

Running Head: THE EXPERIENCE OF ANXIETY

The Experience of Anxiety in Young Adults with
Autism Spectrum Disorder

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Abstract

Anxiety is known to be common amongst young adults with Autism Spectrum Disorder (ASD), yet little is known about the nature of their experiences or the strategies they use to live and cope with their reported anxiety. This qualitative study aimed to begin to address this issue through two focus groups involving 11 young adults with ASD and 10 parents and professionals. Participants in each group were asked to discuss the triggers for anxiety, the consequences of anxiety, and strategies they have used or would like to use to manage their anxiety. The participants identified multiple personal and environmental sources of anxiety, noting the substantial impact it has on their everyday lives at home, work, university, and in the community. Their individual experiences and strategies for living and coping with anxiety are presented.

The Experience of Anxiety in Young Adults with Autism Spectrum Disorder

Anxiety is common amongst people with Autism Spectrum Disorder (ASD; Bellini, 2004; Drahota, 2009; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). These individuals experience a variety of symptoms of anxiety including physiological arousal and panic (Bellini, 2004, 2006), which can greatly interfere with their daily lives (Bellini, 2006). Individuals with ASD are also reported to have poor stress management skills (White, Oswald, Ollendick, & Scahill, 2009). Understanding the phenomenology of anxiety in this population from their own perspective has immense clinical value, and is useful in devising suitable intervention strategies to minimize the adverse experience of symptoms (Gillott & Standen, 2007).

Autism Spectrum Disorder is an umbrella term used to describe a group of lifelong pervasive developmental disorders which includes Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. Each are characterised by impairments in social interaction, communication, and restricted and repetitive behaviours and interests (American Psychological Association, 2000). As many people with ASD have an associated intellectual disability (ID), those individuals without a co-morbid ID are referred to as having 'high-functioning' autism (HFA), as they function within the average or above average range of intellectual ability. Although anxiety is commonly experienced by individuals with ASD, it appears to be more prevalent among individuals with HFA, especially during transition between childhood and adolescence (White et al., 2010).

This paper will report on the outcomes from two focus groups conducted to gain a deeper understanding of the everyday experiences of anxiety in young adults with ASD. The aim was to examine first-person accounts to allow those affected to speak for themselves, using their own words, to explain the impact of anxiety on their lives at home, university, and in the community. To date, research into anxiety in ASD has focused on comparing the

prevalence of anxiety in individuals with ASD compared to typically developing controls, through the use of standardized measures and questionnaires. It is important to note that in this study, participants were asked to speak about anxiety in terms of what they understood the term to mean, with the view to generating information to inform future research and the development of practical strategies. Thus, our aim was not to examine the extent to which symptoms described by participants may fit within the clinical range, but rather to explore the impact of self-reported anxiety on everyday life.

The Nature of Anxiety

When examining the nature of anxiety, it is pertinent to explore the factors which lead or contribute to feelings of anxiety (i.e., the *triggers* - sources of or situations which elicit anxiety), the emotional or behavioural responses that result from these feeling (i.e., the *consequences* - what happens when anxiety has been triggered), and the potential approaches that alleviate the feelings of anxiety (i.e., the *solutions* - what anxiety-reducing strategies work for individuals with ASD). An examination of the triggers and consequences of anxiety is of great practical value as proposed solutions can then aim to alleviate anxiety experienced by individuals with ASD in everyday life (Gillott, Furniss, & Walter, 2001).

Triggers. It is well documented that a range of child factors (e.g., temperament, behavioural inhibition), family factors (e.g., parent-child attachment, marital conflict), and environmental factors (e.g., death in family, change in marital status) can lead to the development of anxiety in the general population (Grover, Ginsburg, & Ialongo, 2005). However, there is evidence that the inherent difficulties in social awareness and social understanding experienced by individuals with ASD may act as an additional trigger for anxiety (White et al., 2010). Bellini (2006), for example, examined the relationship between social skills, physiological arousal, and social anxiety in a group of 41 young people, aged 12-18 years, with Autistic Disorder (n = 19), Asperger's Disorder (n = 16) and PDD-NOS (n

= 6). Based on self-report measures, including the Social Skills Rating System (SSRS; Gresham & Elliot, 1990), the Social Anxiety Scale for Adolescents (SAS-A; La Greca, 1999), and the Multidimensional Anxiety Scale for Children (MASC; March, 1999), Bellini reported that both heightened physiological arousal and social skills deficits may contribute to social anxiety in ASD. Evans, Canvera, Kleinpeter, Maccubbin, and Taga (2005) administered a parent-report fear survey comprising 69 items rated along a 5-point-Likert type scale for 23 children with ASD (mean age = 9.20 years). Compared to comparison groups of typically developing children and children with Down Syndrome who were matched on mental age, the children with ASD exhibited more social anxiety and had fears of specific environments and situations, such as confined spaces and medical situations.

