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The experience and impact of anxiety in autistic adults: A thematic analysis

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Abstract

Background: A high proportion of individuals with Autism Spectrum Disorder (ASD) also meet criteria for anxiety disorders. Few studies have explored the experience and impact of anxiety in autistic adults using qualitative methods.

Methods: Seventeen semi-structured interviews with either autistic adults (n=10) or the supporters of adults with a diagnosis of ASD (n=7) were conducted. The data were analysed using thematic analysis.

Results: Three main themes were identified: contributing and mitigating factors, consequences and the management of anxiety.

Discussion: Findings highlighted the role that uncertainty plays in anxiety in autism, which supports existing theoretical accounts. Implications for clinical practice were discussed. These included ensuring that communication differences are minimised, and highlighting the importance of meaningfully including autistic people throughout the development and evaluation process of interventions for mental health.

Keywords: anxiety; thematic analysis; qualitative; Autism Spectrum Disorders; mental ill health

The experience and impact of anxiety in autistic adults: A thematic analysis

A high proportion of children, adolescents and adults with a diagnosis of Autism Spectrum Disorders (ASD)[1] also meet criteria for comorbid mental ill health (Joshi et al., 2010; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Simonoff et al., 2008; Sukhodolsky et al., 2008; White, Oswald, Ollendick, & Scahill, 2009). Anxiety appears to be one of the most common comorbid mental ill health conditions in this population, with 42% of autistic children and adolescents meeting diagnostic criteria for anxiety disorders (Simonoff et al., 2008). Research interest in anxiety disorders and symptoms in autism has recently burgeoned, which may partially stem from the high prevalence of anxiety disorders experienced by individuals with ASD.

An emerging literature suggests that autistic people may also be more likely to experience anxiety symptoms (that may or may not meet diagnostic criteria for anxiety disorders) compared to individuals without ASD. White et al. (2009) conducted a review that investigated the prevalence of anxiety within children and adolescents with ASD. They reported that between 11% and 84% of children with ASD experienced some level of 'impairing anxiety', with a prevalence of diagnosed anxiety disorders ranging from 42% to 55% (Simonoff et al., 2008; de Bruin, Ferdinand, Meester, de Nijs, & Verheij, 2006). Kerns and Kendall (2012) published an updated review of the prevalence of anxiety in individuals with ASD, and all studies fell within White et al. (2009)'s original range for anxiety symptoms (11-84%). It should be noted that, of the 24 studies included in the review, only two reported data for individuals older than 19 years of age (Bakken et al., 2010; Hofvander et al., 2009), which illustrates the need to also focus on adults with ASD in future research (Howlin, 2000).

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[1] Please note that we use both identity-first (e.g. 'autistic individual') and person-first (e.g. 'individual with autism') language in this article. This is in response to recent discussions concerning preferences of terminology in autism (e.g. Kenny et al., 2016).

Despite increasing evidence that a high proportion of autistic people experience anxiety, there is a lack of understanding about its impact and how best to manage it. Indeed, there is clear direction from the autistic community that focusing on mental health is key: interventions for mental health, and specifically anxiety, have been cited as being, respectively, the first and fourth most important priorities for research (Cusack & Sterry, 2016). There is evidence that anxiety is associated with lower levels of quality of life, at least in children with ASD (van Steensel, Bögels & Dirksen, 2012); gaining a clearer understanding of the nature of anxiety in autism in adulthood, and how it can be managed, is therefore crucial.

There is an on-going debate about the relationship between anxiety and ASD, which Kerns and Kendall (2012) summarised within their review. Specifically, they discussed three distinctions that should be considered:

a. Are anxiety and ASD distinct disorders?
b. If anxiety and ASD are independent disorders, do anxiety symptoms in ASD manifest any differently to anxiety symptoms in individuals without ASD?
c. If they are truly comorbid, is it the case that ASD predisposes to anxiety disorders, or that they are covariants?

The authors concluded that anxiety and ASD do appear to be distinct. One observation that supports this conclusion is that anxiety is not present in every individual with ASD (White et al., 2009). However, they also suggested that there appears to be an increased prevalence and, to a certain extent, an atypical presentation of anxiety in ASD, which would be indicative of an ASD-related variant of anxiety. In terms of the final distinction listed above, Kerns and Kendall reported that there is initial support for the hypothesis that ASD may contribute in some way to the development of anxiety disorders in ASD, but that a great deal of additional research is needed to clarify their relationship. Finally, they reported that it is likely that there could be multiple characterisations of anxiety and ASD, given the heterogeneity of the manifestations of anxiety within this disorder.

Qualitative studies

While quantitative studies allow us to test specific hypotheses and facilitate comparison, they leave the underlying reasons for the behaviour that we observe poorly understood. Utilising qualitative methodologies can allow researchers to gain a comprehensive understanding of human behaviour by improving our understanding of the ‘lived experience’, as well as by elucidating underlying reasons and motivations (Willig, 2013). Accounts that investigate the experience of autistic people can be invaluable, in terms of providing insight into the subjective ‘autistic experience’; a better understanding of the nature and experience of anxiety in individuals with ASD would help support the development of potential anxiety management interventions (Gillott & Standen, 2007).

