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Understanding stigma in the context of help-seeking for eating disorders

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Abstract

Background Stigma is a complex construct and its association with help-seeking among those experiencing eating disorders is not well understood. Rates of help-seeking are low for those with eating disorder symptoms and, therefore, determining the role of stigma and shame in this relationship is needed to help inform effective awareness campaigns aimed at improving prognostic outcomes. The current study examined the associations between perceived stigma, self-stigma, shame, and help-seeking behaviour in a community sample of individuals with elevated eating disorder symptoms.

Methods Participants completed an online survey that included measures of stigma and shame as perceived barriers to help-seeking for individuals with eating disorders. Those with elevated eating disorder symptoms and high clinical impairment were included in the study ($N=333$).

Results Using binary logistic regression models controlling for age and gender, results showed that perceived stigma, self-stigma, and shame predicted 64% of help-seeking behaviour ($p=.005$). The only significant unique predictor of formal help-seeking was "*Being concerned that other people believe eating disorders are not real illnesses*". No other stigma or shame items were found to significantly predict help-seeking.

Conclusions The present findings suggest that while stigma plays an important role in help-seeking, it might not be the primary reason preventing individuals with eating disorders from accessing care. The field is encouraged to investigate these factors to promote help-seeking effectively.

Keywords Stigma, Shame, Eating disorders, Help-seeking, Barriers, Early intervention, Treatment

Plain english summary

Eating disorders are highly prevalent worldwide and have severe mental health and medical consequences. While effective treatments for eating disorders exist, many of those who experience eating disorder symptoms do not reach out for help. Delays in help-seeking are associated with negative outcomes for affected individuals but also their families, caregivers, and the broader healthcare system. To better understand the factors preventing individuals with eating disorders from seeking help, we investigated the role of stigma and shame in this relationship. Participants completed a survey assessing their eating disorder symptoms, help-seeking behaviour, and barriers to seeking help. Those with elevated eating disorder symptoms (e.g., disordered eating and/or high weight and shape concerns negatively affecting their life) were included in the study. Participants reported that stigma and shame, specifically, "*Being*

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concerned that other people believe eating disorders are not real illnesses”, prevented them from seeking help. Our results help to clarify the types of stigma most relevant to help-seeking, which may be targeted in awareness campaigns to improve access to care for people with eating disorders. It would be beneficial for future studies to explore other prominent help-seeking barriers to improve clinical outcomes.

Understanding stigma in the context of help seeking for eating disorders

Eating disorders are severe mental illnesses that affect around 8.4% of women and 2.2% of men worldwide [45]. Despite the availability of evidence-based treatments [58, 59, 81], the rate of help-seeking in those with elevated eating disorder symptoms is low and has remained unchanged in the last decade (Ali et al., 2024 under review; [55]). Help-seeking refers to the process of attempting to gain external support to manage a psychological concern [95]. Low levels of help-seeking and delays in accessing eating disorder treatment are associated with negative outcomes, including illness progression, poorer prognosis, significant psychological distress, and increased healthcare burden [10, 12, 42].

Help-seeking and stigma in eating disorders

One factor found to contribute to low eating disorder help-seeking rates is stigma [5], Daugelat, 2023; [53, 89]. Stigma involves assigning negative attributes and stereotypes to individuals who exhibit characteristics that are viewed as different [28, 70]. Previous studies have shown that individuals with eating disorders are often perceived as being personally responsible for their illness by both themselves [49] and healthcare professionals [77] and that the cessation of symptoms is believed to be within the individuals' own control [33, 49]. Furthermore, the notion that eating disorders are considered a lifestyle choice rather than an illness is common [36]. These beliefs were recently endorsed in the 2022 Australian National Survey of Mental Health-Related Stigma and Discrimination [20], in which respondents were more likely to agree that 'it is their own fault people with [eating disorders] are in this condition', '[eating disorders] are not a real medical illness', and 'people with [eating disorders] could snap out of it if they wanted', compared to other forms of mental illness (p. 2). Indeed, eating disorders are commonly regarded as one of the most stigmatised of all mental conditions [36, 99], evidencing the continued and pervasive stigma experienced by this cohort [20].

Studies investigating the impact of stigma experienced by a person with an eating disorder have found it to hinder willingness or opportunities to seek help [5], Daugelat, 2023; [53, 89], with some suggesting that it

may be a primary barrier to help-seeking. For instance, a systematic review of qualitative and quantitative studies by Daugelat et al. [30] found stigma, shame, and guilt to be the most frequently reported barriers preventing individuals with eating disorders from engaging with treatment services. Similarly, previous reviews [5, 61, 92], have identified stigma and shame to be key barriers to help-seeking in the eating disorder population.

