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Tierney, S., Burns, J. and Kilbey, E. (2016) Looking behind the mask: social coping strategies of girls on the autistic spectrum. Research in Autism Spectrum Disorders, 23. pp. 73-83. ISSN 1750-9467.

Link to official URL (if available):

http://dx.doi.org/10.1016/j.rasd.2015.11.013

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Looking Behind the Mask: Social Coping Strategies of Girls on the Autistic Spectrum

Dr Siobhan Tierney Canterbury Christ Church University^a

Professor Jan Burns Canterbury Christ Church University

Dr Elizabeth Kilbey Oxleas NHS Foundation Trust^b

Correspondence concerning this article should be addressed to Professor Jan Burns.

^aSalomons Centre for Applied Psychology, Canterbury Christ Church University, North Holmes Campus, North Holmes Road, Canterbury, Kent, England, CT1 1QU siobhanljtierney@hotmail.com, jan.burns@canterbury.ac.uk

^bCommunity Rehabilitation Support Team Bromley, 2 Blean Grove, Penge, England, SE20 8QU Elizabeth.Kilbey@oxleas.nhs.uk

Coping strategies of girls with ASC

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Abstract

The socio-communication deficits of individuals on the autistic spectrum are well documented. However, this has largely been based on the male population and less is known about how females with autism manage social relationships across the developmental period.

Ten adolescent female participants with a diagnosis of autism were interviewed and Interpretative Phenomenological Analysis used to explore their experiences of managing their social relationships. The results showed that participants were motivated to develop and maintain friendships, but during adolescence this became increasingly difficult.

Consequently, they developed explicit strategies to manage these relationships, including masking and imitation. The use of such strategies was both advantageous and disadvantageous, and such findings should be considered in developing gender sensitive assessment and developmentally appropriate support.

Keywords: Adolescence; female; Autism Spectrum; social relationships; imitation.

1.1 Introduction

The prevalence of autism in 2010 in the UK was estimated at 3.9/1,000 in eight year old boys and 0.81/1,000 for eight year old girls (Taylor, Jick, & MacLaughlin, 2013). In a review of 32 epidemiological studies between 1966 and 2011, the male: female ratio was estimated at approximately 4:1 in autism and 10:1 in Asperger's Syndrome ([AS] Fombonne, 2003). Whilst exact ratios differ across studies, the gender disparity has been consistent since the condition's initial identification, often credited to Kanner in 1943. Various theoretical accounts for this gender difference have been offered, and criticism has been directed at the research and diagnostic practices which may perpetuate and exaggerate this difference. It is important that the reality of this imbalance and the gender sensitivity of assessment instruments and services are investigated, as it seems that girls with Autism Spectrum Conditions (ASC) may remain un- or mis-diagnosed, and more gender appropriate support not offered (Gould & Ashton-Smith, 2011).

It is beyond the scope of this paper to present the breadth of theories around gender and ASC (see Rivet & Matson, 2011, for a comprehensive review), but one influential theory is the Extreme Male Brain ([EMB] Baron-Cohen, 2002). Here males are described as typically having greater skills in rule-governed, systemising activities whilst typical females are described as having superior empathy and general emotional sensitivity. Hence, males are more likely to be on the autistic spectrum as they are more predisposed to autistic traits..

Whilst the EMB theory describes biological factors as a strong determinant of risk of ASC, Fine (2008) argues that the theory underplays the influence of non-biological factors. Debates around the aetiology of ASCs continue, and there is also mounting evidence that the androcentric nature of assessment instruments, together with the self-confirming bias of gendered expectations about typical presentations within services, are maintaining this gender

difference. Accordingly, there may be deleterious consequences for females on the spectrum as the female phenotype is comparatively undetermined in relation to males.

It has been argued that research has consistently focused on male presentations of ASC, with small, androcentric samples frequently used to validate commonly used diagnostic/screening instruments (Bloss & Courchesne, 2007). For example, the sample used in the original reliability analyses for the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) comprised 20 children (mean age 3-4 years old), 16 of which were male. Subsequent analyses of the ADI-R have also used predominantly male samples (e.g. Cox et al., 1999). Rutter, Caspi, and Moffitt (2003) suggest that the symptoms used as markers of ASC may be male-biased and this may reduce the sensitivity of the instrument towards females.

Additionally, different gendered social expectations across the lifespan may contribute towards differences between genders in the trajectory of ASC. Hsiao, Tseng, Huang, and Gau (2013) suggest that the "impact of ASD traits on social functioning may not present until pressure from demands for new social adaptation arises across major developmental transition" (p. 256). Kopp and Gillberg (2011) describe how, during adolescence, typical female friendships become more demanding than equivalent males' due to their communicative and social nature, posing specific challenges for girls on the spectrum in terms of making and maintaining friendships. Girls' social skills deficits may not be revealed until much later than boys as they emerge in response to female-specific, developmentally-related changes in the social environment. The later emergence of problematic differences is important to consider when females are regularly assessed using the ADI-R, which was developed on a sample of mainly boys with a mean age of 3-4 years.