In a rare implementation of a qualitative approach to the investigation of anxiety in adults with ASD, Trembath, Germano, Johanson, and Dissanayake (2012) conducted two focus groups consisting of young autistic adults, parents and professionals. They used thematic analysis (Braun & Clarke, 2006) to analyse three aspects of anxiety in ASD: the triggers (what causes anxiety), consequences (what happens once anxiety has been triggered) and solutions (which anxiety-reducing strategies work). Three main themes (consisting of ten sub-themes) were identified. The first theme was ‘sources of anxiety’; a variety of different triggers, which arose through everyday situations, were identified. The second theme was ‘the experience of anxiety: dissociation and dislocation’, which consisted of sub-themes encapsulating both the dynamics of anxiety (e.g. the nature of the onset) and its impact on the young autistic adults as well as others. The final theme was ‘living and coping with anxiety’, which comprised both preventative and management strategies. Trembath et al. (2012) concluded that both individual and environmental factors are important when trying to support young people with ASD who also have anxiety.

The current study

This study reports the findings from a series of semi-structured interviews with autistic adults as well as supporters of adults with a diagnosis of ASD (either a partner or a parent). Our aim was to explore how adults with ASD experience anxiety, and the impact that this has on their lives. The rationale for the study was threefold: firstly, we were keen to explore anxiety in autistic adults across the lifespan in their own words, as well as from the perspective of their supporters. This further extends Trembath et al. (2012), as they focused on adults younger than 35 years old. Secondly, as far as we are aware, there have been no qualitative studies investigating anxiety in autism using semi-structured interviews. Although focus groups and interviews are both good data collection methods for qualitative data, there is evidence that individual interviews tend to elicit a broader range of discussion points (Guest, Namey, Taylor, Eley, & McKenna, 2017). Again, this further extends the previous investigation conducted by Trembath et al. (2012). Finally, the study provides insight into the experiences of anxiety in autism. This gave autistic adults the opportunity to express what anxiety means to them, and to detail its impact upon their lives. Therefore, it provides vital information for clinicians that are working with autistic adults, and makes a clear contribution to the on-going debate about the nature of anxiety in autism (e.g. Kerns & Kendall, 2012).

Method

Participants

Pseudonyms were generated for all participants, and all other potentially identifying details (e.g. locations) removed. In order to be eligible for inclusion in the study, participants with ASD had to be over the age of 18, report experiencing anxiety symptoms, and have a diagnosis of Autism, ASD or Asperger syndrome from a clinical psychologist or psychiatrist. The advert for the study specifically mentioned experiencing anxiety symptoms; this could be currently or in the past. Participants were then asked about this experience during the interview itself, and were asked about any interventions that they had received for anxiety. Supporters were required to be the partner or parent of an adult with a diagnosis of autism or Asperger syndrome, and who also reported that the adult they supported experienced significant anxiety symptoms. As with the adults with ASD, we specifically asked for people who supported adults that a) had a diagnosis of autism or Asperger syndrome, and b) had elevated levels of anxiety. Clinical diagnoses were not independently confirmed prior to participation in this study. For participants recruited through the third sector, we relied on confirmation of diagnosis from our gatekeeper. All participants, apart from one, had obtained their diagnosis prior to the interview. In the case of this participant, he was awaiting diagnosis at the time of interview; this was followed up six months later, where it was confirmed that he had, indeed, received a diagnosis of Asperger syndrome from a Psychiatrist. His data was therefore included in the analysis. All participants recruited through the NHS were sourced from local post-diagnostic services, and therefore everyone had a diagnosis from a Clinical Psychologist or Psychiatrist.

Autistic adults. Ten autistic adults were recruited from local third- and health-sector organisations. Participants were provided with an overview of the study and asked to contact the first author (AR) if they were interested in participating. A stratified sampling technique was used, where a balance of genders (male (n=5), female (n=5)), location (rural (n=5), urban (n=5)) and age (18-40 years (n=4), 41+ years (n=6)) was sought. Participants ranged from 19 to 60 years old (M: 40 years; SD: 11.91 years), and had experienced a variety of treatments for anxiety. Further characteristics of the participants with ASD, including self-reported details of types of anxiety intervention experienced, are contained in Table 1.

Table 1 around here

Supporters. Seven supporters of adults with ASD were recruited from third-sector organisations, and participants were asked to contact AR if they wished to participate in the study. Again, a stratified sampling technique was used, where a balance of type of supporter (parent (n=2), partner (n=5)) and location (rural (n=2), urban (n=5)) was sought. Autistic adults that were supported ranged from 24 to 65 years old (M: 40.38 years; SD: 16.06 years), and had experienced a variety of treatments for anxiety. Further characteristics of the supporters and the people they support, including second-hand recollections of types of anxiety intervention experienced, are contained in Table 2.

