



‘Are they just gonna reject me?’ Male adolescents with autism making sense of anxiety: An Interpretative Phenomenological Analysis

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ARTICLE INFO

Number of reviews completed is 2

Keywords:

Interpretative Phenomenological Analysis

Autism

Experience

Qualitative

Anxiety

Emotion

ABSTRACT

Background: Anxiety can be a significant difficulty for people with autism, and rates increase during childhood and early adolescence. Nevertheless, little is known about the subjective experience of anxiety in this population. This study aimed to explore this phenomenon using a method conducive to gaining richer insight into participants' lived experiences.

Method: This study used Interpretative Phenomenological Analysis to explore the lived experience of anxiety, in 14 male adolescents (aged 13–18 years) with autism.

Results: Participants described anxiety which in some ways resembled typically developing adolescent concerns, such as a desire to belong and feel connected to others, and stress linked to academic pressure. However, they also described how their anxiety could be further compounded by qualities that are characteristic of autism, such as difficulty knowing what others felt and how to comfort them, difficulty regulating emotions and the challenge of sensory sensitivities. Some managed their anxiety in ways that might differ from the typically developing population, for example through use of fantasy and role-play. Participants also outlined details about the format and nature of support that they found most helpful.

Conclusions: Themes highlight participants' sensitivity and vulnerability in their unique struggle during this time of adolescence, as well as their resilience and resourcefulness in navigating this. A compassionate response is required from health and education professionals, which considers these young people's human need to feel socially connected, which is sensitive to the way that support is provided, and perhaps makes greater use of creative means of intervention (such as involving fantasy and role-play).

1. Introduction

Anxiety¹ is a common and severe problem affecting many people with autism (Kerns and Kendall, 2014; White et al., 2010), and there is an urgent call to investigate the mechanisms underlying such emotion dysregulation in this population (South and Rogers,

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¹ The definition of ‘anxiety’ differs widely throughout the literature. In keeping with the study methodology, participants were encouraged to speak about whatever ‘anxiety’ or ‘worries’ meant to them personally.

<https://doi.org/10.1016/j.rasd.2018.07.005>

Received 1 April 2017; Received in revised form 22 July 2018; Accepted 23 July 2018
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2017, p. 5). Anxiety is especially common during childhood and early adolescence (Mayes, Calhoun, Murray, & Zahid, 2011), and anxiety disorders may be prevalent in nearly 40% of young people with autism (van Steensel, Bogels, & Perrin, 2011). Adolescence brings with it a number of challenges: with the brain not fully developed, young people are tackling significant body and hormonal changes, and there is a greater importance placed on peer over parent relationships in the context of developing identity. It is not surprising, given the difficulties with social interaction and communication inherent to autism, that navigating this period of life can be particularly challenging and anxiety-provoking. There are further suggestions that difficulties common in autism such as sensory sensitivities (Pfeiffer, Kinnealey, Reed, & Herzberg, 2005), reduced insight into others' intentions and emotions (Demurie, De Corel, & Roeyers, 2011), and peer rejection (Wood & Gadow, 2010), can exacerbate anxiety (White, Oswald, Ollendick, & Scahill, 2009). At the same time, anxiety can negatively affect typical difficulties in autism, such as difficulties with social communication and repetitive behaviours (Wood & Gadow, 2010, p. 288).

There are arguments that anxiety in autism warrants further investigation due to its unique presentation in this population. Firstly, certain subtypes of anxiety, such as social anxiety (Simonoff et al., 2008) and particular, uncommon phobias (Kerns et al., 2014) seem to be more prevalent in people with autism, and anxiety is likely to be triggered by different stimuli (Ozsvadjian, Knott, & Magiati, 2012). Secondly, the way that anxiety presents itself can look different in young people with autism. For example, they may present with more behavioural difficulties and ritualistic behaviour (Ozsvadjian et al., 2012), and the components in anxiety subtypes (such as distress relief through performing a compulsive action) do not seem to feature as with those without autism (Kerns et al., 2014). Researchers have posited ways in which young people with autism may be particularly vulnerable to anxiety, for example because they tend to have fewer friends, fewer stable and reciprocal relationships (Rowley et al., 2012), and are at increased risk of bullying (Kloosterman, Kelley, Craig, Parker, & Javier, 2013). South and Rogers, (2017) posit a relationship between anxiety and difficulties typically seen in autism such as atypical sensory function, alexithymia and intolerance of uncertainty (which can all predict anxiety in autism; Ben-Sasson et al., 2008; Gillott & Standen, 2007; Uljarević, Lane, Kelly, & Leekam, 2016; Maisel et al., 2016; Neil, Olsson, & Pellicano, 2016).

