



Anxiety in adults with autism: Perspectives from practitioners

Kirsty Ainsworth^{a,*}, Ashley E. Robertson^b, Heather Welsh^c, Matthew Day^d,
Jane Watt^e, Fiona Barry^e, Andrew Stanfield^f, Craig Melville^a

^a Institute of Health and Wellbeing, University of Glasgow, Admin Building, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH, UK

^b Centre for Innovative Research Across the Life Course, Faculty of Health and Life Sciences, Coventry University, Priory Street, Coventry, CV1 5FB, UK

^c East Renfrewshire Integrated Learning Disability Team, Barrhead Health & Care Centre, 213 Main St, Barrhead, Glasgow, G78 1SW, UK

^d Autism Initiatives UK, Number 6, 24 Hill Street, Edinburgh, EH2 3JZ, UK

^e Adult Mental Health Psychology Services, NHS Lothian, Department of Psychology, Royal Edinburgh Hospital, Edinburgh, EH10 5HF, UK

^f Patrick Wild Centre, Division of Psychiatry, University of Edinburgh, Kennedy Tower, Royal Edinburgh Hospital, Edinburgh, EH10 5HF, UK



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ABSTRACT

Background: Autism is a neurodevelopmental condition, characterized by differences in social communication and social interaction as well as restricted interests and repetitive behaviours (American Psychiatric Association, 2013). Research has suggested that 50% of adults with autism meet criteria for an anxiety disorder diagnosis (Russell et al., 2013). Despite a call for multi-disciplinary insights (White et al., 2018), few studies have included perspectives of practitioners in this field.

Method: We conducted interviews with eight practitioners (6 Clinical Psychologists, 1 Consultant Clinical Psychologist and 1 Nurse Practitioner) who work with adults with autism and anxiety on a regular basis.

Results: Via thematic analysis, four key themes were identified: 1. Modifications to psychological therapy 2. Thinking outside the box 3. Continued support 4. Issues with anxiety measures.

Conclusion: Modification of standard anxiety interventions are common in practice but the course and nature of these modifications are inconsistent and may depend on practitioner experience. Practitioners may consistently have to think inventively in order to best serve adults with autism and anxiety. Current anxiety measures could be improved in order to accurately gauge anxiety, specific to adults with autism. These findings are discussed in relation to practice and future research.

1. Introduction

Autism¹ is a neurodevelopmental condition that is characterized by differences in social communication and social interaction, as well as restricted interests and repetitive behaviours (American Psychiatric Association, 2013), and is estimated to be prevalent in 1.1% of adults in the UK (Brugha et al., 2012). Recent research indicates that there is a high prevalence of mental health difficulties in autistic individuals, with evidence of 79% meeting criteria for at least one psychiatric disorder at some point in their life (Lever &

* Corresponding author at: Perceptual Neuroscience Laboratory for Autism and Development, McGill University, Room 100, 3724 Rue McTavish, Montreal, QC, H3A 1Y2, Canada.

E-mail address: kirsty.ainsworth@mcgill.ca (K. Ainsworth).

¹ We predominantly use identity-first language (e.g. autistic person) rather than person-first language (e.g. individual with autism) in this article, in order to respect the terminology preferences of the majority of the autistic community (see Kenny et al., 2016).

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Geurts, 2016). Anxiety, in particular, has been highlighted as one of the most common co-occurring mental health conditions in this population (Kerns & Kendall, 2012). Research has suggested that 50% of adults with autism meet criteria for an anxiety disorder diagnosis (Bakken et al., 2010; Hofvander et al., 2009; Russell et al., 2013). Moreover, it has been asserted that anxiety may be compounded by autism symptoms because of a bidirectional link between skills in social cognition and anxiety (White, Oswald, Ollendick, & Scahill, 2009). Hence, the precise manifestation of anxiety in adults with autism is not yet clear.

Kerns and Kendall aimed to classify the manifestation of anxiety in their 2012 review, reporting that although anxiety is not a fundamental part of the autism phenotype, the anxiety symptoms present in individuals with autism were not identical to those observed in anxiety in its independent form. They concluded that there is an unusual presentation and unusually high prevalence of anxiety in autistic individuals. In addition, Maisel et al. (2016) modelled the cognitive mechanisms linking autism symptoms and anxiety in adults. They proposed that three cognitive mechanisms were directly linked to anxiety in individuals with autism: adverse reaction to emotional experiences, difficulties in identifying and understanding emotions (which they define as 'alexithymia'), and intolerance to uncertainty (IU). These findings were supported by South and Rodgers (2017) and build upon the model that

presents IU as being central to the specific manifestation of anxiety in autistic individuals (Boulter, Freeston, South, & Rodgers, 2014).