Table 2 around here

Procedure

Triangulation of data sources is an important concept in qualitative research, allowing researchers to explore areas of agreement and disagreement across different groups (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Therefore, we recruited multiple informants (i.e. individuals with ASD, partners, and parents) so we could explore the concept of anxiety in

ASD from different perspectives. In order to ensure that participants were comfortable before the interview, they were offered the opportunity to meet with the researcher beforehand, to go through what would be expected during the interview and what would happen with the data that was collected. It also meant that the interviewer (AR) had the opportunity to develop a rapport with the participants, which is important when conducting qualitative interviews with participants with ASD (Cridland, Jones, Caputi, & Magee, 2015).

All interviews were held at a time and in a location preferred by each participant (which included home environments and local NHS facilities). In the interviews with autistic adults, participants were asked about their experience of anxiety, the impact that anxiety had on their lives, as well as questions surrounding the management of anxiety, and the barriers that autistic people face in terms of accessing help for their anxiety. Interviews were slightly adapted for supporters, who were asked questions related to their perception of how the person they supported experienced anxiety, the impact of anxiety on both the individual and themselves, the management of anxiety, and barriers for accessing help. Interviews were semi-structured in nature, which meant that participants were asked the same key questions, while allowing for flexibility to follow up on points as they emerged. AR developed the interview schedule after discussion with CM and extensive review of the anxiety in autism literature. It was subsequently refined after discussion with the rest of the project team. Both interview schedules were thereafter presented to our project steering group (consisting of two autistic adults with anxiety, supporters of adults with a diagnosis of autism and anxiety, healthcare providers, and staff member from Autism Initiatives Scotland). The schedule was revised a final time to reflect the suggestions made by the steering group. The key questions asked in the interviews are included in Supplementary Materials.

Data Analysis

All interviews were conducted and audio-recorded by AR and then professionally transcribed. Thereafter, AR checked the accuracy of all transcripts by reading them alongside the original recording and making changes as appropriate. Data were analysed using thematic analysis as outlined by Braun and Clarke (2006). The analysis was conducted by AR, and consisted of six stages: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. Firstly, each transcript was read, with the first author noting potential themes and impressions of the data. Next, initial codes were generated based on the transcripts; these codes were then combined into preliminary themes. Finally, these themes were reviewed and refined, and extracts that illustrated them selected.

A realist theoretical framework was adopted in order to attempt to reflect the meaning of participants' reality. Themes were identified at a semantic level and were based on the explicit meaning of the data; AR did not seek to go beyond what had been said during the interviews. Therefore, we are able to be reasonably confident that our own knowledge and experience of working in the field of ASD and anxiety did not impact on the data coding process. Moreover, it should be noted that AR purposely did not read Trembath et al. (2012)'s paper until after the data analysis was complete; their findings therefore had no influence on the themes observed in the current study.

Inter-rater reliability. Codes were developed by AR and discussed with the rest of the members of the research group as coding developed. Thereafter, AR coded the full transcript and a voluntary Research Assistant (who had no other role in the study) coded 10% of every transcript. AR removed 10% of each transcript: the specific excerpt varied from interview to interview. The reason for this was to ensure that the full breadth of the interviews were included in the process, enabling comparison of the full range of codes, rather than a subset. The codes were explained in detail before commencing the coding; both sets of excerpts were independently coded. A high level of agreement was observed between both sets of codes, $\kappa = .980$, $p < .001$.

Results

The data generated by the semi-structured interviews revealed both variety and commonalities in the experiences and impact of anxiety in autistic adults. Three main themes emerged from these data: contributing and mitigating factors, consequences and the management of anxiety.

Theme 1: Contributing and mitigating factors to anxiety

Participants identified a range of sources and exacerbators of anxiety, which resulted in anxiety symptoms reportedly occurring more frequently or being felt more intensely. Although numerous stressors were identified, uncertainty and change, and miscommunication were most consistently discussed throughout the whole dataset. In addition, feeling accepted was reported to help mitigate anxiety for the participants in our sample.

Uncertainty and change. Uncertainty and change were discussed extensively in terms of how they contributed to anxiety, by both groups of participants. Vicky described the difficulty that Ryan had with changing topics during a conversation:

> *Anything in a conversation that he doesn't expect [is problematic], so if you change the subject then he says "why are you changing the subject?" or if I bring up something that he doesn't expect or doesn't want, he goes in a* complete fury

Vicky went on to explain that change and uncertainty had a wide-ranging impact on Ryan, and that he found the increased uncertainty and change difficult when attending school: “*the major changes to secondary school where secondary school was bigger and more fluid…primary school was easier*”.

Participants reported that unpredictability would increase their anxiety, as described by Elenore: “*I think in general things that are unpredictable [raise my anxiety] … I am much better with a very nice set plan of what happens.*” Interestingly, she went on to discuss how this impacted on her ability to socially interact with other people: “*People are very difficult because people are unpredictable.”* She illustrated her comment with an example, saying that others tend to be less worried about being on time than she is, and that she found this anxiety-provoking: “*Like today, when somebody's coming, I get very stressed about times, but I have to remind myself that not everyone keeps time like I do”.* Elenore was aware that others were less predictable than she was, and made an effort to keep this in mind when interacting with other people.