Still, other recent research suggests stigma may have a lesser impact on help-seeking behaviour. For instance, Ali et al. [8] used a comprehensive stigma measure (the Barriers to Seeking Help for Eating Disorders Questionnaire, BATSH-ED), in a sample of young Australians with eating disorder symptoms, and found that some elements of stigma and shame (e.g., I am embarrassed about my problems, I don't want anyone to know about my problems, I am ashamed of my problems) were endorsed by only a small minority of participants. The BATSH-ED is a 40-item scale, representing 15 different barriers to help-seeking, which was developed based on a systematic review of perceived barriers toward seeking help for eating disorders [5]. In another study using items from the BATSH-ED, Radunz and Wade [91] found that stigma did not predict help-seeking among Australian university students with a range of disordered eating severities. In addition, quantitative investigations by Griffiths et al. [50] and Lipson et al. [71] revealed that only a small number of participants from the United States, Australia, and the United Kingdom with significant eating disorder pathology reported stigma as a barrier to help-seeking.

Evidently, the relationship between stigma and help-seeking remains to be well understood. In particular, issues related to measurement validity and breadth appear to limit the available research in this area. For example, stigma is often measured as a single variable, as seen in Hamilton and colleagues' (2022) research where stigma was highly endorsed. However, stigma is a broad and complex construct, and it is unlikely that this measurement form would be sensitive enough to detect sufficient variability within it [7]. Moreover, different stigma items have been used to measure the same construct across studies. For instance, 'fear of stigma', 'fear of judgement', 'stigma associated with eating disorder', 'I worry about what others will think of me', 'I would feel like there was something wrong with

me if I got help for my eating and body concerns,' and 'How much of a barrier was stigma related to eating disorders to seeking or receiving treatment for your eating disorder?' are some examples of how stigma has been assessed as a barrier in the literature. These items are unlikely to be comparable in terms of the type of stigma they are measuring and thus are likely to lead to conflicting findings. To this point, research suggests that there are different types of stigma [87, 104], namely, perceived or public stigma, internalised or self-stigma, and personal stigma, often referred to as intra- and interpersonal stigma [25, 28, 47, 48, 89]. These stigma types are rarely defined or consistently measured, however, in the help-seeking literature [7, 53], further complicating the present understanding of how stigma affects help-seeking for people with eating disorders. Finally, stigma associated with help-seeking is distinct from stigma associated with experiencing a mental illness [14, 108, 110], yet this distinction is often overlooked or misunderstood in the field. Thus, consistent, clear, and valid stigma definitions and measurement tools are crucial to the advancement of research in this area.

Stigma types

To address the lack of clarity in the stigma literature, we have chosen to provide a clear conceptualisation of stigma in the context of help-seeking and an identification and definition of the stigma types relevant to this. We conceptualise stigma as a perceived help-seeking barrier for eating disorders, as derived from stigma towards mental illness, influenced by two key stigma types: perceived and self-stigma. *Perceived stigma* refers to an individual's beliefs about the negative attitudes of others towards them due to their mental illness [47, 69]. Perceived stigma as a help-seeking barrier is therefore an individual's belief that others would view them negatively

if they sought help for their problems [37, 111]. *Self-stigma* refers to an individual's internalised negative view of his or her own problems [28, 47]. Thus, as a help-seeking barrier, self-stigma refers to an individual's internalised, negative attitude towards seeking help for their problem [65, 111]. *Personal stigma* refers to an individual's personal beliefs about mental health problems [48]. In the context of help-seeking barriers, personal stigma falls under self-stigma, as individuals with their own eating disorder or eating disorder symptomatology need to engage in help-seeking (for a full discussion, see [66]).

Finally, levels of stigma, including interpersonal and intrapersonal stigma, have been noted in the eating disorder literature [89]. *Interpersonal stigma* refers to stigma from other people, including 'teasing and bullying, criticism, discrimination, or physical threats or violence' (p. 1), while *intrapersonal stigma* refers to 'processes that occur within stigmatised individuals, such as anticipated and internalised stigma' [89], p. 2). Considering these levels describe the overarching processes of stigma, perceived stigma is considered to fall under interpersonal stigma and self-stigma under intrapersonal stigma in the present paper. Table 1 describes the conceptualisation of help-seeking stigma in individuals with eating disorders, as described above.

Stigma, shame, and help-seeking

Investigating whether perceived and self-stigma are related to help-seeking might shed light on the complex relationship between stigma and help-seeking for those with symptoms of eating disorders. While most research investigating stigma as a barrier to help-seeking has focused on stigma as a whole (often only measured with a single item), some studies have found that distinct stigma types differentially relate to help-seeking. For instance, a review of quantitative and qualitative studies [30] revealed that 'fear of stigma' (reflecting perceived stigma)

Table 1 Classification and definition of stigma in the context of help-seeking for eating disorders

