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Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence

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Abstract

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Keywords

spectrum, disorders, during, adolescence, world, boys, investigating, experiences, girl, girls, being, autism

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Being a Girl in a Boys' World: Investigating the Experiences of Girls with Autism Spectrum Disorders During Adolescence

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Abstract This study investigates the experiences of adolescent girls with autism spectrum disorders (ASD) during adolescence. Semi-structured interviews were conducted with three mother–daughter dyads and two additional mothers. A range of issues were highlighted covering physical, emotional, social and sexual domains. Some of these issues were similar to those experienced by boys with ASD during adolescence, such as negative implications of late diagnosis, challenges of transitioning to and coping with high school, ‘hands-on’ role of parents into adolescence, difficulties adjusting to the increased demands of adolescent hygiene routines, and the importance of learning personal boundaries in interactions with others. Other issues discussed were of particular relevance to adolescent girls with ASD, such as difficulties socialising with neurotypically developing girls, sex-specific puberty issues, and sexual vulnerabilities. This study highlights an important research area and is a preliminary step towards understanding the experiences of adolescent girls with ASD and their families.

Keywords Autism · Female · Girl · Adolescence · Qualitative · Family systems

Introduction

The aim of this paper is to investigate the experiences of adolescent girls with an autism spectrum disorder (ASD). Studies investigating the experiences of adolescents with ASD have largely focused on males (Hellemans et al. 2007) and those studies that have included females have involved mixed sex samples, preventing detailed exploration of female specific issues (Nichols and Blakeley-Smith 2010; Stokes and Kaur 2005). Consequently, this research area has been highlighted as a significant gap in the literature (Hsiao et al. 2013; Nichols et al. 2009; Stokes and Kaur 2005).

The focus on males with ASD in research to date is attributed to the consistent predominance of males diagnosed with ASD (Holtmann et al. 2007; Krahn and Fenton 2012). The most commonly reported male:female ratio of ASD diagnoses is 4:1; but there is some disparity, with other estimates as high as 16:1 (Fombonne 2002, 2003). A wide range of hypotheses regarding the aetiology of the sex differences have been proposed including genetics, lateralisation of brain function, imprinting, and low validity of current assessment tools in detecting the disorder in girls (For a review see Rivet and Matson 2011b).

Difficulty detecting ASD in girls has been attributed to various factors. Firstly, some research indicates a larger proportion of girls with ASD have lower IQ ranges (Nichols et al. 2009; Rivet and Matson 2011a, b; Volkmar et al. 1993). This can result in females being diagnosed with Learning Disorders (Rivet and Matson 2011b; Volkmar et al. 1993) or vague diagnoses such as Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (American Psychiatric Association APA 2000; Attwood 2012, 2013). However, other research reports more even

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sex-ratios for individuals with ASD with IQ levels in the normal or subnormal range (Mattila et al. 2007)

A second factor contributing to difficulties detecting ASD in girls is their relatively 'strong' social skills, including pretend play (Attwood 2012, 2013; Solomon et al. 2012), communication (Nichols et al. 2009), social imitation (Baron-Cohen et al. 2011; Hsiao et al. 2013; Rivet and Matson 2011b), and ability to focus (Nichols et al. 2009). Additionally, girls with ASD generally have fewer behavioural problems compared to their male counterparts (William et al. 2012).

These 'strengths' can mask underlying social impairments and contribute to delayed diagnosis (Attwood 2012, 2013; Baron-Cohen et al. 2011; Nichols et al. 2009; Solomon et al. 2012). Consequently, many girls with ASD are not diagnosed until they have entered adolescence (Begeer et al. 2013; Bolick 2001; Willey 2003). For example, the imitation of social interactions is often adequate to maintain friendships during childhood, but it is not sufficient during adolescence as the complexity of social relationships increase (Bauminger et al. 2008; Carrington et al. 2003), and it is at this time that their significant social impairments become more evident.

The complexities of adolescent relationships are particularly apparent in adolescent female relationships as they rely primarily on intimate social communication (McLennan et al. 1993; Nichols et al. 2009; Solomon et al. 2012). That is, adolescent female relationships require more complex skills such as reciprocal sharing, emotional support, and social problem-solving. In contrast, adolescent male relationships tend to be based on 'doing' rather than 'talking' (Nichols et al. 2009). Generally, adolescent girls with ASD also need extended time to process and then respond to information (Nichols et al. 2009), which adds to their difficulties following and contributing to fast-paced conversations with their peers. These issues highlight the ways adolescent girls with ASD are more disadvantaged in relation to the development and maintenance of friendships compared to their male counterparts (Hsiao et al. 2013; McLennan et al. 1993; Nichols et al. 2009; Rivet and Matson 2011b).

Additionally, research focusing on neurotypically developing (NTD) adolescent relationships has indicated that males and females differ in relation to conflict management (Card et al. 2008). Whilst boys tend to display overt aggression, girls display anger in more subtle and indirect ways such as spreading rumours, gossiping, exclusion, ignoring, and other non-verbal behaviours like giggling and eye-rolling (Card et al. 2008; Nichols et al. 2009). These latter behaviours have been termed 'relational aggression' as they typically involve a third-party in order to be hurtful to another individual (Nichols et al. 2009). This style of aggression is more socially complex, meaning

girls with ASD are likely to have difficulty acknowledging and understanding this behaviour.