Using a comparatively large sample (N=100), Dean et al. (2014) found that 7-8 year old boys and girls on the autism spectrum both experienced social exclusion by same-gender

peers, but manifested in slightly different ways. Whilst social exclusion may be experienced by both genders, each may use different coping strategies. Boys may withdraw from peers (Wainscot et al., 2008), whereas equivalent females may masquerade their difficulties by using patterns of socio-communication that are largely rote-learnt in order to fit in (Gould & Ashton-Smith, 2011). Lai et al. (2011) found that females with ASC had higher scores on a self-report measure of ASC symptoms, leading them to suggest that females may be more aware of their difficulties and this awareness enables them to mask symptoms. However, there is very little research which has explicitly investigated the social management strategies of people on the autistic spectrum; therefore, it is difficult to establish whether the gender ratio in the prevalence of diagnosed ASC is in any way affected by similar or different coping strategies between genders.

The female ASC profile is not well-understood, due in part to a lack of research designed to investigate gender differences (Mandy, Chilvers, Chowdhury, Salter, Seigal & Skuse, 2012). However, the female presentation of ASC has recently gained increased interest. For example, Rivet and Matson's (2011) review found that girls with ASC tend to be 'clingy' rather than exhibiting 'extreme autistic aloneness'. Gould and Ashton-Smith (2011) note that the intensity and quality of ASC-girls' interests differs to that of non-ASC girls, rather than the topic. Over- and under-reaction to sensory input has also been observed in females but this has not yetbeen established through empirical research (Gould & Ashton-Smith, 2011). Kopp and Gillberg (2011) suggest that males and females express similar degrees of severity in social reciprocity deficits but when each is viewed within the context of gendered-expectations, females' difficulties are overlooked. Nevertheless, there remain few robust empirical studies into gender differences,. In summary, emerging research varies in quality and rigour but does suggest that ASC manifests differently by gender and presents different challenges to males and females.

The implications of unidentified ASC in girls are serious, both as a consequence of neglect of their specific needs, but also as a result of potentially co-occurring conditions. Studies have identified higher rates of internalising pathology in adolescent girls with ASC compared to both boys with ASC and neurotypical girls, (Lai, Lombardo, Auyeung, Chakrabarti, and Baron-Cohen, 2015; Solomon, Miller, Taylor, Hinshaw, and Carter, 2012). Internalising symptomology in girls with ASC may go unrecognised, especially if combined with a suggested propensity to mask differences (Dworzynski et al, 2012).

The adolescent phase of development involves an increase in the intensity, complexity and demands for girls to develop positive social affiliations, making it a particularly challenging time for girls with ASC when adaptive skills must come to the fore. The only published study which has focussed qualitatively on the experience of female adolescents with ASC is Cridland, Jones, Caputi and Magee (2014). This study provides valuable and novel insights into this parental relationship, issues of late diagnosis and managing the transitions of adolescence. However, these were co-constructed narratives, with a foregrounding of the maternal experience and interpretation of their daughter's experience. There remains a gap within the research literature where the direct experience of the adolescent girl with ASC is foregrounded, specifically focussing on the strategies used to manage their neuro-atypical development.

Hence, the purpose of this study is to explore whether adolescent females with ASC use social management strategies, particularly masquerading, to hide socio-communication difficulties to enable them to fit in with peers. The EMB theory suggests that females may be have superior empathy and social sensitivity than males and this may make females on the spectrum appear socially competent when compared to males on the spectrum. Such research may contribute towards understanding the disparity between genders in the diagnosis of ASC.

1.2 Materials and Methods

1.2.1 Design

The study was designed to glean a rich account of how girls with ASC both identify with, and respond to, the social challenges associated with adolescence. Semi-structured interviews were used to explore such experiences. Data was analysed using Interpretative Phenomenological Analysis (IPA) as this methodology aims to understand how a person makes sense of/interprets their experiences within a given context. It utilises an iterative process of analysis which enables the researcher to see the perspective of the participant whilst maintaining awareness of the existing knowledge which shapes the context and also acknowledging reflexive processes in terms of the researcher's own viewpoint. This methodology was particularly appropriate for use with this group as it allowed the researcher to contextualise the data within theory and prior research and understand the responses in relation to the influence of gender, adolescence and ASD. In order to develop awareness of assumptions which may have interplayed with the analytic process, a reflective log was used. After each interview, the lead researcher recorded and reviewed their experience of the interview process in order to maintain awareness of personal biases/beliefs/assumptions which may have affected the study.

