Young women's experiences of having Autism Spectrum Disorder

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name:

Date:

Overview

This thesis focuses on the experiences of high-functioning young women with autism spectrum disorder (ASD). **Part 1** reviews the research literature on relationships and sexuality in adolescents and adults with high-functioning ASD (HF-ASD). There is evidence that individuals with HF-ASD are interested in engaging in sexual behaviours and relationships. However, research suggests that autistic traits may affect satisfaction or access to such experiences. Clinical recommendations to support HF-ASD populations include tailored sexuality education programmes for adolescents. Training is also required for professionals to deliver the appropriate support to the parents of individuals with HF-ASD.

Part 2 reports on a qualitative study applying Framework Analysis to narratives elicited from fourteen young women with high-functioning ASD. Semi-structured interviews highlighted experiences specific to being a young female with ASD, including delays in getting a diagnosis, vulnerability to abuse in relationships and compensatory strategies used in social situations. Challenges specific to females with ASD were singled out for discussion, as were clinical implications such as the need to increase medical and educational professionals' knowledge of female ASD and suggestions for future quantitative research.

Part 3 discusses some of the advantages and challenges of using a qualitative research approach with individuals on the autism spectrum and how the study findings might affect service provision. Qualitative enquiry was particularly useful to identify themes that might be explored in studies with larger populations, as well as to provide findings leading to the design of quantitative tools. Regarding service implications, GPs and teachers were the two main professional groups by whom many women felt that they had been misunderstood. Developing professional training to raise awareness of female ASD could help with early identification in school and clinical settings.

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Part 1: Literature Review

Sexuality in adolescents and adults with High-Functioning Autism Spectrum Disorder

Abstract

Aim

This systematic literature review on sexuality and autism explored the existing knowledge on sexual behaviours, knowledge and experiences in high-functioning adolescents and adults on the autism spectrum.

Method

A comprehensive search of the PsycINFO and Ovid Medline databases was conducted. Hand-searched items were also included. Only studies published after 1994 in peer-reviewed journals written in English were selected.

Results

Seventeen articles meeting selection criteria were reviewed and discussed. The information gleaned from the studies was organised according to three domains: sexual behaviours, sexual selfhood and sexual socialisation.

Conclusions

Sexuality in autism is an understudied research area, with especially few studies exploring the experiences of young people and adults with high-functioning autism. The majority of the literature described sexual behaviours and the roles that carers, peers, professionals and parents play in providing sexuality education and information. The literature on intimate relationships is limited but provides insight into challenges in initiation of partnerships as well as the effect of autistic traits. Further research is required to understand barriers to sexual knowledge and the development of autism-specific sexuality education programmes.

Sexuality in adolescents and adults

with High-Functioning Autism Spectrum Disorder

Introduction

A diagnosis of autism spectrum disorder (ASD) relies on the presence of deficits in social interaction and communication, repetitive behaviours, unusually narrow interests and sensory sensitivities (APA, 2013). In the past two decades the application of the ASD diagnosis has expanded to include ever more individuals with milder atypical presentations and without a learning disability (LD). Indeed, these individuals represent a majority of those with an autism diagnosis with 69% either in the borderline range (IQ = 71 – 85) or the average/above average range (IQ >85) of intellectual ability (Centre for Disease Control, (CDC) 2014). The change in how autism is defined and applied is also reflected in the rising prevalence estimates, with recent high-quality studies returning rates of 1 in 100 (Baird et al., 2006) and 1 in 68 (CDC, 2014). Individuals with a diagnosis of ASD without a LD are referred to as having 'high-functioning autism spectrum disorder' (HF-ASD) and have fluent language and cognitive abilities outside of the LD range (Sanders, 2009). However, due to other autism-related deficits, such as social communication difficulties, they can still experience significant challenges in daily living and functioning (Mandy, Charman, Puura, & Skuse, 2014). In this literature review, HF-ASD[1] will be used as a basic overall term to describe high-functioning individuals with ASD.

Over the past five decades some aspects of ASD, such as its genetic basis and cognitive effects, have been extensively explored whilst other areas have received relatively little attention (Pellicano, Dinsmore, & Charman, 2013). Overall, research has tended to focus on basic science, with less consideration of the day-to-day concerns that impact on the quality of life of people with ASD. One such

[1] The terms HF-ASD and HFA will be used interchangeably throughout this literature review to describe high-functioning autism.

neglected area is sexuality and intimate relationships. Only recently have studies explored the relationship experiences of individuals with HF-ASD (Byers, Nichols, Voyer & Reilly, 2013; Renty and Roeyers, 2007) as well as issues of sexuality education that cause parental concern (Stokes & Kaur, 2005; Stokes, Newton & Kaur, 2007). The idea for this review came from the author's consultation with the autism community as part of a broader project on gender and ASD and it was identified that sexuality in autism was being neglected in the literature and seen as important to review for a number of reasons.

Firstly, experiences of sexuality are a normative part of human development and wellbeing, irrespective of whether a developmental disorder such as HF-ASD is present (Tolman & McClelland, 2011). Therefore, it is important to understand what factors might enable or prevent individuals with HF-ASD from having positive sexual experiences. Whilst it is acknowledged that individuals with HF-ASD are involved in relationships (Byers, Nichols & Voyer, 2013a) there can also be barriers that impede access to sexuality knowledge, such as social interaction deficits (Brown-Lavoie, Viecili & Weiss, 2014). Reviewing the research will provide a clearer illustration of sexuality experiences in individuals with autism and identify areas where they thrive or require further support as they develop into adulthood.

Secondly, the researcher aims to review studies where the majority or all of the participants have a diagnosis of HF-ASD. Previous literature reviews have included studies with both HF-ASD and LD populations but it is argued that the sexual experiences, knowledge and attitudes of lower functioning individuals on the autism spectrum cannot necessarily be generalised to those with HF-ASD. Further, early research on autism and sexuality involved adults with autism living in institutions as opposed to community settings and many tended to have a focus on unusual aspects of sexuality, for example deviant behaviours or fetishes (Haracopos & Pendersen, 1992; Ruble & Dalrymple, 1993). Whilst it is likely that such behaviours may have been a by-product of lack of access to sexuality education or

appropriate teaching of social behaviours, there is also a possibility that level of intellectual functioning could also have contributed to these differences.

Thirdly, reviewing the sexuality literature also has clinical and educational implications. By gaining an overview of the sexuality needs of HF-ASD individuals, researchers can then use this knowledge to develop specific and evidence based clinical and educational interventions. For example, developing a programme for parents or carers who wish to discuss sexuality with their child or providing a therapeutic model to be used for couples where one partner has HF-ASD. The current paper aims to highlight some of the challenges in the domain of sexuality that may be present in HF-ASD populations and how these might be addressed in clinical and educational contexts.

Fourthly, studying sexuality in HF-ASD is a new research field and therefore a systematic review is useful in order to identify the findings of the studies that have been carried out thus far, and to orient and focus future research. As such, four reviews have been carried out on ASD and sexuality (Dewinter, Vermeiren, Vanwesenbeeck & van Nieuwenhuizen, 2013; Gougeon, 2010; Koller, 2000; Rosqvist, 2014) including experiences of both high and low functioning ASD (Dewinter et al., 2013), sexuality education in adolescents (Koller, 2000) and adults (Gougeon, 2010) and a review of articles from a Swedish autism advocacy magazine (Rosqivst, 2013). However, none of these reviews have been systematic in their approach or selective in their target population. This paper aims to provide a review of the sexuality literature exclusively focussed on the experiences of people with HF-ASD.