These differences in relationship styles may be a primary factor contributing to the higher rates of social isolation (Solomon et al. 2012; Sullivan and Caterino 2008) and mental health problems (such as depression, anxiety, eating disorders and poor self-image) (Chan and John 2012; Cottenceau et al. 2012; Rivet and Matson 2011b; Seltzer et al. 2004; Solomon et al. 2012; William et al. 2012) identified in adolescent girls with ASD, compared both to adolescent boys with ASD and to NTD adolescent girls. Together, the literature in this area highlights that adolescence is a critical period for girls with ASD.

Study Aims

There is a need for research focusing on the experiences of adolescent girls with ASD and their families. This point is highlighted both in the research literature and by families themselves. Consequently, this study investigates the experiences of girls with ASD during adolescence, from the perspectives of the individuals themselves and their mothers. By interviewing the individuals with ASD and their mothers, we aimed to gain a multifaceted understanding of their experiences. We chose to focus solely on mothers, rather than all family members, as this is a preliminary investigation. Additionally, by focusing specifically on mother-daughter dyads we were able to conduct an in-depth investigation of the nature of these relationships during adolescence.

Method

Methodological Approach

Interpretative phenomenological analysis ((IPA): Smith 1996; Smith et al. 1999) was used as a guiding approach for data collection and analysis. The aim of IPA is to explore participants' views and personal meanings of an issue, rather than provide objective accounts or explanations (Oliver 1992). In doing so, the researcher aims to get close to each participant's psychological world, while recognising one can at best do this indirectly (Smith et al. 1999). The benefits of this approach include acknowledgement of each participant being the expert of their personal experiences, recognition of both the commonalities and diversities of participants' experiences, and awareness of the investigators' influence during interpretation of interview data. Further, IPA is suitable for clinical psychological research and has been used to inform similar research in

Table 1 Demographic Information

Daughter with ASD ^a pseudonym (age)	ASD diagnosis	Additional diagnoses	Age at ASD diagnosis	Diagnostic pathway	Current education or employment	Mother's pseudonym (age)	Family dynamics (age)
Kasey (16)	Autistic disorder	Epilepsy (treated with left temporal lobectomy) Scoliosis GORD ^c	12	Clinical psychologist	Year 9, mainstream school with ASD support unit	Tina (47)	Father (53) Brother (23), not living at home Sisters (12 and 9)
Erin ^b (12)	Asperger's syndrome	Nil	6	Paediatrician and clinical psychologist	Year 6 equivalent, specialised ASD unit	Sharon (50)	Father (50) No siblings
Bec (16)	PDD-NOS ^d	Learning disorder (estimated at year 6 equivalent)	12	Paediatric psychiatrist	Year 11, mainstream school with ASD support unit	Valerie (50)	Father not present Sisters (19 and 20)
Hannah (17)	Asperger's syndrome	Epilepsy	14	Paediatrician and school counsellor	Supported employment program	Dianne (51)	Stepfather Brother (35), not living at home Sister (23)
Sally ^b (14)	Asperger's syndrome	Nil	9	Psychiatrist	Year 9, mainstream school	Lisa (54)	Father not present Brother (12), diagnosed with ASD

^a Autism spectrum disorder

^b Individual with ASD not interviewed

^c Gastro-oesophageal reflux disease

^d Pervasive Developmental Disorder-Not Otherwise Specified

this field (Carrington and Graham 2001; Petalas et al. 2009, 2012).

Sample

A multiple-case study approach was employed to collect data from three mother-daughter dyads and two additional mothers.¹ This sample is consistent with IPA methodology which typically involves small and homogenous samples, allowing for in-depth investigation of a specific issue (Smith 1996; Smith et al. 1999). The participants with ASD were all female, adolescent (age range 12–17 years), and had a formal diagnosis of ASD based on the Diagnostic and Statistical Manual of Mental Disorders (4th ed.; (DSM); American Psychiatric Association (APA) 2000) [which includes conditions within the Autism spectrum such as

PDD-NOS, Autistic Disorder, and Asperger's Syndrome (AS)]. The annual household income of participants ranged from \$20,000 to \$200,000 ($M = \$84,000$). Participants with ASD and their biological parents were all born in Australia. More detailed demographic information is presented in Table 1.

Procedure

Ethical approval was granted by the University's Human Research Ethics Committee prior to commencing the participant recruitment process. Participants were recruited through local schools and community groups via personal communications from staff at these sites who were informed about the study. Interested participants were then provided contact details of the research team.

Research aims and potential discussion topics were outlined with participants as part of the informed consent process. Following ethical standards for research with children, written consent was obtained from the participants and their

¹ The daughters were not able to be interviewed as one did not have knowledge of her AS diagnosis and parental consent was not provided for the other.

parents before commencement of the interviews. The interviews were conducted face-to-face in the participant's home to promote familiarity and comfort as well as avoid connotations of a clinical interview or school related assessment (Mascha and Boucher 2006). On average, interviews lasted for 60 min (range 20–120 min²). Interviews were recorded for later transcription.

The interviews followed an in-depth, semi-structured format. Interviews began with an open-ended statement ('What have been your experiences of being an adolescent girl with ASD/having an adolescent daughter with ASD?'), allowing participants to lead the discussion. General facilitation was provided to all participants by suggesting topics of discussion (e.g., school, friendships, family, and developmental changes), and asking clarifying questions. This format allowed participants to speak freely and at length about their experiences, minimized researcher control over the discussion, and facilitated rapport building (Barbour 2000). Such interview approaches are consistent with IPA because the researcher is trying to enter the psychological and social world of the participant as she is seen as the expert (Smith 1996; Smith et al. 1999).

