“It is the only constant in what feels like a completely upside down and scary world”: Living with an eating disorder during COVID-19 and the importance of perceived control for recovery and relapse

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ABSTRACT

The COVID-19 pandemic has had a profound, negative impact on the lives and wellbeing of much of the population, and it can raise additional challenges for individuals with eating disorders (EDs). During early stages of the UK lockdown, individuals reported disruptions to many aspects of their lives, including reduced feelings of control and serious concerns over the impact of the pandemic on ED symptoms and/or recovery. This study applied a mixed methods online survey to collect responses from 58 individuals (age 16–65yrs) with lived experience of EDs. Data was collected across two time points (April 2020 and June 2020) to explore the ongoing impacts of the pandemic on this population. The results suggest that higher perceptions of general, external control may be associated with ED recovery. Quantitative results show that individuals who reported recovering from their ED since the first time point, also reported significant increases in perceived control (compared to individuals who had relapsed or whose ED status was unchanged). Thematic analysis generated two themes: ED behaviours as an ‘auxiliary control mechanism’, and loss of auxiliary control after lockdown. Individuals who experienced less perceived control reported a tendency to rely upon eating disorder behaviours as an auxiliary coping mechanism, i.e., diminished external control was directed inwards and replaced with controlling their own behaviour. The preliminary results suggest that perceived control may be a significant factor in ED recovery. Individuals with EDs may be at significant risk of detrimental impacts on their recovery and wellbeing because of the pandemic reducing peoples’ sense of control. These preliminary findings highlight the need for further research in this area, including investigation around potential interventions based upon strengthening perceptions of control to promote ED recovery.

1. Background

Research shows that the COVID-19 pandemic has had a profound, negative impact on the lives of many people with eating disorders (EDs). This has been linked to numerous factors including increased media exposure, disruption to daily activities, social isolation, modified physical activity and sleep, negative affect and fear of contagion (Branley-Bell & Talbot, 2020; Rodgers et al., 2020; Talbot & Branley-Bell, 2021). Recent empirical research from Australia (Phillipou et al., 2020), the United Kingdom (UK; Branley-Bell & Talbot, 2020; Vuillier et al., 2021), the Netherlands and United States (Termorshuizen et al., 2020) reports evidence of increased ED behaviours during the early stages of the pandemic. For example, Phillipou et al. (2020) report increased restricting, binge eating, purging, and exercise behaviours among people with history of EDs; Termorshuizen et al. (2020) report increased food restriction among people with anorexia nervosa and increased binge-eating episodes for individuals with bulimia nervosa and binge-eating disorder; Branley-Bell and Talbot (2020) found people with EDs reported worsened symptoms, changes to physical activity rates and detrimental relationships with food. It is worth highlighting that for some individuals, the pandemic has also had positive impacts, for example Branley-Bell and Talbot (2020) found that a minority of participants reported positive changes to their living situation, engaging in fewer social comparisons, and wearing less ‘triggering’ clothing.

Whilst these findings provide valuable insight into the impact of the pandemic on people with EDs, they tend to rely upon a single point of...
data collection representing a sole ‘snapshot’ in time. To date, little is known about the impacts of the prolonged pandemic and continued lockdown periods on people with EDs. Longitudinal research is required to track their experiences of the pandemic and its impact upon symptoms and wellbeing. The current study aims to investigate the ongoing effects of the pandemic between two time points (first, soon after the start of the UK lockdown, April 2020, and second as the first lockdown restrictions began to ease, June 2020). A mixed-methods online survey was used, including established quantitative measures to investigate five factors related to wellbeing during the pandemic: mental wellbeing, perceived stress, social support, perceived control, and ED rumination, and open-ended questions to gather qualitative data. The five quantitative factors were chosen due to their established links with ED aetiology. Decreased mental health (Doll et al., 2005), low perceived control (Bruch, 2001) and high rumination (Rawal et al., 2010) have been linked to increased ED symptoms. Whilst positive social support has been shown to play a protective role, i.e., helping to decrease symptoms (Marcos & Cantero, 2009).

