

# Ethical implications of insurance coverage limitations in eating disorder treatment

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## Abstract

Eating disorders are the deadliest of all mental illnesses, yet many patients have trouble getting the care they need. Some patients lack insurance altogether, but still another subset of patients struggles to obtain coverage for treatment despite being insured. Lack of insurance coverage stems largely from the controversial question of medical necessity, as well as from the pseudo-pay-for-performance model widespread in the insurance industry. Inadequate coverage has led to insufficient care, worse outcomes, and even death in eating disorder patients, and challenges the motives of insurance companies: are they driven by patient care or by profit? With revenue at the forefront of many decisions, insurance companies are succumbing to waste, neglect, and inequity at the expense of ethical responsibility. Here we will discuss eating disorders, associated health complications, treatment and associated expenses, health care policy, the role of insurance companies, the ethical implications of current practice, and means for improvement in the near future.

## Note

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## Introduction

Eating disorders are complex illnesses with profound medical and psychological implications. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published in 2013, outlines diagnostic criteria for anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorder (BED), as well as other specified feeding and eating disorders (OSFED).<sup>1,2</sup> AN has the highest mortality rate of all psychiatric disorders and is typically associated with the hallmarks of weight loss, distorted body image, and food restriction. BN involves a repetitive cycle of binge eating and compensating for increased consumption using methods such as self-induced vomiting and/or over-exercising. BED is characterized by binges in which an individual consumes large quantities of food, a loss of control during the binge and guilt or shame afterwards, and lack of compensation for the binge. OSFED includes those individuals who do not meet DSM-5 criteria for AN, BN, or BED, but still have an eating disorder.

A recent study of over 30,000 US adults found that AN, BN, and BED affected 0.80%, 0.28%, and 0.85%, respectively, with all three being more common in women, and some suggest prevalence may be as high as 4%, 2%, and 2% in female cohorts.<sup>3,4</sup> These illnesses vary in their mortality and recovery rates as well (Table 1).<sup>5</sup> As the diagnostic criteria and mortality rates in Table 1 suggest, eating disorders are both distressing and dangerous illnesses. Mortality in eating disorders is the result of a combination of heightened suicide rates, comorbid illnesses, and medical complications ranging from esophageal laceration to osteoporosis to cardiovascular disease.<sup>6</sup> Roughly 20% of deaths in AN are due to suicide.<sup>5</sup> Eating disorders are commonly comorbid with other illnesses such as obsessive-compulsive disorder, substance use disorders, personality disorders, and various mood disorders, each which can contribute to physical and mental symptoms and may increase mortality.<sup>7-9</sup>

## Treatment

Because of the complex nature and many consequences of eating disorders, treatment of patients with eating disorders requires a multidisciplinary approach addressing physical problems resulting from disordered behaviors, medication management, and therapy, often along with nutrition counseling and family therapy. The American Psychiatric Association (APA) outlines stepwise level of care guidelines for patients with eating disorders based on medical status, suicidality, weight, comorbid disorders, use of behaviors such as purging, and other factors.<sup>10</sup> These levels of care include outpatient treatment; intensive outpatient treatment (IOP), which provides additional outpatient programming; partial hospitalization (PHP), which increases the frequency of IOP-like programming; residential treatment, in which patients live at a specialized center and are monitored 24 hours a day; and inpatient hospitalization.<sup>10,11</sup> Average stays in residential treatment are anywhere from around 50 to 80 days.<sup>12-14</sup>

As eating disorder treatment is often a lengthy process and may involve many different providers and levels of care, it can be very costly for patients and may limit access to treatment. Much of the research available on the use of different treatment services uses data from insurance claims. While this research thus does not encompass the entire US population, it is eye-opening in that it highlights challenges faced mainly by the insured; it does not address the challenges to access faced by those without insurance, who make up roughly ten percent of the US population.<sup>15</sup>

