What is uncertainty? A grounded theory of the role of uncertainty in anxiety in autism

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Running title: **A theoretical construct of uncertainty**

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Abstract

Background: While previous qualitative work has contributed to identifying intolerance of uncertainty as a significant source of anxiety in autism, there has been little research on what uncertainty means exactly for autistic people and/or what types of uncertainties might be particularly anxiety-provoking.

Methods: 15 autistic adults (5 women) took part in this qualitative interview study in which we probed their understanding and experiences of uncertainty and its links to feelings of anxiety.

The researchers applied a Grounded theory approach to transcripts of the interviews, broadly following Charmaz's

constructivist epistemology, to derive a theory of uncertainty as it is experienced by the autistic people we interviewed.

Results: From the interviews, we derived a model of uncertainty which identified three different levels of uncertainty, ranging from the certainty of the 'known', through to the relatively manageable uncertainty of the 'known unknown', to the anxiety-provoking 'unknown unknown' or that which cannot be made known. We propose in this model, that anxiety can be understood as resulting from difficulties with avoiding or controlling the latter types of uncertainty through planning or information gathering.

Conclusion: Previous researchers had treated uncertainty as a unified construct. However, they may not have explored what uncertainty might mean for autistic people. We have shown in this study that not all uncertainties are experienced equally. We hope that this

research will help develop a more nuanced understanding and that it constitutes the first step in disentangling anxiety from intolerance of uncertainty in autism.

Introduction

High rates of anxiety in autism have been reported in systematic reviews and meta-analyses. For instance van Steensel, Bögels, & Perrin [1] report rates of 30-50% in young people with autism, and Buck, Viskochil, Farley et al [2] report rates of 40-50% in adults. This is compared with anything from 2.2 to 20.9% in children and adolescents (from 6.4% in Europe, and to 18.1% in the US). [3].[1] A more recent systematic review from 2021[4] found substantial heterogeneity in prevalence of co-occurring conditions in autism, with figures of anxiety co-occurring with autism, ranging from 0 – 82% in children and adolescents. An earlier meta-analysis from 2020 [5] found a much lower pooled estimate of co-occurrence of anxiety and autism of 20%.

Anxiety has been linked to poor quality of life for children and adults on the spectrum, as it interferes with achievement of potential in education and later employment [6,7]. In a recent survey asking people on the spectrum what their priorities would be for future research, mental health and anxiety in particular was seen as a key area of concern[8].

Intolerance of Uncertainty (IoU) as a construct was conceived first out of a distinction between fear and anxiety, the latter being directed at the possibility (real or imagined) of something unpleasant happening in the future [9].For Lidell (1964)[10], anxiety was an outgrowth of vigilance as an adaptive function of awareness of potential danger. Anxiety can thus be identified as when this concern for future events is extended and maintained over a long

[1] It is difficult to compare the figures exactly as they change according to time frame: the last three/six/twelve months or lifetime prevalence. The figures nonetheless highlight that there is a stark difference overall.

period of time and consequently quality of life is impaired[11]. Worry is a facet of anxiety which particularly pertains to the persistence of this concern[12]. Lazarus proposed that anxiety was an emotion which was based on appraisal of the anticipatory and uncertain elements of future threats, which, importantly, were also the result of the person perceiving themselves as not having the cognitive resources (in his terms the interpretive schemata) to resolve the situation[13]. Worry and by extension anxiety, then, are related to IoU, which is characterized by thinking that all unknown future events are by definition distressing and that the preferred behaviour is therefore to avoid situations where outcomes are unknown.

IoU is defined as a feeling of stress in the face of uncertainty, and was initially postulated as a factor contributing to Generalized Anxiety Disorder (GAD) in the general population[14]. People who report high levels of IoU on measures such as the Intolerance of Uncertainty Scale (IoUS)[9] find situations of uncertainty stressful, have a tendency to view such situations as inherently threatening and experience difficulty functioning in the face of uncertainty[15–17].

Researchers have tried to identify the causes and risk factors of the high levels of anxiety in autism[7], with an emerging consensus that Intolerance of Uncertainty (IoU) plays a critical role[18] . The majority of this work, however, has been based on the use of self-reports [19].

The IoUS is both a measure of the emotional and cognitive as well as the behavioural responses to uncertainty, whereas Ledoux and Pine [20] argue for two separate neural circuits for emotional and behavioural responses to anxiety. In addition, although the IoUS demonstrates good internal consistency, and is thought to capture a single unified construct [9,15,21], it seems unlikely that all types of uncertainty in life are equally anxiety inducing. For example, uncertainties involved in gambling seem qualitatively different from the kinds of uncertainties that have characterised the Covid pandemic.

Nonetheless, according to findings from studies using self-report questionnaires such as the IoUS, autistic participants consistently report greater levels of IoU [22,23] and modelling studies show that this construct constitutes one of the strongest predictors of self-reported levels of anxiety[18,24]. It is important to note that although self-report are an oft used and quick way of gathering a large amount of data they do not come without their drawbacks. Self-report measures have been developed by and with, non-autistic people (with some exceptions such as the ASA-A (Rodgers et al., 2020) used in our study). This means that questionnaires may not have been designed in the most accessible way for autistic people (Stacey & Cage, 2022). Furthermore, a reliance on 'validity' and 'reliability' may be at the expense of 'relevance' for autistic people; i.e. the existing instruments may not adequately reflect the lived experience of autistic people (Jones, 2022).

