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ABSTRACT

The study aimed to document the impact of the COVID-19 pandemic on the health and well-being of individuals with past and current eating disorders (ED) in Sweden. We re-contacted participants with a known lifetime history of ED from two previous Swedish studies. Participants completed an online survey about health and functioning at baseline early in the pandemic (Wave 1 ca May/June 2020; N= 982) and six months later (Wave 2 Dec/Jan 2020/21; N= 646). Three important patterns emerged: 1) higher current ED symptoms were associated with greater anxiety, worry, and pandemic-related ED symptom increase; 2) patterns were fairly stable across time, although a concerning percentage (23%) who were symptom-free at Wave 1 reported the re-emergence of symptoms at Wave 2; and 3) only a minority of participants (<50%) with a current ED were in treatment, and of those in treatment, many reported fewer treatment sessions and decreased quality of care. The COVID-19 pandemic appears to pose serious health challenges for individuals with an ED, whether currently symptomatic or in remission. We encourage health service providers and patient advocates to be alert to the needs of individuals with ED and to take active measures to ensure access to appropriate evidence-based care both during and following the pandemic.

Clinical implications

- Higher eating disorder symptom status was linked to higher pandemic-related impact
- Especially salient were higher levels of worry, anxiety, and eating disorder symptoms
- A quarter of symptom-free individuals reported re-emergence of symptoms at 6 months

- Only a minority with current eating disorders were in treatment
- Many reported fewer treatment sessions than pre-pandemic and decreased care quality

Introduction

Coronavirus disease 2019 (COVID-19), an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was declared a pandemic in March 2020 by the World Health Organization. In response, countries across the globe implemented varyingly strict measures to limit the spread of the virus, balancing the impact of public health measures on social isolation, disruption of daily routines, and economic factors. Besides the direct and often prolonged impact of COVID-19 on physical and mental health (Butler et al., 2020; Carfì et al., 2020) pandemic-related restrictions have also adversely affected mental health in the general population (The Lancet Psychiatry, 2020; Xiong et al., 2020), and may worsen the symptoms in individuals with pre-existing psychiatric illnesses (Gobbi et al., 2020; Hao et al., 2020). We surveyed a large sample of individuals with eating disorders (ED) in Sweden at two time points: Wave 1 (May/June 2020) and Wave 2 (Dec/Jan 2020/2021). This was done to document the impact of the pandemic and public health measures taken to limit its transmission to individuals with EDs.

Several studies emerged early in the pandemic suggesting the adverse impact of the pandemic and mitigation measures on individuals with ED. Reports included changes in eating, exercise, and sleep patterns due to imposed societal constraints, increased weight and shape concerns, exposure to triggering environments (e.g., having to spend more time in close quarters with family or roommates), and social support, stability, and predictability regarding daily routines and a regular meal structure (Castellini et al., 2020; Schlegl et al., 2020; Vuillier et al., 2021), factors that have been suggested as important to prevent symptom outbreaks and maintain treatment gains (Geller et al., 2017; Lindstedt et al., 2015). Individuals surveyed also reported increases in ED symptoms, anxiety, and stress as a result of the pandemic (Chan & Chiu, 2021; Termorshuizen et al., 2020). In addition, clinical services were disrupted in many countries due to social distancing policies as well as quarantine of infected patients and care providers. Access to care was disrupted and initially, virtual care was rated as less satisfactory than typical face-to-face treatment (Termorshuizen et al., 2020; Weissman et al., 2020), although others suggest virtual treatment can be effective for some patients at certain stages of their illness (Shaw et al., 2021; Stewart et al., 2021). Evidence of exacerbation of ED symptoms in individuals with an ED during the COVID-19 pandemic, including increased restricting, binge eating, and

exercise behaviors, was documented in studies from Spain (Fernández-Aranda et al., 2020), Australia (Phillipou et al., 2020), Germany (Giel et al., 2021; Schlegl et al., 2020), the United States and the Netherlands (Termorshuizen et al., 2020). Worsening of ED symptoms was shown to be associated with low self-directedness, difficulties in emotion regulation, and intolerance of uncertainty (Baenas et al., 2020; Machado et al., 2020; Scharmer et al., 2020). Furthermore, patients with ED may have high-stress vulnerability when lockdown restrictions are lifted, and they are re-exposed to social life. A study in Italy before, during, and after the end of lockdown showed that exacerbation of general psychopathology in ED patients seen during lockdown may persist during the re-opening period (Monteleone et al., 2021).

