

People's lived experience with an eating disorder during the COVID-19 pandemic: A joint virtual issue of research published in leading eating disorder journals

Abstract

The COVID-19 pandemic has profoundly disrupted people's daily life and contributed to adverse health and mental health outcomes. People with pre-existing mental health conditions are particularly likely to experience symptom exacerbation. Complementing the adverse impacts of the pandemic are eating disorder specific risk factors for worsening of eating disorder symptoms and/or impeding treatment progress and recovery. For this joint Virtual Issue, we selected 15 articles that have been published in two leading journals in the field of eating disorders (*International Journal of Eating Disorders* and *Journal of Eating Disorders*) to highlight studies that offer information about individuals' lived experience with an eating disorder during the COVID-19 pandemic. In these studies, most participants reported worsening of eating disorder symptoms which they attributed to challenges arising from changes in daily routines including eating and exercise related habits, increased stress, and diminished social contacts. These research findings reported a mixed picture about patients' perceptions of the ease of the transition to virtual delivery of treatment and the quality of care they received during the pandemic. Qualitative studies suggested strategies for supporting people with eating disorders during pandemic conditions, with some of these holding promise for improving care for individuals who experience an eating disorder.

KEYWORDS

COVID-19, eating disorder, health, lived experience, mental health treatment, treatment outcome

1 | INTRODUCTION

The 2019 novel coronavirus disease (COVID-19) pandemic has caused major disruptions to people's daily life and health status, including loss

of life and a wide range of other adverse changes in health and well-being. Studies of past major population-wide health crises found that pandemics raise people's level of stress, anxiety, and depression (Torales, O'Higgins, Castaldelli-Maia, & Ventriglio, 2020). Individuals with pre-existing mental disorders also have been found to be especially likely to experience a worsening of their mental health status (Wang et al., 2020) and to have an elevated risk for COVID-19 susceptibility, infection severity, and mortality (Liu et al., 2021; Vai et al., 2021).

Eating disorder experts have warned that pandemics such as COVID-19 may be particularly pernicious for people who are at risk for or have experience with an eating disorder (Rodgers et al., 2020; Touyz, Lacey, & Hay, 2020; Weissman, Bauer, & Thomas, 2020). Concerns about infection and economic security, and heightened interpersonal conflict due to being confined in limited living quarters with family or roommates, all may create stress that, in turn, increases risk for or exacerbates existing mental health problems including eating disorders. Moreover, social distancing policies and stay-at-home orders have forced an abrupt change in the delivery of clinical services such as in-person office visits or group therapy sessions. These adverse impacts are complemented by several eating disorder specific factors that exacerbate eating disorder symptoms and/or interfere with treatment and recovery.

The disruptions of daily activities due to lockdown requirements such as decreased opportunities for regular food shopping, social interactions, or physical activity, may worsen clinical symptoms such as dietary restriction or binge eating. Social distancing requirements or outright prohibitions of in-person interactions shifted many social interactions to video supported communications; for some, exposure to their own image may increase body image concerns ("Zoom effect"). There has been pervasive media coverage providing advice about curbing emotional eating or weight gain (Warren, 2020) or about suggestions regarding "looking good" when using visual media (Lasky, 2020). By disrupting typical modes of service delivery, the COVID-19 pandemic exacerbates the already pervasive problem of unmet treatment needs among individuals with an eating disorder, many of whom do not access care specifically focused on the eating disorder, or when they do seek such care, do not receive it (Hart, Granillo, Jorm, & Paxton, 2011; Weissman & Rosselli, 2017).

Global challenges such as the COVID-19 pandemic are best met with a unified approach to finding solutions. As a small step toward addressing the pandemic's impact on the communities our journals seek to serve, the authors decided to work together to highlight research

published in our journals. For this virtual issue, we selected 15 research publications from the *International Journal of Eating Disorders* and the *Journal of Eating Disorders* that provide data on the experiences of individuals with an eating disorder and those who care for them (e.g., family members, health care professionals) during the pandemic with focus on two overarching questions: How have symptoms changed during the pandemic? And how has the COVID-19 pandemic impacted access to or quality of care for the eating disorder? We consider each of these questions and conclude with recommendations for future studies. We note that some of these studies addressed additional questions or included comparison samples without eating disorders; therefore, we strongly encourage readers to access the full study reports which are available open access via the links provided in Table 1.