Gillott et al. (2001) also identified environmental triggers for anxiety in young people with ASD in their study of anxiety and social worry in 15 children with HFA (aged 8-12 years) and two age- and gender-matched comparisons groups (15 typically developing children and 15 children with a specific language impairment). Based on the results of the Spence Children's Anxiety Scale (SCAS; Spence, 1997) and the Spence Social Worries Questionnaire (SWQ; Spence, 1995), the authors identified that children with HFA were more anxious than children in the two comparison groups, experiencing social worries that included difficulties predicting others' behaviour and readily determining what will happen next. These worries were exacerbated by unanticipated changes in the environment or in the sequence of events (Gillott et al., 2001). This finding is consistent with previous reports that even minor changes in the environment may elicit stress, confusion, and anxiety in individuals with ASD. Indeed the fear of possible change can be overwhelming due to the need to preserve sameness (Gillott et al., 2001).

Consequences. Gillott and colleagues (2001) highlighted not only triggers for anxiety in young people with ASD, but also many consequences. The 15 participants with

HFA (aged 8-12 years) reportedly ruminated over their worries and actively avoided social interaction with others. The authors also noted that anxiety-provoking situations may result in both adaptive and maladaptive behaviours which are used by individuals as self-calming strategies. Bellini (2004) also identified a range of consequences associated with anxiety for 41 adolescents aged 12-18 years (mean age = 14.22 years) with ASD. These included physiological manifestations such as arousal, sensory sensitivities, panic attacks, agitation, and low frustration tolerance. These findings are consistent with the notion that anxiety may impede the ability to tolerate everyday stresses, results in decreased coping (Gillott & Standen, 2007) and impedes the capacity of people with ASD to be resourceful and find solutions (Reaven & Hepburn, 2006).

Solutions. The social interaction, communication, and cognitive impairments characteristic of ASD hinder the ability of individuals with ASD to generate effective intervention strategies during anxiety-provoking situations (Reaven & Hepburn, 2006). Therefore, it is pertinent that individuals with ASD are provided with strategies that are designed to promote adaptive behaviours involving techniques for self-calming, self-management, and self-awareness, thus, preventing or decreasing the severity of maladaptive behavioural manifestations of anxious symptomology (Myles, 2003). However, in order to provide effective solutions, it is necessary to first obtain a deeper understanding of the experience of anxiety in affected individuals and the consequences of these feelings. Accurate identification of possible anxiety-provoking situations, signs, and symptoms, as well as potential predisposing and preventive factors, will be pertinent to the development and implementation of effective coping strategies for this population (Bellini, 2006; Reaven et al., 2009).

Currently, there is a lack of empirically-based intervention strategies designed specifically for individuals with ASD who experience anxiety (White et al., 2010). To

illustrate, although Cognitive Behavioural Therapy (CBT) has been identified as a possible treatment for children with ASD, the results of such attempts have been mixed (Moree & Davis, 2010), and the implications for adults with ASD are unknown. One limitation of this approach is the ability of individuals with ASD to institute the necessary cognitive strategies (e.g., identifying and challenging unhelpful thinking) while experiencing anxiety. Thus, researchers need to explore other possibilities, in particular, ways of preventing the onset of anxiety. The first step to developing effective solutions is to understand the phenomenology of anxiety from the first-hand perspective of individuals with ASD, as well as the perspectives of parents with adult sons or daughters with ASD and professionals working to support their needs.

Method

The study was approved by La Trobe University Faculty Human Research Ethics Committee.

Participants

Adults with ASD. The young adults with ASD were 9 men and 2 women, aged between 18-35, who were recruited through the investigators' professional networks across metropolitan Victoria, Australia. Diagnoses were self-reported and all participants were in receipt of relevant services for which a formal diagnosis of ASD is required. The ratio of males to females in the sample was broadly in keeping with that observed in the ASD population (Fombonne, 2009). All participants were verbal, of whom ten contributed their views and experiences independently during the focus groups. One participant contributed with the assistance of a family member, who supported his comprehension by explaining the questions asked of the group and elaborated on his brief comments in order to help relate his experiences to the group. Three participants were attending community access and training

programs, five were enrolled at university, and three were unemployed at the time of the study.

Caregivers and professionals. The caregivers and professionals focus group comprised 10 adults: 3 women and 1 man who were parents of individuals with ASD, 5 women who were professionals working with clients with ASD, and 1 woman who was both a professional and parent of an adult with ASD. The parents and professionals were recruited through the investigators' networks across metropolitan Victoria.

Materials

The two focus groups were audio-recorded and video-recorded to assist with transcription and analysis. Transcriptions were made using Microsoft Word™.