Sweden's pandemic response was different from many other countries, with no lockdowns and a focus on slowing rather than stopping the spread of disease (Ludvigsson, 2020). Social distancing was recommended in public places, as well as working from home and limiting the number of social interactions outside one's household. Visits to nursing homes were banned, physical distancing at restaurants, bars, and events was enforced by restricting opening hours and the number of customers, while universities and schools for older children (>16 years) closed at least temporarily (Ludvigsson, 2020). Pre-schools and schools for younger children remained open. ED treatment units remained open, only transitioning to telehealth with patients where it was deemed appropriate. This less restrictive approach may have resulted in fewer, or different, negative effects for individuals with current or past EDs, compared to countries with a more restrictive approach. Moreover, Sweden has universal health care with free or low-cost, heavily subsidized treatment, and limited poverty. Therefore, temporary or permanent work layoffs had little impact on people's ability to engage in treatment or afford food required by, e.g.,, their treatment plan.

Aims of the study

Analysis of Sweden-specific data is valuable since the country has had a unique response to COVID-19 public health management (Baral et al., 2021; Ludvigsson, 2020). Our primary aim was to field an investigation to characterize the experiences of individuals with a current or past ED in Sweden during the COVID-19 pandemic using a longitudinal design with assessments at baseline early during the pandemic (Wave 1) and after 6 months (Wave 2). Pandemic-related restrictions were similar at both time points, but there were more people in intensive care units and more people dying from COVID-19 when Wave 2 data were collected (https://www.folkhalsomyndigheten.se). We examined descriptive statistics regarding illness status, ED symptoms, anxiety,

treatment availability, and COVID-19-related concerns over time. We also investigated baseline variables that were associated with deterioration or improvement of illness status over time.

Material and methods

Participants and procedure

We contacted all participants from two previous large-scale ED studies in Sweden, the Anorexia Nervosa Genetics Initiative (ANGI) (Thornton et al., 2018) and the Binge Eating Genetics Initiative-Sweden (BEGIN-SE), who had given permission to be recontacted for future research. All participants had lifetime history of an ED (and many had current ED; see Results). Although all ED presentations were included, the majority of participants had anorexia nervosa (AN), given the nature of the parent ANGI study. Although all participants had verified diagnoses from the parent studies, for the purposes of this study, we used self-reported diagnosis and self-reported symptom status. We sent 3,774 emails on May 27th (170 emails were undeliverable) and when we froze the first-wave of data collection after 6 weeks at which point 982 individuals had responded (27%). The second wave, sent only to those who had completed the Wave 1 survey, was administered between December 22nd 2020 and February 2nd 2021, and 646 responded (66% of Wave 1). No additional inclusion/exclusion criteria were applied. The study methodology was approved by the Swedish Ethical Review Authority (Dnr 2020–04136).

