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## **Working Title:**

Adolescent and emerging adult perceptions of eating disorder severity and stigma

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### **Conflict of Interest:**

The authors have no conflicts of interest to disclose.

### Data Availability Statement:

Data from MyVoice is not publicly available, but is available upon request.

**Abstract Word Count: 246/250** 

**Total Word Count: 4279** 

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1002/eat.23772

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### Abstract

Objective: Eating disorders are one of the deadliest mental health conditions, yet most individuals with eating disorders never receive treatment. Previous research has explored barriers to treatment among individuals diagnosed with eating disorders, but little is known about general adolescent and emerging adult perceptions of eating disorders, as compared to other mental health illnesses, a population at greatest risk for developing an eating disorder and a population that may be important sources of information or support for peers.

Method: A sample of adolescents and emerging adults aged 14-24 years (mean age 19 years) from MyVoice, a national text-message-based cohort, (53% female, 38% male, 9% other, race/ethnicity 63% White, 10% Black or African American, 13% Asian, 9% Mixed Race and 5% Other) provided openended responses to questions on the severity of eating disorders as compared to other mental health diagnoses, others' perceptions of eating disorders and potential treatment barriers. Responses were collected using a secure online platform and analyzed using content analysis.

Results: Among respondents (n=792/1283), 91% felt that eating disorders were a mental health condition and 65% felt that eating disorders were as serious as other mental health conditions, while 21% said they were more serious than other mental health conditions. Responses to questions related to perception and barriers illustrated that beliefs of eating disorders involve blame, stigma, and overall lack of understanding.

<u>Discussion</u>: Findings from this study illustrate that there is a lack of understanding around eating disorders that could be addressed in youth-focused initiatives.

**Keywords:** stigma, mental health, eating disorders, SWAG, adolescents and emerging adults, barriers

#### Introduction

The lifetime prevalence of eating disorders among U.S. adults is approximately 10%, surpassing rates of many other mental health diagnoses (Hudson et al., 2007; Smink et al., 2013). Mortality from eating disorders is known to be elevated for both all-cause mortality and suicide, and evidence suggests that suicide mortality may be higher in eating disorders than any other psychiatric diagnoses (Swanson, 2011). Despite their profound public health impact, eating disorders remain highly underdiagnosed (Brandt & Crawford, 2019; Cachelin et al., 2001) and undertreated (Cachelin et al., 2001; Doley et al., 2017), especially in minoritized populations (Acle, 2021).

Historically, stigmatization of a health issue has greatly influenced public health efforts to prevent and address it, as illustrated by the HIV/AIDS epidemic and the opioid crisis (Major et al., 2020). Stigma against mental illness is pervasive worldwide, but unlike other mental health conditions which are understood to occur across the spectrum of gender, race, ethnicity, body size and socioeconomic class, eating disorders are often stereotyped as diseases that affect skinny, white, affluent girls (SWAG) who are appearance motivated (Sonneville, 2018). Furthermore, eating disorders are more likely to be perceived as a choice and are often attributed to lack of self-discipline (Ebneter et al., 2011; Roehrig & McLean, 2010). This framing perpetuates the idea that eating disorders, when compared to other mental health diagnoses, are less severe, easier to overcome, and a matter of personal responsibility (Crisp, 2005). These misconceptions about eating disorders may warp public perception and limit action in the realm of public health and public policy.

Mental health illness is higher in adolescence than in any other life stage (Chandra, 2007). Without help, mental health complications can affect an individual's development and have lasting implications for wellbeing: physically, mentally and socially (Chandra & Minkovitz, 2007; McGorry & Mei, 2018). The majority of adolescents and emerging adults are reluctant to seek help for their mental health and are not in contact with a mental health service (Chandra & Minkovitz, 2007; Nicula et al., 2022). Most adolescents and emerging adults with eating disorders do not believe they need help and do not seek treatment, despite having positive attitudes towards seeking mental health support and

knowledge about how to access resources (Ali et al., 2017). Individuals who experience eating disorders are less likely to seek help than those facing mood or anxiety disorders (del Valle et al., 2017).

Previous literature reviews have highlighted self-reported barriers to treatment among individuals diagnosed with eating disorders (Ali et al., 2017; Doley et al., 2017). In addition to practical barriers (i.e., financial, insurance coverage or accessibility), individuals with eating disorders face a variety of treatment barriers including stigma from others, and self-stigmatization. Those who do not meet the "typical" SWAG stereotype are disproportionately affected (Brelet et al., 2021; Sonneville, 2018). However, little is known about adolescent and emerging adult perceptions of eating disorders, a population at greatest risk for developing an eating disorder and a population that may be important sources of information or support for peers with eating disorders. Therefore, the present study aims to gain adolescent and emerging adult perspectives on perceptions and attitudes toward eating disorders, as compared to other mental health diagnoses, using a national sample of adolescents and emerging adults. Methods

Participants were members of the National MyVoice Text Message Study between the ages of 14 to 24 years; (DeJonckheere et al., 2017). MyVoice participants were recruited via targeted Facebook and Instagram ads using national benchmarks for participant recruitment from the 2016 American Community Survey (ACS; https://www.census.gov/programs-surveys/acs). Participants consented to the MyVoice study online and provided self-reported age, gender (response options: male, female, trans male, trans female, non-binary, "other"), race/ethnicity (response options: White/Caucasian, Black/African American, Asian, Mixed Race, Pacific Islander/Hawaiian, Native/American Indian/Alaskan Native) education, family income, and region of the country upon enrollment. This study was approved by the University of Michigan Institutional Review Board.