A semi-structured interview schedule was developed from questions originating from the existing literature (e.g. Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) and piloted with two adolescents with ASC. To adapt to the specific needs of participants with socio-communication difficulties, specific concrete examples were elicited from the participants and then explored in more depth, making comparisons with how they thought peers coped. To develop rapport and gain an understanding of the social context of the individual participant, each was asked to engage in the development of a sociogram (Bilal & Beheshti, 2014); the participants drew a circle representing themselves in the middle of the

paper and each friend was represented using a triangle. Participants placed the triangle at a distance to the circle in a way which they felt represented the closeness of each friend. The sociogram was used to elicit information about the participant's social world and was not included in the data analysis. Parents¹ or carers could attend the interview if requested to do so by the participants. Whilst it was possible that participants' responses may have been influenced/inhibited by the parent/carer's presence, the inclusion of a parent/carer may have also facilitated a richer, more accurate dialogue for those who preferred this option. A balanced decision was made between consistency of procedure with allowing the participant to choose the situation in which they felt most comfortable. To guard against dominance of parents/carers, it was confirmed during pre-interview discussions with both parties that the perspective of the participant would be prioritised.

1.2.2 Participants

Purposive sampling was used with the following inclusion criteria; female, between 13-19 years old, in the UK, and written evidence of a formal diagnosis of any ASC. Girls with co-morbid diagnoses of neurological or affective disorders were included as co-morbidity is common within the ASC population. Potential participants with issues impinging on their ability to provide informed consent or fully participate in the process were not interviewed. Twenty-five females were contacted regarding participation. Ten were recruited. The remaining fifteen did not meet inclusion criteria, did not wish to participate or were unwell during the data collection phase. Participant demographics are shown in Table 1.

Potential participants were identified by practitioners at two Child and Adolescent

Mental Health Services (CAMHS) and self-referral through the web-sites of two ASC

affiliated charities. Verbal consent was provided before contact details were passed onto the

¹ It is recognised that parents may or may not be biologically related to their child. In the interests of brevity and inclusivity, the term 'parent' is used to describe parents of all origins.

researcher. Informed, written consent was provided by the participants or their parents/carers and interviews arranged. Interviews were completed on a one-to-one basis, unless a parent/carer was present, at a mutually agreed, private location.

Participant Demographics

Table 1

Participant ^a	<u>Age</u>	Recruitment	<u>School</u>	<u>Multiple</u>	<u>Diagnosis</u>	<u>Family</u>
		Channel	<u>Placement</u>	<u>School</u>	(age of	Contact with
				<u>Placements</u>	<u>diagnosis)</u>	$\underline{ASC^b}$
				(number of		
~				moves)	. ~ (1.4)	
Gemma	13	NHS	All-girls	No	AS (12)	Professional
			Grammar			
Janita*	15	NHS	Mainstream	No	High	
			Secondary		Functioning	
			•		Autism (4)	
Laura	14	NHS	Mainstream	No	ASC (4) &	
			Secondary		ADHD (13)	
Kate*	15	Charity	Pupil Referral	Yes (2)	AS (12)	Professional
			Unit			& Personal
Stephanie	16	Charity	Open	Yes (8)	AS (15)	
_		-	University			
Rosie*	15	Charity	Out of Sahaal	Vac (2)	AS (7)	Personal
Kosie.	15	Charity	Out of School (4 years)	Yes (2)	AS (7)	Personai
			(+ years)			
Nadia*	15	Charity	Mainstream	Yes (1)	AS (14)	
			Secondary			
Siân*	13	Charity	Mainstream	No (moved	ASC &	Professional
Stati	13	Charity	All-girls	classes due to	anxiety (10)	Fiolessional
			Secondary	difficulties)	unalety (10)	
Emily*	13	Charity	Mainstream	No	AS (8)	
			Secondary			

Joëlle	15	Charity	Home	Yes (1)	AS (12)	Personal
			Educated since			
			13 years old			

^{*} Mother attended interview

1.2.3 Ethical Considerations

Approval was granted by a NHS Research Ethics Committee and two NHS Trusts' Research and Development Directorates. Informed consent for the thirteen to fifteen year old participants was provided by parents/carers, as advised in the Research Ethics Guidebook (http://www.ethicsguidebook.ac.uk/). Females aged sixteen to nineteen provided their own consent. De-briefing occurred at the end of the interview and appropriate information for gaining additional support was available if required, but was not requested by any participant.

1.2.4 Analysis

The procedures of IPA (Smith & Osborn, 2007) were followed, which involves familiarisation with the data, identification of keywords, clustering of related concepts into themes, cross-referencing between transcripts and collation of initial and final emergent themes which were then grouped into broader super-ordinate themes. Codes and emergent themes were developed inductively throughout the process of analysis and identified both topics and the meaning of that topic for the participants. Contributions made by parents were included in the analysis and this data was viewed as secondary, but substantive to the girls' comments. Parents generally commented only when their daughter was finding it hard to verbalise her experiences. Parents occasionally enriched girls' comments by elaborating upon them, and on these occasions endorsement from the participant was sought. Excerpts from parental reports have been included in the Results section to illustrate the type of contributions made by some parents in the interview process.

