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

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

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25 **Keywords:** autism; anxiety; intolerance of uncertainty; uncertainty

26 **Abstract**

27 **Background:** While previous qualitative work has identified the role of intolerance of  
28 uncertainty in the development of anxiety in autism, there has been little research on what  
29 uncertainty means exactly for autistic people and/or what types of uncertainties may be  
30 particularly anxiety-provoking.

31 **Methods:** 15 autistic adults (5 women) took part in this qualitative interview study in which  
32 we probed their understanding and experiences of uncertainty and its links to feelings of  
33 anxiety. We applied a grounded theory approach to transcripts of the interviews, broadly  
34 following Charmaz's constructivist epistemology, to derive a theory of uncertainty as it is  
35 experienced by the autistic people we interviewed.

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

42 **Conclusion:** Previous researchers had treated uncertainty as a unified construct. However,  
43 they may not have explored what uncertainty might mean for autistic people. We have  
44 shown in this study that not all uncertainties are experienced equally. We hope that this  
45 research will help develop a more nuanced understanding and that it constitutes the first step  
46 in disentangling anxiety from intolerance of uncertainty in autism.

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50

51 **Introduction**

52 High rates of anxiety in autism have been reported in systematic reviews and meta-analyses.  
53 For instance van Steensel, Bögels, & Perrin<sup>1</sup> report rates of 30-50% in young people with  
54 autism, and Buck, Viskochil, Farley et al<sup>2</sup> report rates of 40-50% in adults. This is compared  
55 with anything from 2.2 to 20.9% in children and adolescents (from 6.4% in Europe, and to  
56 18.1% in the US).<sup>3a</sup>

57

58 A more recent systematic review from 2021<sup>4</sup> found substantial heterogeneity in prevalence  
59 of co-occurring conditions in autism, with figures of anxiety co-occurring with autism,  
60 ranging from 0 – 82% in children and adolescents. The heterogeneity in prevalence reported  
61 here may be due to the heterogeneity of design and methods used to estimate this prevalence  
62 in the studies included in the review. An earlier meta-analysis from 2020<sup>5</sup> found a much  
63 lower pooled estimate of co-occurrence of anxiety and autism of 20%. The lower pooled  
64 estimates cited here in this umbrella review could be due to the differences in diagnostic  
65 criteria, as well as the different instruments used in the studies included in the review.

66

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

71

72 Intolerance of Uncertainty (IoU) as a construct was conceived first out of a distinction  
73 between fear and anxiety, the latter being directed at the possibility (real or imagined) of

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<sup>a</sup> 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.

74 something unpleasant happening in the future<sup>9</sup>. For Lidell<sup>10</sup>, anxiety was an outgrowth of  
75 vigilance as an adaptive function of awareness of potential danger. Anxiety can thus be  
76 identified as when this concern for future events is extended and maintained over a long  
77 period of time and consequently quality of life is impaired<sup>11</sup>. Worry is a facet of anxiety  
78 which particularly pertains to the persistence of this concern<sup>12</sup>. Lazarus proposed that anxiety  
79 was an emotion which was based on appraisal of the anticipatory and uncertain elements of  
80 future threats, which, importantly, were also the result of the person perceiving themselves as  
81 not having the cognitive resources (in his terms the interpretive schemata) to resolve the  
82 situation<sup>13</sup>. Worry and by extension anxiety, then, are related to IoU, which is characterized  
83 by thinking that all unknown future events are by definition distressing and that the preferred  
84 behaviour is therefore to avoid situations where outcomes are unknown.

85

86 IoU is defined as a feeling of stress in the face of uncertainty, and was initially postulated as a  
87 factor contributing to Generalized Anxiety Disorder (GAD) in the general population<sup>14</sup>.

88 People who report high levels of IoU on measures such as the Intolerance of Uncertainty  
89 Scale (IoUS)<sup>9</sup> find situations of uncertainty stressful, have a tendency to view such situations  
90 as inherently threatening and experience difficulty functioning in the face of uncertainty<sup>15-17</sup>.

91

92 Researchers have tried to identify the causes and risk factors of the high levels of anxiety in  
93 autism<sup>7</sup>, with an emerging consensus that IoU plays a critical role<sup>18</sup>. The majority of this  
94 work, however, has been based on the use of self-reports<sup>19</sup>.

95

96 The IoUS is a measure of how someone might feel and process uncertainty, but it is also a  
97 measure of behavioural responses to uncertainty. Ledoux and Pine<sup>20</sup> argue for two separate

98 neural circuits for emotional and behavioural responses to uncertainty. This might suggest  
99 that the IoUS could be conflating two different processes.

100

101 Furthermore, although the IoUS is thought to capture a single unified construct<sup>9,15,21</sup>, it seems  
102 unlikely that all types of uncertainty in life are equally anxiety-inducing. For example,  
103 uncertainties involved in gambling seem qualitatively different from the kinds of  
104 uncertainties that have characterised the Covid pandemic.

105

106 Both of these points indicate a need to exercise a degree of caution regarding a possible over-  
107 reliance on self-reported measures of IoU.

108

109 Nonetheless, according to findings from studies using self-report questionnaires such as the  
110 IoUS, autistic participants consistently report greater levels of IoU<sup>22,23</sup> and modelling studies  
111 show that this construct constitutes one of the strongest predictors of self-reported levels of  
112 anxiety<sup>18,24</sup>. It is important to note that although self-report measures are an oft used and  
113 quick way of gathering a large amount of data, they do not come without their drawbacks.  
114 Self-report measures have been developed by, and with, non-autistic people (with some  
115 exceptions such as the ASA-A<sup>25</sup> used in our study). This means that questionnaires may not  
116 have been designed in the most accessible way for autistic people<sup>26</sup>. Furthermore, a reliance  
117 on ‘validity’ and ‘reliability’ may be at the expense of ‘relevance’ for autistic people; i.e. the  
118 existing instruments may not adequately reflect the lived experience of autistic people<sup>27</sup>.

119 However, qualitative research such as interviews do indicate that autistic adults and  
120 adolescents report that uncertain and unpredictable situations are anxiety-provoking for them  
121 and that they try to avoid them as much as possible. For instance Robertson, Stanfield, Watt,  
122 et al<sup>28</sup> conducted semi-structured interviews with autistic adults, carers and partners of

123 autistic adults and found that participants consistently described change and unpredictability  
124 as sources of anxiety. Parents and teachers of autistic children similarly report that  
125 uncertainties, particularly in social contexts, are often the source of distress<sup>29</sup>.

126  
127 Researchers investigating different interventions have shown the importance of including  
128 intolerance of uncertainty as a target for treatment for anxiety in autism. However, while  
129 previous work such as the development of the Coping with Uncertainty in Everyday  
130 Situations (CUES) intervention has focused on Intolerance of Uncertainty<sup>30</sup>, the construct of  
131 ‘uncertainty’ itself remains relatively ill-defined.