Miscommunication. Participants also discussed that not being clearly communicated with, as well as misunderstanding others' intentions, were likely to worsen their anxiety symptoms. Claire described being unable to communicate her feelings, and that this had a negative impact on her anxiety levels: “*I didn't know how to express how I felt because I couldn't speak that well, so I would be panicking…I was just like I can't even tell you how I feel.”*.

In addition, Andrew reported that miscommunication was common in his interactions with other people:

> *[Miscommunication] feeds into the anxiety… I know I don't understand people but they think they understand me, and they don't. So it's a two-way thing, but because I am very direct with how I will say about it that it's then seen as me having the issue and not them, but it's actually both of us having an issue.*

He appeared to be frustrated that the miscommunication was often perceived to be ‘his’ problem (as a result of his ASD diagnosis), rather than a two-way process. This played a key role in the development and maintenance of his anxiety.

Supporters also reported that miscommunication could exacerbate anxiety levels, and mentioned that they often stepped in to minimise the anxiety experienced by their family member. Christine described how she would often ‘translate’ implicit social situations to her son. In this example, John had become anxious, as he had unintentionally offended his aunt:

> *His anxiety is … [having] misunderstood what somebody has said. So, if I simply say to him … your aunt was angry with you because …the way you talked about the food made it sound to her as if you didn’t like [it]… if you put it in those very plain terms, unemotional terms he gets the message very quickly.*

Christine reported that miscommunication between John and other people was perhaps the thing that made the greatest contribution to his anxiety, and she found that being clear and direct in her communication with John was a helpful approach.

Being accepted. Throughout the interviews, participants discussed the importance of feeling accepted, and the positive impact that this could have on their anxiety. For example, Elenore described feeling much more accepted when she spent time with her autistic friends:

> *Whereas you start talking to autistic people and … they just know how it is, so going to socialise … is so much easier, because I know that … I can just get up and walk out and nobody is going to think anything about it*

This had a positive impact on her anxiety symptoms, as she reported that she was able to disclose how she was feeling, and she and her friends would share their anxiety management strategies with each other: *"we still struggle in the same places and they've probably given me the most sort of ideas of what to do because we have all worked round stuff. 'Well this works for me, well this works for me.'… They really get it"*.

Theme 2: Consequences of anxiety

The second theme observed was the significant consequences of anxiety on the lives of autistic individuals, as well as their family members. There were a number of different sub-themes noted. Autistic individuals were the only ones who discussed the sub-theme of 'being judged'; the broader 'impact on life' was more evenly balanced. This is perhaps unsurprising, as perceiving judgement is something very personal, and supporters would be unlikely to be able to comment on whether their loved one felt judged, unless this had been explicitly discussed with them. Conversely, impact on life is much broader, which meant that supporters seemed better able to reflect on this.

Being judged. The adults with ASD in our sample often worried that the manifestations of anxiety would lead to them being judged by other people. Claire questioned:

> *What are they going to think of me being anxious of such stupid things? And to a normal person it would just be "what is your problem?"… like "what makes you anxious about that? There is no reason to be anxious of that" when really, for someone who all their senses are heightened or not, that is terrifying*

This illustrates the perception among the sample that many people without ASD lack understanding, and may be prone to judgement.

In addition to judgement from others, participants reported that they would sometimes judge themselves negatively, after experiencing anxiety in a situation. In particular, they discussed frustrations at not being ‘normal’. For example, Michael described feeling angry about requiring additional support: “*I’m sort of angry at myself for being frightened. In my experience a lot of my peers can get on and do these things whereas I need extra help.*” Elenore felt similarly, expressing anger about being unable to do things that she thought she ‘should’ be able to do: “*I would really beat myself up about the fact that everyone else doesn’t get so scared about the supermarket then why should I?*”

Impact on life. The second sub-theme was ‘impact on life’. The extent of this appeared to be related to the severity of the anxiety that the person experienced. If the anxiety was of a low or moderate level, then the person tended to report being able to manage their anxiety on a day-to-day basis. However, if the anxiety was severe, it had a wide-ranging impact on the individual’s life.

Claire compared her experience of anxiety to that of one of her friends, who also had a diagnosis on the autistic spectrum:

> *One of my friends has the same type of autism as me and he’s horrendous... I remember one time [we] went for a party and … he was in one of those full-on body suits with like the feet things… because he didn’t want his clothes getting dirty*

She went on to say she felt fortunate: *“his anxiety is a lot worse than mine, so I kind of think myself lucky”* and that she attributed this difference to her upbringing: *“[My mum and my family] made me do things I didn’t want to do, which probably made my anxiety a lot better than it would be.”* The majority of examples that Claire discussed during her interview were during her childhood; she reported that her ability to manage her anxiety had improved in adulthood.

