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# Anxiety in female adolescents with autism spectrum disorder: Lessons for healthcare professionals

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## ABSTRACT

**Background:** Despite awareness of the high prevalence of anxiety in females with autism spectrum disorders (ASD), females report high unmet service needs regarding mental health concerns. **Aim:** This study explored experiences of anxiety in female adolescences with ASD, their management of it, and their experiences of mental health services in the United Kingdom. **Methods:** Utilising an Interpretative Phenomenological Analysis, six females with ASD, aged between 13 to 15 years and referred to mental health services, took part in semi-structured interviews. **Results:** The analysis generated the following themes: the central experience of anxiety; the impact of the surrounding world; mismatch between needs and support; and the value of self-management. The themes emphasised a need for a more general acceptance of ASD-related anxiety triggers such as sensory overload and uncertainty to change. **Discussion:** Adolescents raised concerns around the appropriateness of support provided for their anxiety, including awareness raising initiatives around ASD which only served to heighten their anxiety. **Conclusions:** Healthcare professionals need to have a better understanding of ASD-related anxiety in females. To improve outcomes, better service knowledge and communications around ASD-related anxiety are important for the assessment of anxiety as well as tailored ASD interventions.

## KEYWORDS

Adolescents, anxiety, autism spectrum disorder, females, sensory, uncertainty

## BIOGRAPHIES

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## Introduction

Anxiety disorders are commonly reported in children and adolescents with autism spectrum disorders (ASD), with frequency estimates ranging from 55% to 84% (Kirsch et al., 2020; MacNeil et al., 2009). Children with ASD often present with higher levels of phobias, generalised anxiety disorder (GAD) and separation anxiety disorder (Ben-Itzhak et al., 2020). It is important to understand this high level of co-occurrence between anxiety and ASD due to its ramifications for daily life (Adams & Emerson, 2021). For example, adolescents with higher levels of anxiety rate themselves as having reduced quality of life (Raknes et al., 2017), with higher levels of anxiety also associated with increases in self-injury behaviours, stress and depressive symptomology (Kerns et al., 2015). Furthermore, parents have stated that symptoms of anxiety have a greater negative impact on their child's quality of life and family functioning, notwithstanding their child's ASD characteristics (Ozsivadjian et al., 2012). Consequently, there is a high likelihood for children with ASD to present within healthcare settings for a range of anxiety-related issues; therein, clinicians require appropriate knowledge of presenting issues to communicate effectively. This includes knowledge around the contribution of underlying diagnosed health conditions for those with ASD, and the potential these health conditions may have on the ASD presentation; this understanding is central for effective, meaningful assessment and intervention processes.

Clinically standardised anxiety scales such as the Spence Children's Anxiety Scale (SCAS; Spence, 1997) are often used to determine an individual's severity of symptoms. However, there is debate regarding the appropriateness of these scales in individuals presenting with an ASD, where more specialised understanding around differences in how it manifests may be warranted (Kerns et al., 2015). Indeed, many individuals with ASD lack the language ability to articulate their feelings making it difficult for healthcare professionals to accurately record their symptoms (Glod et al., 2017; Hallett et al., 2013). Furthermore, there is overlap between behaviour symptoms associated with ASD and the symptoms commonly associated with mood and anxiety problems (South et al., 2017; Spain et al., 2018). This has been reiterated by the parents themselves, who acknowledge difficulties in distinguishing anxiety from other ASD behaviours (Simpson et al., 2020). Clearly understanding anxiety in ASD is complex, necessitating enhancement in current knowledge and improvements in healthcare communication processes.

### ASD-related anxiety experiences

While there may be shared anxieties between individuals with ASD and the general population, such as intolerance to uncertainty (Boulter et al., 2014; Jenkinson et al., 2020), there are also anxieties that are specific to those with ASD, referred to as ASD-related anxiety experiences (Lau et al., 2020; Simpson et al., 2020). About half of the anxieties young people with ASD experience are ASD-related (sensory, less common specific fears, and worries about change and unpredictability), and the other half are common anxieties not usually reported within anxiety measures (social worries, anxiety about the weather, environmental disasters, and animals) (Lau et al., 2020). Moreover, individuals with ASD show more persistent, stronger

reactions to environmental stimuli considered harmless to others (Evans et al., 2005; Mayes et al., 2014), exacerbating environmental triggers, and intensifying the experience of anxiety.

