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Autistic Women's Experience of Intimate Relationships: The Impact of an Adult Diagnosis

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Abstract

Purpose – The purpose of this study is to explore the experience of intimate relationships of women who have been diagnosed with Autism in adulthood.

Design/methodology/approach – Semi-structured interviews were used to interview eight participants. The data were transcribed and analysed using the interpretative phenomenological analysis method.

Findings – Four overall themes were identified. These included “Response to the diagnosis and receiving more information about Autism”, “Factors influencing dating behaviour”, “Sex and sexual experiences” and “Experience of intimate relationships as a person with Autism”.

Research limitations/implications – The results of this study have implications for both research and clinical practice as it highlights the areas in which women newly diagnosed with autism spectrum disorder (ASD) could benefit from support.

Practical implications – The study adds to the limited existing research on adult women with ASD.

Originality/value – To date no similar research has investigated the qualitative experiences of intimate relationships by women with ASD.

Keywords Women, Autism, Sexuality

1. Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder which is characterised by a number of symptoms described by the DSM - 5 (APA, 2014). The disorder is marked by deficits in social interaction and restricted patterns of behaviour or interests. The difficulties that autistic people have within a social environment are well documented throughout the literature (Tantam, 2000; Howard et al., 2006; Muller et al., 2008). Research indicates that despite their difficulties with interacting in the social world, many people with ASD are interested in establishing sexual relationships (Strunz et al., 2017).

ASD is a relatively new addition to the DSM and therefore many people with these difficulties only receive the diagnosis in adulthood. There is growing research into the experience of receiving a diagnosis of a neurodevelopmental disorder (Young, et al., 2008; Punshon, et al., 2009). Both Young et al., (2008) and Punshon et al., (2009) found that participants reported negative past experiences associated with having a neurodevelopmental disorder which they attributed to not having a rationale to explain their difficulties. In addition to this, receiving the diagnosis led to a complex emotional process. Both studies also referred to a dilemma participants experienced regarding disclosure of the diagnosis.

There has also been some research that highlights the factors influencing the experience of depression on the diagnosed person with ASD. In their study Cage et al., (2018) investigated the experience of mental health difficulties through a social model. They found that both internal and external factors influence the way an autistic person is able to accept their difficulties and in turn alleviate feelings of depression. Other research has also highlighted that the context and the reaction of others plays an integral part in an autistic adult's response to receiving a diagnosis of ASD (Punshon et al., 2009).

Autistic men and women might experience their diagnosis differently due to different societal and relationship expectations for the different genders. Sedgewick et al., (2018) found that it is gender, rather than diagnosis per se, that most dominantly influences the way autistic adolescents experience their social relationships. However the way autistic women engage with social relationships may differ qualitatively from men. Some studies (Bargiela et al., 2016; Lai et al., 2016) have highlighted that women tend to mask their difficulties more than men and that this can impinge on their emotional wellbeing and that this in turn may have consequences for their intimate relationships. Autistic adult women's experience of intimate relationships have not yet been researched. However, many anecdotal accounts on social media tell of women's experiences of trying to 'be more neuro-typical', consequently they only feel 'desirable when they're not themselves' (Tender, 2017).

Taking both the above mentioned research gaps into consideration, this research sets out to explore the experience of women who have been diagnosed with ASD in adulthood and the impact this has had on their intimate relationships.

This research aims to support clinicians in managing the potential responses individuals might have to receiving the diagnosis of ASD and how it may impact on specific areas of an individual's life. Thus assisting clinicians in providing appropriate information and post diagnostic support.

2. Method and Methodology

2.1 Participants

Participants were purposively sampled from two specialist ASD diagnostic clinics in London. Purposive sampling was done in order to identify those individuals that met the inclusion criteria. In addition, participants were also recruited through an advertisement in the National Autistic Society's (NAS) newsletter.

