

Article

The Anxiety Caused by Secondary Schools for Autistic Adolescents: In Their Own Words

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Abstract: Secondary schools are increasingly becoming inclusive of all students whatever their individual needs, but we question whether teachers understand enough about specific needs in order to effectively support all their students. Research indicates that autistic students often struggle with aspects of school (conformity; social communication; sensory challenges; bullying) but very few studies ask autistic adolescents about their experiences. One of the key elements of the school experience for autistic adolescents is the levels of anxiety experienced by many students on a daily basis. This research set out to explore the extent to which autistic students in secondary schools in the UK were able to recognise and reflect on their own anxiety. The eighteen participants in this co-produced qualitative study took part in semi-structured interviews planned by a team of autistic and non-autistic researchers. The themes that emerged from this study, in terms of triggers for anxiety, included other people's behaviour, fear of the unknown, and sensory sensitivities. A theoretical view of their difficulties concurs with the concept of intolerance of uncertainty. Our data suggest that autistic students continue to experience high levels of anxiety throughout their secondary education, despite supports put in place by some schools. Strategies are highlighted that could be implemented by all schools to promote truly inclusive settings.

Keywords: autism; secondary school; anxiety; inclusion; adolescence



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1. Introduction

This paper reports on school-based anxiety through personal accounts by autistic adolescents, designed through a participatory research process with a group of autistic co-researchers. Anxiety is increasingly recognised as a key factor in the level of challenge and success in mainstream school settings. The school environment is one that promotes high levels of anxiety in many students, and particularly in those with autism [1]. Previous studies [2,3] have focused on the transition period from primary to secondary school suggesting that although this represents a significantly difficult time, once students had time to adjust, problems may diminish. Focusing on this point in time we examined the school experiences of young people aged 12–17 years.

In order for educators to better support adolescents, we need a greater understanding of the perspective of the young people themselves, regarding whether they can recognise anxiety in themselves and can express it; what aspects of school exacerbate anxiety and which strategies lead to reduction; and to what extent and in what ways students try to hide anxiety or manage it themselves. We consider intolerance of uncertainty as a key factor in managing emotions in the school setting and suggest that although many strategies schools currently use are appropriately aimed at bringing certainty, more understanding of anxiety could positively impact the lives and education of autistic students. This study is original in two main respects; first, we used a participatory research design in collaboration with young autistic co-researchers who had not long left school; and second, interviews gave a seldom studied group of adolescents the opportunity to describe their anxieties in their own words.

We would like to note here that we have decided to use the term autistic adolescents as it is preferred by the autistic co-researchers in the project reported here; we acknowledge that this is a contested area and that some people prefer person-first language (adolescent on the autism spectrum).

2. Background

It is widely accepted that autistic people experience higher rates of anxiety than the general population [4]. There is debate about whether anxiety is a symptom of autism or a co-occurring difficulty but there are indications that there is a qualitative difference between generalised anxiety and what is experienced by the autistic community [5,6]. A systematic literature review of 31 studies involving 2121 young people (aged ≤ 18 years) found that up to 40% of autistic people experience at least one anxiety disorder compared to 15% of the general population [7]. The most frequent anxiety disorders were specific phobias, OCD, and social anxiety disorder. This meta-analysis identified older teenagers as having higher levels of generalised anxiety disorder than the younger and greater effects in those with a higher IQ (*ibid*). In Kuusikko et al. [8], autistic children reported an increase in social anxiety as they got older in contrast to their neurotypical peers where it typically decreased, supporting a view of anxiety being experienced differently. They found a clinically relevant link between autism/Asperger's and social anxiety symptoms. They also found a 1.5–2.0: 1 ratio of females to males with social phobia symptoms. Similarly, Simonoff et al. [9] identified 70% of autistic participants as having at least one comorbid disorder, with 40% having two or more; the most common of these being social anxiety disorder. Thus, research highlights the prevalence of anxiety in autistic teenagers without intellectual disability being educated in mainstream schools. This makes it an important area of focus, particularly when seen from the student's perspective.

