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Classifying Severe and Enduring Anorexia Nervosa: A Literature Review

by

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Abstract

Little focus is placed on the subsection of the eating disorder patient population who struggle chronically with their illness. This review synthesizes research on the topic to identify gaps in knowledge and reflect on implications for diagnosis and classification of severe and enduring anorexia nervosa. There was some variability between both clinicians and researchers who focused on this patient population, which is discussed based on different classifying criteria used to include or exclude an individual into the study. This review considers traditional methods used for classifying psychiatric diagnoses in relation to this disorder.

Keywords: chronic eating disorders, severe and enduring eating disorders, diagnostic criteria, severe and persistent mental illness

Introduction

Anorexia nervosa is a severe, life-altering eating disorder with the highest mortality rate of any psychiatric condition (Arcelus et al., 2011). It is estimated that 20-25% of those with anorexia nervosa will not recover (Berkman et al., 2007) and the persistent nature of anorexia is mentioned throughout literature in the field of eating disorders. Eating disorders have long been considered chronic psychiatric disorders. Arkell & Robinson (2008) studied the effects of long term anorexia nervosa on quality of life and living skills. They found that this population experienced the same level of impairment as those with other severe and enduring mental illnesses, like schizophrenia and severe depression. Thus, the concept of severe and enduring eating disorders, more specifically, severe and enduring anorexia nervosa (SE-AN) was formed to categorize patients with anorexia nervosa previously described as being “treatment resistant” and “chronic” (Touyz et al., 2016). The importance of acknowledging this unique patient population is immeasurable. However there is a lack of empirical research available to guide the development of treatments for these patients. Furthermore, there is little consensus regarding the operationalization of the diagnosis and classification of SE-AN. Further research is needed to characterize those with SE-AN, to define the disorder consistently, and to provide effective empirically based treatment for those living with SE-AN.

Those who do not fit the stereotypical image of an individual with an eating disorder are historically and continually marginalized in the eating disorder field. Moreover, people of color, men, and those at higher weights represent only a small portion of studies' patient populations and are discussed significantly less than lower-weight young white females (the stereotypical image of the average eating disorder patient). Those living with SE-AN are another population excluded within the field of eating disorder research and treatment. The extremely isolative

nature of the disorder leaves many - sufferers, clinicians, and loved ones - hopeless after multiple failed treatments and medical complications related to the illness. This results in a significantly reduced quality of life (Arkell & Robinson, 2008). It is difficult to conceptualize the experience of any chronic illness, let alone the reality of an individual living with severe and enduring anorexia nervosa. Painting the reality faced by those suffering with severe and enduring anorexia nervosa, Strober (2010) stated the following:

“[I]t is only a matter of time before even the strongest bond to the person chronically ill with AN withers, frayed by years of fury, despair, and resignation, unable to hold firm against the unrelenting defense of ideas for which there is no single shred of truth or evidence. It will come when the family has endured what they consider to be the final, painful offense, when the seductive strand of hope is declared lost to madness forever. It will start as before, how she is now ready to consider her poor health with a more reasoned mind . . . that she truly wishes an end to the misery brought on by her illness. It is not that the wish for change at this particular moment is contrived, or that the dialogue in which sorrow for the agony she has caused is not reflected honestly. But when AN advances to this chronic state . . . no longer will anyone truly care.” (p. 227-228)

While those living with SE-AN represent a small portion of eating disorder sufferers, they are entitled to representation in eating disorder research and they deserve the ability to hope for a better life. Treatments specifically geared towards those with severe and enduring eating disorders are few and far between. Understandably, modern eating disorder treatment programs were developed using the research available, most of which focuses on adolescents, young adults and other acute presentations of eating disorders. Eating disorder specialists often drop these clients as their illness progresses or they continue to not improve with regular treatments.

It is vital that researchers listen to the voices of those with severe and enduring anorexia nervosa. Empirically based research is needed to understand this complex illness especially related to the severity, persistence, and perpetuation of SE-AN. Once we begin to grasp the

reality experienced by those living with severe and enduring anorexia nervosa, and learn to identify the population, then we may begin to define what healing means for this population and how we can best help them on their journey to an improved life.

Broomfield et al. (2017) conducted a similar comprehensive and systematic review of the labeling and definition of SE-AN. Unique to my literature review is the inclusion of commentary, discussion, and case studies in addition to randomized controlled trials (RCTs) and other quantitative and qualitative primary research methods. This review was more liberal in its selection and qualitative in its review, providing an alternative approach to review and additional insight following Broomfield et al.s' contributions.

Review Methodology

Research collection consisted of a comprehensive literature review. Information relevant to the research question was collected through three electronic databases including PsycINFO, Google Scholar, and Wiley Online Library. Further searches on other databases (Sage Premier Journals and Academic Search Premier) yielded only duplicate results. Key terms for searching included words related to disordered eating (anorexia nervosa OR eating disorders) and terms related to the “severe and enduring” concept (severe and enduring OR chronic OR treatment-resistant OR treatment-refractory OR severe and persistent). Inclusion and exclusion were continually monitored throughout the review process. When relevant and available, literature was also collected from references of other articles and books.