Data Analysis

NVivo10 (QSR International 2012), a qualitative data management program, was used to manage and analyse the data. Data analysis followed the inductive coding process outlined by Braun and Clarke (2006), which involves familiarization with the data (the primary researcher conducted and transcribed all interviews), generation of initial codes, collation of codes into potential themes with corresponding quotes, review of themes with credibility checks, and final definition of themes (Braun and Clarke 2006). Credibility of data analysis was facilitated by a systematic record of how data were collected, maintained, and prepared for analysis. Credibility checks involved the research team reviewing all transcripts together with the potential themes identified by the first author. Consultation amongst the research team followed and refinement of themes was undertaken. This consultation process is recognised as an important process in IPA, given that the analysis of the interview material is inevitably influenced by the researchers' characteristics. The research team consisted of four researchers with various backgrounds of involvement with adolescents with ASD including research, clinical, and familial experiences.

Results

Seven key themes emerged from data analysis. The themes are reflected in subheadings. Direct quotations are presented in indented paragraphs, in which brackets indicate information added for clarity and ellipses (...) indicate material omitted for conciseness. For purposes of anonymity, all names have been changed.

Diagnostic Issues

All mothers described the process of obtaining an ASD diagnosis as challenging. Reasons for this included presentation of symptoms, imitation of social behaviour, higher incidence of ASD in boys, misdiagnosis, and reluctance from health professionals (e.g., paediatricians, psychologists, psychiatrists, etc.) to provide a formal diagnosis. Four of the five mothers considered the diagnostic process to be more difficult for girls, when comparing their personal experiences with those of friends who have boys on the spectrum;

A lot of the parents in our group have boys on the spectrum and they got their diagnosis quite early, as early as two years old. We knew there was problems around that age but we didn't know enough about Autism to pursue it... I think Autism is a male thing, I mean more boys get diagnosed but I think also that a lot of girls with Autism sort of slip through the cracks because their behaviour gets put down to something else... I think there is a lot of wrong diagnoses (Tina, mother).

We took her to a psychologist and he said she was showing some features but he didn't want to give her a firm diagnosis... she was 'ghosting of AS'... Basically it was hard at the beginning because she had some atypical symptoms.... she wasn't suffering any anxieties, she wasn't acting up, she wasn't deficient in anything other than social interaction, she hadn't chosen an obsessive subject (she still hasn't, she has multiple) and those things are normally present in boys (Sharon, mother).

I didn't really realise there was an issue with her until probably about Year 4... I think because people look for it more in boys and often it stands out more. They say that sometimes the girls copy behaviour and that can hide it. And Hannah did maintain friendships... That's why I get annoyed when people say to me, 'How did you not know?' (Dianne, mother).

I always knew there was a problem but nobody wanted to put a diagnosis on it... no one was willing to put their name down and say that she had it. It was only when I really started pushing that there was a

² The shortest interview was with a participant with ASD and was cut short because the participant was feeling sick and an alternate time to complete the interview was not available. The interview was included in data analysis because useful information was obtained.

problem... that we got the diagnosis (Valerie, mother).

The mothers discussed a range of negative implications related to obtaining a delayed diagnosis. These implications included inability to access early intervention and support services, and negative judgement from others:

I find the late intervention is a huge problem, whereas if we had had things earlier we could have taught her a lot more things. Like, I still need to teach her about facial expressions because she still doesn't know how to read people at all (Dianne, mother).

Before we had the diagnosis our life was hell...we knew that there was problems but we didn't have a diagnosis and that was really hard to work with the teachers. We changed her schools because they just seemed to think that she was a bad kid... We were so isolated from the whole community because people just looked at us as bad people and looked at her as a bad child (Tina, mother).

Contributing to the challenges of obtaining and coping with a diagnosis was the limited follow-up support received from health practitioners:

It was like, 'Well there's your diagnosis, see ya later.' We were left on our own to work through all this information and because you're going through that grieving process you can't think clearly. You don't know where to start. You actually need someone to come in and go through it with you and say, 'Well what do you think about this? Maybe we can try that?' You can't process it on your own because your brain is so scrambled with dealing with what you have just been diagnosed... it was overwhelming (Tina, mother).

...it was hard to link in with services. Nobody made us aware of what services were available so I have had to do that... (Health practitioners) don't link you in with services they just give you a label and leave you in the dark (Valerie, mother).

Being Surrounded by Boys

Participants discussed the experience of living with a disorder primarily associated with boys. Discussion from the girls and their mothers indicated mixed opinions. The following quote illustrates the feeling of 'being different' that many of the girls and their mothers described:

It's also hard because she's different from the students in mainstream but being a girl makes her different from the kids in the Autism Unit too, she doesn't fit in anywhere (Valerie, mother).

The difficulties fitting in were felt most by the girls who did not have interest in traditionally 'boys' activities such as sports. For example;

Many of the services aren't catered for the girls, so it can be hard to get support. Many of the times boys get preference for using the service and sometimes the activities are geared towards the boys. It makes it hard because Bec doesn't like to do sports and I have to force her to do it (Valerie, mother).

Despite the drawbacks, many of the participants discussed positive aspects of 'being surrounded by boys'. These positive aspects included the perception that adolescent boys were easier to get along with than adolescent girls and that gender may not be important for the girls with ASD as their relationships were primarily built on common interests. For example:

It's good. I get along better with boys than the girls because I'm like more of a tom-boy, like I'm into boys stuff like soccer and skateboarding so me and all the boys have lots in common so I have gotten along well with them. I've got a group of friends with them (Kasey).