The COVID-19 pandemic has already been linked to decreased mental wellbeing and increased stress for both individuals with mental health issues (Yao et al., 2020) and the wider population (Pfefferbaum & North, 2020; Rodríguez-Rey, 2020; Usher et al., 2020). For individuals experiencing – or in recovery from – an ED, prolonged periods of lockdown have the potential to impact upon access to social support and increase ED rumination (Branley-Bell & Talbot, 2020), which could potentially lead to an increase in ED behaviour.

It is likely that many of the population have felt a reduced sense of control about many aspects of their lives as a result of the pandemic (Hou et al., 2020). Control is thought to play a key role in the aetiology and maintenance of EDs (Froreich et al., 2016). Anorexia nervosa, for example, is associated with low levels of openness to unexpected events and avoidance of uncertainty (Hempel et al., 2018). Consistent with this, researchers have found that people with EDs experienced a loss of control at the start of the pandemic; consequently, turning to ED behaviours such as food-restriction to regain some sense of control (Branley-Bell & Talbot, 2020; McCombie et al., 2020; Richardson et al., 2020; Schlegl et al., 2020).

Of course, sense of control is not only important to individuals with EDs, but to the population more widely. A recent study in China by Zheng et al. (2020) indicates that increased perceptions of control can act as a protective mechanism against psychological distress during a pandemic. Their results suggest that individuals with higher levels of perceived control also perceived themselves to be more psychologically distanced from the disease, helping them to cope better with the stresses of the pandemic. Zheng et al. suggest that research into the role of control for other populations and cultures would be beneficial. We therefore investigate whether control played a protective role for UK individuals with experience of EDs during the first few months of the UK pandemic.

The purpose of our study was to investigate the longitudinal impacts of the pandemic on people with EDs. We hypothesised that eating disorder status, mental wellbeing, perceived stress, social support, perceived control, and ED rumination would be negatively impacted between April 2020 and June 2020.

2. Method

Ethical approval was granted by Northumbria University ethics committee (23259) prior to data collection and all participants provided informed consent. Participants were recruited via Twitter and Facebook using opportunistic and snowball sampling. Inclusion criteria were as follows: Over 16 years of age, UK resident with self-reported experience of an ED (including those in recovery). Recruitment was limited to the UK to allow accurate identification of the stage of the pandemic and to ensure that data was comparable in this regard.

Participants in this study completed two anonymous online surveys about their experiences of the pandemic. The first survey took place two weeks after lockdown restrictions were first enforced in the UK (April 2020), and the follow-up 8–10 weeks later when the first lockdown restrictions started to ease (June 2020). Both surveys included established scales linked to ED psychopathology (see measures section), as well as closed and open-ended questions about symptoms, living situation, social isolation, long-lasting impacts of the pandemic, media messages, physical activity, online activities, and coping mechanisms. All participants were debriefed following completion of each survey. 153 participants were excluded resulting in a sample of 129 participants at time point 1. Participants were then e-mailed an invitation to participate in the second survey in June 2020. Of these, 58 participated at the second time point, the data for which is used in this paper (Fig. 1).

2.1. Measures

Established scales were included to measure five key factors linked to ED psychopathology: mental wellbeing (Doll et al., 2005), perceived stress (Hou et al., 2013), social support (Ghaderi, 2003), perceived control (Dalgleish et al., 2001), and ED rumination (Rawal et al., 2010). This enabled the researchers to test for any significant changes in these factors as lockdown progressed.

2.1.1. Warwick-Edinburgh mental wellbeing scale (SWEMWBS)

The 7-item SWEMWBS, was used to measure emotional and functioning aspects of mental wellbeing (NHS Health Scotland, 2016; Tennant et al., 2007). The measure asks individuals how often over the past two weeks they have felt: optimistic about the future; useful; relaxed; and how often they have been: dealing with problems well; thinking clearly; feeling close to other people; and able to make up their own mind about things. An overall mental wellbeing score is calculated, ranging from 7 to 35, with higher scores indicative of greater mental wellbeing. Cronbach’s alpha for this scale in the current study = 0.84-0.88.