In September of 2019, participants were prompted via text message to answer five questions about their perceptions and attitudes toward eating disorders in comparison to other mental health conditions. All five questions were administered within the same day, and participants were compensated one dollar for answer all five questions. For the purpose of this study the following four questions,

corresponding to the topics of *Mental Health, Comparison, Perception*, and *Barriers*, were analyzed (see https://hearmyvoicenow.org/questionbank/ for full question set): 1) "Do you think eating disorders are mental health conditions? Why or why not?"; 2) "How would you compare the seriousness of eating disorders to other mental health conditions (depression/anxiety)?"; 3) "How do you think people view others who have eating disorders?"; 4) "Most people with eating disorders never get treatment. Why do you think that is?". Open-ended text responses were reviewed by the data management team to exclude nonsensical responses and to correct any misalignment in data due to the text messaging system (e.g., long responses that might have carried over to the next column of data). No responses were eliminated based on length. In order to identify distinct codes, responses to the four questions were coded using content analysis. *Content analysis provides a method to examine language and find similar meanings through the interpretation of text data though systematic classification process of coding and identifying or patterns* (Braun & Clarke, 2021). Given that, our participants provided brief sms responses, rather than in-depth accounts/interviews, content analysis was chosen as the most appropriate methodological approach for the present study.

Analysis proceeded in 3 phases. First, the investigative team (KLR, GS, KRS) individually generated initial codes based on reviewing responses for each question. The team then met to review codes and reach a consensus on primary codes. Next, three coders (CN, GS, MB) independently coded twenty-five responses for each question in the data set. Inter-coder reliability was determined by calculating agreement between both coders and codes with low agreement (<90%) were discussed, clarified, and revised. This process was repeated until high agreement was achieved for all codes. Lastly, two coders (KLR, CN) independently coded the remaining responses. The third coder (GS) received the double-coded responses in batches and resolved disagreement between coders.

In an exploratory analysis, we examined whether the prevalence of codes related to *Perception* and *Barriers* differed according to race/ethnicity, gender, and socioeconomic status using chi-squared analysis of independence. Self-reported race/ethnicity was operationalized as a 5-category variable: 1-White/Caucasian, 2-Black/African American, 3-Asian, 4-Mixed Race, and 5-Other Race (including

Pacific Islander/Hawaiian, Native/American Indian/Alaskan Native, and respondents who selected "Other"). Gender was operationalized as a 3-category variable: 1-male, 2- female, 3-gender minority (including transgender, nonbinary, and other write-in identities such as genderfluid). Socioeconomic status was operationalized as a 2-category variable based on the response to the question, "When you were in middle/high school, did you receive free or reduced school? (Yes, No).

#### Results

Respondents were *N*=792 of the *N*=1,283 MyVoice participants (response rate = 62%) who provided a response via text message to a series of questions about eating disorders. Respondents had a mean (standard deviation) age of 19.0 (2.9) years (see Table 1 for demographic information). For the question about *Mental Health* ("Do you think eating disorders are mental health conditions? Why or why not?"), 91% of participants responded affirmatively. For the *Comparison* question ("How would you compare the seriousness of eating disorders to other mental health conditions (depression/anxiety)?"), responses were coded into those that reflected the belief that eating disorders were: as serious as other mental health diagnoses ("*At the same level"-Nonbinary, Mixed Race, 24 years old*), more serious than other mental health diagnoses ("*It think it's more serious because it's way harder to treat and people are more likely to hide it"-Nonbinary Asian, 23 years old*), or less serious than other mental health diagnoses ("*It's less than anxiety*"-Female, Asian, 23 years old). Eating disorders were perceived to be as serious as other mental health diagnoses by 65% of respondents, more serious by 21% of respondents, and less serious by 5% of respondents. The remaining 9% of respondents indicated that eating disorders could not be compared to other mental health diagnoses or that it depended on the case ("*Depends on the case*"-Male, White, 17 years old).

Response codes and sample quotes to the *Perception* question ("How do you think people view others who have eating disorders?") are shown in Table 2. Half of respondents (50.4%) shared the perception that individuals with eating disorders are blamed for their condition and/or judged for suffering The next most prevalent code was general negative perception (15.4%), which included responses

indicating that people had negative or bad perceptions of those with eating disorders, while 14% indicated that people understand that eating disorders are a mental illness and 2.5% reported that people felt concern for others who have eating disorders. Others felt that eating disorders were minimized (10.7%; "A lot of people view them as not real, like the person is just choosing to live like this. If the person is not visibly emaciated then it's often not believed that they have a problem at all" -Nonbinary, White, 20 years old) or misunderstood (9%; "I've seen a lot of people who just tell people with anorexia to just eat and it doesn't work that way"- Female, Asian, 16 years old), and 8.6% felt eating disorders were viewed with stigma or shame. Lastly, 2.0% of responses indicated that people unsure how to help when trying to support someone with an eating disorder. Many responses involved content in multiple codes (for example, the following response captured codes related to stigma or shame, concern for the individual, and lack of understanding, "They're bullied and stigmatized or pitied. People don't understand it's not easy to control"- Transgender American Indian or Native Alaskan, 19 years old).