Survey

The survey (see Supplement 1) was modelled after a similar survey used in the United States and the Netherlands, developed in collaboration across the countries for this project, to rapidly study the impact of the pandemic on individuals with EDs (Termorshuizen et al., 2020), that queried physical and mental well-being related to COVID-19 in the previous 2 weeks. Experienced ED was queried using check boxes and allowing multiple diagnoses, and to describe the sample in the present study we used the following trumping order: AN, bulimia nervosa, binge-eating disorder, and other specified feeding and eating disorder. Participants provided data on age, sex, gender identity, diagnostic and treatment status, exposure to COVID-19, and current situational circumstances (e.g., quarantined and physical distancing). A Likert scale was used to measure the level of concern about changes in ED symptoms, frequency of symptoms, and worry related to COVID-19. The 7-item version of the Generalised Anxiety Disorder Scale (GAD-7) (Spitzer et al., 2006) assessed anxiety, with Cronbach's
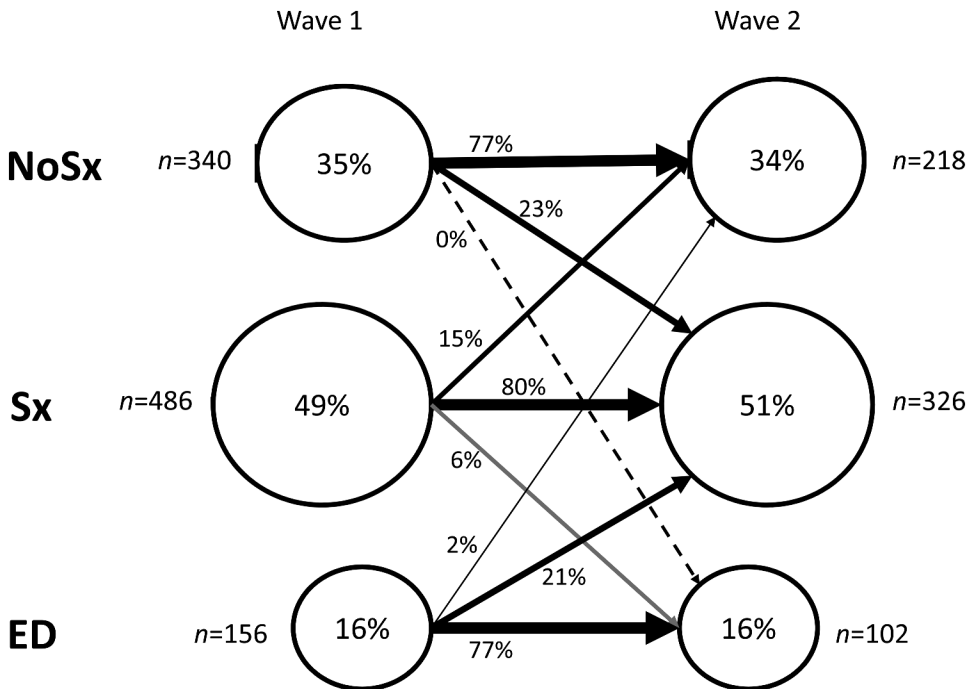
Figure 1. Distribution (*n*, %) of participants into self-reported symptom-level groups at each measurement wave, where **NoSx** = previous ED but no current symptoms, **Sx** = previous ED and remaining symptoms, and **ED** = current ED. Circle sizes approximate group size, and migration between groups (arrows) is displayed with percentage of starting group moving to another.

alpha of .91 at Wave 1 and .92 at Wave 2. In the interests of clinical relevance and ease of communication, we applied the ≥10 cut-off to identify unlikely (<10) or likely (≥10) diagnosable generalised anxiety disorder (Spitzer et al., 2006) to categorize participants. Free-text items invited participants to share additional comments (qualitative analyses not presented here).

Statistical analysis

We defined three subgroups according to self-reported symptom status, with the question "Which of the following statements best describes your experience?" and response options "I have previously had an ED but am currently free of symptoms" (**NoSx**), "I have previously had an ED and still experience some symptoms" (**Sx**), and "I currently have an ED" (**ED**). Statistics for each wave are based on the symptom grouping reported at that timepoint, whereas longitudinal analyses (migration) are based on Wave 1 groupings. Distribution at both time points and migration across symptom groups over time are shown in Figure 1.

We examined variable distributions in each symptom status group and time point. For GAD-7, we used χ^2, Cramer's V (with effect size conventions $\geq.10$ = small, $\geq.30$ = medium, and $\geq.50$ = large), and standardized residuals (where absolute value ≥ 2 suggests a significant difference) to evaluate omnibus and pairwise differences, respectively. For the other survey items, we used χ^2 (see Supplemental Table S1 for χ^2 and p) and Bonferroni-corrected post hoc z-tests. Furthermore, we tested baseline predictors of symptom deterioration or improvement using Welch's t-tests (due to imbalanced design) and Cohen's d effect sizes, by comparing those who changed group over time with baseline group peers who did not change. Three contrasts were made possible based on statistical power: one symptom status deterioration (**NoSx➜NoSx** vs. **NoSx➜Sx**) and two comparisons marked by symptom improvement (**Sx➜Sx** vs. **Sx➜NoSx** and **ED➜ED** vs. **ED➜Sx**). That is, we did not combine all who improved or deteriorated, respectively, since their differing starting points would have risked concealing important effects.

