervisor stated there is a “pretty clear set of data that even if you binge and purge once a year, you’re at a much higher risk for relapse” and that avoidance behaviors based on weight and shape indicated the person was not in full recovery (Psychologist, 20 years). A supervisor stated that “[f]ull recovery would be about functioning in all areas” and “partial remission they might struggle ... with body image and weight gain” at a level that is more like “the average human” (LPC, 5 years). A supervisor believed a cure is possible and posited: “They don’t have the thoughts. They don’t have the urges. They don’t have the symptoms. They don’t have the eating disorder anymore” (LCSW, 1.5 years).

Barriers to recovery. When a patient enters residential treatment, they are compelled to give up behaviors that have previously served a function for them. According to a supervisor, when asked about barriers to recovery, “the disorder itself could be a barrier.” The same supervisor continued, “a lot of times their symptoms, especially in anorexia, are very ego syntonic,” or in harmony with their ideal self-image (Psychologist, 11 years). As a result, many patients are “ambivalent about recovery” (LPC, 5 years). Behaviors associated with EDs create a sense of safety and reduce anxiety. As a result, patients often wish to maintain these behaviors despite presenting for treatment. Residential treatment is more advantageous for treatment because it creates a safe environment and gives patients time to build trust in their treatment team and work through resistance. As an ED can affect all aspects of a patient’s life, and eating cannot be abstained from like other substances, it is essential to maintain a safe and contained space during recovery.

Eating disorder symptoms function as a voice. People suffering with EDs often use the disorder as a voice by communicating with their body rather than with words. A supervisor explained how patients with EDs use their disorder to create non-verbal barriers between themselves and others:

For the anorexic patient a lot of times it is “I want to disappear. I don’t want to be seen ... and sometimes even the binge eating is so that I can get big enough to protect my soul, to be unattractive, to create that kind of boundary. I’m just going to create this physical barrier that you can’t get close to” (LCSW, 6 years).

According to another supervisor, patients use ED symptoms to communicate: “For a lot of [ED patients] it is their way of saying no ... It really does kind of become their boundary, their protector” (LCSW, 5 years). Because ED symptoms function to communicate, it is necessary to replace symptoms with new modes of communication. Supervisors agreed that, in residential treatment, ED patients can be taught more functional and adaptable ways to communicate.

Recovery is a long process. Problems with food often originate in early development, and by the time patients enter treatment, they have been symptomatic for a long period of time. One supervisor lamented, “I think the hardest thing with this population is it takes a long time to really heal from this” (LCSW, 5 years).

Another supervisor affirmed that when the disorder has been ingrained and there is a longer duration of illness, they “really need four or five months of treatment” (LCSW, 6 months). Supervisors concurred that therapeutic effectiveness was limited because treatment was seldom long enough or intensive enough to reach the point of recovery. In addition, patients often relapse, which means multiple courses of treatment are often necessary.

Recovery is possible. Supervisors agreed that recovery was attainable for most ED patients, especially if targeted, specialized ED treatment was provided in the early stages of the disorder. Those who are most successful are often those who “have an early prognosis and early intervention” (LCSW, 5 years). The issue of time is thus critical: not letting too much time pass before a patient receives specialized ED treatment, providing enough time in treatment to eradicate the thinking and behavioral patterns, and recognizing that patients who have been suffering with the disorder for many years often require more time in treatment. It would be inhumane to penalize these patients if the onset of their disorder predated a time when specialized ED treatment was available to them.

Best Treatment? We Don't Know

The majority of ED supervisors interviewed reported that their clinical staff received training in the EBT modalities that are most utilized to treat ED patients, but only a small percentage were certified in those EBTs. Common treatments reported are: Dialectical Behavioral Therapy (DBT), Enhanced Cognitive Behavioral Therapy (CBT-E), Acceptance and Commitment Therapy (ACT), Cognitive Processing Therapy (CPT), Accelerated Resolution Therapy (ART), Eye Movement Desensitization Reprocessing (EMDR), Internal Family Systems (IFS), and Somatic Experiencing (SE), among others.