^a Pseudonyms are used to protect the identity of participants

^b Professional refers to Mother working with people with ASC. Personal refers to family history of ASC

IPA is an iterative methodology, so after analysis, each participant received a brief interpretation of their interview. Participants reviewed the summary and some provided feedback on the interpretation. Feedback was used to check the quality and respondent validity of the analysis. Two participants added information in response to their feedback summaries and this was included in the data analysis. The analysis was reviewed by an independent researcher who audited the course of initial notes through to emergent themes for three transcripts to ensure that the lead researcher could demonstrate transparency in the analytic process. The only information available to the independent researcher was a document which described the process of analysis, from start to end, so that they could audit the rigour of analytic process..The independent researcher concluded that the study was as rigorous and free from obvious bias.

1.3 Results

Four superordinate themes and 13 subthemes emerged (Table 2). Each of the superordinate themes will be presented in turn with reference to the attached sub-themes, using extracts from transcripts to illustrate the findings².

Table 2					
Emergent Themes					
Superordinate Theme	<u>Subtheme</u>				
1. Experiences of Social Environment	1.1 Incommodious				
	1.2 Impenetrable				
	1.3 Misunderstandings and Mis-labellings				
2. Desire for Friendships	2.1 Context for Befriending				

2.2 Challenges to Developing Friendships

² Text within [] denotes text added for clarity. (...) denotes words removed for clarity/brevity.

	2.3 Motivations for Befriending
3. Overcoming Challenges	3.1 External Support
	3.2 Innate Skills
	3.3 Imitation
	3.4 Masking
	3.5 Repercussions of Strategies
4. Developmental Tasks	4.1 Triggers for Difficulties
	4.2 Sexual Identity

1.3.1 Experiences of the Social Environment

This superordinate theme captures participants' perspectives of their social environment, which was often described as incommodious, provoking feelings of distress, lack of safety and rejection. Lack of safety arose from feeling at the mercy of more powerful others, broadly conceptualised as those who understood social rules. Three participants described how they experienced the school environment as predatory.

Emily: *It feels like in my classroom that I'm surrounded by lions ... I feel like a* mouse and everyone else is like a giant cat or something.

The social environment triggered sensory distress for most participants. Six participants described school corridors as highly distressing when moving between classes due to the increased intensity of sensory stimulation combined with heightened sensory sensitivity. This was often described as physically assaultive.

Kate: I was really sensitive to everything and that was a huge stress cos [I] was like hurting physically as well... loud noises used to really scare me and hurt in my head.

A number of participants described this sensory overload as traumatic.

Joëlle: *I* ... *just try to focus on one thing* ... instead of ... noticing everything at once which is a bit sort of traumatic sometimes.

Gender expectations contributed to feeling unable to fit in, leading participants to experience the social environment as impenetrable. Many participants described feeling 'ungirly³' in relation to female peers in terms of appearance, interests and communicative styles.

Janita: Boys aren't as [quick] to judge, like if you say like something they don't ... take it as you being blunt ... they're just more relaxed.

Interviewer: Right. And do you find that girls might take you as being blunt often?

Janita: Yeah, like sometimes I might say something and they might think (pause) like if they said something, *I'd think* ... they were being rude and then they would think I'm being rude.

These differences contributed towards the feeling that the female social environment was impenetrable. In response, participants often aligned more with male peers, as they shared more interests and did not engage in emotion-based conversations.

Stephanie: I think ... it's probably harder for girls with Asperger's in a way than boys cos generally people socialise more with their own gender ... being a boy with Asperger's you're probably more similar to neurotypical boys whereas an Asperger's girl is different to neurotypical girls.

Participants described how sometimes they unintentionally broke covert social conventions (i.e. unspoken but widely-held social expectations such as "respecting elders") and that this was sometimes interpreted and labelled by teachers as intentionally disruptive.

³ A word used by a number of participants to describe their experiences.

Joëlle: The teacher was like "it's a technique that we use for really naughty children" which obviously... I might have come across as naughty, but I never intended to be like that.

This mis-labelling, combined with frequent peer-rejection, led many participants to feel that they could not fit into their social environment, however hard they tried.

Rosie: I would be happy to hang around with them if they would accept me but they don't.

1.3.2 Desire for Friendships

This superordinate theme describes how participants conveyed desire for friendships, their motivations for making friends and some of the challenges to making and/or maintaining friends.

All participants described having a desire to have friends. This intrinsic motivation combined with experience of frequent peer rejection, sometimes stirred up ambivalent feelings about friendships; participants wanted friends, but had to go to great lengths to make and maintain friendships.