2.1.2. Perceived stress scale (PSS-4)

The PSS is a self-report measure of the degree to which an individual perceives situations in their life as stressful, and it is one of the most widely used psychological measures of stress (Cohen et al., 1983). Respondents are asked to evaluate the degree to which they believe their life has been unpredictable, uncontrollable, and overloaded. In this study, the shortened 4-item version (PSS-4) was used. The 4-item version has been widely disseminated and has been shown to be a useful instrument for assessing stress perception levels across many populations (Vallejo et al., 2018), with good internal consistency and reliability (Mitchell et al., 2008). The PSS-4 gives a final score out of 16, with higher scores indicating greater perceived stress. Cronbach’s alpha for this scale in the current study = 0.73-0.77.

2.1.3. Enriched social support inventory (ESSI)

Poor social support has been identified as a risk factor for ED onset (Ghaderi, 2003). The ESSI is a brief 7-item scale designed to measure the existence or availability of people on who an individual can rely (Vaglio et al., 2004). The individual items are summed to create a total score, between 8 and 34, with higher scores indicating greater social support. Cronbach’s alpha for this scale in the current study = 0.81-0.84.

2.1.4. Shapiro control inventory (SCI-general)

Perceived control over external events has been linked to the onset and maintenance of ED psychopathology (Dalgleish et al., 2001). In fact, some suggest that a need for general self-control is often present prior to its manifestation as control over eating behaviours (Fairburn et al., 1999). The SCI general domain scale (Shapiro, 1994) is a 16-item scale encompassing positive and negative sense of control. The SCI-general gives a score between 16 and 112, with higher scores indicating
greater perceptions of control. The scale has been described as a useful instrument for studying control in relation to EDs (Lee et al., 2005). Cronbach’s alpha for this scale in the current study = 0.87-0.90.

2.1.5. Ruminative response scale for eating disorders (RRS-ED)

Rumination refers to a cognitive process involving repetitive negative thoughts. Ruminative thoughts have been heavily linked to eating disorder psychopathology (Rawal et al., 2010; Smith et al., 2018) and is regarded as a key factor in ED maintenance (Cowdrey & Park, 2012; Park et al., 2011). The RRS-ED is the first ED-specific rumination measure. Using 9-items, the measure gives a total score between 9 and 36, with higher scores indicative of greater ruminative thoughts. Cronbach’s alpha for this scale in the current study = 0.84-0.89.

2.1.6. Open-ended questions

Open-ended questions included asking individuals about: changes to living situations since the start of the pandemic, changes to feelings of social isolation, the type of media they have seen about the pandemic, the impact of the pandemic on their ED symptoms so far, any changes to their coping mechanisms since the pandemic, and any foreseen longer-term impacts of the pandemic in relation to their ED (see Supplementary Material).

2.2. Analytical approach

A mixed methods approach was applied. Quantitative data were analysed using SPSS v.26. Before analysis, data were tested for possible violations of the assumptions of normality and no multicollinearity. One extreme outlier on wellbeing score was identified (Z-score > 3), this score was excluded from the data. All other data points met normality assumptions. Changes in self-reported ED status between time point 1 and time point 2 were identified and participants were subsequently grouped into those who were: relapsing, recovering, or experiencing no change in ED status. A series of 2 (Time) x 3 (Group) mixed ANOVAS were then calculated to compare the three groups across wellbeing, enriched social support, ED rumination, perceived stress, and perceived control.

Quantitative analyses were complemented with a thematic analysis (using NVivo) of open-ended responses (Braun & Clarke, 2006) that specifically explored the impact of perceived control on respondents’ ED symptoms and wellbeing. The data were searched for responses relating to control, coded, and subsequently grouped into categories. Categories were developed into themes, with both authors agreeing on the finalised versions.

