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Holly Louise Myers

holly.myers@york.ac.uk

University of York

Lucy Stafford

University of York

Elizabeth Meins

University of York

Alexandra Claire Pike

University of York

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Running head: IU and Disordered Eating

The importance of uncertainty across the stages of an eating disorder: A mixed methods
investigation

Holly Louise Myers^{1*}, Lucy Stafford¹, Elizabeth Meins¹, Alexandra Claire Pike^{1,2}

¹Department of Psychology, University of York, Heslington, York, YO10 5DD, United
Kingdom

²The Institute of Mental Health Research, University of York, Heslington, York, YO10 5DD,
United Kingdom

*Corresponding author: Department of Psychology, University of York, Heslington, York
YO10 5DD, United Kingdom. Email: holly.myers@york.ac.uk

Abstract

Background

Intolerance of uncertainty (IU; a bias towards perceiving uncertain situations as negative and frightening) is proposed to contribute to a range of eating disorder (ED) symptoms. The aim of the present study was to investigate the perceived role of uncertainty in relation to different ED stages and thought processes, exploring any differences depending on type of uncertainty (life events versus everyday experiences).

Methods

Participants with experience of an ED ($n=61$) and mental health professionals (MHPs) who treat them ($n=11$) completed a bespoke measure comprised of Likert scale items and corresponding open-text questions about how they believe uncertainty influences the development, maintenance, relapse, and thought processes in EDs, and how uncertainty is addressed in treatment. Participants in the ED group also completed the Intolerance of Uncertainty Scale (IUS-12) to assess general IU. Quantitative data were analyzed using correlations and t tests. Open-text responses were analyzed using a hybrid inductive-deductive reflexive thematic analysis.

Results

Quantitative analyses showed that individuals who have experienced an ED believe that (a) different types of uncertainty play distinct roles in their disordered eating, and (b) uncertainty plays a greater role in some ED stages than in others. MHPs were less likely to distinguish the different roles of uncertain life events versus everyday uncertainty across the different ED stages. The analytical process yielded the following themes: *1) the socio-temporal architecture of uncertainty, 2) cognitive, physical, and emotional experiences of uncertainty, 3) the utility of disordered eating, and 4) asymmetry in clinical practice and patient perception*. These themes were observed in both ED and MHP responses, but differences were conceptualized in the theme relating to how uncertainty is addressed in treatment. MHPs were more likely than ED participants to believe that uncertainty was addressed in treatment.

Conclusions

The present study's findings highlight the function of disordered eating behaviors in coping with uncertainty, particularly to foster feelings of control. Additionally, findings also highlight the potential for improving ED treatment and understanding by creating predictable treatment environments, informing MHPs about the nuanced role of uncertainty in disordered eating, and explicitly addressing uncertainty in relapse prevention plans.

Plain English summary

This study explored how uncertainty in terms of how both major life events and daily instability relate to the onset, persistence, and return of an eating disorder. Specialized mental health workers and individuals who have experienced eating disorders believed that major unpredictable milestones or events, such as moving to university or parental divorce, can trigger an eating disorder and cause setbacks later in recovery. In contrast, they felt that the small unpredictable stresses of everyday life, such as changes in plans or uncertainty in social interactions, maintained eating disorder symptoms – perhaps because eating disordered behaviors provided a sense of control in everyday life. Results also suggested that therapy might need to change how it addresses uncertainty. Future treatment could be more effective by ensuring treatment itself is predictable, teaching patients about the impact uncertainty, and discussing ways to cope with anxiety around unpredictability.

Keywords: eating disorders, uncertainty, thematic analysis, mixed methods, online research, treatment.

The importance of uncertainty across the stages of an eating disorder: A mixed methods investigation

Eating disorders (EDs) are severe psychiatric disorders that are characterized by harmful eating and weight control behaviors, marked psychological distress, and often life-threatening physical consequences (1). Furthermore, ED recovery rates are only 43% (2), compared to 54% within a year for anxiety and depression (3). The low recovery rate has been attributed to treatment being inaccessible (2,4) or ineffective (5). The relative ineffectiveness of treatments may relate to gaps in our understanding of the psychological mechanisms that underlie ED symptomatology, the bridging of which may lead to more successful clinical interventions (1).

One of the core psychological mechanisms of interest in EDs is intolerance of uncertainty (IU). IU is defined by a bias towards perceiving uncertain situations as inherently negative and frightening (6), leading to excessive worry and safety behaviors such as avoidance (7). The concept of IU originated from research into generalised anxiety disorder and maladaptive worry (8). However, with the high levels of comorbidity between anxiety disorders and disordered eating (9), there has been a move towards examining mechanisms previously explored within the anxiety literature in EDs (10). This emerging research has identified that IU is prevalent in those with EDs with recent research showing individuals with disordered eating have considerably higher levels of IU compared to controls (11,12). Elevated IU is observed in both adolescents and adults with EDs, across clinical and general population samples (13–16).

Some research distinguishes between different types of uncertainty (17), and suggests that the type of uncertainty may change the relation between IU and worry or distress (18). In terms of eating disorders, studies have shown that both types of uncertainty are relevant: smaller (everyday) uncertainties, such as eating foods with unknown calorie amounts (19), as well as more pervasive uncertain or adverse life events, such as bereavement or school or job transitions (20,21). Furthermore, research suggests that uncertain or adverse life events may be particularly important in the development of

disordered eating (21,22). Despite this, there is currently limited evidence exploring how different types of uncertainty relate to specific stages of the disorder, or whether one type is more influential than the other.

Research suggests that IU is a transdiagnostic mechanism, contributing to a range of ED symptoms, including restriction (23), purging (24), and the drive for thinness (16). However, the salience and function of IU may differ based on ED subtype. The majority of research has been conducted on restrictive EDs such as anorexia nervosa (AN). In these populations IU manifests primarily as rigid, pervasive risk aversion. For individuals with AN, uncertainty is experienced as highly threatening; consequently, strict caloric restriction, food rules, and body checking function as predictable behaviors that temporarily alleviate this uncertainty (25). In contrast, individuals with bulimia nervosa (BN) show elevated self-reported IU, but do not show the rigid, proactive behavioral or motor control seen in restrictive phenotypes (26). Instead, high distress related to uncertainty in BN may interact with deficits in distress tolerance and impulse control (27,28). Additionally, research with individuals who struggle with binge behaviors has suggested that IU may not be related to levels of binge eating (12,23), indicating that while IU may still be elevated in individuals that struggle with binge eating, there is no direct correlation between level of binge eating and IU. Other mechanisms may thus relate to the frequency and severity of binge eating episodes (23). This suggests that the behavioral expression of IU varies and is shaped by the specific cognitive and affective features of specific disorder presentations.

Previous research has often used self-report measurements of IU, such as the 12-item Intolerance of Uncertainty Scale (IUS-12) (29). Studies that utilize this questionnaire have found a consistent relation between IU and disordered eating symptoms across populations (11,12). However, an overreliance on standardized self-report instruments may mean that we are not adequately capturing individuals' experiences of IU, why they may struggle with it, and whether it is causally related to ED symptoms. Some research has also used tasks that examine how individuals make decisions under uncertainty to investigate IU and disordered eating (25,30). However, the expected relations between performance on

such tasks, scores on the IUS-12, and ED symptomatology are not always observed (25), perhaps due to lack of construct validity.

Currently, there is limited research that specifically investigates IU in ED using qualitative or mixed methodology (19,31,32). One qualitative study included 9 women experiencing AN who were in inpatient treatment (19). Another included 13 women with restrictive EDs and other specific feeding or eating disorders who were undergoing family therapy (31). The most recent study included 17 parents of young people with restrictive EDs (32). These studies all used focus groups and interpretative phenomenological analysis, which is a method used to understand individuals' experience of a phenomenon (33)—in this case uncertainty and how it relates to their ED—and they all found that uncertainty was an important aspect of the lives of those with EDs (19,31,32). Uncertainty was suggested to arise from a range of factors, such as negative evaluation from others, and lead to significant anxiety and feeling out of control, with disordered eating behaviors being used as a way to regain control (19,31). Furthermore, ED patients suggested that IU triggered a range of negative thought processes, such as catastrophizing (31), which is defined by worrying about the worst-case scenario occurring (34,35), but more research is needed to understand how IU relates to other cognitions. A more nuanced understanding of what thought processes underlie IU in EDs will help us tailor clinical interventions to target how those with disordered eating may be navigating uncertainty and how this may drive disordered eating behaviors.

Although findings indicate IU may be a key mechanism underlying EDs, there is a lack of research about how uncertainty affects individuals across the different stages of an ED. Specifically, qualitative research to date has focused on whether uncertainty is an important ongoing concern for those struggling with disordered eating (19,32). However, there is limited evidence as to whether and how IU may precipitate the onset of an ED, be addressed in treatment, or trigger a relapse, even though these questions are noted to be of utmost importance (31). Investigating how IU may be important in the development and relapse of disordered eating is crucial to move past reactive symptom management and

towards targeted interventions that can prevent initial onset, enhance active treatment, and safeguard patients against relapse during periods of uncertainty. There has also been limited quantitative investigation of the temporal relation between IU and ED symptoms, with the exception of one study finding that IU decreases on discharge from inpatient treatment, and that this is directly related to symptom recovery (36). Moreover, research has typically failed to recognize that uncertainty can arise in response to a variety of contexts (e.g., major life events, everyday experiences) and has not considered if context moderates the association between IU and disordered eating.

Finally, although the link between IU and disordered eating has been explored from the perspective of several stakeholders (individuals with lived experience and parents who support them), there is currently no research exploring how mental health professionals (MHPs) believe IU may be implicated in disordered eating. Consequently, IU as a construct may currently be underutilized or less explicitly recognized by clinicians in standard treatment settings. Capturing the insights of these professionals is essential to bridge the gap between theory and real-world practice. This additional perspective is likely to be critical to the development of feasible and effective IU interventions, whilst also providing information from a population with extensive experience of working with EDs.