Procedures

Focus groups. The two focus groups (parents and professionals first) were conducted two weeks apart at the Olga Tennison Autism Research Centre at La Trobe University, and were facilitated by the fourth and first author, respectively. Each group lasted approximately 120 minutes, including a 15-minute break in the middle. At the start of each group, the facilitator reiterated information contained in a Participant Information Sheet (distributed during recruitment) regarding the purpose of the group, the procedures that would be followed, and the fact that participants were allowed to withdraw at any time without question. To this end, the facilitators explained that if any participants felt anxious during the group they could simply choose to leave the room. The participants were encouraged to say as little or as much as they liked, and to raise any issues that they felt were pertinent. Participants were also encouraged to express their views and experiences through writing and drawing if they felt more comfortable doing so than talking within the group.

The facilitator next outlined a set of rules governing the group discussions focused on ensuring (a) that each person had an opportunity to express their views and experiences, (b)

that each person's comments would be respected, and (c) that participants understood that the comments that others made in the group must not be repeated outside of the group in order to maintain confidentiality. A semi-structured interview guide was used to ensure that a range of issues were discussed including: (a) triggers of anxiety in young adults with ASD (i.e., situations which elicit anxiety), (b) consequences (i.e., what happens when anxiety has been triggered), and (c) solutions (i.e., what helps young adults with ASD manage their anxiety). In addition to these topics, the parents and professionals were also asked to talk about the impact that supporting young adults with ASD and anxiety had on their lives and the lives of others.

Analysis

The focus group transcripts and the written information provided by participants were analysed using thematic analysis, as outlined by Braun and Clarke (2006). This method involves repeated cycles of analysis across six stages using the constant comparative method (Creswell, 2007) leading to an abstract account of participant experiences, and constitutes a rigorous qualitative method in its own right (Braun & Clarke, 2006). First, the focus group transcripts and the written information were read in order to become familiar with their contents.

Line-by-line analysis of the transcripts and written words was then undertaken to identify discrete ideas, incidents, and events in the data, which were assigned preliminary codes. A comment, for example, in which one participant spoke of the anxiety he experienced when explaining his diagnosis to others was assigned the code 'sharing diagnosis.' Similar and related codes were then grouped into potential categories, from which themes emerged. To illustrate, the theme 'disappointment' emerged to account for many different 'triggers' of anxiety which arose from situations in which participants felt strongly disappointed. Finally, each theme was systematically assessed to determine the extent to which it accounted for the

participants' experiences, and its relationship to other themes expressed using a thematic map (Braun & Clarke, 2006) as outlined below in Figure 1.

[Insert Figure 1 about here]

To help ensure credibility of the findings, the codes and themes identified by the first author were reviewed by the second author to identify errors or misinterpretations in the coding. Differences regarding interpretation were resolved through discussion and amended accordingly. In addition, the relevant guidelines for conducting qualitative research outlined by Chiviotti and Piran (2003) were adhered to, including: (a) where possible, using the participants' own words to create the codes and themes, (b) identifying the basis on which the participants were selected, (c) specifying the aims of the research and locations where the study was carried out, and (d) describing how the literature relates to the themes identified.

Results

Three themes, and ten sub-themes, emerged to account for the participants' everyday experiences of anxiety. As illustrated in Figure 1, the three main themes related directly to the participants' (a) sources (triggers) of anxiety, (b) experiences of anxiety (consequences), and (c) the strategies they had developed for living and coping with anxiety (solutions). The three themes, together with their sub-themes, are presented below using the participants' own words. Pseudonyms have been allocated to protect the participants' privacy.

Sources of Anxiety

The young adults with ASD identified 20 sources of anxiety arising from everyday situations, while the parents and professionals identified 16. As presented in Table 1, 15 of the 20 sources were common across both groups. In addition, each of the young adults reported that they experienced multiple sources of anxiety. Through exploring the origin and nature of these sources of anxiety, five sub-groupings emerged: (1) anxiety resulting from the

environment, (2) interactions with others, (3) concern for others, (4) anxiety associated with fearful anticipation of an event or outcome, and (5) anxiety resulting from disappointment.

[Insert Table 1 about here]

Immediate environment. According to the young adults with ASD, their everyday physical environments produced multiple sources of anxiety. Luke, for example, spoke of his fear of germs in his environment and the impact this fear had on his everyday life.

There isn't really a physical surface in the world that I'm not scared of – there isn't anywhere that I'm not scared – it just makes me feel angry and powerless and nauseous wherever I go and whatever I do.

Shane, on the other hand, spoke of the anxiety caused by the sensory environment he had to navigate in going about everyday tasks such as travelling to university.

I get pissed off when I'm on the train in the morning and all the students get on and are talking and talking, and I'm in an enclosed area, and sometimes the fluorescents [lights] are flickering, and I'm like 'No, no'.

Shane went on to explain that crowded environments, such as university lecture theatres and tutorial rooms, were also a source of anxiety, a sentiment shared by Brian in the following statement:

Crowded buses, that makes me anxious too.

