

Barriers to Eating Disorder Treatment: A Review of Socioeconomic Obstacles and Gaps in the Healthcare System

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Abstract

With an increasing number of cases every year, eating disorders have the highest mortality rate of all mental illnesses globally. However, more than half of the diagnosed patients do not receive suitable treatment. This paper identified the barriers to both mental and physical care in eating disorder treatment and their impacts on patients' course of recovery. The reasons for these obstacles are highlighted based on patients' personal experiences and information compiled from different online sources, such as research articles and surveys found through Pubmed and Google Scholar. Research, surveys, and patients' feedback highlighted that treatment barriers are primarily due to high financial costs for care, stigma surrounding recovery, bias against minorities, inconsistent treatment, and insufficient outpatient care. Furthermore, from a medical standpoint, primary care physicians only have surface level knowledge on how to provide treatment to patients but end up having to do so because there are a limited number of eating disorder specialists. If patients are diagnosed and given adequate care in the beginning stages and throughout their eating disorders, then not only will they be more likely to avoid falling into critical mental and physical conditions, but they will likely reach the point of recovery quicker and more efficiently.

Keywords: Eating Disorders, Treatment Barriers, Recovery, Primary Care Physicians, Eating Disorder Specialists.

1. Introduction

Eating disorders (EDs) are psychological disorders with the highest mortality rates among all psychiatric illnesses, with the number being 5.86 times more than the general mortality rate (Neale and Hudson, 2020). Worldwide there has been an 18-fold increase in reported cases, from 0.2% to 3.7%, affecting over 30 million people in the U.S. itself (Maguen et al., 2018; Qian et al., 2013). The average onset age is mainly women between ages 15-19, however research shows that the incidence rate is continuing to become more frequent in younger children, especially those from ages 8-17 (Neale and Hudson, 2020; van Eeden et al., 2021).

Per standard definition, eating disorders are characterized by disordered eating habits and an abnormal relationship with food. However, studies and surveys show that there is most likely an underlying cause for these behaviors whether that be cultural, experiential, familial and/or societal (Fisher, 2006). Additionally there are many types of eating disorders, some of the more common ones being Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Binge-Eating Disorder (BED), each with varying traits.

Despite the chronicity of eating disorders, only a small portion of patients receive treatment, with the average waiting time to accessing care being 5.28 years from onset to treatment-seeking (Hamilton et al., 2021). The principal reasons for these delays in acquiring care are socioeconomic treatment barriers, disruptive transitions between treatment, workforce shortages, and missed diagnoses.

The process of initially reaching out for treatment can be difficult, especially regarding (1) social and weight stigmas amongst patients and caregivers, (2) an under-prioritization of treatment for those from gender, sexual and/or

ethnic minorities, (3) financial troubles in beginning and continuing care, and (4) patients' reluctance to seek treatment. Collectively, these hurdles can lead to missed diagnoses, as well as patients dipping into chronic and severe mental and physical states before receiving adequate treatment. During treatment, abrupt changes in programs and between healthcare providers can upset treatment routines that had formed for patients and guardians, causing relapses and readmissions to the hospital or other care. Even after treatment and a transition to outpatient care, if parents/guardians are not well equipped with resources to support patients, inpatient care may be required once again. This shift between forms of care can result in states of diminished mental health and motivation to recover.

Another, more unspoken cause of unbalanced treatment is workforce shortages. There are few specialists in the eating disorder field and referrals to them usually require waiting for large amounts of time, in many cases over a year (Brown et al., 2016). Furthermore, patients are rarely directed to these specialists, mainly because primary care physicians cannot identify the eating disorder and only intervene once the patient's physical health is impaired, even if their eating disorder has psychologically manifested prior to that.

In relation to workforce shortages, missed diagnoses are a huge factor in a person's eating disorder journey. Without a 'sick' appearance or significant weight loss, many caregivers cannot identify eating disorders unless there is medical instability. This is a harmful mindset as many patients can have atypical eating disorders where they are not underweight but suffer from the same condition and display the same behaviors as those that are. What's more is that general doctors do not screen patients in normal checkups, which could potentially help them catch any intrusive thoughts a child could be having. Both of the above factors impact caregivers as well as patients. Individuals that do not feel 'sick' enough, often will not access care, paving the way for their state to become more chronic.