Secondary schools are large complex environments making the setting unpredictable for autistic adolescents, which can make it difficult to tolerate [10]. Multiple sources of anxiety in schools have been suggested including bullying [11], sensory sensitivity [12], the requirement of conformity, and difficulties understanding others [1] Whereas all children can be victims of bullying, those who are autistic are particularly prone given their core characteristics of social awkwardness and difficulties with communication. One of the core characteristics of many autistic people, to have a narrow range of interests and desire for repetition, is interrupted by the school day, where they are required to follow an agenda other than their own. This sometimes leads to undesirable behaviours, but even in the absence of outward manifestations these requirements to conform may lead to increases in anxiety levels. Sensory sensitivity is also now considered a key characteristic of many people on the autism spectrum [13,14] leading to particular challenges in school. The environment can be noisy, the corridors and lunch queues crowded, teachers and students may shout and push, all leading to aversive reactions in some autistic students.

Hodgson et al. [15] identified the term "intolerance of uncertainty" (IU), which they explored as a concept that could be differentiated from dislike of change and fear of the unknown. Their research used vignettes during focus group meetings with parents, which described situations that could be sorted according to whether participants considered the outcome to be due to IU, general dislike of change, or fear of the unknown. The participants all agreed on the specific situations that would lead to IU in their children. School can offer a respite from uncertainty with regular and timetabled activities; however, it does not take long for a student to realise that there are frequent unexpected changes to deal with and timetables do not ensure a quiet, calm environment will be experienced in each lesson.

In seeking to better support students and find ways to reduce anxiety, schools offer a range of strategies. These tend to fall into two main categories: those that the school provides to minimise the impact of the environment, and those that the student develops as independent coping skills. The most common supports offered by schools are permissions to move classes before the other students to avoid the noise and crowds in the corridors, and the provision of a quiet place, away from the main student body, where those with special

needs can withdraw or be taken. Many schools also offer extra staff to act as keyworkers or mentors for individual students, and teachers frequently adapt the curriculum to meet student learning needs [16]. Tobias [17] studied autistic adolescents aged from 14 to 16 and found that the transition into school still made a difference years after it had been completed. In addition, staff awareness of ASD and how this is presented in an individual, together with support tailored specifically for that person, as well as good communication between school and parents, were all important in reducing anxiety [17,18]. These all appear to offer a more conducive environment, allowing at least some autistic students to feel safe and to learn. However, given that anxiety rates remain high, they evidently do not meet all needs.

Schools also have a role in engendering self-help skills through building confidence, supporting independence, and promoting a sense of belonging [17]. However, Adams et al. [19] identified teachers' actions as inadvertently promoting a lack of independence and increasing anxiety, making professional development a priority. Self-help skills for adolescents can take a range of forms, including trying to minimise or hide their autism. Social camouflaging is defined as the use of strategies to "mask" or hide autistic characteristics from others during social interactions [20]. The discussion of masking is most often associated with girls as it is thought they have the social skills to copy people in their friendship groups in order to make themselves more like everyone else. This can work to a certain extent but research shows that girls often do not understand the subtle social cues and relationships particularly engaged in by adolescents [21,22]. A large-scale international questionnaire developed by Autism Spectrum Australia (2013) found a high proportion of female respondents discussed masking their autistic traits in order to fit in socially [23]. A number of women responding to this questionnaire added comments that indicated a need to "learn" aspects of communication and social behaviour that would help them to fit in and to relate appropriately to others (ibid). This is generally thought to be because females have a natural inclination to want to fit in, to be sociable, and to have friends [24]. This desire puts them at greater risk of social anxiety when they do not feel included in friendship groups [21].

