



The experience of intolerance of uncertainty for young people with a restrictive eating disorder: a pilot study

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Received: 11 December 2018 / Accepted: 2 February 2019 / Published online: 16 February 2019
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Abstract

Purpose Research is consistently reporting elevated levels of intolerance of uncertainty (IU) in individuals with an eating disorder (ED). Less is known about the phenomenology of uncertainty for this clinical group. The present study aims to advance our understanding of the relationship between IU and restrictive EDs by providing insight into young people's subjective experiences of uncertainty.

Methods Thirteen young people with a restrictive ED were recruited from multi-family therapy groups run within the Maudsley Centre for Child and Adolescent Eating Disorders at the South London and Maudsley NHS Foundation Trust. Three focus groups were conducted asking young people to discuss their views, experiences and coping strategies when faced with uncertainty.

Results Data were analysed using interpretative phenomenological analysis which yielded five superordinate themes: (1) young people perceived uncertainty as something negative; (2) high levels of anxiety and stress were identified as primary responses to uncertainty; (3) ED behaviours were given a functional role in reducing uncertainty; (4) need to control various aspects of young peoples' lives was of high importance; (5) young people discussed how they struggled to find ways to cope with uncertainty and often used behaviours associated with the eating disorder psychopathology as coping strategies.

Conclusion Young people's experiences of what uncertainty is like for them revealed a dynamic interplay between ED symptoms and fear of uncertainty. Findings support IU as a relevant concept for young people suffering from a restrictive ED and indicate that further exploration of IU from both theoretical and clinical perspectives could be fruitful.

Level of evidence V.

Keywords Anorexia nervosa · Adolescents · Intolerance of uncertainty · Qualitative research · Eating disorders

Introduction

Intolerance of uncertainty (IU) is defined as a dispositional characteristic associated with a set of negative beliefs about uncertainty and its outcome [1]. Individuals with high levels

of IU tend to experience uncertainty as negative on an emotional, behavioural and cognitive level [2]. Originally studied as a contributor to generalised anxiety disorder [1] and other anxiety disorders (i.e., obsessive compulsive disorder and separation anxiety disorder) [3], fast growing literature suggests that IU is a transdiagnostic concept, contributing to a wide range of psychological pathologies [4].

The current literature shows that individuals with a restrictive eating disorder (ED) tend to be characterised as having rigid, compulsive and obsessional traits [5] with low levels of novelty seeking [6] and high levels of need for control [7]. Furthermore, over half of adolescents with anorexia nervosa (AN) present with a comorbid anxiety disorder [8], which severely compromises the prognosis of AN and treatment outcome [9]. Conceptually, IU could be contributing to the occurrence and maintenance of such traits found in individuals with a restrictive ED.

This article is part of topical collection on Personality and eating and weight disorders.

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At present empirical examination of IU in the field of EDs is in its infancy, yet results are promising. A recent review of 21 studies and meta-analysis of five of these studies found support of IU being significantly elevated compared to healthy controls for AN with some evidence that this may also be true for bulimia nervosa (BN) although the findings for BN are more limited [10]. A growing number of studies are reporting high levels of IU in adults with ED psychopathology compared to healthy controls in both non-clinical [11] and clinical samples (Stewart, unpublished thesis) [12–15] and higher levels of IU have been found to be associated with more severe ED psychopathology, even after controlling for anxiety and depression [13]. Moreover, a recent study shows that IU is associated with insecure attachment and lower levels of extraversion and openness in people with ED symptoms [16]. Personal accounts of adults with AN reveal that uncertainty is viewed as a negative experience that can cause a lot of anxiety, stress, loss of control and should be avoided at all costs [17]. In particular, IU seems relevant to restrictive type ED, with IU being recognised as a significant predictor of drive for thinness (Stewart, unpublished thesis) and with people with AN generally reporting higher levels of IU compared to people with BN [10].

Research examining IU in children and adolescents with an ED is scarce. Preliminary evidence from a small-scale study identified elevated levels of IU in 30 participants with AN (ages 12–45 years) compared to healthy controls [12]. Furthermore, IU has been associated with ED psychopathology in adolescent girls with a diagnosis of AN (Konstantelou, unpublished work; Rovers personal communication). More recently, support for the feasibility and benefits of using a group format to target IU in adolescents with AN

comes from a pilot study [18]. There is a considerable gap in the literature when it comes to IU and adolescents with an ED. The aim of the present study is to reach a deeper understanding of what uncertainty is like for young people with a restrictive ED.

