



## Exploring the nature of anxiety in young adults on the autism spectrum: A qualitative study

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### ABSTRACT

**Background:** Research exploring the nature of anxiety symptoms in autism spectrum disorder (ASD) has thus far focused on children and adolescents, providing evidence for both typical and atypical anxiety symptom presentations associated with ASD. This study builds on previous research by focusing on young adults, and comparing anxiety presentation between individuals with ASD and non-ASD individuals with anxiety disorders. We anticipated that while the non-ASD group would report only typical anxiety symptoms, and the ASD group would report both typical and atypical presentations of anxiety symptoms.

**Method:** Ten individuals with ASD and anxiety ( $M = 21.8$  years,  $SD = 6.76$ ), and 10 individuals with anxiety ( $M = 24.4$  years,  $SD = 4.17$ ) participated in focus groups. Participants responded to semi-structured interview questions specifically developed using the DSM-5 criteria for each of the anxiety disorders, Illness Anxiety Disorder, and Obsessive-Compulsive Disorder. These questions focused on carefully elucidating experiences of anxiety including DSM-5 anxiety symptomatology and ASD-specific anxiety symptomatology.

**Results:** Thematic analysis revealed a theme structure for the ASD group composed of both DSM-5-related (e.g., social anxiety themes) and ASD-specific anxiety presentations (i.e., related to core ASD symptomatology). In contrast, the non-ASD group described predominantly DSM-5-related anxiety symptomatology.

**Conclusions:** Our findings support the predicted outcome that there are both ASD-specific anxiety and DSM-5-related anxiety symptomatology in young adults with ASD, compared with young adults with anxiety who show only DSM-5 symptomatology. Future research elucidating the relationship between ASD symptomatology and anxiety in ASD, utilising both quantitative and qualitative measures, is crucial to enable a more comprehensive understanding of the nuances of anxiety in ASD. Gaining this knowledge is a crucial step for the development of more accurate and appropriate assessment and treatment tools that can target their specific anxiety experiences.

## 1. Introduction

There is limited anxiety research on anxiety in adults with autism spectrum disorder (ASD); research thus far primarily has examined children and adolescents (Uljarević, Nuske, & Vivanti, 2016; van Steensel, Bögels, & Perrin, 2011; White, Oswald,

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Ollendick, & Scahill, 2009). Anxiety prevalence estimates are high, ranging from 11% to 84% for youth (Kerns & Kendall, 2012; MacNeil, Lopes, & Minnes, 2009; White et al., 2009) to 21–72% in adults (Ghaziuddin & Zafar, 2008; Hofvander et al., 2009). Increased anxiety in ASD is associated with increased functional impairments (e.g., Bellini, 2004; Chang, Quan, & Wood, 2012; van Steensel, Bögels, & Dirksen, 2012), therefore timely and accurate diagnosis and treatment is essential. However, the variability across studies in terms of prevalence/frequency may be due to a range of different methodological factors, one being limited sample sizes which are not able to adequately represent the full variation of anxiety expression and severity as seen across the ASD, and the second being that current instruments are not necessarily adequate to tap into the full range of anxiety symptoms. There is a lack of understanding of the anxiety construct in ASD, with the use of potentially inappropriate or poorly validated anxiety measures for this population (MacNeil et al., 2009; van Steensel et al., 2011; White et al., 2009). Most ASD anxiety research generalises outcomes from standard anxiety measures without the psychometric properties of these instruments being validated with ASD populations (Hagopian & Jennett, 2014; Kerns & Kendall, 2012; van Steensel et al., 2011). In order to develop more accurate assessments that capture and identify the presentation of anxiety in this population, research is needed that clearly documents the specific nature of anxiety in ASD (Lecavalier et al., 2014; Uljarević et al., 2018; Wigham & McConachie, 2014) across the lifespan.