Levels of Stigma	
<i>Interpersonal Stigma</i> Stigma from other people including 'teasing and bullying, criticism, discrimination, or physical threats or violence' [89], p. 1)	<i>Intrapersonal Stigma</i> 'Processes that occur within stigmatised individuals, such as anticipated and internalised stigma' [89], p. 2)
Types of Help-Seeking Stigma	
<i>Perceived Stigma of Help-Seeking</i> An individual's belief that others would view them negatively if they sought help for their eating disorder (based on [37, 111]) Derived from the perceived stigma of mental illness: an individual's belief about the negative attitudes of others [47] Also known as <i>public stigma</i> [28]	<i>Self-Stigma of Help-Seeking</i> An individual's negative self-stigmatising attitudes about seeking help for an eating disorder (based on [65, 111]) Derived from the self-stigma of mental illness: an individual's negative view about their own mental illness [28, 47] Also known as <i>internalised stigma</i> [2, 27] Includes <i>personal stigma</i> : participants' personal beliefs about eating disorders [47] in the context of help-seeking barriers [66]

was one of the most frequently cited barriers to eating disorder treatment. However, findings related to other mental health problems have suggested that self-stigma may be more strongly related to help-seeking behaviour than to negative reactions from others [63, 66, 112]. In eating disorder research specifically, self-stigma has been reported to be a predictor of negative recovery attitudes and reduced treatment-seeking behaviours [51], potentially due to its negative emotional consequences, including shame [21].

Shame can be described as a self-conscious emotion that arises when individuals feel judged by others to be flawed, inadequate, inappropriate, or immoral [34, 35]. For example, in the context of eating disorders, shame due to purging symptoms and when speaking with therapists has been commonly reported [100]. Shame about disclosing eating disorder symptoms has also been reported by individuals as a barrier when pursuing help [60]. Thus, shame may have an additive effect on help-seeking, and given its close relationship with stigma [35], it appears important to consider to comprehensively understand the relationship between stigma and help-seeking in individuals with eating disorders.

Altogether, the relationship between stigma and help-seeking for eating disorders is complex and current literature in this area is limited by measurement and definitional inconsistencies. Thus, further investigation is required. In particular, scholars emphasise the need for studies that clearly define, conceptualise, and measure stigma as a multidimensional construct and use quantitative methods to evaluate the link between stigma as a perceived barrier to help-seeking and formal help-seeking behaviour [7, 19, 89]. The present study therefore aimed to examine how perceived stigma, self-stigma, and shame are experienced in a sample of people with eating disorder symptoms and how they influence help-seeking.

Methods

Participants

To estimate the required sample size, an a priori power analysis was performed for logistic regression analysis using G*Power [40]. To detect an odds ratio of 1.5 at an α -level of 0.05 with a statistical power of 0.80, a sample of 308 participants was needed.

Participants were recruited from the broader community and Australian universities through Facebook advertisements and from [blinded for review] research participation pools of first-year psychology students. The study was promoted as “body-image and eating disorder” research. In total, 453 participants (75.7% females) aged between 17 and 59 years (mean age = 26.8; $SD = 9.9$) completed the survey between July 2022 and November 2023. Participants who reported elevated eating disorder

symptoms (as measured with an EDE-Q total score ≥ 2.3 ; [15, 79]) and high clinical impairment due to eating disorder symptoms (as measured with a Clinical Impairment Assessment [CIA] score ≥ 16 ; [16]) were included to accurately reflect a group that would arguably require help for their concerns (see [38]). The final sample consisted of 333 participants: 243 females (73%), 78 males (23.4%), and 4 nonbinary (1.2%) participants (8 participants, 2.4%, preferred not to report their gender). The participants were aged between 17 and 57 years (mean age = 27.7; $SD = 10.4$). Most participants self-reported as Caucasian (89.5%), followed by Asian/Indian (7.2%), other (3.0%), and Aboriginal/Torres Strait Islander (0.3%). More than half of the sample reported that they were currently studying (50.5%), with most students enrolled at Flinders University. Flinders University students received course credit ($n = 43$), while students from other Australian universities and other participants entered a raffle to win one of three \$50 vouchers upon completion. The majority of participants reported senior secondary education as their highest degree (39.3%), followed by a bachelor's degree (15%). In total, 73% of participants reported being employed (i.e., 14.7% full-time, 29.7% part-time, 28.6% casual), while the rest reported not being currently employed. Participants provided informed consent electronically and subsequently completed an online battery of eating disorder attitudes and behaviours, help-seeking, and stigma measures. The study was approved by the Human Research Ethics Committees of Flinders University (5849) and the University of the Sunshine Coast (A232004).

Self-report measures

Eating disorder symptoms

The Eating Disorder Examination Questionnaire (EDE-Q; [39]) was used to measure eating disorder symptoms. The EDE-Q consists of 28 items that measure the severity of eating disorder psychopathology (cognitions and eating disturbances) over the last 28 days. Participants rated their agreement with a series of statements on a seven-point Likert scale from 0–6 for frequency (*no days to every day*) and intensity (*not at all to markedly*). The measure consists of four subscales (Restraint, Eating Concern, Shape Concern, Weight Concern), a global score (combining the four subscales), and six items assessing the frequency of behaviours such as fasting, binge eating, self-induced vomiting, laxative or diuretic misuse, and driven exercise. Internal consistencies were calculated using McDonald's ω for EDE-Q Global, $\omega = 0.85$; Restraint, $\omega = 0.77$; Eating Concern, $\omega = 0.69$; Shape Concern, $\omega = 0.83$; Weight Concern, $\omega = 0.83$.

