October 10, 2024

Attention: The American Psychiatric Association DSM Steering Committee

Proposal for the Immediate Return of Eating Disorder “Severity” Specifiers Back to Optional, Discretionary Status to Prevent Additional Harm to Individuals with Eating Disorders

Submitted Under Type 3 Proposals: Deletion of an existing diagnostic category or specifier/subtype, submitted per the American Psychiatric Association Guide to Submitting Proposals For Changes To DSM-5[1]

Our request is for severity criteria for anorexia nervosa (all types), bulimia nervosa, and binge-eating disorder to revert from defined specifiers back to specifiers determined by and to be used at the provider's or researcher's discretion based on individual clinical characteristics.

History/Introduction

The original eating disorder "severity" specifiers, including "mild," "moderate," "severe," and "extreme," were arbitrarily determined and included in DSM-5 in 2013 without a scientific or empirical basis.[2] They are not widely used in either treatment or research and have not been demonstrated to have clinical utility in the past 10 years since they were introduced. Yet as of October 1, 2024, they are now required. This has created potential for harm to individuals with eating disorders as follows:

1. There is no evidence that the criteria used in DSM for "severity" (body mass index, frequency of binge-eating and purging episodes) in fact represent the severity of a patient's condition, and in many cases may mask the severity of an individual's condition.

2. Because they are unifocal, the criteria given for "severity" do not reflect the actual severity of a patient's condition which is in reality comprised of numerous features. They fail to provide meaningful information because they don’t take into account the actual features and pathologies associated with eating disorders that contribute to severity, complications, medical and mental health status, or risk of death such as cardiac complications, bradycardia, orthostatic hypotension, low blood glucose, sodium, potassium and other electrolytes, longevity or severity of malnutrition, micronutrient deficiencies, pathological exercise or energy imbalance between intake and expenditure, co-occurring psychiatric conditions such as depression, anxiety, obsessive-compulsive disorder, post-traumatic stress disorder, attention-deficit disorder and suicidality, neurodivergence, autism spectrum disorder, intellectual capacity, disability, skeletal bone loss, superior mesenteric artery syndrome, postural orthostatic tachycardia syndrome, concurrent medical diagnoses such as

[1] https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/DSM5-Proposal-Submissions-General-Guidance.pdf

[2] Mora-Maltas B, Lucas I, Granero R, et al. Cognitive flexibility and DSM-5 severity criteria for eating disorders: assessing drive for thinness and duration of illness as alternative severity variables. Journal of Eating Disorders, 2023.

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celiac disease, ulcerative colitis, cancer, diabetes, polycystic ovary syndrome, hypothyroidism, and many, many others.

3. Because they are arbitrary, they do not provide meaningful guidance for clinicians in targeting treatment. And if future treatment protocols are developed based on these criteria, they will fail the majority of patients simply because they would be based on artificial, arbitrary designations.

4. As a patient progresses in treatment and their condition either worsens or improves, their "severity" level as defined in DSM may change frequently, a) not reflecting the actual severity of their condition or need for care, b) creating confusion for patient, support partners and providers on the actual need for treatment, particularly in cases of anosognosia where the patient is unable to recognize the severity of their own condition and symptoms, c) creating false "evidence" for a patient that they do not require what is in fact life-saving care, d) creating the fiction that a patient's condition has improved or deteriorated when in fact only weight has increased or decreased due to hydration status or other weight-related changes, e) allowing facilities and insurers to limit access to care based on arbitrary categories rather than actual imminent need, and others.

Possible negative consequences of the change

The consensus among the providers, organizations, researchers and specialists named below is that we were unable to identify any negative consequences of reverting back to allowing individual providers to determine severity of a patient's condition based on assessment of clinical factors and as an optional specifier.

Magnitude of the change

We selected "modest change" because the correct option, "no change" was not available. We have proceeded for 10 years without the "severity" designation being useful, there will be no change once it is no longer required. If anything, the requirement has created substantial negative changes based on what appears to be a bureaucratic requirement rather than anything promoting the best interest of patients.