As the core symptoms of ASD and anxiety symptoms may overlap, a central research and clinical issue is disentangling anxiety symptoms from core ASD symptomatology (Kerns & Kendall, 2014; Wood & Gadow, 2010). It has been proposed that: (1) anxiety may manifest as a downstream consequence of ASD-related stressors; (2) anxiety and ASD traits reinforce each other – ASD-related stressors lead to anxiety which, in turn, exacerbates ASD symptomatology; (3) anxiety may act as a moderator with the presence of anxiety in ASD leading to increased ASD symptom severity; and/or (4) anxiety might represent core ASD symptomatology (Wood & Gadow, 2010). Thus, the exact nature of the relationship between anxiety and ASD symptomatology remains unclear. To account for the potential overlap between anxiety and ASD symptomatology, it has been proposed that both “typical” and “atypical” anxiety presentations occur in ASD (Kerns et al., 2014). “Typical” anxiety refers to anxiety symptomatology as observed in non-ASD populations and defined by the Diagnostic Statistical Manual (DSM) criteria for anxiety and anxiety disorders (American Psychiatric Association [APA], 2013). Due to reliance on standard anxiety measures, most ASD research has focussed on “typical” anxiety. However, there is increasing evidence to support the presence of an additional “atypical” anxiety presentation in ASD that is associated with ASD symptomatology (Kerns, Renno, Kendall, Wood, & Storch, 2017).

Kerns and colleagues explored “typical” and “atypical” anxiety presentations in children with ASD in a series of studies utilising a modified version of the Anxiety Disorders Interview Schedule: Child and Parent Versions (M-ADIS-C/P; Silverman & Albano, 1996), which included an ASD-specific addendum to capture “atypical”, ASD-specific anxiety presentations. Seventeen percent of the children presented with anxiety consistent with DSM-IV (e.g., Generalised Anxiety Disorder), 15% showed only atypical anxiety, and 31% showed both atypical and typical anxiety symptoms (Kerns et al., 2014). Atypical anxiety symptoms included unusual specific phobias (e.g., fear of balloons) without a generalised sensitivity to sensory stimuli; *Social Fearfulness* without an awareness of social judgement or evaluation; *anxiety around routine, novelty and restricted interests* without the presence of generalised worry; and *compulsive/ritualistic behaviour* without an obvious need to prevent distressing or fearful outcomes (Kerns et al., 2014p.2857). Importantly, Kerns and colleagues found that while the typical anxiety scales had good convergent and discriminate validity in capturing DSM-related anxiety symptoms as measured by the M-ADIS-C/P, they were inadequate for capturing atypical anxiety symptoms (Kerns et al., 2015, 2017). This highlights the importance of further understanding the presentation of anxiety symptomatology in ASD.

Focus groups and thematic analysis have been used previously to explore the nature of anxiety in ASD, focusing on the following aspects: triggers and behavioural signs of anxiety in ASD youth (e.g., Ozsvadjian, Knott, & Magiati, 2012) and young adults (Trembath, Germano, Johanson, & Dissanayake, 2012); the experience and impact of anxiety on adults with ASD (e.g., Robertson et al., 2018); relevant ASD anxiety symptoms, and therefore corresponding anxiety items to add to existing anxiety measures designed for non-ASD populations (e.g., Rodgers et al. (2016)); and the creation of new anxiety measures for children with ASD (e.g., Bearss et al., 2015). Both DSM-related anxiety (e.g., generalised anxiety), and atypical ASD-specific anxiety themes including hypersensitivity, changes to schedule/routine, ASD-specific coping strategies, and difficulties understanding social etiquette and communicating with non-ASD individuals have been reported.

While focus group studies have provided detailed information concerning individual anxiety experiences, an important limitation is that they generally have lacked comparison groups. As relationships between ASD symptomatology and anxiety are reported in non-ASD groups (e.g., Pine, Guyer, Goldwin, Towbin, & Leibenluft, 2008; van Steensel, Bögels, & Wood, 2013), a non-ASD, but anxious comparison group would contribute to elucidating and defining anxiety presentations unique to ASD. Further, qualitative examination of anxiety using criteria from the fifth edition of the DSM (DSM-5, APA, 2013) has not yet been reported. Thus, our aim was to explore and clarify the presentation of anxiety symptomatology in young adults with ASD and anxiety, and compare and contrast this to young adults with anxiety alone. Focus groups using semi-structured interview questions developed from DSM-5 anxiety disorders and Obsessive-Compulsive Disorder (OCD) criteria (APA, 2013) were conducted. We expected that for ASD participants, themes around both DSM-5-related anxiety and atypical anxiety related to DSM-5 ASD would emerge, but that individuals with anxiety alone would only describe themes related to DSM-5 anxiety.

## 2. Method

### 2.1. Participants

Ten participants with ASD (5 females, 5 males) aged from 15 to 36 years ( $M = 21.80$  years,  $SD = 6.76$ ), and ten participants with

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