Response codes to the *Barriers* question ("Most people with eating disorders never get treatment. Why do you think that is?") are shown in Table 3. The two most common treatment barrier identified were stigma or shame (52.4%) and lack of perceived need for treatment (39.3%; "I had an eating disorder & did not get treatment because I didn't recognize it as an eating disorder. Eventually I put on weight on my own"-Female, Black or African American, 23 years old). Further, 16.3% of respondents reported that individuals with eating disorders don't want help/hide symptoms. Lack of access to treatment resources was another code that emerged from the responses, with 11.3% citing access issues including financial strain or inability to access treatment providers. In addition, 5.4% of respondents identified blame and judgement from others as a treatment barrier and 4.6% noted that providers might not be properly trained to screen, diagnose or treat eating disorders. Some respondents indicated that diet culture/thin valuation made it difficult for individuals to access the treatment they need or have their behaviors acknowledged as disordered: (2.1%; "because society tells us that having issues with food is normal and that certain foods you should feel Guilty about and others you can eat endlessly and that's a recipe for a disorder"- Female, "Other", 17 years old). Similarly, to the Perception question, some responses to the Barriers question

highlighted many different codes (for example, the following response captured codes related to stigma or shame, lack of recognition, and diet culture/thin valuation, "I think a large part of it has to do with the stigma I mentioned in my last response to how others view it. Another reason is to get treatment in a lot of places, you need to be in a certain weight class. Aka, you need to look like your eliterally starving to death for people to take you seriously. Otherwise, it's just viewed as doing something good for you, even if it is about as far from that as you could get""- Queer, White, 18 years old).

Differences in *Perception* and *Barriers* by gender, race and socioeconomic class were examined using a chi-squared analysis of independence in an exploratory analysis. While most associations examined were null, there were two response codes for *Perception* ("with blame and judgment", p = .001; "unsure how to help", p=.036) and two response codes for Barriers ("stigma or shame", p=.024; "diet culture/thin valuation", p = .01) that differed according to gender. For the responses to the question about *Perception*, gender minorities (10.5%) were most likely to provide responses consistent with blame and judgement, followed by women (61.0%) and men (28.5%, p for all comparisons < 0.05); gender minorities (4.2%) were most likely to provide responses consistent with being unsure how to help, followed by women (1.9%) and men (0.30%, p for all comparisons < 0.05). For question about Barriers, gender minorities (45.1%) were most likely to provide responses with content consistent with stigma or shame compared to women (32.2%) and men (28.3%, p for all comparisons < 0.05); gender minorities (14.1%) were also most likely to provide responses consistent with diet culture/thin valuation as compared to women (8.6%) and men (4.4%, p for all comparisons < 0.05). Only one significant difference emerged in the analysis of racial/ethnic differences in *Perception* and *Barriers*. Specifically, adolescents and emerging adults identifying as Asian were more likely to provide responses to the question about *Perception* consistent with eating disorders being minimized (17.0%) versus those identifying as White/Caucasian (6.2%, p = .002). Two differences were found when exploring whether content of responses differed by socioeconomic class. For the question on *Perception*, individuals who received free or reduced lunch were less likely to endorse that people viewed individuals with eating disorders with stigma and shame (p=.03) and less likely to provide responses that people viewed

individuals with eating disorders with sympathy (p=.02). For the *Barriers* question, no differences between socioeconomic class and content of responses were observed.

# Discussion

Findings from this study demonstrate that adolescents and emerging adults in the United States believe that eating disorders are seen differently than other mental health diagnoses, despite understanding the seriousness of the condition. Nearly all participants understood that eating disorders are mental health conditions, and eating disorders were predominantly thought to be as serious as other mental health diagnoses. Yet, participants noted that individuals with eating disorders are blamed for their condition and face shame and stigma. Response codes in the present study varied within and across questions, illustrating the range of perceptions about eating disorders. Notably, content across questions about *Perception* and *Barriers* questions shared some similarities, highlighting an overarching theme of stigma which encompassed responses of blame, fear, judgement, shame, and general negative responses, as well as lack of perceived need for treatment. Respondents also shared that eating disorders are misunderstood and that others may not know how to help individuals with eating disorders. Taken together, these findings indicate that eating disorders may not be taken seriously, especially in comparison with other mental health diagnoses, and this may translate to a lack of perceived need for treatment, lack of resources, or lack of recognition, all of which may delay treatment, negatively impact prognosis, and invalidate adolescents and emerging adults who are struggling with symptoms of an eating disorder. While only a few differences by gender, race and socioeconomic class were observed, findings suggest that gender minorities and women may be particularly attuned to the experiences of blame/judgment experienced by people with eating disorders and how stigma and diet culture may serve as barriers to accessing treatment. In addition, Asian respondent were most likely to identify that others minimized eating disorders, while higher income respondents were more likely to identify eating disorder stigma.