132  
133 In this study, we sought to explore further the kinds of uncertainty which might be more  
134 likely to cause anxiety than others for autistic individuals. Additionally, we aimed to help  
135 clarify what kinds of uncertainties may lead to anxiety and to disentangle which emotional  
136 and cognitive responses may lead to which behavioural response. Working towards a better  
137 understanding of the experiences of our interviewees may contribute to future studies aimed  
138 at unpacking mechanisms through which uncertainty may lead to anxiety. In turn,  
139 understanding what uncertainty means for and how it is experienced by autistic people in  
140 their day-to-day lives may help develop more effective support strategies for autistic people  
141 who may find uncertainty difficult. .

142  
143 Thus, in this study, we aimed to explore *how autistic people conceptualise and experience*  
144 *uncertainty*. Thereby, we hoped to refine the definition of the construct of uncertainty, in  
145 order to investigate further the role it may play in anxiety in autism. To this end, we  
146 conducted semi-structured interviews to provide a flexible context within which the  
147 interviewer and participants could freely explore the meaning and experiences of



148 uncertainty. We adopted a grounded theory approach, with a constructivist epistemology<sup>31</sup>,  
149 which provides a systematic yet flexible approach to construct theories grounded in data<sup>31</sup>.

150

## 151 **Methods**

### 152 Participants

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

160

161 To help characterise the patterns of strengths and difficulties across core diagnostic functional  
162 domains and experiences of anxiety, we asked the participants to complete the Social  
163 Responsiveness Scale (SRS-2-ASR)<sup>32</sup> and the Anxiety Scale for Autism (ASA-A)<sup>25</sup>. The  
164 scores for the SRS-2-ASR ranged from 76 to 90+, with 10 participants scoring in the 'severe'  
165 range of above 85 and the rest in the 'moderate' range. Scores for the ASA-A ranged from 17  
166 to 44 with seven participants scoring above 28, which has been suggested to indicate  
167 clinically significant levels of anxiety. Additionally, although we did not ask for any formal  
168 medical history, during the interviews three participants mentioned they had received or were  
169 receiving treatment for anxiety, and three for depression, while two participants talked about  
170 experiencing Obsessive Compulsive Disorder (OCD). One participant also referenced a  
171 family history of ADHD and one a personal history of schizoid personality disorder. None of  
172 the participants in our sample had any identified learning disability or language impairment.

173

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

177

#### 178 Setting

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

183

#### 184 Procedure

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

189

190 We used a semi-structured interview approach to guide the conversation and maintain focus  
191 on the core issue of interest, while providing enough flexibility to allow the participants to  
192 lead the conversation while remaining both relevant and open to their experiences and  
193 understanding. During the development of the interview schedule (see appendix 1), the first  
194 author held informal consultations with parents of autistic people, with researchers and an  
195 autistic person, in addition to the pilot participant who informally provided feedback on her  
196 experience of the interview. The latter person, who wishes to remain anonymous, suggested  
197 that what autistic people may want, rather than not being uncertain, was to be certain. This

198 prompted the main researcher to add questions in the interview schedule regarding the areas  
199 in which participants may need certainty. The main researcher then piloted the interview  
200 schedule with three parents of autistic adults, one tutor of autistic children and young people,  
201 and an autistic adult to obtain rich perspectives that might prompt further revisions to the  
202 initial draft interview schedule. We encouraged the pilot participants to give feedback on the  
203 conducting of the interview as well as on the questions. Only one autistic adult was  
204 interviewed for the pilot as the project was initially to only include interviews with adults and  
205 parents and professionals working with autistic people. However, the main researcher, after  
206 reflecting on the pilot interviews, considered that parents and professionals had a different  
207 narrative concerning what they perceived to be the experience of uncertainty by autistic  
208 people and therefore considered that it was unfeasible to aim to develop a grounded theory  
209 that would be applicable to the different experiences. Therefore, for this study we only  
210 interviewed autistic adults for the main data collection, although we note that interviewing  
211 parents and professionals working with autistic people with little or no spoken language  
212 would be worth pursuing in future studies. Another modification stemming from the pilot  
213 interviews was the order of the questions, which we changed to allow for a suitable space for  
214 a break, should participants need it. Lastly, we defined the topics which were going to be  
215 discussed more clearly at the beginning, so as to give the participants a little time to process  
216 and to give them an idea of what was to come.

217

218 The final version of the interview guide included as Appendix 1, started with broad  
219 conceptual questions (e.g. *“People apply many different meanings to the word ‘uncertainty’.*  
220 *When you say ‘uncertainty’ what do you mean?”*), followed by probes about the experience  
221 of uncertainty in different situations (e.g. *“Can you think of a time recently when you felt*  
222 *uncertain?”*). After advice from the autistic person whom we consulted in the development of

223 the schedule, we added the concept of certainty. Interviews lasted between 35 minutes to just  
224 over an hour and began with the researcher outlining what the participant could expect from  
225 the interview and reminding them of the key information in the participant information sheet  
226 (e.g. right to withdraw etc). We generally avoided small talk before beginning the interview  
227 as there are indications that this can make the participants feel uncomfortable rather than  
228 more at ease<sup>33</sup>. However, the interviewer let herself be led by the participants in this respect.

229

### 230 Research approach and Analysis

231 The interviewer transcribed each interview verbatim either on the same day, or the next day.  
232 She conducted the analysis simultaneously, partly with the use of NVivo 12 pro<sup>34</sup>, through a  
233 process of continuous evaluation and constant checking by testing out nascent ideas and  
234 themes with each new participant. This is known as theoretical sampling and is a key part of a  
235 grounded theory analysis and approach<sup>35-37</sup> that develops new theory whose abstractions are  
236 derived directly from data<sup>38</sup>. The term refers to both the theoretical analysis and the resulting  
237 product of the method<sup>39</sup>. In this current study, we adopted a grounded theory which leant  
238 towards a constructivist approach, as described by Charmaz and Henwood<sup>40</sup>, constructing a  
239 theory about the experiences of participants through interaction with, and interpretation of,  
240 the data in successive levels of analysis involving memo-writing, coding and drawing up of  
241 categories and diagrams.