Inclusion criteria were as follows:

Women between the ages of 20 and 40. The age of 20 was chosen as the lower limit to allow for having adult experiences of intimate relationships. The upper limit age of 40 was chosen as it was hypothesized that women between 20 and 40 might be more homogeneous than those in a broader age range.

All of the women were in an intimate relationship or had experience of an intimate relationship. An intimate relationship for the purpose of this study has been defined as one where a person has been on several dates with someone and resulted in sexual activity; or had the potential of becoming a sexual relationship.

The women had received a diagnosis of ASD (in accordance with either the DSM IV or DSM V) within the last five years. This restriction on time since diagnoses, was made in an attempt to maximise homogeneity amongst the group.

To ensure that each of the participants had sufficient understanding of the English language and to enable dialogue with the current author, it was required that the women had received either secondary or tertiary education in English and obtained a minimum of one GCSE in any subject.

Furthermore, participants were excluded if they were seeing a doctor for an active mental health problem (excluding ASD and associated problems) at the time of data collection. This was to avoid exacerbating any

difficulties associated with co-morbidities and to ensure the results were representative of the experience of having ASD and not due to any co-morbid diagnosis.

The participants' demographic information is depicted in Table 1.

Table 1: Demographics of the participants

<i>Participant</i>	<i>Participant age at time of study</i>	<i>Relationship status at time of study</i>	<i>Participant's description of her sexuality</i>	<i>Children</i>	<i>Ethnic Background</i>
<i>Participant 1</i>	40	In a long term relationship for more than a year	Heterosexual	No	White British
<i>Participant 2</i>	26	In a new relationship	Heterosexual	No	White British
<i>Participant 3</i>	38	Single	Asexual	No	White British
<i>Participant 4</i>	24	In a long term relationship for more than a year	Bisexual	No	White British
<i>Participant 5</i>	37	Married	Heterosexual	Yes	White British
<i>Participant 6</i>	35	Single	Bisexual	No	White British
<i>Participant 7</i>	26	Single	Bisexual	No	White British
<i>Participant 8</i>	27	Divorced, currently single	Bisexual and 'demi-sexual'	No	White Other

Eleven potential participants met the inclusion criteria and gave informed consent to participate. Nine participants attended their interview appointments. Upon follow-up, one participant stated that she was of the opinion that she did not have ASD and therefore withdrew her consent. The final sample consisted of useable data from eight participants. The participants' demographic details are depicted in Table 1. All eight participants met the inclusion criteria which allowed for an ideographic analysis as well as the identification of

common themes. The verification of a formal diagnosis was possible for participants who were identified through diagnostic clinics. Participants who were identified through the NAS were asked to confirm that they had received a formal diagnosis from a clinician. In these instances, external verification was not possible.

2.2. Procedure

Data was collected by a single round of face-to-face interviews with eight participants. Interviews were held in various locations. These included: participants' home and university meeting rooms. Semi-structured interviews involving a series of open-ended questions were used to collect data. Questions included: What has been your experience of intimate relationships? What do you find difficult/challenging about intimate relationships? What do you find good/positive about intimate relationships? Has receiving the diagnosis of ASD changed the way you feel about intimate relationships? In what way do you feel different?

This type of interview and questions allow for a balance between consistency and flexibility (Smith et al., 2010). Consistency was considered important to support the provision of specific topics for discussion. However, flexibility was required to allow for the ideographic nature of the lived experience. The interviews lasted between 60 and 90 minutes.

After the interview participants were offered an opportunity to debrief. None of the participants required additional support after the interview.'

2.3. Analysis

This study utilised a qualitative research method with the aim to provide an in-depth description of the experience of women being diagnosed with ASD in adulthood in relation to their intimate relationships. The authors chose to underpin the analyses by a Constructivist Interpretative paradigm, as is frequently used in phenomenological and narrative research (Finlay, 2006). Furthermore, the authors employed an interpretative phenomenological stance as they acknowledged that the description of a phenomenon cannot delineate from an interpretation thereof (Willig, 2009). Consequently, multiple meanings can be attributed to the data depending on researcher's interpretation. From this epistemological stance the authors employed Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) to conduct the data analysis in.