Eating disorder impairment

Eating disorder impairment was measured using the Clinical Impairment Assessment (CIA; [16]). The CIA is a 16-item self-report measure with items relating to the 28 days before administration that are designed to be completed after the EDE-Q. Items assess impairment across domains of life, including mood and self-perception, work performance, cognitive functioning, and interpersonal functioning, which are specifically related to the pathology of eating disorders. Items are rated on a four-point Likert scale ranging from 0 (*not at all*) to 3 (*a lot*), with higher scores indicating greater severity of clinical impairment. Internal consistencies were calculated using McDonald's ω for the CIA total score, $\omega = 0.72$.

Attitudes and willingness to seek help

Attitudes and willingness to seek help were assessed via the Attitudes Toward Seeking Professional Psychological Help-Short Form (ATSPPH-SF; [41]). The ATSPPH-SF is a 10-item self-report questionnaire rated on a four-point Likert scale ranging from 0 (*disagree*) to 3 (*agree*), with higher scores indicating more positive attitudes toward seeking professional help. Items 2, 4, 8, 9 and 10 were reverse-scored. In line with previous studies, the original version of the measure was adapted to reflect help-seeking for eating disorder symptoms. Therefore, "attitudes towards seeking help for psychological problems" was replaced with "attitudes towards seeking help for eating, weight and shape concerns" [8, 51]. Furthermore, individual items were adapted to reflect help-seeking for eating disorders; for example, "A person with an eating disorder is unlikely to solve it alone; he or she is likely to solve it with professional help".

Stigma and shame as barriers to eating disorder help-seeking

Stigma and shame, as barriers to eating disorder help-seeking, were assessed using the Barriers Towards Seeking Help for Eating Disorders Questionnaire (BATSH-ED; [8]). Nine items from the BATSH-ED were used to measure perceived stigma, self-stigma, and shame as barriers to help-seeking. The items were categorised as measuring perceived stigma (three items), self-stigma (two items), and shame (four items) based on prior measures of stigma and shame in help-seeking research [71, 73, 76, 111]. The BATSH-ED items measuring perceived stigma included "Being afraid to be labelled (e.g., as crazy, mentally ill, having an eating disorder)", "Being concerned that other people believe eating disorders are not real illnesses", and "Feeling afraid of being discriminated against". The items measuring self-stigma were "Believing that seeking treatment is a weakness" and "Believing that eating disorders are not real illnesses".

The items measuring shame were: "Feeling embarrassed about my problems", "Not wanting others to worry about my problems", "Feeling ashamed of my problems," and "Feeling embarrassed if others knew I was seeking professional help".

Participants were asked to indicate whether and how much each item/barrier stopped or discouraged them from getting, or continuing with, professional help for eating, weight and shape concerns. Answers were scored as follows: 0 = *not at all*; 1 = *a little*; 2 = *quite a lot*; 3 = *a lot*. The items were then dichotomised into 1 = barrier endorsed (e.g., "*a little*", "*quite a lot*" and "*a lot*") or 0 = barrier not endorsed (i.e., "*not at all*"). Internal consistency was calculated using McDonald's ω for perceived stigma, $\omega = 0.57$; self-stigma, $\omega = 0.41$; and shame, $\omega = 0.60$. As all the statistics were $\omega < 0.70$, the results are presented at the item level rather than within the subscales of stigma and shame.

Actual help-seeking behaviour

The Actual Help-Seeking Questionnaire (AHSQ; [94]) was used to measure help-seeking behaviour. First, participants were asked about their past help-seeking behaviour: "Have you ever sought help for your eating, weight and/or shape concerns?" Participants who had sought help in the past were presented with various help-seeking sources from the AHSQ, including informal (e.g., friends and family) and formal sources (e.g., mental health professionals, family doctors). Participants who had sought help from at least one of the following professional sources were coded as having sought professional help in the past: mental health professional (e.g., psychiatrist, psychologist, social worker, counsellor), family doctor (e.g., general practitioner) or phone helpline, websites (e.g., Lifeline, Butterfly Foundation). Informal help-seeking was also calculated and included the following sources: intimate partner (e.g., girlfriend, boyfriend, husband, wife, de facto), friend (not related to you), parent, or other relative/family member. Finally, digital help-seeking was calculated separately, including via phone helplines (e.g., Lifeline, Butterfly Foundation) and websites (e.g., Butterfly Foundation).