Summary of data showing validity of the requested change

DSM eating disorder "severity" criteria were not subjected to research, any empirical test of validity or other objective evaluation prior to 2013 publication in DSM-5[3]. And since publication, there has been a robust body of literature published on why the “severity” criteria are not applicable and should not be used.

1. The APA’s own *Practice Guideline for the Treatment of Patients with Eating Disorders, Fourth Edition*[4], contains **no recommendations** for use of the "severity" criteria in question as isolated standards for assessment, treatment or need for higher level of care for an individual with a known

[4] APA Practice Guideline for the Treatment of Patients with Eating Disorders, Fourth Edition, published in 2023 https://psychiatryonline.org/doi/book/10.1176/appi.books.9780890424865

or suspected eating disorder. Instead, the document clearly warns **against** using "severity" criteria (body mass, frequency of binge-eating or purging) alone to support assessment and treatment recommendations for the following reasons:

a) Body mass alone is not diagnostic of severity nor does it indicate the best or proper treatment strategy:

> "In the assessment of a patient with a possible eating disorder, obtaining the patient's weight and quantifying recent or current eating and weight control behaviors can help detect and determine the severity of eating disorder behavior and associated symptoms."
>
> "The decision to use NGT feeding varies with patient age, other clinical characteristics, and availability of specialized treatment programs (e.g., meal-based behavioral treatment for eating disorders); it is not necessarily indicated based solely on medical instability or severity of illness (e.g., BMI)."

c) Self-reported symptom frequency is often incorrect, not diagnostic of severity, nor indicative of the best or proper treatment strategy:

> "In addition, patients often underreport purging severity, and obtaining an ECG can identify concerning cardiac changes."
>
> "Individuals with an eating disorder may not have insight into the presence or severity of eating disorder signs and symptoms."

These examples **published in official APA guidelines** by APA after review by over 340 independent professionals and 30 organizations demonstrate that DSM-5 "severity" specifiers have never been accepted in the field as accurate or as independent diagnostic indicators, severity indicators, or to guide treatment decisions.

2. In addition to the APA itself, the field is robust with additional data demonstrating the DSM-5 "severity" specifiers do not accurately diagnose actual severity of eating disorder conditions and may actually **conceal the severity of an individual's condition**. Examples from the literature:

a) Addressing the inaccuracy of current eating disorder severity criteria for all eating disorders:

> "Our findings question the clinical value of the DSM-5 severity categorization."[5]
>
> "Our findings show limited support for the DSM-5 severity specifiers for eating disorders."[6]

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[5] Krug I, Binh Dang A, Granero R, et al. Drive for thinness provides an alternative, more meaningful, severity indicator than the DSM-5 severity indices for eating disorders. European Eating Disorders Review 2021.
[6] Nakai Y, Nin K, Noma S, Teramukai S, Fujikawa K, Wonderlich SA. The impact of DSM-5 on the diagnosis and severity indicator of eating disorders in a treatment-seeking sample. International Journal of Eating Disroders, 2017.

"Our findings point out the limitations of the DSM-5 severity criteria to categorize cognitive flexibility in eating disorders and support illness duration as an alternative severity approach."[7]

"The current findings provide initial support for an alternative transdiagnostic drive for thinness severity classification for males that may be more clinically meaningful than the DSM-5 severity indices."[8]

"Eating disorders are complex biopsychosocial illnesses and any attempt to codify diagnostic severity should consider a range of clinical indicators, [not just] BMI and the frequency of pathological behaviors."[9]

b) Addressing the inaccuracy of binge frequency as a severity criteria for binge-eating disorder:

"Findings provide support for overvaluation of shape/weight as a specifier for binge-eating disorder as it provides stronger information about severity than the DSM-5 severity rating based on binge-eating."[10]

"DSM–5 severity specifiers for binge-eating had limited validity and utility. Future research is needed to identify more robust severity indicators with clinical utility to inform future DSM revisions and clinical practice."[11]

"Shape/weight overvaluation differentiated binge-eating disorder severity more strongly than binge-eating frequency."[12]

c) Addressing the inaccuracy of binge/purge frequency as a severity criteria for bulimia:

"The DSM-5 bulimia nervosa severity specifier holds questionable utility."[13]

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[7] Mora-Maltas B, Lucas I, Granero R, et al. Cognitive flexibility and DSM-5 severity criteria for eating disorders: assessing drive for thinness and duration of illness as alternative severity variables. Journal of Eating Disorders, 2023.