Our findings align with previous research that implicates stigma as the most impactful barrier (Hamilton et al., 2021) and the driving factor in eating disorder symptom severity due to increased

alienation and social withdrawal (Becker et al., 2010; Brelet et al., 2021; Foran et al., 2020; Griffiths et al., 2015). Further, stigma-related embarrassment and shame may contribute to a delay in seeking help (Brelet et al., 2021; Foran et al., 2020; Griffiths et al., 2015) or premature dropout from treatment (Corrigan, 2004). Among those with an eating disorder, only 45% are diagnosed and 17% seek help for their problem (Becker et al., 2010), often after experiencing symptoms for many years (Oakley Browne et al., 2006). Despite the chronicity of eating disorders, research shows that the public makes erroneous assumptions that treatment is easy and possible (Holliday et al., 2005; Mond, 2014). While respondents in the present study noted that individuals with eating disorders may hide symptoms to avoid treatment, previous studies implicate stigma as a contributing factor of treatment avoidance as individuals with eating disorders may try to hide their symptoms for fear of being labeled as having a mental illness (Cachelin et al., 2001; Foran et al., 2020; Striegel-Moore et al., 1993). Several studies have highlighted lack of perceived need for treatment among individuals with eating disorders, speaking beyond the concept of self-stigma to low mental health literacy (Nicula et al., 2022). Misperceptions around how an eating disorder presents and common signs and symptoms were shown to be associated with low helpseeking behaviors (Mojtabai et al., 2016). Individuals may avoid seeking care due to self-stigmatization or may not access qualified sources of care (Mond, 2014; Mulveen & Hepworth, 2006) exacerbating their condition and decreasing their potential for recovery.

Unlike other mental health diagnoses, individuals with eating disorders are thought to be responsible for their illness (Stewart et al., 2008), and eating disorder behaviors are perceived to be "willingly" performed to attain a certain status (Striegel-Moore et al., 1993). Studies exploring stigmatization of Binge Eating Disorder show that individuals, regardless of weight status, are perceived with negative character traits such as being lazy or weak (Hollett & Carter, 2021). Further, evidence shows that there is a social desirability of eating disorders, despite their severity (Mond et al., 2006). Previous research has shown individuals express envy or admiration towards an individual with an eating disorder, an aspect of stigma not seen in other mental health conditions (Roehrig & McLean, 2010) and a recent literature review found that adolescents were more likely to seek help if they were supported by

family the primary care provider, if they didn't feel shameful for asking for help, and if they understood the signs of an eating disorder (Nicula et al., 2022).

While participants in our study generally understood eating disorders to be serious mental health conditions, previous studies have found that eating disorders are not thought of as a real illness (Cachelin et al., 2001; Stewart et al., 2008) and are perceived as an issue of self-esteem or vanity rather than a mental health problem (Mond et al., 2006). In the present study, this perception was reflected in responses that identified a lack of understanding about eating disorders or how to help, a lack of recognition on the part of clinicians and society's perpetuation of diet culture/thin valuation. Previous research looking at stigma in eating disorders has shown potential differences in treatment due to differential diagnoses. For example, Anorexia Nervosa, which diagnostically requires low body weight and often presents with noticeable physical changes i.e., muscle wasting and severe medical complications i.e., bradycardia, low electrolytes, are visible leading to greater support from family and clinicians than other EDs (Hamilton et al., 2021). A lack of available treatment resources was identified as a potential treatment barrier by some participants in the present study. Indeed, individuals with eating disorders face insurance barriers and limited treatment options (Thomas et al., 2018), illustrating systemic issues within healthcare delivery systems that may exacerbate misconceptions about the severity of eating disorders.

Previous research has highlighted systemic factors that impact stigma and perceptions of eating disorders. Increasingly, it has been recognized that all types of eating disorders are prevalent among different racial and ethnic groups (Acle et al., 2021), and minoritized populations face unique risk factors. Minority Stress Theory posits that the stress responses related to daily life experiences contributes to the risk of eating disorders among individuals with marginalized identities (Le et al., 2021). Experiences of discrimination and/or perceived discrimination is associated with negative mental and physical health outcomes that often result in harmful coping mechanisms such as disordered eating or social withdrawal (Mason et al., 2021). Research has shown that general racism has been associated with disordered eating among Asian American men (Kelly et al., 2018). Further, anti-transgender discrimination has been associated with higher odds of disordered weight control behaviors such as fasting, vomiting or past-year

binge eating (Watson et al., 2017), as well as specific compulsive exercise among transgender men (Velez. et al., 2016)Thus, the role of understanding cultural and systematic factors is essential as heterogeneity in presentation is masked by groups that do not meet the SWAG stereotype resulting in lower rates of help-seeking behavior, lower rates of diagnosis and treatment and experiences of provider bias (Acle et al., 2021). Further, previously held beliefs regarding eating disorders fail to recognize the different reasons an individual may utilize disordered eating behaviors for reasons other than weight loss. Recent research has shown prevalence of eating disorders among those facing food insecurity (Barry et al., 2021) along with additional studies that have shown a recurring theme for trans youth was utilizing disordered eating behaviors for gender-confirming purposes such as delaying puberty or body manipulation rather than weight concerns (Wright, 2018). *Thus, understanding how different marginalized groups are affected by the SWAG stereotype and overall stigmatization of eating disorders is essential to the prevention, screening, and treatment of eating disorders moving forward.* 

While our findings add to this research by highlighting relatively few differences in eating disorder-related perceptions and treatment barriers according to race/ethnicity, we did observe some heterogeneity in responses according to gender identity. Responses showed that gender minorities were more likely than women and men to provide responses that were consistent with blame and judgement and with other being unsure how to help, as well as to identify stigma and diet culture/thin valuation as barriers to treatment. The significant differences seen in these categories may reflect greater eating disorder-related lived experience (personal experience or experience of a friend) that has required navigating stigma and blame/judgement and the normalization of these habits and pursuit for thinness could make treatment access difficult. Indeed, previous studies have shown a high prevalence of eating disorder symptoms among trans adolescents and emerging adults relative to their cisgender peers (Duffy et al., 2019; Guss et al., 2017), and have highlighted issues with "female centric" screening and treatment guidelines for eating disorders that could lead individuals, including those assigned male at birth or transgender, to be missed for proper screening and diagnosis (Murray et al., 2017).