However, qualitative research such as interviews, do indicate that autistic adults and adolescents report that uncertain and unpredictable situations are anxiety-provoking for them and that they try to avoid them as much as possible. For instance Robertson, Stanfield, Watt, et al (2018)[25] conducted semi-structured interviews with autistic adults, carers and partners of autistic adults and found that participants consistently described change and unpredictability as sources of anxiety. Parents and teachers of autistic children similarly report that uncertainties, particularly in social contexts, are often the source of distress[26].

Researchers investigating different interventions have shown the importance of including intolerance of uncertainty as a target for treatment for anxiety in autism. However, while previous work such as the development of the Coping with Uncertainty in Everyday Situations (CUES) intervention has focused on Intolerance of Uncertainty [27], the construct of 'uncertainty' itself remains relatively ill-defined.

In this study, we sought to explore further the kinds of uncertainty which might be more likely to cause anxiety than others for autistic individuals. Additionally, we aimed to help clarify what kinds of uncertainties might lead to anxiety and to disentangle which emotional and cognitive responses might lead to which behavioural response. Working towards a better understanding of the experiences of our interviewees might contribute to future studies aimed at unpacking mechanisms through which uncertainty might lead to anxiety. In turn, understanding what uncertainty means for and how it is experienced by autistic people in their day-to-day lives may help develop more effective support strategies for autistic people who may find uncertainty difficult. .

Thus, in this study, we aimed to explore *how autistic people conceptualise and experience uncertainty*. Thereby, we hoped to refine the definition of the construct of uncertainty, in order to investigate further the role it may play in anxiety in autism. To this end, we conducted semi-structured interviews to provide a flexible context within which the interviewer and participants could freely explore the meaning and experiences of uncertainty. We adopted a Grounded Theory approach, with a loose constructivist epistemology[28], which provides a systematic yet flexible approach to construct theories grounded in data[28]. We have called this 'loose', because we were also interested in the subjective experiences of the autistic people we interviewed, beyond the meaning making that might be constructed in the process of the interview itself.

Methods

Participants

The participants were 15 autistic adults (10 male, 5 female), aged 24-71, who have been given pseudonyms in the analyses below to protect their identity. Their ethnicity was predominantly White European, apart from one participant who was of Chinese origin although born and brought up in the UK. Depending on the time of their diagnosis (ranging from early childhood to late adulthood), participants had received a diagnosis of either Asperger's syndrome, Autism or Autism Spectrum Disorder in line with the relevant DSM diagnostic criteria at that time.

To help characterise the patterns of strengths and difficulties across core diagnostic functional domains and experiences of anxiety, we asked the participants to complete the Social Responsiveness Scale (SRS-2-ASR) [29] and the Anxiety Scale for Autism (ASA-A) [30]. The scores for the SRS-2-ASR ranged from 76 to 90+, with 10 participants scoring in the 'severe' range of above 85 and the rest in the 'moderate' range. Scores for the ASA-A ranged from 17 to 44 with seven participants scoring above a score of 28, which has been suggested to indicate clinically significant levels of anxiety. Additionally, although we did not ask for any formal medical history, during the interviews three participants mentioned they had received or were receiving treatment for anxiety, three for depression and two participants talked about experiencing Obsessive Compulsive Disorder (OCD). One participant also referenced a family history of ADHD and one a personal history of schizoid personality disorder. None of the participants in our sample had any identified learning disability or language impairment.

We primarily recruited participants from a database of participants who had taken part in research of the Autism Research Group at City, University of London before, or through word-of-mouth advertising through the researcher's social networks.

Setting

Due to the pandemic, and the ensuing necessary restrictions to travel and face-to-face contact, all the interviews took place remotely on Zoom (n = 11), Itsi (n = 1), Microsoft Teams (n = 1), over the phone (n = 1) or Skype (n = 1). We recorded the interviews on a digital device and the main researcher who conducted the interviews transcribed them verbatim.

Procedure

All participants provided written informed consent to take part in the study after receiving a detailed information sheet explaining the aims of the research. The Psychology Department Research Ethics Committee (ETH2021-0170) approved the study procedure, in line with ethical guidelines set out in the Declaration of Helsinki.

We used a semi-structured interview approach to guide the conversation and maintain focus on the core issue of interest, while providing enough flexibility to allow the participants to lead the conversation while remaining both relevant and open to their experiences and understanding. During the development of the interview schedule (see appendix 1), the first author held informal consultations with parents of autistic people, with researchers and an autistic person, in addition to the pilot participant who informally provided feedback on her experience of the interview. The former person, who wishes to remain anonymous, . suggested that what autistic people might want, rather than not being uncertain, was to be certain. This prompted the main researcher to add questions in the interview schedule regarding the areas in which participants might need certainty. The main researcher then piloted the interview schedule with three parents of autistic adults, one tutor of autistic

children and young people, and an autistic adult to obtain rich perspectives that might prompt further revisions to the initial draft interview schedule. We encouraged the pilot participants to give feedback on the conduct of the interview as well as on the questions. Only one autistic adult was interviewed for the pilot as, initially, the project was to include interviews of adults and parents and professionals working with autistic people. However, the main researcher, after reflecting on the pilot interviews, considered that parents and professionals had a different narrative concerning what they perceived to be the experience of uncertainty by autistic people and therefore considered that it was unfeasible to aim to develop a grounded theory that would be applicable to the different experiences. Therefore, for this study we only interviewed autistic adults for the main data collection, although we note that interviewing parents and professionals working with autistic people with little or no spoken language would be worth pursuing in future studies. Another modification stemming from the pilot interviews was the order of the questions, which we changed to allow for a suitable space for a break, should participants need it. Lastly, we defined the topics which were going to be discussed more clearly at the beginning, so as to give the participants a little time to process and to give them an idea of what was to come.