Masking can be both a solution and a problem for girls [25]. It can be a positive strategy in that girls are less isolated socially, but it has also led to problems with girls spending so much energy trying to fit in that they start to fall behind with their school work. It has also had the added disadvantage for many girls of meaning they have a delayed diagnosis because they are doing such a good job of successfully covering up their difficulties when there are any professionals around—such as teachers or doctors [22]. Cook et al. [25] found that girls want to make friends but they often gravitate to other girls with autism, or who are neurodivergent, without realising it. The extra effort that it takes for girls to constantly try to "fit in" and to mask their autistic symptoms is exhausting and can contribute to increased anxiety and stress levels [26]. There is some evidence that males might mask their autism in certain situations [27] but this is much less obvious than in females and is an area where further research is still needed. Recent research by Jorgenson et al. [21] looked at the effects of sex and age on camouflaging and found that autistic females had higher levels of camouflaging behaviour when age is not a factor. The project reported here was interested in the idea of masking and whether it would be something that adolescent males and females revealed during interviews.

The aim of this research was to try to uncover the trigger(s) for anxiety in adolescent students in order to gain insight into their experiences and awareness. A better understanding of triggers to anxiety could inform practice, particularly in secondary schools, and lead to more successful inclusive practices. It is also crucial for schools to be able to identify and pre-empt anxiety in autistic pupils, since it may not be evident in all students, and younger students may not recognise the symptoms for themselves.

There is some debate in the literature about the value of hearing the voices of autistic adolescents, particularly due to communication difficulties and the perception of their lack of awareness of their internal states [13]. Some researchers have compared the self-ratings of autistic adolescents to those of parents and teachers, with mixed findings [27]. However,

a systematic review of the literature conducted by Adams et al. [27] found a lack of focus on educational settings and called for qualitative investigations of the presentation of anxiety in school.

3. Research Methods

3.1. Participatory Autism Research

This project was designed as participatory research with a group of autistic adults and university researchers collaborating to design the data generation with autistic secondary school students. There is increasing interest in participatory research and this project was planned with the aim of creating an opportunity for meaningful participation [28]. Although participatory disability research is more common in the fields of health and social care [29], it has a place in educational research. We wanted to make this project more than just drawing on the autistic co-researchers' experience and relationships, as is the case in most studies [30]. A group of eleven researchers worked together to identify the elements of anxiety that can occur in secondary school students based on the experience of the autistic co-researchers. The co-researchers were not all known to each other prior to the project; some had been involved in presentations at the university previously; whilst others were contacted through local autism organisations. An initial meeting was held to establish relationships and to undertake the relevant ethical protocols. At this point, arrangements were also made to pay the autistic co-researchers, which was an extremely important element of the project [28]. The autistic co-researchers were very keen to share their experiences of secondary school and to help devise relevant questions for interviews. One researcher expressed the feelings of the group when they said:

“It was important to me so I could spread awareness to other students in schools and also to have a voice and to make my feelings known. I was glad to be asked to take part” (Autistic Researcher).

This element of empowerment was considered very important in a systematic review of inclusive research carried out by [31].

3.2. Semi-Structured Interviews

Questions to ask in secondary schools were devised in two focus groups by all co-researchers, along with the research protocol that was used. It was agreed that a semi-structured interview approach would work best with the school students and the questions were limited to eleven after the protocol had been introduced and students asked their name, age, and how long they had been at the school. Other questions included what they liked or disliked about school, situations that made them anxious, how they dealt with these, who helped them, and what they did in unstructured time. Students were offered access to fidget toys if they wanted them to help with their concentration and used a picture of a traffic light as a visual way for students to communicate (by tapping the picture) that they did not want to answer a question (amber) or that they wanted to cease the interview altogether (red).

3.3. Inclusion Criteria and Participant Identification

Schools were identified through the local authority autism team and approached to ask for their participation in the project. Four schools with high populations of autistic adolescents were approached and two agreed to take part. Schools were asked to send information and consent forms to the parents of students they identified. The inclusion criteria were a diagnosis of ASD of which the students were aware, inclusion in mainstream lessons, some symptoms of anxiety identified by the school Special Educational Needs Coordinator (SENCo), and willingness to give their informed consent to take part in an interview. Each school contacted approximately twenty parents and had a response rate of half that number who gave their consent to approach their child. All adolescents were able to give verbal and written consent after being talked through the information sheet, resulting in a sample of eighteen students across two schools.