Statistical analysis

Descriptive data analyses were performed to provide means and standard deviations (SDs) for the entire sample. Independent samples *t* tests were used to compare levels of stigma across help-seeking and non-help-seeking groups. To test the likelihood of perceived and self-stigma predicting help-seeking, hierarchical binary logistic regression models, controlling for gender and age, with help-seeking as the outcome variable, were estimated.

Results

Eating disorder symptoms and impairment

The average scores on the EDE-Q Shape and Weight Concern subscales exceeded the clinical cut-off (>4; [39, 80]), while the scores on the Restraint and Eating Concern subscales as well as the global scores were substantially greater than the community norms, as shown in Table 2 [39]. Participants also reported substantial clinical impairment due to their eating disorder symptoms (CIA score ≥16). Global eating disorder symptomatology and psychosocial impairment due to eating disorder symptoms were strongly correlated ($r=0.60$, 95% CI: $0.53=0.67$, $p<0.001$).

Formal help-seeking

Over 65% of participants reported that they had sought some form of help for eating, weight and/or shape concerns. However, less than 43% had sought *formal* help from either a mental health professional (e.g., psychologist, psychiatrist, social worker, counsellor) or their family doctor/GP. Most of the stigma and shame barrier items were highly endorsed by participants (Table 3). On average, the shame items were most highly endorsed ($M=81.2\%$), followed by perceived stigma ($M=70.8\%$). The only barrier that was on average less frequently endorsed by participants was “*Believing that eating disorders are not real illnesses*” (48%).

To predict formal help-seeking (no=0, yes=1), all stigma and shame items were entered into the logistic regression model simultaneously. The overall model test was statistically significant, X^2 (df=9)=23.4, $p=0.005$; Nagelkerke’s pseudo $R^2=0.09$, predicting formal help-seeking with 64.3% accuracy. However, the only significant unique variable in predicting formal help-seeking was “*Being concerned that other people believe eating disorders are not real illnesses*” (perceived stigma; OR=2.43); all other stigma and shame items predicting

Table 3 Frequency of help-seeking behaviours and endorsed stigma and shame barrier items (N = 333)

	n (%)
Sought help for ED (any help)	219 (65.8)
Sought formal help for ED	142 (42.6)
Sought informal help for ED	174 (52.3)
Sought digital help for ED	83 (24.9)
Perceived stigma	
Being afraid to be labelled (e.g., as crazy, mentally ill, having an ED)	244 (73.3)
Being concerned that other people believe EDs are not real illnesses	224 (67.3)
Feeling afraid of being discriminated against	239 (71.8)
Self-stigma	
Believing that seeking treatment is a weakness	218 (65.5)
Believing that EDs are not real illnesses	160 (48.0)
Shame	
Feeling embarrassed about my problems	286 (85.9)
Not wanting others to worry about my problems	272 (81.7)
Feeling ashamed of my problems	267 (80.2)
Feeling embarrassed if others knew I was seeking professional help	256 (76.9)

Note. ED = eating disorder. Formal help-seeking included mental health professional (e.g., psychologist, psychiatrist, social worker, counsellor) and family doctor/GP; informal help-seeking included intimate partner (e.g., girlfriend, boyfriend, husband, wife, de facto), friend (not related to you), parent or other relative/family member; and online help-seeking included phone helplines (e.g., Lifeline, Butterfly Foundation) and websites (e.g., Butterfly Foundation)

formal help-seeking were not statistically significant (all $p>0.05$); see Table 4. “*Being concerned that other people believe eating disorders are not real illnesses*” and actual help-seeking behaviour were significantly correlated, $r=0.20$ (95% CI: 0.09; 0.30), $p<0.001$. Another logistic regression model was tested by entering sex (male=0, female=1; nonbinary sex was not included due to small sample sizes) and age (continuous: 17–57 years) in the

Table 2 Descriptive statistics for eating disorder symptoms, clinical impairment and help-seeking attitudes (N = 333)

	Mean (SD)	95% CI	Range	Normative Data Mean (SD)
EDE-Q Global	3.69 (0.92)	[3.58; 3.79]	2.36–5.90	1.40 (1.13)
EDE-Q Restraint	3.34 (1.26)	[3.20; 3.48]	0.40–6.00	1.25 (1.32)
EDE-Q Eating Concern	3.18 (1.10)	[3.06; 3.30]	0.20–6.00	0.62 (0.86)
EDE-Q Shape Concern	4.19 (1.21)	[4.06; 4.32]	1.63–6.00	2.15 (1.60)
EDE-Q Weight Concern	4.05 (1.16)	[3.92; 4.17]	1.60–6.00	1.59 (1.37)
Clinical Impairment Assessment	27.96 (7.93)	[27.10; 28.81]	16.00–48.00	20.1 (13.4)
Attitudes towards Seeking Professional Psychological Help	17.58 (4.97)	[17.04; 18.12]	3.00–29.00	