This research review will explore the above factors, as each are hindrances to eating disorder patients' course of treatment. We believe this paper has brought attention to the many issues in the eating disorder medical system through a collection of quantitative and qualitative data. Our analysis illustrates that more effective eating disorder care can be accomplished by breaking stereotypes about the illness, improved training to identify and treat patients from early onset, and better understanding of the psychopathologies of the condition.

2. Socioeconomic Treatment Barriers

2.1 Financial

A major factor that prevents patients from seeking treatment is the cost of accessing care. The National Eating Disorder Association (NEDA) has found that inpatient care can cost more than \$30,000 a month, with an average of \$500-\$2000 a day (Thompson and Park, 2016). Moreover, only ten states require insurers to cover treatment for anorexia and bulimia, which are two of a large list of eating disorders. Even with this requirement, insurers generally choose not to cover patients that are not medically unwell, leading to families having to pay out of pocket for psychological, nutritional, and other treatment needs. The medical director of Austen Riggs Center, a non-profit residential treatment facility, states, "insurance companies are using the "wrong criteria" for what makes something medically necessary. They pay enough only to stabilize someone's condition, but not actually to improve it." (Dangor, 2018). Having financial costs deter patients from seeking care can cause them to require more intensive treatment, which can be costlier than the financial coverage of providers in outpatient settings.

2.2 Bias against Ethnic, Gender, and Sexual Minorities

Eating disorders affect those of all genders and backgrounds but are thought to mainly impact the White population. Due to the fact that eating disorder studies are predominantly done with White individuals and that those from ethnic minorities generally prefer concealing their eating disorders, a small percentage of non-Caucasian patients receive care. Demonstrating this, a study showed that in a group of Asians, African-Americans, Latinos, and Caucasians, Caucasians were more likely to receive a recommendation for treatment from a health professional (60%) than individuals from the other backgrounds (31%), despite having the same symptoms (Thompson and Park, 2016).

People from all ethnicities and nationalities can develop eating disorders, making it imperative that they are all given equal opportunity to acquire treatment.

Eating disorders are typically perceived as only affecting the female population, despite there being an increasing number of them in males. Males are largely underrepresented in mental health research and significantly in eating disorders, creating a lot of stigma in their care. A population survey estimates that about 10 million males in the US have or will experience an eating disorder during their life. In fact, approximately one in four patients with eating disorders are male. Regardless of these rising numbers, a study found that 25.6% of males with EDs were not referred to specialized care (Sangha et al., 2019). This is prominently because of the stigma around males seeking care for their EDs, and many being given a wrong diagnosis or none at all. Furthermore, less than 1% of ED research is centered around males, so there are many unknowns about their eating disorder psychopathologies (Lavender et al., 2017). As more physicians and researchers understand eating disorders in male patients, patients can be given accurate diagnoses and adequate care, with less stigma and misunderstandings.

A commonly overlooked minority in regard to eating disorders and mental health in general is the LGBTQ community. However, research shows that those from the LGBTQ population are more likely to develop eating disorders than those that are cisgender, due to reasons such as body dissatisfaction, minority victimization, and other mental health disorders, amongst other factors. For instance, a survey of about 300,000 college students found that transgender students had over 4 times more risk of being diagnosed with anorexia or bulimia than cisgender female students (Gordon, n.d.). An additional research found “approximately 54% of LGBT adolescents have been diagnosed with a full-syndrome eating disorder during their lifetime, with an additional 21% suspecting that they had an eating disorder at some point during their life.” (Parker and Harriger, 2020). Nevertheless, it is harder for LGBTQ patients to access care, not only in the eating disorder field, but the medical field in general. For example, a study found that 1 in 4 transgender people were denied equal health care (Jaffee et al., 2016). The LGBTQ community already faces many mental and physical health disparities, which themselves contribute to their development of eating disorders. As caregivers begin to learn more about how to approach LGBTQ patients, patients can start receiving more appropriate and equal care.