3.4. Interview Process

The schools each provided a room for researchers to meet students and interviews were all conducted by two members of the research team. In one school the SENCo was asked by the students to sit in on the interviews with them. The majority of interviews were around fifteen minutes long, although some with more articulate and confident students lasted for closer to thirty minutes. All interviews were audio-recorded and fully transcribed.

3.5. Data Analysis

Data were analysed using thematic analysis to identify and code specific answers to interview questions using the framework developed by Braun and Clark [32]. The transcripts were independently coded by two researchers and then compared. Some codes were consolidated at this point to define three clear themes.

Ethical approval was given through the University of Nottingham, School of Education Research Ethics Committee.

A paper describing the participatory research process in detail is published separately.

4. Results

Eighteen adolescents were interviewed in inclusive mainstream schools during May and June 2018. There were 11 boys and seven girls between the ages of twelve and seventeen.

4.1. Autistic Adolescent Interviews

Three main themes were identified from the data. These were: awareness of anxiety (sub-themes; extent of awareness; physical sensations of anxiety); sources of anxiety (sub-themes; uncertainty; assessment; bullying; other people's behaviour); and support and strategies (sub-themes: school support; self-help; "fitting in"). Aspects of these themes that relate specifically to uncertainty are discussed with the use of quotes from autistic students. All names are pseudonyms.

4.1.1. Awareness of Anxiety

Extent of Awareness

The majority of participants said that they knew what anxiety was and could explain it to some extent. They equated anxiety to worry, pressure, stress, fear, anger, and nervousness, and linked these feelings to things that they did not want to do. Several students explained that their feelings led to them wanting to leave the classroom or not being able to speak.

I get worried sometimes about stuff and I get anxiety maybe straight away. I worry about things and they don't go off my mind. Priya, 17.

Like, scared and you always think something bad is going to happen but like, you're always worried and you can be with a million people and still get it because you still feel alone or nervous. Daniel, 15.

A few participants appeared to have less awareness when asked directly about anxiety but then mentioned something in the interview that suggested that they do experience it, for example, talking about the behaviour of other pupils that bothers them, describing how no one wants to hang around with them and how that makes them feel.

Descriptions of Physical Sensations

Five of the participants gave descriptions of the physical manifestation of anxiety, in order to explain what it is like for them. Students located feelings in their chest and stomach.

It feels like you're suffocating a bit and you can't breathe. Abigail, 15.

Sometimes I get shivers coming down in my body. Sometimes I get a bit of a stomach ache, not a real bad one but just a bit and I feel uncomfortable. Marc, 13.

One participant said she felt sick, another “hyper”, and another linked anxiety to their heart rate increasing. Several students described feeling helpless and at the mercy of their physical sensations, which others said led to difficulties communicating, such as stuttering.

4.1.2. Causes of Anxiety

All participants who stated that they do experience anxiety were able to provide explanations, and some of those who said they no longer had anxiety were able to recall situations they found difficult or showed awareness of these in their friends.

Uncertainty

Despite the regularity of schools, they are still places that engender feelings of uncertainty. The nature of the demands of schools such as fitting in socially, managing academic work adequately, and not getting into trouble were aspects included in participant data. Even at a basic level, negotiating the secondary school day, the physical space and number of people, and being on time, poses difficulties. Participants who had been at the secondary school for several years still thought back to the difficult transition they had to make from the primary.

When I was in Year 7, when I started, I became very upset because it was a very big change from being at my small school to this very big school. Michael, 17.

And when you’re autistic and when you’re about to start secondary school you’ve got to learn. I moved here a year ago and it made me anxious because I didn’t know what the students were going to be like, I didn’t know what the lessons were going to be like or what the topic was going to be so I was really anxious about that, it was also getting lost at school and being late to my lesson. Andrew, 13.

One female participant focused repeatedly on her anxiety about being judged by other people.

Your brain does a horrible thing where it kind of tricks you and makes you think oh this is going to happen, what’s going to happen, and that people are going to look at you and judge you. Abigail, 15.

This student described herself as overthinking, feeling she was going to fail, and thus leading to her feeling suffocated and out of control. Other students feared doing the wrong thing, even if inadvertently, and getting into trouble.