The present study has several strengths. MyVoice is a large-scale mixed-methods cohort that helps give adolescents and emerging adults a voice via open-ended text message responses, which provided a unique opportunity for adolescents and emerging adults to share their perspectives about eating disorders. Specifically, the ability to better understand the general population's perceptions on eating disorders, rather than those diagnosed, adds to existing literature by providing insight into population-level interventions that may best support those struggling with eating disorders. Data collected via text messages is higher quality than voice interviews due to the anonymous nature that text message responses allow (DeJonckheere et al., 2017). While every effort is made to recruit a diverse sample, MyVoice is not nationally representative, and we recognize the potential for self-selection bias among those who chose to respond to questions. We recognize that by choosing a content analysis approach, many responses have overlapping codes. Additionally, as this is a non-clinical sample, we have no additional information on past or current mental health diagnoses. Previous studies have highlighted the internal stigma that patients with eating disorders face (Mond, 2014; Mulveen & Hepworth, 2006) but little is known about external stigma among those diagnosed with eating disorder. While our studies population adds to the generalizability of responses, it highlights potential for both external and/or internal stigma related to individual symptomatology, adding to the current literature.

Overall, our findings show that among adolescents and emerging adults, eating disorders are understood as a severe mental illness that is not taken seriously by others, especially in comparisons with other mental health diagnoses. Responses illustrated that there is a lack of understanding around eating disorders (i.e. low mental health literacy) that could be directly addressed in youth-focused prevention initiatives that target misperceptions around how an eating disorder presents and common signs and symptoms. Findings from this study illustrate that adolescents and emerging adults perceive eating disorders to be more stigmatized than other mental health diagnoses and identified fear of stigma and judgement from others and their internalized stigma prevents as salient barriers to treatment, underscoring the unique needs of individuals with eating disorders face that should be addressed in eating disorder prevention initiatives. Future studies should explore why adolescents and emerging adults perceive

individuals with eating disorders to be responsible for their condition, as opposed to other mental health diagnoses, how to screen for individuals that may utilize eating behaviors for purposes other than weight and shape concerns, how societal body ideals may serve to normalize or perpetuate eating disorder behaviors among adolescents and young adults, and how systemic changes to the treatment of eating disorders through increased clinical representation of minority populations, increased education of health care providers, and inclusion of eating disorders in mental health programs and policies may lessen stigma around eating disorders.

- Acle, A., Cook, B. J., Siegfried, N., & Beasley, T. (2021). Cultural Considerations in the Treatment of Eating Disorders among Racial/Ethnic Minorities: A Systematic Review. *Journal of Cross-Cultural Psychology*, 52(5), 468–488. https://doi.org/10.1177/00220221211017664
- Ali, K., Farrer, L., Fassnacht, D. B., Gulliver, A., Bauer, S., & Griffiths, K. M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. In *International Journal of Eating Disorders*. https://doi.org/10.1002/eat.22598
- Barry, M. R., Sonneville, K. R., & Leung, C. W. (2021). Students with Food Insecurity Are More Likely to Screen Positive for an Eating Disorder at a Large, Public University in the Midwest. *Journal of the Academy of Nutrition and Dietetics*, *121*(6), 1115–1124. https://doi.org/10.1016/j.jand.2021.01.025
- Becker, A. E., Hadley Arrindell, A., Perloe, A., Fay, K., & Striegel-Moore, R. H. (2010). A qualitative study of perceived social barriers to care for eating disorders: Perspectives from ethnically diverse health care consumers. *International Journal of Eating Disorders*. https://doi.org/10.1002/eat.20755
- Brandt, H. A., & Crawford, S. F. (2019). Eating Disorders 2018: New Insights in Diagnosis, Research, and Treatment. In *Psychiatric Clinics of North America*. https://doi.org/10.1016/j.psc.2018.11.001
- Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37–47. https://doi.org/10.1002/capr.12360
- Brelet, L., Flaudias, V., Désert, M., Guillaume, S., Llorca, P. M., & Boirie, Y. (2021). Stigmatization toward people with anorexia nervosa, bulimia nervosa, and binge eating disorder: A scoping review.

  Nutrients, 13(8), 1–29. https://doi.org/10.3390/nu13082834
- Cachelin, F. M., Rebeck, R., Veisel, C., & Striegel-Moore, R. H. (2001). Barriers to treatment for eating disorders among ethnically diverse women. *International Journal of Eating Disorders*. https://doi.org/10.1002/eat.1084