Further, inherent difficulties in social awareness and social understanding in ASD may act as additional triggers for anxiety (White et al., 2013); these may also impact on effective communication within the assessment and intervention process where those with ASD may struggle with ambiguous open questions, and/or struggle to know how to recognise or articulate internal experiences. Perhaps compounding this difficulty, is the tendency for those with ASD to mask or camouflage their behaviours to manage everyday social interactions (Hull et al., 2017; Schuck et al., 2019). For example, a desire to avoid negative responses from others and be treated normally can lead many adolescents to mask autistic behaviours, a phenomenon known as social camouflaging (Cage & Troxwell-Whitman, 2019; Hull et al., 2021; Mandy, 2019). Camouflaging can encompass a range of strategies from jokes or previously learned phrases to non-verbal behaviour, such as imitation of other people's gestures and expressions (Dell'Osso et al., 2021). Camouflaging can make it difficult to understand and identify ASD behaviours, impacting effective understanding by healthcare professionals. Furthermore, continuous efforts to adopt these camouflaging techniques can be stressful, exacerbating anxiety and depression (Cage et al., 2019; Dell'Osso et al., 2020).

Standardised measures of anxiety developed for the general population are often based on common anxiety-related symptoms and may explain why typical anxiety scales inadequately capture the presentation of anxiety symptoms in individuals with ASD (Kerns et al., 2015). To address these concerns, recent scales have been developed to assess anxiety symptomology in ASD, such as the Anxiety Scale for Children with ASD (ASC-ASD; Rodgers et al., 2016), and the Parent-Rated Anxiety Scale for Youth with ASD (PRAS-ASD; Scahill et al., 2019). While the contribution of these scales is welcomed, they have been developed using largely male populations (den Houting et al., 2020); few studies have focused on female-related symptomology, further compounding effective communication processes with healthcare professionals for females with ASD. For example, as females are more likely to camouflage to facilitate interactions in social contexts (Allely, 2019), their increased experiences of peer and school related social interactions may also mean they have experienced negative interpersonal feedback and rejection from others, potentially increasing anxieties when communicating more generally.

## **Anxiety and females with ASD**

Females with ASD are more vulnerable to experiencing higher levels of anxiety than males with ASD (Mandy et al., 2012; May et al., 2014). For example, in females with ASD, higher levels of anxiety have been noted from child and parent-reported measures (Boulter et al., 2014), and females show higher anxiety arousal scores (Ambrose et al., 2020). Moreover, females with ASD may be more prone to social camouflaging due to being better adept at imitating behaviour considered socially acceptable (Allely, 2019). Despite this, anxiety in females with ASD is under researched (Ratto et al., 2018; Tint & Weiss, 2018). Exploring ways in which adolescents with ASD understand their own anxiety is crucial to building our understanding of their mental health and wellbeing (Mesa & Hamilton, 2021). However, relatively few studies directly include the perspectives of autistic young people themselves (Rasmussen & Pagsberg, 2019).

Therefore, given the lack of specialisation in clinics related to ASD diagnosis in females (Young, Oreve, & Speranza, 2018), and high unmet service needs regarding mental health concerns (Tint and Weiss 2018), it is important to understand first-hand experiences and management of anxiety for female adolescents with ASD as well as their experiences of support services. To our knowledge, this is the first qualitative study exploring this, with the aim of providing not only more awareness to support the work of healthcare professionals working with ASD, but specifically to address better guidance to help and support females with ASD.

## Methods

### Design

As Interpretative Phenomenological Analysis (IPA) is informed by hermeneutics (Smith et al., 2009), this methodology was chosen for its ability to explore individual females' lived experience of ASD and co-occurring anxiety. The interview schedule was designed through consulting the literature on ASD and anxiety, and ASD specialists in neurodevelopmental diagnostic and Child Adult Mental Health Services (CAMHS) services, as well as parents of young people with ASD and anxiety. The schedule was then reviewed and refined by the research team and included (see Appendix 1 for full interview schedule):

- When people talk about feeling anxious do you know what this feels like for you? Can you describe it?
- Are there any environments or experiences around you that trigger these feelings or make them worse?
- Can you tell me about when you first talked to someone about these feelings? Was it helpful/unhelpful?

Prior to the interview, the schedule was shared with the parents of the participants invited to take part in the study. An information sheet describing the study was provided, and interview topics, confidentiality and publication discussed. Participants were interviewed face-to-face, with a parent present, and at a time and private location of their choice. Questioning was flexible allowing spontaneous probes to explore experiences in depth. Interviews were audio-recorded and lasted between 20-50 minutes. Once completed, participants were asked if they had any questions, they were thanked for their time, reminded they could withdraw at any time and given the debrief sheet which included contact details of local support groups. Interviews were then transcribed verbatim, pseudonyms applied, and recordings securely deleted.