242

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

247

248 Importantly, she was not completely naïve of autistic experience or theory, as she is a  
249 researcher in autism, the parent of an autistic adult, and someone who has worked as a carer  
250 and support worker of autistic children and young people and their families. Her background  
251 helped to sensitize her approach<sup>41</sup> and to *‘be more sensitive to concepts in data but also*  
252 *enable them to see connections between concepts’* (Corbin & Strauss <sup>41</sup>, p79). It may also  
253 have influenced how she interpreted statements where there might have been ambiguity. To  
254 counter this, as part of the continuous theoretical sampling, the interviewer checked her own  
255 interpretations and thoughts during, as well as after, the interviews. The other researchers,  
256 while being less involved in the analysis, nonetheless helped shape and refine it. The first is a  
257 qualitative researcher who has no autism experience but was able to guide the main  
258 researcher in her methodology and the second is a researcher, who although having no  
259 personal or lived experience of autism has been a researcher in autism for many years and as  
260 such could provide guidance regarding theoretical underpinnings of the analysis. Thus, we  
261 adopted grounded theory in this study as a process of co-construction<sup>42</sup>, which combines a  
262 form of informed induction (the formulation of a theory based on observation and reflection)  
263 with abduction (deciding on a ‘best’ description of the data from amongst a number of  
264 possible different explanations).

265

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

270

271

272

273 **Findings**

274 In the findings set out below, we will first describe the themes and resulting categories  
275 regarding how the participants conceptualised and experienced uncertainty. In contrast to a  
276 thematic analysis where one might seek to find discrete themes, in grounded theory these are  
277 interrelated as they are progressive building blocks for the eventual construction of the theory  
278 itself.

279

280 **Part 1: Themes and Categories**

281 **What is uncertainty?**

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

286

287 Not knowing what is going to happen, what things are going to be like, what the outcome of  
288 one's decisions might be.

289 For some, uncertainty was primarily related to not knowing what was going to happen or  
290 what the outcome would be of one's decisions and behaviour. For instance, Sylvia, during  
291 the pandemic when things were likely to be cancelled at the last minute felt "*really uncertain,*  
292 *even up to the morning [she] went [anywhere], whether [she] was going to be able to go.*"

293 What made it uncertain was that unexpected changes could happen at the last minute, not  
294 giving her enough time to plan.

295

296 For others, uncertainty was not knowing what things were going to be like, more than  
297 whether or not they would happen. For instance, Jeremy, when planning a holiday, would do

298 a lot of research prior to going. He would look things up, including on StreetView, yet  
299 “would still retain a sense of ...not actually knowing what it was actually going to be like,  
300 when [he] got there”. For Jeremy, this was compounded by his difficulty anticipating how he  
301 would or should be feeling in any given situation, saying: “I think if I have, if the, uhm,  
302 autism thing has any effect on me, really, is that I’m never sure what I’m thinking (...) I don’t  
303 know, what I feel in any particular situation”. For others, not knowing what something could  
304 be like could be exacerbated by increased sensory sensitivities. For instance Rachel, who  
305 needed to know if somewhere was going to be noisy. Note that she did not phrase it in such  
306 terms, nor did she underline that this was a way in which she may have been different from  
307 non-autistic people.

308

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

320

321 For participants who did not have solid foundations (a permanent home or income),  
322 transitions from a known to an unknown, on a grander scale were also deeply unsettling.

323 Francis, for example, when made redundant and having to start a new job, was very anxious  
324 about “*the fact that [he didn’t] know where the job [was], where [he was] going to be*  
325 *relocating*”.

326

### 327 People as unpredictable

328 Another aspect of ‘now knowing what was going to happen’ was specific to social situations  
329 and interactions, most often with non-autistic people, an example, perhaps, of a double-  
330 empathy problem<sup>43</sup>. The autistic interviewees fearing to be misunderstood by , as well as not  
331 always understanding, non-autistic people . The participants expressed that they found non-  
332 autistic people as inherently confusing and unpredictable. For Fred, it was the  
333 unpredictability in any social interaction which was uncertain: “*But you don’t know what will*  
334 *happen. I mean someone could say something that - or I could say something that - offends*  
335 *someone and then it goes a bit wrong, and I feel depressed about the world and that kind of*  
336 *thing*”.

337

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

343

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



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

351

352    Unsure of what to do

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

358

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

371

372

373 Uncertainty as pervasive

374 Finally, the meaning of uncertainty for participants also often comprised an element of  
375 something that is omnipresent and unavoidable. As Steven put it, the “*unbounded unknown*”:  
376 it was everywhere, anything situated in the future and all around. For Stuart, “*anything that*  
377 *[was] in the future [was] uncertain*”. For Sylvia, life itself was uncertain: “*I suppose it’s the*  
378 *whole of life [laughs] (...) That’s just what life is, uncertainty.*”

379

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

386

387 **Experience of Uncertainty**

388 Uncertainty as anxiety-provoking

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

394

395 A number of participants experienced uncertainty as a persistent worry about making or  
396 having made a mistake which would only be assuaged with validation or reassurance. For

397 Arthur, it was important to know that he had done or was doing the right thing, and for this he  
398 needed feedback and communication:

399 *“when you’re doing it remotely, all you can see is just the status on the dashboard*  
400 *and you can’t see whether the computer’s got stuck or (...) yeah, it’s things like that*  
401 *which kind of panicked me a few times, I have to admit (...) they didn’t even, respond,*  
402 *kind of thing (...). It really knocks your confidence”.*

403 Uncertainty made worse by lack of control

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

409

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

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

418

419 As a committed planner, Susan tried to prepare for every eventuality (even those which may  
420 not seem likely at the time): *“It’s not that I think that the plane will crash but I want to know*  
421 *what happens if it does; I will think about it, have a plan”.* This is a process of regaining

422 control by making the unknown known, preparing for what might happen so as not to be  
423 taken by surprise.

424

#### 425 Uncertainty as a challenge

426 It is worth mentioning here that not all uncertainty was thought of as negative or problematic.

427 John relished puzzles and ‘*complex analytical problems*’ which he saw as a more positive

428 form of uncertainty, and one he could, and often would, choose to engage in.

429

430 Amelia saw uncertainty as inherently stressful, as she felt that it meant “*that [she did not]*

431 *have complete control of the quality of [her] life*” and that there were “*decisions that were out*

432 *of [her] hands*”. Nonetheless, she also felt that “*whereas if you have a bit of uncertainty, you*

433 *[would] have a bit more stress in your life, but there [would be] potential for your life, for it*

434 *to be better*”

435

436 This was emphasized by Francis, who liked “*not knowing what [he was] going to do,*

437 *somehow, because it [gave him] a bit more choice and [he felt] more in control, when [he*

438 *felt] that options were open to [him]*”

439

440 **In summary:** For all the participants uncertainty was at the very least a stressful experience.

441 The kind of uncertainty that participants discussed as being particularly stressful and anxiety-

442 provoking was characterized by a lack of control. For some, though, a degree of uncertainty

443 was necessary, could also be useful, and was even sometimes pleasurable, as long as they

444 retained their agency in how to engage with it.