Methods

Participants and recruitment

Young people were recruited from pre-existing groups as part of the Multi-Family Therapy programme for AN (MFT-AN) delivered by the Maudsley Centre for Child and Adolescent Eating Disorders, South London, and Maudsley NHS Foundation Trust. Inclusion criteria involved having a diagnosis of AN (DSM-IV) [19] or Eating Disorder Not Otherwise Specified restrictive subtype (EDNOS-R; DSM-IV) [19] established at initial clinical assessment by the clinical team and aged between 12 and 18 years. A total number of 13 young people took part in the study. See Table 1 for participant clinical and demographic characteristics.

Design

A focus group design was chosen for this study's purpose. Focus groups are considered an appropriate design for young individuals as they can reduce any power imbalances between the young participant and the moderator [20]. The topic of uncertainty was not viewed as too sensitive for young people to discuss in a group setting. Furthermore, young people knew each other from attending the MFT. Using already established groups is thought to have positive

Table 1 Clinical and demographic characteristics of participants

Participant	Group	Age	Gender	Diagnosis	%m BMI at assessment	LI (months)	LT (months)
P1	FG1	13	Female	AN-R	80.19	13	3
P2	FG1	13	Female	AN-R	82.70	27	3
P3	FG1	15	Female	AN-R	75.00	13	4
P4	FG1	16	Female	AN-R	85.0	8	4
P5	FG1	17	Female	AN-R	74.45	26	2
P6	FG2	15	Male	EDNOS-R	90.50	13	6
P7	FG2	16	Female	AN-R	83.00	16	10
P8	FG2	15	Female	EDNOS-R	78.60	8	2
P9	FG2	18	Female	AN-R	80.87	14	2
P10	FG2	17	Female	EDNOS-R	89.90	14	2
P11	FG3	16	Female	AN-R	65.90	8	2
P12	FG3	12	Female	AN-R	81.42	24	3
P13	FG3	15	Female	AN-R	70.80	14	10

AN-R anorexia nervosa restricting subtype, %m BMI percentage mean body mass index, LI length of illness, LT length of therapy, EDNOS-R eating disorders not otherwise specified restrictive subtype

effects, encouraging engagement in discussions [21]. Three focus groups were run, two of which consisted of five young people while the third one three young people. The composition of young people in all three focus groups was similar in terms of their age, diagnosis and illness duration (see Table 1).

Topic guide

The same topic guide was chosen for the present study as one used with adults affected by AN [17]. Previous experience of running focus group with adults confirmed that the topic guide was positively accepted by participants and successful in instigating discussions on uncertainty.

Procedure

All three focus groups were moderated by the first author and the second or third author acted as a facilitator. The topic guide was then used to stimulate discussion. The facilitator made notes on non-verbal information and group dynamics. All focus groups lasted approximately 45 min.

Analysis

Data were analysed using interpretative phenomenological analysis (IPA) [22]. IPA is concerned with in depth explorations of individuals' subjective experience on a given phenomenon, how they make sense of it and what meaning they attach to it [23]. IPA was chosen for the present study as the main aim is to understand how young people with a restrictive ED experience and manage uncertainty moving beyond a descriptive level and reaching a more psychological understanding. Interviews were transcribed verbatim by the first author and cross-validated by the second author. A bottom-up process of analysis was used following recommendations by Smith and Osborn [23].

The chosen method of analysis places emphasis on the interpretative role of the moderator, and the potential of the moderator to influence the analysis process. The fact that the moderator had extensive knowledge on the area of ED and IU could have unconsciously directed participants to answer in certain ways that re-affirmed the moderator's assumptions about how adolescents with AN may experience uncertainty. In order to control for this, the moderator stuck to the topic guide and involved in the analysis process a second researcher to cross check themes. Both moderator and facilitators were female in their mid-20s; this could have encouraged young people to open up and decrease any power imbalances.

Group dynamics

The composition of all three focus groups was similar in terms of participants' age range and illness duration, see Table 1 for detailed information. All young people in FG1 and FG3 contributed equally in discussions, while in FG2 one female young person dominated group discussions. It is further worth mentioning that FG2 was a mixed group with one male, which could have influenced the dynamics of the group and flow of discussion. However, no differences in body language or contribution to discussions were noted for the male participant in FG2.

Results

Five superordinate themes were identified across all three focus groups, with a number of subordinate themes. Although most subordinate themes run across groups, a few differences between groups emerged. These variations may reflect the differences in participant characteristics or a chance variation due to the dynamic of the evolving conversation in each group. Each theme is described below and illustrated with participant quotes. Table 2 shows an overview of the superordinate and subordinate themes for each focus group.