[88] Krug I, Dang AB, Sánchez I, Granero R, Agüera Z, Gaspar-Perez A, Jimenez-Murcia S, Fernandez-Aranda F. How to assess eating disorder severity in males?The DSM-5 severity index versus severity based on drive for thinness. Eating Disorders, 2024.

[9] Aouad P, Bryant E, Martenstyn J. Are DSM–5 eating disorder severity indicators clinically meaningful? A commentary on A systematic review and meta-analysis on the DSM–5 severity ratings for eating disorders. Clinical Psychology: Science and Practice, 2022.

[10] Carlos M. Grilo, Valentina Ivezaj, Marney A. White, Evaluation of the DSM-5 severity indicator for binge eating disorder in a community sample, Behaviour Research and Therapy, 2015.

[11] Lydecker JA, Ivezaj V, Grilo CM. Testing the validity and clinical utility of the severity specifiers for binge-eating disorder for predicting treatment outcomes. Journal of Consulting and Clinical Psychology, 2020.

[12] Forrest LN, Jacobucci RC, Grilo CM. Empirically determined severity levels for binge-eating disorder outperform existing severity classification schemes. Psychological Medicine, 2022.

[13] Gorrell S, Hail L, Kinasz K, et al. A test of the DSM-5 severity specifier for bulimia nervosa in adolescents.

"The presence of multiple purging methods provides more information about eating disorder severity than purging frequency."[14]

"DSM-5 severity specifiers may not adequately capture severity, as intended, for males with bulimia nervosa… Future research should evaluate additional clinical validators of DSM-5 severity categories (e.g., chronicity, treatment non-response), and consider alternate classification schemes."[15]

d) Addressing the inaccuracy of body mass index as a severity criteria for anorexia:

"This study found little evidence for anorexia nervosa risk factors being related to the DSM-5 severity ratings."[16]

"This study found little empirical evidence to support the utility of DSM-5 severity rating scheme to differentiate adults with anorexia nervosa in terms of core eating disorder pathology or associated psychosocial impairment."[17]

"There was no difference across severity groups on measures of eating pathology, depression, or measures of self-reported physical or emotional functioning."[18]

"[The] group [that] reported significantly *lower severity ratings* displayed *more severe* eating disorder psychopathology."[19]

"The *mild* anorexia nervosa group [as determined by body mass index] evidenced *greater* eating disorder symptoms compared to the severe group [as determined by body mass index]. Results demonstrated limited support for the validity of DSM-5 severity specifiers. Future research is warranted to explore additional validators and possible alternative indicators of severity in eating disorders."[20]

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[14] Edler C, Haedt AA, Keel PK. The use of multiple purging methods as an indicator of eating disorder severity. International Journal of Eating Disorders, 2007.
[15] Zayas LV, Wang SB, Coniglio K, Becker K, Murray HB, Klosterman E, Kay B, Bean P, Weltzin T, Franko DL, Eddy KT, Thomas JJ. Gender differences in eating disorder psychopathology across DSM-5 severity categories of anorexia nervosa and bulimia nervosa. International Journal of Eating Disorders, 2018.
[16] Dang AB, Kiropoulos L, Anderluh M, et al. Do risk factors differentiate DSM-5 and drive for thinness severity groups for anorexia nervosa?. Journal of Eating Disorders, 2024.
[17] Reas DL, Rø Ø. Investigating the DSM-5 severity specifiers based on thinness for adults with anorexia nervosa. International Journal of Eating Disorders, 2017.
[18] Gianini L, Roberto CA, Attia E, et al. Mild, moderate, meaningful? Examining the psychological and functioning correlates of DSM-5 eating disorder severity specifiers. International Journal of Eating Disorders, 2017.
[19] Nakai Y, Nin K, Noma S, Teramukai S, Fujikawa K, Wonderlich SA. The impact of DSM-5 on the diagnosis and severity indicator of eating disorders in a treatment-seeking sample. International Journal of Eating Disroders, 2017.
[20] Smith KE, Ellison JM, Crosby RD, et al. The validity of DSM-5 severity specifiers for anorexia nervosa, bulimia nervosa, and binge-eating disorder. International Journal of Eating Disorders, 2017.