The interviews were transcribed verbatim and anonymised. This was followed by using the IPA stepwise approach where researchers firstly become familiar with the individual narratives and aware of the interpretations that are made about it. Themes were then identified in individual narratives before finally identifying themes across participants. The final analysis of overall themes was done in collaboration with all the authors.

In addition, the analysis adhered to the principles for ensuring validity of the phenomenological account in qualitative research (Yardley, 2000, 2008). These principles were adhered to by providing specific examples from the raw data alongside any conclusion drawn. This allows for the reader to make an informed conclusion regarding the plausibility of the phenomenological account. Finally, following discussion between the authors, themes were identified based on the likely importance and relevance to aims of this study.

3. Results

The main themes were: Response to receiving the diagnosis and information about ASD; Factors influencing the decision to date; Experience of relationships as a person with ASD and lastly, Sex and sexual experiences. Each of these themes has several sub-themes. Whilst the major themes encapsulate the commonalities between all participants' accounts, areas of divergence emerged in the subthemes. The themes are depicted in figure 1.

Figure 1: Overall Themes and Associated Sub-Themes

3.1 Response to Receiving the Diagnosis and Information about ASD

All the participants spoke about their experience of receiving the diagnosis. It had relevance to the current study as it seemed to provide some context for how they engaged with intimate relationships.

3.1.1 Emotional reaction to the diagnosis.

Five participants spoke of their emotional reaction to receiving a diagnosis of ASD. The emotional reactions reported suggesting a possible continuum of emotional responses ranging from relief to grief, hopelessness and self-doubt:

“... this is a form of grief... one thing I find really gutting about the diagnosis, is for all I tried, there actually wasn’ t a hope of actually being able to do it” (Participant 5).

“...there’ s definitely been a lot of worry about getting it wrong, more since the diagnosis. There’ s a lot more sense of awareness... things that I might be wrong about ... kind of like... my instinct isn’ t right ...” (Participant 6).

“...it was a relief when I did get the diagnosis because it’ s like okay, I understand why I do this, this and this while everyone else does something different...” (Participant 3)

3.1.2 Self-reflection since the diagnosis.

Six participants spoke about how they viewed themselves since receiving the diagnosis. Five of them described how they had developed a greater sense of self-acceptance and confidence as a result of receiving their diagnosis:

“Yeah... [since the diagnosis] I’ m more comfortable with who I want to be and who I am... and I can like say to people if they say something that isn’ t very nice - give a reason to them for why I am the way I am” (Participant 3).

Consequently, some participants reported that the acceptance of themselves had a positive influence on their interpersonal relationships. This seemed to be through a process of being less self-critical:

“I sort of... before the diagnosis I wouldn't even entertain the possibility [of having a relationship], it was just no, life is too hard, my brain is working too hard already. Having someone that close, no, that's not gonna happen. And then, I got the diagnosis and it's like, ok then you can talk. I don't have to be turned on all the time. It is ok to say I'm overwhelmed and if it's ok to say those things then maybe it's ok to maybe think about maybe in the future there might be someone I can just be me with” (Participant 7).

3.1.3 Improved understanding of themselves.

Participants described how having an improved understanding of themselves, as a result of their diagnoses, allowed them to explain to others the reasons behind certain interpersonal behaviours with the aim of maintaining their relationships:

“...but I have warned him: if I want to be on my own, if I don't want to talk, it's not a comment on you - it's a comment on me needing rest... away from people but because it may be misinterpreted as not wanting to be around or a personal comment on him - and it is not. Or, if it was, I would let him know. It's kind of... it's all a bit much to handle” (Participant 2).

3.2 Factors Influencing the Dating Behaviour

Participants reported on their reasoning behind dating and the factors that influenced their decision. All eight participants shared their thoughts on dating.