I’m worried about something going wrong in lessons . . . like me causing a distraction and getting in trouble for it. Krishnan, 13.

In terms of negotiating social relationships, some participants expressed difficulty in ensuring that they did not cause offence, and frequent mentions were made about getting into fights or falling out with other people.

Assessment

Some students suggested the demands of academic work as a cause of anxiety, either linked to concentration in class, managing noise, and distraction, or the pressure of performance. One student mentioned exams, despite them being some years away, and other students talked about managing exam anxiety.

Well I had exams last year and I worked with a teacher here, they went through an anxiety booklet with me. Priya, 17.

For others, their focus was more on the day-to-day demands of class such as making a presentation, or answering questions.

Like, if the teacher says “Daniel, answer this question”, you’d get a bit like, everyone would get a bit nervous, wouldn’t they? But if you have anxiety, you’d feel it more, you know what I mean. Daniel, 15.

Other People’s Behaviour

A focus of all the interviewees was the behaviour of other people, both positive and negative.

Well, I have some friends that I hang out with and we just talk and have some fun in the break times and ever since I've met them they've actually been quite a good help because they've tried to help me in certain situations. Blake, 15.

Although most participants talked about the importance of their friends, and the support provided by staff, the bigger focus was on the sorts of behaviour that broke rules, disrupted, or was otherwise difficult to predict.

In my exam when I was doing my test, some people weren't even doing or writing anything, and sometimes they were laughing and giggling. Obviously, my mind was going "oh they're so annoying why can't they accept that they've got to do it!" Abigail, 15.

Many students described wanting to work in lessons and finding it very frustrating that the noise or behaviour of other people got in the way of their success.

They always distract me in lessons and I can't concentrate. And like, my grades are low because I get distracted for ages and I can't get on with my work. Alice, 12.

Apart from noise and disruption another aspect of student behaviour that caused anxiety was physical i.e., crowds, pushing, rough boisterous activities, and fighting.

Bullying

The majority of participants named other people's behaviour bullying or described what might be considered as such.

Just like people pick on me and stuff. Dean, 13.

Students described feeling either sad or angry when faced with bullying behaviour. Several students claimed that they were picked on because they attended the support unit.

There are some scary kids that pick on others and sometimes I don't like that because the main thing that I like to see is like people getting on and not fighting. Blake, 15.

Two of the girls identified being isolated as a form of bullying.

Not all the time because no one really wants to hang around with me... I'm always lonely on breaks. Ashley, 12.

Just sit on my own. Because of my autism, it is very hard to make friends socially. I just sit on my own at break and lunch. Priya, 17.

4.1.3. Support and Strategies

School Support

The supports most mentioned by participants were having people to talk to and, particularly for those in one school, a place to go away from the mainstream (the learning support centre). Students were mostly aware that there were adults in the school who they could turn to for help and support.

You always have someone to go and speak to and if you feel worried or you just want to talk to someone there is always a member of staff to talk to. Michael, 17.

However, students also discriminated between staff members they would choose to talk to, emphasising trust and relationship. For some, this was a particular keyworker, whereas other students mentioned a number of staff.

I think that when it comes to letting people see you in a vulnerable state you have to trust that person so it's more like, those people are who you trust than who you prefer in a way. Abigail, 15.

Me and my teacher, in today fourth period we have like a little key worker session where we work on my skills like how to cope and we just try to get over these worries and try to make them better. Marc, 13.

This feeling was not unanimous however, some did not appear to have made any particular attachment and said either that they did not like talking to teachers, or did not want to, or did not know who to go to, particularly in a large school with so many staff. Another theme was participant desire to be in calm and ordered classrooms, particularly in order to be able to work without distraction, and they spoke of staff management of this.

I think we are very lucky to have members of staff who take control of classes and calm it down. Michael, 17.

In English, though the teacher knows what they're doing so they just send the student out. There's this science teacher though that just does nothing, and I'm not even being rude I'm just saying. Andrew, 13.