In comparison, some of the participants described anxiety having a catastrophic impact on their lives. Deborah described her experience clearly, stating that her anxiety was so chronic that she felt she was not able to live a full, meaningful life: "*I just feel that my life is in limbo, do you know? I don't have a life, I exist, that's all I can say. I exist*".

Lewis described that anxiety severely impacted upon his wife Hayley's life. He focused on the consequences in terms of employment, discussing that although she had been a successful businesswoman in the past, she was now no longer able to work due to her anxiety:

> *she ran a café, she was an English teacher, she used to do property investment, buying properties, doing them up, renovating them, decorating them selling them on again… [now] she's becoming more and more phobic of being with strangers…she's becoming more and more isolated.*

As well as finding interaction with people difficult, Lewis described that Hayley appeared to be exhibiting signs of agoraphobia, as she no longer wanted to leave the house, and preferred to be accompanied when she did: *"she's very reluctant a lot of the time to go out at all, and she's highly unlikely to want to go out on her own".* This would be likely to impact on many facets of Hayley's life.

Participants also described how anxiety reduced their sense of pleasure when engaging in enjoyable activities. When anxiety was at manageable levels, it would impact on enjoyment, but would not prevent the individual from engaging in the activity altogether. When anxiety was high, this often led to avoidance, meaning that activities that used to provide pleasure were no longer undertaken at all.

Justine described how anxieties around transport impacted on her experiences of visiting family:

> *In two days' time I am on the train down to England to see my folks…it is nice to see them and catch up, but because of the anxieties about other aspects of the journey, [it] takes away from the pleasure that I should be feeling.*

Marjorie also reported that this was the case with her husband, Keith, who had recently received a diagnosis of Asperger syndrome: *"If we are going on holiday, it's not really a pleasure … the anxiety kicks in and he is worried about everything … it's just a nightmare really"*. Marjorie has found that the strain of doing something out of the ordinary raises Keith's anxiety so much that it impacts on their ability to enjoy themselves.

However, Deborah described having to withdraw from all pleasurable activities in an effort to minimise her anxiety. She described how she would like to go away on holiday, but was unable to do so:

> *you think wouldn't it be nice like to go away a holiday but you are sort of imprisoned … I've got a thought of being in a cottage in the middle of nowhere … [but] that's just a pipe dream*

Being unable to engage in previously enjoyable activities appeared to be restricted to people who were experiencing significant and debilitating levels of anxiety, while individuals with more manageable levels did not report this to the same degree

Theme 3: Management of anxiety

There were a number of different strategies that were employed, both by autistic individuals themselves and their family members. These fell into two different types: those that were used in advance to minimise the frequency or impact of anxiety and those that were employed 'in the moment' to manage the anxious episode.

Participants mentioned that it was helpful to have a range of coping mechanisms that they could employ when they began to feel anxious. Justine, an adult with a diagnosis of Asperger syndrome, discussed the value of this:

> *I find identifying coping mechanisms and consciously employing them [helpful]… it took me a long time to actually realise what some of my coping mechanisms were, so that helps, like in a really stressful situation going "okay what will make this better?"*

She was of the opinion that, if a person was able to identify and use one of these strategies, it could ultimately be a useful part of experiencing anxiety: "*It can be a constructive thing if the trigger of anxiety makes people come up with a plan with coping strategies*". However, participants often struggled to identify mechanisms that could help them, especially when they were feeling anxious.

Samuel found that seeking support from other people with ASD (which he did online) was helpful:

> *The ability to voice that anxiety, even if it is anonymously, and someone that listens tells you what you are doing is right and other people tell you perhaps you should buck up or give you strategies to deal with it.*

Samuel lived in a rural area, with no access to local autism charities and little contact with other autistic people. He found that accessing support online was of great benefit to him.

Preparatory techniques. The most common way that people tried to minimise the likelihood of experiencing anxiety in advance was to increase structure and control, and to reduce unpredictability. This was discussed extensively throughout both the interviews with the adults with ASD as well as the interviews with supporters. This could take the shape of ensuring that they were prepared in advance for any commitments. For example, Andrew described having friends over to play a role-playing game:

> *I had to have people over because we were doing dungeons and dragons the other day and I am meant to be planning the campaign that we are doing and that was an extremely stressful thing for me to do … being so well planned out beforehand helped me deal with that*

Using calendars and wall planners to plan things in advance was commonly used, and was helpful in reducing anxiety. Claire described: "*I've told my uni to tell me exactly when all my dates are for the next three years … that helps me*". Marjorie said that Keith relied on the calendar, and she had to ensure all of her own activities were added, so he was aware of what was happening:

> *I mainly write things on the calendar - even if I said I am going out on Wednesday night, which is a weekly thing I go to, he would still look at the calendar*

Andrew described that, as well as having structure, it was important to obtain enough notice of events, in order to be able to process them:

> *If I am told about an event over a week before the event and I put it on my calendar, that seems to be fine … if it's within a week it's too stressful, I can't really cope with that … if I was given advance warning, then it gives my brain time to process the fact that I need to go out to this thing.*

Peter echoed this sentiment - he wanted to have things planned out as far in advance as possible: "*I have a wall planner … [everything gets] put on there as far ahead as possible, [but]* *never as far ahead as I like*”. Although Andrew had specified that less than a week was problematic, Peter preferred to have as much notice as possible.

