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Preliminary Data on Help-Seeking Intentions and Behaviors of Individuals Completing a Widely Available Online Screen for Eating Disorders in the U.S.

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Abstract

Objective: Scaling an online screen that provides referrals may be key in closing the treatment gap for eating disorders (EDs), but we need to understand respondents' help-seeking intentions and behaviors after receiving screen results. This study reported on these constructs among respondents to the National Eating Disorders Association (NEDA) online screen who screened positive or at high risk for an ED.

Method: Respondents completed the screen over 18 months (2/9/18–8/28/19). Those screening positive or at high risk for an ED (n=343,072) had the option to provide data on help-seeking intentions (after screen completion) and behaviors (2-month follow-up).

Results: Of eligible respondents, 4.8% (n=16,396) provided data on help-seeking intentions, with only 33.7% of those reporting they would seek help. Only 7.6% of eligible respondents opted in to the 2-month follow-up, with 10.6% of those completing it (n=2,765). Overall, 8.9% of respondents to the follow-up reported being in treatment when they took the screen, 15.5% subsequently initiated treatment, and 75.5% did not initiate/were not already in treatment.

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Data Sharing Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Discussion: Preliminary results suggest that among the small minority who provided data, only one-third expressed help-seeking intentions and 16% initiated treatment. Online screening should consider ways to increase respondents' motivation for and follow-through with care.

Keywords

eating disorders; health care utilization; help-seeking; referral; screening

Only 23% of individuals with eating disorders (EDs) seek treatment (Hart, Granillo, Jorm, & Paxton, 2011). Because identifying one's symptoms as requiring help is associated with help-seeking (Gratwick-Sarll, Mond, & Hay, 2013; Grillot & Keel, 2018), scaling a screen that provides feedback/referrals may be a key step in closing the treatment gap (Kazdin, Fitzsimmons-Craft, & Wilfley, 2017).

We partnered with the National Eating Disorders Association (NEDA) in the U.S. to disseminate an online EDs screen, with treatment resources (e.g., NEDA Helpline) being presented upon screen completion. Our prior work showed most respondents (86.3%) screened positive for an ED, most of whom (85.9%) had never received treatment (Fitzsimmons-Craft et al., 2019a). To understand the potential for this screen to impact uptake of mental health services, it is important to examine respondents' help-seeking intentions and behaviors.

This descriptive/exploratory study aimed to, first, present the help-seeking intentions of respondents who screened positive for an ED or at high risk (i.e., elevated weight/shape concerns without an ED) immediately following screen completion. We included the high-risk group, as elevated weight/shape concerns are consistently associated with ED onset (e.g., Jacobi, Hayward, de Zwaan, Kraemer, & Agras, 2004; Keel & Forney, 2013); consequently, facilitating service engagement in this group is important. We also compared help-seeking intentions across ED diagnostic/risk status and demographic groups. Second, we present the help-seeking behaviors of respondents screening positive or at high risk for an ED among those who participated in a 2-month follow-up survey to shed light on potential for this screen to facilitate access to care.

Method

Over ~18 months (2/9/18–8/28/19), 353,115 respondents completed an online ED screen that NEDA made freely available (https://www.nationaleatingdisorders.org/screening-tool). We received institutional review board approval to analyze this de-identified dataset.

Measures

Demographics.—Participants self-identified their gender, age, race, and ethnicity.

Probable ED diagnoses and risk.—The Stanford-Washington University Eating Disorder Screen (SWED; Graham et al., 2019) was used to identify possible DSM-5 ED diagnoses and risk: 1) anorexia nervosa (AN); 2) bulimia nervosa (BN); 3) binge-eating disorder (BED); 4) subclinical BN; 5) subclinical BED; 6) purging disorder; 7) unspecified feeding or eating disorder (UFED); 8) avoidant/restrictive food intake disorder (ARFID); 9)

likely ED (i.e., elevated weight/shape concerns and/or presence of ED behaviors) with missing height/weight; 10) high risk for an ED (i.e., elevated weight/shape concerns) but no ED; 11) unlikely ED with missing height/weight; or 12) not at ED risk. In college-age women, SWED sensitivities range from 0.68 (subclinical BN) to 0.90 (AN) and specificities range from 0.79 (subclinical BED) to 0.99 (AN) compared to diagnostic interview (Graham et al., 2019); it has been used with men and individuals of various ages (Fitzsimmons-Craft et al., 2019a, 2019c).