3. Results

3.1. Sample demographics

58 participants completed both the initial survey and the follow-up survey. Participants were aged between 16 and 65 years (M = 30.86 yrs, SD = 11.12 yrs), with 57 identifying as female (98.3%) and one as male (1.7%). The majority (n = 37, 63.8%) of the sample described themselves as currently experiencing an ED (or in a period of relapse from recovery), with the remaining 21 (36.2%) describing their status as in recovery. Of those 21 participants in recovery, 4 (19%) reported being in recovery for less than 3 months, 3 (14.3%) participants had been in recovery for 3–12 months, and 14 (66.7%) for over 1 year.

Twenty-eight of the participants (48.3%) identified themselves as having anorexia nervosa, 7 (12.1%) bulimia nervosa, 3 (5.3%) Other Specified Feeding and Eating Disorder, 2 (3.5%) 1 (1.7%) binge eating disorder, and 12 (20.7%) reported symptoms of multiple EDs. Seven participants (12.1%) chose not to reveal their specific ED.
3.2. ED recovery and relapse during lockdown: Quantitative analysis

Bivariate correlations (Table 1) were explored prior to the ANOVA analysis. At both time points, perceived control was negatively correlated with perceived stress and ED rumination, and positively correlated with mental wellbeing (the latter was also negatively correlated with stress at both time points, and rumination at time point 1). At the second time point, perceived stress was positively correlated with ED rumination and negatively correlated with social support and, as aforementioned, perceived control.

The ED status for some of the participants changed between time point 1 and time point 2, with 9 (15.5%) participants relapsing during this time, 11 (19%) participants recovering, and the remaining 38 (65.5%) reporting no change in their ED status.

Comparing the three groups (stable, recovery, relapse) using a series of (2 Time) x 3 (Group) mixed ANOVAs showed no significant between-group effects, nor within group effects for 4 of the variables: wellbeing, enriched social support, ED rumination and perceived stress.

However, some interesting results were found for perceived control. The main effect for group was not significant (F(2,55) = 3.02, p = .06, η² = 0.10) with similar control scores for the recovery group, relapse group and the stable/no change group at each time point. There was also no significant main effect of time, F(1,55) = 3.42, p = .07, η² = 0.06, with control scores at both time points remaining similar.

However, there was significant interaction effect between time and group, F(2,55) = 4.80, p = .01, and this was a large effect (η² = 0.15). The interaction was investigated using post-hoc paired t-tests using a Bonferroni correction for multiple comparisons (α = 0.05/3 = 0.017). The results show a significant increase in control scores for individuals in the relapse group from Time 1 to Time 2, t(10) = -4.01, p = .002. In comparison, there was no significant difference between the time points for individuals in the stable group, t(37) = 0.562, p = .577; or the relapse group, t(8) = -0.166, p = .873. Mean scores and standard deviations for all measures are shown in Table 2.

This interaction can also be clearly seen by plotting the estimated marginal mean scores for each of the groups at each time point (Fig. 2), with a sharp increase in perceived control evident for the recovery group.

3.3. Exploring the impact of control: Qualitative results

Qualitative findings supported the quantitative analysis in demonstrating changes to perceived control. The thematic analysis also yielded deeper insights into the different ways in which control was impacted for people with EDs. The results show that control is more multifaceted than perhaps would be assumed from just the quantitative data; rather than just focusing upon a loss of control in the external environment, individuals reflected on increased control in other areas – primarily their eating and exercise behaviours.

Two key themes were generated: (1) ED behaviours as an ‘auxiliary control mechanism’; (2) Loss of auxiliary control after lockdown. The development of these themes was informed by Froreich et al.’s (2016) observation that ED behaviours serve as an ‘auxiliary control mechanism’ when there is a perceived lack of control. The first theme reflects concerns around reduced control during lockdown, and the second focuses on reduced control after lockdown.

3.4. Theme one: ED behaviours as an ‘auxiliary control mechanism’

Respondents reflected upon the unpredictable nature of the pandemic, and how this led to reduced feelings of control. Loss of general daily routine(s) was a major negative factor for many participants, an impact that has been felt by much of the population (Hou et al., 2020). This loss of external or ‘general’ control is likely to explain the quantitative differences in perceived control by the recovery group, versus the stable and relapse groups.