Indeed, most young adults with ASD identified interacting with other people, whether on a crowded bus or a one-to-one conversation, as a key source of anxiety.

Interactions with others. Shane described the sources and feelings of anxiety that arose for him in interacting with other people as part of his university training. This included the anxiety associated with his attempts to adapt his communication style to meet the styles of others without ASD.

I'm a very blunt and direct person but, apparently, the people in my course, they get offended when I'm being honest. [They tell me that] I have to use white lies and I have to talk in a more indirect manner. So then I have anxiety about how to talk in a more indirect manner and how to appeal to their 'emotions' and how to sound 'flowery' and 'pleasant'.

Shane went on to speak about the difficulties associated with adapting his communication style, including the physical and emotional tension.

I can only do that for a certain amount of time each day and I get burnt-out talking to people.

Melissa too noted that attempting to adapt to the communication styles of others, in this case through making eye contact, was a key source of anxiety:

I actually get quite anxious with [having to make] eye contact.

Andrew said that he felt anxious, distracted, and at times 'paranoid' during interactions because he felt his behaviour was constantly being watched and judged by him and others.

It feels as though I've got a surveillance, [a] video camera in my head, watching my every move and it's basically judging me, saying 'Why the hell are you doing this?', 'Why the hell are you doing that?' – 'You should've done it this way or that way'.

Andrew's comments were echoed by Brian who reported that he became anxious in situations where he felt he was being watched by others.

[I feel anxious] when someone looks over my shoulder for no reason.

Consistent with these reports of the young adults with ASD, the parents and professionals identified interactions with others as a key source of anxiety for young adults

with ASD. Linda, for example, explained that the manner in which high school teachers talk with young adults with ASD can trigger anxiety.

So, in the senior school, some of the students can be provoked quite easily, even if the teacher is trying to help the clients comprehend, even adjusting tone of voice and things like that. And, if their tone is too aggressive, then the students will become extremely anxious.

Similarly, Susan noted that young adults with ASD may become anxious if they have difficulty comprehending what is said in a conversation.

You know, two or three members of the family get together and they forget that my son is only really picking up half of the conversation and it's invariably the wrong half. And things that he will then sense as a threat to some things being changed or whatever. So, those threats really come through, I think, quite strongly in everyday life – increasing his levels of arousal.

In fitting with these observations, there was consensus among the participants in both groups that communication partners (i.e., other participants in the interaction) play a key role in mediating the anxiety experiences of young adults with ASD.

Concern for others. In addition to feeling anxious in their interactions with others, the young adults with ASD expressed feeling anxious out of concern for others and their communities at large. To illustrate, Shane expressed concern and suspicion that people are being misled, to their detriment, by politicians.

I get very anxious about how the parliaments, they do policies only to sway people to vote for them and not because it genuinely benefits society.

Jennifer expressed similar concern, explaining that she felt anxious about a recent change in Government and had deep concerns about perceived injustices in society.

I become anxious about politics – the government doing things wrong – partially and especially about people being oppressed – I can't stop thinking about it, I can't focus on good things and it exhausts me. I was relieved when [the election] was finally over!

Shane's and Jennifer's comments were consistent with the reports of the parents and professionals, who also identified having 'concern for others' as a key source of anxiety amongst some young adults with ASD. Victoria, for example, noted that her adult son had become very concerned about the 12-year drought that was occurring at the time of the study, and its impact on others, after hearing media reports.

[He is] stressing about the environment and [asking] are we getting enough rain? He is checking the water meter every day.

Victoria then went on to explain that her son had also become anxious out of concern for others after hearing media reports regarding the effects of smoking, eventually losing his job as a direct result of the anxiety.

[He is also] concerned about people smoking in that he is worried for their health because I've had to stop him say 'Smoking is a health hazard' to them all the time. You know, because he was concerned. In fact, he lost a job because he was so upset that other people were smoking near him.

Fearful anticipation. Both groups of participants identified anticipation as a key source of anxiety. Peter, for example, said that he feels anxious about the future.

I've been unemployed probably for seven years - with the global financial crisis and all that, it's been hard for a lot of people to get work – not just me. And I hate volunteering – I mean, I need money to survive. So for me, what makes me anxious is just what will happen in the future – the uncertainty of it all, I guess.

Shane, on the other hand, said he quickly became anxious when a situation arose in which he might need to speak in front of others.

I get anxiety when I have to talk in public like if I, for example, if the lecturer finishes a lecture and says 'Does anyone have questions?' and I have a question, my heart starts beating faster. Whenever my heart beats faster, I get anxious.

Susan, a parent, however, spoke more broadly about the types of situations that may lead to anxiety, before providing specific examples.