Joëlle: [after a period of no contact with her friends] *I suddenly realised "oh God! I really miss them, I wanna keep in touch with them"*.

Stephanie: I definitely couldn't be some kind of hermit. As much as I would like to be able to I don't think it would be good for me at all.

Participants valued their friendships. They appreciated the support their friends offered and enjoyed providing support to their friends. Support from friends appeared to have a protective element for many participants, in the context of their sense of social vulnerability.

Rosie: When I'm not with friends ... I ... think of all the bad things in life and just carry on thinking about them over and over and over and over until I get really depressed.

Misunderstandings obstructed the development of relationships and made them challenging. Participants could not read the intentions or meanings in others' communication and their own style of communication was difficult for their peers to understand. Mutual misunderstandings led participants to feel very confused and anxious in social interactions.

Emily: AS is talking to another person through an intercom machine or something and somehow the wires get crossed and they get the wrong message.

Joëlle: I have to be really careful when I'm talking to her cos... otherwise I'll... slip up or say something stupid or misinterpret it.

Nearly all participants described finding group communication challenging. This impacted on their ability to maintain friendships because the people they befriended often had a group of friends which the participant struggled to integrate into. If they could not access the group, the participant would often be left behind by the friend. Difficulties with groups also impacted on participants' educational experience, as they were often set group tasks with which they felt ill-resourced to cope. This led to disengagement from group tasks and negative repercussions from peers and teachers.

Emily: With a group, there's loads of different people all at different times and it turns into a murder mystery game of Cluedo where somebody made this go wrong, we've got to find out who it is, people blaming each other, splitting each other up and just wrecking everything. I don't like it at all.

Two participants described being members of very large social groups, stating that they had around 100 friends. Participants sometimes explained that whilst they had large numbers of friends, they positioned themselves on the periphery.

Laura: You know they have them interview rooms where you can see in but they can't see out? I'd rather be on the outside of one of them than the other way round.

Possibly arising from encountering frequent misunderstandings in the context of a stressful social environment, many participants described social contact as exhausting. This led to them spending less time with peers and introduced the risk of deterioration in the friendship, which was concerning to the participants.

Kate: I don't really talk to people as much as most other people cos quite often, you know, it's too much effort. So it's a bit stressful cos you have to sort of think about the other person's feelings, it's just a bit too much for me sometimes ... but I do worry quite a bit like if the friendship starts to deteriorate and they don't see me as friends any more.

1.3.4 Overcoming Challenges

This superordinate theme presents accounts of how participants attempted to overcome challenges in developing and maintaining friendships.

All participants had struggled to form friendships and external support had been vital in making and maintaining friendships. Oftentimes, initiation of friendships was assisted by parents; some mothers described how they could see that their daughter was struggling to socialise and encouraged her to do so by setting up contact with female peers. When choosing friends for themselves, participants tended to befriend people who nurtured them; participants often described female peers who had actively supported them in their acquisition of social skills.

Kate: I think they probably noticed that I was ... not very good at it so they probably pitched in a bit more but I did try to do my best at trying to talk to them.

Nadia: There was something about them that was more like mothering rather than like "oh, get out of here, you're strange, we don't want anything to do with you".

Nine participants described how they had used their natural abilities to develop strategies in order to establish friendships. Some of the strategies were built upon what

were sometimes described as very strong innate empathising skills; three participants described themselves as having a naturally strong ability to empathise.

Joëlle: People say that people with AS aren't empathetic ... I think that's so wrong ...

I'm really actually quite good at putting myself into other peoples' situations.

Often, empathy was informed by a naturally good memory, with the accounts suggesting that participants built empathy skills like a jigsaw puzzle (e.g. matching corresponding memories to another person's situation in order to create a concrete reference point with which they could identify). Five participants described consciously developing empathy as they knew that being able to take another's perspective would enhance their befriending skills. Overall, empathy skills were either described as innate or were developed using other innate strengths (i.e. memory).

Gemma: I have a very good memory so I can ... relate that to a situation the other person's in ... I sort of used that memory and just associated with what she knew.

Difficulties in understanding implicit social conventions were sometimes overcome by using innate observation skills. Participants described how they naturally absorbed a lot of information and had consciously turned their observations towards peer interactions. Such observations then informed development of a social code they could adhere to.

Gemma: I [would] be quiet and listen and record that for next time.

The activities of imitation and acting featured in most interviews. Six participants were involved with drama classes and described how this had improved their confidence and skills in social situations. Participants also described sophisticated levels of peerimitation, sometimes pretending to be occupied with an activity (e.g. reading) when they actually were observing peers in order to imitate them. The attempts to imitate peers were driven by a strong desire to not stand out as different to them. Copying

included facial expressions, postures, tone of voice, topic of conversation, choice of interests; the breadth of imitation was vast. Participants went to great lengths to disguise their imitation as they were fearful of being 'caught out'.