Tolman and McClelland (2011) proposed a model of sexuality that highlights the developmental nature of sexuality development and what it means to become a healthy, sexually aware adult. They place a particular emphasis on the normative aspect of sexual identity development, as opposed to more common themes of risk that tend to be narratives more often used in adolescent sexuality literature. Their

paper focuses on three main domains considered to be important in normative sexual development. These domains will be used as an organizing structure in this review as they offer a parsimonious, internally consistent model of the diverse constructs and experiences encompassed by 'sexuality'. The domains are *sexual behaviour,* focussing on the behavioural repertoire related to sexuality, solitary or in relation to others; *sexual selfhood*, seen as the internal development of people including knowledge, attitudes, identity and ideas on the self as a sexual being; and *sexual socialisation* which discusses the different contexts (home and parents, peers, school, partners, Internet) in which people learn about relationships and sexuality.

Literature Review Questions

This review aims to address the following questions:

1. What sexual behaviours are individuals with HF-ASD engaging in?
2. What aspects of sexual selfhood are individuals with HF-ASD exploring and aware of?
3. What sexual socialisation opportunities do individuals with HF-ASD have access to?

Method

Search Strategy

In order to identify relevant studies that satisfied the inclusion criteria, PsycInfo and Ovid Medline databases were searched using the following terms and their synonyms in the keywords: (1) adult and adolescent (2) autism spectrum disorder (3) sexuality (4) relationship. The search terms selected were based on keywords from relevant papers. Studies that involved reporting of particular sexual acts or deviant behaviours were not included in the final selection as this was not the focus of the literature review.

Inclusion Criteria

The review included studies meeting the following criteria: (1) the target population were adults and adolescents diagnosed with an Autism Spectrum Disorder (2) the majority of participants did not have a learning disability in addition to their autistic disorder; studies were only included if the paper discussed high-functioning and low-functioning findings separately (3) the article discussed either sexuality, sexual knowledge or intimate relationships (4) the study was published in a peer-reviewed journal (5) the study was written in English (6) the study was carried out after 1994 when the diagnostic construct of Pervasive Developmental Disorder (DSM-IV) was introduced, which corresponds closely with current diagnostic conventions for ASD (Huerta, Bishop, Duncan, Hus, & Lord, 2012).

Table 1. Search Terms used in PsychINFO

	Searches	Results
1	(adult* or adulthood or adolescen*).mp	5729947
2	(autism or High-Functioning autism or ASD or developmental disability or autism spectrum disorder or Asperger Syndrome).mp	62012
3	(sexuality or sexual behavio* or sex education or sexual orientation).mp	141553
4	(romantic relationship or relationship satisfaction or relationship well-being or double ABCX model).mp	6051
5	1 and 2	19911
6	3 or 4	147009
7	5 and 6	160
8	Remove duplicates from 7	145

Results

The PsycINFO and Ovid Medline search identified 145 studies. An additional four papers were identified through hand searching – these were literature reviews related to sexuality and ASD (DeWinter, et al., 2013; Gougeon, 2010; Koller, 2000; Rosqvist, 2014). Abstracts of all the studies were screened according to the

inclusion criteria cited above. Seventeen studies met the six inclusion criteria. Eleven of these 17 studies were published in the last five years (between 2010 and 2015) – showing an increase in research interests on sexuality. Of the 17 study samples, ten consisted of adults with HF-ASD, five of parents or caregivers of adolescents or young adults with HF-ASD, one of adolescents with HF-ASD and one of paediatricians who care for families with a child with ASD. However, it is important to note that of the parent samples, three were asked to give their views of sexuality on behalf of their adolescent child with HF-ASD. Questionnaires were the favoured data collection method, with 12 studies using quantitative questionnaires, and one using qualitative analysis. Of the remaining four studies, two used semi-structured interviews and two used focus groups. The studies using self-report methods focussed on HF-ASD individuals' accounts of sexual behaviours and knowledge and their experiences of sexual relationships. The parent and carer studies mainly focussed on their concerns on how to communicate sexual knowledge to their children with HF-ASD and their beliefs about the sexual behaviours that their adolescent child engaged in. The study from a paediatrician's perspective also discusses concerns around sexual knowledge and providing appropriate information on sexuality to parents and young people with ASD. A measure of study quality was not appropriate for this type of review, given the wide range of methodologies used in the reviewed studies.

Sexual Behaviours

Research on observable sexual behaviours reported by adolescents and adults with HF-ASD and their carers is examined in this section. This includes solitary sexual behaviours, sexual behaviours in relationships and the impact of autistic traits on couples in relationships.

Solitary sexual behaviours

Solitary sexual behaviours are defined as masturbation and practising sexual acts alone. Most individuals with HF-ASD engage in solitary sexual behaviours, as evidenced from studies since 1994 using self-report (Byers et al., 2013; Dewinter et al., 2014; Konstantareas & Lunsky, 1997) and carer and parent report methods (Hellemans et al., 2007; Stokes & Kaur, 2005). Research using self-report methods is considered first. An early residential study by Konstantareas and Lunsky (1997) compared sexual behaviours in 16 adults with autism to 15 adults with a learning disability. They found that three quarters of adults with autism reported solitary activities such as masturbating and tended to 'endorse' more sexual behaviours compared to residents with a learning disability. A more recent online survey by Dewinter and colleagues (2014) compared sexual behaviours in 50 adolescent boys with ASD and 90 boys without ASD. Similar to earlier findings, males with ASD were found to engage in solitary sexual behaviours at a frequency that was comparable to their age matched controls. Almost all boys with ASD reported masturbation (94%) and had experienced an orgasm (90%). Gender differences in reported solitary sexual activity and wellbeing were reported in the literature. Byers and colleagues' (2013*a*) study of 61 men and 68 women with HFA living in the community assessed psychological functioning, autism symptoms and sexual functioning using an online questionnaire. Building on findings by Konstantareas and Lunsky (1997), both HFA men and women were found to engage in solitary sexual activities, with 33.3% of women and 77.8% men reporting having masturbated. However, females also described having fewer sexual thoughts, lower sexual desire and genital activity compared to men, who reported greater overall solitary sexual wellbeing (Byers et al. 2013). When compared to rates of sexual activity in the general population, the same gender differences apply, suggesting that HF-ASD populations may not differ in their rates of self-reported solitary sexual behaviours (Peterson & Hyde, 2010).