The final version of the interview guide included as Appendix 1, started with broad conceptual questions (e.g., "*People apply many different meanings to the word 'uncertainty'. When you say 'uncertainty' what do you mean?*"), followed by probes about the experience of uncertainty in different situations (e.g., "*Can you think of a time recently when you felt uncertain?*"). After advice from the autistic person whom we consulted in the development of the schedule, we added the concept of certainty. Interviews lasted between 35 minutes to just over an hour and began with the researcher outlining what the participant could expect from the interview and reminding them of the key information in the participant information sheet

(e.g., right to withdraw etc). We generally avoided small talk before beginning the interview as there are indications that this can make the participants feel uncomfortable rather than more at ease [31]. However, the interviewer let herself be led by the participants in this respect.

Research approach and Analysis

The interviewer transcribed each interview verbatim either on the same day, or the next day. She conducted the analysis simultaneously, partly with the use of NVivo 12 pro [32], through a process of continuous evaluation and constant checking by testing out nascent ideas and themes with each new participant. This is known as theoretical sampling and is a key part of a Grounded Theory analysis and approach [33–35] that develops new theory whose abstractions are derived directly from data[36]. The term refers to both the theoretical analysis and the resulting product of the method[37]. In this current study, we adopted a Grounded Theory which leant towards a constructivist approach, as described by Charmaz and Henwood[38], constructing a theory about the experiences of participants through interaction with, and interpretation of, the data in successive levels of analysis involving memo-writing, coding and drawing up of categories and diagrams.

The interviewer initially coded the transcripts line-by-line, at first adding new codes to the existing list with every new participant transcript. She then expanded, redefined, or refined the codes as she identified different themes and questioned them with repeated reading of the transcripts.

Importantly, the researcher was not completely naïve of autistic experience or theory, as she is a researcher in autism, the parent of an autistic adult, and someone who has worked as a carer and support worker of autistic children and young people and their families. Her background helped to sensitize her approach (Corbin & Strauss 2015) and to '*be more*

sensitive to concepts in data but also enable them to see connections between concepts' (Corbin & Strauss 2015[39], p79). It may also have influenced how she interpreted statements where there might have been ambiguity. To counter this, as part of the continuous theoretical sampling, the interviewer checked her own interpretations and thoughts during as well as after the interviews. The other researchers, while being less involved in the analysis, nonetheless helped shape and refine it. The first is a qualitative researcher who has no autism experience but was able to guide the main researcher in her methodology and the second is a researcher, who although has no personal or lived experience of autism has been a researcher in autism for many years and as such could provide guidance regarding theoretical underpinnings of the analysis. Thus, we adopted Grounded Theory in this study as a process of co-construction[40], which combines a form of informed induction (the formulation of a theory based on observation and reflection) with abduction (deciding on a 'best' description of the data from amongst a number of possible different explanations).

In a final stage of the analysis, we sent a brief summary of the theoretical framework that was derived from the interviews to all participants for member checking. Generally, the participants responded that the theory did resonate with them, with some providing minor clarifications that were incorporated into the final formulation of the theory.

Findings

In the findings set out below, we will first describe the themes and resulting categories regarding how the participants conceptualised and experienced uncertainty. In contrast to a

thematic analysis where one might seek to find discrete themes, in grounded theory these are inter-related as they are progressive building blocks for the eventual construction of the theory itself.

Part 1: Themes and Categories

What is uncertainty?

When exploring how the participants experienced uncertainty, the main researcher increasingly found that participants conceptualised it as all that was unknown and drew important distinctions between different types and levels of unknowns. They can be summarised as follows:

<u>Not knowing what is going to happen, what things are going to be like, what the outcome of one's decisions might be.</u>

For some, uncertainty was primarily related to not knowing what was going to happen or what the outcome would be of one's decisions and behaviour. For instance, Sylvia, during the pandemic when things were likely to be cancelled at the last minute felt "*really uncertain, even up to the morning [she] went [anywhere], whether [she] was going to be able to go*." What made it uncertain was that unexpected changes could happen at the last minute, not giving her enough time to plan.

For others uncertainty was not knowing what things were going to be like, more than whether or not they would happen. For instance, Jeremy, when planning a holiday, would do a lot of research prior to going. He would look things up, including on StreetView, yet "*would still*

retain a sense of …not actually knowing what it was actually going to be like, when [he] got there". For Jeremy, this was compounded by his difficulty anticipating how he would or should be feeling in any given situation, saying: "*I think if I have, if the, uhm, autism thing has any effect on me, really, is that I'm never sure what I'm thinking (…) I don't know, what I feel in any particular situation*". For others, not knowing what something could be like could be exacerbated by increased sensory sensitivities. For instance Rachel, who needed to know if somewhere was going to be noisy. Note that she did not phrase it in such terms, nor did she underline that this was a way in which she may have been different from non-autistic people.