2 | CHANGES IN EATING DISORDER SYMPTOMS FOLLOWING THE COVID-19 OUTBREAK

COVID-19-related changes in eating disorder symptoms were examined either by (a) combining pre-COVID-19 patient data with newly collected (during the pandemic) data, or (b) collecting cross-sectional data during the pandemic and asking participants to report their perceptions about symptom changes since onset of the pandemic. We note parenthetically that because individuals

cannot be randomly assigned to COVID-19 exposure, conclusive causal attribution of symptom change to the pandemic is impossible.

2.1 | Studies comparing pre-pandemic data with newly collected data

Two studies recruited patients for comparisons of available pre-pandemic data with new data collected during the pandemic. However, some of the patients continued to receive treatment during the pandemic, making it difficult to discern whether the continued provision of treatment may have mitigated some of the potentially adverse impacts of the pandemic on patients' mental health and well-being.

Castellini et al. (2020) recruited 74 adult female patients (ages 18–60 years) with anorexia nervosa (AN) or bulimia nervosa (BN) at a specialty clinic in Italy to compare patients' last clinical assessments performed pre-COVID-19 with clinical measures collected during the COVID-19 period April 22, 2020–May 3, 2020 (during lockdown, T2). Patients with AN continued to gain weight by T2; no symptom improvement at T2 was found for patients with BN. Across diagnostic groups, frequency of binge eating and of compensatory exercise increased significantly during lockdown, the former associated with fear for the safety of loved ones and the latter associated with domestic verbal conflict.

TABLE 1 Articles featured in the virtual issue on COVID-19 research in eating disorders

- Branley-Bell & Talbot (2020). Exploring the impact of the COVID-19 pandemic and UK lockdown on individuals with experience of eating disorders. <https://doi.org/10.1186/s40337-020-00319-y>
- Brothwood et al. (2021). Moving online: young people and parents' experiences of adolescent eating disorder day programme treatment during the COVID-19 pandemic. <https://doi.org/10.1186/s40337-021-00418-4>
- Castellini et al. (2020). The impact of COVID-19 epidemic on eating disorders: A longitudinal observation of pre versus post psychopathological features in a sample of patients with eating disorders and a group of healthy controls. [10.1002/eat.23368](https://doi.org/10.1002/eat.23368)
- Lewis, Y. D., Elran-Barak, R., Grundman-Shem Tov, R., & Zubery, E. (2021). The abrupt transition from face-to-face to online treatment for eating disorders: a pilot examination of patients' perspectives during the COVID-19 lockdown. <https://doi.org/10.1186/s40337-021-00383-y>
- Machado, P. P. P., Pinto-Bastos, A., Ramos, R., Rodrigues, T. F., Louro, E., Gonçalves, S., ... Vaz, A. (2020). Impact of COVID-19 lockdown measures on a cohort of eating disorders patients. <https://doi.org/10.1186/s40337-020-00340-1>
- Phillipou, A., Meyer, D., Neill, E., Tan, E. J., Toh, W. L., Van Rheenen, T. E., & Russell, S. L. (2020). Eating and exercise behaviors in eating disorders and the general population during the COVID-19 pandemic in Australia: Initial results from the COLLATE project. <https://doi.org/10.1002/eat.23317>
- Raykos, B. C., Erceg-Hurn, D. M., Hill, J., Campbell, B. N. C., & McEvoy, P. M. (2021). Positive outcomes from integrating telehealth into routine clinical practice for eating disorders during COVID-19. <https://doi.org/10.1002/eat.23574>
- Schlegl, S., Maier, J., Meule, A., & Voderholzer, U. (2020). Eating disorders in times of the COVID-19 pandemic—Results from an online survey of patients with anorexia nervosa. <https://doi.org/10.1002/eat.23374>
- Shaw, H., Robertson, S., & Ranceva, N. (2021). What was the impact of a global pandemic (COVID-19) lockdown period on experiences within an eating disorder service? A service evaluation of the views of patients, parents/carers and staff. <https://doi.org/10.1186/s40337-021-00368-x>
- Simone, M., Emery, R. L., Hazzard, V. M., Eisenberg, M. E., Larson, N., & Neumark-Sztainer, D. (2021). Disordered eating in a population-based sample of young adults during the COVID-19 outbreak. <https://doi.org/10.1002/eat.23505>
- Spettigue, W., Obeid, N., Erbach, M., Feder, S., Finner, N., Harrison, M. E., ... Norris, M. L. (2021). The impact of COVID-19 on adolescents with eating disorders: a cohort study. <https://doi.org/10.1186/s40337-021-00419-3>
- Spigel, R., Lin, J. A., Milliren, C. E., Freizinger, M., Vitagliano, J. A., Woods, E. R., ... Richmond, T. K. (2021). Access to care and worsening eating disorder symptomatology in youth during the COVID-19 pandemic. <https://doi.org/10.1186/s40337-021-00421-9>
- Stewart, C., Konstantellou, A., Kassamali, F., McLaughlin, N., Cutinha, D., Bryant-Waugh, R., ... Baudinet, J. (2021). Is this the “new normal”? A mixed method investigation of young person, parent and clinician experience of online eating disorder treatment during the COVID-19 pandemic. <https://doi.org/10.1186/s40337-021-00429-1>
- Termorshuizen, J. D., Watson, H. J., Thornton, L. M., Borg, S., Flatt, R. E., MacDermod, C. M., ... Bulik, C. M. (2020). Early impact of COVID-19 on individuals with self-reported eating disorders: A survey of ~1,000 individuals in the United States and the Netherlands. <https://doi.org/10.1002/eat.23353>
- Vuillier, L., May, L., Greville-Harris, M., Surman, R., & Moseley, R. L. (2021). The impact of the COVID-19 pandemic on individuals with eating disorders: the role of emotion regulation and exploration of online treatment experiences. <https://doi.org/10.1186/s40337-020-00362-9>