Figure 1. Flow Diagram of Literature Search

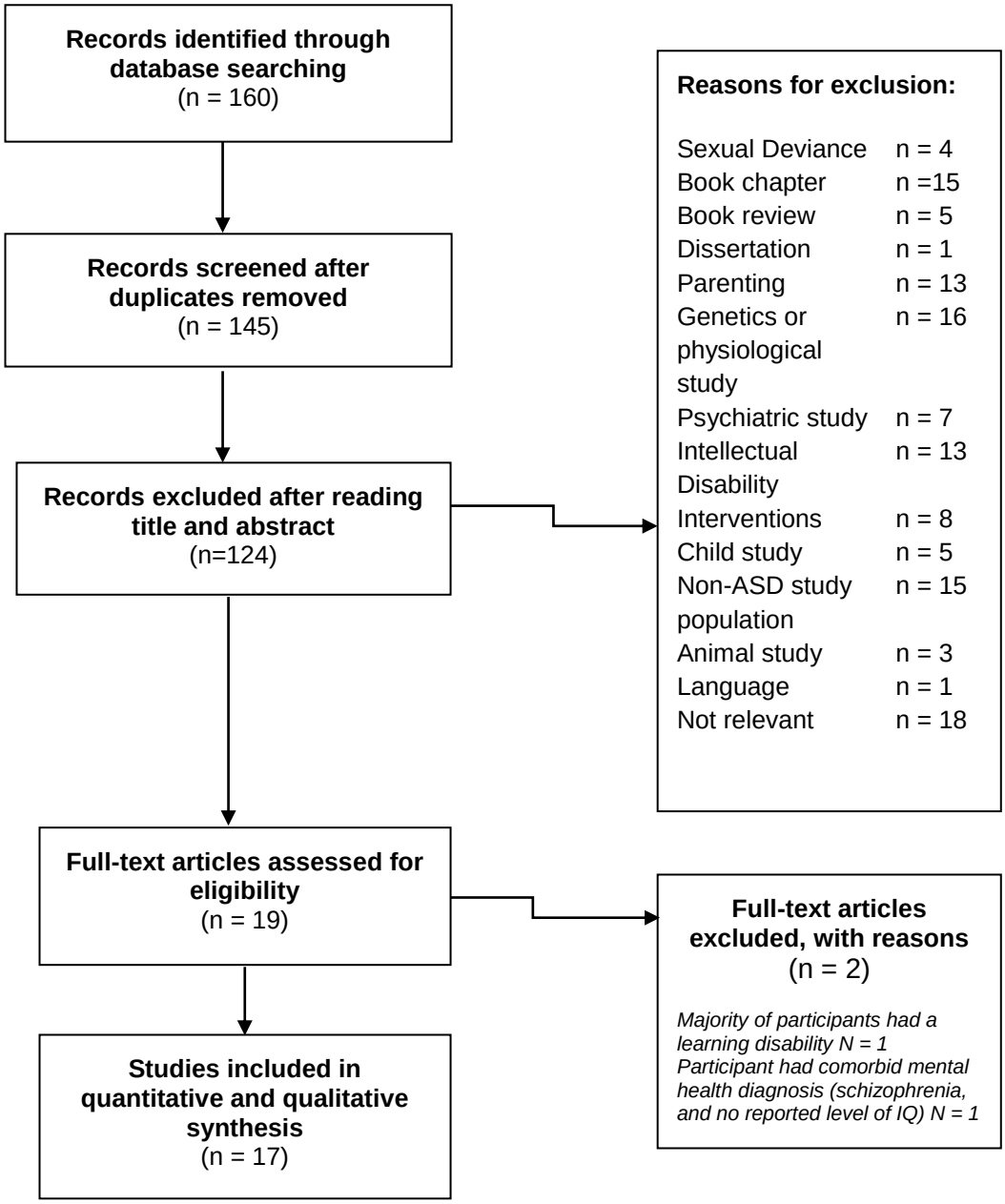
Records identified through database searching
(n = 160)
Records screened after duplicates removed
(n = 145)
Records excluded after reading title and abstract
(n=124)
Reasons for exclusion:
Sexual Deviance n = 4
Book chapter n =15
Book review n = 5
Dissertation n = 1
Parenting n = 13
Genetics or physiological study n = 16
Psychiatric study n = 7
Intellectual Disability n = 13
Interventions n = 8
Child study n = 5
Non-ASD study population n = 15
Animal study n = 3
Language n = 1
Not relevant n = 18
Full-text articles assessed for eligibility
(n = 19)
Full-text articles excluded, with reasons
(n = 2)
Majority of participants had a learning disability N = 1
Participant had comorbid mental health diagnosis (schizophrenia, and no reported level of IQ) N = 1
Studies included in quantitative and qualitative synthesis
(n = 17)

Table 2. Summary Table of Reviewed Studies

SB	SS	SK	Study	Focus	Method	Control	*N.*, *Sex*	Diagnosis	Age	IQ	Findings
			Brown-Lavoie, Veicili & Weiss (2014)	Sexual knowledge and victimization in adults with ASD	**Quantitative / Self-report** Sexual Knowledge Sources Questionnaire Knowledge of Sexual Health questionnaire Autism Spectrum Quotient (AQ) Perceived Knowledge Questionnaire The Sexual Experiences Survey, Victimization version	**117** 51 F 66 M	**95** 36 F 58 M	HFA	*M*=27.83 Range: 19-43 SD=4.33	13% High school 58% College 27% University	- Individuals with ASD obtained less of their sexual knowledge from social sources, more sexual knowledge from non-social sources, had less perceived and actual knowledge and experienced more sexual victimisation than controls. - The increased risk of individuals with ASD being subject to sexual victimisation was partially mediated by their sexual knowledge.
			Byers, Nichols, Voyer & Reilly (2013)	Factors associated with sexual well-being in HFA/AS	**Quantitative / Self-report** Autism Spectrum Quotient (AQ) Global Measure of Sexual Satisfaction (GMSEX) Self-Esteem Subscale of the Sexuality Scale Hurlbert Index of Sexual Assertiveness Sexual Arousability and Anxiety Inventory Sexual Desire Inventory Sexual Activity Questionnaire Sexual Functioning Questionnaire Sexual Knowledge Questionnaire Sexual Cognitions Checklist	No	**141** 56 M 85 F	HFA / AS	*M*=39.6 Range: 21-73	High Functioning 60% completed University degree	- Participants currently in a romantic relationship had more frequent partnered sexual activity and greater sexual assertiveness and satisfaction. - Men and individuals with less autism symptomatology in social and communication domains reported greater dyadic sexual wellbeing, sexual satisfaction, assertiveness, arousability and desire, lower sexual anxiety & fewer sexual problems. - Men reported better solitary sexual wellbeing but had lower sexual knowledge compared to women.
			Byers, Nichols & Voyer (2013a)	Sexual Functioning of Single Adults with HFA	**Quantitative / Self-report** (Online survey) Autism Spectrum Quotient (AQ) Depression, Anxiety, and Stress Scales-21 Sexual Knowledge Questionnaire Sexual Arousability and Sexual Anxiety Inventory (Short) Sexual Desire Inventory Sexual Activity Questionnaire Sexual Functioning Questionnaire Sexual Cognitions Checklist Online Sexual Experience Questionnaire	No	**129** 61 M 68 F	HFA	*M*=35.3 Range: 21-73	High Functioning 54 % completed university degree	- HFA individuals reported positive sexual functioning. - Those without prior relationship experience were significantly younger, more likely to be male and heterosexual. -Heterosexual HFA without prior relationship experience also reported greater sexual anxiety, lower sexual arousability and dyadic desire and fewer positive sexual cognitions. - Men with HFA reported better sexual function compared to HFA women, in a number of areas.