The Present Study

The aim of the present study was to use a mixed-methods approach to further our understanding of how uncertainty may contribute to ED symptomatology across the course of an ED, considering the perspectives of MHPs and those with experience of an ED. In particular, we aimed to distinguish between major uncertain life events and daily uncertainty, whilst understanding how each may contribute to the development, maintenance, and relapse of EDs. Furthermore, the present study aimed to investigate how uncertainty may relate to the thought processes of those with EDs, and to understand how IU and uncertainty could be addressed within (cognitive behavioral) treatments. Given the lack of previous research, no directional hypotheses about the quantitative data were made with regard to (a) differences in IU across the ED stages, (b) the comparative role of major uncertain life

events and daily uncertainty in IU across the ED stages, and (c) differences in the views of individuals with EDs and MHPs on the role of major uncertain life events and daily uncertainty in the ED stages. However, we hypothesized that the type of ED would moderate relations with IU, with those with AN showing the highest IU and binge eating disorder the lowest. We also hypothesized that the role ED participants perceived uncertainty to have across the stages of an ED would relate to higher scores on a general, commonly used measure of IU (the IUS-12). Regarding the qualitative data collected in this study, no hypotheses were made.

Methods

Participants

Participants were eligible to take part if they were aged 18 or over, spoke fluent English, and (a) identified as having struggled with disordered eating/were diagnosed with disordered eating (ED group), or (b) professionally supported individuals with disordered eating (MHP group). We included individuals who self-identified as having an eating disorder, as individuals often face significant barriers to accessing treatment and diagnosis (37). Participants were recruited through social media, via an online participant pool run by the Department of Psychology (SONA), and physical advertisements placed around the University of York campus. Data were collected from 100 ED participants and 72 MHPs. Ethical approval was obtained from the Department of Psychology Research Ethics Committee at the University of York in January 2025, reference number: 202469.

Procedure

Data collection was conducted online using the Qualtrics experimental platform (38). All participants read the information sheet and provided informed consent to take part. Participants within the ED group then indicated their age, gender, and which ED they were diagnosed with or best reflected their eating difficulties. Note that individuals were able to select more than one diagnosis due to the comorbidity and overlapping symptom profiles of EDs (39). The MHP group provided their job title. All participants then completed a series of bespoke mixed methods uncertainty items, which we refer to henceforth as the Eating

Disorders and Uncertainty Measure or EDU, comprised of 8 Likert scale questions, and 10 open-text questions (see below). The ED group also completed the IUS-12 (29).

Both groups completed attentional checks integrated into the questionnaires. Responses where people did not answer the attentional check correctly were excluded. The design, analysis plan, and materials used, including the deductive code book to thematically analyze participants' open text responses, were pre-registered on the Open Science Framework (<https://osf.io/d2tfs>). Note that much of our quantitative analysis was exploratory, so it did not form part of the pre-registration.

Measures

Intolerance of Uncertainty was assessed using the 12 item Intolerance of Uncertainty Scale (IUS-12) (29) in the ED group only. Item responses are based on a 5-point scale from 1 (*Not at all characteristic of me*) to 5 (*Entirely characteristic of me*) and the range of possible scores is 12–60, with scores above 29 indicating high levels of IU (40). The IUS-12 has shown a strong correlation with the original 27-item IUS ($r = .96$) and has excellent internal consistency ($\alpha = 0.94$) and internal reliability ($\alpha = 0.91$). In the present study, Cronbach's $\alpha = 0.90$. Total scores were used in the analyses.

Eating Disorders and Uncertainty Measure (EDU). Questions were designed for the purpose of this study to assess uncertainty specifically in relation to disordered eating (see Table 1). Participants were first told that the questions would address both uncertain life events and everyday uncertainty. They were told that life events referenced longer periods of uncertainty or more major life changes, such as parental divorce, and that everyday uncertainty was defined as day-to-day uncertainties, such as a friend not responding to a text message. Some examples of potential thought processes that could emerge in relation to uncertainty were also given to participants (catastrophizing, jumping to conclusions) so participants had a clearer understanding of the relevant questions. Participants were asked to rate using a 5-point scale from 1 (*strongly disagree*) to 5 (*strongly agree*) how important uncertain life events or everyday uncertainty are to the (a) development, (b) maintenance,

(c) relapse, and (d) thought processes of EDs. For example, “**Uncertain life events** in childhood and adolescence are implicated in the **development** of eating disorders”; “**Everyday uncertainty** plays a role in the **maintenance** of eating disorder behaviors”. For each of (a) to (d), after rating the importance of uncertain life events or everyday uncertainty, participants expanded on their response in a free text box. For example, “How do you believe **uncertain life events** in childhood and adolescence are implicated in the **development** of eating disorders?”; “How do you believe **everyday uncertainty** plays a role in the **maintenance** of eating disorders?” Two additional open text questions asked individuals to reflect on how uncertainty is addressed in treatment, and how it could be better addressed.

Data Analysis Plan

Data were cleaned using R version 4.4.2 (41). Participants with incomplete IUS-12 questionnaire responses were excluded from quantitative but retained for qualitative analysis. Participants who did not complete the open-text and Likert scale items were excluded. We also excluded participants who used under 20 words across all open text boxes. If participants put N/A within open text responses, their data were still used if they had more than 20 words over the whole questionnaire. Data were also excluded when there was suspected fraudulent or untruthful participation (see Supplementary Material for how this was determined). After these exclusions, the final total sample size was 61 individuals with experience of ED and 11 MHPs.

Frequentist quantitative analyses were run using R version 4.4.2. Given the small sample for the MHP group, results were interpreted in terms of effect sizes. Qualitative analysis of the open-text responses was conducted using NVivo qualitative data analysis software, version 15 (42). This study employed a hybrid inductive and deductive approach to thematic analysis (43), which differs from more typical reflexive thematic analysis by the transparent and explicit acknowledgement of pre-existing subjective views on the data via a set of pre-defined codes within a codebook, with additional codes constructed from the data. First, a deductive codebook was established based on previous literature and

questionnaires. In step 2, this code book was reviewed and validated by three independent researchers, who each examined one transcript per population. Each coder highlighted parts of the transcript that fit the code book, providing evidence that the code book was applicable to the data. These extracts were then discussed between coders, and code book labels, definitions, and descriptions were changed if needed; these changes had to be agreed between the three coders. In step 3, coders familiarized themselves with the data and summarized the core emergent points. Step 4 involved deductive coding by applying the code book to the data set. Step 5 involved inductive coding, using the codes not included within the code book that were constructed from the data set. In step 6, broader themes were developed from finalized codes and corroborated by three independent coders to enhance interpretive rigor.

Reflexivity and positionality

Throughout the research, the first author (HM) reflected on her experience of conducting research on uncertainty in eating disorders by taking notes during the analytical process. These notes included ongoing reflections on key patterns and interpretations of participants' responses. Furthermore, creation of themes and subthemes was iterative; members of the research team had weekly meetings to adapt the thematic map until the team was happy that the themes and subthemes accurately reflected the experiences of participants. Supervision was helpful to remain focused on the question throughout and to identify preconceived ideas and biases, and how they could influence the qualitative analysis. See Supplementary Materials for researcher position statements.

Results

Descriptive Statistics and Preliminary Analyses

Table 1 shows the background variables for the ED and MHP groups.

Table 1: Summary of background variables for both participant groups

Variable	ED group (N=61)	MH professional group (N=11)
Age	M = 21.48 (SD 3.68), range 18–41	–
Gender	Women n= 52, men n=8, non-binary n=1	–
Diagnosis	22 anorexia nervosa, 1 bulimia nervosa, 3 avoidant restrictive food intake disorder, 10 other specific feeding and eating disorder, 6 binge eating disorder, 19 more than one diagnosis	–
Job role	–	6 clinical psychologists, 1 assistant psychologist, 1 psychiatrist, 1 occupational therapy assistant, 1 supporter, 1 clinical researcher

Table 2 shows the descriptive statistics for the individual uncertainty items. Data for Likert scale responses were non-normally distributed. Non-parametric and parametric analyses on these responses gave the same pattern of findings; parametric analyses are therefore reported for ease of interpretation of effect sizes. For the gender analyses, women were compared with the combined group of men and non-binary participants due to small sample size.

Scores for uncertain life events items were not significantly related to age (r_s -.21 to .22, $p_s > .101$) or gender (t_s -.1.03 to 0.18, $p_s > .309$). Scores for everyday uncertainty items were also not significantly related to age (r_s -.10 to .07, $p_s > .442$) or gender (t_s -0.22 to 1.32, $p_s > .193$). Table 2 also shows the IUS-12 scores; these were unrelated to age, $r(59) = .15$, $p = .258$, and gender, $t(59) = -0.38$, $p = .07$, $d = -.14$. Age and gender were therefore not included in the analyses reported below.