### Participants

The Department of Education (2021) recognises the difficulties people with ASD face in respect to associated anxiety-related issues and inequities in healthcare provision. The current study was conducted in a south-eastern county in the United Kingdom (UK), known to have long waiting list and lack of access to mental health services (Children's Commissioner, 2021). Using snowballing methods and adverts placed with local ASD support groups, a purposive sample of participants were recruited. All those who contacted the lead author were parents

of adolescents with a formal diagnosis of ASD and co-occurring anxiety disorder, aside from one, who had a diagnosis of ASD and was being assessed in services for GAD with marked anxiety making school attendance and day-to-day activities difficult. All had accessed mental health provision. Six female adolescents aged 13 to 15 years old were recruited (Table 1).

*Table 1. Participant demographic information*

Name	Ethnicity	Age	Age ASD diagnosed	Co-occurring diagnosis <sup>1</sup>	Age of co-occurring diagnosis <sup>1</sup>	Schooling
Ellie	White British	14	12	GAD	13	Home School
Sarah	White British	15	14	GAD	14	Mainstream
Mia	White British	13	8	Anxiety	Being assessed	Mainstream
Juliette	White British	13	9	OCD <sup>2</sup>	9	Mainstream
Immy	White British	13	7	OCD <sup>2</sup>	11	Mainstream
Macie	White British	15	12	GAD	12	Mainstream

<sup>1</sup> Formally diagnosed by a healthcare professional

<sup>2</sup> Obsessive compulsive disorder

## Ethical Considerations

Ethical approval was obtained through the university's ethics committee (LMS/PGR/UH/03651) and developed in line with the Declaration of Helsinki as revised in 2000. Confidentiality was maintained throughout, and given the age of participants, informed consent to participate was signed by the adolescents and a parent/caregiver. Parents were also present during the interview. Whilst having a parent present may have impacted the interview, given the age and potential vulnerability of the participants, this was deemed important. Following the interviews, all participants and caregivers obtained a debrief sheet signposting to additional support if needed.

## Data Analysis

IPA was used for the analysis (Smith et al., 2009); to ensure immersion with the data, analysis was conducted by the first author who repeatedly reviewed the recordings and transcripts. The analysis incorporated several stages: data familiarisation; line-by-line analysis of claims, concerns and perceptions, descriptive & linguistic comments; eliciting emerging themes; reviewing themes; and engaging in reflexive discussions with the research team to facilitate the defining and development of the final superordinate and subordinate themes. Quotes were identified across the sample to ensure the themes represented the participants' words. To further ensure validity and triangulation (Treharne & Riggs, 2015; Nizza et al., 2021), the three authors discussed and reviewed the emerging themes throughout the process of coding; conducted separate coding on sections of transcripts exploring the emerging themes which

were generated; considered convergent and divergent themes across the transcripts; and attained agreement on the final themes and quotes used in the paper. Furthermore, to add rigor to the analysis, member checking was conducted; participants were sent a summary of their interview and themes for participants to review and provide feedback. None of the participants requested changes.

## Results

Analysis of six semi-structured interviews resulted in 10 subordinate themes grouped into four superordinate themes outlined in Table 2:

*Table 2: Superordinate and subordinate themes*

Superordinate themes	Subordinate themes
The central experience of anxiety	No words for emotions Somatic symptoms
The impact of the surrounding world	Pervasive Interactions with ASD features Demands from others Comparisons by others Exposure
Mismatch between needs and support	Professionals' misperceptions Incompatibility with uniform standardised procedures
The value of self-management	Avoidance and being alone Needing individualised choice

### The central experience of anxiety

This theme explores the pervasive nature of anxiety and how participants had always experienced anxiety as a physical sensation, addressed by two subthemes: no words for emotions and somatic symptoms.

#### *No words for emotions*

Whilst all participants identified anxiety as a central part of their daily lives, rather than utilising emotional or psychological language, all described it using physical descriptors. The words anxiety or anxious were rarely used with participants using terms such as “flipped out” “nervous”, or “stress”.

All six participants were able to trace their anxiety back to a young age. For example, both Macie and Juliette recognised their anxiety as beginning young and linked to physical sensations and reactions:

I was young in primary school I used to think I was nervous but [...] I'd always need to go to the toilet. (Juliette)

I was always nervous before school [...] I always had tummy aches walking to school even when I was really little. (Macie)

Furthermore, they all had difficulty identifying associated feelings, almost as though this phenomenon was normal, had always been with them and was beyond language. This made

it hard to differentiate from their normal experiences giving a sense that describing anxiety was difficult. For example, when asked when she first felt anxiety Juliette queried: “Do I have anxiety?”. Juliette then went on to explain that she had always felt anxiety was a part of her which her mum was able to recognise: “I don’t think I noticed it but mum did.” It was almost as though an outsider perspective was needed to observe behaviours and then name the emotion underpinning this. Similarly, Ellie stated: “I don’t know when it started, it’s just always been there”; Immy explained, “it’s just normal for me. I always feel panicked”; Sarah said, “I was always a nervous person” and Mia concluded, “I’ve always been upset, I think. Things have always bothered me.” Likewise, Macie explained her anxiety beginning “um at school maybe? It’s hard to tell, I always felt it was just me”. Terms such as “always”, “it was just me”, “it’s just normal” all served the function of implicating the centrality of anxiety within participants’ very core.