2.3 Stigma

Although there are treatment options where patients with eating disorders can be cared for in residential treatment, where they are secluded from the public, they ultimately must continue to recover and re-enter society. Not only can this be challenging after diagnosis, but stigma in healthcare and from the public can lead to hesitancy in initially asking for help as well. In fact, a study recorded stigma causing longer illness durations and “that a substantial proportion of people with anorexia nervosa waited a long time before visiting a physician and starting treatment because they were afraid of being stigmatized. The average period between disease onset and the first medical consultation or treatment initiation was around 8–9 months.” (Brelet et al., 2021). Stereotypes and stigmatization of those with eating disorders can provoke negative feelings around seeking and being in treatment, as well as causing hesitancy to recover.

Even away from health care, the general population tends to have negative perceptions of individuals with eating disorders. For instance, a survey aimed at the public, found that “more than a third of the respondents blamed people with EDs for their situation, thought that people with EDs would be able to pull themselves together if they wanted to, and found communication with them challenging.” (Brelet et al., 2021). Stigma is not just communicated orally but is largely involved online with pro-ED websites. An article studying social support noted that when websites advertise “ED support” it is generally superficial and correlates to the maintenance of ED behaviors (Rouleau and von Ranson, 2011). As people learn more about eating disorders, they can become more cognizant of how to support and interact with anyone with the illness, encouraging a helpful environment.

3. Disruptive Transitions Between Levels of Care and Treatment Programs

Transitions in eating disorder care are very common and are normally required when patients' support needs change. The most beneficial transitions are well thought out and thoroughly discussed with the patient, their family, and their current and future treatment teams. However, due to circumstantial urgencies and limited availability in programs, transitions can be uncalled for and disruptive for a patient, ultimately leading to negative outcomes in their care.

The transition from adolescent to adult care can be overwhelming, especially when a patient's entire treatment team suddenly changes. A study that found "out of 76 cases of transition between CAMHS [Children and Adolescent Mental Health Services] and general adult services (not confined to[but including] eating disorder services), only 4 met all their criteria for optimal transition." (Crockett et al., 2017). Furthermore, a carer shares their daughter's experience when transitioning to an adult:

"My daughter feels that she's not being taken seriously. Her anorexic thoughts and body dysmorphia are still strong. She sees an ED nurse every 2–3 weeks if she's lucky. That's it." (Crockett et al., 2017). Adults are automatically expected to be more independent in dealing with their EDs even when they need the same support as when they were adolescents, leading to relapses and instability in treatment.

Another notable transition can occur when patients go to a university/college, away from home and any treatment established there. A paper found that compared to the general eating disorder population, 14% of females and 4% of males that go to universities have clinical EDs. Moreover, 54% of females and 19% of males exhibit sub-clinical EDs that can easily develop into clinical ones. In relation, a study found that many individuals forget to consider treatment options before going to and at universities because of the notion of having a "fresh start." This on top of a newfound freedom and distance from caregivers can cause a decline in patients' health and stability (Webb and Schmidt, 2020).

An additional change is the transition between inpatient and outpatient care, affecting patients of all ages equally. A qualitative study recorded a patients' feedback on transition support:

"I feel it's a process that you need to go through with a key worker or a therapist or whatever, just to walk you through it and make sure you're actually ok with the stepping-down process and the discharge process ... because it is such a big deal." (Bryan et al., 2022). Many factors need to be taken into account when transitioning from treatment, especially when moving to less intensive care, and this process should be as smooth as possible for both the patient and their family.

There is also distress going from outpatient care to more intensive treatment. Patients can feel a complete loss of control and loss of contact with family, friends, and their work/education. Parents may feel relief that their child is receiving adequate care, but may also feel a loss of control regarding their child's treatment (Crockett et al., 2017). The above transitions in treatment demonstrate that although smooth adjustments are required for patients to have positive outcomes in care, they are hard to come by for several reasons. If more time was taken to discuss and consider these changes, individuals could receive the support they need in a manner that they can navigate and manage.

4. Parents/Guardians Lack of Experience for Outpatient Care

One of the most efficient methods for treating eating disorders in outpatient care is Family-Based Therapy (FBT), a type of treatment where parents are empowered to help the patient manage their eating disorder behaviors with guidance from a trained professional. A 2009 study at the Child Guidance Clinic in Philadelphia found that there were successful outcomes in 86% of the patients (Webb and Schmidt, 2020). Moreover, a study conducted at Maudsley Hospital in London with a group of adolescents with AN, reported that 90% of patients who took part in family therapy fell into "good" or "intermediate" categories (regarding weight and presence of disordered symptoms) compared to the 18% in individual therapy (Bryan et al., 2022). Although FBT doesn't work for all families, it is proven to have the most successful outcomes compared to other forms of therapy.