Table 2: Descriptive Statistics for EDU Items for the Eating Disorder and MHP Groups

	ED group M (SD)	ED group Range	MHP group M (SD)	MHP group Range
IUS-12 score	42.34 (9.32)	19–60	-	-
The importance of uncertain life events in ED development	3.70 (1.10)	1–5	4.00 (0.78)	2–5
The importance of everyday uncertainty in ED development	3.89 (0.93)	1–5	3.73 (0.65)	2–4
The importance of uncertain life events in ED maintenance	3.51 (1.21)	1–5	3.55 (0.93)	1–4
The importance of everyday uncertainty in ED maintenance	3.95 (1.02)	1–5	3.82 (0.75)	2–5
The importance of uncertain life events in ED relapse	3.59 (1.45)	1–5	4.00 (1.10)	1–5
The importance of everyday uncertainty in ED relapse	3.36 (1.25)	1–5	3.64 (0.51)	3–4
The importance of uncertain life events in ED thought processes	4.26 (0.73)	2–5	4.36 (0.67)	3–5
The importance of everyday uncertainty in ED thought processes	3.85 (1.01)	2–5	4.09 (0.70)	3–5

Uncertainty in the ED Group: relations among variables

Relations among the individual uncertain life events and everyday uncertainty items for the ED group were explored. As shown in Table 3, scores for uncertain life events in ED development, maintenance, and relapse were positively intercorrelated, but these scores were not related to those for uncertain life events in ED thought processes. Internal reliability for the uncertain life events items was not acceptable: Cronbach's $\alpha = .66$.

For everyday uncertainty, scores for thought processes were positively correlated with those for maintenance and relapse, and scores for maintenance and relapse were positively correlated (see Table 3). Internal reliability for the everyday uncertainty items was not acceptable: Cronbach's $\alpha = .57$. Table 3 also shows that there were few significant associations between uncertain life event and everyday uncertainty items. Internal reliability for all eight items was unacceptable: Cronbach's $\alpha = .65$. Items were therefore treated separately in the analyses below.

Table 3 also shows the zero-order correlations between IUS-12 scores and those for the individual uncertain life events and everyday uncertainty items. As shown in Table 3, IUS-12 scores were positively correlated with all individual items for both uncertain life events and everyday uncertainty, but adjusting for multiple comparisons ($.05/8 = .0063$) meant that only the correlations between IUS-12 scores and (a) thought processes in relation to both uncertain life events and everyday uncertainty, and (b) everyday uncertainty in relation to relapse remained significant.

Table 3: ED Group Correlations for Uncertain Life Events and Everyday Uncertainty across Different ED Stages

	1	2	3	4	5	6	7	8
1. ULE development								
2. ULE maintenance	.53***							
3. ULE relapse	.56***	.36**						
4. ULE thought process	.14	.13	.12					
5. EU development	.19	.04	.37**	.12				
6. EU maintenance	.08	.05	.12	-.01	.22			
7. EU relapse	.08	.12	.32*	.24	.26*	.20		
8. EU thought process	-.11	-.05	-.08	.28*	.23	.35*	.25*	
9. IUS-12	.30*	.26*	.29*	.44***	.28*	.27*	.47***	.37**

* $p < .05$; ** $p < .005$, *** $p < .001$.

Note: ULE = uncertain life events, EU = everyday uncertainty, IUS-12 = 12-item Intolerance of Uncertainty Scale.

Uncertainty at Different Stages of Disordered Eating in the ED Group

Paired samples t-tests, adjusting alpha for multiple comparisons ($.05/6 = .0083$), showed that scores for uncertain life events did not differ between (a) ED development and maintenance, $t(60) = 1.37$, $p = .176$, $d = .18$, (b) ED development and relapse, $t(60) = 0.72$, $p = .472$, $d = .09$, and (c) ED maintenance and relapse, $t(60) = 0.42$, $p = .675$, $d = .05$.

Additionally, paired samples t-tests, adjusting alpha for multiple comparisons ($.05/6 = .0083$), showed that scores for everyday uncertainty did not differ between ED development and maintenance, $t(60) = 0.42$, $p = .677$, $d = .05$, but scores for everyday uncertainty were significantly lower for ED relapse than for ED development, $t(60) = 3.04$, $p = .004$, $d = .39$, and maintenance, $t(60) = 3.17$, $p = .002$, $d = .41$.

Comparing scores for uncertain life events and everyday uncertainty at the different ED stages, paired samples t-tests (adjusted alpha $= 0.05/4 = 0.0125$) showed no difference for ED

development, $t(60) = 1.09$, $p = .282$, $d = .14$, maintenance, $t(60) = 2.24$, $p = .029$, $d = .29$, or relapse, $t(60) = 1.13$, $p = .263$, $d = .14$.

The role of uncertainty in thought processes in the ED group

Paired sample t-tests adjusting for alpha for multiple comparisons ($.05/6 = .0083$) found that uncertain life events were considered to play a greater role in changing thought processes than in driving any particular stage of an ED. Specifically scores for the importance of uncertain life events on thought processes were higher than ratings of the importance of uncertain life events on ED development, $t(60) = 3.53$, $p = .001$, $d = .45$, maintenance, $t(60) = 4.45$, $p < .001$, $d = .57$, and relapse, $t(60) = 3.40$, $p = .001$, $d = .44$. However, scores for everyday uncertainty and ED thought processes did not differ to those for ED development, $t(60) = 0.21$, $p = .833$, $d = .03$, and maintenance, $t(60) = 0.66$, $p = .512$, $d = .08$, but were significantly higher than those for relapse, $t(61) = 2.75$, $p = .008$, $d = .35$. Additionally paired sample t-tests found that scores for the importance of uncertain life events were higher than those for everyday uncertainty for thought processes, $t(60) = 2.99$, $p = .004$, $d = .38$.

Comparison across ED groups

We had hypothesized that individuals with AN would show the highest IU and those with binge eating disorder the lowest IU. Given the small numbers of participants in all diagnostic groups apart from AN (and only 6 in the binge eating disorder group), this hypothesis was investigated by comparing those with only an AN diagnosis with the combined group of all other types of eating disorder. Table 4 shows the descriptive statistics and results of the independent samples t-tests comparing the AN and combined other ED groups. As shown in Table 4, the two groups did not differ on scores for any of the uncertain life event or everyday uncertainty items, or the IUS-12.

Table 4: Comparison of the AN and Combined Other ED Uncertainty Measures

AN (n=22)	Other ED (n=39)			
<i>M (SD)</i>	<i>M (SD)</i>	<i>t</i>	<i>p</i>	<i>d</i>
<hr/>				

ULE development	3.59(1.18)	3.77 (1.06)	0.60	.548	.16
ULE maintenance	3.50 (1.37)	3.51 (1.12)	0.04	.969	.01
ULE relapse	3.55 (1.50)	3.62 (1.44)	0.18	.859	.05
ULE thought process	4.18 (0.85)	4.31 (0.66)	0.65	.521	.17
EU development	4.09 (0.87)	3.77 (0.96)	1.30	.198	.34
EU maintenance	4.09 (1.15)	3.87 (0.95)	0.80	.427	.21
EU relapse	3.36 (1.40)	3.36 (1.18)	0.01	.989	.004
EU thought process	4.05 (1.05)	3.74 (0.99)	1.12	.268	.30
IUS-12	39.82 (10.86)	43.77 (8.15)	1.61	.113	.42

Note: ULE = uncertain life events, EU = everyday uncertainty

Uncertainty in the MHP Group – relations between variables

Table 5 shows the correlations between the scores for the uncertain life events for the MHPs. As noted above, the sample size for this group is very small, so we focus here on effect sizes rather than statistical significance, and report uncorrected p-values in the table and text. Mirroring the pattern seen in the ED group, scores for uncertain life events in ED development, maintenance, and relapse were positively intercorrelated, but these scores were not related to those for uncertain life events in ED thought processes. For everyday uncertainty, there were large positive effects for relations between MHPs' scores between development and maintenance and between development and relapse, and medium positive effects for the relation between maintenance and relapse and between relapse and thought processes (see Table 5). This pattern of findings is therefore potentially different from that observed in the ED group.

Table 5 also shows the correlations between the uncertain life event and everyday uncertainty items. In contrast to the largely null associations observed in the ED group, there were positive correlations between uncertain life event and everyday uncertainty items

across the development, maintenance, and relapse (but not in thought processes) items, with large effects for all of these correlations (see Table 5).

Table 5: MHP Group Correlations for Uncertain Life Events and Everyday Uncertainty across Different ED Stages

	1	2	3	4	5	6	7	8
1. ULE development								
2. ULE maintenance	.69**							
3. ULE relapse	.83**	.88***						
4. ULE thought process	.00	-.19	-.14					
5. EU development	.80**	.93***	.85***	.02				
6. EU maintenance	.86***	.73**	.85***	-.05	.71**			
7. EU relapse	.51	.46	.54*	.13	.59*	.34		
8. EU thought process	.00	-.39	-.26	.56*	-.16	-.16	.24	

* $p < .10$; ** $p < .005$, *** $p < .001$.

Note: ULE = uncertain life events, EU = everyday uncertainty

Uncertainty at Different Stages of Disordered Eating in the MHP Group

Mean scores for the different ED stages are shown in Table 2. For uncertain life events, paired samples t-tests showed scores for ED development were higher than those for maintenance, with a medium to large effect, $t(10) = 2.19$, $p = .053$, $d = .66$, and scores for maintenance were lower than those for relapse, $t(10) = 2.89$, $p = .016$, $d = .87$, with a large effect observed. Scores did not differ between (a) development and relapse, $t(10) = 0.00$, $p = 1.00$, $d = .00$.

For everyday uncertainty, paired samples t-tests showed that scores for all comparisons between disorder stages did not differ (ts 0.56–1.17, ds .17–.35).

Comparing scores for uncertain life events and everyday uncertainty at the different ED stages, paired samples t-tests showed a small to medium effect, $t(10) = 1.40$, $p = .192$, d

= .42, and there was a medium-size effect for scores for uncertain life events being higher than those for everyday uncertainty for ED development, $t(10) = 1.94$, $p = .082$, $d = .58$.