Machado et al. (2020) recruited 41 women and two men with AN who were currently ($n = 26$) or previously ($n = 17$) in treatment at a specialty center in Portugal. The last available clinical assessments performed before onset of COVID-19 comprised the pre-pandemic data; participants were asked to complete online surveys during the first week of May 2020. Sixteen individuals (42% currently in treatment; 29% previously treated) reported a decrease in symptoms, 17 (31% currently in treatment; 53% previously treated) reported unchanged symptom status, and 10 (27% currently in treatment; 18% previously treated) reported an increase in symptoms, compared to pre-pandemic status.

2.2 | Studies collecting participants' retrospective reports about pandemic-related symptom change

We selected five studies that employed cross-sectional (Phillipou et al., 2020) or mixed-method (Branley-Bell & Talbot, 2020; Simone et al., 2021; Termorshuizen et al., 2020; Vuillier, May, Greville-Harris, Surman, & Moseley, 2021) designs. With one exception where a clinician confirmed the diagnosis (Schlegl, Maier, Meule, & Voderholzer, 2020), eating disorder status was based on participant self-report.

Phillipou et al. (2020) recruited 5,469 adults (including a subset of 180 self-identified cases with a current or past eating disorder, 95.6% female; largest diagnostic subgroup: 88 with AN) for an online study launched in Australia in April 2020. Respondents were asked whether in the past week they had engaged in restrictive eating, binge eating, or purging “more so than before the COVID-19 pandemic,” and whether there were any significant changes in their exercise behavior, “more so than before the COVID-19,” with five-level options ranging from a lot more to no difference to a lot less. The eating disorder group reported pandemic-related increases in restrictive eating (64% vs. 28% unchanged and 8% decreased), binge eating (35% vs. 57% unchanged, 8% decreased), purging (19% vs. 77% unchanged, 4% decreased), and exercise (47% vs. 17% unchanged, 36% decreased). It is unclear how many of the participants with an eating disorder were receiving treatment during the pandemic.

Termorshuizen et al. (2020) used ongoing studies and social media to recruit individuals with self-reported eating disorders between April 8, 2020 and May 6, 2020, resulting in a sample of 511 adults (97% female) in the United States (US) and 510 individuals ages 16 years and older (99% female) in the Netherlands (NL) for a mixed-method study examining self-reported effects of the pandemic on participants eating behavior and measures of health and wellbeing. In both countries, the largest diagnostic subgroup comprised participants with AN (62% US, 68% NL). In both countries, a majority (79% US, 66% NL) were concerned about worsening of their eating disorder due to disrupted routines or being in a triggering environment (58% US, 57% NL). The prevalence of changes in eating disorder symptoms in the past 2 weeks “because of COVID-19-related factors” varied considerably by behavior (and, to a lesser extent by country): “binged on food that I (or my family or roommate) have stockpiled”: 49% US, 29% NL; “restricted my intake more”: 77% US, 64% NL; “more compensatory behaviors”: 57% US, 62% NL; and having “felt anxious

about not being able to exercise” was reported by 82% of US respondents (question was not asked in the NL survey).