Attrition analyses compared Wave 2 responders with those who responded only at Wave 1 to investigate representativeness of the longitudinal subsample, on anxiety, worry about symptom increase, and ED symptoms. We selected baseline anxiety level (GAD-7, *anx_covid, anx_2019*; see Supplement) and variables that captured ED symptoms and concerns about factors that might increase ED symptoms (items *ed_exp, concern*, and *ICB*; see Supplement).

Results

Sample characteristics and distribution of ED symptom groups

The sample consisted of 98% biological females, and gender identity distribution was 97% female, 2% male, and 1% non-binary or other, and mean age was 32.1 (SD = 8.73; range 18–77). Self-reported previous or current ED diagnosis distribution was as follows (participants could mark several response alternatives): AN 64%; bulimia nervosa (BN) 37%; binge-eating disorder (BED) 24%; and other specified feeding and eating disorder (OSFED) 45%; with 12%

Table 1. COVID-19 exposure and preventive measures; % "Yes" responses. See supplement for full questionnaire.

Item	Wave 1 n (%)	Wave 2 n (%)
Practicing social distancing	749 (77%)	556 (87%)
Forced isolation	10 (1%)	3 (1%)
Work/study from home	457 (47%)	341 (53%)
Ordered home stay	51 (5%)	37 (6%)
Tested positive for COVID-19	17 (2%)	56 (9%)
Clinical COVID-19 diagnosis	6 (1%)	4 (1%)
Have not had COVID-19	618 (63%)	443 (69%)
Maybe had COVID-19 but not sure	336 (34%)	139 (22%)

Table 2. Proportions of each response option regarding self-reported anxiety at each time point, by symptom group. See supplement for items.

Item	Group	"No change"		"Increased"		"Decreased"	
		Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2
Anxiety level changed since the end of 2019?							
	NoSx	48%	43%	34%	41%	17%	17%
	Sx	35%	29%	51%	54%	14%	17%
	ED	33%	20%	58%	67%	10%	14%

NoSx = No ED symptoms; Sx = Some remaining symptoms; ED = Current eating disorder

other; and 1% responding "Don't know/prefer not to answer." Table 1 shows descriptive statistics for COVID-19-related exposure and preventive measures at Wave 1 and Wave 2. No significant differences emerged between individuals who responded to both waves of data collection and those who responded to Wave 1 only on any tested baseline variables.

Figure 1 shows the distribution of the symptom groups **NoSx, Sx**, and **ED** at each time point. Thirty-four percent had no ED symptoms, 49%/51% (at the respective waves) had lingering symptoms, and 16% reported a current active ED at each time point. Although the percentages at each time point were very similar, migration did occur. A full 23% of the individuals transitioned from **NoSx** at Wave 1 to **Sx** at Wave 2 (i.e., deterioration); 15% of the individuals with **Sx** at baseline reported **NoSx** at Wave 2 (i.e., improvement); and 21% of the individuals with **ED** at Wave 1 reported **Sx** at Wave 2 (i.e., improvement). Most individuals, however, remained in the same symptom category across time; **NoSx** = 77%, **Sx** = 80%, and **ED** = 77% (see Figure 1).
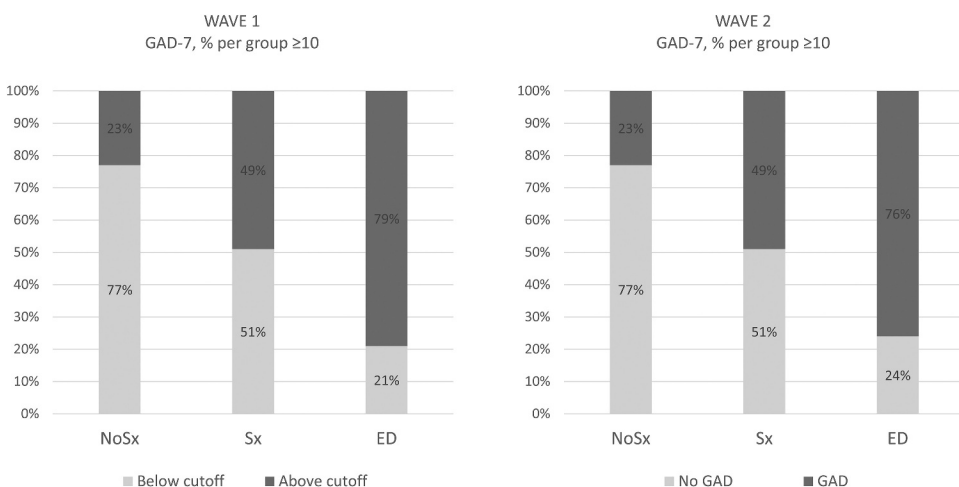