Two studies examining private insurance claims for adults found that eating disorder patients have 4.7 to 18.1 annual visits with outpatient treatment providers.<sup>16-18</sup> These numbers stand in stark contrast to standard of care recommendations, some of which recommend up to 40 weeks of outpatient treatment.<sup>19,20</sup> In many cases it can take years of treatment to achieve full remission or even medical maintenance. One 1995 study examining insured eating disorder patients found that when days of inpatient and outpatient treatment were combined in this population, the average number of days remained less than the minimum recommended by standard of care.<sup>18</sup> Furthermore, the rates of eating disorders observed in this study were about

one-tenth of the point prevalence rates predicted by epidemiological studies of eating disorders. This suggests that many people with eating disorders fail to receive treatment, which is supported by various other studies.<sup>17,21,22</sup>

One of the main factors limiting access to mental health treatment in general is cost, and eating disorder treatment is no exception.<sup>23,24</sup> The aforementioned 1995 study examined annual age-adjusted costs for the treatment of AN, BN, and eating disorder not otherwise specified (EDNOS, now OSFED per the DSM-5) – for AN, females paid \$6,045 and males \$2,746; for BN, \$2,962 and \$3,885, respectively; and for EDNOS, \$3,207 and \$2,165.<sup>18</sup> These are substantial sums, especially considering this is the same group that was receiving insufficient coverage (4.7 to 18.1 annual visits) and that this is 1995 data, as health care costs have increased considerably since then.<sup>25</sup> A more recent study of BN patients found that for 62 weeks of treatment and follow-up, the cost was \$12,146 for stepped care and \$20,317 for cognitive behavioral therapy (CBT).<sup>26</sup> A study of inpatient costs for AN patients hospitalized at least two days found that each case averaged \$6,831.<sup>27</sup> Finally, a study examining costs of an inpatient-partial hospitalization program for AN patients found average cost per day to be \$2295 for inpatient and \$1567 for outpatient treatment.<sup>28</sup>

As the last of the above studies reflects, costs differ by level of care. Outpatient therapy varies widely based on number of sessions and number of providers. The CEO of one IOP quoted that at nine hours per week, six weeks of treatment costs between \$7,000 and \$10,000, this being typical for IOPs in large cities.<sup>29</sup> At this same program, PHP costs between \$17,000 and \$20,000 per month. Residential programs cost roughly \$30,000 per month, which can amount to over \$100,000 for a longer stay.<sup>13,30</sup> Inpatient treatment is also very expensive, as the above studies suggest.

While treatment costs differ by level of care, severity of illness, location, and other factors, these numbers point toward the difficulty of paying for eating disorder treatment out-of-pocket, even with assistance from insurance companies.

## **Insurance Coverage**

Insurance coverage for eating disorder treatment depends on both access to insurance and insurance companies' willingness to pay for treatment. Both of these, in turn, are affected by insurance policy in the US. The Mental Health Parity and Addiction Equality Act (MHPAEA) of 2008 is a federal law that prevents insurance companies from imposing annual limits or higher co-pays or deductibles on mental health treatment than on medical and surgical treatment.<sup>31</sup> The MHPAEA itself, however, does not require mental health coverage; rather, it addresses coverage guidelines if coverage is required in an insurance plan.<sup>32</sup> This highlights the importance of the passage of the Affordable Care Act (ACA) in 2010, which offered more insurance plans that included mental health coverage and required that Medicaid provide mental health coverage.<sup>33</sup> Thus, between the MHPAEA and the ACA, Americans have been presented with more opportunities for mental health coverage with fewer potential exemptions by insurance agencies, and there was a significant reduction in the uninsured rate for those with mental disorders after the 2014 ACA insurance expansions.<sup>34</sup> However, health insurance policy can change, particularly with transfers of power, and potential repeal of parts of the ACA could leave people without mental health coverage.