In some cases, uncertainty was epitomised by small, unexpected changes to their routine. The unknown here is more nebulous: going from the stability of what is known (their routine) to the less secure unknown (a new way of doing things or even a different day for doing them). For instance Stuart found it very difficult to adapt to changing his shopping day from a Wednesday to a Thursday, when his wife suggested it. This was despite the fact that his unease and resistance weren't "*based on any reality"* or on *"any fear that anything was going to happen*". The uncertainty resided on his not knowing what the alternative would be like, what he would do on the Wednesday, now that he was not going shopping, or if his experience of shopping on a Thursday would be different, at a visceral, rather than a rational level. Change was inherently uncertain, although exacerbated by not being able to process the change, for instance if the change came about out of the blue.

For participants who did not have solid foundations (a permanent home or income), transitions from a known to an unknown, on a grander scale were also deeply unsettling. Francis, for example, when made redundant and having to start a new job, was very anxious about "*the fact that [he didn't] know where the job [was], where [he was] going to be relocating".*

People as unpredictable

Another aspect of 'now knowing what was going to happen' was specific to social situations and interactions, most often with non-autistic people, an example, perhaps, of a double-empathy problem [41]. The autistic interviewees fearing to be misunderstood by , as well as not always understanding, non-autistic people . The participants expressed that they found non-autistic people as inherently confusing and unpredictable. For Fred, it was the unpredictability in any social interaction which was uncertain: "*But you don't know what will happen. I mean someone could say something that - or I could say something that - offends someone and then it goes a bit wrong, and I feel depressed about the world and that kind of thing*".

For Rachel, this was because they were seen as inherently unreliable – "*you never quite know if things are going to be as they say*" – meaning if situations were going to happen the way that non-autistic people said that they would. This was echoed by John, for whom non-autistic people's behaviour was often unpredictable, and therefore difficult to understand: "*Oh, for autistic people, yeah, because they're completely unpredictable.*"

Participants also frequently commented on the fact that the unpredictable nature of other people was often compounded by social rules to which non-autistic people seem to be privy in an unconscious way, but that are not intuitive to many autistic people who have to learn them more consciously instead. For example, according to Steven:

> *"rules are fluid and there's some part of a neurotypical brain that does them, and the [stories] that society tells about itself are mostly false, and yet people operate as if they were true, to greater or lesser degrees - while ignoring them when it suits them"*

Unsure of what to do

For other interviewees, uncertainty meant not knowing what to do, or whether they had made the right decision. Rachel experienced uncertainty in this context as both not knowing if she had made the right decision and not knowing what to do next: "*Am I doing the right thing? Am I better still staying, although things were not good? (…) I'm putting myself, not only myself but my three children ... am I putting my three children at more risk?*".

Another expression of this uncertainty about *what to do* is an avoidance of making decisions. For example, John explained that he had many pairs of the same headphones he liked and trusted so that he would not be in a position of having to choose another type, whereas Amelia explained that she always has the same lunch so that she does not have to think about what to choose. The uncertainty in these contexts was expressed as not knowing what would be the right choice of product to suit their needs, as well as the act of choosing taking up more cognitive resources than they were prepared to spare. According to John, for instance, what distinguished him from the way non-autistic people might deal with situations, is that he worked better if he could be in 'flow' and was not disrupted or if his 'cognitive processes' were not wasted on matters of less interest, stating: "*if you've got a lot of things that are exactly the same, you don't have to think about them (…) you can use your mind, your cognitive processes, to think about other things*".

Uncertainty as pervasive

Finally, the meaning of uncertainty for participants also often comprised an element of something that is omnipresent and unavoidable. As Steven put it, the "*unbounded unknown*": it was everywhere, anything situated in the future and all around. For Stuart, "*anything that*

[was] in the future [was] uncertain". For Sylvia, life itself was uncertain: "*I suppose it's the whole of life* [laughs] *(...) That's just what life is, uncertainty*."

In summary: Participants largely defined uncertainty as *not knowing* something in different situations and contexts. Underlying it all was a sense of powerlessness: the interviewees often explained that they would often try to gather as much knowledge and information as they could, but there were always some hidden unknowns that couldn't be resolved (at least not in time to be useful). These hidden unknowns were the unexpected, the uncontrollable or unpredictable and were the greatest source of anxiety.

Experience of Uncertainty

Uncertainty as anxiety-provoking

Some, like George, experienced uncertainty as something physical, that from the outside is akin to the beginnings of a panic attack: *"I can feel it (...) in my stomach (...) there are other physical symptoms like my palms might sweat more*". Whereas for Maria, the anticipation of stress and anxiety made the reaction to uncertainty much worse: "*uncertainty is sort of whether doing [this] is going to bring up those unpleasant emotions in me*".