I was the only girl in the (electronics) class... at first it was really weird but then I got used to it and I got to know them... I have noticed that I get along with boys better than girls... I'm not sure (why) (Hannah). When I saw the Autism Unit was all boys I thought it was going to be really hard for her... but I must say that she has fitted in and I think it's because they are boys because girls are bitchy and they get jealous and they try to bring you down whereas boys aren't like that and like they'll go play soccer and she'll join in... I think the fact that there are not a lot of girls there makes her feel a bit more secure because when she has been around girls they have really bullied her (Tina, mother).

She knows everyone in her class so I don't think she's worried about being the only girl in the class. I think it's not a problem because she's more likely to like some of the subjects they like, they all like space and animals and the detail of things. She's more like a boy in that sense. I don't think it worries her that you're a boy and I'm a girl (Karen, mother).

Experiences of High School

Experiences at high school were discussed by all participants. Mixed experiences and opinions were discussed both by girls with ASD and by the mothers. Positive aspects of high school included being exposed to a

broader range of subjects and students, and the more structured environment:

It was ok changing classes and having lots of teachers was different but it was ok. It didn't bother me having to pack up my bag and move classes... (Bec).

I think she's coping with (high school) ok, I didn't think she would but she organises herself well with her diary. And I've seen her write little notes on her school bag going, 'remember to take sports uniform'. So she's actually quite organised... The thing with high school is that even though they are going to different classes with different teachers, I think because they get a diary and a timetable they're ok because it's probably structured more than what primary school is (Tina, mother).

I think the high school environment is more academic and there is a bigger range of people, she's not with the same 25 kids day in, day out. She will be changing subjects, so she has a chance to meet people with her interests and they also have social clubs and groups so she can join one that suits her interests. So I think that is a friendlier environment than primary school which can be really nasty if you don't fit in (Sharon, mother).

Negative aspects of high school raised by girls with ASD included finding the class work difficult and/or uninteresting, challenges making friends, and managing the larger school environment:

(High school is) boring... It's not interesting, it's boring (and it's hard) trying to keep up with the work... both (class work and home work), it's too hard (Bec).

High school was harder because I had friends in primary... (Going to a larger school) was hard sometimes. It was different (Hannah).

Negative aspects raised by mothers involved mainstream teachers' limited knowledge of ASD symptomology in girls:

School has been one of the biggest struggles that we have had... the teachers just didn't have an understanding about Autism and they were sending her home from school for doing things that were clearly autistic... We got the spot at (School X, a high school with an Autism unit and)... she absolutely loves it and they totally get her. Her behaviours have settled down, her marks are improving. It is just sad because it took so long because you're dealing with people that don't understand the disability... (Tina, mother). The problem I found with the schooling system when

she was in mainstream was that the teachers didn't always understand the problem. They didn't always acknowledge that there was a problem there at all and if they did they didn't always know how to deal with it. The ones that knew about Autism knew more about what it was like in boys like the stereotype things like hitting their head against the wall. And the issue was that a lot of those 'bad' behaviours she doesn't display (Valerie, mother).

The transition from primary to high school was discussed by all mothers, with the general consensus that this transition was a difficult period. The main challenges involved adjusting to new routines such as having multiple teachers:

(The transition from primary to high school) was a nightmare... She struggled with all the different classes, the physical stuff of having to carry a bag... she didn't like most of her teachers, she didn't like the different buses... The first two years of high school she didn't use her diary and she was carrying the wrong books every day... This year when I ask her how it is going she says, 'Aw good' (Lisa, mother).

The transition from primary to high school was difficult, even the change from one teacher to another at the beginning of the year at primary was always difficult for her so going from primary to high school was extremely difficult for her. I was constantly up at the school talking to her year advisor and discussing issues with teacher... She didn't cope at all, then when she finally got into the Autism Unit in year 8 it made it a lot easier (Valerie, mother).

Complexity of Adolescent Female Relationships

A participant with ASD eloquently described her negative experiences of trying to develop friendships with her NTD peers:

Because I have a disability, they ignore me or pick on me and bully me just because of that. It's hard, especially with like the really popular girls, they won't even listen to me- as soon as they hear that I have a disability they just won't even listen to me and what I have to say (Kasey).

Similarly, all five mothers described the difficulties their daughters experienced developing and maintaining friendships with NTD adolescent girls. Topics discussed included; the increasing complexity of adolescent female friendships, experiences of relational aggression, and for some an apparent disinterest in relationships:

She had friendships but then they all just fell apart... (When she was younger) she could play with others, I don't know if she learnt it from watching others, like she would do the 'Barbie thing' with the other girls and she had sleepovers and all that.... but between Year 4 and Year 6 they just went downhill dramatically, she could not read what people expected of her, she didn't know how to do the conversation thing of I talk then you talk.... (Dianne, mother).

As far as friends-wise she has to rely on the mainstream kids to become friends with (but) I've noticed that other teenage girls are a lot more social than she is. She tends to be more of a loner, so that whole thing of being a teenager and being off with your friends all the time hasn't happened yet (Valerie, mother).

...(adolescent girls with ASD) get shunned by the others and they get left on their own and they get picked on because adolescence is so much about fitting in for girls (Tina, mother).

Girls are so nasty. I took her to the movies a couple of months ago and... these girls just stood there laughing at her and Hannah didn't realise what was going on but I certainly did... I think girls have such high expectations within their own little social groups... Like, you know how they all kiss and cuddle and that? Hannah can't do those things, like she would know when she is supposed to... So if you don't know the rules, how are you going to survive in a little pod like that? (Diane, mother).