Lack of control over global situation has meant a bit more restrictive behaviours.

Some individuals reflected on their ‘need’ to establish new routines to regain a sense of control. However, this led to some respondents focusing their attention on controlling their eating behaviours – primarily as this represented an aspect of their life that they were able to control during these uncertain times:

I am more rigid about the times that I eat, this has only been since the pandemic began. I think it is because I need a new rigid routine as my old routines are missing that were not related to food or eating.

My eating disorder feels more valuable to me than ever. It is the only constant in what feels like a completely upside down and scary world, it is my only locus of control.

For these respondents, ED behaviours served as an important coping mechanism against a perceived loss of control in the external world, replacing this with a sense of control that was based on controlling their own behaviour. A similar discrepancy between desire for control and

Table 1

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<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1a</th>
<th>1b</th>
<th>2a</th>
<th>2b</th>
<th>3a</th>
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<th>4b</th>
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<td>3.83</td>
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Note: *p < .05, **p < .01, ***p < .001. T1 = time point 1, April 2020, T2 = time point 2, June 2020.
perceived control has been shown to motivate Obsessive Compulsive Disorder (OCD) symptoms (Froreich et al., 2016).

Establishing increased control over their own eating and/or exercise behaviours was not as straightforward for some individuals, compared to others. In our initial survey, over one fifth of respondents reported changes to their living situation (Branley-Bell & Talbot, 2020). For some this change meant increased isolation, but for many it involved suddenly finding themselves living with others. At follow-up, respondents living with others reported feeling less control over food purchases and meals, leading to stress, and worsened wellbeing:

Live with my parents so have found it quite stifling not having the space to eat how/where I would like.

Our findings suggest that ED symptoms can be driven by a discrepancy between respondents desire for control and low perceptions of actual control during the pandemic. ED behaviours can provide a means to (re-)establish some sense of control. However, further tensions can occur when an individual’s control over their own behaviour is limited due to changes to living situations.

3.5. Theme 2: Loss of auxiliary control after lockdown

Our second theme focuses on reduced control after lockdown. However, again this relates to two sources of control: the wider control of the external world, and the narrower more self-focused control over eating and/or exercise behaviours. As aforementioned, whilst individuals felt that their general control had been negatively impacted due to the pandemic and lockdown, for many their control over their eating behaviours had increased. One respondent described having ‘full and total control’ over what they ate during the lockdown period:

I’ve been left to my own devices in isolation to have full and total control over what I eat.

However, respondents recognised that they would lose this element of control once lockdown measures eased. They described situations in which they would have reduced control and expressed concerns about their ability to cope, for example eating in social settings and/or having meals prepared by others:

I’m terrified at the thought of having to socialise over food again, and lose that aspect of total control I have over my life.

As the follow-up survey was completed when the first lockdown restrictions started to ease, respondents sometimes provided examples of situations when they felt a reduced sense of control:

I’ve found it harder now I can see friends as I have to deal with eating situations I’ve not been dealing with for a while e.g., picnics, where I am losing control which I had not been doing during lockdown. So I feel more guilt as I’m eating more and not losing weight.

In our initial survey, we found that going ‘out’ for food was an important factor in ED recovery that lockdown had impeded (Branley-Bell & Talbot, 2020). Unfortunately, our findings suggest that people with EDs may face challenges transitioning from an environment in which they have increased control over their eating and/or exercise behaviours, to ‘normality’ where they typically have less control – even if this is a positive and necessary factor in their long-term ED recovery.

4. Discussion

In this study, we investigated the role of perceived control for people with experience of EDs during the early months of the COVID-19 pandemic. Our findings suggest that perceived control was a significant factor in ED recovery during this time, with higher perceptions of external control being associated with recovery. In contrast, those who experienced less perceived control reported relying on ED behaviours as an auxiliary coping mechanism. This presented challenges once the first
lockdown restrictions started to ease, with some feeling anxious about relinquishing control over their eating habits.