Anything that he's anticipating should happen or could happen or he would like to happen, and doesn't. For example, someone not replying to an e-mail immediately and radio stations not playing the right songs or they're missing out on playing one song from the 60s, at least one an hour – those sorts of things – the fine, minute [details] tied up with his obsessions.

Similarly, Stuart, a professional who worked in a University, spoke of the generalised sense of anxiety experienced by many students with ASD at the start of each academic year due to a desire to control unpredictability.

Something that triggers our students often is at the start of the year, at the start of the semester, selecting your tutorials and your timetable causes anxiety, and that's anticipating or wanting something to be put in place, and it's an unknown because they might get that tutorial, but they might not.

Disappointment. The final source of anxiety identified by participants in both groups was disappointment. Brian explained that he often felt disappointed and became anxious when public transport did not arrive on time.

Trains being late – five minutes [late].

Andrew, on the other hand, who was interested in cricket, explained that the disappointment associated with his team losing was a key source of anxiety.

I used to get anxious about Australia winning and that sort of thing.

Andrew, as well as Victoria who was a parent of a young adult with ASD, noted that the anxiety experienced as a result of sporting disappointment was different to that which might be experienced by a devoted sporting fan.

Especially at the football, if his team doesn't win, although I have no control of it and [my son] has no control of it, I am somehow held accountable.

The analysis revealed that the experiences of anxiety amongst young adults with ASD are complex, often difficult, but certainly painful and debilitating, and that the impacts of anxiety are often felt well beyond the specific situation in which it originates. It was through this process that the theme 'the experience of anxiety' emerged.

The Experience of Anxiety: Dissociation and Dislocation

The young adults with ASD provided rich accounts of their personal experiences of anxiety, with both similarities and differences across the group in relation to the dynamics of anxiety (e.g., onset and course) and its impact on their lives. These reports were echoed by parents and professionals, based on their observations of young adults with ASD, resulting in two sub-themes described below ('dynamics' and 'impacts on young adults with ASD'). The parents and professionals also noted the impact of anxiety on those around young adults with ASD including family and members of the public, leading to the emergence of a third sub-theme labelled 'impacts on others.'

Dynamics. Some participants, including Luke, described the experience of anxiety as unavoidable with a sudden onset.

It's entirely circumstantial – mine's pretty much circumstantial so, you know, as soon as I see – as soon as something happens that upsets me, it's instantaneous – BANG! Like a bucket of cold water to the face.

However, other participants, including Ben, described a more gradual onset.

I find that it builds up, it doesn't just happen like an explosion – it, ah, sort of one thing might trigger it, get it rolling, and then, something else might crop up um that might cause me to get a little bit more anxious like losing stuff.

Either way, most of the young adults indicated that once triggered, their feelings of anxiety tended to grow as they became increasingly aware of the inexorable panic and their own reaction to it, as Jennifer explained.

Sometimes, anxiety can build up on itself like a brick on an accelerator pedal - whenever you make a mistake due to anxiety, you become more anxious. It's just something that keeps being in your head and you can't get it out and you can't focus on other things.

Impacts on young adults with ASD. The participants all said that they were aware of their anxiety and described physiological signs including increased heart rate, sweating, and nausea, as Melissa's comment illustrates.

I get heaviness in the centre of my chest and I start getting very, very hot and the more anxious I am, the more difficult it is for me to get my ideas into words – either written or verbal.

As Melissa noted, anxiety not only resulted in a range of physiological signs, but it also had real impacts on her ability to engage in everyday activities. Indeed, the impact of anxiety on everyday activities was emphasised by participants in the parents and professionals group also.

The parents and professionals were unanimous in their concerns regarding the impact of anxiety on the participation of young adults with ASD in everyday activities. Stuart, for example, noted that anxiety can act as a barrier to young adults accessing tertiary education.

They get removed from the situation or they remove themselves – they just can't participate.

Similarly, Emma noted the impact that anxiety has on her adult daughter's ability to communicate with others.

With my daughter, probably one of the main things that happens in stressful situations is that she gets flustered, she loses the ability to really say what she wants or thinks or what she has to say. If given time, she'll calm down herself but, mostly, she tends to withdraw from the situation rather than engage.

The parents and professionals also raised concerns regarding the impact that anxiety can have on the way others perceive young adults with ASD, noting that this is a further barrier to participation in everyday activities.

Impacts on others. The key concern raised by parents and professionals was that people often misinterpret the anxiety-related behaviour of young adults with ASD. To illustrate, Stuart spoke of an experience when a high school student became anxious and upset, leading to humiliation for that person.

One student becomes very, very verbose and emotional and scares people around her. If people aren't aware of her or her behaviour, security might be called. So there is a lot of potential humiliation, but people then make assumptions about this behaviour that may not be true or accurate. And that's unfortunate.

Parents also noted that knowing their son or daughter may have difficulties in particular situations due to anxiety created uncertainty for them, as Victoria explained.