### *Somatic symptoms*

The physicality of anxiety was a central and intense experience, making it distressing. All the adolescents described symptoms of panic when identifying anxious feelings within their body. For example, Macie stated: “my chest gets tight [...] I feel like I’m going to faint”; and Ellie and Emma both additionally stated, “I can’t breathe”. Immy described how, with anxiety: “I feel like I’m suffocating”, a somatic symptom of panic attacks. Juliette described her anxiety as akin to feeling nauseous stating: “I feel sick [...] and I get really hot”. Perhaps it was no wonder that participants’ sense of vulnerability was amplified by their surrounding environments - the heat, nausea, inability to breathe, and feelings of suffocation, seemed intense and frightening, an experience they had lived with since their earliest memories.

### **The impact of the surrounding world**

All participants identified the interrelationship between the environment, ASD features and the social context, often intensifying their anxiety.

### *Pervasive interactions with ASD features*

All participants highlighted that one of the strongest triggers for anxiety was the interrelationship between their ASD features and their experience of sensory aspects within the environment (noise, touch, smells, sights), resulting in sensory overload. In all accounts, one could sense an intensity and distress – beyond anxiety, towards fear and terror in the way they described their personal experience. Four of the participants described sensory overload in the auditory modality. For example, Sarah identified an internal sensitivity to “people breathing too loud and people chewing [...] it makes me feel ill [...] I get stressed out”, and Immy described the sensation of someone filing their nails as “painful”, saying “it makes me feel awful.” Macie, Ellie and Immy immediately identified that “loud noises”, such as fire and car alarms induced anxiety, with Immy expanding with: “It’s the loud noises, and I think like, I panic”. Mia and Juliette both declared that “busy places” and “big crowds” triggered anxiety.

Whereas Juliette explained that “It’s so loud and people bump into you” demonstrating tactile sensitivity as a presenting feature.

The school environment particularly induced sensory overload for two of the adolescents with a range of sensory modalities interacting together. For example, Mia described how “the lockers” at school made her feel anxious saying “I don’t like having all these people around me” whilst she was struggling to get in and out of her locker. Additionally, Ellie recognised that “the corridors at school” induced her anxiety. She was unable to expand on why, highlighting a difficulty articulating her experience.

The uncontrollable nature of the surrounding environment was a key trigger for half the participants. Whilst not directly stated, it was almost implicated that they were trying to cling onto a sense of stability for survival through familiarity and order. For example, Immy stated: “if things happen out of nowhere [...] I don’t like it”. Ellie also explained that when surprises or unexpected events were sprung on her she found this difficult as, “I won’t know what’s going on”. It would appear, conversely, that a sense of not knowing or making sense of experiences was not just about their experience of anxiety but also what was going on around them; as Immy explained this was: “Because I can’t prepare, I can’t plan it out and have it organised in my head”.

### *Demands from others*

Five participants identified that demands from others were anxiety triggers including school-based authority and rules, often making them feel misunderstood. Both Macie and Immy explained that school was too demanding, seeming to be unpleasant; for example, Immy emphatically stated: “I don’t like school”, explaining: “I don’t like it when they [teachers] tell me what to do”. Macie more forcefully echoed this sentiment, saying: “I hate school”, stating the teachers “don’t understand me or what I need [...] they tell me off for fiddling with my scarf but I have to do it”. It was the very nature of the environment, and the demands triggered by the rules and directions from others, which Juliette explained made her feel “stressed out” and “makes me want to do the opposite”. This was echoed by Sarah who articulated: “When someone tells me how to do something. It stresses me out” and Ellie stated that “Being told what to do and when to do it” was stressful. It was almost as though participants experienced school akin to a prison with teachers dictating what they should do and what must be done; the distress seemed to trigger a resistance in some participants, a response based more on survival (“it stresses me out”) rather than defiance.

### *Comparisons by others*

Some of the participants concerns revolved around others comparing their own experience of anxiety to their own. Ellie, Juliette and Immy clearly recognised differences in their experience, such that attempts by others to share and connect through comparisons actually exacerbated the sense that others did not understand, to the point that even talking directly about it induced more anxiety. For example, Ellie explained: “they compare their experiences to mine but it’s not the same and I don’t care about theirs...it doesn’t help me it makes it worse”.