Most effective? It depends on the patient. Nearly all of the supervisors agreed that no single treatment is universally effective, except for one who believed DBT was most effective at the residential level of care (LCSW, 5 years). The reality of treating residential ED patients, and the difficulty of maintaining treatment programs, requires a “thoughtful and planned” approach:

[W]hen you're doing residential and higher-level care, you've got people who are, you know, more fragile in a way, arguably, more acutely ill. ... [and] there are many, many other maintaining factors for eating disorders beyond the cognitive factors, that if you don't deal with temperament, capacity for social connection or social relations, don't deal with underlying mood disorders, anxiety disorders, PTSD, substance abuse disorders.... You need to think really broadly and conceptualize broadly, but then you have to narrow it down and focus on the things you can really take care of and in the time-frame you're going to be working in. (Psychologist, 20 years)

Effective treatment thus requires a complex, “compassionate” approach—one that “includes evidence-based strategies and informs and helps patients and families build skills” (Psychiatrist, 33 years). During interviews, it became clear that individualized treatment in a residential setting involves multiple factors and nuances. A supervisor described working with a unique group of ED patients:

It's really up to the individual clinician leading that group that day. It's up to what's going on in the milieu this week. Today, for example, I walked in with a prompt for a group that was really about support. The whole group wanted to talk about how badly they feel in their body today because it's going to be 80 degrees, a lot of them are wearing shorts, and it's the first time they're having to look down at their thighs for 90 minutes ... We veered off into grounding skills, because somebody started having a flashback in the middle of the group. Then, that triggered somebody else to be thinking about her trauma. All of a sudden, we're doing something totally different. So, I think that what makes us unique is the fluidity that we're able to have, because we're not manualized. (LCSW, 1.5years)

The supervisor felt that a flexible and fluid treatment strategy was necessary to handle the unique challenges each patient presented with and to meet each patient in their present moment of recovery.

Supervisors found it challenging to adhere to EBT, while also tailoring treatment to the patient's needs. There was a consensus amongst all of the supervisors that EBT should be the scaffolding upon which all treatment is built, but EBT is only one part of the structure of treatment. Within the ED umbrella, there are AN, BN, BED, unspecified feeding and eating disorders (UFEDs), and other specified feeding and eating disorders (OSFEDs), each of which requires a tailored treatment approach to deal with the multitude of clinical presentations. Supervisors need to be flexible when implementing treatment to the individual patient and take into account the complexity and uniqueness of the ED patient's symptom presentation.

Mind-body disconnect. Many of the supervisors agreed that, in order to treat the mind-body disconnect, it was necessary to implement bodywork and SE. According to one supervisor, "in order to perpetuate an eating disorder, you have to separate your mind from your body so there is really a lack of that mind body connection" (LPC, 5 years). Many residential ED treatment facilities offer interventions that attend to healing the mind-body disconnect. The supervisors validated the positive aspects of interventions like yoga, mindfulness, breathing, nature walks, massage, equine therapy, dance, and movement classes. However, there was a sentiment among the supervisors that more research on these modalities is required before they can be implemented fully in residential treatment centers.

Is it really only a white female disorder? Among the supervisors interviewed, most acknowledged that the majority of residential patients, more than 90 percent, are white and female. While this demographic might be the majority who seek treatment, one supervisor suggested, it "is not reflective of the people who struggle" (LPC, 5 years). Another supervisor ponders:

I imagine there are many people who may want to talk about their eating disorder if they are African American, but can't find anyone who looks like them, with whom they feel safe enough to talk about it. ... But I guarantee you there are probably lots of African American kids ... they're struggling, they see a doctor who thinks ... she can't have an eating disorder, she's not an upper middle-class white girl. So, they don't get detected. (Psychologist, 20 years)

This supervisor further reflected on the need to work with male ED patients in residential treatment since "there's a real sharp or distinct barrier for ... males ... it's still very hard if you're a ... male to find your way to residential care (Psychologist, 20 years). Another supervisor found that "[i]t is interesting working with males [as] the eating disorder really suppresses ... the femininity of ... emotion" (LCSW, 5 years). You know there is still a lot of shame and stigma around it just in general and then, if you're a male from a different ethnicity or culture, it is even harder to talk about it, and they are less likely to be diagnosed by practitioners and less likely to admit to it and seek help (LPC, 5 years).