I am aware that my son does a lot of transport by himself and I send him off into the world because there is no way I can keep him at home because he would become too frustrated. So, he goes off into the world and I just have to hope that if anyone approaches him, he'll run away rather than try and converse with them because that's when the situation arises. But I have had phone calls from the police worried about whether I knew where he was and, generally, I don't know where he is, but I know roughly where he is, and they've been satisfied with my responses that he's OK but, obviously, people have called the police and I think they've been worried about what he was doing – I think.

There was consensus across both groups that the development and use of practical strategies played a key role in addressing the sources, experiences, and impacts of anxiety in everyday life for young adults with ASD, and for exploring new solutions

Living and coping with anxiety

The young adults with ASD and the parents and professionals all identified strategies for preventing and managing anxiety that they had used themselves, would like to use, or had observed. The parents and professionals focused on strategies aimed at preventing the onset of anxiety, whereas the young adults tended to focus on strategies to manage the anxiety once it had occurred. The two sub-themes - 'preventing anxiety' and 'managing anxiety' - are presented below.

Preventing anxiety. For Emma, a parent, a key strategy for helping her daughter avoid anxiety was to be organised.

She gets stressed if she's running late for anything. [Therefore], we try to make sure she gets there in plenty of time. If she has an 11am lecture, she'll head off at 20mins to 11am to make sure that she is there on time.

Claire used another strategy, feeling that her adult son benefited from a regular exercise program, which helped to not only manage, but reduce, his anxiety due to its predictability.

[He] has a program at the gym such as 12 repetitions on one exercise, 10 minutes on that so there are a lot of number sequences behind the program. I've noticed, over time, there's a little bit of diminished anxiety because of the consistency of exercise.

Shane, a young adult with ASD, explained that he was trying to avoid anxiety by learning strategies for interacting with people without ASD.

I read social skills books and 'Yahoo Answers' on what people regard as polite, and I try to copy that. So, to me, it's rote memory. It doesn't come to me naturally. I have to manually learn it and people have to specifically teach me what is considered polite – I don't know it naturally so I feel very robotic when I talk to neurotypicals.

Despite the use of these proactive strategies, the vast majority of strategies identified by young adults with ASD focused on managing existing anxiety.

Managing anxiety. The most common strategy for managing anxiety was to escape, either physically or through diversion and distraction.

I've got some strategies [for dealing with anxiety]. I go for a walk or run. I wish I could literally run to the hills.

Music was another commonly identified de-stressor:

I find listening to music on my iPod to be really helpful. If I am really down and depressed and in the dumps, I'll start listening to a series of songs. (Andrew)

Retreat into the comfort of other technologies provided frequent respite also. Melissa, for example, identified a computer game that she liked to play to manage her anxiety, in addition to escaping and listening to music.

With me, there are probably three main things, which help me calm down; (1) my music; (2) removing myself from what is the trigger – either physically or emotionally somehow, and; (3) fiddling – say knitting or something. However, [computer company] has this really good game, which I enjoy – it usually gets all those three things (mentioned above) in one go. It's a game where you're patting fish, basically. It's a very basic, very simple game – it removes me from the stress triggers and it has the music going for it.

Similarly, Luke noted that he found computer games offered a distraction from feeling anxious.

I lose myself in computer games because it's something linear, it's something that you don't have to devote all your thoughts at once to and dealing with neurotypicals.

Other participants, including Brian, reported that listening to music and relaxation techniques were effective in managing anxiety.

Go for a walk, take some deep breaths, listen to music, relax in your bedroom.

Several participants, including Luke, spoke of the benefits associated with talking with other people who understand what it is like to have ASD and experience anxiety.

Sometimes talking about your stressful situation with other people who are familiar with – with you. Neurotypicals probably aren't recommended, except for your parents but if you're talking about someone who has it, you know, you can sort things out, you calm down a little bit.

Andrew suggested that social networking sites, through which he can communicate with other people with similar experiences without the pressures associated with face-to-face communication, were helpful.

I've found that, with a lot of people on the spectrum are using social networking sites to ah sort of keep them in contact with other people without - you know - being in the comfort of their own home without having to go out and into public, open environment and socialise face-to-face. For example, I talk on Skype with various mates of mine and I also find that – that really helps.

Ben suggested that it would be helpful to have a support line, available specifically to adults with ASD, where they could access support from trained professionals.

It would be cool if there was a hotline specifically for people with autism, particularly if they're feeling stressed. Have a counsellor on the other end of the line.

Several participants had learned strategies for managing anxiety from professionals and friends. Jennifer described the strategies she had been taught by her psychologist.

My psychologist taught me to get grounded – to concentrate on what I can see, hear, smell, taste, and feel inside and outside my body.

Andrew explained a method his friend had taught him.

One of my mates has taught me to just treat it like it's not an important thing, that it doesn't matter if you're not perfect all the time. That sort of stuff.