The role of uncertainty in thought processes in the MHP group

In contrast to results in the ED group, the importance MHPs gave to the role of uncertain life events in thought processes didn't differ to the importance they believed uncertainty had in development, $t(10) = 1.17$, $p = .267$, $d = .35$, or relapse $t(10) = 0.89$, $p = .397$, $d = .27$. Moreover t-tests showed scores for ED relapse were marginally lower than those for thought processes in relation to everyday uncertainty, with a medium to large effect, $t(10) = 2.19$, $p = .053$, $d = .66$.

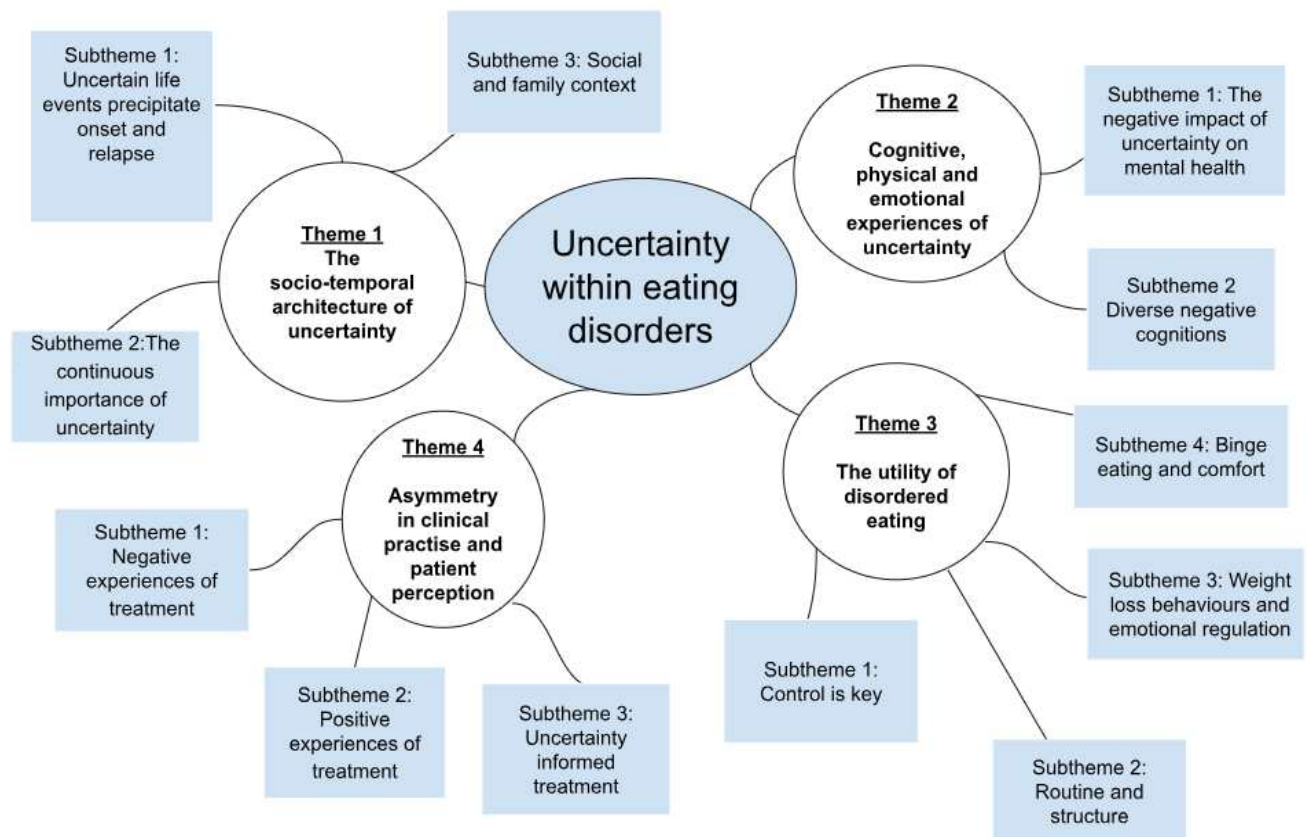
Comparing Uncertainty in the ED and MHP Groups

Table 2 shows the scores for the ED and MHP groups for uncertain life events and everyday uncertainty across the different ED stages. Independent samples t tests showed that the groups' scores did not differ for any of the ED stages (ts 0.10–0.89, ds .03–.29).

Qualitative Analysis

Reflexive thematic analysis identified several themes and subthemes (Figure 1). These are presented in turn below, and additional supporting quotes can be seen in Table 3 in the supplementary materials.

Figure 1: Shows a thematic map of the themes and subthemes that were constructed from MHP and ED groups' questionnaire responses.



Theme 1 - The socio-temporal architecture of uncertainty

The first theme was constructed from differential reports of the importance of different types of uncertainty across stages of an ED, which also related to social and family context.

There were several subthemes:

1.1 Uncertain life events precipitate onset and relapse. Both groups highlighted acute uncertain events, particularly within childhood and adolescence, as a primary trigger for the onset of disordered eating. Examples given included uncertainty associated with transitions: **“In my experience, many young people...develop these difficulties.... in response to stressful life events and transitions (such as moving from primary to secondary school) (MHP9)”**. Uncertain life events were also seen to contribute to the risk of relapse, with individuals describing a pattern of experiencing an uncertain life event, then

relapsing: **“When my dad ended up suddenly poorly my relapse came out of nowhere...I anticipate the same thing will happen when he has his next operation” (ED10).** MHPs suggested that individuals were at an elevated risk of relapse in response to uncertain events if they have low emotional resilience **(MHP9, Supplementary Table S3)** or have not experienced full recovery: **“Significant events often trigger relapse especially when full recovery was not achieved” (MHP7).** This was supported by ED participants, who suggested that **“It’s difficult to focus on altering such deeply ingrained habits when dealing with significant stressors” (ED42).** In the ED group, responses were mixed in terms of whether uncertain life events contributed to the maintenance of disordered eating, however MHPs more consistently agreed that uncertain life events were not primary drivers of disorder maintenance: **“I think that an uncertain life event may be a trigger for development of ED behaviors, I don’t think the event itself is implicated in the maintenance” (MHP10).**

1.2 The continued importance of everyday uncertainty. Individuals in the ED group suggested that everyday uncertainty was not a significant factor in the development of their ED, and felt uncertain life events were more salient **(ED22, Supplementary Table S3).** However, everyday uncertainties, such as changes in plans or uncertainty in social interactions, were seen to act as a chronic destabilizer that fuels ongoing anxiety **(ED7, Supplementary Table S3)** and contribute to the maintenance of the disorder: **“Uncertainty in daily life increases stress and negative feelings, disordered eating helped alleviate this which made me more likely to continue” (ED49).** MHPs also viewed everyday uncertainty rather than uncertain life events as very important in the maintenance of disordered eating **(MHP8, Supplementary Table S3).** Additionally, both groups indicated that this link is particularly difficult, as the world is inherently uncertain, meaning that ED behaviors are consistently maintained: **“It is hard to avoid some element of everyday uncertainty in our lives and so I think it’s definitely more likely to contribute to the maintenance of my behaviors more” (ED30).**

ED participants suggested that everyday uncertainty and uncertain life events were both implicated in relapse; however, everyday uncertainties led to **“smaller urges to relapse” (ED3)** and the events themselves were often **“smaller and more manageable” (ED6)**. Uncertain life events were suggested to lead to **“more significant longer lasting relapse” (ED3)**. However, some individuals indicated that everyday uncertainty was particularly destabilising, with an accumulation of small everyday uncertainties contributing to relapse: **“It makes everything feel hectic and [I feel] unable to control situations” (ED25)**, **“I do think a build-up of everyday uncertainty can contribute” (ED10)**. MHPs often did not see everyday uncertainty as a risk for relapse, and they suggested that the uncertainty would need to be more chronic to be seen as a risk factor (**MHP8, Supplementary Table S3**).

1.3 Social and family context. Both groups often mentioned the social and family context. ED participants focused on how uncertain family events, such as instability within the family unit (**ED13, Supplementary Table S3**) and parental divorce (**ED11, Supplementary Table S3**), may contribute to the emergence of disordered eating as individuals felt they needed to gain some control (**ED21, Supplementary Table S3**) also coded under control is key. Furthermore, MHPs suggested that there is a cyclic pattern, whereby people avoid social situations, which in turn negatively impacts their social relationships: **“People with EDs avoid social activities due to lack of confidence in their eating behaviors and body shapes. As a result, they lose the support of relatives and friends and normal interactions” (MHP3)**. These weakened social relationships cause individuals to feel **“lonely and helpless” (MHP3)**. Critically, this causes individuals to turn to disordered eating behaviors as a way of coping with these emotions: **“They rely more on disordered behaviors to relieve emotions, fall into a vicious cycle, and maintain a disordered state” (MHP3)**. MHPs also highlighted that EDs themselves cause significant amounts of uncertainty within the family system, as caregivers are unsure how to support their child: **“The presence of the eating disorder is incredibly difficult for families to manage...parents often feel helpless and uncertain what to do” (MHP9)**. Ultimately, it

was suggested that the family environment is fundamental to the course of EDs and should be addressed in treatment, especially within child and adolescent care.

Theme 2 - Cognitive, physical, and emotional experiences of uncertainty

The second emergent theme summarises the varying emotional, physical, and cognitive effects of uncertainty. This theme had two subthemes:

2.1 The negative impact of uncertainty on mental health. Anxiety and stress were the most commonly endorsed responses to both uncertain life events (**ED4, Supplementary Table S3**) and everyday uncertainty (**ED5, Supplementary Table S3**). Often, ED participants suggested that they had experienced an anxiety disorder before the onset of their ED. Indeed, some highlighted that physical symptoms of anxiety, such as nausea, directly led to restriction to avoid consequences such as vomiting (**ED33, Supplementary Table S3**). This acted as a barrier for recovery, specifically when trying to increase food intake: **“Low mood and anxiety often make me feel nauseous, making it harder to stick to meal plans or eat nutritious food” (ED14)**. MHPs also believed uncertainty-related anxiety was problematic due to its links with maladaptive coping mechanisms, with one participant noting anxiety led to **“avoidance... this includes school, social situations and ED treatment”**, along with **“endlessly looking for reassurance and information”**, which in turn **“will allow the ED to continue thriving” (MHP10)**. Critically, MHPs suggested individuals think avoiding uncertainty will reduce their anxiety, but in the long term, avoidance perpetuates the anxiety and continues to trigger ED behaviors: **“Seeing that life is full of uncertainty...uncertainty will trigger anxiety and anxiety may trigger relapse in ED behaviors” (MHP10)**.