Experiences of uncertainty

Within this theme two subordinate themes were identified. These are outlined below.

Negative experiences of uncertainty

Uncertainty was predominantly expressed across all three groups as a negative experience that was unpleasant. Young people often referred to uncertainty as 'bad uncertainty'.

'...well uncertainty kind of scares me ...' (FG1, P4).

'I think I've found uncertainty quite hard and stuff...' (FG3, P12).

Uncertainty was also more troubling when it was directly influencing oneself versus an external event that was not threatening one's self-esteem. Particular concern was also placed on how other people viewed them.

'I think that also when it is more affecting you, like ... something that is going to happen ... in a football match...

Table 2 Superordinate and subordinate themes across all three groups

Superordinate themes	Subordinate themes	FG1	FG2	FG3
Experiences of uncertainty	Negative experiences of uncertainty	√	√	√
	Positive experiences of uncertainty	√	√	√
	Uncertainty experienced by everyone	√	√	√
	Cognitive bias and uncertainty	√	√	√
Responses to uncertainty	Negative responses to uncertainty	√	√	√
	Positive responses to uncertainty	√	√	X
	Before and after experiences of uncertainty	√	X	√
Anorexia and uncertainty	Function of anorexia nervosa	√	X	√
	Uncertainty and presence of anorexia nervosa	√	√	√
	Uncertainty and recovery	√	X	√
Control	Need for control	√	√	√
	Total control is unfeasible	√	√	√
	Change and control	√	X	X
Coping with uncertainty	Effective coping	√	X	√
	Maladaptive coping	√	√	√

√ present in group, X not present in group

is much less anxiety provoking than when you are uncertain about what others think of you...' (FG2, P7).

Positive experiences of uncertainty

Some young people identified positives to uncertainty. For instance, the exciting and fun side of uncertainty was put forward by P1, while the notion of uncertainty helping one to keep an open mind was discussed by others.

'...well I really like uncertainty and I've just moved school and yeah I just... it's quite fun for me' (FG1, P1).

'I think that the good uncertainty... it can keep you with an open mind...' (FG3, P12).

'Good uncertainty' was conceptualised by some young people as knowing that the outcome would likely be positive and one would benefit from it. Lastly, 'good uncertainty' was thought to be instigated by oneself rather than by someone else, as that meant you had a measure of control over the situation.

'...uncertainty can be good but it's primarily when you kind of instigates it yourself...it's like OK to not be certain about something when it is you who has kind of changed it because that way you still have a measure of control over it...' (FG1, P4).

'...when it is good uncertainty it's like you know that something good is going to happen, and it is not going to result in something bad...' (FG3, P13).

Uncertainty experienced by everyone

Uncertainty was acknowledged as an essential part of life, experienced across the life span. However, some young

people reported not thinking much about uncertainty when they were younger. Young people viewed variations in levels of acceptance and coping of uncertainty to be related to certain personality traits and past life events.

'I think it's inevitable that everyone experiences uncertainty at some point, it just depends on the degree and how people cope with it as to how it affects them' (FG1, P4).

'I think everyone experiences it [uncertainty] and even from like young children to adults...' (FG3, P13).

Cognitive bias and uncertainty

Across all three groups there was strong consensus that when confronted with uncertainty the first expectation is for something negative to happen. Young people referred to this as 'worst case scenario'. This was believed to be due to past life events which have shaped one's personality and one's response to uncertainty.

'...you are just so fixated on all of the bad possibilities that you kind of lose your mind to what could possibly be really helpful...' (FG1, P2).

'I can't think of anything else, I just think about what could happen and how bad it could be...' (FG3, P12).

'With the bad uncertainty it is like you feel there is a worst case scenario that could happen and you are always focussing on that...' (FG3, P13).

Responses to uncertainty

This theme captures young peoples' cognitive and emotional reactions when faced with uncertainty. Three subordinate themes were identified which are discussed below.

Negative responses

All three groups expressed strong negative responses towards uncertainty, both at a physical level (e.g., panic attacks) but also on a more cognitive level (e.g., increased worrying). One participant discussed how anxiety was always present in the face of uncertainty up until the uncertain situation becomes certain.

‘... just like panic erm, just fear... quite overwhelming’ (FG1, P5).

‘I get anxious and get really stressed can’t concentrate or focus my mind on anything else’ (FG3, P12).

Positive responses

Most young people acknowledged the potential for positive sides to uncertainty, only P1 from FG1 talked about positive responses to uncertainty, without any pre-conditions.