> "Our data suggest that the DSM-5 severity specifiers for anorexia nervosa may have limited clinical utility in predicting treatment outcomes of CBT-E."[21]
>
> "Weight history was independently associated with markers of malnutrition in inpatients with restrictive eating disorders across a range of body weights and should be considered when assessing illness severity on hospital admission."[22]
>
> "In adolescents with restrictive eating disorders, total weight loss and recent weight loss were better predictors than admission weight of many physical complications."[23]
>
> "Those with non-extreme anorexia nervosa [as determined by body mass index] reported *more impaired* scores on all measures. Our data support the lack of validity of current BMI specifiers in anorexia nervosa, even in the acute setting."[24]
>
> "Our findings provide no evidence for the DSM-5 anorexia nervosa severity ratings based on BMI."[25]

<u>Summary of data on reliability of the requested change</u>

Not applicable. The reliability of the current "severity" specifiers is really what's in question, as it was not to our knowledge ever considered or tested prior to publication in DSM-5.

<u>Summary of data on clinical utility of the requested change</u>

Not applicable. We are not proposing new criteria, simply the return to the optional use of "severity" specifiers at the clinician or researcher's discretion until evidence-based severity criteria have been proposed, tested and determined to be useful.

<u>Deleterious consequences of current DSM</u>

1. Missed Diagnoses: The most significant harmful consequence of the previously optional eating disorder "severity" criteria for eating disorders now being required is the increased risk for missed

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[21] Dalle Grave R, Sartirana M, El Ghoch M, Calugi S. DSM-5 severity specifiers for anorexia nervosa and treatment outcomes in adult females. Eating Behavior, 2018.
[22] Garber AK, Cheng J, Accurso EC, Adams SH, Buckelew SM, Kapphahn CJ, Kreiter A, Le Grange D, Machen VI, Moscicki AB, Saffran K, Sy AF, Wilson L, Golden NH. Weight Loss and Illness Severity in Adolescents With Atypical Anorexia Nervosa. Pediatrics. 2019.
[23] Whitelaw M, Lee KJ, Gilbertson H, Sawyer SM. Predictors of Complications in Anorexia Nervosa and Atypical Anorexia Nervosa: Degree of Underweight or Extent and Recency of Weight Loss? J Adolesc Health. 2018
[24] Toppino F, Longo P, Martini M, Abbate-Daga G, Marzola E. Body Mass Index Specifiers in Anorexia Nervosa: Anything below the "Extreme"? Journal of Clinical Medicine, 2022.
[25] Machado PP, Grilo CM, Crosby RD. Evaluation of the DSM-5 Severity Indicator for Anorexia Nervosa. European Eating Disorder Review, 2017.

diagnoses.[26,27] In our collective experience, totaling thousands - if not hundreds of thousands - of patients, we have seen the life-threatening effects of using a patients' body size or self-report as the sole measure of eating disorder severity. Without a review of symptoms or nutritional assessment, a patient can appear well and be told inappropriately by a medical provider or insurance company that they're "not sick enough" to need or deserve treatment.

2. Discouraging Patients to Seek Care: With eating disorders already under-diagnosed at an alarming rate, often being mistaken for numerous other illnesses and conditions, patients are already experiencing complications without appropriate treatment until their conditions are severe and possibly irreversible. Add to these contributors to missed diagnoses the common eating disorder symptom of anosognosia, a patient's inability to perceive the seriousness of their condition. In this context, the word "mild" is likely to worsen the mistaken belief that they are not in need of care, reinforced by medical and mental health providers using only these criteria to determine "severity" and therefore need for psychiatric care or hospitalization. The easily predictable result will be fewer patients receiving needed care leading to preventable deterioration requiring emergency department visits and possibly untimely deaths. In addition to the cost to individual patients, missed diagnoses will result in incorrect prevalence rates which as you know can influence research funding and treatment availability.