Cultural competency is a major issue in residential ED treatment, especially for treatment centers with a majority white clinical staff. One supervisor shared her experience, when an African-American therapist tried to refer a patient who practiced Santeria, an Afro-Caribbean religious tradition:

She says, "Do you have any staff who are Black?" I was like, "Honestly, we have a couple, but none of our therapists are." ... How do we still be sensitive to her [patient] without being condescending? How do we appropriately allow for her religious practices, and her cultural practices, and have her feel comfortable here? (LCSW, 1.5 years)

The same therapist shared her frustration in trying to recruit non-white interns and hire a diverse clinical staff: I actually tried really hard the last time we had a therapist leave ... to find somebody of a different culture to work here. I went on the Facebook message boards, I asked people what professional organizations I should look into? How can I find people with different backgrounds than me? I was not successful. (LCSW, 1.5 years)

The challenges supervisors face when trying to diversify their staff may be part of a larger, systemic pattern that includes MSW training and education.

While all of the supervisors reported that a majority of patients are white females, all of the supervisors attested to the fact that men and other races and ethnicities also suffer with acute ED symptoms and may need residential treatment. One deficit might be the lack of non-white clinical staff who work at many of the residential treatment centers in this country. The only non-white supervisor who was interviewed for this study astutely pointed to how online staff pages for residential treatment centers, where few non-white ED therapists are represented, reflects this deficit.

Research. Research. Research.

Absent a cure, ED research must receive priority. During one interview, a supervisor made an impassioned plea for more research to address the scale of ED problems in the United States: “if you look at how many research dollars are assigned to Alzheimer’s and how many people struggle with Alzheimer’s in our country, the amount of people struggling with eating disorders is like ten times the amount” (LPC, 5 years). Many supervisors believed that the ED problem is more prevalent, affecting more people than is reflected in the statistics. More research may also help to alleviate the high morbidity of ED patients. Those suffering with EDs are capable of having high functioning lives, provided they have access to the proper treatment.

There also need to be more outcome studies in ED residential treatment. Ascertaining what does and does not work will require moving beyond the large academic ED treatment centers. As with any mental health treatment, this research will be challenging. There are many logistical challenges to the collection of data on ED patients who have completed residential treatment (whether by phone, email, or mailed paper questionnaires), including confidentiality factors, like HIPAA, and the questionable reliability of patient self-reporting.

One supervisor spoke about the importance of research in the area of the microbiome: “What’s growing in your gut, and how that effects not just your physical health and digestion and stomach, [but also] has an impact on mood and anxiety, ... eating disorders and psychiatric disorders” (Psychologist, 20 years). The same supervisor underscored the need to connect breakthroughs in neuroscience to broader research into clinical treatment:

There’s a lot of exciting work with anorexia and reward dynamics ... we don’t really know what the clinical applications are yet and there are no large-scale trials on treatments that focus on the neuroscientific targets. But it makes a lot of conceptual sense. ... We have reasonably good treatments, but they are getting out to a fraction of people. So that’s a societal issue more than a science issue. (Psychologist, 20 years)

In short, biological bases of EDs were also on the minds of supervisors and their desires for more research.

In the dark ages. There are multiple factors that may contribute to the onset of an ED, such as genetics, temperament, trauma, psychosocial stressors, and personality. Many of the supervisors recounted patients with interactions from early childhood and adolescence, often the influence of a family member or authority figure. One supervisor reported how many patients were affected by family doctors’ concerns about weight gain in adolescence and states: “There is such an emphasis in our culture and the medical community is really trained on—you have got to prevent and diagnose early when you see kids having weight problems” (LCSW, 1.5 years).

This supervisor ponders that not enough medical professionals are receiving adequate training in ED diagnosis and how fears about childhood obesity feed early ED symptoms:

Your average general practitioner is going to give your ... 12-year-old a BMI chart and ... [s]ay here is ... where you are... It’s a perfect storm. As a result, some [p]arents [are] taking their kids to Weight Watchers at age eight or Jenny Craig. ... A lot of our clients say that was when it started for them. ... This goes for the nutrition community, too. All of their training is in weight management, and diabetes prevention. ... Even for us finding dietitians, a lot of people will say they have a competency in eating disorders, but, they don’t really (LCSW, 1.5 years).