Note. EDE-Q = Eating Disorder Examination Questionnaire. Normative data are based on Fairburn and Beglin [39], the EDE-Q and Bohn et al. [15], and the Clinical Impairment Assessment. Norms are not provided for Attitudes towards Seeking Professional Psychological Help

Table 4 Regression coefficients and odds ratios predicting formal help-seeking (N = 333)

Variable	Estimate	SE	p	OR (95% CI)
Being afraid to be labelled (e.g., as crazy, mentally ill, having an ED)	0.51	0.30	.093	1.66 (0.92; 2.99)
Being concerned that other people believe EDs are not real illnesses	0.89	0.29	.002	2.43 (1.38; 4.31)
Feeling afraid of being discriminated against	0.25	0.28	.386	1.28 (0.73; 2.33)
Believing that seeking treatment is a weakness	-0.02	0.27	.947	0.98 (0.58; 1.68)
Believing that EDs are not real illnesses	-0.07	0.25	.767	0.93 (0.57; 1.52)
Feeling embarrassed about problems	0.22	0.37	.550	1.25 (0.61; 2.57)
Not wanting others to worry about my problems	-0.06	0.34	.857	0.94 (0.49; 1.83)
Feeling ashamed of my problems	-0.60	0.32	.062	0.55 (0.29; 1.03)
Feeling embarrassed if others knew I was seeking professional help	-0.41	0.31	.177	0.66 (0.36; 1.210)

Note. Formal help-seeking (no = 0, yes = 1), ED = eating disorder, SE = standard error, OR = odds ratio, 95% CI = 95% confidence interval

second step. Neither variable significantly predicted formal help-seeking; gender: $b = 0.13$, $p = 0.679$; age: $b = 0.01$, $p = 0.298$.

Discussion

This study examined how perceived stigma, self-stigma, and shame were experienced in a sample of individuals with eating disorder symptoms and how these factors influenced help-seeking. Of the community sample, almost three-quarters reported elevated eating disorder symptoms causing significant functional impairment. Stigma and shame were found to moderately predict help-seeking, although only a single perceived stigma variable (“*Being concerned that other people believe eating disorders are not real illnesses*”) was significant in this relationship.

The rates of formal help-seeking (i.e., from a health professional) in the present sample were found to be higher than those in previously reported studies [8, 71]. This may be in part due to phases of recruitment occurring throughout the COVID-19 pandemic, where an increased uptake of help-seeking in eating disorder services was observed with symptom worsening and a need for support [68, 93, 113]. However, these help-seeking rates are still low (i.e., below 50%) relative to the sample’s high frequency of eating disorder impairment.

Although we found that stigma and shame predicted actual help-seeking behaviour with moderate accuracy, only a single aspect of perceived stigma (“*Being concerned that other people believe eating disorders are not real illnesses*”) was found to be significant in this relationship, and the association was weak. The finding that stigma might not be the strongest barrier to help-seeking for individuals with eating disorders is in line with results from recent studies [8, 50, 71, 90]. Furthermore, our finding that the “*concern that others believe eating disorders are not real illnesses*” uniquely predicts help-seeking might help to disentangle which aspects of stigma and

shame are relevant in the context of help-seeking for individuals with eating disorders. This is consistent with a qualitative study among ethnically diverse health care consumers that found the perception by others that eating disorders are not serious illnesses to impede help-seeking [13]. Qualitative and quantitative investigations by Daugelat et al. [30] and Hepworth and Paxton [60] also noted a fear of stigma (i.e., perceived stigma) to be one of the most frequently mentioned barriers and likely reasons for a delay in accessing eating disorder treatment in their research. Somewhat related, perhaps as an internalised version of our finding, are the results of other studies that indicate the barrier “*denial or failure to perceive the severity of the eating disorder*” to prevent people with eating disorders from seeking help [5], Cachelin & Striegel-Moore, 2006; Fabry et al. 2022; [61, 90, 92]. It, therefore, seems that a salient theme in preventing help-seeking for this population relates to misperceptions of the severity or seriousness of eating disorders by both individuals with the illness themselves and the general public.

Self-stigma and shame were not significantly associated with help-seeking behaviour in our sample. While the variable “*feeling ashamed of my problems*” was highly endorsed among participants and showed a trend towards significance, its actual relationship with help-seeking was the opposite. This implies that individuals who feel ashamed of their disordered eating problems may even be *encouraged* to reach out for help, as opposed to being discouraged. Future explorations of stigma, shame, and help-seeking are suggested to consider this item to properly assess and validate this relationship.

Implications

These findings have several implications for the field. First, the high-level of eating disorder symptomatology found in the sample has important implications for stigma. The greater the prevalence of eating disorder symptoms in the community, the more normalised they

might become, and the less likely they are to be perceived as disordered, thus contributing to stigma that eating disorders are not serious illnesses. However, the prevalence of eating disorder pathology does not take away from their significant psychiatric, medical, functional, and financial burden; eating disorders have one of the highest mortality rates of all mental conditions [57, 85, 107]. Thus, while eating disorder symptoms may be becoming more common, it is crucial to remember that they are symptoms of serious disorders and not lifestyle choices.