3.2.1 Reasons for dating.

Four participants explained that finding someone interesting or attractive would be a reason to date them. This seemed to capture physical as well as intellectual attraction and a sense of shared interests. In addition participants spoke about valuing having companionship:

“... [enjoys being] just being around their personality, I can find their personality really interesting, really funny, really sweet... it can make me think a lot about things in a good way rather than this sort of conflicting challenging way... and then there's the thing that sometimes they're just pretty to look at” (Participant 6).

“I would be less lonely in an empty flat a (Participant 4).

Four of the participants reported that they experienced a social expectation that they should be dating.

Participant 4 even went so far as to fabricate a relationship in order to prevent other people from discovering that she in fact, did not have a partner. Her giggling while talking about this suggested that she was aware this could be perceived by others to be strange:

“But I didn’ t want anyone to know [that she did not have a partner]. I pretended to have an imaginary boyfriend - and people would say: now why haven’ t we met this man, and I would say he’ s very busy [giggles] - but I invented him” (Participant 4).

3.2.2 Reasons for not dating.

Five participants reported a number of reasons for not engaging in dating. This covered a number of factors that they felt made it difficult for them to date..

Three participants reported experiencing some doubts regarding their ability to determine whether or not someone was interested in an intimate relationship with them. This led to feeling apprehensive about dating:

“I am a bit slow on the uptake... like walking away I was thinking he was actually trying to chat me up, maybe ... I would know... occasionally. It’ s not the sort of thing I am good at... some missed opportunities I guess” (Participant 2).

Another barrier to dating that emerged from two interviews, was that dating was considered to be a lot of effort. This appeared to have made some participants fearful of dating and consequently avoiding it:

“I just didn’ t get involved... cannot understand it - it’ s like a ritual I do not understand... don’ t get the ground rules... don’ t know how it works... therefore cannot play along ... to me it looks like an awful lot of hard work and hassle to figure it out... I could probably be better off with a book!” (Participant 5).

Some participants reported that they did not understanding the nature of dating and therefor avoiding it:

“... It's like watching a TV show and having the soundtrack of something else. It's meant to be this one thing, I've put this thing on specifically because I want to watch this thing but I'm getting a soundtrack of something else...” (Participant 7).

3.2.3 Disclosing the diagnosis to potential partners.

Participants spoke about disclosing the diagnosis to their partners or potential partners. They spoke about how doing so influenced factors, which had an effect on their dating behaviour.

3.2.3.1 Reasons for disclosing the diagnosis.

One of the main reasons given for deciding to disclose their diagnoses involved supporting others to understand and accept some of the difficulties which the participants faced. The participants quoted below seemed to feel that an improved understanding or insight into the cause of their difficulties could help a partner or potential partner to accept and or better understand them:

“It [disclosing the diagnosis] gives a reason for why: why are you the way you are. So it helps them to understand you. If they are going to walk out on you because of your Asperger' s, they are not worth having in anyway. Warts and all” (Participant 1).

Four of the participants described feeling obligated to disclose their diagnosis to others. The need to disclose appeared to reflect a value judgement suggesting a belief that transparency is an important quality in a relationship:

“I suppose it is like buying a house or a car - you want to know what the problems are with it before you choose to make a decision about it rather than discovering something later along the line” (Participant 2).

3.2.3.2 Concerns about disclosing the diagnosis.

Five of the participants raised concerns relating to the disclosure of their diagnosis and associated behaviour.

“Actually I don’ t tell him everything because some stuff I do... I find embarrassing” (Participant 2).

“A little bit scared. I think Autism still has this really big stigma so that if I tell someone that I’ m Autistic - they like just think of someone who can’ t communicate... yeah, I think that’ s like a really bad portrayal” (Participant 3). I was kind of worried that he wouldn’ t understand what it was or he’ d think I was just this kind of person who would just sit in the corner and like rock because I wouldn’ t communicate and this was like no, it’ s really not like that” (Participant 3).