Three of the five mothers felt that the difficulties experienced by their daughters in connecting with their NTD peers were greater than those experienced by boys they knew with ASD. The main reason proposed was the tendency for male relationships to be based on hobbies:

... (Boys with ASD) sort of fit in so they don't have the problems at school like the girls have... like if you're a bit of a geek these days it doesn't matter, it can even be a cool thing! But it's not cool for a girl... I can see the difference in the boys who can just slide under the radar but the girls stick out like a sore thumb... I think the girls do want it more whereas I think the boys don't care. And if they're into their video games well that is normal for a boy! (Tina, mother).

The Autism boys tend to like sports and that makes them more socially acceptable... (the ones) who don't fit in aren't terribly sporty and they like more intellectual things (Sharon, mother).

All mothers discussed their daughters' limited interest in fashion in comparison to NTD adolescent girls in a Wes-

tern culture. Reasons for this disinterest included preference for practical clothes and difficulty understanding of the social aspects of fashion, such as 'dressing-up' for certain occasions, and dressing to impress others or portray femininity:

... Hannah has always liked pretty plain, more like boys clothes. I think it's because they are easy and practical. And she's never really understood the thing of clothes for going out and clothes for just day time stuff. Like I might say, "Go and put something nice on because we are going out" and she'd say, "But I don't know what you mean! What do you mean?" (Dianne, mother).

If I tell her that something is the sort of thing you wear to a party then she will wear it and look the part but she's not a 'girly' girl... I don't know how many 'girly' girls there are on the spectrum. I have never met one... Their Mums' might be teaching them how to look nice but I don't think it's innately in them.... (Sharon, mother).

The mothers described the ways their daughters' disinterest in fashion had impacted negatively on their opportunity to fit in with NTD peers:

I think being a girl and having to go through all those girly stages like having the nice hair and the trendy clothes (must be hard). And I think sometimes the girls (with ASD) will wear something that is just not right and they think it looks great but it's so hard to actually say, "Look don't wear that because you'll get bullied (Tina, mother).

Puberty and Its Related Issues

Puberty was a major issue of discussion in all interviews with the mothers. Onset of menstruation was by far the greatest puberty-related concern for the mothers. However, of those whose daughters had begun their periods (4/5), all described surprise at how well their daughters had managed. Factors contributing to this positive coping included the logical and factual attitude their daughters showed towards periods, and their daughters' willingness to discuss issues:

I was dreading her getting her periods because I didn't know how she was going to cope but I think she might be better than my NTD children! ... she's always prepared and if there's any problems she will come and talk to me about it. So she's open about it, she doesn't try to hide it, she's not embarrassed... I find that quite refreshing actually; I like that she is

open and feels she can talk to me about things (Tina, mother).

When I talked to Erin (about puberty)... she was very factual about it... for her this was a whole bunch of facts about her body and it wasn't emotional... for the girl on the spectrum... it is pretty black and white. So it is easy to tell them facts (Sharon, mother).

The mothers also highlighted various challenges associated with the logical attitude towards puberty described previously in this section. The main challenge was their daughters having little discretion about usually private matters:

...the concept I had to get my head around was how she does everything literally, like I would say, "Ok, when you're finished with your pads you need to put them in the bin" so Hannah would walk through the house with them in her hand. My son was like, "Argh!" because they weren't wrapped up or anything. So then you have to go, "Ok, I need to think how Hannah needs to hear this." ... Even now she will put it in the bin ... (but) she wouldn't think that she should hide it or anything... (Dianne, mother).
...when she's got her periods we all know about it! Whereas a NTD child would probably be a bit shy and quiet and not say anything about it.... she's not discrete and I guess that's part of the Autism (Tina, mother).

Hygiene routines was another issue discussed by all mothers, with four of the five saying they continued, from childhood, to be involved in a 'hands-on' role with their adolescent daughters. The main issues discussed involved their daughters' difficulties adjusting to the increased demands of hygiene practices (e.g., use of deodorant and need for daily showering), and the impact these hygiene practices had on themselves as mothers of an adolescent girl with ASD:

I have to remind her to have a shower every day... And she'll get in the shower and she'll stand there and play with the water if I don't remind her to put her shampoo in her hair and rinse it... She'll be in the shower for half an hour and do nothing! After years of having showers and baths she's not bothering to learn and yet she can learn really complicated things. It's typical of AS girls that that sort of thing isn't important to them. So yeah I would like to stop doing that... And I do see my friends and their (NTD) girls seem to take all that responsibility onto themselves and it would be nice not to have to do it but it's the way it is (Sharon, mother).

I have to take more responsibility for her in terms of hygiene and making sure she has a shower every day

(and) getting her to use deodorant and basic hygiene stuff (Valerie, mother).

Sexual Relationships and Concerns

Increasing exposure to sexual issues and romantic relationships was another issue discussed by the mothers. Three of the five mothers felt that their daughters were less involved in these adolescent issues than their NTD peers. Reasons for this included showing little interest romantically in boys, knowing personal boundaries and rules, and willingness to talk to parents about issues. For example:

She's not interested in the whole boy issue or the sexuality stuff. In that sense I'm kind of happy because I was always worried about what my other (NTD) girls were getting up to! (Valerie, mother).
(Regarding sex) I think she understands it and knows about it but I think she is not interested at this stage... she actually has a boyfriend... but because they are all on the spectrum they sort of know their boundaries, like they know that there are things they shouldn't do before they get married... I have to kind of trust her. And because she will come and talk to me about anything I think that if anything happens she will come and talk to me more than my other kids might! (Tina, mother).