A number of participants experienced uncertainty as a persistent worry about making or having made a mistake which would only be assuaged with validation or reassurance. For Arthur, it was important to know that he had done or was doing the right thing, and for this he needed feedback and communication:

> "*when you're doing it remotely, all you can see is just the status on the dashboard and you can't see whether the computer's got stuck or (...) yeah, it's things like that*

which kind of panicked me a few times, I have to admit (…) they didn't even, respond, kind of thing (…). It really knocks your confidence".

Uncertainty made worse by lack of control

Fred felt more at ease if he could opt out of an event: "*I'd achieve it [overcome his anxiety and attended the event] almost, yeah, just by never putting myself in a position where I just have to do it*." What worked for him was to "*just slowly introduce myself to things that make me uncomfortable*", which could be interpreted as keeping control by deciding how to engage with the unknown.

For John control was important in the context of aspects of communication where he found the anticipation of the unexpected stressful. He therefore preferred emails that allowed him to choose when and how to respond, rather than phone calls, which could happen at any time, with no time to prepare:

"*It's why a lot of autistic people don't like using the telephone. Because the telephone rings and you're not expecting it, so you're going to answer it. They much prefer emails because you look at the email, you don't have to open it straight away, you can open it when you want to open it*".

As a committed planner, Susan tried to prepare for every eventuality (even those which may not seem likely at the time): "*It's not that I think that the plane will crash but I want to know what happens if it does; I will think about it, have a plan*". This is a process of regaining control by making the unknown known, preparing for what might happen so as not to be taken by surprise.

Uncertainty as a challenge

It is worth mentioning here that not all uncertainty was thought of as negative or problematic. John relished puzzles and '*complex analytical problems'* which he saw as a more positive form of uncertainty, and one he could, and often would, choose to engage in.

Amelia, saw uncertainty as inherently stressful, as she felt that uncertainty meant "*that [she did not] have complete control of the quality of [her] life*" and that there were "*decisions that were out of [her] hands*". Nonetheless, she also felt that "*whereas if you [would] have a bit of uncertainty, you [would] have a bit more stress in your life, but there [would be] potential for your life, for it to be better*"

This was emphasized by Francis, who liked "*not knowing what [he was] going to do, somehow, because it [gave him] a bit more choice and [he felt] more in control, when [he felt] that options were open to [him]*"

In summary: For all the participants uncertainty was at the very least a stressful experience. The kind of uncertainty that participants discussed as being particularly stressful and anxiety-provoking was characterized by a lack of control. For some, though, a degree of uncertainty was necessary, could also be useful, and was even sometimes pleasurable, as long as they retained their agency in how to engage with it.

Managing uncertainty and the need for certainty.

Following informal feedback from an autistic friend who mentioned the importance of needing certainty for her, the researcher also asked participants to consider how they understood and experienced certainty. This helped to develop the theory of uncertainty as a process of moving away from and then back towards the safety of the known, the certainty.

Conceptualising certainty

Interestingly, participants found this section harder than they had anticipated, and often talked about 'certainty' as the absence of 'uncertainty' rather than having a clear conceptualisation of it in its own right.

For Rachel, being certain meant "*being sure that something's definitely going to happen*" which meant that "*you can plan for it*". When Henry thought about certainty, he thought about things happening "*how you expect*" and things he felt "*that you have control over*". Certainty also meant something definitive, for Francis:

"*Certainty is when you know* (…) *it's going to happen this way, whether comforting or not (...), you know what to action in advance. (...) It allows me to predict how I can minimise the impact of anything*".

Francis also felt less anxious about the uncertainty around not knowing either the content or the outcome of an exam if he had had time to prepare and was told what to revise: "*playing the piano knowing what exactly what's required for the exam (...) to be able to prepare in advance - and I know that certainty, that they're going to test me on that*."

Here, underlying it all was the notion that having certainty equated with what they *needed* to know. For Rachel, the things she needed to know were: "*what time do you have to be there, how many people, if it's a meeting; it's less likely now (...) if it's going to be a noisy environment, or a quiet environment*". Certainty was confidence in the knowledge, the reliability of the information and the sense of control and agency this gave them over unfolding events.

Certainties and knowns as anchors in people's lives

The participants' reliance on routine and established patterns was interpreted as sticking to what they know and have already experienced or staying in the 'known', their place of safety. For instance, George had a fairly set routine, and always ate the same foods at the same time, and went for the same walks every day. He worked "*very hard to make sure everything's pretty certain, around [him]*."

For John, knowing what was going to happen was a way for him to be able to switch off and concentrate on what he was interested in. Certainty of what was going to happen meant that there would be no surprise: "*you do everything absolutely by a routine, because if you've got routine, you've got an expectation of certainty*".

Having an anchor, a certainty to hold on to, was something they needed to counter their anxiety over things being out of their control. For Amelia, for example, who was unexpectedly made redundant and had to quickly find somewhere else to live, changes which were imposed by others left her with a feeling of not having control and agency in her life, and meant that she valued certainty as:

"*things that can't be changed by other people, basically. (…) so I have complete control, or, not necessarily me, but I don't have a lack of control over it, because it's already definite, what's going to happen.*"

Continuing this theme of anchors and structures, guidelines and rules of behaviour could also provide a framework. This 'known' could be generalised and could make unknown situations easier to manage. For instance Henry enjoyed going to work with other people, because at work he and his colleagues have a purpose. While he would avoid parties with free, structureless interactions, he enjoyed going to concerts, as there, too, everyone had a purpose and focus.