While this supervisor did not fault pediatricians or nutritionists and acknowledged that many seek additional training in the field of EDs, often at their own time and expense, they believed medical schools do not train the medical community on the intricacies of diagnosing and treating EDs.

Economic Factors Affecting Residential Eating Disorder Treatment

All of the supervisors who were interviewed agreed that the most stressful factor for a patient’s family is the financial challenge of residential treatment. Having financial and social supports is critical to recovery: “being able to take a break from work or from life and have people financially support you allows you to stay the course of full residential, partial, outpatient treatment [and] to really do treatment all the way through” (LCSW, 5 years). Because specialized ED treatment is costly, the challenge of managing the financial aspect of treatment can be difficult for patients and their families.

Who has access to treatment? After interviewing the ED supervisors, it became clear that access to specialized ED residential treatment is limited to those patients who have insurance, or the financial means to pay out-

of-pocket for care. Unless a patient has good-to-excellent commercial insurance, residential ED treatment can be prohibitively expensive. One supervisor expanded:

[A]bout 95 percent of our patients have insurance. I believe the quality of treatment is definitely driven by economics, and it is really difficult to get insurance to pay because it is very expensive treatment. You have the extensive medical piece, you have around-the-clock, 24/7 nursing, you have a medical director, you have a director of nursing, all required elements of a residential program and those are often not cheap and so it costs a lot of money. You have therapists, registered dietitians, and psychiatrists that all make up a team for one person, so that is a lot of labor for one person. (LCSW, 6 years)

Even if patients have access to insurance, their insurance may not include residential benefits. A supervisor states: “they’re supposed to because of mental health parity, but we don’t always see that playing out. Oftentimes, there are some insurance companies that don’t provide residential care as a benefit” (Psychologist, 11 years). Many supervisors stressed how closely insurance companies manage residential benefits. For example, one supervisor revealed, “insurance companies do tend to cut off quickly and before the patient is ready, which results in readmission” (LPC, 5 years). Research has shown that weight restoration prior to discharge from inpatient/residential treatment is associated with lower relapse rates and better recovery outcomes (Guarda et al., 2016). Therefore, discharging patients prior to weight restoration is not a sound policy and may even lead to negative outcomes.

A common practice among insurance companies is to create barriers to residential treatment. One common practice is to require patients to fail outpatient care, before the insurance company will pay for residential treatment (Brewerton & Costin, 2011). According to a supervisor, “[s]ometimes, even if they have the benefit, the insurance company will say, ‘Well they haven’t failed outpatient yet.’ So, then they have to fail outpatient before they can come to a higher level of care” (LCSW, 6 months). Without access to insurance, “[o]nly one in 10 people get treatment who have an eating disorder” (Psychologist, 11 years). All the supervisors interviewed reported that, without insurance, patients do not receive treatment. “If they have no resources, there’s very little we can do for them... There are some scholarships out there, but there’s so many people that are applying now, they are nearly impossible to get” (LPC, 5 years).

In order to work around mandated treatment, insurance companies often try to limit coverage. One supervisor observed that “insurance companies ... invest a lot in lobbying to not have any kind of mandates” (Psychiatrist, 33 years). Many individuals are currently suffering with debilitating and life-threatening EDs. Many never receive treatment for their disorder because of the barriers that insurance companies put in place in the pre-certification process (Eating Disorders Review, 2017).

What is our goal? Insurance companies decide how many days an ED patient can stay in residential treatment. Because residential treatment is more expensive, there is a push for ED patients to move into outpatient treatment. A supervisor revealed: “We are always striving for weight restoration, but ...there is this push from insurance companies that ‘okay they have been there for 20 days, you need to start stepping them down.’ It’s a numbers game for them” (LCSW, 5 years).

All of the supervisors who were interviewed agreed that it is vital for patients to get as close as possible to their ideal body weight (IBW) before being discharged to a lower level of care. According to one supervisor, achieving that IBW is more likely in a residential treatment setting and “[f]rom a BMI perspective, the research says that they need to be ... ideally close to 100 of their IBW” prior to discharge from residential treatment. “[O]nce you get into the lower levels of care ... it is really, really hard” to achieve IBW (LCSW, 6 years). After patients are discharged from residential treatment, the goal is to maintain body weight, which underscores the importance of achieving an IBW prior to discharge. In fact, barriers to higher levels of care early in the course of the disorder may increase the strength of the ED: “when someone really needs a higher level of care ... they really need a machine gun and you’re making them use a hammer, and then a screwdriver” (Psychologist, 11 years).