In the interviews with spouses and parents of people with ASD, as well as in some of the interviews with autistic individuals themselves, the role that the family plays in helping to manage anxiety was also discussed. Supporters would notice what caused anxiety, and take action to minimise this. Janice described how she took steps to prevent Michael’s anxiety, by dealing with official paperwork herself: “*He doesn’t get anxious because I deal with it … I deal with all the paperwork for the house*”. Other adults also described that dealing with paperwork was very difficult, and it tended to increase their anxiety.

Dealing with anxiety ‘in the moment’. Participants discussed how they dealt with anxiety when they were in the throes of it. Interestingly, it appeared that the approach selected would depend on how anxious they felt. For example, if anxiety was at a relatively low level, then it might be possible to manage it sufficiently in order to remain in the situation. Examples of techniques employed in these situations would include deep breathing: “*I try and do the breathing things*” (Alison) and distraction “*I have a couple of … online courses I am participating in at the moment… [I’m] using them to distract myself, deflect thoughts into more positive things*” (Samuel).

A few participants discussed the value of staying in a situation. Michael discussed that it was important to remain in social situations, even though he often found them anxiety-provoking:

> *In a new situation or social circle with anything, at first I will just be so nervous and I won’t say anything or do anything. Hopefully, by the end I will be integrated and socialising and being all funny and charming or whatever.*

He found approaching people and taking the initiative in terms of joining social situations very difficult: "*I am never one to make the first move. I have always preferred people to come to me...that's in any situation*". He normally found that, if he waited, someone would invite him to join in: *"[I] sat in the corner and basically stared at everyone... it was a good hour before anyone sort of came up to me".*

However, when anxiety was high, it seemed that avoidance was the only way to deal with it effectively. Everyone in the sample reported using avoidance at some point to deal with particularly anxious situations. Justine discussed when she would choose avoidance, and when she would try to stay in the situation:

> *If the anxiety is …getting past the point where I can just use simple techniques then I will…I am really concerned not to go down the avoidance pathway, [but] sometimes I have to cut something short and what I will then do is go back to it as soon as possible.*

It is important to note that Justine had undertaken Cognitive Behavioural Therapy (CBT) for her anxiety and depression for many years, and had evidently gained from the process. She was very self-aware in terms of knowing how to best manage her anxiety to keep it at manageable levels.

Family members and friends were also reported to have an extremely important role in the management of chronic anxiety. Lewis describes the use of different strategies to try to help his wife, Hayley, when she is experiencing a 'meltdown' due to her anxiety:

> *It's reassurance that she's safe … if it's in a meeting and somebody's getting sharp with her, it's…getting them to play nice [and] … emotional support if that's possible … if she's in a meltdown it's the big, sort of, compression hugs…there are times where all of these things work and there are times when they all fail.*

It should be noted that Lewis also a diagnosis of ASD, and experiences significant anxiety himself. This made it particularly difficult to be there for his wife while simultaneously managing his own anxiety.

In the example above, Lewis described reassurance as being important – this emerged multiple times during the interviews. Both supporters and autistic individuals described that having reassurance was extremely important for an autistic person when they felt anxious. Typically, family members were the first point of contact. Peter described: "*I will probably ring my mother or my sister to try and get some kind of reassurance*". However, Elenore discussed that a relative or close friend was not always necessary for this type of support; sometimes just having someone to speak to on the end of the phone was helpful: "*having somebody to sit and talk it through with on a one-to-one and being on the phone to NHS 24 and they are quite good at even telling you to breathe*". She found this reassuring when she was feeling particularly anxious.

Discussion

The aim of this study was to explore the experience and impact of anxiety in the lives of adults with ASD, from their perspective as well as that of their parents and partners. The findings indicate that anxiety can be a significant feature in the lives of autistic adults, and can have a profound impact on their lives. Three main themes were identified during the course of the analysis: contributing and mitigating factors, consequences, and management of anxiety. The results and the potential implications of the research are discussed in relation to existing literature.

Our findings echoed those of Trembath et al. (2012) in multiple ways. We also had three main themes, which were similar to their themes of 'triggers', 'consequences' and 'solutions'. Although our sub-themes were different for the first two themes, the sub-themes for 'solutions' were similar. However, there were some differences – Trembath et al. (2012) detailed that their autistic young adults did not volunteer many preventative strategies whereas our participants were just as likely to do so as the supporters. One potential reason for this could have been the age of the participants in each group. Participants in our sample of autistic adults ranged from 19 to 60 years old, whereas the participants in Trembath et al. (2012)'s sample were younger, ranging from 18 to 35 years old. In our study, Justine reported that she became more able to deal with her anxiety as she got older, and Elenore described how she had learned new coping strategies after receiving a diagnosis of autism in her forties. It could be the case that older autistic adults are more practiced at trying to prevent anxiety than younger adults with ASD. However, little research has been conducted into aging in autism (Michael, 2016) and there may be another reason for this observed difference.