Macie expanded on this stating that speaking with others was detrimental as “they don’t understand”.

There was a sense of this sharing being an isolating experience rather than one that helped them connect with others. For example, for Juliette, when others compared their experiences of anxiety and OCD to hers, it was unhelpful as “it’s not the same”. She further elaborated saying: “then it makes it all worse trying to talk about it to make them see that it’s different”, suggestive of a distressing experience with expectations to explain clearly, it was almost as though she felt forced into this unwinnable position, if she succeeded in articulating why it was dissimilar she would only highlight her difference, if she was unsuccessful in articulating this, she risked feeling even more misunderstood, thus separating her further away from a common ground. This sentiment was echoed by Mia who found comparisons minimised the pervasive and intense nature of her anxiety when others simply worried: “Because people are like ‘oh my god, I’m so worried, I have anxiety’, and I’m like, ‘no you don’t’ [...] Anxiety’s reoccurring and it controls you”. Clearly Mia struggled to articulate this when she concluded with the statement: “I don’t know”.

### *Exposure*

Five participants spoke about attention being drawn to their ASD as a trigger for their anxiety. For example, Immy described her intense response to a situation where a peer asked if she was autistic: “I just flipped out. I stormed off and slammed the door and felt so tight and like I couldn’t breathe”. Such an intense reaction was driven by Immy’s underlying concern about misconceptions about ASD: “In case she thinks it’s something bad, or something she can catch [...] or that I’m ill”.

Fears that others would think it was contagious only resulted in her further separating herself from others. With the intensity of their anxiety triggering a different reaction to others, Ellie stated: “If people try and ask why I’m acting different, I flip out”. It was almost as though underlying this reaction was a deep-seated shame around the way environments that others managed triggered sensory overload in her. Indeed, the intensity of core emotional responses to experiences typically viewed as normal just triggered a reaction highlighting her differences and separating her further – she was in a no-win situation.

More specifically, Juliette described conversational topics on ASD triggering unease: “People talking about autism makes me worried”; recalling a class topic around students with different needs, when the topic of ASD arose she felt exposed and visible: “It made me feel worried that people would pick up that that’s what I have”. There was a sense of being looked at through a looking glass with all her private internal experiences being on show for all to see. Similarly, Sarah viewed her diagnosis as private around peers and found it difficult when people around her discussed her needs: “when people talk about [ASD] in an open way [...] I don’t like it”, further explaining: “that’s not for anyone else to talk about”.

Again, we can only wonder about the underlying impact of this disconcerting experience, although there was clearly an intense fear of exposure and being defined by what they perceived others saw were public displays of unacceptable emotions and behaviours.

## Mismatch between needs and support

Five participants recalled their experiences of local mental health services, implicating a mismatch between standard anxiety provision advocated by professionals and their individualised needs, subsequently impacting on their ability to form an alliance.

### *Professionals' misperceptions*

When talking about support from local mental health services, half the young people highlighted professionals lacked a sound understanding of anxiety or of themselves as individuals with ASD, which hindered their experience of support. Juliette suggested that professionals should have some lived experience of anxiety and ASD to understand how “hard” expression is when “you’re autistic”:

Yeah they should get to know the person first. And I think it’s better if the professional is someone who’s actually had it because then they understand it more because it’s really hard when you’re in therapy, especially when you’re autistic to express how you actually feel and [...] Yeah what works for one won’t work anyone else.

Whilst difficulty expressing experiences was highlighted, Juliette clearly articulated this individualised experience of ASD, perhaps what seemed more apparent was others’ difficulty understanding her experience. The barriers derived from difficulties communicating were echoed by Sarah who centralised this misunderstanding to her very core:

“They don’t understand me. Or what it’s like. And I don’t like talking about it [...] actually getting to know me, and to understand me”.

Such difficulties seemed to implicate all talking therapies focused directly on ASD, were unhelpful heightening the barrier experienced with others. The tendency to follow standard approaches for anxiety by professionals in CAMHS made them seem “up themselves” aggravating Ellie’s feeling of being misunderstood:

I guess just be more understanding? [...] Yeah like they act really up themselves and they don’t know me. Makes me not want to speak to them. Yeah, because it’s not all the same you know.

Again, a sense of survival seemed to underpin Ellie’s resistance rather than a sense of defiance; the misalignment in the alliance seemed to be a factor shutting Ellie down, again implicating that this misunderstanding went to her very core, evocatively highlighted when she concluded “my anxiety is about me not anyone else”.

### *Incompatibility with uniform standardised procedures*

Four participants reported similar techniques and strategies within the support received via local mental health services, struggling to understand the aims or relevance; this understandably made them dislike the suggestions. For example, Macie explained:

They suggested an app to go on every night, um and, to like keep using it. And it was, there was something else, like to look at a square, find the square but I didn’t see why I should, like what’s the point?