Figure 2. Proportion of individuals scoring above/below the GAD-7 cut-off (≥10) at each time wave, separated by ED status group.

Table 3. Worry about impact of COVID-19 by symptom group and measurement wave for items related to concern about factors leading to increased ED symptoms, ED symptoms themselves, and worry about the impact of COVID-19 on others and own health. See supplement for items.

Variable	Response options shown	Symptom group	Wave 1	Wave 2
concern_3: Worry that ED symptoms increase due to lack of structure	Per cent responding "Somewhat concerned" to "Very concerned"	NoSx	10% [a]	7% [a]
		Sx	33% [b]	31% [b]
		ED	56% [c]	61% [c]
concern_4: Worry that ED symptoms increase due to lack of social support		NoSx	3% [a]	4% [a]
		Sx	20% [b]	19% [b]
		ED	51% [c]	48% [c]
concern_5: Worry that ED symptoms increase due to being in a triggering environment		NoSx	9% [a]	6% [a]
		Sx	32% [b]	32% [b]
		ED	56% [c]	53% [c]
ICB_1: Binge eating bunkered food	Per cent responding "Frequently" to "Daily or more"	NoSx	1% [a]	1% [a]
		Sx	8% [b]	7% [b]
		ED	24% [c]	23% [c]
ICB_2: Restricted food intake due to COVID-19-related factors		NoSx	5% [a]	2% [a]
		Sx	14% [b]	11% [b]
		ED	27% [c]	24% [c]
ICB_3: Compensated for food intake food intake due to COVID-19-related factors		NoSx	1% [a]	1% [a]
		Sx	9% [b]	8% [b]
		ED	26% [c]	28% [c]
ICB_4: Worried about not being able to exercise		NoSx	17% [a]	18% [a]
		Sx	36% [b]	37% [b]
		ED	39% [c]	46% [c]
covid_worry_1: Worry about self being infected	Per cent responding "Somewhat worried" to "Very worried"	NoSx	23% [a]	39% [a]
		Sx	28% [a]	38% [a]
		ED	32% [a]	40% [a]
covid_worry_2: Worry about others being infected		NoSx	79% [a]	79% [a]
		Sx	78% [a]	84% [a]
		ED	80% [a]	86% [a]
covid_worry_3: Worry about physical health being affected		NoSx	28% [a]	39% [a]
		Sx	37% [b]	50% [b]
		ED	45% [b]	54% [b]
covid_worry_4: Worry about mental health being affected		NoSx	42% [a]	50% [a]
		Sx	59% [b]	65% [b]
		ED	65% [b]	73% [b]

NoSx = No ED symptoms; Sx = Some remaining symptoms; ED = Current eating disorder.
Proportions with different superscripts within each time point and item are significantly different at Bonferroni-corrected $p < .05$, i.e., symptom status groups differ significantly for those items.

Anxiety and ED symptom variables by symptom status group

Table 2 presents responses to questions regarding whether their anxiety had increased since the end of 2019. In all three symptom groups, a higher proportion of individuals indicated that this was true at Time 2 than at Time 1. In most cases across symptom groups and both waves, participants were more likely to attribute their increases in anxiety to COVID-19 (data not shown).