Help-seeking intentions (assessed at screening).—All respondents received feedback on screen results and resources for accessing treatment. Upon receipt, respondents who screened positive or at high risk for an ED were presented optional questions, developed for this study, regarding their intention to seek professional help (see Appendix 1). Questions appeared on the same webpage as the screen feedback/resources.

Two-month follow-up survey.—Respondents who screened positive or at high risk for an ED at screening could opt-in for an online follow-up survey (see Appendix 1) on help-seeking behaviors two months later (i.e., to allow sufficient time to initiate intervention if they so chose). This survey assessed: 1) what recommendation respondents believed they received upon screen completion; 2) whether they agreed with and their reaction to the feedback, if they endorsed receiving a referral; and 3) reasons for seeking treatment. Questions were modified from Fitzsimmons-Craft et al. (2019b) and Cachelin and Striegel-Moore (2006). Respondents who endorsed seeking treatment were asked about treatment received.

Analytic Strategy

Data are presented descriptively. Chi-square tests were used to compare ED diagnostic/risk and demographic groups on help-seeking intentions.

Results

Descriptive Statistics

Among the 353,115 screen respondents, 88.3% were female, 86.5% were between the ages of 13–34, 78.3% were White, and 11.4% were Hispanic. Of these, 88.1% screened positive for an ED (i.e., all SWED ED diagnoses including likely ED with missing height/weight) and 9.0% as high risk (n=343,072 total ED/high risk cases) and thus were eligible for the help-seeking intention question at screening and follow-up survey.

Help-Seeking Intentions at Screening

Of 343,072 eligible respondents, 4.8% (n=16,396) completed the help-seeking intention question. As Table 1 shows, completion differed across ED diagnostic/risk groups, $\chi^2(6, N=343,072)=71.04$, $p<.001$: those with AN, BN, and purging disorder were most likely to answer the question (5.0–5.3% completion) versus other groups (4.3–4.6% completion). Table 2 shows differences by gender, $\chi^2(2, N=337,097)=318.15$, $p<.001$, and age, $\chi^2(2, N=342,878)=830.11$, $p<.001$: respondents of other genders and respondents aged ≤17 years were most likely to answer. Completion significantly differed across race, $\chi 2(1,$

N=339,631)=13.83, $p<.001$, and ethnicity, $\chi 2(1, N=340,329)=45.72$, $p<.001$, with respondents of other races and Hispanic respondents most likely to complete.

Of those who completed the help-seeking intention question, 10.3% reported they would definitely seek help, 23.4% probably, 40.8% probably not, and 25.5% definitely not. As Tables 1 and 2 show, intentions differed across ED diagnostic/risk, $\chi^2(6, N=16,396)=198.69$, $p<.001$, gender, $\chi^2(2, N=16,144)=7.85$, $p=.020$, and age, $\chi^2(2, N=16,396)=747.59$, $p<.001$, groups. Groups most likely to report they would definitely/probably seek help were those with clinical/subclinical BED versus other diagnoses; females and individuals of other genders versus males; and respondents aged 35+ years, with those ≤17 being least likely. No significant difference in help-seeking intention emerged across race, $\chi^2(1, N=16,413)=2.40$, $p=.122$. However, Hispanic respondents (35.8%) were more likely to report they would seek help versus non-Hispanic respondents (33.4%), $\chi^2(1, N=16,330)=4.66$, $p=.031$.