‘I get the sort of like quite excited feeling in my stomach when something different happens...’ (FG1, P1).

‘I quite like it [uncertainty] at times it gives you an adrenaline boost...’ (FG2, P7).

Before and after experiences of uncertainty

In both FG1 and FG3 young people described an increase in levels of anxiety prior to the uncertain situation and a decrease afterwards.

‘...that’s the thing after the uncertain thing happens, you...feel a whole lot better.....and I kind of feel better than I did before the uncertainty’ (FG1, P3).

Anorexia and uncertainty

Young people in all three groups spontaneously discussed their experiences of uncertainty within the context of their eating disorder. Three subordinate themes were identified reflecting three different ways young people discussed a link between their ED and their experiences of uncertainty.

Function of AN

Young people in FG1 and FG3 discussed how their eating disorder has a functional role in reducing uncertainty/anxiety while increasing a sense of safety and control.

‘... one of the things that I think sort of you get anorexia is from sort of not being in control of your life

and you want something to be able to control, and food is one of those aspects’ (FG1, P1).

‘... I felt more safe and secure like you said you can kind of you feel more in control and not eating made it easier coz I wasn’t as anxious’ (FG3, P12).

Uncertainty and presence of AN

Differences in one’s experiences of uncertainty prior and after the onset of the illness were discussed. Young people strongly expressed how their ED amplified and maintained one’s original fear of uncertainty.

‘sometimes you have like a predisposition to get things like anorexia just because of your personality ...[AN] then increases it [uncertainty] to a whole new level, and just takes it to the kind of extreme so though you may already have had a difficulty with facing change... it just magnifies it...’ (FG1, P2).

‘I’ve always had uncertainty, like before I had the eating disorder...But I think you know the eating disorder has just really highlighted how much uncertainty was in my life ...’ (FG3, P11).

Uncertainty and recovery

Young people in FG1 and FG3 discussed uncertainty in relation to treatment, the recovery process and accompanied feelings.

‘...the thing I’m most like uncertain about is when am I going to be in normal weight... I just don’t know when it will happen I don’t know ...how I will feel about it when it does...’ (FG1, P3).

‘...The whole every day what’s uncertain what is going to come next, is it going to be bad, if worst come to worst what is going to happen to me in after been in treatment, will I still be in treatment?’ (FG3, P13).

Control

Control was a prominent theme across all three groups. Three subordinate themes were identified and are outlined below.

Need for control

The theme of need for control was present across the three groups and particularly dominated discussions in FG1. Two different aspects of need for control were recognised. Firstly, young people discussed a need to control their weight, how others perceive them and a need to prevent

negative outcomes from taking place. Secondly, young people expressed a strong need to be in the know regarding all aspects of their life. What seems to increase young peoples' stress is the combination of high uncertainty in relation to what others think of them and perceived low control over a situation.

'I like to kind of be in control of what I do' (FG1; P2).

'I have this compulsive urge to kind of ...know...kind of everything and if it doesn't work your way then it's quite distressing if you've gone to the trouble of like planning it' (FG1, P2).

'Fear of not knowing...' (FG3, P11).

Change and control

This theme was present only in FG1 and covers young people's expression of distress when faced with change. Change appeared to be an unsettling situation whereby young people need to know and need for control increased dramatically. If change was inevitable, young people preferred to instigate it themselves, rather than others.

'...I tend to kind of get quite upset when situations present themselves to me that I had not expected... sometimes it is kind of worse when somebody tries to kind of make it how it was because it's already been changed and situations have already happened...' (FG1, P4).

'... if something like did change, I'd prefer it if like if like on the spur of the moment it was me doing the change not like someone else telling me like this is the change you're going to do it.' (FG1, P3).

Total control is unfeasible

A number of young people in FG1 acknowledged that one can't control everything and that certain things are out of one's control. However, food and weight seemed to be an exception and controlling one's eating could prevent bad things from happening.

'... the hard thing is trying to grasp the fact that not everything is in your hands and grasp the fact that you can't, you can't really plan everything because you don't actually know what is actually going to happen' (FG1, P3).

Coping with uncertainty

When young people were prompted to discuss how they cope with uncertainty some helpful strategies were mentioned but

most young people expressed how they struggle to cope with uncertainty or don't know how.

Effective coping

Being around people, friends and family were identified as helpful ways to deal with uncertainty. Accepting the situation and getting on with things was also mentioned.

'So, you just have to try and keep things balanced ... So, I think you just have to get on with it, because otherwise you are going to spend your whole life worrying, that's no life really' (FG1, P2).