Laura: I see how other people act first then copy them in my own way... I change it a little bit so it's not like I'm really copying them.

Gemma: I would try and copy them but not look like I was exactly copying them, so if they were playing a game and they moved and they did something then I would try and copy it but not exactly like them.

All participants described feeling unhappy and anxious in social situations and they masked their true feelings by wearing either an excessively happy facial expression or a very blank one in most social environments. Even when they had developed friendships, they often maintained their mask, through fear of losing the friendship should their true feelings be unveiled.

Laura: I thought "what if I can't make any friends? I'm going to have to make sure that I'm always perfect for everyone"

Nadia: I do hide many of my emotions and I'm used to like having a smile on my face.

The consequences of frequently using highly sophisticated imitation and demanding masking strategies resulted in emotional consequences when participants surpassed their threshold to maintain their efforts. Some participants described a stark contrast between their social-persona and how they interacted with family, where they felt they could be their 'true selves'.

Interviewer: Do you think it takes a lot of effort from you to be like a chameleon?

Gemma: Yes, it's very hard and when I came home from my primary school I was very exhausted and tired cos I'd acted so much.

The repercussions of trying to cope were severe for many participants, leading to feelings of anxiety and depression. Five participants had used self-harm as a way to cope with feelings associated with frequent rejections and miscommunications. Mental health difficulties, self-harm and/or suicidal ideation had brought eight participants to the attention of CAMHS.

Joëlle: I was getting to the point where I actually couldn't control some urges that I had ... I was a little bit suicidal.

For Stephanie, the impact of constantly pretending to be like her peers led to her identity crisis:

Stephanie: I think I had a sort of identity crisis really because I wasn't quite sure who I was anymore because I was so used to ... pretending to be the same as everyone else when really I knew that I wasn't.

Stephanie started speaking to herself as she had no friends to interact with and she started to experience voices in response. The combination of hearing voices, self-harm and depression led to her spending three months in hospital:

I would sort of talk to myself and reply to myself and that was when I started to hear voices and things like that as well and I think that just stemmed from being really lonely.

Since participants had used their masking and imitation strategies so effectively, those around them were surprised when they learnt that the participant was masking her true feelings. Participants provided accounts of teachers expressing disbelief when it was reported to them by the participant themselves or their family that they were struggling so severely. The absence of externally observable struggles created extra stress for mothers who endeavoured to get their daughters' needs met through health, education or social care services.

Nadia: They [teachers] didn't believe me that I was upset because I was always happy cos I was trying to mask that I was upset.

Siân's Mum: It really is just conforming and holding it in that does mask it...

you can go 10 years and, well, I knew when she was a lot younger but her

teachers and things they would go "no! no!" ... a girl can mask so well that

she can present as even looking happy when actually everything's going wrong

... we've had a lot of that in school. We've all had lots and lots of meetings and

I've had to really train them, you know with my knowledge, to say ... "it just

doesn't work like that! Yes, you know, you'll walk into a room and see her

smiling and happy but you can't take that as an indication of actually what's

going on and that things are ok because it has no real significance at all".

1.3.5 Developmental Tasks

This theme presents changes in expectations resulting from progression along the developmental timeline which prompted differences to either emerge or become problematic. Some participants described how they made sense of their emerging sexual identity.

All participants identified the transition from primary to secondary school as a point where they felt that difficulties emerged. Some described being aware of differences at a young age but differences became problematic only when they reached adolescence. Others perceived no differences until adolescence and cited the changes in social expectations as the trigger for struggles. Adolescence brought about multiple major unspoken changes in social etiquette which confused participants. These covert changes seriously challenged participants' ability to both understand and abide by new social norms.

Emily: If they just decided "I'm gonna list a giant book of teenage girl etiquette so that ... every single teenage girl has to live to these standards" ... if only that happened ... I'd be able to interact with them in the right way.

Changes included peers developing interests and objectives which participants did not share. These changes, alongside increased social expectations in adolescence, sometimes led to friendship groups disintegrating around the participant, one-by-one, as members of the group became aware that the participant was not following the same direction as the rest of the members; the peer group were moving towards new interests and new ways of relating with each other, whereas the participant often retained her preferences of interest and interpersonal relationships.

The transition between schools led to the diagnosis of ASC for around a third of participants. Some cited the size of the school as problematic; it increased opportunities for triggering sensory distress and for tripping up over new covert rules. Extra demands were placed on the participants' socio-communication skills as they were expected to make new friends. When participants began to struggle to cope with these tasks, serious problems surfaced in terms of the expression of ASC core-deficits in socio-communication. Secondary mental health difficulties (e.g. affective disorders) often then emerged. The emergence of these core and secondary difficulties often prompted referral for professional support, which for six participants resulted in a diagnosis of ASC. Referral also led to support for affective difficulties, self-harm and social-skills training, for those who required it.