Inclusion Criteria

Inclusion criteria consisted of the following requirements and the assessment that each article met requirements was monitored throughout the review process. Acceptable articles included discussion, or direct study, of participants with diagnosed eating disorders (all subtypes

of Anorexia Nervosa, Bulimia Nervosa, and other eating disorders) and a specific focus on the "chronic" or "severe and enduring" eating disorder population. Most important to the nature of this review, articles were selected if they either explicitly or implicitly outlined, proposed, or expressed favor of, particular standards or measurements for classifying, diagnosing, or categorizing patients with eating disorders as "severe and enduring" or otherwise considered to have a serious and chronic eating disorder.

Articles were required to have gone through the double-blind peer-review process. Only articles where full-text was accessible by the author were included. Efforts were made to retrieve full-text from other databases when possible. This review also required articles be published in English or full-text available translated into clear, understandable English.

Exclusion Criteria

Contrary to the nature of this study, mention of "chronic" or "severe and enduring" eating disorder population without this being the primary subject matter were not included (this included articles which discussed severe and persistent mental illnesses and articles which discussed eating disorders of varying durations or severity). This decision was made due to the lack of detailed discourse surrounding severe and enduring eating disorders - as opposed to the vast amount of information given on more acute cases. These articles were not found to provide any new information and were therefore excluded. Also excluded were addendums of included articles, where updates or changes did not impact the data collected from the original article and duplicates of existing articles. Articles where the authors did not outline any sort of criteria classifying, diagnosing, or categorizing patients with eating disorders as "severe and enduring" or otherwise considered to have a serious and chronic eating disorder were also excluded as this directly opposes the inclusion criteria. Finally, articles in which authors only focused on

“treatment refractoriness” or “treatment resistance” without particular attention to the “severe and enduring” population were excluded. These articles were not eligible because treatment resistance is a hallmark indicator of disordered eating at all stages and does not apply specifically to severe and long-standing presentations. Many of these aforementioned articles were found to focus on adolescents or other populations at acute/emerging stages of their eating disorder.

Research which met the above criteria was included, regardless of time published or participant: age, body weight/BMI, duration of illness, setting, gender, and diagnosis (any eating disorder diagnosis was considered acceptable and no comorbidities were considered exclusionary factors).

Initial collection was completed in February 2021, re-checked in February 2022 and February 2023 to determine if new research was published or if full-text was now accessible for previously excluded articles. The final literature collection yielded 82 articles, of which the full-text was accessed and read in full to further ensure appropriateness for review. These findings were recorded in a spreadsheet, along with the type of research being done, and labeling terms used which were similar to or served in place of “severe and enduring.”

Results

While this article emphasizes anorexia nervosa as the diagnosis of focus, all eating disorder presentations were included in data collection. Still, nearly all articles placed primary focus on Anorexia Nervosa, making this diagnosis a requirement for their study.

The most common classifying factor used to identify severe and enduring presentations was duration of the illness. Sixty-two out of 82 sources mentioned minimum illness duration as part of the inclusionary criteria or documented the actual length of illness for case studies. The most commonly used criteria identifying eating disorders as severe and enduring was an illness

duration of greater than seven years. Fourteen sources used this marker. Nine sources used greater than 10 years and another nine sources used greater than three years. Illness durations ranged from 1-66 years. The mean duration of illness (used as either minimum inclusion criteria or as presented in the case study) was 12.90 years.

The following most common classifying criteria was age, with 34 sources indicating a minimum age or particular age range. This was most often age 18 or older. However four articles did place their focus on youth. Ages ranged from 14-85 and the mean of these ages was 36.09 years old.

BMI was also frequently used as an indicator of severe and enduring eating disorders, as it was mentioned in 25/82 sources. The most common classifying criteria was a body mass index below 17.5 which is the same criteria used for diagnosing standard cases of Anorexia Nervosa. Among BMI ranges and those mentioned in case studies, BMIs ranged from 9-18.5. The mean body mass index was 14.63.

Treatment history was recorded or used as inclusion criteria in 31 articles. The specifics of treatment attempts or failures varied greatly, with most requiring the trial of at least one recognized therapeutic treatment. Many case studies focused on patients currently in treatment or hospitalized. The types of treatments attempted included inpatient psychiatric and medical hospitalization, day programs and partial hospitalization, cognitive behavioral therapy, and other forms of psychotherapy, psychopharmacology, residential treatment, deep brain stimulation, and involuntary medical refeeding.