Sometimes this guideline was a trusted person, organisation or family member. Friends and family provided support for Francis, who needed reassurance and validation both from his existing friends (known) and his new colleagues who could show him the ropes in his new job. Susan, on the other hand, would feel able to do things she mightn't otherwise, as long as she had her daughter with her. The researcher interpreted this as having a known as an anchor and source of knowledge that helped one to navigate the unknown.

Certainties and constants helped the participants deal with uncertainties in their everyday life. Francis talked about routines (for example at work or school), and having a home and, importantly, a network of friends as being his 'structure' which gave him a sense of security:

> "*because at least I know that something was in place, I felt that it was a bit under control and that, knowing that I have a place to go to and then, that I have a job (...) It was just nice to have everything that fitted like a jigsaw puzzle*".

For Susan, knowing where things were going to happen was important, as a sense of place was a certainty that she needed: "*because they're known (...); they're constant in a changing world, I suppose*".

In summary: Certainty consisted of anchors and 'knowns' which helped maintain a degree of control in the process of managing uncertainty and ultimately arriving at a state of knowing. The more the various aspects of their lives were certain, the more they knew and could rely on it in any given situation, and the more secure they felt.

In other words, certainty was a known that the participants could rely on and depend upon to help them navigate the more stressful unknown. Predictability and knowns helped create a sense of being safe, secure, and ultimately at peace, or, as John put it, '*equanimity'.* Not being taken unawares gave them time to process and, by being prepared, exercise agency in their life and in a sense control their environment.

Part 2: A Grounded Theory of Uncertainty

[Insert Figure 1 here]

Three degrees of knowns

The meaning of uncertainty for participants, therefore, was very closely linked to that which is unknown. Different types of unknowns were experienced as anxiety-provoking to varying degrees. This model of uncertainty is illustrated in **Figure 1**, which represents uncertainties that are increasingly anxiety-provoking as a series of concentric circles. The different degrees and types of knowns and unknowns are described in more detail below.

The analysis also suggested that participants seek to mitigate these uncertainties by reducing the unknown through information gathering or the adherence to routines. This was interpreted as a way of regaining control over the uncertainty. When participants experience a lack of such control over the unknown, feelings of anxiety and distress are typically severe. We therefore propose the framework set out in **Figure 2** as a theoretical model to understand the causal relationship between uncertainty and anxiety in autism (and possibly the general population).

[Place Figure 2 here]

A key feature of the model is the prediction that uncertainty-related anxiety is dependent on the level of perceived control/agency that participants have over the unknown. In this context the model distinguishes between the following different degrees of knowns and unknowns (see also **Figure 1**):

Knowns

The knowns are certainties: the constants in a changing world. These provide stability and security and also provide a toolkit of techniques and opportunities to navigate situations of uncertainty. These are Francis' structure , Susan's plans , and John's and George's routines.

Known unknowns

The known unknowns are situations with limited certainties, but for which the parameters of the uncertainties are known, or for which one retains a degree of control. This can range from situations such as exams, gambling with known ratios and risks, uncertain situations from which one can escape (e.g., a party which one can decide to leave), or situations which are avoidable or that one can carefully plan and prepare for (e.g., what the weather is going to be like when travelling). This type of known unknown is exemplified by Francis' exams, George's investments as well as Susan relying on her daughter to take her to new places, Henry preferring the structured social interactions of an office environment, or Fred building slowly on previous success to get to know this unknown.

Unknown unknowns

The unknown unknowns are those situations over which one has little if any control, for which one cannot plan or prepare, and which are unavoidable. These prove to be the most

anxiety-provoking situations and can range from unexpected events, unplanned changes or cancellations, events for which relevant details are very loosely specified (timing, what exactly is involved etc), or social situations with limited structure or specific goal. Such situations are particularly challenging when there are limited opportunities for escape or avoidance and no guidance regarding possible outcomes or processes. These types of situations range from the (then) current situation of living through a pandemic and not knowing if things are going to be cancelled, to train cancellations and the inherent unpredictability of people.

Uncertainty and Anxiety

The construct of uncertainty as different degrees of 'known' therefore lends itself to the beginning of an explanation regarding its relationship to anxiety in the following manner: certainty, or knowns, represent a place of safety and John's '*equanimity'* . As this 'known' becomes increasingly 'unknown', anxiety increases too. What became clear from the interviews is that the participants who openly expressed that they disliked and avoided uncertainty as well as discussing the fact that they suffered from anxiety, and in cases had undergone therapy to deal with their anxiety were likely to need less of an 'unknown' before becoming anxious. They were more likely to view this 'unknown' as either dangerous or negative, and catastrophise by imagining the worst case scenarios. Whereas others were perhaps more open to exploring the 'unknown' as long as there was no loss of control or agency (i.e.: choice).