In line with standard anxiety interventions, three participants recalled being taught deep breathing to manage their anxiety, however, this was particularly aversive for all three, for

example, Immy stated: “That does not help. I hate deep breaths I hate deep breathing”. Reflecting back on participants’ experience of anxiety, it was almost as though standardised interventions for anxiety exacerbated their deep-seated bodily response rather than ameliorated it.

Again, participants seemed to indirectly implicate a different physical quality to their experience of anxiety and how standard psychologically based provision exacerbated their difficulties. For example, when recalling strategies CAMHS had suggested would help manage her anxiety Sarah said: “They haven’t really. Deep breathing which is stupid and doesn’t help”.

Whilst this was implicit rather than explicit, participants were able to articulate what they needed from others to help them manage; simply to learn about anxiety in ASD and to understand and accept their individualised entrenched experience differed from others - they needed a different environmentally based and personalised approach to help them manage.

## The value of self-management

All participants were able to identify individualised ways of coping with their anxiety that seemed to intuitively fit their needs, yet perhaps contrasted with traditional approaches to anxiety. These ways of coping largely fell into two main sub themes: ‘avoidance and being alone’ and ‘needing individualised choice’.

### *Avoidance and being alone*

A key adaptive coping method was avoiding situations they recognised as an anxiety trigger. For example, Sarah found the sensory elements within school anxiety inducing, thus, missing school when her anxiety would be triggered was her way of coping. She explained, “Not going to school helps. So keeping out the way of them”. This adaptive avoidance technique was echoed by two other young people who also struggled within the school environment:

Having my recovery days – so these are my days off school. (Immy)

Sometimes I just remove myself from the situation and usually go home. But it’s probably not the best way to deal with it, but it’s where I’m comfortable and I’d rather not be anywhere else when I’m like that [...] I’d rather be home. (Macie)

Whilst there was recognition that “it’s probably not the best way to deal with” anxiety, “recovery days” and being somewhere safe was still essential. In contrast to seeking support from others, five participants identified that being alone and by themselves was crucial in managing their anxiety through active techniques involving music, reading and art. The important factor in these moments was their wish to be left alone to self-regulate. For example, Sarah, Ellie and Mia all stated that “leaving me alone” helped when they were feeling anxious. Sarah expanded upon this, explaining: “I like to just listen to music on my phone by myself and just forget about what’s going on around me”. Whilst this was not articulated, there was the sense that avoidance did not isolate them, it allowed them to cope in private with anxiety in the moment, so they could then return and blend back in with others. Thus, visible displays of anxiety seemed to be the isolating variable, making participants feel disconnected from others.

Two participants identified that being alone and reading were useful for their self-regulation:

I do read a lot as well and last night I sat in my parents' bedroom and read and that helped. (Immy)

Just let me be myself. I have to just be in the playroom where I can read and play with the cats. (Juliette)

Interestingly, both Immy and Juliette identified specific spaces where they liked to be alone - the playroom and parents' bedrooms; perhaps there was an element of a safe environmental space playing a part in the self-regulation process, either triggering anxiety (school) or regulating it (home). One is left wondering if there were any safe quiet places like this being truly available at school.

### *Needing individualised choice*

Half of participants identified that taking control of the situation around them helped calm them and utilised this as a way of managing anxiety. For example, Immy described a sensory trigger to her anxiety and the game she had developed to distract and take control of the situation:

I sometimes do super mouse. It's a toy mouse and I cut up some of dad's old clothes and made costumes and when she [sister] is screaming or storming off I use super mouse to distract her.

Individualised control was linked with their need to be alone, choice in where to go, and how long was needed: "Not putting a time limit on my calm down time I have to stay there as long as I need to" (Juliette).

Conversely any boundaries and time constraints imposed by others could accelerate their emotions rather than contain them: "Don't tell me where I can go to be alone. Just let me choose and leave me to it. When mum says no you need to come downstairs it just makes it worse" (Ellie).

Again, safe places and people were implicated to be at home, although these could be stripped away when the ability to make this choice was taken away. Perhaps, it was no wonder participants felt misunderstood and not heard given how they consistently highlighted their ASD-friendly approach to anxiety, which was diametrically opposed to standardised anxiety interventions and social rules and expectations. Their recognition of boundaries and time limits demonstrated the necessity of avoiding demands for females with ASD to help regulate anxiety, and reflected how these situations, if handled incorrectly could exacerbate and entrench levels of anxiety rather than ameliorate it.