When speaking about different levels of care, supervisors often used the analogy of dosage. Residential treatment is considered the highest dosage of treatment. A partial hospitalization program, where clients attend program five days a week, is a lower dosage. An individual outpatient program, where clients attend program three days a week, is lower still, followed by outpatient treatment, where clients work with a therapist, psychiatrist, and nutritionist who specializes in EDs. A higher dosage of treatment may be necessary to prevent relapse and to aid long-term recovery.

Even fewer options for people with Medicaid and Medicare. Few residential clinics in the United States currently serve those with Medicare and Medicaid. This gap in service is attributed to the fact that “very few [residential treatment centers] within the country ... takes Medicare because you are not going to get paid what it costs you to treat them, and it is very sad but that is the reality” (LCSW, 6 years). In seeking insurance certification for residential treatment, supervisors reported that they have not had success billing Medicare or Medicaid for residential ED treatment. The process to bill Medicare is challenging for residential treatment facilities because Medicare is “geared more toward medical illnesses and ... medical hospitalization”:

[Medicare] uses a computerized system. It’s just a drop-down box. ... For example, we had a patient with a low phosphorous that was 2.1. If this person had commercial insurance, that would be a slam dunk, but Medicare’s guidelines are that the phosphorous has to be between 1.0 and 2.0. (LPC: 5 years)

Ultimately, a major obstacle to lifesaving treatment is insurance, which excludes treatment for many individuals in resource poor communities. Would we, as a society, allow insurance companies to refuse care to someone on life support? Why, then, would we allow insurance companies to deny the necessary treatment for someone with a deadly malady, such as an ED?

Discussion

Treating EDs is not an exact science. Until recently, there was not very much specialized treatment for EDs outside the hospital setting (Attia et al., 2016). Over the past 25 years, residential clinics, offering specialized ED treatment, have proliferated across the country. Despite this growth, supervisors are still faced with limited resources. Because burnout in the field is high, supervisors who are in charge of crafting these residential programs are also tasked with treating patients, training therapists in the field, and teaching a new crop of clinical staff.

Patients who suffer from EDs are among the most disordered of those patients with psychiatric illnesses, as evidenced by high mortality rates (Arcelus, Mitchell, Wales & Nielsen, 2011; Hoang, Goldacre & James, 2014). The acuity is complicated by the fact that ED patients have many levels of resistance and ambivalence about giving up food as a coping device (Redgrave et al, 2015). By the time patients seek ED residential treatment, they have likely been suffering with their ED for a long time. If the patient is young and entering residential treatment, it is usually because she or he has had major medical complications to meet the admission requirements.

In order to navigate the complexity of EDs, therapists need to be adept at many treatment modalities. The structure and makeup of EDs can include other co-morbid psychiatric disorders, such as Obsessive-Compulsive Disorder, Generalized Anxiety Disorder, Substance Use Disorder, Post Traumatic Stress Disorder, and Personality Disorders. Most treatment centers reported using a mix of treatment modalities. All of the supervisors agreed that ED treatment requires an approach that is patient-focused, rather than one that is rigidly focused on one EBT. Residential treatment centers treat patients who are suffering with AN, BN, and BED. No one treatment is adaptable to treat all patients, each of whom has specific treatment needs and complex symptom presentations. A combination of treatments, based on the therapist’s clinical assessment of the best-targeted EBT, along with patient preference, is the best course. This approach is in line with the current literature, which argues that the best treatment is a three-legged stool of EBT, therapist preference, and patient preference (Peterson, Becker, Treasure, Shafran & Bryant-Waugh, 2016).

Some supervisors reported that treatments that enhance the mind-body connection, like SE, mindfulness, and yoga, were providing promising results. Continuing to focus on cognitive factors may help those ED patients who are good at learning treatment modalities and mastering skills. However, more substantial changes might occur if ED patients also learned to listen to their bodies’ cues and to build up a tolerance and capacity to handle emotions. Supervisors would like to see more research dedicated to finding a cure for EDs, as some felt that much of the treatment of EDs is trial and error.