- Chandra, A., & Minkovitz, C. S. (2007). Factors that influence mental health stigma among 8th grade adolescents. *Journal of Youth and Adolescence*, *36*(6), 763–774. https://doi.org/10.1007/s10964-006-9091-0
- Corrigan, P. (2004). How stigma interferes with mental health care. In *American Psychologist*. https://doi.org/10.1037/0003-066X.59.7.614
- Crisp, A. (2005). Stigmatization of and discrimination against people with eating disorders including a report of two nationwide surverys. *European Eating Disorders Review*, 13(3), 147–152. https://doi.org/10.1002/erv.648
- del Valle, G., Belloch, A., & Carrió, C. (2017). The long and complex road in the search for treatment for mental disorders: An analysis of the process in five groups of patients. *Psychiatry Research*, 253(March), 1–8. https://doi.org/10.1016/j.psychres.2017.03.024
- DeJonckheere, M., Nichols, L. P., Moniz, M. H., Sonneville, K. R., Vydiswaran, V. V., Zhao, X., Guetterman, T. C., & Chang, T. (2017). MyVoice National Text Message Survey of Youth Aged 14 to 24 Years: Study Protocol. *JMIR Research Protocols*. https://doi.org/10.2196/resprot.8502
- Duffy, M. E., Henkel, K. E., Ph, D., Joiner, T. E., & Ph, D. (2019). Prevalence of Self-Injurious Thoughts and Behaviors in Transgender Individuals With Eating Disorders: A National Study. *Journal of Adolescent Health*, 64(4), 461–466. https://doi.org/10.1016/j.jadohealth.2018.07.016
- Doley, J. R., Hart, L. M., Stukas, A. A., Petrovic, K., Bouguettaya, A., & Paxton, S. J. (2017).
  Interventions to reduce the stigma of eating disorders: A systematic review and meta-analysis. In
  International Journal of Eating Disorders. https://doi.org/10.1002/eat.22691
- Ebneter, D. S., Latner, J. D., & O'Brien, K. S. (2011). Just world beliefs, causal beliefs, and acquaintance:

  Associations with stigma toward eating disorders and obesity. *Personality and Individual Differences*. https://doi.org/10.1016/j.paid.2011.05.029
- Foran, A. M., O'Donnell, A. T., & Muldoon, O. T. (2020). Stigma of eating disorders and recovery-related outcomes: A systematic review. *European Eating Disorders Review*, 28(4), 385–397. https://doi.org/10.1002/erv.2735

- Griffiths, S., Mond, J. M., Li, Z., Gunatilake, S., Murray, S. B., Sheffield, J., & Touyz, S. (2015). Self-stigma of seeking treatment and being male predict an increased likelihood of having an undiagnosed eating disorder. *International Journal of Eating Disorders*, 48(6), 775–778. <a href="https://doi.org/10.1002/eat.22413">https://doi.org/10.1002/eat.22413</a>
- Guss, C. E., Williams, D. N., Reisner, S. L., Austin, S. B., & Katz-Wise, S. L. (2017). Disordered Weight Management Behaviors, Nonprescription Steroid Use, and Weight Perception in Transgender Youth. *Journal of Adolescent Health*, 60(1), 17–22. <a href="https://doi.org/10.1016/j.jadohealth.2016.08.027">https://doi.org/10.1016/j.jadohealth.2016.08.027</a>
- Hollett, K. B., & Carter, J. C. (2021). Separating binge-eating disorder stigma and weight stigma:

  A vignette study. *International Journal of Eating Disorders*, *54*(5), 755–763.

  https://doi.org/10.1002/eat.23473
- Kelly, N. R., Cotter, E., & Guidinger, C. (2018). Men who engage in both subjective and objective binge eating have the highest psychological and medical comorbidities. *Eating Behaviors*, *30*(June), 115–119. https://doi.org/10.1016/j.eatbeh.2018.07.003
- Le, T. P., Bradshaw, B. T., Pease, M., & Kuo, L. (2021). An intersectional investigation of Asian American men's muscularity-oriented disordered eating: Associations with gendered racism and masculine norms. *Eating Disorders*, 00(00), 1–23. https://doi.org/10.1080/10640266.2021.1924925
- Hamilton, A., Mitchison, D., Basten, C., Byrne, S., Goldstein, M., Hay, P., Heruc, G., Thornton, C., & Touyz, S. (2021). Understanding treatment delay: Perceived barriers preventing treatment-seeking for eating disorders. *Australian and New Zealand Journal of Psychiatry*, 00(0). https://doi.org/10.1177/00048674211020102
- Holliday, J., Wall, E., Treasure, J., & Weinman, J. (2005). Perceptions of illness in individuals with anorexia nervosa: A comparison with lay men and women. *International Journal of Eating Disorders*, *37*(1), 50–56. https://doi.org/10.1002/eat.20056
- Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication. *Biological Psychiatry*.

- https://doi.org/10.1016/j.biopsych.2006.03.040
- Major, B., Rathbone, J. A., Blodorn, A., & Hunger, J. M. (2020). The Countervailing Effects of Weight Stigma on Weight-Loss Motivation and Perceived Capacity for Weight Control. *Personality and Social Psychology Bulletin*. https://doi.org/10.1177/0146167220903184
- Mason, T. B., Mozdzierz, P., Wang, S., & Smith, K. E. (2021). Discrimination and Eating Disorder Psychopathology: A Meta-Analysis. *Behavior Therapy*, *52*(2), 406–417. https://doi.org/10.1016/j.beth.2020.05.003
- McGorry, P. D., & Mei, C. (2018). Early intervention in youth mental health: Progress and future directions. *Evidence-Based Mental Health*, 21(4), 182–184. https://doi.org/10.1136/ebmental-2018-300060
- Mojtabai, R., Evans-Lacko, S., Schomerus, G., & Thornicroft, G. (2016). Attitudes toward mental health help seeking as predictors of future help-seeking behavior and use of mental health treatments.