Discussion

The main researcher interviewed fifteen autistic people in order to explore the way in which autistic people conceptualise and experience uncertainty. The main theme that recurred in

people's narrative was that 'uncertainty' was 'not knowing'. This 'not knowing' however, was not always experienced as anxiety provoking. Rather, 'not knowing' became a source of anxiety only when it felt difficult to plan for, or control. In this study, we refined the construct of Uncertainty and its relationship to anxiety to a model including three different levels of knowns: ranging from the certainty of what is 'known', through the relatively manageable uncertainty of the 'known unknown', to the anxiety provoking 'unknown unknown', which is difficult to avoid or manage through planning or information gathering. There were aspects of this relationship which could be unique to autism, such as their need for certainty in terms of environment, timing and their difficulty in making predictions in their relationships with non-autistic people.

Indeed, autistic people tend to score consistently higher on measures of intolerance of uncertainty (however this is defined) and measures of anxiety (e.g. [6];[7,42–44]. Boulter, Freeston, et al's framework [45]), indicated that although there is a relationship between IoU and Anxiety in both typically developing and autistic children, this relationship is stronger in autistic children. Autistic people also score more highly on questionnaire measures of sensory processing differences and assessments measuring Rigid and Repetitive Behaviour (RRB), which constitute facets of the criteria for a diagnosis of autism. RRB includes an '*insistence on sameness*' and sensory processing differences as diagnostic descriptors (Boucher, 2017), and research examining the relationship between RRB and anxiety consistently finds a positive correlation in autistic children and adults [46–49]. Furthermore, in their study examining the relationship between sensory processing differences and RRB, Wigham and colleagues [24] found that there was evidence for a direct connection between sensory under-responsiveness and both the repetitive motor behaviours and the insistence on sameness components of RRB and that IoU acted as a mediator between autism and anxiety. These differences in interaction with the environment could have an impact on how much

622 uncertainty there may be to deal with in the world that autistic people inhabit, above and
623 beyond what non-autistic or neuro-typical people may be exposed to.
624
625 Research into the role of uncertainty in anxiety in autism has thus far focused almost
626 exclusively on the Intolerance of Uncertainty Scale and its relationship to measures of
627 anxiety and different types of emotional processing [14,18,43]. One of the potential pitfalls of
628 self-report measures is that for different populations or samples the nature of uncertainty is
629 not defined or explored in any specific detail. Additionally, what the questionnaires and the
630 analyses that explore relationships between them cannot say, is *why* autistic people score
631 highly on these measures.
632 The Intolerance of Uncertainty Scale short version[9] in effect consists of two subscales:
633 Prospective IoU measures the extent to which people are anxious about the future, have a
634 need for predictability and seek information to increase certainty, whereas Inhibitory IoU
635 measures behavioural responses to uncertainty by measuring the extent to which people avoid
636 situations of uncertainty and experience paralysis in the face of it[50]. As well as exploring the
637 participants' responses to uncertainty, this research sought to clarify further the reasons for
638 being anxious about the future and the need for predictability and information, helping to
639 disentangle which uncertainties might lead to which behavioural responses and why.
640
641 By adopting a Grounded Theory qualitative approach, the present study makes an important
642 contribution to the literature by refining the construct of uncertainty in terms of different
643 levels of 'unknown' that are distinguished on the basis of the level of perceived control or
644 agency that individuals can exercise in reducing uncertainties. Conceptualised in this way, the
645 relationship between uncertainty and anxiety can be understood in terms of such levels of
646 perceived control, whereby uncertainties that are difficult to control or escape from are

experienced as distressing and anxiety-provoking, whilst uncertainties that can be controlled are not (or at least less anxiety-provoking).

Implying a lack of control as an important mechanism linking IoU and Anxiety resonates with some earlier literature about the role of the locus of control in Anxiety. Mandler and Watson (1966[51] and Watson, 1967[52]) hypothesised that if people perceive events that may affect them as being outside of their control, they are more likely to feel anxious. To this Abramson added that if one's own actions were perceived as having no effect on the external environment, then a sort of resigned 'helplessness' would ensue, and no further action would be taken to remedy a problem perceived as unsolvable[53]. Bandura (1982)[54] looked at the extent to which expectations of success were matched with estimations of self-efficacy. More recently Weems and Silverman (2006)[55] integrated these earlier models by conceptualising anxiety as different levels of discrepancy between control (actual or perceived; internal or external) and our perceived capacity for doing anything about it: a maladaptive response would stem from a dissonance between actual power and the reality of one's capacity to effect change (either an over- or underestimate).

The model of uncertainty proposed in the current study, posits that it is not just the perception of a lack of control which makes uncertainty more anxiety-provoking, but actual control over those resources which may help alleviate it – be they the anchors of the familiar (routine, family and other certainties and knowns), sources of information, or escape routes and choices. Knowledge enables them to prepare for eventualities and make informed decisions to suit their needs thereby providing them with a degree of control.

The findings of this research indicate further that the autistic participants conceptualised uncertainty as two different types of external locus of control. The first type was predictive,

and therefore future-orientated. If the future was unpredictable, then it needed to be controlled, through planning, routine, structure etc, where possible.

In their focus group study with young autistic adults and people working with young autistic adults, Trembath and colleagues[56] found that both professionals and autistic adults themselves identified 'anticipation' of an unknown event (either in terms of timing or the event itself) as being a significant trigger for anxiety. This concurred with Hodgson and colleagues' focus group study[57] with mothers of autistic school-aged children, which also found that unexpected events and situations were seen as anxiety-provoking.