Interviewer: Can I ask ... why you got to age 12 before you were diagnosed?

Kate: Well that was because when I went to high school I got quite depressed because of all the stress and chaos that happened at high school.

Nadia's mum: All the way through primary [school], it didn't really matter to her too much whether she had a best friend or not ... she was monitored once and she was spotted going round to all the different groups and they'd rebuff her and she'd just go onto the next group. They felt that it didn't seem to bother her so much ... I think when she started secondary she was more aware ... that she couldn't keep a friend.

Stephanie: I think it was more a gradual realization ... I think that they just became more and more interested in things that I was less and less interested in and then I just realized that ... all the time I'd been pretending to be interested when I wasn't.

Interviewer: And what age do you think that you were when you started to realize that? Stephanie: I'd say at the end of year 7 when I moved schools.

During adolescence, the expression of sexual identity develops and four participants made reference to having sexual relationships. Two participants described themselves as bisexual and discussed their sexual minority status as being another defining marker in terms of differences to peers.

Joëlle: I wanna know... if... other teenage girls with Asperger's think the same way as me because I think like or identify with another gender ... sometimes, like I don't feel like particularly female occasionally or I feel like I'm not particularly attracted to one gender or anything like that and ... I've always wondered whether that's something to do with me personally or it's something to do with like every other girl with Asperger's.

1.4 Discussion

The aim of the study was to explore the experiences and management strategies of adolescent girls with ASC in social situations. The results are discussed in relation to the research aim and existing theory. Clinical implications, limitations and directions for future research are noted.

Participants recognised the emotionally-intimate quality of peers' female-to-female friendships and often found that they did not understand, and therefore could not abide by, the covert rules within these relationships. When participants broke these rules, they were identified as different and consequently experienced rejection. This, in combination with not adhering to gendered social expectations, led to participants feeling unable to fit into social situations. Participants' socio-communicative difficulties were a barrier to developing friendships as mutual misunderstandings made bonding difficult. Participants were motivated to have friendships; therefore, obstacles to making friends caused discomfort and distress. This issue was also noted by Cridland et al (2014), who identified the increased challenge during adolescence due to the growth in gender related factors within friendships such as fashion, dating, and sexual identity, increasing the complexity of negotiating dynamics of difference.

Most participants developed sophisticated strategies which utilised innate strengths and enabled them to appear socially-competent to observers. Participants often used masquerading strategies to hide/overcome obstacles to developing and maintain friendships, and manage socio-communication difficulties. This finding emerged from a small sample of self-selected participants so generalisation must be established by further research. However, within this group of participants, all individuals had developed methods which were designed to ensure that their ASC-core difficulties were not identified by others.

1.4.1 Secondary Impact of Coping

For the majority of participants, use of these strategies had negative repercussions on their psychological wellbeing and also possibly hampered access to support since their difficulties were hidden. There are subjective accounts from females with ASC (e.g. Craft, 2012) and from specialist clinicians (e.g. Attwood, 2006) which suggest that females with ASC are motivated and able to develop and use strategies to access social relationships. This study presents fresh insight into the motivation and methods adolescent girls with ASC employ in building these friendships and their subjective experiences of the consequences of using masking/imitation strategies.

1.4.2 ASC-Associated Difficulties

Core ASC-difficulties resulted in frequent peer-rejection and loneliness. This led a number of participants to develop secondary mental health difficulties which triggered referrals to CAMHS. This is consistent with studies which suggest that females with ASC may be referred to services due to either more severe social deficits or greater concomitant psychopathology than males with ASC (Hofvander et al., 2009). Aloneness has often been conceptualised as a characteristic preference of the ASC profile; however, as this study and others has shown, being alone may be an undesired consequence of a lack of social skills and understanding, and the emotion of loneliness is subsequently experienced (Jobe & Williams White, 2007).

However, social environments were hard for participants to tolerate. Difficulties with sensory distress and peer-rejection led many participants to endure multiple school-placements in an attempt to find an accommodating environment. Adapting to high school was recognised in Cridland et al's (2014) paper as a difficult period, but their accounts focussed more around the social and academic transition, and a lack of understanding on the part of the School. In contrast to the Cridland et al. (2014), in this study, participants

commented on the additional social complexity and they also highlighted the sensory overload which led to distress. Accounts of sensory distress in the younger ASC population are well documented (e.g. Stewart, 2012) and this study supports previous findings that adolescent females with ASC can experience frequent and intense sensory disturbances.

1.4.3 Gender-specific Challenges

Some participants described an ability to easily integrate with their peers during early childhood but factors around early adolescence (e.g. the transition to secondary-school; changes in social expectations) seemed to catalyse difficulties in the social abilities of participants. This led to alienation from peers, mislabelling of behaviours and often to a decline in mental health. This supports previous findings that adolescence presents ASC-females with demands which they struggle to meet, due to core ASC-deficits (e.g. Cridland et al, 2014; Gould & Ashton-Smith, 2011). This is a gender-specific difficulty; females with ASC face a different set of social expectations and norms to males with ASC (e.g. Wood, 2011). This, in combination with differences in symptom profiles between females and males (e.g. Rivet & Matson, 2011), presents unique challenges for females with ASC.