GAD-7 was strongly associated with symptom group, and patterns were similar across waves , see Figure 2. At Wave 1 and Wave 2, 23% of the **NoSx** group, 49%/51% of the **Sx** group, and 79%/76% of the **ED** group scored above the cutoff for GAD-7. At each time point, symptom status group was significantly associated with GAD-7 group (above/below cutoff); Time 1 $\chi^2 = 139.55$, $p < .001$, Cramer's $V = .38$, Time 2 $\chi^2 = 84.65$, $p < .001$, $V = .36$. Within NoSx and

ED but not Sx at each time point, proportions were also significantly different, as attested to by standardized residuals for GAD≥10: T1 NoSx = −5.9, Sx = 1.3, ED = 6.3; T2 NoSx = −4.8, Sx = 1.3, ED = 4.7.

Table 3 shows that concern about ED symptom increase due to the pandemic [1] was strongly related to symptom status group (see Supplemental Table S1 for omnibus χ^2 and *p*-values). Participants in **ED** were more significantly concerned about increased symptoms due to lack of structure and social support, and being exposed to triggering environments, than **Sx**, who in turn were more concerned than **NoSx**. Patterns were similar across waves. Table 3 further shows that more participants reported being worried about others being infected by COVID-19 than themselves, and increased ED symptom level status **Sx** or **ED** was associated with higher worry than **NoSx**. Further, participants were descriptively much more worried about their mental health being affected by COVID-19 than their physical health.

A similar pattern emerged with ED symptoms, with significantly higher symptoms of binge eating, restrictive eating, and compensatory behaviours the more severe the ED symptom status. Concern about not being able to exercise was similar in both **ED** and **Sx**. Patterns were similar across the waves.

Treatment

Table 4 presents treatment-related results. Most notably, a majority (58% and 51% at Waves 1 and 2, respectively) reported not being in the current ED treatment; 40% had had fewer sessions in the last 2 weeks, and 40% (Wave 1) and 46% (Wave 2) experienced their treatment quality as worse or much worse than before the pandemic. On the other hand, 27%/28% (representing around half of those in treatment; 47% and 55%, respectively) still had face-to-face sessions, and 60%/54% reported their treatment being as good or better than before the pandemic.

Table 4. Experiences of treatment. See supplement for items.

Item								
	"F2F sessions"		"Transitioned to virtual"		"No sessions"		"Not in treatment"	
Presence and format of treatment	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2
	27%	28%	10%	9%	7%	13%	58%	51%
	"Fewer sessions"		"As many sessions"		"More sessions"			
Change in session frequency	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2		
	40%	41%	53%	54%	7%	5%		
	"Better"		"As good"		"A little worse"		"Much worse	
Change in ED treatment quality	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2
	4%	5%	56%	49%	29%	30%	11%	16%

F2F = Face to face; ED = eating disorder. Responses regarding treatment were reported for the ED group only (Wave 1*n*= 156, Wave 2*n*= 102). Responses regarding change in session frequency and treatment quality were asked only to those who responded to have had face-to-face or virtual sessions in the past two weeks (Wave 1n = 55, Wave 2n = 37).

Table 5. Descriptive statistics, Welch's t-tests, and Cohen's d effect sizes of the three migration analyses using baseline variables; Stable *NoSx* vs. *NoSx*→*Sx* (n = 168 vs. 51), Stable *Sx* vs. *Sx*→*NoSx* (n = 252 vs. 45), and Stable *ED* vs. *ED*→*Sx* (n = 84 vs. 23). See Supplementary 1 for item wording.