Only one participant, whose pseudonym identity has also been withheld for additional privacy, reported using drugs and alcohol in the past in an attempt to manage anxiety.

I feel anxious – like at parties, I feel very uncomfortable so I have to drink lots of alcohol. I also tried marijuana because someone gave it to me as a birthday present and that actually reduced my anxiety but it is illegal and, also, I don't have access to it anymore so, yeah, but that's not in Australia.

A complete list of the strategies for living and coping with anxiety identified by the participants in both groups are presented in Table 1.

Discussion

The aim of this study was to explore the everyday experiences of young adults with ASD based on their first-hand experiences, as well as the reports of parents and professionals who support them. The results clearly demonstrate that anxiety impacts on the lives of young adults with ASD and those around them. The results also demonstrate that the sources of anxiety, the symptoms and experience of anxiety, and the strategies young adults with ASD use to manage anxiety are highly individualised. The implications of these preliminary findings for clinical practice and future research directions are discussed with regard to the existing literature.

Understanding the Sources of Anxiety

The young adults with ASD reported difficulties with social interactions (e.g., ‘small talk’) which are inherent to ASD, and performance anxiety (e.g., public speaking), as key sources of anxiety, consistent with the findings of Bellini (2006) in their study of adolescents with ASD. In addition, the participants reported that environmental noise, health concerns, unexpected change, and disappointment were also key sources of anxiety. The fact that unexpected change, disappointment, and environmental noise were all identified as triggers suggests that the relationship between key characteristics of ASD and anxiety may extend beyond the impact of social impairment, previously reported in the literature. That is, other ASD related characteristics such as a strong desire for routine and sameness, and sensory aversions, may also be implicated. Either way, the fact that each participant identified a unique set of multiple sources indicates that a ‘one size fits all’ approach to supporting young adults with ASD is unlikely to be successful. Nevertheless, given that the young adults with ASD, parents, and professionals identified essentially the same sources, the results may provide a starting point for beginning to address these sources through tailored interventions.

An important finding of this study relates to the clear concern that young adults with ASD expressed for others and society at large, to the extent that it was a source of anxiety for many. Shane and Jennifer, for example, expressed concern that other people were being misled by politicians and about injustice in society more broadly. Victoria reported that her adult son was very anxious about rainfall and the environment, and that he had lost his job due to expressing concern for people who were smoking outside his workplace after watching an anti-smoking campaign on TV. The fact that young adults with ASD are concerned about others and society at large should not come as a surprise, but it has rarely been documented in the ASD literature. The results suggest that any attempts to support young adults with ASD manage their anxiety must address both inward and outward sources of anxiety, while acknowledging that some outward sources, such as the health and political choices of others, cannot be controlled.

Experiences of Anxiety

Irrespective of the sources of anxiety, the participants' reports of the emotional and physical consequences were compelling. Participants spoke of feeling frustrated, depressed, withdrawn, and robotic, while at the same time experiencing racing heartbeats, sweating, and nausea. Although previous reports (e.g., Reaven & Hepburn, 2006) have documented these symptoms in relation to children with ASD, the present findings extend the scope of study to young adults with ASD and highlight the consequences on their lives and the lives of others. That is, the participants in this study reported that anxiety represented not just an emotional or physical state but rather a key barrier to their participation in everyday activities such as using public transport, meeting with friends, and attending university.

The participants' comments indicate that the dynamics of anxiety including onset and escalation differ for each person. Luke, for example, described a sudden onset like a 'bucket of cold water to the face' while other participants described a more gradual roller-coaster.

Several participants, as well as parents and professionals, emphasised the fluctuating nature of anxiety which makes predicting difficult in relation to how an individual may feel or cope in a specific situation on any given day. The parents, in particular, said that these fluctuations made it difficult to plan and provide support, and thus appeared to be a source of carer burden. Nevertheless, all participants indicated that they had insight into their own level of anxiety, or anxiety in others in the case of parents, and had identified strategies for living and coping with it accordingly.

Living and Coping with Anxiety

The participants identified a range of strategies for living and coping with anxiety including withdrawing, relaxing, and exercise. Of these, withdrawing from anxiety-inducing situations to a context or place in which the triggers are not present, or the people within that context will be understanding, was the most common across participants. Several young adults with ASD spoke of escaping to online social networking sites where they could talk with others with ASD, or immersing themselves in computer games, as ways of coping. Others said that they retreated to a quiet room, listened to music, watched movies, or exercised to escape. In contrast to these reactive strategies, far less emphasis was placed on preventing or pre-empting anxiety by the participants in this study. It is not clear from the findings whether this is due to the inherent difficulties associated with trying to prevent the multiple sources of anxiety the participants reported or whether this reflects a preference for reactive strategies. Either way, the results provide clear evidence of the importance of coping strategies in the lives of young adults with ASD who experience anxiety and those close to them.