One participant explained that she was apprehensive about disclosing her diagnosis as potential partners might shy away from the prospect of establishing a long term relationship, and the possibility of having children together due to the genetic risk involved:

“... because I guess you kind of see it through a disability kind of lens and people think: maybe if I was to have children with this person, would they also have Asperger’ s Syndrome and I think it’ s that kind of thing that can go on in people’ s heads. You then don’ t get a chance for them to sort of know you because of that but yeah, I guess that’ s why I want it to be out there...” (Participant 8).

3.2.3.3 Experience of actual disclosure.

Some participants described their experience of actually disclosing their diagnosis of ASD within intimate relationships. Their disclosure evoked different reactions such as acceptance and being more accommodating to feelings of disappointment:

“... uhm... he was like okay... that’ s fine... that’ s not a problem... that’ s like part of you and I like all of you, so... I like that too...” (Participant 3).

“...I think he was really disappointed because I think for years he thought if I work hard enough on this girl, I’ ll get her to change and then he realised that wasn’ t ever going to happen” (Participant 5).

“...and then I told him... I could see that wall come down. It was like I was now off limits... it was like, it was like I suddenly told him I had the plague. It was like, ok, you're cool to talk to and everything but no...It was an ok thing to maybe consider dating the quirky girl but dating an autistic girl is not ok” (Participant 7).

Four participants elaborated on the responses that they had received by talking about how both parties attempted to accommodate each other's needs and perceptions. For example, Participant 3 described how her partner supported her in managing social situations where she was uncomfortable or struggling:

“...He knows exactly what to do and he knows like if other people are saying like inappropriate things, he can tell if I'm uncomfortable and he'll like take me out of that situation” (Participant 3).

3.3 Sex and Sexual Experiences

All eight participants spoke about sex although they reported on this in different ways.

3.3.1 Sexuality.

All eight participants spoke about their sexuality. Some reported being heterosexual while others identified as being bisexual. Two participants described themselves as being on an a-sexual continuum. They reported that their lack of interest in sex limits the possibility of them engaging in relationships:

“... I was born without sexual feelings... Nobody's going to have a non-sexual relationship - everyone has sexual feelings... I'm in the minority” (Participant 4).

3.3.2 Difficulties relating to sex.

Some participants talked about difficulties that they had encountered regarding sex within their intimate relationships. Some participants inferred that they found the spontaneous nature of a sexual encounter challenging:

“...that can be quite awkward... the sort of need of... awkward clarification... in advance... and it's a lot of trial and error as well, which can mean that the first time or the first few times, it can be really... almost like um... watching an embarrassing comedy...when it comes to sex the map is a lot less clear...” (Participant 6).

Another participant was concerned that her partners might misinterpret some of the coping strategies she had or managing her sensory difficulties during sex;

“Like the sensory sensitivity kind of things... skin against skin contact could be quite unpleasant ... sometimes trying to put a sheet or pillow between me and the other person... and it gets kind of interpreted as a sort of rejection... or just I think probably what bothered me a bit more was the idea that they thought that I was weird ...” (Participant 8).

A participant reported that she and her partner had different ways of approaching sex and that she struggled to understand his approach in these circumstances:

“We’ d sort of do this, spend ages just touching one another and enjoying the atmosphere and... well, I don’ t see the point in wasting loads of time doing that” (Participant 5).

3.3.3 Negative sexual experiences.

Four participants talked about how they had been sexually taken advantage of or exploited in the past:

“...he was able to manipulate me... and kind of made me do things that I wouldn’ t otherwise have done. And when I look back on that, it was a massively, incredibly exploitative ...” (Participant 8).

One participant described feeling objectified by a past encounter and that she did not know how to respond to this feeling:

“He was treating me like some kind of possession or something! I was mad at him. I felt like I was a cream cake he was looking at - drooling ...I didn’ t know how to respond so I just kept my mouth shut” (Participant 1).

3.4 Experience of Relationships as an Autistic Person

This theme aims to capture the participants’ experiences of being in relationships and how they perceived this as being linked to ASD.