Compared groups	GAD-7	Worry about mental health being affected	Concern about lack of structure	Concern about lack of social support	Concern about triggering environment	Binge eating	Restrictive eating	Compensatory symptoms (e.g., vomiting)	Worry about no exercise
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Stable NoSx	6.0 (4.24)	1.7 (.78)	1.4 (.68)	1.2 (.42)	1.3 (.58)	1.1(.27)	1.2 (.52)	1.1 (.30)	1.6 (.83)
vs.	***, ††		*; †	*; †	**; ††				**; ††
NoSx →Sx	9.2 (5.60)	1.8 (.67)	1.7 (.88)	1.4 (.64)	1.8 (1.02)	1.2(.43)	1.3 (.68)	1.1 (.35)	2.1 (1.04)
Stable Sx	10.2 (5.43)	1.8 (.68)	2.2 (.97)	1.8 (.96)	2.1 (1.02)	1.4 (.64)	1.5 (.76)	1.4 (.65)	2.1 (1.09)
vs.			**; †	**; †	*; †			*; †	
Sx →NoSx	9.4 (5.62)	1.8 (.64)	1.8 (.84)	1.4 (.69)	1.7 (.92)	1.3 (.64)	1.5 (.76)	1.2 (.46)	2.0 (1.02)
Stable ED	14.5 (4.95)	1.8 (.58)	2.7 (1.13)	2.6 (1.13)	2.6 (1.07)	1.6 (.94)	1.7 (.94)	1.7 (.96)	2.1 (1.11)
vs.	*; ††								
ED →Sx	11.6 (4.98)	1.6 (.66)	2.6 (1.23)	2.4 (1.11)	3.0 (1.07)	2.0 (1.04)	1.5 (.73)	1.7 (.94)	2.3 (1.02)

* $p < .05$; ** $p < .01$; *** $p < .001$. † $d \geq .20$ (small effect); †† $d \geq .50$ (medium effect). These symbols appear in rows between cells containing significantly different means in each of the tested migration group pairs. If no symbol appears, there was no significant difference.

NoSx = No ED symptoms; Sx = Some remaining symptoms; ED = Current eating disorder; GAD-7 = Generalised anxiety disorder 7-item scale; ICB = name of the ED symptom items.

Migration between symptom status groups

We explored predictors of change in symptom status between Wave 1 and Wave 2 (Table 5): one analysis investigated factors associated with deterioration and two analyses related to improvement. Those individuals who transitioned from **NoSx** to **Sx** (23% of Wave 1 **NoSx** in Figure 1; compared to those who stayed in **NoSx**) had significantly higher Wave 1 mean GAD-7 scores, greater concern about being in a triggering environment, and higher worry about not being able to exercise, with medium effect sizes. They also had significantly higher concern about lack of structure and social support, but with small effect sizes. Individuals who transitioned from **Sx** at Wave 1 to **No Sx** at Wave 2 (15% of Wave 1 **Sx** in Figure 1; compared to those who stayed in **Sx**) had lower scores on concerns about lack of structure, social support, and being in a triggering environment and lower scores on compensatory behaviours, with small-to-medium effects. Individuals who moved from **ED** at Wave 1 to **Sx** at Wave 2 (21% of Wave 1 **ED** in Figure 1; compared to those who stayed in **ED**) had lower baseline GAD-7 scores.

Discussion

The present study investigated the experiences of a Swedish sample with a current or past ED early during the COVID-19 pandemic and six months later. Using a survey developed in collaboration with researchers in the USA and the Netherlands (Termorshuizen et al., 2020), we identified three important patterns. First, more severe ED symptom status was associated with greater anxiety, worry, and ED symptom increase. Second, the results were fairly stable across time, with some exceptions. Third, and quite concerningly, only a minority of participants with current ED were in treatment, and of those who were in treatment, many reported fewer treatment sessions than usual as well as decreased quality of care.

Overall, our results are in line with other findings that the COVID-19 pandemic appears to pose considerable challenges to ED patients (Branley-Bell & Talbot, 2020; Schlegl et al., 2020). Our results closely mirror those reported in the methodologically highly similar study from the US and the Netherlands (Termorshuizen et al., 2020), suggesting that despite considerable differences in the public health measures adopted by these three countries to limit transmission of COVID-19 (e.g., no lockdowns or closing of schools for children <16 years), the impact on individuals with EDs was comparable. In particular, our data suggest that people with a previous ED, those with enduring symptoms, or a current active disorder, are especially vulnerable to anxiety (a common co-morbid symptom in ED: e.g., (Fairweather-Schmidt & Wade, 2020; Ulfvebrand et al., 2015)), which may worsen due to healthcare disruptions and societal restrictions that have been