Limitations and Opportunities

The results of this study extend the existing literature by documenting anxiety in this adult population of individuals with ASD, as opposed to children and adolescents, and by

doing so through their own words as opposed to formal tools and measures. Nevertheless, given that qualitative research makes no claims about generalisation, the findings are limited to accounting for the experiences of the participants in the study. Future studies involving larger groups and a combination of quantitative and qualitative methods will further advance understanding of what is an important issue in the lives of young adults with ASD, their parents, and professionals who support them. Such studies should include standardised measures of anxiety in order to better characterisation of the anxiety symptoms experienced by participants, thus allowing for a more detailed analysis of these experiences as well as their strategies and outcomes.

The focus groups provided a forum in which participants could share and discuss their experiences and views freely, allowing them to present the issues most meaningful to them. In addition, the involvement of three different groups of participants (young adults with ASD, parents, and professionals) allowed for triangulation of the data. Focus groups involve social interaction in a semi-structured environment, and some young adults with ASD may have been reluctant to participate or to express themselves fully during the study. Future studies could incorporate additional modes of data collection such as one-to-one interviews, either face-to-face or online, in an attempt to ensure that methods employed do not deter full participation.

Future Research Directions

The findings indicate that attempts to support young adults with ASD to live and cope with anxiety must address both individual and environmental factors. There are opportunities to develop and evaluate practical approaches for making community and educational environments more accessible, such as working with Universities to provide greater support to young adults with ASD at the time of enrolment and reducing unnecessary public speaking requirements in classes. Similarly, there are opportunities to develop and evaluate new

technologies that may help young adults with ASD monitor and manage their anxiety. Fundamental to any approach, in moving forward, is the need to (a) understand and address the social difficulties inherent in the disorder, (b) utilise existing treatments for clinical anxiety where appropriate and to the greatest extent possible, and (c) ensure that young adults with ASD are partners in the process so that any solutions developed are relevant and useful in their everyday lives. Indeed, the results clearly demonstrate that the young adults with ASD, along with their parents and professionals who support them, are the best source of information and ideas for strategies.

Conclusion

The focus groups confirm the reported research which indicates high levels of anxiety among people with ASD. A novel aspect of this study was to approach the experience of anxiety in three ways – by examining triggers, consequences, and solutions, and through the views of the clients, their parents, and expert professionals. It is clear from this study (and related studies) that anxiety is caused by unexpected change and social encounters, and many other situations, but there is a lack of understanding of solutions that may assist young adults with ASD to cope with the anxiety. Our use of focus groups allowed the voice of those intimately involved to be enunciated comprehensively. Qualitative data analysis complemented the process of elicitation of key concerns and issues, and led to a description of six contexts for anxiety creation. These were identified as external surroundings, personal interactions, concern for others, self-recrimination, hyper-alertness, and serious disappointments. Further research could focus productively on the gamut of solutions suggested by the participants in this study.

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Table 1. Anxiety Sources, Experiences, and Strategies

	Young Adults with ASD	Parents and Professionals
Sources of Anxiety	Sound and light sensitivities Crowds Uncertainty/making decisions Delays (e.g., transport) Anticipation and disappointment Unexpected or sudden change Health concerns (germs) Public speaking Communicating with others Perceived injustice to self or others Authority (e.g., police, security) News reports and other media Meeting deadlines Making eye contact Losing things Bullying and gossip Managing finances Perceived surveillance of self Explaining diagnosis Life transition (e.g., leaving school)	Lack of sleep Crowds Uncertainty/making decisions Delays (e.g., transport) Anticipation and disappointment Unexpected or sudden change Health concerns (self and others) Public speaking Communicating with others Tone of voice Radio station not playing song News reports and other media Meeting deadlines Ambiguous/open questions Understanding social etiquette
The Experience of Anxiety	Increased heart rate Sweating Obsessive thoughts/behaviour Emotional (e.g., crying, screaming) Frustration Nausea Distraction	Emotional (e.g., crying, screaming) Challenging & repetitive behaviour Obsessive thoughts/behaviour Emotional (e.g., crying, screaming) Frustration Humiliation
Strategies for Living and Coping with Anxiety	Listening to music Singing Watching movies or TV Developing multiple interests Alternative therapies Study social skills resources Sleep Exercise (walk, swim, run) Journaling Looking at pictures Withdrawal (physically/mentally) Talking with trusted person Riding motorbike Self-talk Deep breathing and meditation Online social networking Computer games Drugs and alcohol	Heart rate monitors Allowing extra travel time Watching movies or TV Online learning Alternative therapies Humour Mood monitor (visual chart) Exercise (walk, swim, run) Journaling Looking at pictures Withdrawal (physically/mentally) Talking with trusted person

Figure 1. Thematic Map of the Anxiety Experience