Beyond anxiety and disordered eating symptoms, participants in the ED group also discussed other mental health concerns or neurodiversity which caused uncertainty to be more problematic. MHPs did not comment on comorbid conditions within EDs, only the presence of symptoms of anxiety and depression. One individual with autism stated that they particularly struggled with uncertainty, and their ED was a coping strategy that provided them with a feeling of being in control when faced with unfamiliarity: **“I am autistic and**

struggle a lot with uncertainty and unfamiliar situations. My ED gave me a sense of predictability and certainty which I found it impossible to get elsewhere” (ED7).

Individuals suggested that in the face of uncertainty, depression influenced how optimistic and rational they were about their future (**ED7, Supplementary Table S3**), and that their mood had a direct link with their eating habits: **“When uncertain things happen it would affect my mood which would affect my eating habits” (ED57).** In general, ED participants suggested that uncertain life events often interacted with existing mental health difficulties: **“These life events are more difficult to manage on top of existing mental health difficulties, contributing to a vicious cycle” (ED14).**

2.2 Diverse negative cognitions. Negative cognitions in response to uncertainty were experienced by individuals in both groups. Some of these seemed indicative of ‘negative affective bias’, including a tendency to overestimate the likelihood of negative events (44): **“Their estimated likelihood of negative events and positive events get skewed” (MHP8).** MHPs felt the patterns experienced in response to uncertainty became habitual and were **“hard to break” (MHP5).** Individuals with disordered eating also felt uncertainty triggers thoughts that things will not only go badly, but will never change: **“I feel more pessimistic when everything is going wrong and I feel like it will stay that way” (ED44).**

Catastrophizing about food and weight proved to be a common distortion (**ED27, Supplementary Table S3**), often when individuals experienced uncertain events: **“I would feel the worst about myself....based on uncertain life events and I would then start to think the worst would happen when I would eat or put on weight” (ED15).** Individuals also catastrophized about other people's perceptions of them (**ED26, Supplementary Table S3**), leading to restriction: **“I need to not eat or else everyone will hate you”, “If I eat in front of these people they will bully me for stuffing my face” (ED15).** This was mirrored in the MHP group, who linked these cognitions to self-esteem: **“Individuals often experience low self esteem...therefore jump to worst case scenario when presented with every day uncertainty” (MHP7).** A range of other cognitive distortions appeared

across both groups such as **“mind reading”** and **“black and white thinking”** (MHP6 & MHP1). Jumping to conclusions was a distortion that was also mentioned by both groups. ED participants suggested that it can be observed as a result of new situations and can lead to individuals trying to gain control through diet (ED34, **Supplementary Table S3**). MHPs suggested that this often occurred in individuals that have rigid thinking and have experienced adverse life events with negative outcomes (MHP7).

Theme 3 - Utility of disordered eating

This theme focused on responses that highlight how disordered eating has a utility in responding to uncertainty. Several subthemes were constructed:

3.1 Control is key. Across both groups, control was interpreted as a central motivator for disordered eating: **“I think when uncertain things happen it makes me lose control of external events so I take control of internal things which I can control”** (ED48). Participants also suggested that this perceived lack of control may have contributed not only to the maintenance of disordered eating, but precipitated the onset of their disorder: **“May have contributed to my eating disorder... try to find things to control such as my weight.”** (ED41) and to disordered eating behaviors such as calorie counting (ED16, **Supplementary Table S3**). Professionals reinforced this, noting that disordered eating can provide a sense of safety and certainty when life feels chaotic: **“Helps to give (an illusion of) control over an aspect of their life - which might be the only certain thing for them”** (MHP6). Often this may be restrictive behaviors: **“They might “restrict food intake as a means of exerting control in the face of external uncertainty”** (MHP4, also see MHP5 in **Supplementary Table S3**).

However, both MHPs and ED participants expressed that although ED behaviors are used to gain control, they can often in turn become out of control: **“Trying to 'control'....but losing control of them instead”** (ED20). This loss of control was suggested by one individual to indicate a relapse in disordered eating. Participants in both groups also suggested that individual differences in ‘need for control’ might act as a risk factor for

uncertainty triggering eating disorder symptoms: **‘Fear of the unknown and dependence on control led to development of unhealthy coping mechanisms to grasp hold of one thing I could have complete control of (food)’ (ED2)**. MHPs supported this, with one individual suggesting that the individuals with ED that they work with express high levels of rigid thinking, which is exhibited through a need to control **(MHP, Supplementary Table S3)**.

3.2 Routine and structure. ED behaviors and food rules offered predictability when the world lacked certainty: **“Need for routine and structure. Food can be completely controlled and rigid even when uncertain events are going on around the day” (ED2, also see ED34, Supplementary Table S3)**. Some individuals also suggested that a lack of structure and routine led to an increased chance of bingeing **(ED22, Supplementary Table S3)**. An ED participant also felt that having a life that lacked structure initially triggered their eating disorder, and may have contributed to relapse and negative thought processes **(ED4, Supplementary Table S3)**.

3.3 Weight loss behaviors and emotional regulation. It was commonly noted that individuals in the ED group felt restrictive/weight loss behaviors such as purging and restriction of food intake elicited positive feelings: **“Making myself throw up made me feel relief and calm” (ED26)**, in contrast to uncertainty, which caused negative emotions: **“Helping me ignore the uncomfortableness of uncertainty” (ED2)**. MHPs echoed this, suggesting that individuals may rely on **“dietary restraint or restriction for emotional regulation” (MHP1)**. Eating disorder behaviors also provided distraction from uncertainty **(ED10, Supplementary Table S3)**, particularly when individuals fixated on calories and exercise **(MHP6, Supplementary Table S3)**. Restrictive behaviors also numbed the negative emotions that resulted from uncertainty **(ED41, Supplementary Table S3)**. Individuals suggested that without these ED behaviors they would be vulnerable to uncertainty and the negative emotions and feelings associated with it, maintaining the disorder: **“Letting go of the disorder would make me vulnerable for the uncertainty” (ED2)**, **“Disordered eating helped alleviate this which made me more likely to continue” (ED51)**.

3.4 Binge eating and comfort. Binge eating provided comfort for individuals in response to uncertainty. It appeared to be a habitual response to the stress uncertainty causes, with one participant likening it to an addiction: **“Comfort. It’s the quickest way to feel some kind of relief. I guess it’s similar to addiction in that way. I derive a lot of comfort from eating sugary foods” (ED43).** Additionally, MHPs suggested that binge eating acted as an **“emotional escape” (MHP4)** and was **“relied on for emotional regulation” (MHP1, Supplementary Table S3)** when encountering uncertainty, such as emotional volatility within families **(ED42, Supplementary Table S3)** or in individuals with high trait IU. However, participants also suggested that bingeing perpetuates a cycle of negative thoughts and emotions. Specifically, uncertainty causes negative feelings that lead to bingeing, but bingeing then leads to feelings of guilt, causing further urges to binge: **“Encourages the cycle of eating for comfort” (ED39).** Individuals suggested that this guilt can also lead to restriction, as they need to prove they are still in control of their eating: **“So restricting after that makes me feel like I am in control and almost empowered in a way, because I am proving that I can do difficult things and control myself” (ED43).** On the other hand, one individual suggested that uncertainty means they lose their appetite, so they are less likely to binge **(ED18, Supplementary Table S3).**

Theme 4 - Asymmetry in clinical practice and patient perception

Participants responded to questions about how uncertainty was addressed within treatment with wide-ranging discussion on their perceptions of eating disorder treatment, leading to an emergent theme that is not wholly linked to the topic of uncertainty. In particular, the absence of clear discussion of how uncertainty is addressed in treatment, especially by the ED participants, may suggest that it is not comprehensively discussed or is dealt with inadequately. Furthermore, the highlighted barriers to treatment are important to consider when considering developing treatments that target uncertainty.

4.1 Negative experiences of treatment. Many individuals in the ED group suggested that their experience of treatment/services was not what they had hoped. Participants reported that accessing treatment was difficult, and support for managing

uncertainty was not provided. Many barriers to treatment were mentioned, including **“waitlist times” (ED21, Supplementary Table S3)** or weight thresholds: **“I also think therapists I’ve had in the past have thought I’m fine because my body size was in the healthy BMI range” (ED13)**. Individuals who did gain access to treatment often did not mention uncertainty, or specifically said they did not receive support for managing uncertainty: **“It was not something that was discussed in therapy sessions for me personally. So maybe simply asking if there is an issue there” (ED47)**. In contrast, individuals suggested that their treatment and experiences of services were often accompanied by significant uncertainty. One individual suggested that they often felt clinicians were not **“certain in their own work” (ED2)**, and there were frequent changes across many aspects of their care which was particularly triggering for them: **“Changing treatment plans, teams, staff members and actual severity of my illness. The uncertainty around my care is perceived as a lack of care for me and triggers a lot of the thought processes mentioned in the questionnaire” (ED2)**. Uncertainty was also seen in transfers between services, as people were unsure when they would receive help **(ED14, Supplementary Table S3)**. MHPs also highlighted the need to create a safe and predictable treatment environment, so individuals are not expending mental energy trying to cope with changing treatment conditions **“By providing safety and predictability within our services, this should be a safe space for those going through times of uncertainty to be able to speak about those problems and concerns whilst knowing they are within a service that provides them with that bit of certainty” (MHP5)**.