## **Discussion**

This study aimed to explore experiences of anxiety for female adolescents with ASD. Participants spoke of anxiety being deeply interconnected with the surrounding world. Given drawing attention to their ASD made them feel exposed, increasing their anxiety, this impacted on their willingness to engage in standardised interventions. Furthermore, participants reflected on their experiences of mental health services, revealing problematic areas in current interventions which exacerbated a lack of understanding around their ASD-related anxiety experiences. Instead, they identified personalised approaches to managing anxiety, emphasising the importance of individualised control and the value of avoidance.

An overwhelming finding was the need for more understanding around how females with ASD express their anxiety and the best ways to manage it. In this study, the term *anxious* was rarely used, preferring descriptive terminologies such as “stressed out” and “flipped out”. In line with the literature on ASD and alexithymia (Hamaideh, 2017; Milosavljevic et al., 2016), many struggled to attach emotion or psychological factors to the expression of anxiety. Instead, they focussed on physical and descriptive language; they also found it difficult to define these behaviours outside of their ASD, which is synonymous with the accounts of parents in other studies (Simpson et al., 2020). Given the deep rooted and pervasive experience of anxiety centering on physical descriptions, when others compared their momentary experiences of anxiety through psychologically based language, this raised intense feelings of uncertainty. The females in this study did not know how to respond, further exacerbating their anxiety. As they could not always identify anxiety as a separate phenomenon to their core self, any misunderstandings around their core experience seemed to exacerbate feelings of being misunderstood by others. Addressing this has important implications within clinical practice, where effective communication is central to engagement in interventions, enhancing outcomes (Rilveria, 2022). Thus, given the communication difficulties associated with ASD and the likelihood that abilities to have coherent, direct and clear dialogues may be underdeveloped, acceptance-based responses from clinicians would be useful to facilitate a reconceptualization of resistance and avoidance-based behaviours/responses as sometimes being adaptive and functional.

Another core finding in this study was the impact environmental factors had on anxiety. Whilst previous research has identified anxiety-inducing aspects of school environments in children around test and separation anxiety (Last & Strauss, 1990; MacNeil et al., 2009); our research unearthed intense and terrifying feelings of “pain” and “panic” arising from sensory overload from environmental factors, including school corridors and locker areas. For participants, when they were able to, this was more effectively managed by using controlled avoidance. This contrasts with standardised interventions for anxiety, even those adapted for ASD, which focus on psychologically driven factors which increase exposure and reduce avoidance through anxiety management techniques (Delli et al., 2018). Thus, by following recommended, standardised advice and interventions, healthcare professionals may inadvertently worsen engagement and outcomes for females with ASD.

Complicating matters further is the psychological need for young people from an early age to fit into society; sources of distress such as self-image and peer group relationships can be difficult for any young person to manage, particularly for girls (Lewis et al., 1984). Females with ASD may consequently mask ASD behaviours and difficulties (Cook et al., 2018), making interactions within healthcare services more problematic. The camouflaging of ASD behaviours can trigger considerable anxiety (Cage et al., 2019; Tubío-Fungueiriño et al., 2020). While increased understanding of ASD in wider school communities has often been considered important and helpful in reducing negative experiences for autistic pupils (Roberts & Simpson, 2016), our findings suggest that when expectations are directly placed on adolescent females with ASD to actively participate in autism-related school discussions, for those who are not ready for this, this lens can enhance negative experiences of exposure, thus having a deleterious effect on them. Feeling different was already a complex experience for participants, and unnecessarily drawing attention to this was experienced as exposing; subsequently triggering anxiety and resistance as a form of protection. Females who show higher levels of camouflaging may be those most vulnerable to anxiety-related symptoms

when attention is drawn directly to their ASD or differences (Cage et al., 2019). Such awareness-raising initiatives are the cornerstone of current practices in healthcare and education in the UK, yet, inadvertently, may be problematic for females with ASD when this potential outcome is not considered, or is not managed sensitively or discreetly. Indeed, for some females with ASD, discreetly opting out prior to or during ASD awareness raising events, may be warranted, with clear and direct communication permitting these options.

Further, while all participants in the study had accessed mental health services, they found standard interventions hard to understand and implement; indeed, adolescents with ASD believe mental health services are not tailored to meet their needs (Crane et al., 2019). As noted in this study, the entrenched internal experience of anxiety seemed to make it less of a psychological phenomenon and more a pervasive physical one, making it less malleable to change through standardised interventions. Factoring in the feelings of being misunderstood and communication barriers in ASD, it is of upmost important that strategies and therapy interventions are tailored more effectively to ensure delivery is emotionally beneficial to those impacted by anxiety (Grundy et al., 2017). This necessitates the use of autism-specific measures when understanding presentations and identifying symptomatology which capture the spectrum of autism-related anxiety (Adams et al., 2019); and the utilisation of ASD adapted acceptance-based strategies (for example, Pahnke et al., 2019), which allow experiences to exist as they are, whilst living life according to one's values.