445

446

447 **Managing uncertainty and the need for certainty.**

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

452

453 Conceptualising certainty

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

457

458 For Rachel, being certain meant “*being sure that something’s definitely going to happen*”  
459 which meant that “*you can plan for it*”. When Henry thought about certainty, he thought  
460 about things happening “*how you expect*” and things he felt “*that you have control over*”.

461 Certainty also meant something definitive, for Francis:

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

465

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

470

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

477

#### 478 Certainties and knowns as anchors in people’s lives

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

484

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

489

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

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

498  
499   Continuing this theme of anchors and structures, guidelines and rules of behaviour could also  
500   provide a framework. This ‘known’ could be generalised and could make unknown situations  
501   easier to manage. For instance Henry enjoyed going to work with other people, because at  
502   work he and his colleagues have a purpose. While he would avoid parties with free,  
503   structureless interactions, he enjoyed going to concerts, as there, too, everyone had a purpose  
504   and focus.

505  
506   Sometimes this guideline was a trusted person, organisation or family member. Friends and  
507   family provided support for Francis, who needed reassurance and validation both from his  
508   existing friends (known) and his new colleagues who could show him the ropes in his new  
509   job. Susan, on the other hand, would feel able to do things she might not otherwise, as long as  
510   she had her daughter with her. The researcher interpreted this as having a known as an anchor  
511   and source of knowledge that helped one to navigate the unknown.

512  
513   Certainties and constants helped the participants deal with uncertainties in their everyday life.  
514   Francis talked about routines (for example at work or school), and having a home and,  
515   importantly, a network of friends as being his ‘structure’ which gave him a sense of security:

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

519

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

523

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

528

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

534

535

## 536 **Part 2: A Grounded Theory of Uncertainty**

537

538

539 [Insert Figure 1 here]

540

### 541 Three degrees of knowns

542 The meaning of uncertainty for participants, therefore, was very closely linked to that which  
543 is unknown. Different types of unknowns were experienced as anxiety-provoking to varying  
544 degrees. This model of uncertainty is illustrated in **Figure 1**, which represents uncertainties



545 that are increasingly anxiety-provoking as a series of concentric circles. The different degrees  
546 and types of knowns and unknowns are described in more detail below.

547

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

555

556

557 [Place Figure 2 here]

558

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

563

564 Knowns

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

568

569

570 Known unknowns

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

580

581 Unknown unknowns

582 The unknown unknowns are those situations over which one has little if any control, for  
583 which one cannot plan or prepare, and which are unavoidable. These prove to be the most  
584 anxiety-provoking situations and can range from unexpected events, unplanned changes or  
585 cancellations, events for which relevant details are very loosely specified (timing, what  
586 exactly is involved etc), or social situations with limited structure or specific goal. Such  
587 situations are particularly challenging when there are limited opportunities for escape or  
588 avoidance and no guidance regarding possible outcomes or processes. These types of  
589 situations range from the (then) current situation of living through a pandemic and not  
590 knowing if things are going to be cancelled, to train cancellations and the inherent  
591 unpredictability of people.

592

593

594

## 595 Uncertainty and anxiety

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

607

## 608 **Discussion**

609 The main researcher interviewed fifteen autistic people in order to explore the way in which  
610 autistic people conceptualise and experience uncertainty. The main theme that recurred in  
611 people’s narrative was that ‘uncertainty’ was ‘not knowing’. This ‘not knowing’, however,  
612 was not always experienced as anxiety-provoking. Rather, ‘not knowing’ became a source of  
613 anxiety only when it felt difficult to plan for, or control. In this study, we refined the  
614 construct of uncertainty and its relationship to anxiety to a model including three different  
615 levels of knowns: ranging from the certainty of what is ‘known’, through the relatively  
616 manageable uncertainty of the ‘known unknown’, to the anxiety-provoking ‘unknown  
617 unknown’, which is difficult to avoid or manage through planning or information-gathering.  
618 There were aspects of this relationship which could be unique to autism, such as their need

619 for certainty in terms of environment, timing and their difficulty in making predictions in  
620 their relationships with non-autistic people.

621

622 Indeed, autistic people tend to score consistently higher on measures of intolerance of  
623 uncertainty (however this is defined) and measures of anxiety (e.g. <sup>6,7,44-46</sup>. Boulter, Freeston,  
624 et al's framework<sup>47</sup>), indicated that although there is a relationship between IoU and anxiety  
625 in both typically developing and autistic children, this relationship is stronger in autistic  
626 children. Autistic people also score more highly on questionnaire measures of sensory  
627 processing differences and assessments measuring Rigid and Repetitive Behaviour (RRB),  
628 which constitute facets of the criteria for a diagnosis of autism. RRB includes an '*insistence*  
629 *on sameness*' and sensory processing differences as diagnostic descriptors<sup>48</sup>, and research  
630 examining the relationship between RRB and anxiety consistently finds a positive correlation  
631 in autistic children and adults<sup>49-52</sup>. Furthermore, in their study examining the relationship  
632 between sensory processing differences and RRB, Wigham and colleagues<sup>24</sup> found that there  
633 was evidence for a direct connection between sensory under-responsiveness and both the  
634 repetitive motor behaviours and the insistence on sameness components of RRB, and that IoU  
635 acted as a mediator between autism and anxiety. These differences in interaction with the  
636 environment could have an impact on how much uncertainty there may be to deal with in the  
637 world that autistic people inhabit, above and beyond what non-autistic or neurotypical people  
638 may be exposed to.

639

640 Research into the role of uncertainty in anxiety in autism has thus far focused almost  
641 exclusively on the Intolerance of Uncertainty Scale and its relationship to measures of  
642 anxiety and different types of emotional processing<sup>14,18,45</sup>. One of the potential pitfalls of self-  
643 report measures is that for different populations or samples the nature of uncertainty is not

644 defined or explored in any specific detail. Additionally, what the questionnaires and the  
645 analyses that explore relationships between them cannot say, is *why* autistic people score  
646 highly on these measures.

647

648 The Intolerance of Uncertainty Scale short version<sup>9</sup> in effect consists of two subscales:  
649 Prospective IoU measures the extent to which people are anxious about the future, have a  
650 need for predictability and seek information to increase certainty, whereas Inhibitory IoU  
651 measures behavioural responses to uncertainty by measuring the extent to which people avoid  
652 situations of uncertainty and experience paralysis in the face of it<sup>53</sup>. As well as exploring the  
653 participants' responses to uncertainty, this research sought to clarify further the reasons for  
654 being anxious about the future and the need for predictability and information, helping to  
655 disentangle which uncertainties might lead to which behavioural responses and why.