4.2 Positive experiences of treatment. In contrast, MHPs often felt that uncertainty was addressed within treatment. A common approach was increasing individuals’ tolerance to uncertainty, with emphasis on developing healthy coping skills rather than ED behaviors to utilize in times of uncertainty **(MHP8, Supplementary Table S3)**. This was addressed through methods such as **“acceptance and commitment therapy” (MHP1, Supplementary Table S3)** and behavioral experiments in a cognitive behavioral framework **(MHP10, Supplementary Table S3)**. One clinician also suggested that they worked on

reframing uncertainty and seeing the positives in uncertainty instead of the negatives:

“Seeing opportunity in change and the potential and the space for some excitement rather than just anxiety” (MHP6).

Some ED participants agreed with this approach and felt that they were supported in tolerating uncertainty in treatment: **“I believe services already do well to improve coping with uncertainty, when I was using these services...” (ED42).** Some specific methods included helping individuals see positive alternatives to uncertainty **(ED42, Supplementary Table S3)**, **“journaling” (LE33)**, strong family support, and frequent contact with the hospital **(ED32, Supplementary Table S3)**. However, one individual suggested that although the support was good for processing and handling uncertainty while they were receiving treatment, the effects were not long-lasting: **“However this stopped when I stopped going to these services” (ED42).**

4.3 Uncertainty-informed treatment. Both groups maintained that addressing uncertainty in treatment can be improved, not just in terms of creating a more predictable treatment environment, but in terms of the methods used to teach individuals to manage uncertainty. For example, one person suggested that focusing on strategies to handle emotions triggered by uncertainty, and helping individuals focus on strategies other than disordered eating to create a sense of certainty may be beneficial **(ED23, Supplementary Table S3)**. This was echoed by MHPs, who suggested increasing tolerance to uncertainty may be beneficial **(MHP8, Supplementary Table S3)**, through techniques such as cognitive restructuring or mindfulness **(MHP1, Supplementary Table S3)**. Additionally, given the co-occurrence of EDs and other conditions, participants suggested the need to create coping strategies for uncertainty which recognize this nuance: **“Understanding autism and my anxieties related to change and unfamiliarity. Working with me to identify what I am afraid of and create strategies to cope with this” (ED7), “Allowing people with eating disorders to access treatment for mental health difficulties outside of their ED - I was previously denied therapy for my OCD and anxiety because I was under the ED team” (ED20).** One MHP felt there should be a focus on psychoeducation around the impact of

uncertainty, IU, and how it contributes to ED behaviors: **“A short IU intervention that focuses on psychoeducation of how IU maintains ED behavior, and then teaches tools to reduce uncertainty-related anxiety and ED behaviors” (MHP11)**. Furthermore, an individualized approach to understanding how much psychoeducation an individual needs for uncertainty was also suggested; however, this is likely only to be appropriate where resources are available **(MHP6, Supplementary Table S3)**. Finally, it was suggested that there was a need to identify individuals at risk of EDs early **(MHP10)**, and to add **“uncertainty to relapse and prevention plans” (MHP7)**.

Discussion

The aim of the present study was to explore beliefs about the relation between different types of uncertainty and the course of disordered eating using both quantitative and qualitative analyses, encompassing the perspectives of individuals with lived experience of EDs and MHPs who treat and support them. In the quantitative findings, there was little consistency in beliefs about uncertain life events or everyday uncertainty across ED development, maintenance, relapse, and thought processes in participants in the ED group. Our quantitative results show that our bespoke measure does not have high internal validity; this isn't surprising as we were not trying to design a measure of a single construct, but were instead measuring the importance of uncertainty across three different disorder stages, and also examining how people considered it related to eating disorder symptoms such as disordered thought processes. These analyses suggest that individuals who have experienced an ED believe that different types of uncertainty play distinct roles in their disordered eating and believe that uncertainty plays a greater role in some ED stages than in others.

Participants in the ED group believed that uncertainty was particularly important in relation to thought processes associated with disordered eating. Notably, participants in the ED group indicated that uncertain life events were statistically more important to their thought processes than everyday uncertainty. However, there was no quantitative difference in the importance that ED participants assigned to uncertain life events and everyday life

events across disorder stages (development, maintenance and relapse). Potentially this indicates that it is easier for participants to see a proximal link between uncertainty and their thought processes. Additionally, this could indicate that the role of uncertainty is mediated through changes to thought processes and cognition. Future research is needed to empirically test this relationship between uncertainty and disordered thought processes in EDs. Including a measure of general intolerance of uncertainty (the IUS-12) also allowed us to investigate whether beliefs about uncertainty were specific to disordered eating. Specifically, we found that IU scores were related to the role of both uncertain life events and everyday uncertainty on thought processes, and the role of everyday uncertainty in relapse. However, IU scores were not related to responses on the EDU about the role of uncertainty across disorder stages (development and maintenance). This suggests that beliefs about the role of uncertainty in disordered eating cannot simply be explained in terms of trait-like IU: perhaps the EDU is capturing a more specific impact of uncertainty.

In the MHP group, with the exception of items relating to uncertainty in relation to ED thought processes, there were positive correlations among MHPs' beliefs about the role of both uncertain life events and everyday uncertainty across the ED stages. This indicates they may believe the two types of uncertainty to be closely related. Although caution is warranted in interpreting the results due to the small sample of MHPs, the correlations between the individual items represented large effects. MHPs also tended to believe that uncertain life events played a less important role within maintenance compared to development and relapse. These findings therefore contrast with those observed in the ED group and suggest that MHPs are less likely to distinguish the different roles of uncertain life events and everyday uncertainty across the different ED stages. However, despite these contrasts in beliefs between the two groups, there were no group differences in scores for any of the individual items, suggesting that the difference between individuals who have experienced disordered eating and MHPs lies in their comparative emphases of both different types of uncertainty and the role of uncertainty across different ED stages.

The present study also sought to investigate whether the type of ED would moderate relations with beliefs about uncertainty in disordered eating. On the basis of previous research that finds IU is related to restriction, restraint, and body image but not binge eating (23,36), we predicted that those with AN would be most likely and those with binge eating disorder least likely to believe that uncertainty was implicated in ED stages. Due to the low numbers of participants in all diagnostic groups apart from AN, our analyses compared individuals in the AN group with those in all other ED groups combined. Our findings provided no support for the hypothesis that individuals with AN hold stronger belief about the role of uncertainty in disordered eating than do individuals with other types of ED.

Turning to the qualitative results, the thematic analysis showed that uncertainty was thought to be important throughout all disorder stages, with uncertain events being most salient in development and relapse and everyday uncertainty being particularly important within disorder maintenance. Uncertainty triggered a range of responses such as disordered eating behaviors, anxiety, and maladaptive thought processes. There appeared to be a mismatch in how well MHP and ED participants thought uncertainty was addressed within treatment, however both highlighted that there was room for improvement. Four themes were identified.

Theme 1 - The importance of uncertainty

Uncertainty was highlighted as a key factor within disordered eating by both groups. This is in line with previous qualitative research that suggests individuals who have AN struggle with uncertainty (19,31), and the finding that individuals with disordered eating consistently demonstrate higher levels of IU on the IUS-12 compared to healthy controls (11). The present study expands the literature base as it specifically examines beliefs about how IU may differentially affect disordered eating depending on the disorder stage.

Both groups identified a range of uncertain events implicated in the emergence of disordered eating. MHPs suggested that these events are demanding for this population due to characteristically low tolerance of uncertainty. Frequently mentioned events included those related to the family or social environment, such as parental divorce or illness of loved

ones. This supports research indicating that uncertain and adverse events may contribute to the emergence of both IU and disordered eating (45). Significant transitional periods such as the move to university, or from childhood into adulthood, were also prominent, consistent with "emerging adulthood" being one of the peak onset periods for EDs (46).

Beyond ED development, uncertainty was viewed to have a continued impact on the maintenance of eating disordered behaviors, with everyday uncertainty, such as instability within the home environment, one's social life, work, or university, reinforcing disordered eating. Consequently, uncertainty appears to serve as a significant barrier to recovery, regardless of whether it is present as major life stressors or the cumulative effect of daily instability and uncertainties (19,47). Notably, current research indicates that IU levels are directly related to the change in restrictive eating symptoms throughout treatment (36). Participants also suggested that an accumulation of smaller everyday uncertainties or an uncertain life event can lead to relapse. This is comparable to the quantitative results that suggest that those with EDs and MHPs may view both types of uncertainty as important to relapse. This is in line with previous research showing stressful life events are a significant predictor of relapse within ED (48).

Theme 2 - Cognitive and emotional impact of uncertainty

Anxiety was continually mentioned as the most common response to uncertainty, with individuals often suggesting that they experienced significant anxiety in response to uncertain events preceding the onset of their EDs. This is supported by a large body of literature that suggests EDs and anxiety disorders often co-occur (49), with estimates that up to 62% of individuals with EDs meet the criteria for at least one anxiety disorder (50). Additionally, research has suggested that many of these individuals indicate that the anxiety disorder predated their ED (51). Furthermore, feelings of discomfort and anxiety in response to uncertainty are supported by the original IU literature that finds uncertainty is met by those with high IU with feelings of stress, frustration, and a sense of unfairness regarding the unknown (7). Anxiety in response to uncertainty in those with disordered eating has also been seen in qualitative research. Specifically, in those with restrictive EDs, anxiety was the

primary response to uncertainty, with individuals suggesting that anxiety was felt until the situation became certain (31). This is further corroborated by quantitative evidence that finds both IU and anxiety contribute to ED symptoms (52). However, there is a lack of evidence investigating the directionality of this relation.