Two mixed-method studies conducted in the United Kingdom (UK) reported especially high estimates of worsening of eating disorder symptoms related to COVID-19. Branley-Bell and Talbot (2020), in early April 2020, recruited 129 UK residents aged 16–65 years (121 female) via Twitter and Facebook who self-reported recovery from or currently experiencing (62%) an eating disorder. Almost 87% reported that their eating disorder had worsened, including 30% of indicated that their symptoms were “much worse.” In their qualitative analyses, a worsening of eating symptoms was attributed to: an increased sense of social isolation and loneliness (86.4%); changes in living situation leading to increased interpersonal stresses or feelings of being trapped and afraid others might discover the respondent's eating disorder (85.2%); changes in physical activity (about 50% reporting decreases and about 33% reporting an increase in activity); exposure to triggering social messages due to spending more time online (81.4%); disruptions to routines and adverse impact on usual coping behaviors (65.9%); and increased or decreased availability of food (66.7%). Similarly worrisome results were reported by Vuillier et al. (2021) in a sample of 207 (76 male) adult UK residents who were recruited using social media and a participant recruitment website. Most (83.1%) participants reported that their eating disorder had worsened during the pandemic and similar themes were found in qualitative data such as increased social isolation, disruption of routines, changes in physical activity, and exposure to toxic social message (e.g., about dieting). Whilst in both studies more than 80% of participants reported worsening of the eating disorder, it is unclear whether this reflects selection bias toward individuals who experienced pandemic-related worsening of their eating behavior. We recommend readers to access the articles to learn more about the varied and complex explanations participants provided for the deterioration of the clinical status.

Simone et al. (2021) reported a mixed methods cross-sectional general population survey in the US of adults (447 women, 263 men, 10 another gender) who had been initially recruited a decade earlier in their mid-adolescent years. Somewhat contrary to expected, the proportion with binge eating (14% vs. 12%) or extreme weight control behaviors (8% vs. 13%) differed little from a 2018 survey. However, the time periods of asking behavior frequency were 1 month in 2020 and 1 year in 2018. Forty-one percent reported increases in disordered eating behaviors, of which the most common (17.3%) was mindless eating and snacking.

In early May, 2020 (shortly following a lockdown period), Schlegl et al. (2020) recruited 159 female adolescents and adults with AN who had been discharged from an inpatient facility in Germany in 2019. Participants completed an extensive battery of questions about their experience related to the pandemic. We focus here on the data about changes in eating disorder symptomatology: about 25% of participants indicated that they were “undecided” whether they had experienced worsening of their eating disorder symptomatology since onset of the pandemic; 41.5% agreed; and 23.4% disagreed that their eating disorder symptoms had worsened. A majority (73%) reported that their weight had remained stable, while 18.9% reported weight loss and 8.2% reported weight gain.

Most of these patients continue to receive treatment for their eating disorder during the pandemic (including 8.2% inpatient).

In conclusion, the studies paint a worrisome, albeit somewhat mixed picture of the impact of the pandemic on eating symptomatology, as experienced by patients or individuals who self-report an eating disorder. Overall, if not always a majority then still a considerable subset of participants reported a deterioration of their eating disorder symptoms. Qualitative data yielded important themes that point to possible steps that might help reduce risk of symptom worsening such as finding ways to reduce the sense of social isolation, managing stress, or reducing exposure to social media. One major form of intervention to help those experiencing an eating disorder is, of course, treatment. In our next section, we describe findings related to changes in access to or modes of care.

3 | CHANGES IN ACCESS TO TREATMENT, MODE OF SERVICE DELIVERY, OR TREATMENT OUTCOME

Several studies collected quantitative data on access to eating disorder treatment and, although to varying degrees, found that access was reduced during the pandemic. For example, in the German sample of former inpatients with AN, only 10.7% reported being unable to access any form of treatment during the pandemic; a majority reported switching from face-to-face delivery to some form of technology supported sessions (Schlegl et al., 2020). About half of participants in the US/NL study (Termorshuizen et al., 2020) reported receiving some form of treatment at the time of the study. US participants (but not NL participants) with difficulty in accessing care scored higher on pandemic-related eating disorder impacts than those who had access to treatment. Notably, 47% of US and 74% of NL participants rated the quality of their treatment “in the last 2 weeks” worse or much worse than usual. In a sample of 73 participants recruited from a patient registry, 92% reported that they were able to continue treatment during the pandemic, although 32% indicated they perceived some disruption in their treatment and 33% found the quality of their care worse than before (vs. 59% good as usual or 8% better than usual) (Spigel et al., 2021). As described next, qualitative data from mixed-method studies may help generate hypotheses about the reasons for the perceived disruptions or decline in the quality of care for individuals with an eating disorder.