The contribution of change and unpredictability to anxiety for adults on the spectrum was the most consistent finding in the data. Not only was it reported by both groups of participants as a contributing factor to the frequency and impact of anxiety, but also that reducing change and unpredictability by increasing structure was the most common preventative method of attempting to minimise anxiety across the whole dataset. Gomot and Wicker (2012) reported that individuals with ASD find it particularly difficult to deal with change and unpredictability. They reviewed evidence to suggest that autistic people tend to rely more on sensory input (Loth, Carlos Gómez, & Happé, 2008; Gomot et al., 2011), which appears to be at the expense of the systems used to help with prediction (Gomot & Wicker, 2012). For example, Gomot et al. (2011) conducted an auditory change-detection task. They found that children with ASD were likely to switch their attention when presented with deviant events, and that this was significantly more marked in children with a lower ability to tolerate change. The authors suggest that this atypical processing of auditory information could be related to the need for sameness observed in ASD. Furthermore, Sinha et al. (2014) recently proposed that autism is a ‘disorder of prediction’; this would result in individuals finding it hard to predict events reliably, and could cause great stress in terms of interacting with the environment. This is an emerging hypothesis at present and our findings suggest that it would be worthy of further exploration.

Miscommunication emerged as another significant source of anxiety for the participants in the study. Supporters seemed to be aware of this, with Christine stating that John’s anxiety primarily stemmed from being misunderstood. A similar theme emerged in a focus group study investigating the nature and impact of anxiety in children with ASD (Ozsivadjian, Knott, & Magiati, 2012). Parents reported that their children experienced difficulty with expressing their anxiety verbally, which led to behavioural means being utilised instead. Davis et al. (2011) explored the role that communication plays in the relationship between anxiety and ASD, finding that, for individuals with autism, an increase in communication difficulty was associated with a decrease in anxiety. Conversely, individuals with PDD-NOS demonstrated the same pattern as typically developing individuals – anxiety levels increased as difficulties with communication increased. The authors hypothesised that there could be two potential explanations for this finding: 1) those with autistic disorder have a more severe presentation across many areas of functioning, and are therefore less ‘able’ to be anxious than those with PDD-NOS; 2) the communication difficulties that are present in the autistic disorder group may preclude researchers and clinicians from adequately assessing anxiety. However, we would like to highlight that communication should not be considered to be a unidirectional process that is wholly reliant upon the communication skills of autistic people. In our study, Andrew described that misunderstandings were often attributed to him, rather than being considered to be a result of two different communication styles. Moreover, he reported that the experience of interacting with healthcare professionals was much more positive, and beneficial, when his communication preferences (e.g. use of direct questions) were respected.

It is important to consider the benefits that identifying with the groups that we belong to may bring. For example, the extent to which one identifies with the groups they belong to has been demonstrated to be predictive of mental health in adults (Sani, Herrera, Wakefield, Boroch, & Gulyas, 2012). This was echoed in our data, as some of the autistic participants discussed how important it was to have the support of other individuals with a diagnosis of ASD. For example, Elenore, Justine and Samuel all mentioned that they benefited from being a part of a group of autistic adults (whether that was in person or by using the internet). In particular, Elenore preferred spending time with her autistic friends, as she felt that they were more likely to understand how she was feeling. There is evidence that *identification* with a group, rather than contact, is important for mental health (Sani et al., 2012). Therefore, it would be potentially fruitful to explore the relationship between wider group identification and mental health in autistic individuals. It may be the case that being part of a group that they *identify* with could be helpful for some individuals with ASD. Indeed, there is evidence to suggest that having a positive self-identity as an autistic person is associated with higher self-esteem and lower levels of depression and anxiety (Cooper, Smith, & Russell, 2017). It is also important to consider the role of acceptance in autism. Our participants discussed that perceiving they were accepted by others was a mitigating factor for anxiety. Although they did not find a significant relationship with anxiety, Cage, Di Monaco and Newell (2017) did find a clear association between higher levels of perceived acceptance and lower levels of depression and stress.

An important aim of the current study was to explore the experiences of autistic adults, as their views are often under-represented. Resources for research tend to be allocated to those focusing on children with autism rather than adults (Buescher, Cidav, Knapp, & Mandell, 2014). Moreover, there is a dearth of research in older adults, with many of the studies that do focus on adulthood, concentrating on those in early adulthood. It is therefore of utmost importance to conduct research into autism and ageing (Michael, 2016). In particular, it is vital to study anxiety across the lifespan in autistic individuals. The pressures and experiences that individuals have often change as they age; this is likely to impact upon both the triggers of anxiety, as well as coping mechanisms that are developed. Therefore, a strength of the current study is that we actively recruited autistic adults themselves (and supporters of autistic adults) who were in their forties and older. Future research should be conducted which focuses on anxiety in older adults with autism, ideally tracking development across the lifespan.