Along with research, there needs to be more ED education in general. The majority of patients who are treated at ED residential clinics are still predominantly white females. Supervisors feel strongly that there needs to be a concerted effort to break down the barriers to treatment for other ethnic groups, as well as for males and gender non-conforming individuals. One supervisor stated that the shame and stigma associated with EDs can make it more difficult for males and minorities to speak up. Another supervisor posited that implicit bias on the part of medical professionals may also be a factor in the lack of referrals to treatment.

All of the supervisors who were interviewed for this study stated that a large majority of the therapists who worked under them and provided direct patient care were white females. Some believed that there needs to be a push for more diversity in their clinical staff in order for minority ED patients to feel comfortable and understood in a recovery milieu.

Access to care was also a pervasive theme in the interviews, and it became clear that access to residential care was determined by whether one had insurance and the resources to pay for any copays that were not covered by insurance. However, insurance alone will not enable a person suffering with an ED to receive residential treatment—rather, it must be insurance with a residential benefit. Residential treatment is a very costly level of care and requires a multidisciplinary team of licensed professionals and staff to facilitate treatment.

As a result, insurance companies manage this benefit with intense scrutiny. Even if one gets the opportunity to go to a residential level of care, insurance companies oftentimes prematurely pressure the residential treatment clinics to move the patients to a lower level of care. Supervisors report that this generally begins to happen around 20 days, regardless of the clinical picture. In the past, length of stay was based on weight restoration for patients with AN. Now, with BN and BED patients receiving residential treatment due to the severe medical complications associated with these disorders, it is not always clear what constitutes appropriate transfer to lower levels of care. More and more, insurance companies are cutting off residential benefits for patients who are suffering with AN, which makes long-term recovery unlikely. Additionally, insurance companies will deny residential treatment to patients, regardless of the acuity of the clinical picture, if the person has not previously failed outpatient treatment, thus prolonging their illness. Because of this standard, ED patients are often acutely ill by the time they are approved for residential treatment.

Another major barrier for receiving treatment is whether or not specialized ED treatment clinics accept Medicare and Medicaid. Medicare typically focuses on medical stabilization and will cover inpatient ED treatment for a short period for stabilization. According to the blog, “Can I Still Get Treatment for My Eating Disorder with Medicare?” Medicare may cover treatment on a single-case agreement with the residential treatment center (Lyons, 2017). However, many residential treatment centers will not accept these patients because they will not be reimbursed for the costs of treatment. Medicare’s billing system is designed for acute hospital stays, which inhibits residential treatment centers from working within the Medicare system. Patients with Medicare are left to suffer with few options for quality residential treatment. Many people in their 50s and early 60s on Medicare/Medicaid have had a long history of struggling with EDs and may benefit from residential treatment. However, they are excluded from receiving treatment because of these barriers.

There are even fewer residential ED clinics that take Medicaid. Medicaid is a joint federal and state program that provides insurance for low-income people. Residential ED clinics generally do not take Medicaid, so most people who have Medicaid insurance and who are at a lower socioeconomic status are categorically excluded from specialized ED treatment (Centers for Medicare & Medicaid Services). People of color make up 58 percent of non-elderly Medicaid recipients, which is nearly 6 out of 10 Medicaid enrollees (Kaiser Family Foundation). Limiting residential ED treatment to those with commercial insurance excludes many low-income people with Medicaid. Even worse, people who are enrolled in Medicaid often have limited financial resources. Social work’s core value of social justice directly opposes this unequal distribution of treatment.

Eating disorders are psychiatric disorders with a medical basis. Therefore, ED patients often interface with the medical community. Pediatricians need to be aware of how they handle complex issues like weight, body image, and disordered eating, because their advice can create a lasting impression on a child’s developing mind and body. Another aspect that is important to consider for medical professionals is that a person could be struggling with an ED while their labs might look normal. The body of a person with an ED seems to get used to dysfunction and finds ways to maintain homeostasis, thus giving the false appearance of a healthy subject. Also, many of the self-controlling behaviors exhibited by a patient with ED can seem socially acceptable or praiseworthy. One supervisor reported that, if ED patients looked into their past history, they could usually find some other obsessive-compulsive behaviors or traits that appeared socially acceptable at the time. Pediatricians also need to be aware of the personality types of those who are vulnerable to an ED, without confusing an obsessive-compulsive behavior for a positive personality trait.