656

657 By adopting a grounded theory qualitative approach, the present study makes an important  
658 contribution to the literature by refining the construct of uncertainty in terms of different  
659 levels of 'unknown' that are distinguished on the basis of the level of perceived control or  
660 agency that individuals can exercise in reducing uncertainties. Conceptualised in this way, the  
661 relationship between uncertainty and anxiety can be understood in terms of such levels of  
662 perceived control, whereby uncertainties that are difficult to control or escape from are  
663 experienced as distressing and anxiety-provoking, whilst uncertainties that can be controlled  
664 are not (or at least less anxiety-provoking).

665

666 Implying a lack of control as an important mechanism linking IoU and anxiety resonates with  
667 some earlier literature about the role of the locus of control in anxiety. Mandler and Watson<sup>54</sup>  
668 and Watson<sup>55</sup> hypothesised that if people perceive events that may affect them as being

669 outside of their control, they are more likely to feel anxious. To this Abramson added that if  
670 one's own actions were perceived as having no effect on the external environment, then a sort  
671 of resigned 'helplessness' would ensue, and no further action would be taken to remedy a  
672 problem perceived as unsolvable<sup>56</sup>. Bandura<sup>57</sup> looked at the extent to which expectations of  
673 success were matched with estimations of self-efficacy. More recently Weems and  
674 Silverman<sup>58</sup> integrated these earlier models by conceptualising anxiety as different levels of  
675 discrepancy between control (actual or perceived; internal or external) and our perceived  
676 capacity for doing anything about it: a maladaptive response would stem from a dissonance  
677 between actual power and the reality of one's capacity to effect change (either an over- or  
678 underestimate).

679

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

686

687 In this research, we found that the autistic participants conceptualised uncertainty as two  
688 different types of external locus of control. The first type was predictive, and therefore  
689 future-orientated. If the future was unpredictable, then it needed to be controlled, through  
690 planning, routine, structure etc, where possible.

691

692 In their focus group study with young autistic adults and people working with young autistic  
693 adults, Trembath and colleagues<sup>59</sup> found that both professionals and autistic adults

694 themselves identified ‘anticipation’ of an unknown event (either in terms of timing or the  
695 event itself) as being a significant trigger for anxiety. This concurred with Hodgson and  
696 colleagues’ focus group study<sup>60</sup> with mothers of autistic school-aged children, which also  
697 found that unexpected events and situations were seen as anxiety-provoking.

698

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

705

706 The second type of locus of control was more related to self-efficacy and self-awareness. A  
707 number of participants reflected on how uncertainty used to be more difficult to manage  
708 when they were younger. One of the strategies used by parents and teachers in the Hodgson,  
709 Freeston, Honey et al<sup>60</sup> study involved exposing the children to the idea of the unexpected.  
710 This resonated with the experience of the interviewees, who found that along with a growing  
711 awareness and acceptance of themselves, what had helped was gradual exposure to situations  
712 and demands, providing them with a bank of experiences on which to draw to help them deal  
713 with challenges in their current and future lives. It is undeniable that age can often bring  
714 greater material independence and with it, agency and control over the circumstances in one’s  
715 life.

716

717 A related concept is that of the locus of evaluation<sup>61</sup>. This can either mean, in a  
718 psychotherapeutic relationship, where the locus of evaluation might lie (usually with the

719 client) or, more generally, locus of evaluation as it pertains to personality organization. The  
720 latter refers to emphasis given by the individual to a source of information, either internal or  
721 external to the self, which is then used to form an attitude towards the self<sup>61</sup>. It is possible that  
722 there was a sense of distrust of self-evaluation in some of the participants, particularly for  
723 Jeremy who had difficulty in understanding how he felt, or how he ought to feel in any given  
724 situation. Steven, on the other hand, felt that he wasn't quite able to fit in with unknown  
725 rules he felt that non-autistics inherently 'knew' and yet changed seemingly in a haphazard  
726 manner.

727

728 Increasingly, autistic people are beginning to see 'their' autism as a key part of their  
729 identity<sup>62</sup>. It has been proposed that the minority stress model, originally designed to  
730 investigate the effect of social stigma on the mental health and wellbeing of people of diverse  
731 sexual and ethnic identities, could also apply. The stressors include victimization and  
732 discrimination, physical concealment of autism, as well as expectation of rejection and  
733 internalized stigma: all potentially contributing to psychological distress. Some participants  
734 in this study did indicate that they expected a social interaction to go wrong (e.g. Fred) and it  
735 is possible that they could have internalized that the 'fault' somehow resided in them.

736 However, when the participants discussed their diagnosis and indeed their identity as autistic  
737 people, it was largely positive, some (e.g. John) even stating that it is through a process of  
738 better self-understanding that they were better able to cope with stress and uncertainty now.

739

#### 740 **Limitations**

741 It is possible that the fact that the study was advertised as a study on the role of uncertainty in  
742 anxiety may have biased the sample towards participants who had an interest in anxiety –  
743 either through their own experience of it, or through personal connections with it. We



744 collected some questionnaire data in order to verify that the sample was a representative one  
745 of the autistic community. The percentage of the participants who scored at or above  
746 threshold on the ASA-A scale was 40%, which is around what we might expect for anxiety in  
747 a sample of autistic adults (e.g. van Steensel et al<sup>1</sup>; Buck et al<sup>2</sup>).

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

756 Because this study involved interviewing autistic people one-to-one in order to learn about  
757 experiences first-hand, we only interviewed autistic people who were able to express  
758 themselves orally, and meaningfully respond to the questions without support. This is a  
759 limitation to this research. A possible follow-up to this study, therefore, would be to explore  
760 ways in which autistic people who do not express themselves verbally with ease could  
761 nonetheless be included and their experiences of uncertainty be explored in different ways,  
762 such as photovoice<sup>63</sup>

763

## 764 **Conclusion**

765 The in-depth analysis of the interviews in the current study and the subsequent development  
766 of a grounded theory conceptualised uncertainty as different levels of unknowns, and  
767 identified the issue of control as an important mediating factor in experiencing uncertainty as

768 anxiety-provoking. Planning, preparing and gradual exposure are all examples of exercising  
769 control over the unknown.