Maisel et al. (2016) modelled the cognitive mechanisms of anxiety in autism, finding that alexithymia and emotional acceptance explained 64% of the effect of the relationship between symptom severity and anxiety level. Intolerance of uncertainty was both a predictor and mediator of anxiety, but not when alexithymia and acceptance were also included in the model. Therefore, it appears that most of its predictive power is explained by alexithymia and acceptance. Within our study, our participants reported that they were more likely to feel anxious when experiencing change in their environment, or if things were uncertain and unpredictable. Moreover, emotional acceptance was an important component - the authors suggested that mindfulness-based approaches to anxiety could be helpful for this population. In our sample, Elenore reported that she found mindfulness very helpful, and she routinely employed the techniques she had been taught, in order to manage her anxiety. Likewise, there was evidence of difficulties identifying and understanding emotions contributing to anxiety – for example, Lewis discussed that Hayley found it very difficult to manage her emotions.

Our findings also give insight into the views of anxiety, and of seeking help, that are held by autistic people and their supporters. Prins, Verhaak, Bensing, and van der Meer (2008) reported the health beliefs and perceived need for mental health care of anxiety and depression in the general population. Barriers to treatment were identified, with ‘practical’ barriers (e.g. time, resources) being identified as more important than ‘emotional barriers’ (e.g. difficulty opening up to a therapist). The participants in our sample also identified practical barriers to treatment, but there was also a focus on the ‘appropriate-ness’ of treatment (e.g. Justine described that her rigid thinking in autism meant that her gains from CBT were limited), and whether the therapist had appropriate levels of autism understanding and awareness.

Limitations

A significant limitation of the research conducted was that, due to logistical constraints, we were unable to independently confirm ASD diagnoses using gold-standard measures. However, we did make significant efforts to ensure that all participants had a diagnosis of ASD from a clinical psychologist or psychiatrist. For example, all participants recruited through the NHS were sourced from the adult post-diagnostic service (which they are only able to attend after receiving a diagnosis from a clinician). Moreover, participants recruited through the third-sector organisation had their diagnoses confirmed by the gatekeeper before interview (or, in the case of one participant, afterwards). He was able to confirm that the participants had been diagnosed by a clinician. Moreover, it should be highlighted that we did not use standardized assessments to ascertain levels of anxiety. Doing so would have allowed us to ensure that participants reported elevated anxiety symptoms. However, there is evidence that many anxiety measures lack validity in children with autism (Lecavalier et al., 2014), and there is scant information about the suitability of self-report anxiety measures in autistic adults. Nevertheless, including these measures in our study would have provided valuable additional information about the severity of anxiety experienced by the interviewees.

In terms of the analysis, there were a number of constraints that meant that it was not possible to have more than one person develop the codes and themes for the analysis, which is important in terms of increasing rigour (Mays & Pope, 1995). However, steps were taken to improve the rigour of the analysis as much as possible. For example, codes and initial themes were discussed with the wider research group as coding was taking place. Furthermore, an independent researcher (i.e. not a member of the research group) coded 10% of each transcript and the inter-rater reliability between their codes and those of the first author was computed. A high level of agreement was reached, indicating that the codes attributed by each rater was significantly higher than expected by chance.

Implications

There are a number of potential clinical applications for the findings detailed in this paper. They echo the modifications that are already undertaken for anxiety interventions designed for children and adolescents with ASD (Walters, Loades, & Russell, 2016). For example, it may be important to include support for individuals undertaking an intervention for their anxiety. This has already been identified as helpful in anxiety management interventions for children with ASD (Sofronoff et al., 2005), but the evidence here suggests that this might also be the case for adults. Furthermore, as adults reported feeling that they enjoyed interacting with other autistic people, it would be important to test whether running autism-only groups in terms of anxiety interventions helps outcomes or other aspects related to the feasibility of anxiety management programs (e.g. retention of participants).

Based on the findings from this study, we have a number of recommendations for individuals designing modified anxiety management interventions for adults with a diagnosis of ASD and significant anxiety symptoms. Firstly, minimising change and reducing uncertainty would be likely to help clients with ASD engage with interventions to manage anxiety. Secondly, it would be important to reduce miscommunication. Asking the person with ASD what their communication preferences are (e.g. Andrew preferred direct questions) may be particularly helpful. Thirdly, there could be potential implications in terms of designing interventions for anxiety management (e.g. providing support for participants in a group intervention to contact each other after the sessions have ended, specifically stimulating identification with the group rather than focusing on group contact). Finally, it is important to consider the views of autistic adults in the process of developing and adapting interventions to manage anxiety, as they are in the best position to provide insight about their own experiences of receiving help, and to provide suggestions for further improvement.

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