Research around control as a factor in ED risk, maintenance and/or recovery can appear conflicting, particularly when considering quantitative findings. It has been suggested that this may be due to the multiplicity of constructs used to define control in the literature (e.g., sense of control, locus of control, mastery, need for perfectionism, and ineffectiveness). If studies are measuring different constructs of control, this will produce different results in relation to EDs, thus complicating our understanding of the link between ED and control (Froreich et al., 2016).

Thankfully, most researchers are beginning to recognise that control is a multi-faceted, domain-specific factor (Froreich et al., 2016; Shapiro et al., 1993). Our results support the view that control should not be regarded, or referred to, as a singular factor. It is not sufficient to talk only of ‘control’ in relation to EDs, but to recognise that whilst individuals with ED symptoms may experience low perceptions of control in some areas (e.g., external control of their wider world/life), they may have high levels of control in others (e.g., internal control of their own behaviour). It is also important to recognise that some forms of control are healthy, whereas others can be debilitating.

Recently, Froreich et al. (2016) stated the importance of “determining which operationalisation of control is most centrally relevant to ED” (p.2). Our findings show that individuals experiencing ED recovery scored higher for general perceived control (measured by the SCI-general). However, those who did not experience improvement in their ED symptoms described other forms of control in their life – those that evolved around their eating and/or exercise behaviours. For these individuals, controlling their eating and exercise behaviours acted as a coping mechanism which allowed them to regain some sense of control. This is consistent with what has been found by others (e.g., internal control of their own body), but may also reflect an individual’s unique way of dealing with the situation (Kings College London News, 2020). All these approaches add to the complexity of constructs used to define control in the literature (e.g., sense of control, locus of control, mastery, need for perfectionism, and ineffectiveness). It has been suggested that this may be due to the multiplicity of constructs used to define control in the literature (e.g., sense of control, locus of control, mastery, need for perfectionism, and ineffectiveness). If studies are measuring different constructs of control, this will produce different results in relation to EDs, thus complicating our understanding of the link between ED and control (Froreich et al., 2016).

Our findings suggest that perceived control may play an important role in ED recovery, this has implications for future ED prevention, treatment, and assessment. For instance, should future research support our findings in larger, more diverse samples, then future healthcare interventions may wish to introduce, or strengthen, aspects of treatment based upon increasing individuals’ general sense of control in their life.
and the external environment. An example of this may be in cognitive behavioural therapies, which traditionally aim to assess and modify maladaptive beliefs. Biased beliefs in control are a prevalent cognitive distortion among people with EDs, particularly anorexia nervosa (Sassaroli et al., 2008). Our preliminary findings suggest that there may be value in therapies that aim to challenge beliefs about control in different domains.

Government bodies may also wish to consider the impact that wording around the pandemic could have upon this population (Talbot & Branley-Bell, 2021). For example, public health campaigns may be more beneficial and/or effective if they emphasise ways in which individuals can (re-)gain a sense of control over the situation.

5. Conclusions

In conclusion, our findings demonstrate that perceived control may be an important – albeit complex - factor in the aetiology of EDs. High levels of general control appear to be beneficial and associated with ED recovery. When general control of the external environment is low, individuals may rely on more harmful coping mechanisms around controlling their own eating and/or exercise behaviours. Implications for future research (within the field of ED research and more widely) include the recognition of the multifaceted nature of control, and that the impact of control - whether beneficial or debilitating – may depend upon the specific domain and circumstances.

Author contributions

DB managed the project. Both authors conceived the study design and oversaw data collection. DB conducted the quantitative analysis; CT conducted the qualitative analysis. Both authors agreed on the themes generated by thematic analysis. DB prepared the manuscript draft, both authors edited and approved the final submitted manuscript.

Data availability

Upon request to the corresponding author.

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Ethics approval and consent to participate

Ethical approval was granted by Northumbria University ethics committee (23259) prior to data collection and all participants provided informed consent.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.appet.2021.105596.

References