Second, our findings reflect those of other recent studies that suggest that stigma is not necessarily the strongest barrier to accessing eating disorder care, at least in the Australian context. Although significant stigma has been reported to persist at a societal level towards those with eating disorder pathology [20], there is the potential that awareness campaigns coordinated by Australia's national eating disorder organisations may have at least curtailed its effect on help-seeking. Whether these findings are consistent across other countries is less known; however, Griffiths et al. [50] and Lipson et al. [71] also found weak associations between stigma and help-seeking in individuals with significant eating disorder pathology sampled from the United States and the United Kingdom. It, therefore, appears that orienting the focus of future research and advocacy campaigns to other treatment barriers, such as denial or failure to perceive the severity of the eating disorder, may be a more effective strategy to increase help-seeking for those with eating disorder pathology.

Third, our finding that only a single aspect of perceived stigma ("*Being concerned that other people believe eating disorders are not real illnesses*") uniquely predicted help-seeking, albeit weakly, refines our understanding of the specific stigma and shame types most relevant to help-seeking for eating disorders. Future studies should seek to validate these findings to inform effective interventions to improve help-seeking. Indeed, of the few programs that have specifically targeted eating disorder stigma, research shows that considerable attention needs to be given to the specific messaging employed in these interventions for them to be helpful [19, 29].

Interventions designed to improve help-seeking may also benefit from the inclusion of lived experience. Voices of lived experience have been found to aid in normalising eating disorder experiences and promote treatment engagement by fostering motivation and hope [6, 67]. Lived experiences may be shared through several media, including podcasts, which provide an engaging and persuasive storytelling format suitable for targeting stigma [98]. In particular, research has shown that the inclusion of explicit stigma and discrimination discussions in podcasts is more likely to reduce stigma than the

sharing of general eating disorder experiences alone [24, 102]. The curation of podcasts that allow an individual to divulge, not only their experience of having an eating disorder but also their struggle to reach out for help, may therefore be powerful in lessening stigma and preventing help-seeking. Social media platforms, including the popularised TikTok, also represent a potential medium through which lived eating disorder experiences, including positive help-seeking experiences, may be shared [46]. Although in its infancy, early scholarship in this area suggests the potential of the TikTok platform to engender a positive community and atmosphere through which the sharing of lived experience videos may reduce stigma [44]. Thus, alongside podcasts, TikTok may be a relevant avenue through which future lived experience initiatives may be developed. It is also noted that the inclusion of lived experiences in the development of awareness campaigns is integral to reducing the unintentional perpetuation of stigma [89].

Health professionals have a crucial role to play in stigma reduction. "*Being concerned that other people believe eating disorders are not real illnesses*" might reflect little faith in healthcare professionals and healthcare systems to offer help, even if an individual wants it. Health professionals need to be aware of this and assist in representing the seriousness of eating disorders in the media and the general public (i.e., that eating disorders are not 'lifestyle choices', 'easy to overcome', and 'just a phase'). This may be best achieved through public health campaigns whereby healthcare professionals acknowledge concern for what others think as a common barrier to seeking treatment, whilst also describing eating disorders as serious illnesses. Healthcare professionals also have a role to play in educating afflicted individuals, their families, community groups, and other clinicians about the severity of eating disorders and their need to be treated. For individuals who are eventually able to access professional help, clinicians should be mindful of the struggle they have likely experienced in doing so; in feeling their eating disorder was not serious enough to warrant care and worrying that others might have thought the same. Clinicians should seek to validate and normalise these experiences when seeing a client for the first time, as well as routinely throughout treatment, especially if a client exhibits ambivalence towards getting better, as stigma can not only prevent engagement in treatment but can result in treatment drop-out [110].

Considering that stigma is, historically, the most commonly cited perceived help-seeking barrier in the eating disorder literature, often assessed without simultaneously measuring actual help-seeking [5, 30, 61, 92], the current findings make an important contribution to how stigma is operationalised and measured hereafter. Specifically,

we found that only one of the nine stigma variables measured using the BATSH-ED correlated with help-seeking. It, therefore, seems that while one item of stigma may be predictive of help-seeking, another may not, and future studies need to reflect this by utilising a robust measure that captures the multidimensionality of the stigma-help-seeking relationship. According to the results of our study and others [8, 91], the BATSH-ED appears to be one such measure that can tap into different stigma types.