  \*Psychiatric Services\*, 67(6), 650–657. https://doi.org/10.1176/appi.ps.201500164
- Mond, J. M. (2014). Eating disorders "mental health literacy": An introduction. In *Journal of Mental Health*. https://doi.org/10.3109/09638237.2014.889286
- Mond, J. M., Robertson-Smith, G., & Vetere, A. (2006). Stigma and eating disorders: Is there evidence of negative attitudes towards anorexia nervosa among women in the community? *Journal of Mental Health*, 15(5), 519–532. https://doi.org/10.1080/09638230600902559
- Mulveen, R., & Hepworth, J. (2006). An interpretative phenomenological analysis of participation in a pro-anorexia internet site and its relationship with disordered eating. *Journal of Health Psychology*. <a href="https://doi.org/10.1177/1359105306061187">https://doi.org/10.1177/1359105306061187</a>
- Murray, S. B., Nagata, J. M., Griffiths, S., Calzo, J. P., Brown, T. A., Mitchison, D., Blashill, A. J., & Mond, J. M. (2017). The enigma of male eating disorders: A critical review and synthesis. *Clinical Psychology Review*, *57*(April), 1–11. https://doi.org/10.1016/j.cpr.2017.08.001
- Nicula, M., Pellegrini, D., Grennan, L., Bhatnagar, N., McVey, G., & Couturier, J. (2022). Help-seeking attitudes and behaviours among youth with eating disorders: a scoping review. *Journal of Eating*

- Disorders, 10(1), 1–18. https://doi.org/10.1186/s40337-022-00543-8
- Oakley Browne, M. A., Wells, J. E., Scott, K. M., & McGee, M. A. (2006). Lifetime prevalence and projected lifetime risk of DSM-IV disorders in Te Rau Hinengaro: The New Zealand Mental Health Survey. *Australian and New Zealand Journal of Psychiatry*. https://doi.org/10.1111/j.1440-1614.2006.01905.x
- Roehrig, J. P., & McLean, C. P. (2010). A comparison of stigma toward eating disorders versus depression. *International Journal of Eating Disorders*, 43(7), 671–674. https://doi.org/10.1002/eat.20760
- Sonneville, K. R., Lipson, S.K. (2018). Disparities in eating disorder diagnosis and treatment according to weight status, race / ethnicity, socioeconomic background, and sex among college students.

  September 2017, 1–9. https://doi.org/10.1002/eat.22846
- Smink, F. R. E., Van Hoeken, D., & Hoek, H. W. (2013). Epidemiology, course, and outcome of eating disorders. *Current Opinion in Psychiatry*, 26(6), 543–548.
  https://doi.org/10.1097/YCO.0b013e328365a24f
- Stewart, M. C., Schiavo, R. S., Herzog, D. B., & Franko, D. L. (2008). Stereotypes, prejudice and discrimination of women with anorexia nervosa. *European Eating Disorders Review*. https://doi.org/10.1002/erv.849
- Striegel-Moore, R. H., Silberstein, L. R., & Rodin, J. (1993). The Social Self in Bulimia Nervosa: Public Self-Consciousness, Social Anxiety, and Perceived Fraudulence. *Journal of Abnormal Psychology*. https://doi.org/10.1037/0021-843X.102.2.297
- Swanson, S. A. (2011). Prevalence and Correlates of Eating Disorders in Adolescents. *Archives of General Psychiatry*. https://doi.org/10.1001/archgenpsychiatry.2011.22
- Thomas, K. C., Shartzer, A., Kurth, N. K., & Hall, J. P. (2018). Impact of ACA health reforms for people with mental health conditions. *Psychiatric Services*. https://doi.org/10.1176/appi.ps.201700044
- Velez, B. L., Breslow, A. S., Brewster, M. E., Cox, R., Jr., & Foster, A. B. (2016). Building a pantheoretical model of dehumanization with transgender men: Integrating objectification and

minority stress theories. *Journal of Counseling Psychology*, 63(5), 497–508. H ttp://www.embase.com/search/results?subaction=viewrecord&from=export&id=L616639586

Table 1. Demographic features of respondents			
Self-reported characteristic	n (%)		
Gender			
Female	422 (53.2%)		
Male	297 (37.4%)		
Transgender	32 (4%)		
Nonbinary	27 (3.4%)		
Other <sup>1</sup>	12 (1.5%)		
Race			
Asian	106 (13.4%)		
Black or African-American	77 (9.7%)		
White or Caucasian	502 (63%)		
Mixed Race	74 (9.3%)		
Other <sup>2</sup>	31 (4.6)		
Age			
14-17	311 (39%)		
18-21	283 (35.7%)		
22-24	198 (25%)		
Educational level (parent)			
8 <sup>th</sup> grade or less	38 (4.8%)		
Some high school	391 (4.9%)		
High school graduate	70 (8.8%)		
Additional training	207 (20.4%)		
Completed a bachelor's degree	69 (22.8%)		
Some graduate school	9 (1.1%)		
Some graduate training beyond a masters' degree	1 (0.1%)		
Completed a master's degree	6 (0.8%)		
Completed a doctoral degree	101 (10.8%)		
Free or reduced lunch	286 (36%)		

 $<sup>^{1}</sup>$  options for individuals to specify i.e. genderfluid)  $^{2}$  individuals who identified as American Indian or Alaskan Native, Native Hawaiian or other Pacific Islander and the other category where individuals were able to specify more options