A variety of miscellaneous criteria were also collected as part of this literature review. Park et., al. (2018) described severe and enduring eating disorders as presenting with disabling and substantial functional impairment. Four additional sources identified functional impairment

as a marker for severe and enduring classification. Long et., al. (2012) identified an entrenchment of anorexic patterns and an identity intertwined with the illness as indicators of severe and enduring presentation. Two sources indicated persistent low weight as a marker for severe and enduring eating disorders. Bambford and Mountford (2012) described low motivation to fully recover as a key factor of severe and enduring illness. Martinez et. al., (2020) described a clinical worsening or unwillingness to continue treatment as an indicator of severe and enduring presentations.

Discussion

This literature review found a wide array of opinions and possible criteria for classifying severe and enduring eating disorders. This variability highlights the lack of consensus regarding how clinicians and researchers identify and classify severe and enduring eating disorders. As previously discussed, a general consensus or standardization is necessary for efficient and effective research on the population. This is a requisite to developing empirically based care models for this treatment resistant population.

Duration of illness is the most commonly discussed marker used for identifying a patient as severe and enduring. The literature presented a general consensus that the disorder reaches a chronic state approximately seven to 10 years into the progression of the illness. Individual presentation is still important when determining if someone has a severe and enduring presentation. A 23 year old with a 13 year history of Anorexia Nervosa may have a different likelihood of recovery than a 40 year old with the same duration of illness. Similarly, clinicians and researchers should differentiate between chronic presentations of eating disorders that have remained persistent versus those with a longstanding eating disorder, but with remissions in between relapses. An individual with a 40 year history of disordered eating will have different

care needs than an individual whose eating disorder started 40 years ago, but for which they maintained remission for 15 years and are again seeking treatment following a relapse. These sorts of situations present the need for flexibility in the standardization process, whereby individual illness progression and age can be accounted for in determining if they have a severe and enduring form of the disorder.

One way to guide researchers when developing and identifying classifying criteria for severe and enduring eating disorders is to look at how other mental health conditions are identified in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) and World Health Organization's *International Classification of Diseases* (ICD-11). Both the APA and the WHO have worked together to come to similar agreements in diagnosis descriptors and qualifiers. In the most updated revisions, they have also prioritized diversity and multi-disciplinary expert opinion, and cultural considerations, when developing diagnostic criteria (Regier et. al, 2013). This presents the questions as to if severe and enduring eating disorders should be a separate diagnosis from acute or standard presentations of eating disorders. It also opens the possibility of a staging model for eating disorders. Maguire et. al, (2017) conducted a study to examine a staging model for anorexia nervosa. This consisted of a standardized clinical interview which assessed "seven general domain areas: weight/weight history, onset and duration of illness, dietary control, compensatory behaviors, psychological status (including depression, obsessionality, and motivation for change), physical status, and egosyntonic features" (p. 3). While promising, these stages are yet to make their way into official revisions of diagnostic manuals. However, the harm this may cause to the eating disorder population may be great (eating disorders may be competitive in nature and several populations have faced chronic invalidation of their disorder by the medical system and by diagnostic

criteria). Nevertheless, staging models have proven beneficial for some disorders. In *The Diagnostic and Statistical Manual of Mental Disorders*, there are mild, moderate, and severe presentations of Major Depressive Disorder. Providers can also indicate the presence of psychotic features, and whether the patient may be in a stage of remission from this disorder (5th ed.; DSM–5; American Psychiatric Association, 2013). The DSM-5 does mention illness severity for anorexia nervosa, but it is determined solely by BMI, with the caveat that “The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.” (p. 339, 5th ed.; DSM–5; American Psychiatric Association, 2013)

The careful approach to delineating between SE-AN and non SE-AN individuals and emphasis on proper diagnosis and differentiation should not lose its reason. Clinicians and researchers should seek to identify the appropriate categorization as this is the best interest of the patient. Caution should be taken against the avoidance of diagnosing severe and enduring eating disorders for fear they will then lack proper care and access to resources. While current treatment models do focus on more acute presentations, there is hope that upcoming research develops more appropriate care options for this population. Clinicians should be reminded that severe and enduring eating disorders are not a death sentence. Like any population, folks with severe and enduring eating disorders deserve hope too, even if their version of recovery may vary from the norm. Accepting these individuals is the first step to ensuring they are comfortable seeking help in a system which has repeatedly let them down or been ineffective. Identifying diagnostic criteria is a vital next step in further research.

The findings in this paper could be strengthened by further research that directly obtains the perceptions of researchers and clinicians, as to what qualifies as “severe and enduring.” This would provide an even more comprehensive and precise understanding of current opinions in the

field of eating disorders. Psychiatric and eating disorder organizations which influence and educate clinicians and treatment programs, could then develop and publish a standardized method to identify this patient population. Implications for this research include the ability for future research of severe and enduring eating disorders to identify populations based on empirical data, rather than the subjective opinion of a few clinicians. This is an indispensable feature for future research, on the journey to develop treatment centered around those with severe and enduring eating disorders.

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