In the current study, too, for most participants, not knowing what might happen in the future or what it would be like represented the most anxiety-provoking aspect of uncertainty. They tried to alleviate this anxiety by planning for eventualities so that an idea of the unknown would already be formulated and envisaged. Dealing with uncertainty meant either accepting the future as an unknown and making as much as possible known, or exercising control by being prepared or relying on known certainties.

The second type of locus of control was more related to self-efficacy and self-awareness. A number of participants reflected on how uncertainty used to be more difficult to manage when they were younger. One of the strategies used by parents and teachers in the Hodgson, Freeston, Honey et al (2017)[57] study involved exposing the children to the idea of the unexpected. This resonated with the experience of the interviewees, who found that along with a growing awareness and acceptance of themselves, what had helped was gradual exposure to situations and demands, providing them with a bank of experiences on which to draw to help them deal with challenges in their current and future lives. It is undeniable that age can often bring greater material independence and with it, agency and control over the circumstances in one's life.

A related concept is that of the locus of evaluation[58]. This can either mean, in a psychotherapeutic relationship, where the locus of evaluation might lie (usually with the client) or, more generally locus of evaluation as it pertains to personality organization. The latter refers to emphasis given by the individual to a source of information, either internal or external to the self, which is then used to form an attitude towards the self[58]. It is possible that there was a sense of distrust of self-evaluation in some of the participants, particularly for Jeremy who had difficulty in understanding how he felt, or he ought to feel in any given situation. Whereas Steven felt that he wasn't quite able to fit in with unknown rules he felt non-autistic inherently 'knew' and yet changed seemingly in a haphazard manner. Increasingly, autistic people are beginning to see 'their' autism as a key part of their identity[59]. It has been proposed that the minority stress model, originally designed to investigate the effect of social stigma on the mental health and wellbeing of people of diverse sexual and ethnic identities, could also apply to the nascent neurodivergent identity[60]. The stressors include victimization and discrimination, physical concealment of autism, as well as expectation of rejection and internalized stigma: all potentially contributing to psychological distress . Some participants in this study did indicate that they expected a social interaction to go wrong (e.g. Fred, and it is possible that they could have internalized that the 'fault' somehow resided in them. However, when the participants discussed their diagnosis and indeed their identity as autistic people, it was largely positive, some (e.g. John) even stating that it is through a process of better self-understanding, that they were better able to cope with stress and uncertainty now.

Limitations

It is possible that the fact that the study was advertised as a study on the role of uncertainty in anxiety may have biased the sample towards participants who had an interest in anxiety –

either through their own experience of it, or through personal connections with it. We collected some questionnaire data, in order to verify that the sample was a representative one of the autistic community. The percentage of the participants who scored at or above threshold on the ASA-A scale was 40%, which is, admittedly, at the higher end of what we know of the prevalence of anxiety in autism.

This was not participatory research insofar as the autistic community was not consulted regarding the general topic of the research, nor did we seek advice on the method of analysis. However, we did try and ensure that, by using a grounded theory approach which is, as the name indicates, grounded in the data, and by sending them summaries of our findings for 'checking' before finalising our analyses, that we ensured that our findings were a true reflection of the experience of our participants. Future research could involve autistic people and, where appropriate, their family and/or carers or advocates, at all stages of the research, including the design of the research protocol, and choice of analytical approach.

Because of the nature of this study, which consisted in interviewing autistic people one-to-one in order to learn about experiences first hand, we only interviewed autistic people who were able to express themselves aurally, and meaningfully respond to the questions without support. This is a limitation to this research. A possible follow-up to this study, therefore, would be to explore ways in which autistic people who do not express themselves verbally with ease could nonetheless be included and their experiences of uncertainty be explored in different ways, such as photovoice[61]

Conclusion

The in-depth analysis of the interviews in the current study and the subsequent development of a Grounded Theory conceptualised uncertainty as different levels of unknowns, and

identified the issue of control as an important mediating factor in experiencing uncertainty as anxiety-provoking. Planning, preparing and gradual exposure are all examples of exercising control over the unknown.

This is an exploratory study with a relatively small sample. Acknowledging the limitations of the study, we hope that a better understanding the different types of uncertainty which might be anxiety-provoking will help foster further research on how increasing agency, self-understanding and confidence in making choices may help improve well-being for autistic people. It is possible that ensuring people have a degree of control over their life and decisions that are made about it, and that they are given time to process and resources to exercise their agency, may also help reduce anxiety.

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Author contributions

Laura Lennuyeux-Comnene (LLC) conceived of the idea as part of her PhD thesis at City, University of London, which was supervised by Dr. S.B.Gaigg (SBG). LLC designed the interview protocol with support from Dr J. Yates (JY) and SBG, with additional support from personal acquaintances (parents of autistic adults and an autistic adult). LLC recruited participants, and analysed the data with support from JY. LLC wrote the findings up as part of her dissertation. All authors contributed to the final manuscript and approved the final version.

Conflict of interest

The authors have no conflicts of interest to declare.

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Figure legends

Figure 1: *An illustration of uncertainty as different levels of knowns*

Figure 2: *A theoretical model of the relationship between uncertainty and anxiety in the experiences of autistic adults*