Code (frequency)	Code definition	Sample quote
	people view others who have eating disorders?"	
With stigma or shame (8.6%)	Response mention that individuals who have eating disorders are viewed disgracefully, with shame, and/or with stigma.	"I think people with eating disorders are stigmatized because people act like it's a choice they made, not a mental disorder." - White, Female, 19 years old  "Eating disorders have a more negative
Well II.		perception than many other mental illnesses. There is an extreme stigma around the physical effects"- White, Male, 19 years old
With blame or judgement (50.4%)	Response mentions individuals with eating disorders being to blame for their eating disorder, being seen with disgust, or being seeing differently.	"People might judge them and consider them weak and don't acknowledge that they have a problem and how hard it is to live with it."-White, Female, 23 years old
		"They might think they have complete control over it and that they're just using it as an excuse or for attention" Female, Black or African American, 15 years old
With concern for the individual (2.5%)	Response mentions individuals feel afraid both for those with eating disorders.	"Concerned, worried, they don't understand." – White, Male, 20 years old
<i>J</i> )		"They view them with sympathy"-Male, Asian, 16 years old
Unsure how to help (2.0%)	Response mentions people not knowing how to help individuals with an eating disorder.	"I think it's a scary thing that they don't know how to help with."-White, Female, 24 years old
		"I think that most people feel sympathy, but don't know how to help. And I know some don't understand anything about them" - Female, White, 17 years old
Not taken seriously, minimization (10.7%)	Response mentions individuals with eating disorders being viewed as "not very seriously".	"I think they don't see it as a real disease and assume people can just get over it by eating."-White Female, 21 years old
2		"A lot of people view them as not real, like the person is just choosing to live like this. If the person is not visibly emaciated then it's often not believed that they have a problem at all" - Nonbinary, White, 20 years old
As mentally ill (14%)	Response mentions individuals with eating disorders being viewed as mentally ill	"I think other people view eating disorders as a disease of some sort." – Black, Female, 16 years old
		"They probably think that they need to get help"- Female, Black or African American, 15 years old
With a lack of understanding (9%)	Response mentions people not understanding eating disorders.	"I think they don't understand the seriousness of it or they don't understand that it is a mental disorder that is hard to fix. They can't snap out of it. It takes time it takes therapy it take professional care."- Black, Female, 21 years old
$ \mathcal{I} $		"I've seen a lot of people who just tell people with anorexia to just eat and it doesn't work that way"-Female, Asian, 16 years old

<sup>&</sup>lt;sup>3</sup> Codes are not mutually exclusive (i.e. responses could be coded for more than one code)

General negative perception	Response mentions individuals with eating disorders being viewed in a	"I think there is a more negative view on eating
(15.4%)	generally negative light, but the response is does not fall into other	disorders than on things like depression."-
	categories.	White, Male, 18 years old
		"People seem to not care too much for a person with a eating disorder. I think they might once they see the way they look" - Female, White, 21 years old

Code (frequency)	Code definition	Sample quote		
QUESTION: "Most people with eating disorders never get treatment. Why do you think that is?"				
Stigma or shame (52.4%)	Response mentions reasons individuals do not receive treatment is due to fear of stigma or shame.			
		"Ithink the stigma is worse than for other mental illnesses. Anxiety and depression can lead to suicide if untreated. But deaths caused by eating disorders aren't as directly linked in a lot of people's minds."- White, Male, 18 years old		
		"Since we are afraid of the stereotypes"-Male, White, 22 years old		
Blame or judgement (5.4%)	Response mentions individuals with eating disorders do not receive treatment because they are to blame for their eating disorder.	"Probably because most of us don't want to tell others and face the judgement from them."- Whi Female, 24 years old		
		"Fear of judgement/ embarrassment"- Male, Wh 15 years old		
Lack of perceived need for	Response mentions reasons individuals with eating disorders don't	"They don't realize or want to admit they have a		
treatment (39.3%)	receive treatment is due to individuals not realizing they have an eating disorder	problem."- White, Female, 21 years old		
	Caring disorder	"I had an eating disorder & did not get treatment because I didn't recognize it as an eating disorder Eventually I put on weight on my own"-Female,		
Lack of resources (11.3%)	Response mentions the reasons individuals with eating disorders do not receive treatment is due to lack of resources.	Black or African American, 23 years old "It's very hard to find the correct resources and sometimes friends and family can be enablers fo		
$\sigma$	not receive treatment is due to tack of resources.	the disorder"- White, Female, 19 years old		
5		"Treatment isn't covered by insurance"- Female, Black or African American, 17 years old		
Lack of recognition (4.6%)	Response mentions that individuals with eating disorders do not receive treatment due to providers not recognizing the eating disorder.	"Medical providers don't believe their patient of acknowledge the concern, also stigma risk."- As Female, 24 years old		
		"Many general therapists or other professionals (doctors, nutritionists, etc.) may not be very knowledgeable- Female, White, 22 years old		
Diet culture/thin valuation (2.1%)	Response mentions reason individuals with eating disorders do not receive treatment is due to the normalization of current thin body ideals or diet culture.	"Diet culture and fat phobia encourage and rewa eating disorders."- White, Gender Fluid, 21 year old		
		"because society tells us that having issues with food is normal and that certain foods you should feel Guilty about and others you can eat endless and that's a recipe for a disorder"- Female, "Oth 17 years old		
Don't want help (16.3%)	Response mentions the reason individuals with eating disorders do not receive treatment is due to patients not wanting help or hiding symptoms from others.	"Because most people likely won't seek treatme on their own and some people probably have no interest in treatment."- White, Female, 23 years		
		"and I think they don't got help because they do want people telling them what they already know but are ignoring"- Female, Black or African American, 16 years old		

<sup>&</sup>lt;sup>4</sup> Codes are not mutually exclusive (i.e. responses could be coded for more than one code)