770

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

778

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781

#### 782 **Author contributions**

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

790

#### 791 **Conflict of interest**

792 The authors have no conflicts of interest to declare.

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796

797 **References**

- 798 1. van Steensel FJA, Bögels SM, Dirksen CD. Anxiety and quality of life: clinically anxious  
799 children with and without autism spectrum disorders compared. *J Clin Child Adolesc*  
800 *Psychol.* 2012;41(6):731-738. doi:10.1080/15374416.2012.698725
- 801 2. Buck TR, Viskochil J, Farley M, et al. Psychiatric comorbidity and medication use in  
802 adults with autism spectrum disorder. *J Autism Dev Disord.* 2014;44(12):3063-3071.  
803 doi:10.1007/s10803-014-2170-2
- 804 3. Kent R, Simonoff E. *Prevalence of Anxiety in Autism Spectrum Disorders.* Elsevier Inc.;  
805 2017. doi:10.1016/B978-0-12-805122-1.00002-8
- 806 4. Bougeard C, Picarel-Blanchot F, Schmid R, Campbell R, Buitelaar J. Prevalence of  
807 Autism Spectrum Disorder and Co-morbidities in Children and Adolescents: A  
808 Systematic Literature Review. *Front Psychiatry.* 2021;12:744709.  
809 doi:10.3389/fpsyt.2021.744709
- 810 5. Hossain MM, Khan N, Sultana A, et al. Prevalence of comorbid psychiatric disorders  
811 among people with autism spectrum disorder: An umbrella review of systematic reviews  
812 and meta-analyses. *Psychiatry Research.* 2020;287:112922.  
813 doi:10.1016/j.psychres.2020.112922
- 814 6. van Steensel FJA, Bögels SM, Dirksen CD. Anxiety and Quality of Life: Clinically  
815 Anxious Children With and Without Autism Spectrum Disorders Compared. *Journal of*

- 816 *Clinical Child and Adolescent Psychology*. 2012;41(6):731-738.  
817 doi:10.1080/15374416.2012.698725
- 818 7. South M, Rodgers J, Van Hecke A. Anxiety and ASD: Current Progress and Ongoing  
819 Challenges. *Journal of Autism and Developmental Disorders*. 2017;47(12):3679-3681.  
820 doi:10.1007/s10803-017-3322-y
- 821 8. Cusack, J. & Sterry, R. Your questions: Shaping future autism research. In: ; 2016.
- 822 9. Carleton RN, Norton MAPJ, Asmundson GJG. Fearing the unknown: A short version of  
823 the Intolerance of Uncertainty Scale. *Journal of Anxiety Disorders*. 2007;21(1):105-117.  
824 doi:10.1016/j.janxdis.2006.03.014
- 825 10. Liddell H. The role of vigilance in the development of neurosis-Anxiety. *Ed P Hoch, J*  
826 *Zulin, New York*. Published online 1964:183-196.
- 827 11. Spielberger CD. *Anxiety and Behavior*. Academic Press; 1966.
- 828 12. Dugas MJ, Gosselin P, Ladouceur R. Intolerance of uncertainty and worry: Investigating  
829 specificity in a nonclinical sample. *Cognitive Therapy and Research*. 2001;25(5):551-  
830 558. doi:10.1023/A:1005553414688
- 831 13. Lazarus RS. Emotion and cognition; with special reference to anxiety. *Anxiety; Current*  
832 *trends in theory and research*. Published online 1972.
- 833 14. Boulter C, Freeston M, South M, Rodgers J. Intolerance of uncertainty as a framework  
834 for understanding anxiety in children and adolescents with autism spectrum disorders.  
835 *Journal of Autism and Developmental Disorders*. 2014;44(6):1391-1402.  
836 doi:10.1007/s10803-013-2001-x

- 837 15. Buhr K, Dugas MJ. The Intolerance of Uncertainty Scale: psychometric properties of the  
838 English version. *Behav Res Ther.* 2002;40(8):931-945. doi:10.1016/s0005-  
839 7967(01)00092-4
- 840 16. Buhr K, Dugas MJ. The role of fear of anxiety and intolerance of uncertainty in worry: an  
841 experimental manipulation. *Behav Res Ther.* 2009;47(3):215-223.  
842 doi:10.1016/j.brat.2008.12.004
- 843 17. Laugesen N, Dugas MJ, Bukowski WM. Understanding adolescent worry: the application  
844 of a cognitive model. *J Abnorm Child Psychol.* 2003;31(1):55-64.  
845 doi:10.1023/a:1021721332181
- 846 18. Maisel ME, Stephenson KG, South M, Rodgers J, Freeston MH, Gaigg SB. Modeling the  
847 cognitive mechanisms Linking autism symptoms and Anxiety in adults. *Journal of*  
848 *Abnormal Psychology.* 2016;125(5):692-703. doi:10.1037/abn0000168
- 849 19. Jenkinson R, Milne E, Thompson A. The relationship between intolerance of uncertainty  
850 and anxiety in autism: A systematic literature review and meta-analysis. *Autism.*  
851 2020;24(8):1933-1944. doi:10.1177/1362361320932437
- 852 20. LeDoux JE, Pine DS. Using neuroscience to help understand fear and anxiety: a two-  
853 system framework. *American journal of psychiatry.* Published online 2016.
- 854 21. Carleton RN. The intolerance of uncertainty construct in the context of anxiety disorders:  
855 Theoretical and practical perspectives. *Expert review of neurotherapeutics.*  
856 2012;12(8):937-947.

- 857 22. Jenkinson R, Milne E, Thompson A. The relationship between intolerance of uncertainty  
858 and anxiety in autism: A systematic literature review and meta-analysis. *Autism*.  
859 2020;24(8):1933-1944. doi:10.1177/1362361320932437
- 860 23. Vasa RA, Kreiser NL, Keefer A, Singh V, Mostofsky SH. Relationships between autism  
861 spectrum disorder and intolerance of uncertainty. *Autism Research*. 2018;11(4):636-644.  
862 doi:10.1002/aur.1916
- 863 24. Wigham S, Rodgers J, South M, McConachie H, Freeston M. The Interplay Between  
864 Sensory Processing Abnormalities, Intolerance of Uncertainty, Anxiety and Restricted  
865 and Repetitive Behaviours in Autism Spectrum Disorder. *Journal of Autism and*  
866 *Developmental Disorders*. 2015;45(4):943-952. doi:10.1007/s10803-014-2248-x
- 867 25. Rodgers J, Farquhar K, Mason D, et al. Development and Initial Evaluation of the  
868 Anxiety Scale for Autism-Adults. *Autism in Adulthood*. 2020;2(1):24-33.  
869 doi:10.1089/aut.2019.0044
- 870 26. Stacey R, Cage E. “Simultaneously vague and oddly specific”: Understanding autistic  
871 people’s experiences of decision-making and research questionnaires. *Autism in*  
872 *Adulthood*. Published online 2022.
- 873 27. Jones SC. Measuring the Wrong Thing the Right Way? Time to Rethink Autism  
874 Research Tools. *Autism in Adulthood*. 2022;4(2):104-109. doi:10.1089/aut.2021.0050
- 875 28. Robertson AE, Stanfield AC, Watt J, et al. The experience and impact of anxiety in  
876 autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders*. 2018;46:8-  
877 18. doi:10.1016/j.rasd.2017.11.006