Despite these important potential differences from the typically developing population, few studies focus on the *nature* of anxiety for young people with autism (White et al., 2009; Sterling et al. 2014). Research on the nature of anxiety in young people with autism is therefore lacking and critically needed to inform assessment, formulation, and treatment (White et al., 2009). Research into the effectiveness of anxiety treatment in this population is also lacking (McNally Keehn, Lincoln, Brown, & Chavira, 2013), despite some evidence for adapted Cognitive Behaviour Therapy (CBT) (e.g. Vasa et al. (2014)). Learning more about the nature and origins of anxiety (Wood & Gadow, 2010) will help to develop more effective treatment programs and elucidate the efficacious components of treatment (Danial & Wood, 2013), including mechanisms in anxiety which appear to be unique to people with autism (South and Rodgers, 2017). Mazefsky and White (2014) highlight that difficulties with emotion regulation (organising responses to emotional experiences in an adaptive way) are very common in this population, and may be “inherent” to the condition. Therefore, it is not surprising that research exploring the lived experiences of anxiety, as well as emotional responses more generally, is somewhat lacking in people with autism.

In order to expand this research base, it is important to select methodology which gives participants with autism the best and most valid opportunity to share their experiences. A qualitative approach allows exploration of the phenomenon of anxiety and experience of it, with the possibility of some guidance through multiple choice questions (which support clients with autism (Attwood, 2003)) but without reducing the interview to questions set by the authors' pre-conceptions. This is particularly significant given that the current mechanisms underlying anxiety in autism are not well-known or understood (South and Rodgers, 2017).

One qualitative approach exploring individuals' lived experiences is Interpretative Phenomenological Analysis (IPA). IPA seeks to ‘focus on personal meaning and sense-making in a particular context, for people who share a particular experience’ (Smith, Flowers, & Larkin, 2009, p. 45). IPA interviews seek for the participant to ‘tell their story, in their own words’ (Smith et al., 2009, p. 57). It is hoped that this “facilitates the discussion of relevant topics” by attempting “to come at the research question sideways” (Smith et al., 2009, p. 58). IPA interviewing methodology thus creates a discussion which is participant-led, so participants can follow up their own concerns. This is especially relevant to novel topic areas where closed questioning would otherwise limit data to researchers' pre-conceived ideas about participants' priorities.

IPA has been used in a limited number of studies illuminating the experience of young people with autism (Humphrey & Lewis, 2008; Huws & Jones, 2008; King, Brown, Petch, & Wright, 2014; Petalas, Hastings, Nash, & Duff, 2013). The current study explores participants' experience of anxiety, contextualised within their wider experience of home and school life.

2. Method

2.1. Study design and participants

IPA was employed to analyse data from semi-structured interviews. Participants were recruited using purposive sampling: adolescents from all contactable local groups supporting young people with autism or their parents were invited. Participants were adolescent males aged 13–18 (mean age: 16 years), who described their ethnicities as White British (n = 13) or Caucasian (n = 1). Most attended mainstream secondary schools and accessed youth groups in urban or rural settings. All participants had been diagnosed with autism, ASD or Asperger syndrome, diagnoses / terms grouped under ‘autism’ according to the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5; American Psychiatric Association (2013b)). Autism diagnoses were verified through parents and again with participants, and where possible participants reported the source of their diagnosis (e.g. that it was made in CAMHS, or at a specific centre for ASD diagnosis which was known to interviewers). All participants scored above 15 on the Social

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