One mother also discussed how she thinks puberty is different for adolescent boys with ASD compared to girls because she speculated that the boys may have more sexual urges that need to be managed:

...I think as the boys (with ASD) mature it may be harder for them to deal with those urges than what it might be for a girl...so I think the boys are probably more involved in the sex stuff than the girls (Tina, mother).

All mothers agreed that their daughters faced unique challenges related to sexuality and romantic relationships due to their ASD. Such challenges included their propensity to become fixated on particular issues, possible misunderstandings about personal boundaries, and confusions over typical adolescent behaviour such as flirting:

Sometimes I have thought she is gay... or that she's asexual. It's nearly like she doesn't want anyone to touch her because she never gets that close to anybody. But then if the physical gratification makes her feel that somebody likes her then she might become really into sex. I think it could go either way, either totally into sex or totally not (Lisa, mother).

(Romantic relationships are) not as factual and not as scientific. It's so much more judgemental- 'How do I

know that when he's touching me, he's just touching me in an ok way?' How exact can you be? It's so grey (Sharon, mother).

She doesn't understand it, like my niece is 15 tomorrow and she's all over boys and Hannah just says, 'What is she doing Mum? What does she act like that? Why does she wear those short shorts?' She doesn't understand any of it. She doesn't understand how other girls are wearing revealing clothes to attract men or boys or whatever, she doesn't understand it... and the whole sex thing- she gets all that, but her difficulty is that she doesn't understand why, she's always like, 'Yeah, but why?' (Dianne, mother).

Related to this issue was concern that their daughters with ASD may be vulnerable to being exploited by others. The primary concern related to this issue was that their daughters can be overly trusting of others.

One of the parents I know, who also has AS, has told me that when she was young she slept with lots of boys because they told her that they loved her. So I do worry that she doesn't have a deep understanding of these issues and I don't worry that Hannah would do something, it's the case of somebody taking advantage of her (Dianne, mother).

...it is a worry that she may meet someone who is NTD and knows that she is not NTD and takes advantage of her, so there is always that worry. And the fact that she is very trustworthy, like if somebody says something she believes that to be true... But that worry will become bigger when she gets older and leaves school and starts working and starts going out of a night... because there are people out there that would take advantage of her and to fit in she would probably do things to fit in (Tina, mother).

...it's coming to that point where I am going to have to have very specific conversations with her... to make sure we have the same understanding around who can do what and who can touch what... I know she won't like it because she will think she knows the answers. But I will have to because a couple of boys are paying attention to her... you do worry what would happen if they were in a room alone together, like whether he would take advantage of her (Sharon, mother).

Impact of Having an Adolescent Daughter with ASD

Throughout the interviews mothers discussed various ways having an adolescent daughter with ASD impacted on them. The predominant theme was that they remained very involved in their daughters' lives compared to mothers they

knew who have NTD adolescent girls. Such 'involvement' included being connected with the school and other activities, helping with homework, facilitating hygiene routines, and undertaking high levels of planning for activities:

I was constantly up at the school talking to her year advisor and discussing issues with teachers. I've always been very active and involved with her... For other parents adolescence is a time of stepping back, like still being there for them and giving them advice or whatever, but I have to constantly push her along... I see other parents with teenagers and it's like they are getting their lives back but for me it is ongoing (Valerie, mother).

We are thinking about her all the time... virtually our whole lives have revolved around her... Even planning a day out to a beach takes lots of planning and things you have to think about. You can't just on the spur of the moment go and jump in the car and go somewhere... all of that constant thinking is really draining... I guess because she has Autism we are a little but more protective of her than what we are of the others. We virtually know where she is all the time, there hasn't been a situation where we haven't known exactly where she was and who she was with... I feel like I am a hands-on parent until the day I die and I will be (Tina, mother).

The mothers also discussed the impact of having a daughter with ASD in comparison to how they perceived the impact of having a son with ASD would be. Issues discussed primarily involved remembering the importance of being accepted by other teenage girls and a desire for their daughters to experience acceptance:

I think it's heart breaking for the Mums, and it probably is for the Mums of boys (with ASD) as well, but I think for the girls it's different because you're a girl and you know what it is like going through school and how it was to be popular and look nice and be accepted and to be involved in things and to be invited to things. I think when they are not invited to parties and outings with kids their own age, I think it hurts you more than it hurts them. I think they deal with it in their own way but I think the parents take it on board themselves and it is just heart-breaking to see... (Tina, mother).

At her formal when she left primary school she wore black pants and a black and white check shirt with a black leather hat.... The comments from the Mums... hurt because she wasn't in a dress, massive heels and all glammed up like the other girls.... (Lisa, mother).

Throughout the interviews the mothers indicated various attitudes towards having an adolescent daughter with ASD.

These attitudes ranged from a focus on the challenging aspects (such as reduced career and social opportunities) to acceptance, positive meaning making, and even personal growth:

For me, because I had kids so early, I always felt like at some point I would get my life back... Then I realised that that wasn't going to happen... It is like a loss... And now that she's becoming more clingy it makes it really hard (Dianne, mother).

It's such hard yakka just keeping things going so I've had to step back. I can't put any more time into her, I have done 150 % but if I did 300 % it still wouldn't be enough for her. Also, I have felt she doesn't want that attention. I remember helping her with homework and she was like, 'Oh you don't do it that way!' And it was just this horrible battle where she would turn on me but I was just trying to help... It used to hurt. I am disappointed about it because I think, 'I'm her Mum but she won't hug her Mum.' It used to bother me more but I am sort of over it... I'm totally exhausted and totally burnt out (Lisa, mother).