In one school many of the participants talked about the two systems in place to help them manage anxiety; the pass that allowed them to transition between classes five minutes before other students, to avoid crowded corridors; and the pass that allowed them either "time out" from the lesson or to withdraw from the lesson completely and go to the learning support centre.

I have a time out pass as well so it's like if I'm getting stressed or angry or whatever I can just step outside for 10 min. Andrew, 13.

The learning support centre appeared to offer a place where they could "calm down", feel comfortable, avoid other students, and particularly a place to go at lunchtime and meet students who they felt understood them.

School helps me to calm down and it helps me to calm down when I'm worried most of the time. Krishnan, 13.

The importance of the regularity of school is highlighted in this quote from a 12-year-old: Everything is the same at school, every day, so I don't feel worried. Maisie, 12.

Self Help

As well as direct help and support from staff, some students appear to have a number of strategies that they could implement to help them cope and reduce anxiety.

I do like a routine, I like to know that I've got everything sorted out, like I've got all my revision done, and all my homework. Abigail, 15.

Students spoke of turning to their friends for help and support in the first instance, and only turning to adults as a last resort. Participants wanted to turn to someone they saw as being either like them or in the same position as themselves in order to be understood.

If there was something I am worried about at school, I would like help with the anxiety. I say to my friends "I am a bit anxious today can I talk to you about my feelings." I don't really tell a teacher because I am too shy. Priya, 17.

Students described calming techniques such as taking deep breaths, listening to music, playing computer games, tapping their fingers against something, and challenging their own anxious thoughts by reminding themselves that they can cope and that other people's opinions do not matter.

If I have forgotten my homework I'll be like "oh you're going to get a detention, you're going to get, police are going to come for you" or something like that. But really I have to concentrate on the fact that it is just a piece of homework, they understand, they know you don't do this often so you just have to keep thinking this is not going to happen. So that's how I maybe control it in a way. Abigail, 15.

There was a strong focus on the importance of trying to ignore people who were annoying them, with advice on this coming from staff and parents.

Sometimes I try and just think about something else and completely ignore them to get them out of my mind. Blake, 15.

An apparently contested strategy mentioned by some students was the use of fidget toys which participants said helped them to concentrate, however, one participant said they were "not allowed in lessons".

Sometimes, some stuff I bring with me I can fidget with under the table. So when I start to fidget it helps to keep my mind away from the situation. Blake, 15.

For some of the older students, their ability to cope alone appeared important, either stemming from their own motivation or through the efforts of the school.

They help me read the questions and they explain what you need to do and then you have to do it straight away independently. Sally, 14.

No real help in lessons, I want to do it all by myself because I want to be a normal teenager in a way. Abigail, 15.

Fitting In

In terms of whether students described hiding their feelings, there were several who suggested that they chose to camouflage in this way in order not to be noticed. Several students talked about not seeking help, particularly when they first started school, and only after several years there feeling safe to ask for help.

Back in Year 7, I never told anyone I was anxious or if I was upset about something and I don't think that really helped me at all. Abigail, 15.

As students developed relationships, both friendships and with staff, they were more willing to seek help, however, as they grew older they seemed to feel the pressure to manage alone again.

You have to look nice in front of everyone. To admit that you're weak, it's quite hard to do, it's like losing a bit of your dignity. Abigail, 15.

Participants explained their awareness of social pressures and how they responded to them.

When you're autistic you just don't really understand secondary school a lot, all you know is you've got to stay in line and don't do anything stupid, you've just got to try and fit in. Bruno, 13.