Maladaptive coping

Young people mentioned a number of alternative strategies. These included avoidant behaviours such as avoiding certain emotions and thoughts as well as striving to increase control in their life and reduce uncertainty. ED-related behaviours were also often mentioned as coping strategies to ameliorate distress associated with uncertainty in the short term. Some young people mentioned how they did not know of any effective coping strategies and did not manage well with uncertainty.

'...coz I think you can end up having quite negative coping strategies that don't actually deal with it, they just steer it on to something else, like to deal with the uncertainty to try and get control in other areas or something' (FG1, P5).

'I don't think I cope very well, don't know how to or what ways...' (FG2, P8).

Discussion

This study used focus groups to explore experiences of uncertainty in young people currently undergoing treatment for a restrictive ED. Five superordinate themes and a number of subordinate themes were identified. Young people predominantly referred to uncertainty as 'bad', evoking a number of negative responses including anxiety, worry and stress, which can be interpreted as a cognitive bias towards expecting and fearing the worst-case scenario happening. 'Bad uncertainty' was also mentioned when one could not predict and control what would happen in the future and in terms of what others thought of them. Situations that involved some element of change, and so some level of uncertainty, were also mentioned as troubling by young people. Finally, young people in the current study associated uncertainty with a lack of control, which contributed to a fear towards uncertainty. Only two young people identified

uncertainty as a positive experience but this was not in relation to their illness. Most importantly, ‘good uncertainty’ was understood as a situation where one anticipated a positive outcome, when it did not pose a threat to oneself, or when the uncertain situation was instigated by oneself rather than someone else, thus perceiving some level of control over the situation.

When prompted to share their thoughts on ways of coping with uncertainty, some young people mentioned how their AN helped them cope with uncertainty. Similarly, young people described how their illness takes up a functional role, providing them with safety and security whilst distracting them from dealing with more difficult feelings. Viewing AN as serving a purpose of security and control echoes research in adults with AN [24].

Young people’s overall experiences of uncertainty as distressing were comparative to a similar study carried out with adults [17]. In contrast to the adult sample, some young people in the present study acknowledged a potentially positive side to uncertainty and showed flexibility in their thinking about ways to deal with uncertainty and move on with life. A recent study showed significant associations between high IU and cognitive inflexibility, but only when cognitive flexibility was low (Sternheim, personal communication). This could be due to developmental differences but could also reflect differences in the stage of the illness.

Findings from the present study contribute to a growing literature positing IU as an important contributor to the development and maintenance of ED such as AN [12, 13, 16–18]. Specifically, this is the first qualitative study investigating IU in young people with a restrictive ED, its qualitative nature increasing our understanding of the dynamic interplay between IU and AN in this group.

Findings further provide evidence that IU is of clinical importance during the treatment for EDs. Clinically, young people with a restrictive ED could benefit from interventions that target IU and subsequently decrease levels of comorbid anxiety, need for control and weaken any positive value associated with ED symptoms. More broadly, the negative emotional responses associated to IU, and the importance of social evaluation fit in with studies showing strong associations between IU and anxious and depressive symptomatology [3, 4]. Future research replicating this study would add to the confidence of the conclusions. Furthermore, running similar focus groups with young people at different stages of their illness will allow for better understanding of the temporal relationship between IU and restrictive ED.

The present study has a number of strengths and limitations. This is the first qualitative study exploring how uncertainty is experienced in young people with a restrictive ED. The focus group design was positively accepted by young people and was thought successful in allowing for in depth access to the subjective experiences of young

people on the topic of uncertainty. Furthermore, all groups were run by the same individual thus controlling for any moderator influences across groups. Validity of findings was further strengthened by having the third author cross validate themes. However, identified themes were not cross-validated by young people themselves. Finally, as with all small qualitative studies, caution needs to be taken regarding the transferability of current findings.

Conclusion

This pilot study suggests that IU is likely to be an important construct in restrictive ED presentations, contributing to high comorbid levels of anxiety, but also maintaining AN as part of a cognitive process underpinning the need for control. From a clinical point of view, targeting IU offers novel, potentially helpful treatment avenues for this clinical group. In addition, examining potential differences in how uncertainty is managed and what impact that may have on treatment between adolescents and adults with AN could be fruitful lines of enquiry.

Funding None required.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This study was granted ethical approval by the Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee (09/H0807/65). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study. Young people gave written consent for discussions within the groups to be audio-recorded and used for research purposes only. Parental informed consent was sought for individuals under 16 years of age.

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