I feel that having Bec has isolated me due to the sheer time she demands... I need help with getting her more independent because the more independent she becomes the more independent I can be... (As she gets older) I have a better understanding of her and understand the ways she is different from an ordinary teenager (Valerie, mother).

I think it has been like a roller-coaster, in the beginning we didn't know a lot about it (ASD). When you get the diagnosis I think you go through a sense of grieving... now that we are getting more connected with the services and we are not feeling so isolated like it is just us, I'm a lot more confident and the positives are coming out a lot more... it's like we've come through the fog and are coming out through the other end... I can see how far she has come and she has come that far because we are learning as well as her... (Tina, mother).

The mothers discussed a range of practical strategies they used to cope with these challenges. The main strategies included taking 'time-out', and social involvement with mothers of both NTD children and those with ASD:

I make time to myself and I sit down and read a book... I also talk to other parents of kids on the spectrum; I make time to do it... You need people that you can trust with your information. I think I'm lucky that I have people like that both on the spectrum and off the spectrum... (Sharon, mother).

The parents get a lot out of it (social group) too... its always like, 'Gee, this is what has happened with my

son or daughter this week, has that ever happened to you?' and others will be like, 'Oh yeah, exactly the same!' And I think just hearing it come out of other parents mouths- that their kids are doing the same as your kids, you sort of get that feeling that you're not the only ones and that you're not that different. We may not belong in the NTD society but we can form our own little group. It makes you feel like your socialising again and you're not isolated... (Tina, mother).

Discussion

To our knowledge, this is the first study to investigate the experiences of adolescent girls with ASD from the perspectives of the individuals themselves and their mothers. The main themes included: diagnostic challenges; the impact of 'being surrounded' by boys; experiences of high school; the complexity of adolescent female relationships; puberty and sexual issues; and positive and negative impacts of having an adolescent daughter with ASD.

Some of these issues may be similar to the experiences of adolescent boys with ASD, such as negative impact of late diagnosis (Kabot et al. 2003); challenges of transitioning to and coping with high school (Adreon and Stella 2001); 'hands-on' role of parents into adolescence (Brewin et al. 2008); difficulties adjusting to the increased demands of adolescent hygiene routines (Bolick 2001; Chan and John 2012); and the importance of learning personal boundaries in interactions with others (Nichols and Blakeley-Smith 2010). Other issues seem to be unique to the experiences of adolescent girls with ASD and their families, such as difficulties developing and maintaining friendships with NTD peers; the implications of having a condition with a skewed sex differentiation; sex-specific puberty issues; and sexual vulnerability. These issues will be discussed in more detail in the next section.

Challenges Developing and Maintaining Friendships

All participants with ASD reported experiencing difficulty developing and maintaining friendships with NTD adolescent peers. Contributing factors discussed by participants were in line with the literature, and include reliance on imitation skills during childhood to mask underlying social deficits; difficulty following conversations due to the length of time needed to process information; and difficulty fitting in due to disinterest and minimal understanding of fashion (Nichols et al. 2009; Solomon et al. 2012).

Another factor which may have contributed to the girls' difficulties developing and maintaining friendships with

their NTD peers is their history of socialising predominantly with males who have ASD (McLennan et al. 1993; Nichols et al. 2009). Greater socialisation with males with ASD (in school classes and social groups) is natural given the preponderance of males diagnosed with the disorder. The implications of socialising predominately with males with ASD may be that the girls develop friendships that are more in line with 'male' friendships (Knickmeyer et al. 2008). Characteristics of adolescent ASD male friendships include: more numerous, casual friendships (Card et al. 2008); companionship based on activities (Bauminger et al. 2004; Carrington et al. 2003); and less socially complex interactions (Bauminger et al. 2003, 2008; Koning and Magill-Evans 2001). These characteristics were reflected in the interviews, with participants indicating that males with ASD were easier to get along with than NTD girls, especially when they shared similar interests.

Puberty-Related Challenges and Concerns

This study also highlighted the range of changes and challenges that adolescent girls with ASD, and consequently their mothers, experience related to puberty. Apprehension regarding the onset and ongoing management of menstrual care was the most salient puberty-related concern reported by the mothers. Maternal concern about the onset and management of menstruation for daughters with ASD is echoed in the broader literature (Klett and Turan 2012; Koller 2000; Nichols et al. 2009). Specific concerns highlighted in this study and, by the literature, include explaining menstruation in a developmentally appropriate way; management of the practical aspects of menstruation; and importance of hygiene practices (Nichols et al. 2009). Despite these concerns, our findings and other research indicate that girls with ASD generally cope well with this aspect of puberty (Koller 2000). However, it should be noted interviews did not capture the girls' perspectives about menstruation. We suspect this was a result of the open nature of the interviews, in which participants were asked generally about 'developmental changes' but not asked specifically about menstruation.

Another puberty-related concern expressed by mothers was the potential sexual vulnerability of their adolescent daughter with ASD. Specific concerns highlighted by this study, and echoed in the literature, include fears of sexual exploitation, the need to play a protective role for their child, and concern their child may misinterpret the intentions and behaviours of others due to their intrinsic social and communicative impairments (Murphy and Elias 2006; Nichols and Blakeley-Smith 2010; Stokes and Kaur 2005; Sullivan and Caterino 2008). It should be noted that the prominence of sexual concerns may be inflated in this sample as the majority were older adolescents. Despite this, sexual

concerns appear warranted with estimates that 16–25 % of individuals with ASD have been sexually abused (Chan and John 2012). Additionally, the literature indicates sexual vulnerability concerns are shared by both parents of girls and boys with ASD (Ruble and Dalrymple 1993).