Regarding type of professional help respondents planned to seek, $n=6,264$ provided data, with 49.5% of those reporting they would make an appointment with a mental health professional, 30.1% would make an appointment with a medical doctor, 16.7% would sign up for an online/mobile program, 13.2% would attend a support group, 10.2% would contact the NEDA Helpline, and 17.2% other.

Help-Seeking Behaviors at Two-Month Follow-up

Only 7.6% ($n=26,094$) of eligible respondents opted in to the 2-month follow-up survey, with 10.6% ($n=2,765$) of those completing it.

Reactions to receiving a referral after screening (assessed at follow-up).— Most (68.2%) correctly remembered receiving a referral, 27.5% did not remember, and 4.2% misremembered (reporting results indicated they were not at risk). Among those who correctly remembered receiving a referral, the majority (60.2%) agreed with the feedback. In response to the referral, 35.0% endorsed feeling validated, 32.0% nervous, 27.0% ashamed, 21.4% sad, 12.1% indifferent, 7.0% surprised, 5.4% annoyed, 3.7% angry, 2.9% proud, 2.5% happy, and 5.1% other.

Reasons for seeking treatment (assessed at follow-up).—Seventy percent believed they had a significant eating problem when they took the screen. The majority of follow-up survey respondents (61.6%) reported wanting help for an eating problem in the past two months, and 25.1% of survey respondents sought treatment. The primary reason for seeking treatment was emotional distress (25.2%), concern with eating (17.3%), concern with weight (16.3%), health concerns (10.8%), encouragement of friends (8.2%), referral from the NEDA screen (7.5%), initiated by parents (7.3%), and other (4.3%).

Health care utilization.—Among follow-up survey respondents who endorsed seeking treatment ($n=694$), 67.4% made an appointment with a mental health professional, 47.0% made an appointment with a medical doctor, 8.5% attended a support group, 5.0% contacted the NEDA Helpline for treatment referrals, 4.2% signed up for the recommended online/mobile program, and 12.0% endorsed other forms of treatment. Overall, 8.9% of

respondents (n=233) reported they already were in treatment at the time of screening, 15.5% (n=404) initiated treatment since screening, and 75.5% (n=1,968) did not initiate treatment since screening/were not already in treatment. Of those who initiated treatment since taking the screen (n=404), 70.0% reported receiving outpatient therapy, 31.7% self-help (e.g., book), 30.9% psychiatric medication treatment, 13.4% partial hospitalization or intensive outpatient treatment, 9.9% inpatient treatment, 9.7% online/mobile program, and 5.0% residential treatment.

Discussion

This study presented the help-seeking intentions of respondents who screened positive or at high risk for an ED following completion of a widely-available online screen for EDs, as well as the help-seeking behaviors of those who participated in a 2-month follow-up survey. First, only a small minority of eligible respondents completed the optional help-seeking intention question directly following the screen (4.8%), and of those, only one-third intended to seek help. Because those interested in seeking help may have been more likely to provide data, results may overestimate help-seeking intentions of the overall population; indeed, those who provided data on help-seeking differed in meaningful ways from non-responders. Nevertheless, those screening positive for BED were most likely to endorse help-seeking intentions. Other work found individuals with binge-type EDs sought treatment more often than other EDs (Cachelin, Rebeck, Veisel, & Striegel-Moore, 2001). Help-seeking intentions also differed across genders and age groups. Previous research has shown women are more likely to seek treatment than men, and positive associations between age and treatment-seeking (Bohrer, Carroll, Forbush, & Chen, 2017; Fatt et al., 2019). However, other work has not found gender to be a primary predictor of help-seeking (Thapliyal, Mitchison, Mond, & Hay, 2019), suggesting the need for additional research. No differences in help-seeking intention emerged across racial groups, but Hispanic respondents reported greater intention. Prior work did not find differences in treatment-seeking based on ethnicity (Cachelin et al., 2001), although we are unaware of other work on intentions. Finally, of those intending to seek help, most were interested in traditional forms of treatment, rather than, for example, contacting the NEDA Helpline or initiating an online/mobile program.