4.4.1 Challenges experienced in relationships.

All eight participants spoke about a wide range of difficulties which they experienced in their intimate relationships.

4.4.1.1 Difficulty in understanding partners.

One of the pertinent difficulties that the participants and their partners shared was related to the incompatible ways of expressing care towards one another. This seemed to hold implications for the sustainability of their relationships:

“... [referring to the difficulties in relationships] like learning that I don’ t want to hug all the time... yeah... it definitely was tricky because...if I was particularly upset, I just kind of wanted my own space and because I was upset, he would want to hug me and like try to make me feel better but that would make me feel worse.”

(Participant 3).

Some participants spoke about finding it difficult to hold in mind that others might perceive a situation different to themselves:

“But I suppose not being able to work out if somebody else might be reading the situation different to you, is something I could think about quite theoretically now. So I can say to you yes, even I think this is going on but that does not necessarily mean that they have the same interpretation of the same situation that I do. But I think actually in that situation I would find it very hard to have the kind of theory of mind to have that awareness”

(Participant 2).

Some participants found it difficult to hold in mind that their partners might not share their interests and have been depicted in the descriptions provided by the participants below. These participants seemed to suggest a sense that they potentially had little control over the direction of their attention at any given time. This was especially challenging when coupled with an awareness that their partners could find this difficult, particularly when they (the partners) expected to be the focus of attention:

“So like the biggest kind of thing that would affect our relationship in the beginning is that if he was talking to me and I saw a dog, I would like completely blank him out and just be all consumed by the ... he used to really get upset ...” (Participant 3).

4.4.1.2 Managing the spontaneous nature of a relationship.

Five participants highlighted being aware they had a need for clear rules and consistency in their lives, and talked about how this created difficulties in relationships when they expected that others would follow with these rules:

“I like to see them as requests but people see them as rules and see me as very demanding” (Participant 4).

Some participants described that the need for structure and routine extended to less tangible areas such as conversations with others:

“We talked about things we have in common, common interests... it’s easier for me to talk about things rather than just kind of... I don’t know... chat” (Participant 2).

Four participants found it difficult that not all intimate or dating relationships follow a similar pattern or set of rules. Some appeared to suggest that they experienced some level of anxiety as a result of the lack of rigid structure and rules for dating relationships:

“... I don't do change at all! It's just no. It doesn't work, it's like it should be a, b, c, d. If you go from a to d and miss out b and c, my brain shuts down. And when you're in relationship, it's... often times it's unpredictable and it doesn't follow rulebook and ... there is no pattern, there is no continuity and it's just... no...” (Participant 7).

The effort it took to engage in a socially effective manner was highlighted as a factor that impacted on participants’ relationships. Participants talked about a need for respite after interaction due to the strain of needing to consistently and actively assess interactions whilst engaging in social activities. This experience is likely to have implications for the sustainability of their relationships.

“... there’s a sort of weird kind of a thing that goes on where like that self-focus and the loneliness are almost kind of part of the same thing... why have this incredibly strong almost addictive like drive to be by myself, and yet feel this like enormously crushing loneliness at the same time... I just don’t understand how they kind of can be reconciled... it’s kind of being pulled into two directions at once...” (Participant 8).

4.4.2 Concerns regarding the future of relationships.

Three participants spoke about their concerns regarding the natural progression of intimate relationships. They appeared somewhat nervous about how they might cope in situations where others may become dependent on them or where their relationship shifts to a higher level of intimacy or inter-dependency:

“... whereas pair [implying intimate relationships and not friendship or familial relationships] relationships where it’ s all equal and you look after each other - I’ m not very good at looking after someone else, I’ m afraid. So, no it would not work.” (Participant 4).

Another talked about how in the initial stages of her relationships she was able to hide her difficulties from a partner. However, as the relationship progressed she felt this had become more challenging:- “...when you are seeing somebody about once a week and he lives about 40 miles from here, you can kind of present a sanitised version of yourself, you could reign it in” (Participant 2).