Byers & Nichols (2014)	Sexual satisfaction of HFA adults in a 3 month + relationship	**Quantitative / Self-report** (Online survey) Autism Spectrum Quotient (AQ) IEMSS Questionnaire which contains the Global Measure of Relationship Satisfaction, Global Measure of Sexual Satisfaction, Sexual Rewards and Costs Checklist-Revised, and Exchanges Questionnaire.	No	**205** 77 M 128 F	HFA	*M*=38.6 Range: 21-62	59% completed university degree	- All IEMSS components (relationship satisfaction, balance of sexual rewards and costs, balance of relative sexual rewards and costs, equality of rewards, equality of costs) were significantly associated with sexual satisfaction. - Participants with more autism symptoms related to social functioning reported lower sexual satisfaction. Men and women equally satisfied with their relationships but some men reported lower satisfaction in some domains.
Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Nieuwenhuizen (2014)	Sexuality in adolescent boys with autism spectrum disorder: Self-reported behaviours and attitudes	**Quantitative / Self-report** (Computerised survey at home / in the classroom) Autism Spectrum Quotient (AQ) Sexual Functioning questionnaire devised by researchers	**90** all M	**50** all M	ASD or AS	*M*=16.65 SD=.78	> 70 on IQ M=104.29, SD =15.62 Range = 76-142	- Similar levels and frequency of sexual behaviours in both groups. - Only significant difference: boys with ASD reacted with more tolerance towards male homosexuality compared to the control group.
Gilmour, Schalomon & Smith (2012)	Sexual attitudes and behaviours of adults with an ASD	**Quantitative / Self-report** (Online Survey) Autism Spectrum Quotient (AQ) Sexual Experience Questionnaire The Sexual Vocabulary Test Sell Scale of Sexual Orientation	**282** 180 F 102 M	**82** 55 F 17 M	ASD, confirmed by AQ	*M*=28.9 SD=9.3	Unknown	- Findings revealed that individuals with ASD display an interest in sex and sexual behaviours. No significant differences in sexual behaviours and comprehension of sexual language compared to NT controls. - Higher rate of asexuality in individuals with ASD. - Females with ASD showed a lower degree of heterosexuality compared to males with ASD.
Hellemans, Colson, Verbraeken, Vermeiren & Deboutte (2007)	Sexual Behaviour in HFA young adults	**Qualitative / Carer Report** (Semi-structured Interview) Interview on Sexuality in Autism.	No	**24** Care Staff	ASD	*M*=17 Range: 15-21	IQ: M=90 Range: 71-113	- Most residents had expressed sexual interest and displayed sexual behaviours and some knowledge. - Half of the sample had experienced a relationship; while 3 reported having had sexual intercourse. The number of reported bisexual orientations was higher than in the general population. - One third of the group needed intervention regarding sexual development or behaviour
Holmes, Himle, Sewell, Carbone, Strassberg & Murphy (2014)	Addressing Sexuality in young people with ASD – paediatrician perspectives	**Quantitative / Professional Report** (Online survey) Questionnaire on sexuality education, comfort & barriers to discussing sexuality with families	No	**203** Doctors	Doctors of children with ASD	N/A	N/A	- Doctors discussed an average of 10.9 of 26 sexuality topics with all families during their clinic. - Experience in caring for youth with ASD was positively correlated with the number of sexuality-related topics discussed and with how comfortable doctors felt. - Common barriers to providing sexuality-related information included discomfort, lack of training.

Holmes & Himle (2014)	Brief Report: Parent-Child Sexuality Communication and Autism Spectrum Disorders	**Quantitative / Parent Report** (Online Survey) Social Responsiveness Scale-2nd Edition Online Sexuality Survey	No	**190** Parents of children with ASD	ASD	Range: 12-18	IQ: *68.9%* 86-116 *12.6%* 71-85 *8.4%* 56-70 *4.7%* 41-55 *5.2%* <40 (10% below 70)	- HFA and LFA groups interested in sexuality and displayed sexual interest and behaviours - HF youth, most parents reported having covered topics related to privacy, sexual abuse prevention, puberty and hygiene, and some basic relationship and sexual health topics – post pregnancy. However, many parents did not cover topics related to relationships, sexual health and prevention, or general sexuality. - Specific ASD characteristics (especially social deficits) were better predictors of whether parents provide sex education than overall ASD severity (considered as distinct from level of intellectual function).
Konstantareas & Lunsky, (1997)	Sociosexual Knowledge, Experience, Attitudes, and Interests of HFA and LD	**Qualitative / Self-Report** (Semi-structured interview and Visual Aids) Socio-Sexual Knowledge, Experience, Attitudes, and Interests Vocabulary Knowledge Test-Receptive Part Vocabulary Knowledge Test-Expressive Part Experience, Attitudes, Interests (measured by flash cards with sexual images)	**16 DD** 8 M 8 F	**15 ASD** 9 M 6 F	ASD / DD	ASD M *M*=27.44 SD=6.19 ASD F *M*=34.75 SD=5.12 DD M *M*=29.25 SD=10.1 DD F *M*=25.25 SD=6.94	Range – Matched on IQ with DD individuals.	- Similar levels of interest in sexuality in both groups. - Individuals with autistic disorder endorsed more sexual activities than those with developmental delay. - Increased sexual knowledge in HFA was related to increased negative attitude towards sexuality – staff attitudes could be a factor. - Lack of complex understanding relating to sexuality and staff expressed concerns and a need for further education.
Mehzabin & Stokes (2011)	Self-assessed sexuality in young adults with High-Functioning Autism	**Quantitative / self-report** (Questionnaires, online or hard copy) Sexual Behaviour Scale	**39** 15 M 24 F	**21** 12 M 9 F	HFA	HFA M *M*=25.3, SD=3.6 HFA F *M*=23.4, SD=1.9 NT M *M*=23.7, SD=3.1 NT F M = 22.6 SD =2.1	HFA and Asperger's Syndrome	- HFA individuals reported having had fewer social opportunities to engage with others, had less sex education and fewer sexual experiences, - HFA individuals also had more concerns for the future (e.g. finding future partners) - However, HFA showed similar levels of privacy knowledge and public sexualised behaviour when compared to NT controls.
Nichols & Blakeley-Smith (2010)	Family Work to improve healthy sexuality for individuals with ASD	**Qualitative / Parent Report** Focus groups Pre-test/post-test evaluation of a sex education curriculum for parents of children with ASD The Comfort Ratings Questionnaire—Parent Version	No	**21**	ASD (Autism, AS, PDD-NOS)	8-18	IQ ranges from severe delay (65) – to above average (115)	- The main themes that emerged included: the effect of social impairments, children's desire for relationships, exploitation prevention and available parent resources. - Many parental goals were met through the sex education programme - Parents reported increased confidence more able to talk to their child about sex / future relationships.