In addition to these aspects of US health care policy, existing law allows for loopholes that limit the coverage that mental health patients can receive. First, insurance companies can limit services depending on "medical necessity," which can be difficult to prove or argue. Cases are evaluated – often by an insurance company physician who does not personally know the patient – after a certain treatment or number of sessions to determine whether additional treatment is "medically necessary" under insurance company criteria.<sup>35</sup> It is crucial to consider all components of an eating disorder patient's health when determining the optimal level and amount of care; however, often only the physical aspects, and sometimes only weight, are

considered in insurance reviews. To reduce an eating disorder patient to a weight ignores the psychological foundation of the disorder itself and can have dangerous consequences.

Another hindrance to complete treatment for eating disorders is the stagnant or declining reimbursement rates for mental health treatment. Administrative costs of operating a practice have increased, but many insurance companies have not increased reimbursement rates for decades.<sup>36</sup> Thus, many networks lack mental health professionals, inhibiting access to care.

Furthermore, even when patients are able to receive mental health care that is covered by insurance, this does not cover all treatment costs. A report by NEDA revealed that when covered by insurance, patients and/or their families may still be forced to pay the following after meeting their deductible: 0-40% for inpatient treatment, 20-50% for tube feeding and surrounding services, and 20-50% for residential treatment;<sup>32</sup> outpatient treatment is more variable. Recalling cost data from above, this can result in a fully insured patient having to pay \$50,000 for a single admission in residential treatment.

### **Reasons for Denial**

While data on insurance denial rates are limited, anecdotal evidence highlights the detrimental effect this system can have on patients with eating disorders. The case of Katherine West, who died at the age of 15 from complications of BN, is one example: West's treatment, prescribed by her physicians, would have lasted 12 weeks inpatient and cost more than \$50,000, but insurance stopped paying after about 6 weeks because her weight was considered sufficient.<sup>35</sup> Despite her doctor's warnings that she would lose the weight after being discharged, insurance overruled the doctor, and she died shortly after. The impersonal insurance review process and the improper application of medical necessity criteria often fail to address the complex nature of eating disorders. As Katherine West's mother stated, "You don't cure a mental illness in six weeks."

Much of eating disorder insurance coverage is based on weight: if a patient's weight is sufficient, according to insurance doctors, he or she may not meet medical necessity criteria. This is problematic on many accounts. First, while AN is characterized in part by low weight, BN and BED patients often have average or above-average weights while still being deep in their disorders. Additionally, atypical anorexia nervosa (AAN) is a subtype of AN characterized by the psychological features of AN and weight loss comparable to those with AN, but weight within a healthy range; individuals with AAN, despite being in a healthy weight range, can experience complications similar to those with AN. Thus, the patient's weight alone does not adequately depict his or her condition.<sup>36-39</sup>

Second, regardless of eating disorder diagnosis, weight restoration does not cure the condition – eating disorders are rooted in deeper psychological issues. While it is essential to overcome malnourishment to achieve the most effective treatment, this is not the end of the story. Still, in some cases of severe AN, insurance will only cover partial weight restoration, even though studies indicate that only full weight restoration is associated with improved prognosis.<sup>40</sup>

Another reason patients may be denied insurance benefits is because of their treatment history.<sup>41</sup> Patients typically must fail lower levels of care before receiving coverage for residential or inpatient treatment. A patient may also be denied care if past treatments at the same level of care have been ineffective. Insurance companies may also deny care due to a patient's lack of progress. For example, if a patient is not restoring weight or is continuing to use eating disordered behaviors (i.e., purging, restricting, over-exercising, binging), he or she may be cut off from receiving benefits. This highlights the often-disingenuous nature of the insurance industry – claims can be denied if a patient fails to restore weight, but once weight is restored, claims can be denied on the grounds of medical necessity. Similarly, while continued behavior use can result in denial, absence of behaviors may signify enough progress to warrant removal

of benefits. Thus, insurance companies may spin a patient's status – no matter what it may be – into something unworthy of receiving insurance coverage for treatment.