5. Discussion

These results indicate that anxiety plays a central role in the life of autistic adolescents. Participants identified strongly with anxiety as a major aspect of their lives at school and something which they needed to continuously manage. Their comments suggested that they could locate anxiety in their bodily sensations and their thoughts. The research team was interested in when young people become aware of their own anxiety since this would be a prerequisite to them putting strategies in place to manage their symptoms. This research suggests that awareness may be linked to maturation and that the younger participants (12–14 years old) were likely to rely on the support of a trusted adult, often in a specialist learning support centre, to help them to regulate their emotions. However, they indicated that they were able to identify their own anxiety to some extent, even if they struggled to express this. As the students matured (15–17 years old) they became more aware of their own anxiety, often wanting to be independent and manage on their own. Most of them had developed a series of strategies to put in place to try to mitigate the effects of the anxiety whilst in school. It is interesting to speculate on the extent to which this represents typical maturity or the development of self-insight through interaction with others, and in some cases direct intervention from the school, as our data suggests. This could also be linked to the development of "impression management" (or self-monitoring), as discussed by Jorgenson et al. [21], as particularly important during adolescence as they try to fit in and work out what is expected of them. The development of self-monitoring strategies appears to change with maturation (ibid). There were certain suggestions in the data that the work of staff had been key in helping students monitor their feelings and behaviour and learn new ways of being.

The student interviews confirmed the main sources of anxiety as other people's behaviour and fear of the unknown/change i.e., some within-person factors and some environmental. A range of aspects of school triggered anxiety, many of which can be argued to relate to the difficulty in predicting what is likely to happen and therefore feeling unsafe. Participants found the behaviour of other people to be particularly troublesome, such as students who broke the rules or were "rude". The role of adults in the environment is key to enabling students to feel calm and in control. Careful and long-term efforts to build trust between adults and autistic pupils appear to support the development of independent skills and coping strategies [18]. However, for many of the participants, a key focus was calm and ordered lessons where the teacher had strong and effective classroom management.

Further support for intolerance of uncertainty (IU) as a way to understand triggers of anxiety can be seen in the strategies participants suggested as helpful. Supports such as timetables, and access to quiet spaces helped make life more predictable, more controllable,

and therefore less likely to cause anxiety. There is, however, some evidence that too much intervention by the school can lead to dependence [19], so the type and level of support offered by teachers needs to be specific and targeted to where it can have the most impact. The data reported here highlight the need for informed and committed staff who are not only trained in key strategies but have an insight into anxiety in autism in order to develop effective provision for every student. Staff should be provided with training in IU and work with pupils to develop skills to combat these reactions.

One of the areas for enquiry in this study was to try to uncover whether camouflaging/masking was an issue for secondary school students. Although this is a relatively small sample, there was evidence from the conversations with both boys and girls that they think it is important to “fit in” and that they spend a lot of time and energy worrying about doing the wrong thing or causing a disturbance. Whilst these activities may be a conscious or unconscious attempt to hide autistic characteristics, they might also be a result of adolescent concerns with impression management [21]. This need for approval adds to the growing body of literature that identifies masking or camouflaging as characteristics of autistic people with no intellectual disabilities [20–22,26] When students try to manage their anxiety themselves they frequently do this by making attempts to fit in and hide what they are feeling. Awareness of masking emotions has increased in recent years since many students are found to hide their feelings to help control anxiety [22]. The implication of this for supporting students to manage anxiety is that staff may not be aware of when students are feeling anxious and therefore not provide the timely help. Schools, therefore, need to more routinely manage triggers of anxiety, pre-empting difficult situations for students, rather than immediately expecting them to do so independently.

Recognising that other people’s behaviour is a key trigger suggests ways to support students such as the use of Social Stories™ [33] for regular situations such as lunch queues. The use of buddy systems and peer support for both in and out of class activities could help remind autistic students of what might happen and how to cope. The regular school day, published timetables, and advance warning of changes are recognised as essential for autistic students [34–36]. Staff members need to be aware of the need to warn of changes, and to know at what point in time this is helpful for an individual since needs are likely to vary. Transition into secondary school was highlighted by our participants as highly stressful, particularly striking since some of them looked back several years when describing this as a difficulty. Although many schools make efforts to prepare autistic students for life in secondary school it is likely that this needs to be done for a longer period of time and at gradually increasing intensity to make the experience as predictable as possible [16]. Again, Social Stories™, and perhaps video modelling of specific situations that students can watch repeatedly, may help some individuals.

