One Size Doesn't Fit All: The Need to Improve Eating Disorder Assessment Tools

Health Equity

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Eating disorders are serious psychiatric illnesses associated with high morbidity, mortality and psychosocial impairment. They can affect anyone regardless of culture, race, ethnicity, gender identity or socioeconomic status.

Early identification and treatment of eating disorders improves prognosis and reduces the likelihood of relapse. However, accurate assessment and diagnosis and connecting individuals to evidence-based care is made more difficult by structural, individual, and cultural barriers patients may face, including mental illness stigma, inability to self-detect symptoms, expensive treatment options, limited insurance coverage, discrimination, and misconceptions that eating disorders only affect "skinny, White, affluent, girls" (SWAG stereotype).

Even when adolescents and their families *are* able to overcome these hurdles and attain care, their symptoms may initially be missed by well-intentioned but inadequately trained providers. Although there are many reasons why an eating disorder may be missed, the available measures of assessment are increasingly recognized as potentially biased or insufficiently sensitive to diverse populations.

ONE SIZE DOESN'T FIT ALL

Most eating disorder assessment and screening tools were developed and validated for cisgender, White, Western girls and women. However, research demonstrates that eating disorder risk factors, symptoms and presentations often vary across cultural groups. For instance, historically marginalized racial/ethnic groups often report different weight/shape pressures and motivations than their White counterparts, leading to possible under-identification of symptoms and risk in these groups. Many groups often describe difficulties juggling competing appearance pressures. As an example, Black and Latinx women describe pressures to simultaneously appear thin to appeal to American culture, while also striving for a curvy figure to fit with Black/Latinx beauty ideals.

In addition to differing beauty standards, underlying motives for disordered eating may differ across cultures. For example, rather than the White-dominant motive of weight loss, Latinx individuals may restrict their food intake for the purpose of attaining control, and South Asian individuals may restrict for perceived health-related purposes. However, most available English-language assessments focus on White appearance ideals and weight loss. This is why developing measures that assess these important differences across groups is critical for improving accurate screening, referrals and diagnosis.

Although there have been recent efforts to highlight diversity in eating disorder presentation and risk, these efforts generally continue to consider White, cisgendered women as the norm. Individuals who identify with other racial/ethnic groups are frequently collapsed into an "other category," which hides possible differences between groups that contribute to diagnosis and treatment decisions. If groups are stratified, researchers may still combine people who descend from one region into a single category. The "Asian" label typically used includes numerous regions and cultures with distinct histories and values that almost certainly influence attitudes and behaviors surrounding eating, weight and body shape. Even more concerning, researchers may neglect to report the racial/ethnic distribution of their sample, further limiting our understanding of eating disorder symptoms in underrepresented groups.

CREATING EQUITY IN EATING DISORDER ASSESSMENT AND DIAGNOSIS

Continuing to approach assessment and screening of eating disorders from a “one size fits all” perspective leads to inequities in screening, diagnosis and treatment referrals for youth who are suffering from eating disorders. One way to address these inequities is by improving assessment and screening tools.

Evidence suggests that our current diagnostic criteria are increasingly culture-bound and biased, often excluding boys and men, marginalized racial/ethnic groups, and sexual and gender-diverse populations. This exclusion increases the risk that any assessment, prevention, and treatment tools developed using these criteria are also biased and ineffective. Modifying existing assessments and creating more sensitive tools can improve accurate identification of risk, diagnosis, and referral to evidence-based care, especially for youth whose signs and symptoms may be missed by conventional screeners and assessments. By making assessments more culturally sensitive and appropriate, we can empower and support providers to notice warning signs and provide appropriate care to all patients, including those who are traditionally bypassed by currently available evaluations and clinical practices.

Bringing equity to screening, diagnosis and access to evidence-based eating disorders treatment requires a team of policymakers, researchers, clinicians, patients, caregivers and families working together to foster change. Without collective support for change, marginalized individuals with eating disorders will continue to slip through the cracks.

Although equity can require a large paradigmatic shift, one small concrete step that we can take towards improving care for all is to invest in developing and testing culturally appropriate eating disorder assessment tools. This will not only improve diagnosis and treatment referrals but will also send a larger message that *all* patients’ experiences matter.

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