Furthermore, research suggests that individuals with high IU will exhibit safety behaviors such as avoidance, repeated checking behaviors, or reassurance-seeking to try to reduce anxiety caused by uncertainty (53,54). This is mirrored in the present study, in which we found evidence that disordered eating behaviors were believed to have utility in counteracting uncertainty. MHPs suggested avoidance of treatment and counting calories as instances where these safety behaviors emerge in ED. In the long term, these behaviors are said to maintain anxiety, disordered eating, and IU (55,56). Safety behaviors have been previously suggested to be an important factor in disordered eating (56), however IU may provide a deeper understanding as to why anxiety is so prevalent in EDs and how it may be implicated in individuals' safety behaviors.

Autism was also referenced within the ED group, with individuals suggesting that co-occurring autism made managing uncertainty and trying to recover inherently difficult. This is in line with a large body of literature that suggests comorbidities and co-occurrence of other mental health conditions or neurodiversity within EDs are extremely common and that they can act as barriers to recovery (50,57). Specifically, research suggests that IU may contribute to the need for rigid routines and repetitive behaviors seen in autism to try to increase certainty (58).

Conversely, other than some references to anxiety and depression (which are also common within disordered eating (59), comorbidity was not mentioned in the MHP group. This may be due to MHPs wanting to remain focused on the topic of EDs, or it could be that there is a mismatch between how MHPs and service users want comorbidities to be addressed and how important they consider them to be. ED participants seem to consider that it would be beneficial to address comorbidities alongside disordered eating, rather than treating disorders as completely separate entities. For example, one individual discussed

how they would like to receive treatment for OCD alongside treatment for their ED. However, often it can be difficult for treatment providers to ascertain what the clinical priority is, and due to the risk for serious medical complications, EDs may be prioritized (60). Evidence suggests early identification of comorbidities in individuals with EDs may improve both initial response to treatment and overall treatment outcomes (50).

A range of maladaptive thought processes was identified by both groups. The most commonly cited were catastrophizing and jumping to conclusions. Catastrophizing is defined as imagining the worst possible outcome and inflating the possibility of this occurring (35,61), whereas jumping to conclusions is defined as a tendency to make rash decisions based on minimal evidence (62). Individuals in the ED group suggested that in times of uncertainty or when things did not go to plan, they would start to catastrophize about food or putting on weight, or jump to conclusions about how others were perceiving them. This is supported by the quantitative finding from this study suggest participants consider both uncertain life events and everyday uncertainty to be important influences on their negative thought processes. A potential limitation of this study is availability bias, as catastrophizing and jumping to conclusions were provided as examples of negative thought processes which may have biased individuals' responses. However, previous literature that suggests IU is related to catastrophizing (63), and may mediate between IU and symptoms of emotional disorders such as anxiety (51). Crucially there is limited exploration of catastrophizing within disordered eating, with only one study examining this relationship outside of chronic pain, to the authors' knowledge (64).

Literature relating both disordered eating and IU to jumping to conclusions is less supportive of this association, with previous research finding that those with AN do not display a jumping to conclusions bias compared to healthy controls (65). On the other hand, research examining the relationship between uncertainty processing and jumping to conclusions has found that those with high trait anxiety may experience jumping to conclusions bias under conditions of uncertainty (66). However, this bias may be more consistent in populations struggling with delusions rather than individuals with anxiety or high

levels of IU (67,68). Taken together, this study and the current evidence at hand suggests a need to explore catastrophizing and jumping to conclusions within disordered eating.

Theme 3 - Utility of eating disorders

Our third emergent theme groups responses that highlighted the utility of eating disordered behaviors as a response to uncertainty. Firstly, control was conceptualized as a key maintenance factor within disordered eating across both groups. Specifically, both everyday uncertainty and uncertain life events often made individuals feel they had a lack of control, and the only way they could regain control was through disordered behaviors such as food restriction or excessive exercise. This is consistent with research that has found individuals with disordered eating struggle with the unknown and changing plans, and believe that controlling one's eating can stop bad things from happening under uncertainty (31). Importantly, uncertainty was suggested to be related to a range of disordered eating symptoms that present across ED subtypes, in line with quantitative findings that showed no differences in IU or the ratings of importance of uncertainty across disorder subtypes.

Our study expanded on this by examining how control may be related to different stages of an ED. Within our study, individuals suggested that this 'need for control' caused by transitions such as the move to university and events such as parental divorce may have triggered the onset of their ED. This is consistent with previous studies that have found having a lower internal locus of control (perceived low self-agency) and higher external locus of control (feeling a lack of control over one's life) leads individuals to struggle to adjust to major life events (69). Furthermore, there is research suggesting that transitional periods are often related to onset and escalation of disordered eating (21), though these changes have not previously been related to IU. One previous study involving a non-clinical sample found that transitioning in and out of college was not implicated in the relation between control and disordered eating (70), but this finding may not replicate in an ED population.

Control was also implicated in the relapse of disordered eating, with both groups noting that ED behaviors were often used to regain control in the presence of uncertainty, leading to relapse. However, individuals in the ED group often felt they eventually lost control

over these behaviors. Previous qualitative research has supported this, finding that when individuals begin to relapse, they are unable to control their disordered eating, despite their desire to maintain their recovery (71). Ultimately, these findings suggest that feelings of loss of control are a key response to uncertainty, underscoring the need to support individuals to shift their focus away from disordered eating behaviors toward more benign coping strategies.

Individuals indicated a range of ways they implemented routine and structure to gain control, such as rigid routines around types of foods eaten or timing of meals. Previous research in the context of the COVID-19 pandemic supports this: individuals felt that their rigid rules and routine around food were the only way they could feel some semblance of control when the situation around them felt out of control (72). This can be detrimental to individuals, particularly if the types of foods or times they allow themselves to eat become too narrow. For example, previous research in a sample of individuals with AN found high adherence to food rules was related to higher preoccupation with food and weight, and lower levels of intuitive eating (73). Furthermore, previous research has found that having overly rigid routines and structure (around food and within the general environment) can be detrimental to recovery. This is particularly true when individuals transition from inpatient to outpatient treatment, and the shift away from having their meals, therapy, and activities at set times, and being provided with a set amount and type of food (74). Ensuring support is given to individuals when they are discharged from inpatient care back into the wider community is therefore paramount.

On the other hand, ED participants also indicated that routine and structure related to food was helpful to their recovery, particularly in relation to stopping binge eating behaviors. This is supported by a study with treatment-seeking individuals that reported individuals with BN found eating smaller but more regular meals and having more control over their eating in turn displayed less bingeing behaviors (75). Striking the balance between using routines and structure to aid recovery, but not becoming over-reliant on these scaffolds when individuals are faced with stressful or uncertain life, seems particularly important. Future research

should aim to understand how this balance can be met and what parts of routine and structure individuals find particularly helpful, and whether this differs by disorder subtype.

Purging and food restriction were endorsed across groups as a mechanism to cope with and regulate anxiety triggered by uncertainty. This is supported by an expanding body of qualitative evidence that finds individuals use restrictive ED behaviours to combat feelings of anxiety triggered by uncertainty (31), and quantitative evidence that finds IU is related to a range of weight loss behaviors, such as dietary restriction, purging (23), and excessive exercise (15). The present study expands on this evidence by developing a deeper understanding of how weight loss behaviors are implicated in reducing uncertainty and the associated anxiety. Specifically, it seems that individuals use these behaviors to regulate emotions, distract from uncertainty, numb negative emotions resulting from uncertainty, and feel positive emotions such as calmness and control. Future research should aim to understand how we can provide individuals with coping mechanisms that provide distractions and support positive emotions in the face of uncertainty.

Currently, to our knowledge, there is no qualitative exploration of how binge eating is related to IU, perhaps because the existing quantitative evidence on whether there is a relation between binge eating and elevated IU is inconclusive. Some evidence suggests those with binge eating may have difficulty making decisions under uncertainty (76), however other evidence suggests that those with binge eating disorder actually have greater tolerance of certainty (77) or that binge eating behaviors do not relate to IU (23,36,78). Overall, previous evidence suggests that IU is more closely related to restrictive ED behaviors. The current study found that uncertainty elicited negative feelings such as stress, which individuals combated by using binge eating to gain a feeling of comfort. However, binge eating then elicited feelings of guilt, which for some individuals caused more urges to binge, but in others it triggered a cycle of restrictive eating behaviors to regain a feeling of control. Previous research has linked binge eating to lower levels of impulse control when trying to regulate emotions (79), consistent with our finding that individuals use binge eating to cope with uncomfortable feelings of uncertainty. However, the specific role of IU as a

cognitive catalyst remains unexplored. Specifically, there is a lack of research exploring how IU may be a mediator between the subjective feeling of 'loss of control' and the manifestation of binge eating behaviors.

Theme 4 - Treatment

There were some key similarities and differences in how those with disordered eating and MHPs felt treatment addresses uncertainty. One issue that both groups agreed on is that there needs to be continuity and less uncertainty within care. Individuals need a predictable and safe environment to help them build the skills to cope with uncertainty and tackle recovery. This is aligned with previous research (80) that noted transitions such as the move from child and adolescent to adult services create significant uncertainty and often coincide with major life milestones like entering higher education. Furthermore, there is often significant uncertainty in how to address EDs, which can lead to caregivers experiencing uncertainty, which is detected and feeds into the overall levels of uncertainty felt by individuals with EDs (32).