- 878 29. Goodwin, J., Plant, A., Henry, A., Freeston, M. and Rodgers, J. Living with Intolerance  
879 of uncertainty: Experiences from families of autistic children. In: ; 2017.
- 880 30. Rodgers J, Goodwin J, Parr JR, et al. Coping with Uncertainty in Everyday Situations  
881 (CUES©) to address intolerance of uncertainty in autistic children: study protocol for an  
882 intervention feasibility trial. *Trials*. 2019;20(1):385. doi:10.1186/s13063-019-3479-0
- 883 31. Charmaz K. *Constructing Grounded Theory*. 2nd edition. Sage; 2014.
- 884 32. Constantino JN, Davis SA, Todd RD, et al. Validation of a brief quantitative measure of  
885 autistic traits: Comparison of the social responsiveness scale with the Autism Diagnostic  
886 Interview-Revised. *Journal of Autism and Developmental Disorders*. 2003;33(4):427-  
887 433. doi:10.1023/A:1025014929212
- 888 33. Bagatell N. Orchestrating voices: Autism, identity and the power of discourse. *Disability  
889 and Society*. 2007;22(4):413-426. doi:10.1080/09687590701337967
- 890 34. Hutchison AJ, Johnston LH, Breckon JD. Using QSR-NVivo to facilitate the  
891 development of a grounded theory project: An account of a worked example.  
892 *International Journal of Social Research Methodology*. 2010;13(4):283-302.  
893 doi:10.1080/13645570902996301
- 894 35. Birks M, Mills J. *Grounded Theory: A Practical Guide*. SAGE Publications; 2015.
- 895 36. Birks M, Hoare K, Mills J. Grounded Theory: The FAQs. *International Journal of  
896 Qualitative Methods*. 2019;18:1-7. doi:10.1177/1609406919882535
- 897 37. Hoare KJ, Mills J, Francis K. Dancing with data: An example of acquiring theoretical  
898 sensitivity in a grounded theory study. *International Journal of Nursing Practice*.  
899 2012;18(3):240-245. doi:10.1111/j.1440-172X.2012.02038.x

- 900 38. Denzin NK, Lincoln YS. *The Sage Handbook of Qualitative Research*. sage; 2011.
- 901 39. Charmaz K, Belgrave L. Qualitative interviewing and grounded theory analysis. *The*  
902 *SAGE handbook of interview research: The complexity of the craft*. 2012;2:347-365.
- 903 40. Willig C, Stainton Rogers W, eds. *The Sage Handbook of Qualitative Research in*  
904 *Psychology*. 1. publ. paperback ed. SAGE; 2013.
- 905 41. Corbin JM, Strauss AL. *Basics of Qualitative Research: Techniques and Procedures for*  
906 *Developing Grounded Theory*. Fourth edition. SAGE; 2015.
- 907 42. Thornberg R, Charmaz K. Grounded Theory and Theoretical Coding. In: *The SAGE*  
908 *Handbook of Qualitative Data Analysis*. SAGE Publications, Inc.; 2014:153-169.  
909 doi:10.4135/9781446282243.n11
- 910 43. Milton DE. On the ontological status of autism: The ‘double empathy problem.’  
911 *Disability & society*. 2012;27(6):883-887.
- 912 44. South M, Rodgers J. Sensory, emotional and cognitive contributions to anxiety in autism  
913 spectrum disorders. *Frontiers in Human Neuroscience*. 2017;11(January):1-7.  
914 doi:10.3389/fnhum.2017.00020
- 915 45. Joyce C, Honey E, Leekam S, Barrett S, Rodgers J. Anxiety, intolerance of uncertainty  
916 and restricted and repetitive behaviour: insights directly from young people with ASD.  
917 *Journal of Autism and Developmental Disorders*. Published online 2017.
- 918 46. Rodgers J, Herrema R, Garland D, et al. Uncertain Futures: Reporting the Experiences  
919 and Worries of Autistic Adults and Possible Implications for Social Work Practice.  
920 *British Journal of Social Work*. 2019;49(7):1817-1836. doi:10.1093/bjsw/bcy117



- 921 47. Boulter C, Freeston M, South M, Rodgers J. Intolerance of uncertainty as a framework  
922 for understanding anxiety in children and adolescents with autism spectrum disorders.  
923 *Journal of Autism and Developmental Disorders*. 2014;44(6):1391-1402.  
924 doi:10.1007/s10803-013-2001-x
- 925 48. Boucher J. *Autism Spectrum Disorder: Characteristics, Causes and Practical Issues*.  
926 Second edition. SAGE; 2017.
- 927 49. South M, Ozonoff S, McMahon WM. The relationship between executive functioning,  
928 central coherence, and repetitive behaviors in the high-functioning autism spectrum.  
929 *Autism*. 2007;11(5):437-451. doi:10.1177/1362361307079606
- 930 50. Lam KSL, Bodfish JW, Piven J. Evidence for three subtypes of repetitive behavior in  
931 autism that differ in familiarity and association with other symptoms. *Journal of Child*  
932 *Psychology and Psychiatry and Allied Disciplines*. 2008;49(11):1193-1200.  
933 doi:10.1111/j.1469-7610.2008.01944.x
- 934 51. Szatmari P, Georgiades S, Bryson S, et al. Investigating the structure of the restricted,  
935 repetitive behaviours and interests domain of autism. *Journal of Child Psychology and*  
936 *Psychiatry and Allied Disciplines*. 2006;47(6):582-590. doi:10.1111/j.1469-  
937 7610.2005.01537.x
- 938 52. Uljarević M, Richdale AL, Evans DW, Cai RY, Leekam SR. Interrelationship between  
939 insistence on sameness, effortful control and anxiety in adolescents and young adults  
940 with autism spectrum disorder (ASD). *Molecular Autism*. 2017;8(1):11-14.  
941 doi:10.1186/s13229-017-0158-4