Second, few respondents opted in to the 2-month follow-up, of whom only 10.6% completed it. The majority remembered receiving a referral, suggesting value to providing referrals following screen completion. The most common reactions were feeling validated, nervous, ashamed, and sad, similar to prior work among college students screening positive for AN (Fitzsimmons-Craft et al., 2019b). Because stigma, shame, and denial of illness severity are the most common barriers to help-seeking for EDs (Ali et al., 2017), screen feedback/referrals might be modified to address this.

Third, only 15.5% of respondents reported initiating treatment at 2-month follow-up. Prior work found that 26.2% of college students screening positive for AN initiated treatment over nine months (Fitzsimmons-Craft et al., 2019b), and 28% of college students screening positive for binge-type EDs and referred to on-campus care sought treatment over two years (Fitzsimmons-Craft et al., under review). Current study rates were thus lower, but reported over a shorter time-frame. The most common reasons for seeking treatment were emotional

distress and eating concerns, and the most common next steps respondents took were making an appointment with a mental health professional or medical doctor, again highlighting traditional intervention approaches.

Study strengths included partnering with the leading U.S. EDs non-profit organization to disseminate a screen, completed by 350,000+ respondents in 18 months. To our knowledge, this is also the first examination of help-seeking behaviors following a publicly-available online ED screen. However, findings should be interpreted in light of limitations. Few eligible respondents provided data, with notable differences between those who completed the help-seeking intention question versus those who did not. It is not known how individuals who completed the follow-up survey differed from those who agreed to but did not actually complete it, or from the larger sample. We did not collect data on individuals who may have been in treatment when they took the screen and who subsequently dropped out prior to the follow-up, did not assess atypical AN, and used a screen validated in college-age women. Future work will need to validate this screen in other gender and age groups. The screen and follow-up responses were not linked, precluding predictive modeling; future work should examine predictors of follow-up completion and treatment uptake.

Overall, our preliminary data suggest that among the small minority assessed for help-seeking, only about one-third expressed help-seeking intentions and 16% initiated treatment following screen completion. Further, relatively few expressed interest in digital options, which offer immediate intervention in a scalable format. Mass online screening should consider ways to increase respondents' motivation for treatment and follow-through with recommendations. Future research may also provide more education about digital intervention options to facilitate greater acceptance and uptake.

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Appendix 1

Help-seeking intention optional questions presented after the screen

Do you intend to seek professional help and/or take any steps to address these concerns?

- Definitely
- Probably
- Probably not
- Definitely not

What kind of professional help do you plan to seek? (select all that apply)

- Contact the NEDA Helpline for treatment referrals
- Make an appointment with a mental health professional
- Make an appointment with a medical doctor

- Sign up for an online/mobile program
- Attend a support group
- Other

2-month follow-up survey

What recommendation did you receive after completing the screening tool?

- My results did not indicate I was at risk for an ED
- I was given a recommendation to seek further evaluation and/or treatment for eating and/or body image concerns
- I don’t remember

[If respondents endorsed receiving a referral] Did you agree with the feedback provided?

- Yes
- No
- Not sure

[If respondents endorsed receiving a referral] What was your reaction to receiving this referral? (select all that apply)

- Surprised
- Happy
- Proud
- Validated
- Annoyed
- Angry
- Sad
- Nervous
- Ashamed
- Indifferent
- Other

At the time you took the NEDA screening tool, did you believe you had a significant eating problem?

- Yes
- No

Since that time, do you believe you have had a significant eating problem?

- Yes

- No

In the past two months, have you wanted help for an eating problem?

- Yes
- No

In the past two months, have you sought treatment from a physician, counselor, or other health care provider for an eating disorder or associated weight problem?

- Yes
- No
- Was already receiving treatment at the time I took the screen

[If respondents endorsed seeking treatment] What made you decide to seek treatment?

