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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 to anxiety’, ‘consequences of anxiety’, and ‘management of anxiety’.

Discussion: Findings highlighted the role that uncertainty plays in anxiety in autism, supporting 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.

1. Introduction

A high proportion of children, adolescents and adults with a diagnosis of Autism Spectrum Disorder (ASD)¹ also meet criteria for comorbid mental ill health (Joshi et al., 2010; Kim et al., 2000; Simonoff et al., 2008; Sukhodolsky et al., 2008; White et al., 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

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

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% (de Bruin, Ferdinand, Meester, de Nijs, & Verheij, 2007; Simonoff et al., 2008). 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).

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 deemed, 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.

1.1. 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.

1.2. 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).

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