1.4.4 Limitations

Whilst the use of IPA may have facilitated exploration of this under-researched population, generalisation from this idiographic methodology has limitations (Willig & Billin, 2011). Nevertheless, triangulating findings from this study with other sources of knowledge gained from empirical and clinical experience increases the validity of the results (Hefferon & Gil-Rodriguez, 2011). Participants self-selected which may limit the experiences uncovered within the study. Whilst perhaps participants within this study may have been better able to articulate these issues than those who did not come forward, the research did reveal common strategies amongst the group which may well be relevant to the broader ASC-female population. However, it should be recognised that the majority of these

girls were higher functioning which might mean that they were able to detect, learn and engage in these social strategies to a greater extent that girls more severely affected.

The participants all had a diagnosis of an ASC; therefore, clinicians had agreed that the girl had met the male-based criteria necessary for diagnosis. Hence, there is an issue of circularity within the sample. The findings cannot be extrapolated out to all females on the spectrum as it is likely that there are many girls who have ASC characteristics but do not have a diagnosis. This study does not offer comparisons between males and females on the spectrum, and, given the small sample size, the findings cannot be used to support changes to current practice without further investigation. However, the results offer valuable information which may, in combination with other research (e.g. Cridland et al. 2014), support the need for further development of theories around gender differences within the ASC population and suggest further directions for research.

1.4.5 Clinical Implications

All participants identified coping strategies, especially in terms of techniques to mask their differences. This had benefits in terms of aiding social cohesion, but costs in terms of emotional energy and masking when support really is needed. Understanding the existence and use of such techniques allows clinicians and carers to recognise such strategies, 'look behind the mask', and provide balanced support, such that more helpful strategies are identified and supported. Exploration of the coping strategies of females with ASC has been identified as crucial in uncovering what may be hidden aspects of the ASC-female profile (Dworzynski et al., 2012). Whilst masking may have benefits to individuals with ASC, it may also be important to look at why many social situations are so impenetrable for people on the spectrum so that appropriate education and adaptive interventions can be developed to increase social accessibility to those who have such differences.

None of the strategies (e.g. masking, imitation) or characteristics (e.g. motivation to have friends) described by participants in this study are assessed for in ASC-diagnostic procedures. Current methods measure against a male characterisation of ASC yet much of the data here came from comparisons between the participant and TD-female peers. It is therefore suggested that there is a poor fit between current diagnostic procedures and the ASC-related difficulties described within this sample. As suggested by Lai et al. (2011, 2015), revisions to existing diagnostic procedures should give more focus to females and thus increase diagnostic equity between genders.

Participants clearly identified developmental points when their differences became problematic and hence it may be useful to adopt a gendered, developmental framework when assessing for ASC. Difficulties may only emerge when gendered and developmentally-driven demands exceed the abilities of the ASC-female (Hsaio et al., 2013).

Interventions which develop empathy through utilisation of meta-cognitive processes may be used to enable peer relationships. The use of drama classes is a good example used by the participants, allowing them to study social behaviour and perfect their 'social performance', undetected under the protective umbrella of an ordinary social activity. However, this needs to be balanced with a supportive environment which allows the individual to 'drop their act', as described by the participants, and express their needs in an authentic way.

1.4.6 Areas for Future Research

The majority of this sample was diagnosed with AS; future research might explore whether girls with more severe deficits and/or co-morbid difficulties employ similar strategies, or what happens if they do not have the capacity to employ such strategies. Further research may help understand how ability and/or awareness interplay with masquerading

strategies. Replicating this study with a larger group of adolescent males and females to draw direct comparisons may also be useful.

It is likely that current assessment instruments do not meet the needs of females with ASC. Future research into alternative male/female forms of assessment instruments, which also reflect the developmental demands and hence challenges across the developmental period may be useful.

1.5 Conclusions

In conclusion, the majority of females with ASC in this sample were motivated to have friendships. After facing frequent peer-rejection and experiencing their social environment as incommodious, they developed sophisticated methods of masquerading (i.e. peer-imitation/masking) in order to blend in with TD-peers. These findings imply that, as predicted by the EMB theory, females on the spectrum may have an innate social drive and social abilities which motivates them to devise strategies to overcome socio-communication difficulties. Such strategies could be at different times both helpful and unhelpful. A more gender-sensitive and developmentally-appropriate approach needs to be taken to provide adequate assessment and support for girls on the spectrum.

1.6 Acknowledgements

We thank those who participated in this study; the offering of their insights and experiences made this work possible.

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