Referral from the NEDA screening tool

- Concern with weight
- Encouragement of friends
- Concern with eating
- Initiated by parents
- Emotional distress
- Health concerns
- Other

[If respondents endorsed seeking treatment] What steps did you take to seek professional help? (select all that apply)

- Contacted the NEDA Helpline for treatment referrals
- Made an appointment with a mental health professional
- Made an appointment with a medical doctor
- Signed up for the recommended online/mobile program
- Attended a support group
- Other

[If respondents endorsed seeking treatment] “Have you actually received treatment for eating problems in the last two months?

- Yes
- No

[If yes] What type? (select all that apply)

- Outpatient therapy

- Inpatient treatment
- Partial hospitalization or intensive outpatient treatment
- Residential treatment
- Psychiatric medication treatment
- Online/mobile program
- Self-help (e.g., book)

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Table 1.

Comparison of answering help-seeking intention question and endorsing help-seeking intentions across eating disorder diagnostic/risk status groups

	AN	BN	BED	PD	ARFID	Other ED	At risk	Significance	Pairwise comparisons[a]
Answered help-seeking intention question	1466 (5.3%)	6240 (5.0%)	1364 (4.4%)	280 (5.0%)	784 (4.6%)	4890 (4.6%)	1372 (4.3%)	$\chi^2(6, N=343,072)=71.04$, $p<.001$	AN, BN>BED, ARFID, other ED, at risk; PD>BED, at risk; Other ED>at risk
Endorsed they would definitely or probably seek help	427 (29.1%)	2061 (33.0%)	688 (50.4%)	85 (30.4%)	261 (33.3%)	1601 (32.7%)	409 (29.8%)	$\chi^2(6, N=16,396)=198.69$, $p<.001$	AN<BN, BED, ARFID, other ED; BN>at risk; BED>BN, PD, ARFID, other ED, at risk; Other ED>at risk

Note. AN = anorexia nervosa group. BN = clinical/subclinical bulimia nervosa group. BED = clinical/subclinical binge-eating disorder group. PD = purging disorder group. ARFID = avoidant/restrictive food intake disorder group. Other ED = other eating disorder group (unspecified feeding or eating disorder or likely eating disorder with missing height/weight). At risk = at risk for an ED group.

Percentages represent proportion of that group (e.g., AN) that either answered the help-seeking intention question or endorsed they would definitely or probably seek help. Pairwise comparisons listed were significant at least at $p<.05$.

[a]For follow-up analyses, clinical and subclinical presentations of BN and BED were collapsed, and UFED and likely eating disorder with missing height/weight groups were collapsed, to decrease the number of groups/pairwise comparisons and subsequently increase interpretability.

Table 2.

Comparison of answering help-seeking intention question and endorsing help-seeking intentions across gender and age groups

	Females	**Males**	**Other (includes non-binary/ third gender and those preferring to self-describe)**	**Significance**	**Pairwise comparisons**
Answered help-seeking intention question	14,171 (4.7%)	1038 (4.8%)	935 (8.3%)	$\chi^2(2, N=337,097)=318.15$, $p<.001$	Other>females, males
Endorsed they would definitely or probably seek help	4807 (33.9%)	321 (30.9%)	345 (36.9%)	$\chi^2(2, N=16,144)=7.85$, $p=.020$	Females>males; Other>males
	Age 17 or younger	**Age 18–34**	**Age 35 or older**	**Significance**	**Pairwise comparisons**
Answered help-seeking intention question	7379 (6.0%)	6770 (3.8%)	2247 (5.5%)	$\chi^2(2, N=342,878)=830.11$, $p<.001$	Age 17 or younger>age 18–34, age 35 or older; Age 35 or older>age 18–34
Endorsed they would definitely or probably seek help	1751 (23.7%)	2604 (38.5%)	1177 (52.4%)	$\chi^2(2, N=16,396)=747.59$, $p<.001$	Age 18–34>age 17 or younger; Age 35 or older>age 17 or younger, age 18–34

Note. Percentages represent proportion of that group (e.g., females) that either answered the help-seeking intention question or endorsed they would definitely or probably seek help. Pairwise comparisons listed were significant at least at $p<.05$.