Pollmann, Finkenauer & Begeer (2010)	Mediators of the Link between Autistic Traits	**Quantitative / Self-Report** Autism Spectrum Quotient (AQ) Dyadic Adjustment Scale (DAS) Rosenberg self-esteem questionnaire Experiences in Close Relationships Questionnaire Relationship-specific self-disclosure scale Responsiveness, Intimacy & Trust Scales	No	**195**	ASD (AQ)	Husbands With ASD *M*=33.05, SD=4.86 Wives *M*=30.11, SD=4.25	Not reported	- More autistic traits were associated with lower relationship satisfaction for husbands but not for wives. - More autistic traits do not necessarily influence the partner's perceptions of relationship satisfaction. - Husbands' responsiveness towards their wives mediated the link between autistic traits and their perceived relationship satisfaction. - Autistic traits may affect men's relationship satisfaction because they impede relationship-specific feelings and behaviour (e.g. intimacy).
Renty & Roeyers (2007)	Individual and marital adaptation in men with ASD and their wives	**Quantitative / Self-report** Autism Spectrum Quotient (AQ) Social Provisions Scale Camberwell Assessment of Need The Ways of Coping Questionnaire The Symptom Checklist-90 Dyadic Adjustment Scale (DAS)	No	**21**	Autism, AS, PDD-NOS	Husbands With ASD *M*=43.52, SD=4.98 Wives *M*=42.01, SD=5.25	IQ > 70 All educated to university level	- Informal support is a strong predictor of adaptation in both spouses. Coping did not add to the prediction of adaptation. - Autism-specific traits are related to marital adaptation in wives of ASD men. Perceived spousal support acts as a buffer for the demands of living with a partner with ASD. - Husbands who showed fewer autism-specific traits reported higher levels of marital satisfaction.
Sperry & Mesibov (2005)	Social challenges of adults with ASD	**Qualitative / Self-report** Focus Group	No	**18** 17 M 1 F	ASD	22-49	High school and college majors	- Emergent themes included relationships at work, developing and maintaining personal relationships, appropriate behaviours around members of the opposite sex and personal perspectives on having ASD.
Stokes & Kaur (2005)	High-functioning autism and sexuality: A parental perspective	**Quantitative / Parent-report** Courting Behaviour Scale Social Functioning Subscale Romantic Functioning	**50** Parents **40** NT children 32 M 6 F	**23** Parents **24** HFA children 17 M 6 F	HFA or AS	HFA M *M*=12.6, SD=1.9 HFA F *M* = 13.0 SD = 0.6	Unknown – but with diagnosis of HFA or AS	- Children with HFA demonstrated more socially inappropriate behaviours, knew less about sex education and knew less about privacy. - Parents of HFA children were more concerned regarding long-term outcomes. - Parental concern increased as children with HFA aged and decreased as NT children aged.
Stokes, Newton & Kaur (2007)	Stalking, and Social and Romantic Functioning Among Adolescents and Adults with ASD	**Quantitative / Parent-report** Sexual Behaviour Scale	**38** Parents of NT children **30** NT children 32 M 6 F	**25** Parents of HFA children **25** HFA children 16 M 9 F	HFA	*M*=22.21 Range: 13-36	IQ >70	- For people with HFA, knowledge on social, romantic and sexuality skills was less likely to come from peers - Individuals with HFA had lower levels of social functioning compared to NT peers - Individuals with HFA exhibited more atypical social & romantic behaviours and spent more time fixated on targets (romantic) compared to NT controls.

Key to Abbreviations: SB = Sexual Behaviours, SS = Sexual Selfhood, SK = Sexual Knowledge. Colour codes highlight which of the 3 domains (SB/SS/SK) is discussed in a study. NT = Neurotypical, ASD = Autism Spectrum Disorder, AS = Asperger Syndrome, HFA = High-Functioning Autism, PDD-NOS = Pervasive Developmental Disorder – Not Otherwise Specified, AQ = Autism Quotient, IQ = Intelligence Quotient, M = Male, F = Female, *M* = Mean, SD = Standard Deviation

There are differences in reported frequencies of solitary behaviours when studies using self-report measures are compared to carer or parent-report literature. Residential caregivers reported on sexual behaviours of 24 males with HF-ASD in their care (Hellemans, et al., 2007). Care staff confirmed that only 42% of the residents engaged in masturbation, a frequency that is lower than that reported in the general population. Parents of 25 HFA boys and 38 non-HFA boys were asked to report on their children's sexual behaviours using the Sexual Behaviour Scale (SBS) in Stokes and Kaur's (2005) study. Compared to controls, HF-ASD adolescents displayed poorer social behaviours and were more likely to display inappropriate sexual behaviours such as touching their private body areas, masturbating and undressing in public (Stokes & Kaur, 2005). For example a 15 year-old adolescent with HF-ASD displayed a level of sexualised behaviour similar to a ten year-old typical adolescent, but when age and social behaviour were statistically controlled for, no between group differences were found. This analysis suggests that differences in the appropriateness of HF-ASD sexual behaviours may be a function of age and social behaviour. The differences in reported frequencies of sexual behaviours between self-report and carer-report studies could be explained by methodological limitations. There is a greater likelihood that many high-functioning residents would use the privacy of a bathroom or bedroom in order to masturbate, and therefore be less likely to be observed by care staff.

Overall the evidence confirms that HFA individuals do engage in solitary sexual behaviours, but that differences lie in frequencies and appropriateness of expression. Self-report findings suggest that there is no convincing evidence for any difference in rates of solitary sexual behaviour between HFA and typically developing adolescents. Instead, carers report lower frequencies of solitary sexual activity in HF-ASD residents (Hellemans, et al., 2007) and parents reported higher rates of inappropriate solitary sexual behaviours in their HF-ASD adolescent children compared to parents of typically developing adolescents (Stokes & Kaur,

2005). A number of methodological limitations are raised to explain the differences in findings.

Early studies of autism and sexuality have been criticised for failing to ask the individuals directly about their experiences, though the self-report methods used in more recent studies also have their limitations. Dewinter et al.'s (2014) use of an online questionnaire asking adolescent boys about their sexual activity, could have been vulnerable to exaggeration or over-reporting of sexual behaviours and experiences, especially given the social pressures related to sexual performance for young males (O'Sullivan & Byers, 1996). Another limitation in Konstantereas and Lunksy's (1997) methodology was their use of flashcards with sexual images to record participants' sexual experiences. Researchers asked participants to give 'thumbs up' or 'thumbs down' signals to indicate whether they had experienced and endorsed what was shown in an image. However, when a participant 'endorsed' or 'disapproved' of an image, the researchers did not ask what aspect of the image they endorsed nor did they check that the participant understood what they saw in an image card. Further, Konstantereas and Lunsky did not use a control group from the general population, therefore it is difficult to comment on how different the participants with ASD might have differed from the general population with regards to their sexual attitudes. The main limitation of parent (Stokes & Kaur, 2005) and carer (Hellemans et al., 2007) studies was that the participants would only have been able to report on the behaviours they had observed or inferred. This is likely to have varied, especially when reporting on individuals who were aware of a need for privacy when engaged in sexual activities. The finding that social behavior, defined as social skills and knowledge, is a possible mediating factor in the expression of appropriate solitary sexual behaviours in adolescents with HF-ASD (Stokes & Kaur, 2005) highlights the need for specialised sex education programmes with an emphasis on social skills.

Sexual behaviours in relationships

Experiencing satisfying relationships is an important part of psychosocial wellbeing (Baumeister & Leary, 1995). Previous stereotypes of individuals on the autism spectrum assume that they either lack interest or the ability to form intimate and romantic relationships (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Recent research suggests otherwise. Many individuals with HFA both desire and are able to engage in partnered sexual activity as well as long-term relationships (Hellemans et al. 2007; Konstantareas and Lunsky, 2007; Byers & Nichols, 2014), including marriage (Pollmann, Finkenauer, & Begeer, 2010; Renty & Roeyers, 2007).

Self-report studies on the rate of sexual relationships in adults are considered first. An online sexual wellbeing survey of 58 men and 85 women with HFA aged between 21 and 73, found that almost half of the participants reported living with a spouse or romantic partner (Byers, Nichols, Voyers & Reilly, 2013). In a later study, most participants (59%) reported that they had either been or were currently in a relationship lasting longer than three months (Byers et al. 2014). These findings therefore challenge the assumption that individuals with ASD are commonly perceived as asexual and unable to have romantic relationships (Konstantereas & Lunsky, 1997). It was notable that participants who had experienced a relationship were older, whereas younger participants were less likely to have had a relationship experience (Byers, Nichols & Voyer, 2013a). This finding suggests that perhaps lack of relationship experience is not due to psychological factors or skill deficits but rather, it may be a developmental issue, as suggested by previous findings that adults with ASD are delayed with their social development (Bauminger et al., 2008; Rao, Beidel, & Murray, 2008).