One final reason for denial of insurance benefits is that many insurance doctors are paid by the case.<sup>35</sup> Thus, an insurance doctor makes more money denying a case and moving on to the next patient than continually reviewing the case of a patient who remains in residential treatment for months. In short, denial is subsidized by the structure of insurance reviews.

### **Ethical Implications**

Though it is no surprise that at least some medical conditions are shaped by considerations of cost and profit, today's treatment for eating disorders is especially egregious. If, as should be uncontroversial, eating disorders have psychological underpinnings and if, as should by now be obvious, mental health deserves parity with physical health, then it follows that eating disorder care is not meeting ethical standards in the United States. This is not an ethical dilemma or puzzle – it is just wrong. There are several reasons this is so.

First, it is wasteful. Proper management of eating disorders can reduce costs incurred by exacerbation of the malady. While it would be financially impractical to provide the highest level of care for every eating disorder patient seeking treatment, studies have shown that earlier and/or more complete care at certain stages of eating disorder treatment can be beneficial for the patient, treatment providers, and insurance companies in the long run. One such study revealed that in adolescent AN patients, for example, weight gain was strongly related to psychological improvement.<sup>42</sup> However, many insurance companies cut off patients' coverage before full weight restoration is achieved, limiting progress and potentially contributing to relapse. Similarly, a 2011 study found that patients with lower BMIs upon admission, which were associated with lower BMIs at discharge, had significantly higher likelihoods of readmission within one year.<sup>43</sup> This further emphasizes the importance of complete weight restoration, as well as the likely benefit of earlier treatment – that is, before BMIs get too dangerously low, which is often required to receive insurance coverage for inpatient treatment. Other studies have highlighted the association between duration of follow-up and remission from eating disorders – in AN, for example, one European study reported a 29% remission rate with shortest duration follow-up, and another noted that remission increased from 68% with 8 years of follow-up to 84% with 16 years of follow-up.<sup>44,45</sup> Trends are similar for BN; other disorders have not been studied as closely. These studies suggest that allowing patients earlier care – that is, before they may meet current criteria for coverage – with longer stays and longer duration of follow-up care could improve treatment outcomes and prevent relapse. Relapse prevention is key in lowering health care costs long-term; thus, these measures would allow insurance companies to do more good while recognizing valid financial concerns.

Next, the insufficient treatment for eating disorders constitutes a form of medical neglect. Eating disorders are one condition in which ending treatment prematurely can do more harm than treatment itself did good. This is particularly true in the context of depressive and suicidal ideation as it relates to body shape. When underweight eating disorder patients endure the re-feeding process – one of the first aspects of care that is often covered by insurance, as it is difficult to argue lack of medical necessity – they gain weight and experience other physical changes. These changes can include acne, bloating, constipation, and more, and may be particularly distressing for patients who “were previously pathologically in control of their own body,” possibly contributing to depression and/or suicidality.<sup>16</sup> Cutting off insurance coverage when a patient reaches a proper weight but has not had appropriate psychological treatment may not only lay the groundwork for relapse, but also leave the patient in a more vulnerable place psychologically with potentially detrimental or even lethal implications.

Finally, current practice is unfair. Justice demands that all individuals are treated equally and equitably. Typically this topic is considered on a smaller scale: is a physician discriminating against a patient because of his or her race? However, in the context of insurance, it can be

viewed on a larger scale: are benefits being distributed appropriately to all groups in society? While a complete analysis of this question is beyond the scope of this paper, it is clear that unaffordability is a major hindrance to medical treatment – medical bills are major contributors to debt and even bankruptcy – and individuals of lower socioeconomic status are not able to receive the same amount and quality of care.<sup>46,47</sup> The changes to the ACA likely limiting mental health coverage for Medicaid patients, highlighted above, further bring justice into question in the field of eating disorder treatment. While these stipulations are under governmental regulation, insurance companies face challenges in providing equitable and equal care as a result.