3. Inapplicability and Unreliability of Research: The eating disorder field drastically needs research on every front from prevention to prevalence to treatment. Reliance in research on the unifocal "severity" criteria will reduce reliability, applicability and utility of future research studies on eating disorders and eating disorder treatment, as patients will fluctuate frequently between levels at a rapid pace during the study period. This will result in inapplicability of the results to real-world treatment and will put the reliability of any studies using these criteria into question.

4. Additional harm to individuals with "atypical" anorexia nervosa because the current use of body mass as a "severity" specifier for anorexia nervosa suggests that an individual with "atypical" anorexia nervosa is therefore at lower risk, when in fact a substantial body of literature documents individuals with anorexia nervosa and *higher* body mass are at equal or higher risk of complications:

> "Patients with atypical anorexia nervosa have been recognized to have similar, if not more severe, medical and psychological complications compared with patients with typical anorexia nervosa."[28]

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[26] Kennedy GA, Forman SF, Woods ER, Hergenroeder AC, Mammel KA, Fisher MM, Ornstein RM, Callahan ST, Golden NH, Kapphahn CJ, Garber AK, Rome ES, Richmond TK. History of Overweight/Obesity as Predictor of Care Received at 1-year Follow-Up in Adolescents With Anorexia Nervosa or Atypical Anorexia Nervosa. J Adolesc Health. 2017

[27] Sim LA, Lebow J, Billings M. Eating disorders in adolescents with a history of obesity. Pediatrics. 2013

[28] Vo M, Golden N. Medical complications and management of atypical anorexia nervosa. J Eat Disord. 2022

> "Adolescents who present with both eating disorder symptomology and obesity demonstrate poorer outcomes within weight control treatments and are at greater risk for future development of full threshold eating disorders and additional weight gain."[29]

> "Atypical anorexia nervosa considerably affects physical and psychological functioning, despite adolescents presenting within or above the normal weight range. There was little evidence that the morbidity of adolescents with atypical anorexia nervosa was any less severe than that of adolescents with full-threshold anorexia nervosa."[30]

> "Findings suggest that adolescents with a history of overweight or obesity represent a substantial portion of treatment-seeking adolescents with restrictive eating disorders, underscoring that extreme weight loss in adolescents is not healthy, regardless of whether the end weight is theoretically within a healthy range. Because eating disorders in adolescents who have history of overweight take longer to be identified, they consequently may have a poorer prognosis."[31]

Summary

The DSM-5 eating disorder "severity" criteria, formerly optional and determined by the clinician's discretion and as of October 1st required, are not appropriate for use.

Quite simply, they are harmful, and they put patients at risk.

By virtue of being unifocal and based on clinically invalid parameters, they do not reflect the true severity or imminent danger of an individual's condition.

They will allow individuals whose medical, psychiatric or nutritional status is critical yet not reflected in their body mass or frequency of binge-eating or purging episodes to be excluded from needed care.

They will exacerbate the current crisis of primary care providers, emergency room providers and non-specialist therapists to misunderstand and undertreat eating disorders.

It is unclear if a single specifier can adequately capture the complexity of eating disorders, but the evidence above demonstrates clearly that the current specifiers definitely don't.

The return of eating disorder "severity" specifiers to the discretion of providers is necessary to improve the accuracy and consistency of diagnosis, facilitate effective treatment, and reduce the risk of negative consequences for individuals with these conditions.

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[29] Rancourt D, McCullough MB. Overlap in Eating Disorders and Obesity in Adolescence. Curr Diab Rep. 2015
[30] Sawyer SM, Whitelaw M, Le Grange D, Yeo M, Hughes EK. Physical and Psychological Morbidity in Adolescents With Atypical Anorexia Nervosa. Pediatrics. 2016
[31] Lebow J, Sim LA, Kransdorf LN. Prevalence of a history of overweight and obesity in adolescents with restrictive eating disorders. J Adolesc Health. 2015

Please expedite your review of this issue and let us know your determination as soon as possible.

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