Lewis, Elran-Barak, Grundman-Shem Tov, and Zubery (2021) conducted a quantitative survey 63 adolescents and adults with an eating disorder (diagnoses, $n = 17$ AN, 20 BN, 16 BED, and 3 other) in Israel. There was a range of views on the quality of the move to online treatment experience during the pandemic; a majority (68%) reported that they would prefer not to continue online and 54% indicated that they would not recommend it. Similarly, a mixed methods clinic audit of staff and patients/families in the UK (Shaw, Robertson, & Ranceva, 2021) found mixed support for online/virtual delivery of care during lockdown (March–July 2020); moreover, this study also found that there were fewer referrals in 2020 compared to 2019, but the acuity was higher.

A mixed methods study of 51 adolescents with an eating disorder and their parents and clinicians (Stewart et al., 2021) found few differences in perception of care between those who started with online therapy and those who transitioned from in person to online during the March 2020 UK lockdown, with about 50% indicating they were “happy” with either form of treatment delivery. However, thematic analyses revealed more mixed views with, for example, themes of “something lost” and “something gained.” Brothwood, Baudinet, Stewart, and Simic (2021) similarly conducted in-depth thematic analyses of 14 adolescents with AN and 19 parents' experiences of an online intensive partial hospitalization program during the pandemic (March–November 2020) in the UK. They reported one more positive (“new discoveries”) and two less positive (“lost in translation” and “best of a bad situation”) emergent themes. Positive aspects were increased flexibility and accessibility. Negative aspects were the disruption in the therapeutic relationship and loss or personal connectivity.

One study reported large symptom *improvements* in eating pathology and mood in 25 patients (93% female, age 16–47 years) who had received at least one in-person treatment session and whose symptoms were assessed pre-COVID-19 and at end of treatment; moreover, benchmark data of patients treated during the 2 years prior to the pandemic suggested comparable treatment gains in the COVID-19 cohort and the pre-COVID-19 patients (Raykos, Erceg-Hurn, Hill, Campbell, & McEvoy, 2021). Although based on a small sample, the study suggests that it is possible to make progress in treatment even during a pandemic.

In conclusion, the studies found that it is possible to go to virtual and achieve comparable symptomatic outcomes to those obtain in in-person modalities. However, telehealth or digital health modalities may not be people's choice and some individuals reported diminution of the therapeutic relationship.

4 | FUTURE DIRECTIONS

The papers in this virtual issue highlight the challenges that confront people with eating disorders and those who care for them, professionals and non-professional, during this COVID-19 pandemic. The increased stress, isolation, and food insecurity undoubtedly have impacted some people, but who, to what degree, and in what ways requires more representative general population studies with less selection bias. For example, research suggests that people are experiencing more severe and/or prolonged eating disorders with increases in symptom severity and relapse rates during the pandemic. Thus, there may be an increase in prevalence. However, it is unclear if there is an increase in incidence. There may be potentially also greater barriers to care for those with less medical compromise and thus less perceived need from providers. Moreover, as was noted by one study participant, access to services may be due to a “postcode lottery” (Branley-Bell & Talbot, 2020, p. 7) in that some, but not all, providers or facilities may be well-equipped to offer telehealth services. Likewise, not all patients may have geographic access to broadband or own devices for technologies required for digital mental health. Whilst lockdowns may become less frequent and severe with high levels of vaccination, COVID-19 is not

yet over, and there is an imperative for more research investigating putative moderating and mediating environmental and other factors to reduce adverse effects from global pandemics. The use of virtual platforms to deliver treatments, and in particular psychological therapies, would benefit from development with adaptations to improve/enhance the “relatedness” of the experience. Beyond COVID-19, online delivery has an untapped potential to improve acceptability and improve access, but only if it is perceived as an acceptable and preferable alternative to in person care. Finally, the scale of the challenges posed by COVID-19 calls for collaborations across geographic, disciplinary, and institutional boundaries. We hope that our modest effort at setting aside the typical competition among journals will inspire other attempts to find unified approaches to our field’s pressing problems.

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