However, few patients and families have access to these services, with there being only 52 certified FBT providers within 13 U.S. states, and with wait times from receiving an initial evaluation to starting therapy ranging from 5-10

months (Bruett et al., 2022). With this treatment gap, parents must take charge and care for their child, but many are inexperienced and struggle without resources. In a qualitative study recording parent experience with dealing with a child with an eating disorder, one father states:

“She became weaker and I stood alone without much help from anyone. This (illness) is unknown to most of us when it occurs. You do not have anything to compare it with. You have no experience or references. You feel helpless, do not know what to do or whether you are pushing the right buttons or making the right moves.” (Karlstad et al., 2021). Many parents are not equipped with resources to care for their child, especially if their child hasn’t been part of specialized treatment.

This helplessness can have health impacts on parents/guardians as well. In a study measuring distress levels in individuals caring for someone with an eating disorder, about 36% had high mental difficulties and 17% faced high psychological stress (Whitey et al., 2007). If parents received proper resources and support when caring for their child with an eating disorder, more intensive treatment could be avoided and more patients could stay stable at home.

5. Workforce Shortage

5.1 Limited Number of Specialists

The majority of patients with eating disorders end up requiring or seeking treatment from eating disorder specialists. However, there is a shortage of specialists in this field, which leads to the majority of patients' referrals being disregarded. A 2020 study found, “Systemic factors such as clinicians’ concerns about use of manualized evidence-based treatments and a shortage of clinicians trained in these can impede dissemination and implementation of evidence-based treatments so that even those who do seek care may not receive appropriate treatment.” (McLean et al., 2020). Additionally, psychological support is also crucial but can be limited to individuals as well. To resolve this problem, caregivers have started providing online treatment, which has proven advantageous, but still is restricted to the availability of therapists. A report states, “While these approaches [online therapy] clearly have advantages in making treatment more available, they still rely on trained eating disorder therapists who are in short supply.” (Cooper and Bailey-Straebler, 2015). As more physicians and therapists receive credentials for eating disorder specialization, more patients will receive the care that they require.

5.2 Few Patients Receive Specialist Care

Primary physicians play a key part in diagnosing eating disorders in patients and guiding families to access more specialized/professional care. However, this can be a huge demand of these doctors, who often do not have experience with eating disorders. In a qualitative study, in which general physicians that dealt with eating disorders spoke about their experiences, themes of uncertainty regarding what to tell and how to treat patients/families were identified. In these instances, many physicians would seek guidance from more experienced eating disorder specialists or refer back to the treatment guidelines (Fogarty and Ramjan, 2016). Primary physicians' borderline knowledge of eating disorders can make it hard for them to guide patients and families in pursuing care.

Situations where general physicians care for eating disorder patients rather than specialists are common due to few specialist services being available and accepting patient referrals. A review from south London about adult eating disorder patients’ treatment found, “only two-thirds of referrals resulted in an assessment. Of these, only three-quarters entered treatment. Finally, only half of those who entered treatment completed it.” (Waller et al., 2009). The numbers presented display that only one-fourth of the patients referred to specialist services actually complete treatment. If there are more eating disorder services, not only in densely populated areas, but in more rustic areas as well, there will be a higher chance of more eating disorder patients reaching recovery.

6. Missed Diagnoses

6.1 Ineffective Screening

Similar to screening of other mental illnesses, such as depression and anxiety, there are effective methods to screen individuals for eating disorders, such as the Eating Disorder Screen for Primary Care (EDS-PC) and the SCOFF questionnaire. However, many primary care settings do not routinely use these screening mechanisms to detect eating disorders in individuals. Screening can pose negative effects such as false-positive results that lead to added stigma and unnecessary financial expenditures (Davidson et al., 2022). On the other hand, without screening, 50% to 80% of eating disorders go undetected or incorrectly diagnosed (Baranauskas et al., 2022). As of right now, a universal screening system for eating disorders hasn't been implemented because there is not enough evidence to back up if its benefits outweigh its cons. Regardless, a survey found that in a group of medical providers, 54% of them supported applying a screening method (Inville et al., 2010), which professionals are continuing to perfect. As screening policies become more accurate and efficient, they can be useful assets to medical providers for diagnosing eating disorders.