A recent qualitative study conducted by Robertson et al. (2018) explored the experience of anxiety from the perspectives of autistic adults and their supporters (i.e. parents or partners) in semi-structured interviews. They found that three themes consistently arose: contributing and mitigating factors to anxiety (for example, uncertainty, change, and miscommunication contributed to anxiety while feeling accepted mitigated it), consequences of anxiety (negative judgement from self and others, feelings of missing out or being 'in limbo') and managing anxiety (trying to implement both preventative and 'in the moment' strategies- while recognising that awareness of anxiety in the moment can be difficult). In addition, a series of focus groups conducted with autistic adults with anxiety by Trembath, Germano, Johanson and Dissanayake (2012) reported similar themes. There is, therefore, a growing body of research dedicated to improving our understanding of how anxiety presents, from the perspective of autistic adults themselves.

There is a somewhat limited evidence base for the effectiveness of psychological therapies in reducing anxiety in autistic adults. White et al. (2018) reviewed the literature on treatments of anxiety and depression in adolescents and adults with autism and found that, for anxiety, Cognitive Behavioural Therapy (CBT) was the most commonly researched treatment and suggested that overall, CBT was found to have moderate to large treatment effects. However, treatment was frequently modified, with the changes across studies being varied. Examples of modifications included: an increased reliance on parents to support therapy, a slower pace of treatment, use of visual aids, and ensuring content was highly structured. Similarly, Spain, Sin, Chalder, Murphy and Happe (2015) conducted a review on the use of CBT for autism and co-occurring psychiatric disorders, and reported that there appears to be some improvement of anxiety symptoms in autistic adults with the use of CBT. However, it should be noted that the 'typical' structure of CBT was modified to best suit autistic service users in each study included in the review. Although there has been an effort to systematically identify modifications to CBT for young autistic people (Walters, Loades, & Russell, 2016), a similar evidence base for autistic adults does not yet exist.

There is, however, evidence that some studies have begun to explore this in more detail. For example, in a pilot study, Ekman and Hiltunen (2015) applied a modified version of CBT to autistic adults (namely, adapting basic CBT to focus of visual communication: 'visualizing and systematizing "the invisible" in the conversation'). They found a significant improvement in anxiety levels as measured by the behavioural excess and avoidance components of the Global Function Rating Scale, however, there was no treatment as usual or waitlist control group included as a comparison.

South and Rodgers (2017) proposed that adapting psychological therapies to incorporate improving alexithymia and tolerance of uncertainty, while increasing emotional acceptance, may be particularly useful in reducing anxiety in autistic adults. Supporting this, there is an emerging evidence base which suggests that mindfulness-based therapies may be useful in the management of anxiety in autism (Kiep, Spek, & Hoeben, 2015; Spek, van Ham, & Nyklicek, 2013). Sizoo and Kuiper (2017) compared a modified version of CBT to a modified version of Mindfulness Based Stress Reduction (MBSR). They reported that CBT and MBSR therapies were equally useful for managing anxiety. Overall, despite growing evidence that different kinds of modified psychological therapy may play a role in helping address anxiety issues, more empirical evidence is needed regarding its effectiveness in autistic adults.

There is a clear 'research-to-practice gap' in the application of interventions in autism (Dingfelder & Mandell, 2011). Clearer communication between research evidence and practice is needed for the implementation of effective interventions (Lane, Reynolds, & Dumenci, 2012) and so data from practitioners is an important addition to the scientific conversation surrounding anxiety in autism. Therefore, an exploration of practitioner experiences is imperative in creating more effective anxiety interventions for autistic adults. Moreover, an increased awareness of the practitioner – service user experience may help cultivate a more supportive environment for autistic adults, which in turn could improve adherence and reduce attrition. Despite a call for multidisciplinary insights (White et al., 2018), to our knowledge, only one study has explored practitioner perspectives of anxiety in individuals on the autistic spectrum. Spain et al. (2017) conducted focus groups with a multi-disciplinary teams of practitioners. Two major themes were identified in the data: conceptualizing social anxiety in autism, and service provision. Although Spain et al. (2017) indicated that CBT can be an effective treatment of anxiety, they highlighted that a considered approach is important, namely an adapted clinical delivery and a greater number of sessions. Focus groups are an effective means of generating discussion around a topic, however, there is evidence that one-to-one interviews can elicit a broader range of discussion points (Guest, Namey, & McKenna, 2017), hence, this study builds on Spain et al. (2017) by exploring practitioners' experience of anxiety in autistic adults through semi-structured interviews.

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