Despite this agreement, individuals in the ED and MHP groups differed in terms of how effectively they believed uncertainty is currently addressed in treatment. MHPs were generally more optimistic, citing a range of methods that they used to address uncertainty within treatment, such as using behavioral experiments and addressing cognitive distortions such as catastrophizing. These methods align with evidence-based protocols for addressing IU in generalised anxiety disorder (55,81). The experiences of individuals who had experienced EDs were more varied, with some suggesting that uncertainty was not specifically targeted. It was telling that many of our ED participants did not mention uncertainty within their answers to questions about treatment, indicating that it was not comprehensively and/or explicitly addressed. This was not the case for everyone, however, with some ED participants suggesting uncertainty was targeted through techniques such as journaling, altering thought processes, and keeping consistent contact between family members and the hospital. That said, one individual suggested that the effects of treatment, specifically support in handling uncertainty, were not maintained post-treatment. This is

problematic, as the time after treatment cessation is a significant risk period for relapse (82), potentially due to the transition away from structured support and the uncertainty this causes. This variability highlights the need for standardized awareness and use of IU-focused interventions within treatment protocols.

The quantitative results may be useful in understanding these differences in perspective between the ED and MHP groups. Recall that, compared with MHPs, ED participants had a much more nuanced understanding of uncertainty arising from life events versus everyday experiences could influence disordered eating, and particularly recognized the link between uncertainty and ED thought processes. These differences may account for the qualitative finding that MHPs generally believed that uncertainty was already addressed in treatment, whereas more critical views were expressed by ED participants.

Both groups agreed that there were ways that uncertainty could be better addressed within treatment beyond creating a more predictable treatment environment. Two MHPs highlighted psychoeducation, with one individual suggesting that an intervention including psychoeducation around IU and tools to cope with uncertainty would be beneficial. This is in line with IU interventions used to treat anxiety, and a group IU intervention that has been piloted in the treatment of ED (55,83). Enhancing individuals' understanding of IU may better help individuals to engage with tools that facilitate uncertainty tolerance to improve treatment outcomes. Furthermore, one MHP highlighted the need to take an individualized approach to how much psychoeducation is needed, which was supported by one ED participant who suggested that an understanding of how their autism may make coping with uncertainty more challenging would be helpful. Finally, MHPs suggested a need to identify people at risk of developing ED from uncertain or stressful life events and that including uncertainty within relapse prevention plans would be valuable, consistent with the relapse prevention plans used in the anxiety literature (81). This holistic approach ensures uncertainty is not just addressed as a symptom, but as a vulnerability that requires individualized strategies to mitigate the development of disordered eating, and if integrated into relapse prevention, can be a protective factor for long term recovery.

Limitations

Participants were not required to have a formal diagnosis to participate in the present study. This was to ensure individuals who do not have access to ED treatment and diagnosis were not excluded, given that around 85.9% of individuals who meet the criteria for an ED never receive formal diagnosis and treatment (84). Additionally, recent National Health Service data suggest that there is a vast subclinical population that do not meet the criteria for an ED diagnosis but are experiencing significant distress (85). It is important to capture these experiences so we can understand how to support these individuals and stop progression to a full diagnosis. However, it would be useful for future research to attempt to replicate our findings on the relation between uncertainty and ED stages in a clinical population.

AN was over-represented in our sample, which meant that we were unable to explore whether beliefs about the relation between uncertainty and disordered eating differed across fine-grained ED diagnostic categories. In particular, we were unable to test our hypothesis that individuals with binge eating disorder would be better able to cope with uncertainty than would those with other types of ED because of too few participants in this category. Future research should recruit a more diverse sample with larger numbers of participants in the individual ED categories to establish a more complete picture of beliefs about the relation between uncertainty and disordered eating in the ED population as a whole.

An additional limitation is that our sample mainly consisted of cis female, young adult participants. This is a broader issue within ED research as research often ignores the perspectives of individuals that fall outside of this category (86). Additionally, the absence of data regarding participants' ethnicity or culture, factors which may moderate individuals' experiences of uncertainty or their consequences. For example, research has found that Korean university students often prioritize tradition-oriented motivational profiles where uncertainty is seen as a threat to social harmony, whereas American university students adopt growth-orientated profiles and see uncertainty as an opportunity for autonomy (87). In the context of EDs, this distinction is important. While western individuals may use restrictive

eating as a maladaptive way to reclaim personal control over an uncertain future, an individual from a collectivistic culture may utilize disordered eating behaviors to manage interpersonal anxiety or maintain social conformity. Without culturally diverse data, we cannot assume that the cognitive pathways between IU and disordered eating are uniform across populations. Furthermore, individuals will experience different types of uncertainty based on their age and life stage. Previous research found that older adults have lower levels of IU compared to adolescents (88). In the context of EDs, understanding the developmental trajectory is crucial as peak onset of EDs aligns with adolescence and emerging adulthood (89), which is a period of significant uncertainty related to identity and peer relationships (90,91). This is different to the uncertainty that may be experienced in later life, such as uncertainty around health or work. This nuance is important, particularly in relation to tailoring age-appropriate IU interventions. Investigating how IU and uncertainty may impact EDs in individuals from more diverse groups is therefore an important avenue for future research.

A further limitation concerns the use of online questionnaires. We had concerns that some individuals were fraudulent respondents, pasting responses from large language models such as ChatGPT, taking the study a large number of times, misrepresenting their own characteristics to take part (e.g., pretending to have ED symptoms), or using bots to take the study for them. This is an emerging issue across online mental health research in a multitude of domains (92,93). Detection procedures (see supplementary materials), conducting further fraud-detection analysis in R, and manually contacting potentially fraudulent participants allowed us to identify and exclude problematic respondents from the ED group ($n=11$) and MHP group ($n=44$). Although these measures will increase the credibility and integrity of our findings, this did result in a substantial reduction in sample size and statistical power.

Finally, our results cannot definitively establish the direction of cause and effect between IU and disordered eating. While individuals in the ED group typically believed that uncertainty played a causal role across the stages of their ED, it is possible that disordered

eating was instrumental in individuals becoming less able to cope with uncertain situations. Furthermore, this relation may be mediated by a third variable. For example, qualitative research has found that individuals with AN often engage in catastrophic interpretations of uncertainty rooted in previous negative experiences of uncertainty (31). Future research should employ a mediation analysis and longitudinal methodology to investigate the complex relationship between IU, uncertainty processing, and catastrophizing within disordered eating.

Conclusion

A synthesis of qualitative and quantitative data from both MHPs and people with experience of EDs indicated that uncertainty is important in the symptom profile of disordered eating across the course of the disorder. Specifically, it seems that uncertain life events and high trait IU may act as vulnerability factors for disordered eating, with IU remaining high throughout the duration of an ED. It appears that ED behaviors may operate as a way to gain control, routine, and structure in response to uncertainty, to combat uncomfortable feelings of anxiety and maladaptive cognitions. Notably, treatment environments and transitions may be a significant cause of uncertainty for individuals with ED history, and there was also a mismatch in how effectively MHP and individuals with EDs felt that uncertainty is addressed within treatment. There may also be a mismatch in terms of how ED participants and MHPs view uncertainty. Specifically, those with disordered eating may separate macro (life event) and micro (everyday experience) uncertainties and believe they have varying levels of importance at different disorder stages, but are central to ED thought processes. In contrast, MHPs may see uncertainty as a unitary concept that is consistently important throughout the whole course of an ED. These findings suggest a need for more individualized discussions about what uncertainty means to patients for treatment to be most effective. Furthermore, individuals with EDs may benefit from more psychoeducation around IU and uncertainty, and how it can influence ED behaviors, to attempt to reduce relapse risk after treatment cessation.

Availability of materials

The bespoke questionnaire used within this study along with the coding manual are provided on open science framework [<https://osf.io/d2tfs>]. However, in line with the ethical approval for this project, individual-level data are not available.

Abbreviations

AN: Anorexia nervosa

ARFID: Avoidant restrictive food intake disorder

BN: Bulimia nervosa

BED: Binge eating disorder

ED(s): Eating disorder

EDU: Eating disorders and uncertainty measure

EU: Everyday uncertainty

IU: Intolerance of uncertainty

IUS-12: 12 item Intolerance of uncertainty scale

M: Mean

MHP(s): Mental health professionals

OSFED: Other specified feeding and eating disorder

SD: Standard deviation

ULE: Uncertain life events

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Author information

Authors and Affiliation

Department of Psychology, University of York, Heslington, York, YO10 5DD, United Kingdom

Holly Louise Myers

Department of Psychology, University of York, Heslington, York, YO10 5DD, United Kingdom

Lucy Stafford

Department of Psychology, University of York, Heslington, York, YO10 5DD, United Kingdom

Elizabeth Meins

Department of Psychology, University of York, Heslington, York, YO10 5DD, United Kingdom

Alexandra Claire Pike

Contributions

HLM: Conceptualization, methodology, investigation, resources, project administration, data curation, software, validation, formal analysis, funding acquisition, writing – original draft.

LS: Validation, writing- review and editing.

EM: conceptualization, methodology, investigation, writing – review and editing, supervision.

ACP: conceptualization, methodology, investigation, validation, writing – review and editing, supervision.

Corresponding author

Correspondence to Holly Louise Myers.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Department of Psychology Research Ethics

Committee at the University of York in January 2025 (ref number: 202469). Our study was

conducted in accordance with APA and BPS ethical standards for treatment of participants.

All participants received an online information sheet and provided online consent to participate in this research.

Consent for publication

Not applicable

Competing interests

ACP currently sits on the Council for the British Association for Psychopharmacology, and has received funding from the Wellcome Trust and Academy of Medical Sciences (the latter of which relates to a project on the topic of control seeking and eating disorders). ACP declares no other conflicts of interest.

Supplementary information

Additional file 1 (DOCX)

Includes research positionality statements, fraud detection and a quote table.

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