### **Future Directions**

Despite challenges to receiving treatment for eating disorders, some advancements have been made in the past decade. The Anna Westin Act was passed in 2016 as the first eating disorders legislation in history and improved health insurance coverage for eating disorders as it relates to mental health parity.<sup>48</sup> However, there is still room for improvement to ensure more ethical coverage of eating disorder patients.

To begin, research is needed to more fully understand eating disorders and effective methods of treatment. While we do argue that improved insurance coverage may be economically beneficial long-term, the argument remains that insurance companies have limited resources and cannot afford to pay for unlimited treatment for these patients. In order for consumers' economic resources to be spent more prudently and more equitably, and for insurance companies to allocate their resources appropriately, research must be done to determine long-term costs and benefits of various treatment modalities. There is an extreme dearth of information on BED and OSFED, and on eating disorders in general, and funding for eating disorders research could allow for great strides in treatment. In addition, studies are currently underway to examine the efficacy of different levels of eating disorder treatment, with a focus on the residential level of care. With more concrete data on the outcomes of different methods of treatment, patients will hopefully be able to receive better care.

In the realm of insurance, insurance companies should provide earlier, more complete care with longer follow-up to improve overall patient health, improve remission rates, and decrease rates of relapse. This would require a shift in insurance companies' standards for providing coverage. First, medical necessity criteria should become less stringent, allowing for earlier and longer-term care. Second, coverage should be based on factors other than weight – in considering necessary and optimal treatment, the input of a patient's psychiatrist, therapist, and other treatment team members should be more heavily emphasized.

The process of determining a patient's appropriate level of care should be adjusted from the standpoint of the insurance physician as well. While it would be impractical to suggest in-person appointments with insurance physicians to determine the true severity of a patient's disorder, it would be beneficial for treatment decisions for mental health conditions to be made not solely by a physician, but also to include the input of a therapist or other mental health professional. This would help shift the focus from weight to overall well-being. In addition, insurance physicians should not be paid by the case, but rather for a salary or by an adjusted scale according to long-term treatment outcomes. Payment by case contributes to the profit-driven nature of insurance coverage at the individual level (that is, that of the insurance physician) and enhances the industry's overall emphasis on money – measured partly in denial rates – rather than on the patient.

The future of insurance policy is largely dependent on the evolving political landscape. Government officials, eating disorder advocacy groups, and individuals alike should support and lobby for continued pre-existing treatment coverage and mental health parity. Even the current policies guiding insurance coverage of eating disorder treatment leave many patients lacking the care they need, whether on the basis of "medical necessity" or superficial insurance reviews. The drive for financial gain over patient well-being underlies the inadequate treatment of

patients with eating disorders and contributes to insurance companies' outright ethical violations against these patients. While there are many problems with the US insurance system, the gap in care that underlies eating disorder treatment – and other mental health conditions – should be at the forefront of policy conversations. Changes in the criteria that determine insurance coverage and in the denial process, as well as advocacy for continued and improved mental health coverage policy, would benefit patients with eating disorders and allow for care that is more comprehensive, effective, and ethical.

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**Tables**

**Table 1.** Mortality and Recovery Rates in Eating Disorders

| <b>Eating Disorder</b>  | <b>Anorexia Nervosa</b> | <b>Bulimia Nervosa</b> | <b>Binge Eating Disorder</b> |
|---|-------------------------|------------------------|------------------------------|
| <b>Standardized Mortality Ratio (per 1000 person-years)<sup>a</sup></b> | 5.9                     | 1.9                    | Scarce data                  |
| <b>Five-Year Recovery Rate</b>  | 69%                     | 55%                    | Scarce data                  |

<sup>a</sup> Percentage of observed deaths in study population (e.g., patients with eating disorders) divided by percentage of expected deaths in population of origin