Sexual behaviours in relationships include sexual intercourse, kissing and hugging. In comparative studies of partnered sexual activity the evidence is contradictory. Dewinter et al.'s (2014) study of sexual behaviour in adolescent boys found that typically developing and HF-ASD boys reported similar levels of sexual

activity. When comparing adults, the results are different. Gilmour and colleagues, (2012) found fewer adults with HF-ASD had experienced partner-oriented sex when compared to controls from the general population. One explanation for the difference in reported partnership rates was the availability of a partner for adults with HF-ASD, as opposed to lower desire or difficulties meeting people due to ASD traits. When 21 young adults with HF-ASD and 39 typically developing controls were asked about their sexual experiences using the Sexualised Behaviour Scale, HF-ASD participants had less sexual knowledge, had engaged in fewer social behaviours and had higher anxieties about finding a future partner (Mehzabin & Stokes, 2011). These variables could also account for the lower rates of partnered sexual activity in HF-ASD adults.

In keeping with self-report findings, parent and caregiver studies found that adolescents with HF-ASD in their charge were interested in relationships. However, many raised concerns regarding young people's sex education and questioned their understanding of sexually appropriate behaviours. Staff working in supported accommodation told Hellemans and colleagues (2007) that half of the adolescents and young adults in their care had expressed the desire to have a romantic relationship. Indeed, many residents had taken the steps to establish an intimate relationship with a partner, with staff reporting that three individuals had engaged in sexual intercourse. However, carers estimated that a third of their residents required further intervention regarding their knowledge of sexual relationships. Indeed, staff recognised that institutionalised individuals may have been delayed in their social development due to their residential context. Parents of adolescents with HF-ASD living in the community also raised concerns around the appropriateness of their adolescent's social behaviours and expressed future worries. Parents of 25 adolescents with HF-ASD and 38 from the general population reported on their children's social, romantic and courting behaviours (Stokes, Newton and Kaur, 2007). Findings suggested that adolescents with HF-ASD expressed an interest in

having a romantic relationship but were more likely to become fixated on romantic targets for longer and display more atypical social and romantic behaviours such as stalking, compared to their typically developing controls. In an earlier study by the same authors, researchers asked the parents of 23 adolescents with HF-ASD and 50 adolescents from the general population to complete the Sexual Behaviours Scale (Stokes & Kaur, 2005). Parents of adolescents with HF-ASD were more likely to worry about their child finding a partner as their child increased with age, compared to parents of typically developing children. Parents also expressed anxieties about their child having a limited understanding of sexual relationships.

The findings indicate that HFA individuals would like to have romantic relationships and many report having experienced such partnerships. The theme of anxieties around relationships is raised in both self-report and parent studies, where individuals may not be entering into relationships either because they are too anxious to (Mehazabin and Stokes, 2011) or, as their parents have suggested, because they think their children are unsure how to start a relationship (Stokes and Kaur, 2007). A number of factors proposed by Byers and Nichols (2014) explain why individuals with HF-ASD may be less likely to engage in romantic relationships. These include social communication and flexibility difficulties, internalisation of negative societal stereotypes associated with a diagnosis of autism and negative early interpersonal experiences, such as bullying. Given that having a diagnosis is likely to be experienced as a challenge in itself, the review also considers the literature on autistic traits and how they may influence relationships in the following section.

Autistic traits and relationships

Research on the effects of autistic traits on romantic relationships has found that ASD symptoms did not appear to affect the likelihood of being in a relationship (Byers et al., 2013). However, the presence of autistic traits in a spouse has been

found to influence reported relationship satisfaction (Pollman, et al., 2010; Rentyand Roeyers, 2007). Adult studies using the Global Measure of Relationship and Sexual Satisfaction, found that individuals with HF-ASD who reported more autistic deficits in social functioning domains also experienced lower sexual satisfaction in relationships (Byers & Nichols, 2014). Similarly romantic functioning such as desire, knowledge and experience of intimate relationships was reported to be lower in adults with HF-ASD compared to typically developing controls (Stokes et al. 2007). One of the main themes that emerged from focus groups of 18 adults with HF-ASD was that deficits related to social communication were a hindrance when trying to form personal relationships. The same individuals also reported uncertainties with regards to knowing what would be considered 'socially acceptable behaviour' with the opposite sex (Sperry & Mesibov, 2005).

The findings regarding relationship satisfaction vary when considering married couples where the husband has a diagnosis of HF-ASD. Pollmann and colleagues (2010) studied the link between autistic traits and level of relationship satisfaction in 195 newly married couples. Researchers found that having a greater number of autistic traits was related to reported lower relationship satisfaction in husbands, but not in wives. Men who had fewer autistic traits reported higher intimacy with their wives and higher satisfaction in their relationship. They also felt more able to trust their spouses – the opposite was true of men who had a greater number of autistic traits. Of note was that wives' relationship satisfaction was not affected by their husband's autistic traits. The authors explained that this could be related to husbands with high AQ scores *describing* themselves as less responsive, whilst still *behaving* in a responsive manner.

Another study by Renty and Roeyers (2007) considered protective factors that offset the difficulties autistic traits might introduce into a relationship. Informal support from friends and family was a reliable predictor of marital adaptation in both spouses and seen as a 'buffer' for the demands that living with a partner with HF-

ASD may present. Furthermore, wives whose husbands had fewer autistic traits, reported higher levels of relationship satisfaction. This contrasts with Pollman et al.'s (2010) findings, where wives' satisfaction was not affected by their husband's autistic traits. One reason for differences could be related to length of relationship. Pollman's (2010) sample consisted of newlywed couples, whereas the mean length of relationship in Renty and Roeyer's (2007) couples was 15 years. Therefore wives, who had been with their partners for longer, may have found it increasingly difficult to live alongside their husbands' autistic traits.

Although the evidence is limited, it suggests that autistic traits can impact on relationship satisfaction, both from individual and married couple's perspectives. In some cases, the presence of autistic traits is related to the likelihood of experiencing a romantic relationship at all (Stokes et al, 2007). However, it is difficult to compare studies closely as different self-report measures were used to gauge relationship satisfaction in every study. Notwithstanding, there is a clear indication from Renty and Roeyers (2007) study that social support is an important factor for both spouses in a relationship; a finding that could be used in future intervention programmes when supporting couples with a HF-ASD diagnosis, in a clinical setting.

Sexual Selfhood

Sexual selfhood includes internal experiences of sexuality, including sexual knowledge, victimisation, and attitudes to sexuality and sexual orientation in high-functioning adolescents and adults.

Sexuality Knowledge

Individuals with HF-ASD are likely to have less knowledge on sexuality due to their social communication deficits, social isolation and limited access to sexual education (Hénault, 2005; Koller, 2000; Nichols and Blakely-Smith, 2010).

Nonetheless, there is some variability in the findings on the levels of sexuality knowledge in people with HF-ASD, with some studies reporting similar rates of knowledge amongst HF-ASD individuals when compared to the general population. The implications on individuals with HF-ASD lacking sexuality knowledge are also considered.

A community study by Gilmour, Schalomon, & Smith, (2012) comparing young adults with and without HF-ASD found no significant differences in the comprehension of sexual language. Byers and colleagues (2013a) also reported that their sample of 129 young adults with HF-ASD reported having 'good' sexual knowledge. However, this particular study did not have a control. It is debatable whether a sexual vocabulary test used in Gilmour et al.'s (2012) study is a sufficiently valid measure of sexual knowledge especially given that this was administered online as participants may have had the opportunity to look up answers online. Notwithstanding, the findings do suggest similar levels of comprehension. Other studies have found significant differences when comparing control and HF-ASD samples. In Mehzabin and Stokes' (2011) study using the Sexual Behaviour Scales (SBS) found that the 21 adults with HF-ASD reported less sex education and knowledge compared to the 38 typically developing controls.