Some of the participants also described concerns that they would end up co-habiting with an intimate partner:

“Nobody can live with me - I’ m intolerable” (Participant 1).

Another area, which concerned some of the participants, was their perception that intimate relationships would move to a point where they might be expected to think about having children. The participants concern seemed to be underpinned by anxiety about their abilities to parent:

“I don’ t not want to be a parent, though I don’ t feel any particularly strong urge to be a parent. I mean, I like children but I am not sure I can cope with them” (Participant 2).

4.4.3 Positive aspects of relationships.

Seven participants spoke about a number of areas they enjoyed in their intimate relationships.

Some participants spoke about the activities they enjoyed doing with their partners. These included: watching movies, going to the pub, treating each other, communicating on social networking websites, giving one another gifts, and listening to each other.

Some participants suggest that activities could acquire meaning when experienced alongside a partner or potential partner:

“you get to share (activities) that with one another and it means that the world is twice as big, twice as colourful, twice as detailed...” (Participant 6).

Two participants describe their experiences of successful intimate relationships as though they were not a given in life, rather they considered these were an achievement despite their difficulties:

“When it all works it's amazing and it feels great and I feel really good about myself, it's like 'look I have a personal connection to the other living being'. I can do it like everyone else can. I can have this like everyone else can. I am not that abnormal that I cannot form a simple connection to another person. I can do this! I imagine it's what winning the lottery feels like” (Participant 7).

4. Discussion

Participants reported a range of responses when receiving the diagnosis and information about ASD. This could be attributed to the tension between becoming aware of specific difficulties and yet, not necessarily being able to use this insight to better navigate their social worlds (Hill & Frith, 2003). It is also possible that their reaction could have been dependant on the meaning they attributed to the diagnosis, similar to the emotional responses of participants with ADHD in the study by Young et al., (2008). No data was collected about the nature of the post diagnostic support the participants had received. However, it is likely that this kind of support, particularly support in accepting their difficulties, could have impacted on participants' emotional experience (Pahnke et al., 2014, Cage et al., 2018). Participants' reactions may also be due to them commenting on different homo and hetro-sexual relationships. It is likely that these types of relationships could differ qualitatively, as there might traditionally be different social expectations for women in homo-sexual relationships than in heterosexual relationships.

Congruent with recent research (Strunz, 2017), most of the participants expressed a wish to date and be in an intimate relationship. Only two participants stated that they preferred not to have a partner, because of a perceived lack of confidence in their ability to establish and maintain intimate relationships. This is consistent with the findings of Sperry & Mesibov (2005) who noted that a difficulty with social and emotional

understanding can compromise participation by people with ASD in more intimate relationships, including marriage.

Most participants found that they could explain their difficulties to their partners. However, their partner's responses varied which seem had implications for the sustainability of their relationship. This is an important consideration in light of the findings of Dindia & Timmerman (2003) who reported that the disclosure of personal information to a partner was a strong predictor of relationship satisfaction. Some individuals were strongly in favour of disclosing the diagnosis to their partner, whilst others felt it was not useful to disclose. It is hypothesised that the reasons for deeper levels of self-disclosure and the timing of this, are likely to relate to a sense of social intuition within the relationship - which perhaps is not as easy for individuals with ASD (Baron-Cohen et al., 1985; Tantam, 2009). Therefore, people with ASD might have difficulties in assessing when might be the best time to disclose.

All the women spoke about sex during the interviews. The variety of responses made it difficult to draw specific inferences and it is unclear as to whether this is different from what would be found if discussing relationships with women without ASD.

Participants spoke about experiencing some difficulties during sex which included finding it 'awkward' or needing to accommodate for sensory difficulties experienced during the sexual interaction. This is perhaps to be expected given that sensory sensitivities are common to this population (Bogdashina, 2013).