Limitations and Conclusions

There are inherent limitations when conducting any qualitative study. The conclusions of this study, in particular, are limited by the sample size. Of the eight supervisors who were interviewed, most were white females. In addition to the limitations of the sample size, the study is limited by the fact that no supervisors of inpatient ED treatment facilities were interviewed.

Of all psychiatric disorders, EDs are some of the most acute, complex, and resistant. Despite the complexity of the ED population, supervisors report that the real challenge in the field is finding a treatment that will work with specific patients. There is no one-size-fits-all approach in the field of ED treatment. For residential ED patients, who are stabilizing from an acute medical and psychiatric condition, particular modalities, like CBT, DBT, CPT, EMDR, etc., are realistic only after the more acute medical and psychiatric symptoms are quelled. Therapists are also constrained by the limited timeframe allotted by most insurance companies, and the potential denial of residential treatment can hinder the therapist's attempts to motivate change and build rapport with patients.

It is a paradox that, while residential treatment has the potential for deep and intensive change, many supervisors report that they are tentative to begin intense trauma work because they are unsure how much time they will have left to work with their patient.

Additionally, ED patients have a psychiatric disorder that affects the body, so treatments that only target cognition and behavior leave the somatic aspects of the disorder ignored. Many supervisors say they have seen promising results with SE therapy, but there are not many therapists who are certified in that treatment approach. Somatic experiencing therapy requires a three-year certification process and is extremely costly. Other somatic interventions, like yoga, mindfulness, breathing, nature walks, massage, equine therapy, dance, and movement classes, have therapeutic value for ED patients. These interventions have an important place in residential treatment but need further studies to validate their effectiveness.

The most profound, and tragic, revelation of this study was that, for many people, residential ED treatment is not even an option. For those individuals with no residential benefit in their commercial insurance plan, for those who are on Medicare or Medicaid, and for those who lack insurance, specialized residential ED treatment is not even an option. Those with insurance constraints are often from lower socioeconomic groups but are left to suffer with an ED. This social justice issue warrants further investigation.

The findings indicate that more research and outcome studies on the residential level are required. There also needs to be improved access to residential ED treatment for non-white and low-income individuals. Current insurance policies and practices need to be examined. Rather than force patients to fail outpatient treatment multiple times before authorizing residential treatment, insurance companies need to take into account the efficacy of early intervention with a higher dose of treatment. There also need to be more non-white ED therapists working in residential treatment clinics to meet the needs of those patients who are underserved by current programs. Finally, MSW programs should be encouraged to implement specialized tracks for EDs. The goals of these tracks would be: to educate MSW students on current ED research, including the research which shows the prevalence of male and non-white patients who suffer from EDs, to promote the ED field to minority students while in graduate school, and to develop incentives for internships in ED clinics for students of color.

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Abbreviations

ACT: Acceptance and Commitment Therapy
AN: Anorexia nervosa
ART: Accelerated Resolution Therapy
BED: Binge eating disorder
BN: Bulimia nervosa
CBT-E: Enhanced Cognitive Behavioral Therapy
CEDS: Certified eating disorder specialist
CPT: Cognitive Processing Therapy
DBT: Dialectical Behavioral Therapy
EBT: Evidence-based treatment
ED: Eating disorder
EMDR: Eye Movement Desensitization Reprocessing
HIPAA: Health Insurance Portability and Accountability Act
IBW: Ideal body weight
IFS: Internal Family Systems
LCSW: Licensed clinical social workers
LPC: Licensed professional counselor
MSW: Master of Social Work
OCD: Obsessive-compulsive disorder
OSFED: Other specified feeding and eating disorders
PTSD: Post-traumatic Stress Disorder
SE: Somatic Experiencing
UFED: Unspecified feeding and eating disorder

Declarations**Ethics Approval**

Informed consent was obtained from each participant in the study. The survey was approved by the XX Institutional Review Board (Study ID: Pro20170002077) [blinded for review].

Consent for Publication

Not applicable.

Availability of data and materials

To ensure full anonymity for the participants the transcribed interviews are not possible to share publicly.

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BN conducted the study and wrote the paper.

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