Studies using carer and parent report support self-report findings that HF-ASD had lower levels of sexual knowledge. Stokes and Kaur (2005) compared responses on the SBS of parents with and without adolescent children with HF-ASD and found that parents of HF-ASD adolescents were more likely to report that their child had poorer privacy knowledge and less sex education when compared to typical adolescents. However, in their analysis, authors found that when age was accounted for, between-group differences did not exist. The authors suggest that a developmental pattern is present for the variables of 'privacy knowledge' and 'sex education': as HF-ASD individuals got older, they acquired more knowledge. Carers in Hellemans et al.'s (2009) study also indicated that a third of their residents lacked

knowledge in certain domains of sexuality and would benefit from specialist sex education.

The variability in findings from the self-report studies could be explained by the differences in the way knowledge was defined and measured. Self-report studies supporting the hypothesis that HF-ASD individuals had less sexual knowledge compared to typically developing participants had used standardised measures of sexual knowledge and compared their HF-ASD participants to a control group from the general population. Other studies found HF-ASD had comparable sexuality knowledge to typical controls, but only used a vocabulary scale as a measure of sexuality knowledge (Gilmour, et al., 2012). Another study did not have a control group to compare against, but reported 'good' sexuality knowledge in HF-ASD participants (Byers, et al. 2013a).

Overall, there is compelling evidence from self-report, parent and carer studies that individuals with HF-ASD have less sexuality knowledge than typical peers. Given the deficits manifest in social communication and interaction domains in individuals with HF-ASD, and the influence of social behavior on level of sexual knowledge (Stokes and Kaur, 2005) this finding is unsurprising. It also highlights the need for further education and specific support for individual and their parents to introduce sexuality knowledge at an appropriate age, in order to decrease potential risks that individuals may encounter and gaps in their social development as compared to their peers.

Sexual victimisation

Sexual education and its availability for young people on the autism spectrum is related to the likelihood of them being taken advantage of by others. Brown-Lavoie, Viecili, & Weiss, (2014) asked HFA and NT adolescents to complete questionnaires on sexual knowledge sources, actual knowledge, perceived knowledge and sexual victimisation. Compared to NT adolescents, they had less perceived and actual

knowledge, and experienced more sexual victimisation than controls. Sexual victimisation was also reported in Dewinter and colleagues' (2014) study of adolescent sexual behaviour where three adolescent boys with HFA reported that they had been sexually abused. However, given that the boys in this sample reported equal sexual knowledge to the typically developing control group, the reasons for their increased vulnerablility may have been due to other variables.

Attitudes to Sexuality

Attitudes towards aspects of sexuality such as roles in sexual relationships and engagement in sexual behaviour have been explored in two studies of individuals with HF-ASD. When presented with different sexuality statements, young adolescent boys with and without HF-ASD held similarly permissive attitudes regarding sexuality (DeWinter et al., 2014). Statements included sexual contact in different male-female relationships, gender roles in relationships and disapproval of many different sexual partners. Both groups also reported equally positive attitudes to same sex relationships between to girls. However, there was one significant difference between groups: HF-ASD participants were significantly more positive in their attitudes towards male homosexuality compared to their typical peers.

Positive attitudes towards sexuality behaviours were also found amongst individuals with HF-ASD in Konstantareas and Lunsky (1997) study which compared the responses of HF-ASD residents with same age individuals with a learning disability (LD). Participants with HF-ASD were more likely to express approval of sexual behaviours (presented to them by the researchers as images on cards). However, individuals with more knowledge on sexual behaviours were more likely to have negative attitudes towards sexuality. This could have been related to how sexuality is discussed with clients in care settings, where carers have an agenda to protect the individual. Therefore, as an individual's knowledge of the potential risks increased, so did their likelihood of developing a more risk-averse view of sexual

experiences. Overall, both studies suggest that attitudes towards sexuality and sexual behaviours are positive amongst HF-ASD populations. It is difficult to draw firm conclusions regarding attitudes from Konstantereas and Lunksy's (1997) sample, as factors such as the residential setting and the lack of a typically developing control group, may have compared to those found in the general population.

Sexual Orientation

Findings on sexual orientation suggest a higher prevalence of homosexual or bisexual interest in people with ASD compared to the general population (Byers et al. 2013; Gilmour et al. 2012; Hellemans et al., 2007). A household survey produced by the Office of National Statistics in the UK provided figures for sexual orientation for the period of April 2011 to March 2012 for the general population. Of the 350,000 adults that responded to the survey, 93.9% identified as heterosexual; 1.1 % identified themselves as lesbian or gay; 0.4% as bisexual; 0.3% as 'Other'; 3.6 % as 'Don't know' and 0.6 % selected 'No response' to the question (ONS, 2012). Research with HF-ASD populations suggests that the rates of sexual orientation differ to those found in the general population. A study of 24 male adolescents with HF-ASD living in residential settings using carer-report described 58% of residents as heterosexual, 13% as bisexual and 4% as homosexual and 25% as 'unknown' (Hellemans et al., 2007). Compared to the general population the differences in rates of homosexuality and bisexuality are significant, however, most striking was the rate of individuals recorded as 'unknown'. Similarly, Haracopos and Pedersen's (2004) survey of 38 residents with HF-ASD was unable to classify 15% of the residents' orientations. The remaining residents were described as follows: 41% as heterosexual, 35% as bisexual and 9% as homosexual. Relying on carers' opinions of residents' orientation is problematic, as observations of sexual activity are likely to be limited and a proportion of the behaviours that individual is likely to

have displayed publicly. Self-report data in such studies would have been more accurate, however, they too suggest rates that differ from those found in the general population. In one self-report study comparing adults with and without HF-ASD using the Sell Scale of Sexual Orientation, participants with HF-ASD reported higher rates of bisexuality and homosexuality, and lower rates of heterosexuality (Gilmour et al., 2012). In contrast, Brown-Lavoie and colleagues' (2014) survey of 117 adults with and without HF-ASD found 79% of HF-ASD described themselves as 'heterosexual' compared to 67% of typical controls. Interesting to note was that fewer HF-ASD individuals (21%) described themselves as 'not heterosexual' compared to typical controls (33%). It is possible that a binary category system may not have encompassed all of the range of sexual interests that individuals might have needed to describe their experiences and thereby forced a choice which may not have been representative of their actual sexual orientation. Further studies with larger samples and similar selection criteria to those used in the ONS survey would be helpful to gaining a clearer result regarding sexual orientations in the HF-ASD population. It is also important to acknowledge that the ONS survey was chosen to represent sexuality rates in the general population as they are regarded as a useful data source due to their large population sample. However, in this context, it is potentially problematic, as there is marked difference between those in the general population that describe themselves as heterosexual in the ONS survey (93.9%) compared to a control group where only 67% identified as heterosexual (Browne-Lavoie et al., 2014). Similar differences arise in the reporting of same sex interests or bisexual orientation, whereby the ONS reports very low figures compared to those found in studies, where 1 in 3 controls reported same sex interests. This could suggest that many young people may be unlikely to share their sexual orientation in ONS surveys and therefore may not represent the true range of orientations found in the general population.