Strengths, limitations, and future directions

The present study has several strengths. We provided a clear definition and conceptualisation of stigma in the context of help-seeking and hope that this may guide future studies and improve clarity within the field. We also included a measure of *actual* help-seeking behaviour, which, compared to the use of help-seeking attitudes or intentions to approximate help-seeking behaviour, contributes to the validity of our findings. In addition, we specifically measured *formal* help-seeking, which is most indicative of effective eating disorder treatment [85, 86] and, therefore, builds understanding of ways to improve access to eating disorder care that could lessen their significant burden. Further, the complex concept of stigma was measured with several items, reflecting the breadth of stigma. Finally, we used both the CIA, alongside the EDE-Q, to procure a group of individuals who not only met the clinical cut-off for weight, shape, and eating concerns, but also reported significant clinical impairment related to their eating disorder symptoms (and not to that of other symptoms of psychological distress) and thus, would arguably need to seek professional help for their concerns.

In light of these strengths, some limitations should be considered. First, causality cannot be determined given the cross-sectional nature of the study. Second, help-seeking behaviour was measured retrospectively, which can be subject to errors of recall and social desirability [78], especially if help-seeking took place several years ago [60]. To this point, the present study did not include a timeframe of past help-seeking behaviour; therefore, information about when participants sought help was unavailable. Response reliability and validity are also improved when specified timeframes are available for participants [96]. A longitudinal design would be the most auspicious to overcome these shortfalls; however, we were not able to achieve this in the present paper, and in the absence of such a design, future studies should at least seek to measure the time point at which participants sought help.

It is also possible that the stigma items included in the present study do not capture the complexity of this

broad construct (e.g., disgust, ridicule, weight stigma). Further research is required to address this issue. Moreover, we did not assess how perceived self-stigma and shame may be experienced as a function of eating disorder symptom type or severity. Such investigations could shed light on how individuals with different eating disorder behaviours engage in help-seeking, and we implore forthcoming studies to consider these relationships. In addition, demographic variables, including age and gender, were not found to correlate with help-seeking. This is curious given past research suggesting that adolescents [43, 97] and men [72, 103] report lower rates of help-seeking than adults and women. The predominance of women in the present sample (75.7%) and the exclusion of those younger than 17 years may have precluded the detection of a link between these variables and help-seeking. Another explanation, however, concerning gender specifically, is that increased awareness and occurrence of eating disorders in men [18, 52] has led to an understanding that eating disorders are no longer a female-only affliction [18, 52, 57], and this may have encouraged male help-seeking in our study. In support of this, some [62, 92, 106], but not all [17, 43, 105], recent studies have reported that men with eating disorders are as likely as women to seek help. Stigma and shame have also been noted as barriers to help-seeking in males with eating issues [31]. However, differences across diagnostic groups may moderate the relationship between gender and help-seeking [106], and this relationship should be examined in future studies.

Finally, our study may be subject to sampling bias in that individuals who were interested to participate in research about body image and eating disorders were recruited; individuals who endorse high levels of stigma towards seeking help for eating disorders might be less likely to participate in such a study. Thus, our findings may represent an underestimation of stigma's impact and stigma may be a more significant barrier to help-seeking in the broader community than can be assessed. Sampling bias may also explain why so many participants fell into the elevated range of eating symptomatology. Our study was promoted as "body-image and eating disorder" research, which would more likely appeal to individuals who have experienced symptoms of disordered eating and body image concerns themselves. Future research should therefore seek to include more diverse sampling methods [52]. In particular, the inclusion of LGBTQIA+ individuals, Aboriginal and Torres Strait Islander Australians, and other underrepresented, diverse groups is highly important given the prevalence of eating disorders but the lack of targeted health care in these populations [22, 52, 56].

Conclusion

Although stigma towards individuals with eating disorders continues to exist, the present findings suggest that stigma may not play as significant a role in predicting help-seeking for individuals with eating disorders as initially conceived. We propose that the strength of stigma as a help-seeking barrier might have been inflated due to issues relating to measurement validity, breadth, and consistency in the literature. Directing the efforts of future research to other barriers, for example, denial of the illness, may therefore be necessary to improve help-seeking. Engendering awareness of the severity of eating disorders and their need for treatment by incorporating the voice of lived experience may also be a key objective for imminent prevention and early intervention. Additionally, clinicians are encouraged to be mindful of the perceived stigma that prospective help-seeking individuals may face in endeavours to access care and are encouraged to assist in educating the community that eating disorders are serious illnesses.

Abbreviations

AHSQ	The actual help-seeking questionnaire
ATSPPH-SF	Attitudes toward seeking professional psychological help-short form
BATSH-ED	Barriers towards seeking help for eating disorders questionnaire
CIA	Clinical impairment assessment
ED	Eating disorder
EDE-Q	Eating disorder examination questionnaire
LGBTQIA+	Lesbian, gay, bisexual, transgender, queer, intersex, and asexual. The additional "+" stands for all of the other identities not encompassed in the short acronym
OR	Odds ratio
SD	Standard deviation
SE	Standard error

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Author contributions

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Declarations

Ethics approval and consent to participate

The study was approved by the Human Research Ethics Committees of Flinders University (5849) and the University of the Sunshine Coast (A232004).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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