6.2 Psychological Manifestation vs. Physical Manifestation

Despite eating disorders being psychological disorders, they are mainly diagnosed based on physical manifestation, such as weight loss or emaciated appearance. However, over half of eating disorder patients do not meet the full hospital admission criteria but have the same psychological issues and behaviors (Fisher, 2006). In fact a study recorded that the percentage of patients with atypical anorexia (who have all the symptoms of anorexia, but are not underweight) had risen from 8% to 47% in four years (Strand et al., 2020). Additionally, a participant (parent) of a Cambridge University study regarding patient and guardian treatment experience gave feedback about the treatment they received:

“One of the main challenges is getting help early enough. There is too much attention paid to weight loss and not enough to the behavior patterns and so they are dangerously low in weight before you get referred...” Individuals generally only receive care once reaching a medically dangerous place, which typically happens due to the little attention given to the psychological aspect of their illness.

Patients also mentally struggle at home despite reaching healthier weights, but are not given the required support, which can lead to relapses and readmissions. This is highlighted by a patient taking part in the above study:

“I spoke to my psychiatrist once I got to a healthy weight, and she said there is not much they can do if I'm not ill which really upset me...I wish she hadn't said there was nothing she could do because I wasn't ill physically because that makes you think you need to make yourself ill to get help which shouldn't be the case!” (Mitrofan et al., 2019). Lulls in proper care can deprive a patient of sufficient support in reaching “complete” recovery, and in some cases lead to severe relapses.

6.3 Few Patients Reach Out for Help

The majority of individuals with eating disorders are reluctant to seek treatment; those that do so are mainly adolescents brought to caregivers by their guardians (NHS England, 2015). The chief reasons for this are: patients' not acknowledging problematic behaviors, shame around asking for help, mainly due to perceived and experienced stigma, and few known resources to reach out to. A study shows that in a sample of individuals with eating disorders, only 30.7% felt the need to reach out for help (Sonnevile and Lipson, 2018). Another study by a 'Health Body Image' Program communicated similar results, with 41.7% of the screened patients claiming they didn't need therapy, 19.9% being unsure of how serious their condition was, and 19.5% not having time for treatment (Bryant et al., 2022). This reluctance to receive care highly impacts the amount of time before being treated and both the physical and mental severity of the patient's illness when they are.

6.4 Lack of Experience

The majority of patients with eating disorders are treated by their primary care physicians (PCPs) or general doctors, many of whom tend to have little experience surrounding eating disorders and provide inadequate support to patients. A survey in Queensland found that out of 136 primary care providers, 73% felt that they weren't experienced enough in treating eating disorders (Bryant et al., 2022). Furthermore, many providers also lack the understanding that eating disorders are illnesses not decisions. For example, a study found that out of a total of 82 caregivers (32 nurses and 50 residents), 58.2% of them felt the patient was responsible for their disease. Additionally, 68.8% of the residents and 45.2% of the nurses had often felt frustrated with patients (Raveneau et al., 2013). These statistics show that a large percentage of caregivers do not truly understand the nature of an eating disorder, which can prevent them from giving the emotional support needed for patients.

7. Conclusion

The results of this review illustrate the various challenges that present themselves in eating disorder treatment. Socioeconomic barriers, such as financial difficulties, stigma, bias, disruptive treatment transitions and inadequate outpatient care, all contribute to the discouragement of seeking care and the stunting of progress made in recovery. Furthermore, the process of receiving treatment is challenging itself due to shortages in the number of caregivers, namely specialists, and the lack of patient referrals from primary physicians that are actually treated in specialized care centers. Lastly, primary physicians generally are not experienced in diagnosing patients especially without a difference in physical appearance. Eating disorders are mental illnesses and many individuals go undiagnosed because they do not appear “sick.” What’s more is that there is not an effective screening practice in place as a baseline to help physicians diagnose patients. This can be detrimental as few patients truly reach out for help on their own or without a guardian doing so for them. In the future, there can be more positive outcomes in treatment if healthcare providers and the general population learn more about how to provide a safe and supportive environment for patients with eating disorders.

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