The onslaught that a secondary school makes on the senses, ensures autistic adolescents are in a permanent state of heightened arousal and vigilance [10]. Once arousal is heightened, tolerance for the environment diminishes. For the young people in this study, this lack of control often meant they had to take themselves out of a situation. In some schools, this is facilitated with break cards and early passes, in order to try to alleviate situations that cause anxiety and to help adolescents to start to manage their own emotions, and to keep them in the classroom as much as possible. However, students need systems and support that enable them to feel safe within the classroom for the majority of the time. The two schools in this study appeared to have differing philosophies in relation to student support. For one the provision of an “inclusion unit”, which students could withdraw to during breaks, and for either timetabled lessons or as “time out”, appeared to be the main provision. Participants reported that staff in the “inclusion unit” provided high levels of support, which appeared to gradually build independence skills. However, one student who was managing the transition to another school where this provision did not exist, expressed his fears of managing without it, supporting the finding of Adams et al. [13] that too much support from school can stifle independence. This feeds into the debate of the best way to support autistic children. It can be argued that allowing students to

spend reduced amounts of time in mainstream lessons reduces their anxiety and with adult support, they can gradually build the skills to manage at secondary school. However, the alternative perspective is that students who spend large periods of time away from other students have less opportunity to develop social skills and strategies to manage social anxiety.

6. Limitations and Areas for Future Research

The sample size in this pilot study was necessarily small, including eighteen adolescents, from two schools. The aim of the study was to explore anxiety in autistic adolescents and its impact on their experience of secondary school in order to inform a larger-scale study. A key aspect of this research is the feasibility of asking autistic adolescents about their anxiety, and the extent to which this data will be reliable. There were considerable differences between participants in the way in which they were able to articulate their thoughts and feelings. In the interviews which included a member of staff, there were a few points where this person interjected because the student was suggesting that they did not experience anxiety. She reminded them of certain situations which the student then expanded on, clearly describing something which had worried or frightened them and led them to require adult support. This indicates that students may under-report their own anxiety, and suggests the need for an adaptation of the data collection method for the development of this research.

This research had the support of two schools with large autistic populations, suggesting there could be more awareness and support in place for young people than in other schools with a small number of autistic pupils. It will be important to repeat the research in a wider range of secondary schools with and without specialist SEND or autism provision.

The research highlighted the possible link between image management, anxiety, and camouflaging, which is an area that needs to be further researched with a focus on autistic adolescents. The influence and impact of the secondary school setting are also crucial in this research and need to be researched further from the perspective of the young people themselves. It is the intention to use this pilot project to develop a larger scale project involving a wider range of schools and more autistic adolescents who could report the impact of schooling on their experiences of anxiety. An additional sample of non-autistic adolescents could be recruited in order to differentiate the experiences of autistic adolescents from the general population.

7. Conclusions

We need to have a greater understanding of how anxiety manifests in autistic adolescents and impacts in the inclusive secondary school setting in order to make the experience of schooling more bearable and enjoyable for all young people. The key to understanding what this feels like and what we as professionals can do to help is listening to the young people themselves. This research was a co-produced project with a group of autistic and non-autistic co-researchers so that we had an idea of some of the key issues relating to anxiety before we went into schools, and had focussed the questions to try to elicit the most valid data in a short period of time. What we found was that all of the young people were able to talk about their experiences of anxiety. One school had effective strategies in place to support autistic adolescents, which could easily be replicated in all secondary schools. The young people themselves increasingly recognised the symptoms of anxiety as they matured and were able to put strategies in place to manage whilst they were in school; for some of them, this involved masking their autistic characteristics, and importantly their feelings, in order to “fit in” and not draw attention to themselves. It is important that teachers in mainstream schools recognise how hard autistic adolescents have to work, and how much working memory and emotional capital that takes, just to be in school and in the classroom before they even begin to learn new material. We suggest that understanding the role of the theory of intolerance of uncertainty in anxiety and of the drive-in adolescents for image management might help teachers to support students to discuss their feelings

and plan ways of coping. Many of the existing strategies are likely to be supportive, but theoretical awareness may lead to helpful nuances of design. It is imperative that schools make the environment as predictable for autistic students as possible, and establish ways in which they can support students to build their ability to cope with uncertainty so that they can plan for and navigate their school day successfully.

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