Given the communication issues in ASD, many clinicians advocate for specialised training in supporting individuals with ASD, yet the training procedures in place are currently inadequate (Kalb et al., 2019), with 39.5% of GPs in the UK receiving no formal training at all (Unigwe et al., 2017). Furthermore, research indicates that mental health professionals hold several inaccurate beliefs about ASD (Heidgerken et al., 2005; Brookman-Frazeem et al., 2010), which can impede effective communication. Thus, inadequate training or lack of training and knowledge presents a significant barrier to ASD females accessing beneficial mental health support. Indeed, the opposite to standard practices may be more effective, and thus, when implemented appropriately should become acceptable for females with ASD.

Uncertainty and a lack of control were also raised as issues in the study. Previous research has identified control-related beliefs as a self-management technique for anxiety (Moulding & Kyrios, 2006), and parent-based interventions focusing on managing intolerance of uncertainty have shown promising results (Rodgers et al., 2017). This study additionally highlighted the value of avoidance and individualised personal control which evoked a calming influence for participants. Such adaptive management strategies helped females with ASD in this study better manage environmental factors before they became overloaded and overwhelmed by their anxiety.

Individualised control has previously been identified as necessary for those with ASD to regulate emotions and gain control of their environment (Stuart et al., 2020). Whilst avoidance is usually associated with an exacerbation of anxiety symptoms, with females more likely to use this than males (Panayiotou et al., 2017), the young females in the current study stated that removing environmental and sensory pressures around them, helped them to better regulate their emotions. One young person coined the phrase "recovery days" to better manage anxiety-triggering situations over time. Perhaps, it is the combination of planned avoidance and access/integration into mainstream education systems which may support the

inclusion of females with ASD, enhancing their ability to attain their potential by accessing opportunities, in a manageable way, alongside their peers.

For this study, whilst the sample was small and from a limited geographical area potentially resulting in region-specific findings, this is a common limitation of qualitative research which, instead, aims to provide a nuanced understanding of lived experience, through case-to-case transfer generalisation (Treharne & Riggs, 2015). Further, the age range of participants was narrow, limiting understanding around females at primary school, or females entering adulthood and beyond. With a focus on anxiety, this study has no data on the experience of other mental health issues for those with ASD, such as depression, eating disorders, or self-harm, limiting understanding on mental health in general. Nevertheless, this is the first study directly exploring the experiences of adolescent females with ASD and co-occurring anxiety and the sample is appropriate for a rigorous, in-depth IPA analysis accurately reflecting the context and experiences of this group of participants (Smith et al., 2009). Indeed, qualitative research in anxiety in ASD has been recommended due to limitations in measurements of anxiety to enrich understanding about its presentation and impact across settings (Adams et al., 2019). Further research is warranted on larger samples of females to expand understanding and improve the quality of healthcare communication processes for females with ASD.

## Conclusions

There clearly is significant variability in our understanding and support provided to young females with ASD and anxiety. Young females with ASD can experience anxiety as a central experience, impacted by the environment, with daily tasks and generalised routines missing individualised choice. Expectations and comparisons from others accelerated anxiety symptoms, and the need for understanding, personalised control within environments, and avoidance was evident throughout the study findings. An awareness of anxiety in young people with ASD is critical for accurate diagnoses related to anxiety symptoms and to provide appropriate treatment options or referrals to healthcare professionals to meet the individual needs of those with ASD. Therefore, understanding and knowledge of individualised experiences of anxiety specific to females with ASD, along with more appropriate mental health interventions is paramount to support their wellbeing and development.

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## Declaration of interest

The authors report no conflicts of interest

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## Appendix 1

### Interview Schedule

1. When people talk about feeling anxious do you know what this feels like for you?  
Can you describe it?
2. Where do you feel anxious feelings in your body?
3. Can you tell me the earliest memories you have of feeling this?
4. Are there any environments or experiences around you that trigger these feelings or make them worse?
5. Can you tell me about when you first talked to someone about these feelings? Was it helpful/unhelpful?
6. When you get those feelings now is there anything you can do to make them go away/to feel better?
7. When you get those feelings what makes them worse?
8. Is there anything other people do that makes those feelings better/that makes them worse?
9. Can you tell me about your experience with your mental health service?
10. What kinds of strategies have they suggested to help you manage your anxiety?
11. When you get those feelings now is there anything you can do to make them go away/to feel better?
12. Is there anything you do that helps that you think services could offer?



QUALITATIVE HEALTH COMMUNICATION

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