put in place to control COVID-19. GAD-7 results suggested that full three-quarters of individuals with active EDs were also likely to have generalised anxiety disorder. However, in the absence of pre-pandemic data, it was not possible to determine whether this is higher than would be expected; nonetheless, it reflects the importance of attending to anxiety in the treatment of individuals with EDs during the pandemic. Baseline anxiety, weaker social support and structure, as well as fears about not being able to exercise were all associated with exacerbated ED symptoms. To some extent, symptom improvement showed the opposite pattern, as it was associated with lower anxiety and higher ratings on social support and structure. Although we found relatively few relapses into full ED, a concerning number of individuals who initially reported being symptom-free reported the re-emergence of symptoms as the pandemic progressed.

Clinically, given the pervasive problems with relapse and achieving long-term recovery (Keel & Brown, 2010; Khalsa et al., 2017), coupled with the social anxiety and interpersonal problems associated with ED (Arcelus et al., 2013) our results suggest that it may be important for clinicians working with EDs during the pandemic to focus on helping patients to address anxiety, maintain daily structure and develop social connectedness to aid recovery. Even if patients have been transitioned to virtual care, it may be important to ensure that they receive adequate social support via families, peers, advocacy organizations, or even online forums to maintain accountability and motivation for recovery. There may also be a need to assess directly individuals' living arrangements. Given limitations on socializing and recommendations for physical distancing during the pandemic, individuals may find themselves with less freedom and flexibility to extricate themselves from unhelpful or even toxic environments that could potentially exacerbate ED symptoms. Caregivers should, therefore, remain vigilant for potentially triggering situations and be prepared to provide practical assistance when necessary.

Although our study provides important knowledge about how individuals with ED are coping with the pandemic in Sweden, it has several limitations, mainly due to our rapid deployment of the inventory in response to the pandemic. First, given our intention to field a survey soon after COVID-19 was declared a global pandemic, we rapidly translated and adapted a survey used in the US and the Netherlands. This precluded steps to ensure sound psychometric properties, except for the GAD-7, which is well tested and had high internal consistency. Second, we relied on a convenience sample (i.e., individuals who had participated in previous studies who agreed to be contacted for future research), which did not reflect the distribution of diagnoses to be expected from a community sample and may have biased results. Third, we relied on self-report diagnosis and symptom reports to characterize patients, we did not collect current weight status, nor did we query race/ethnicity (which is

not regarded as ethically acceptable in Sweden barring a clear aim related to these factors). Although all participants had formal diagnoses in the past, the use of self-reports to establish their current status remains a limitation. Fourth, our response rate to the initial survey was low (27%) and we experienced attrition between the waves, potentially introducing bias and limiting generalisability. Finally, we were underpowered for some analyses; group sizes were low for analysing transitions between symptom levels across time.

Nevertheless, we were able to capture fairly early in the pandemic how individuals in Sweden with ED were being affected, and our results provide valuable information for patients and families, clinicians, and advocacy groups about the needs of individuals with EDs in Sweden and have the potential to guide care strategies and resource planning during this and future pandemics. As anticipated, COVID-19 has been particularly challenging for those with existing active mental disorders, and even those who are currently symptom-free are challenged to remain healthy. As a recent editorial in the Lancet argued, "those who wish to build fairer societies and health systems after the pandemic ends must learn about and prioritise the needs of people living with severe mental illness as a matter of urgency" (The Lancet Psychiatry, 2020). We encourage ED practitioners and advocacy groups to discuss and develop effective resources for patients, families, and clinicians for mitigating the effects of COVID-19 during and following the pandemic. Given the high percentage of individuals with active EDs who reported not being in treatment in our study, along with the concerning number who initially reported being symptom-free but who subsequently reported the re-emergence of symptoms 6 months later, development of such resources is a matter of urgency.

Note

1. Some response options in this item ("concern," see Supplement 1) are not shown since scores were very low as the response options are relatively irrelevant for Swedish conditions; these related to concern about not being able to afford food or treatment, which is not an issue in Sweden at this point

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