- 942 53. Birrell J, Meares K, Wilkinson A, Freeston M. Toward a definition of intolerance of  
943 uncertainty: A review of factor analytical studies of the Intolerance of Uncertainty Scale.  
944 *Clinical Psychology Review*. 2011;31(7):1198-1208. doi:10.1016/j.cpr.2011.07.009
- 945 54. Spielberger CD. *Anxiety and Behavior*. Elsevier Science; 2014. Accessed August 14,  
946 2022. <http://qut.eblib.com.au/patron/FullRecord.aspx?p=1837595>
- 947 55. Watson D. Relationship between locus of control and anxiety. *Journal of Personality and*  
948 *Social Psychology*. 1967;6(1):91-92. doi:10.1037/h0024490
- 949 56. Abramson LY, Seligman ME, Teasdale JD. Learned helplessness in humans: Critique  
950 and reformulation. *Journal of Abnormal Psychology*. 1978;87(1):49-74.  
951 doi:10.1037/0021-843X.87.1.49
- 952 57. Bandura A. Self-efficacy mechanism in human agency. *American Psychologist*.  
953 1982;37(2):122-147. doi:10.1037/0003-066X.37.2.122
- 954 58. Weems CF, Silverman WK. An integrative model of control: Implications for  
955 understanding emotion regulation and dysregulation in childhood anxiety. *Journal of*  
956 *Affective Disorders*. 2006;91(2-3):113-124. doi:10.1016/j.jad.2006.01.009
- 957 59. Trembath D, Germano C, Johanson G, Dissanayake C. The Experience of Anxiety in  
958 Young Adults With Autism Spectrum Disorders. *Focus Autism Other Dev Disabl*.  
959 2012;27(4):213-224. doi:10.1177/1088357612454916
- 960 60. Hodgson AR, Freeston MH, Honey E, Rodgers J. Facing the Unknown: Intolerance of  
961 Uncertainty in Children with Autism Spectrum Disorder. *J Appl Res Intellect Disabil*.  
962 2017;30(2):336-344. doi:10.1111/jar.12245

963 61. Bucur DR. *Defining the Self: Locus of Evaluation, Self-Esteem, and Personality*. Purdue  
964 University; 2007.

965 62. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both?  
966 Autism and neurodiversity. *Developmental Psychology*. 2013;49(1):59-71.  
967 doi:10.1037/a0028353

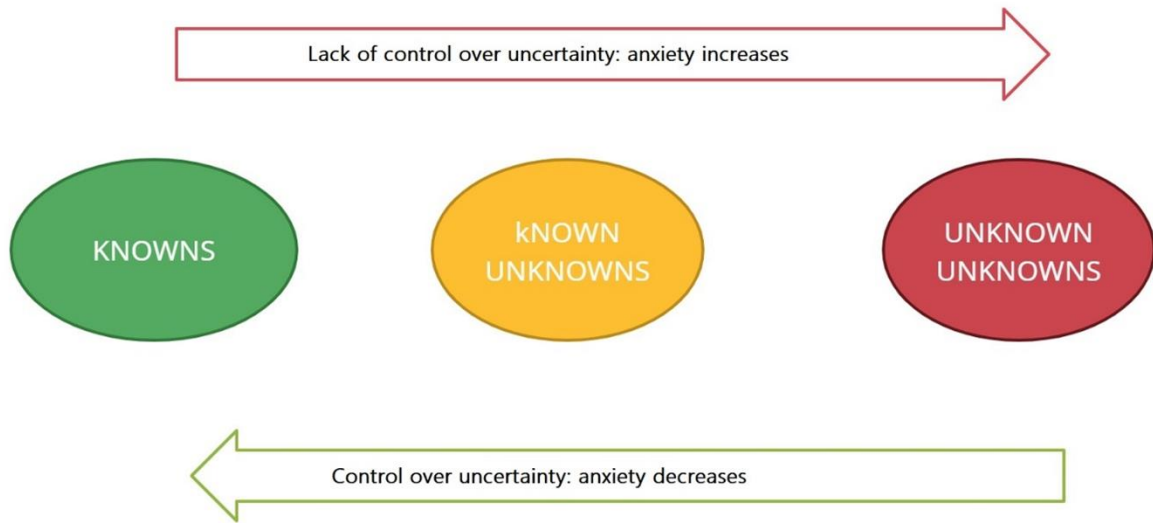
968 63. Seitz CM, Orsini MM. Thirty years of implementing the photovoice method: Insights  
969 from a review of reviews. *Health promotion practice*. 2022;23(2):281-288.

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972 **Figures**

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



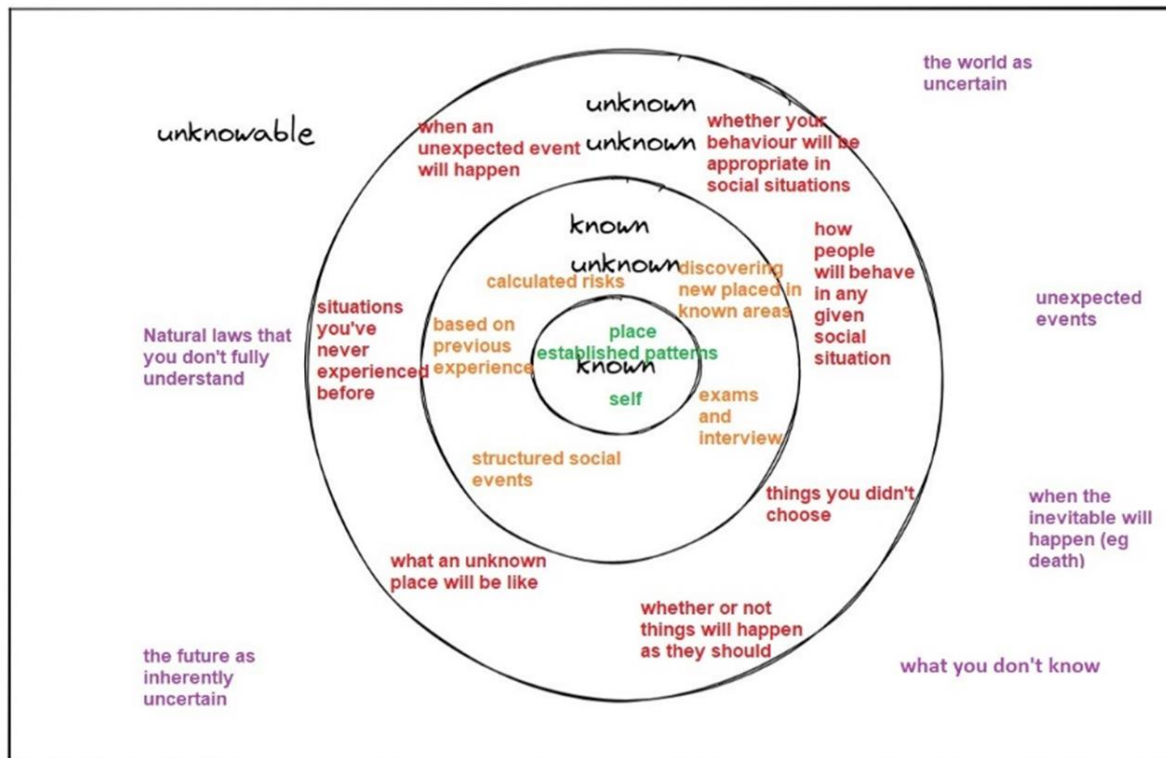
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977 Figure 2: A theoretical model of the relationship between uncertainty and anxiety in the

978 experiences of autistic adults



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