Experience of Being a Mother of an Adolescent Girl with ASD

Throughout the interviews mothers reflected on the impact of having an adolescent daughter with ASD. Some mothers discussed the challenges associated with ASD during adolescence, including the need for high involvement in daily activities with their adolescent daughters, and experiencing a sense of isolation associated with this. Positive aspects of parenting a child with ASD were also evident. These positive aspects included close relationships with their daughters, increased understanding of ASD over time, witnessing improvements in their daughters' functioning, and connecting with other families living with ASD. Importantly, interviews also reflected multifaceted attitudes that included both positive and negative elements. Such attitudes included positive meaning making of challenges, altered expectations for their daughters, and acceptance of their role as a parent of a child with ASD. These mixed attitudes highlight the complex impact of ASD on families. The theoretical concepts of 'Ambiguous Loss' (Boss 1999, 2004; O'Brien 2007) and 'Traumatic Growth' (Heiman and Berger 2007) account for such impact by recognising that distress and psychological growth often co-exist. Cridland et al. (2013) discuss the importance of acknowledging the complex impact ASD has on families by investigating both positive and negative implications of living with ASD.

Limitations and Recommended Future Research

The following points highlight some limitations of the current study and how these issues may be addressed in future research.

1. Findings highlight various issues which may be unique to the experiences of adolescent girls with ASD and their families (e.g., implications of having a condition with a skewed sex differentiation; sex-specific puberty issues; and sexual vulnerability). Whilst replication of these findings is needed, they acknowledge the need to investigate the experiences of adolescent boys and girls with ASD, and their families, separately.
2. This study utilised the perspectives of adolescent girls with ASD as well as their mothers. However the perspectives of other family members are also needed. Future research may benefit from including perspectives

of various family members (e.g., fathers, siblings) and other significant individuals (e.g., teachers, extended family).

3. Whilst this sample may be considered homogeneous relative to other studies, there remain areas to be improved. For example, future studies could aim for greater diagnostic homogeneity within the Autism spectrum (i.e., level of social and/or cognitive functioning); more specific age of participants (young, middle, and late adolescence); and greater attention to the influence of family dynamics (e.g., sibling age, birth order, and gender).
4. This study utilised an open-ended interview format, in which participants were merely provided with a suggestion of topics related to their experience of being an adolescent girl with ASD/having an adolescent daughter with ASD. Whilst this approach allows participants to speak freely about issues which are most salient to them, future research may benefit from utilising a more structured approach with specific questions related to adolescent issues (e.g., regarding adolescent girls' with ASD experience of menstruation).

Clinical Recommendations

The following clinical recommendations are based on the issues raised in this study, and may be useful for health practitioners, clinicians, teachers, and families living with ASD.

1. Clinicians need to become more aware of the presentation of ASD in females and the ways this may differ from typical male presentations (Attwood 2012, 2013). Greater awareness of ASD by clinicians is likely to facilitate less challenging diagnostic pathways and earlier access to support services.
2. The difficulties experienced with peer relationships (and the social isolation that can often occur as a result) are a key factor contributing to mental health problems, such as depression and anxiety, during adolescence (Müller et al. 2008). Clinician support may include in-depth measurement of mood symptoms (Kim et al. 2000), communication and social skills training, strategies to increase self-esteem, and exploration of identity (Cotterenceau et al. 2012; Nichols et al. 2009). Peer education and coaching programs at schools may also be important for increasing peer acceptance and understanding about ASD (Chan et al. 2009; Humphrey 2008; Humphrey and Symes 2010). Families should endeavour to provide accepting home environments and involve their adolescent with ASD in support services with a social component to facilitate friendship opportunities.

3. The sexual vulnerability of adolescent girls with ASD was highlighted in this study. Sexual education and support should begin during childhood (Chan and John 2012) and needs to be individualised and developmentally appropriate (Sullivan and Caterino 2008). Appropriate topics to cover include physical changes associated with puberty, personal boundaries, and healthy strategies for expressing sexuality (Klett and Turan 2012; Tarnai and Wolfe 2008). The most efficacious sexual education and support will be provided collaboratively between parents, clinicians, and teachers (Klett and Turan 2012; Nichols and Blakeley-Smith 2010; Travers and Tincani 2010).
4. Involvement in social support services is recommended for all adolescents with ASD and their families (Lasaard et al. 2010; Pinkerton and Dolan 2007). Further, gender specific groups may be helpful for adolescent girls with ASD, and their parents, given the unique issues they face (Holliday-Willey 1999; Nichols et al. 2009).

Conclusion

We conducted this qualitative study with no intent of generalizing the results to all adolescent girls with ASD and their mothers. Nonetheless, the experiences discussed by the participants may well be shared with other adolescent girls with ASD and their families. The themes highlight a range of issues covering physical, emotional, social and sexual domains. Some of these issues were similar to those experienced by boys with ASD during adolescence; such as negative implications of late diagnosis, challenges of transitioning to and coping with high school, 'hands-on' role of parents into adolescence, difficulties adjusting to the increased demands of adolescent hygiene routines, and the importance of learning personal boundaries in interactions with others. Other issues discussed were of particular relevance to adolescent girls with ASD; such as difficulties socialising with NTD girls, sex-specific puberty issues, and sexual vulnerabilities. It is important that we, as researchers, clinicians, and family members, attempt to understand these issues in order to provide these individuals with appropriate support.

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