Some of the women reported having had negative sexual experiences. Their evaluation of these experiences was often made in hindsight. This is a similar pattern to what might be reported by some victims of sexually abusive experiences (Moore & Brown, 2006). However, it could be hypothesised that the struggles individuals with ASD have in reading situations and understanding communication, may increase their level of vulnerability. This is perhaps consistent with Muller et al., (2008), participants spoke about having difficulties in understanding a partner's intent and acknowledged their tendency to not consider both verbal and non-verbal communication. There has been growing research indicating that Autism can increase the risk of women being sexually abused (Cridland et al., 2014, Barbiela et al., 2016).

Despite the aforementioned difficulties, some of the participants in the current study demonstrated an understanding of, and ability to reflect on subtle social interactions. Their difficulty often seemed to stem from

being unsure about how to respond to, or accurately interpret these subtle non-verbal communications - rather than a lack of awareness that they existed.

Participants spoke about other difficulties in managing intimate relationships caused by the spontaneous and idiosyncratic nature of relationships, as well as the absence of a specific set of ‘rules’. This is perhaps consistent with Muller et al., (2008), who found that participants spoke about having difficulties in understanding a partner’s intent and acknowledged their tendency to not consider both verbal and non-verbal communication.

When describing their experiences within intimate relationships, some of the participants talked about activities and communication with their partners that may be suggestive of enjoying the element of reciprocity. On further analysis, it tended to be the participants who had been in long-term relationships and who had disclosed their diagnoses, who spoke about these elements of reciprocity. All the aforementioned may suggest that, where difficulties are better understood and strategies are developed to accommodate these, individuals with ASD are afforded improved chances to develop reciprocal intimate relationships. Further research would be required to explore this.

Some of the participants appeared to demonstrate some apprehension as to remaining in a relationship long enough to allow the above process. In these cases, the participants appeared to describe a sense of concern as to how they might manage the natural progression of relationships and the degree to which they may need to conceal their difficulties. The extent of this experience is perhaps more pronounced in women who camouflage or conceal their difficulties more than men might (Lai et al., 2016). The current findings echo existing research which highlight the negative impact camouflaging has on the well-being of the autistic person (Cage et al., 2018). Participants’ attempts to conceal their difficulties could go unseen and potentially unaccommodated for, which in itself could have re-enforce their belief that relationships are too hard work.

5. Implications

The findings indicate a benefit in providing post-diagnostic counselling with a specific focus on intimate relationships, both for individuals who are in relationships and those who want to pursue relationships. This should aim to include elements designed to increase insight into the likely challenges they may face, making sense of past relational difficulties, preparing for and developing/practising skills likely to be useful in the

initiation and maintenance of intimate relationships. Input may also help individuals with ASD to come to accept some of the inherent difficulties and paradoxical feelings they may experience (Pahnke et al., 2014).

Although there is limited research available it seems that in some instances, couples counselling might be helpful. The findings suggest that receiving the diagnosis seems to impact on the dynamic of the relationship, which will be an area of the relationship which might be particularly difficult to manage for someone with ASD. The quality of this experience might differ between homo and heterosexual relationships, however further research will be needed to verify this hypothesis.

The findings indicate a need to support women with ASD in how to manage their sexual interactions. This could include support on how they both protect themselves and communicate their difficulties in this area in a helpful way to a partner. Sensory difficulties, negative past experiences and difficulties inferring the spontaneous nature of sexual interactions could impact on an individual's sexual identity. Further qualitative and quantitative research is needed to gain a better understanding of the sexual identity of people with ASD and if it is different to the neuro-typical population group.

Finally, it is important to note that the sample consisted of only white western women. It would be interesting to investigate how the diagnosis of ASD could impact on the intimate relationships of women from different cultural groups.

6. Conclusions

The findings from the current study suggest that difficulties relating to ASD, and the meaning participants assigned to the diagnosis, has an impact on the nature and the sustainability of their relationships. Some individuals may therefore benefit from post-diagnostic counselling with a specific focus on intimate relationships.

7. Ethical Considerations

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Ethical approval was granted by a NHS Research Ethics Committee (Cornwall-Plymouth NRES Committee) and Middlesex University.

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