One anecdotal hypothesis regarding greater prevalence of bisexuality in individuals with HF-ASD is that they are more likely to consider a romantic partner on the basis of personal characteristics rather than their gender and are therefore more flexible in their orientation (Lai et al. 2011; Mandy et al. 2012). Gilmour and colleagues (2012) counter this suggestion, arguing that people with ASD still tended to choose partners that matched their stated sexual orientation. An alternative explanation is that differences in rates of between NT and HFA might be explained by individual adherence to social norms as opposed to sexual orientation. Individuals with HFA may be less concerned with social norms compared to NT individuals (Izuma, Matsumoto, Camerer, & Adolphs, 2011), therefore, if they have both homosexual and heterosexual interests, they may be less likely to suppress alternative sexual interests and behaviours. Regardless of the reason for greater rates of bisexuality, it is important that sexuality education for young people with HFA normalises attraction to both genders and empower individuals to adopt the sexual identity that best fits their self-concept (Byers et al., 2013).

Sexual Socialisation

Sexual socialisation describes the process by which young people acquire and share sexual knowledge and information. Social deficits inherent in individuals with HF-ASD can influence their engagement and confidence in sexual interactions, such as dating or negotiating sexual relationships (Hénault, 2005). This section considers different agents of sexual socialisation including parents, peers and professionals, and how they may help or hinder the process of acquiring sexual knowledge.

Parents as socialising agents

Experts recommend that parents are best placed to educate their children with ASD regarding sexuality education and that the material discussed should be tailored to

the child's developmental level (Holmes & Himle, 2014; SIECUS, 2012). Despite these recommendations, parents often report feeling uncertain of which topics to discuss with their children and often feel unsupported by professionals (Nichols & Blakely-Smith, 2010). Parent's confidence in discussing sexuality topics with their children was evaluated after participating in an 8-week sex education programme. Contents of the programme were based on focus group discussions in which parents raised issues they needed support with regarding sexuality education for their child with HFA (Nichols & Blakeley-Smith, 2010). The themes that emerged from the focus groups included: finding a meaning for healthy sexuality for individuals with autism, supporting their children's desire for relationships, the significance of social impairments and exploitation prevention. After the 8-week programme, parents felt more comfortable about discussing all areas of sexuality with their child, including sexual and future relationships with confidence.

Holmes and Himle's (2014) study considered the obstacles that prevented parents from discussing sexuality topics with their child. Specific ASD characteristics, especially social deficits, were better predictors of whether parents provided sex education to their children rather than their child's overall ASD severity (considered here as distinct from cognitive functioning). Therefore, whilst parents were able to cover certain topics with their child, such as privacy, sexual abuse prevention and some basic sexual health topics such as pregnancy; they did not discuss relationships, general sexuality or sexual health; with many parents reporting that they couldn't imagine their children in relationships later in life.

Professionals as socialising agents

Professionals shared similar uncertainties with regards to knowing what sexuality information to provide to families with HFA children. A recent online survey of 212 paediatricians found that the most common barriers to providing sexuality-related care to youth with ASD were paediatrician and parent discomfort, lack of training for

the professional supporting the family and absence of information for paediatrician (Holmes et al., 2014). Doctors reported discussing an average of 10.9 sexuality topics out of a possible 26 topics, with all families who attended clinics for a routine visit, with the most frequently discussed sexuality-related topics being emotional maturity (73%), physical changes related to puberty (67%) and risk for abuse (54%). The topics least likely to be discussed directly with youth, without a parent present, included sexual abuse (25%), contraception and practising safe sex (32%), pregnancy (26%) and sexual orientation (8%). Physicians who felt most competent and comfortable in delivering sexuality related education were those who had previous experience in caring for youth with ASD.

Peers as socialising agents

In the general population, young people tend to be each other's source of knowledge and learning regarding sexuality and romantic skills (Stokes and Kaur, 2005). Given the social communication deficits, including difficulties maintaining friendships, associated with ASD (APA, 2004), high-functioning adolescents are less likely to seek information from peers (Stokes, Newton and Kaur, 2007). Instead their primary source of romantic knowledge was from parents and from making social observations. Other adolescents with HFA accessed information on sexual behaviours from non-social sources, such as educational brochures and television (Brown-Lavoie et al., 2014). However, this contradicts earlier findings where HF-ASD participants told researchers they learnt their sex education from friends and peers, rather than from parental figures (Mehazabin & Stokes, 2011). The difference in findings is difficult to explain, however, it may be that the sample Mehazabin and Stokes (2011) recruited felt more socially competent compared to other HF-ASD individuals in previous studies and therefore more likely to approach their peers for sexuality information.

Discussion

The findings in this under-researched area provided overwhelming support to the view that sexuality is a normal stage of development in individuals with HF-ASD. Further, they discredit the 'asexuality' myth of a lack of interest in sexual behaviours and relationships amongst those with autism. In this discussion, findings from the three domains: i) *sexual behaviours, ii) sexual knowledge* and *iii) sexual socialisation* are considered and clinical recommendations are included throughout the discussion of each domain. The reviewer then goes on to contrast the 'deficit' narrative of autism, present in early sexuality literature, with person-centred and values-based approaches to guide the design of sexuality educational programmes. The methodological limitations of the reviewed studies are considered first.

The measures used in the reviewed studies varied widely in quality and suitability to measure particular constructs. For example, 'sexual knowledge' was measured using both standardised and informal measures in two different studies, yielding differing results. In six of the studies, only parents and carers were the source of information. This was problematic because their accounts might not have been accurate representations of the behaviours they were reporting, due to some sexual behaviours being carried out in private. Nevertheless, parent and carer accounts provided useful insights regarding their anxieties in providing adequate support and information to individuals in their charge. The number of participants varied widely from study to study, as did the age, ranging from adolescence to middle adulthood. This made it difficult to compare findings on certain domains, such as sexual knowledge, as age and therefore stage of development would have been a mediating variable of individual knowledge. Differences in participants included in each study may also have introduced bias. For example, some studies included participants living in institutions, whose experiences of sexuality and education were likely to differ to those living in the community. On the other hand,

participants who responded to studies that used survey methods may have been more likely to have a high pre-existing interest in sexuality. Typically developing controls were only present in a third of the studies. These limitations may hamper the possibility of generalising and comparing findings. Nevertheless, the extant literature offers a preliminary insight into a population which is often voiceless regarding theirs and their guardians' view on sexuality. Clinical recommendations are included throughout the discussion of each domain.

Sexual Behaviours: the effects of autistic traits and possible interventions

Interest and engagement in sexual behaviours and relationships was reported by adolescents and adults with HF-ASD (Byers et al., 2013a; Dewinter et al., 2014),as well as their parents and carers (Hellemans et al., 2007; Stokes & Kaur, 2005). However, some individuals with HF-ASD reported feeling hindered by their autistic traits, such as social communication deficits when entering or negotiating intimate relationships (Sperry & Mesibov, 2005). This resulted in limited engagement in social activities, thereby reducing opportunities to meet prospective partners. The presence of traits was also found to influence perceived satisfaction in a relationship, in both husbands (Pollman, et al., 2010) and wives (Renty & Roeyers, 2007).

These findings clearly indicate that HF-ASD young adults and adolescents may require specific support with either initiating or sustaining relationships. Support is also required for the partners of those with HF-ASD. Preliminary studies of young adults with HF-ASD used focus groups to identify barriers to initiating relationships. These included uncertainty regarding 'appropriate' behaviours and initiating contact with the opposite sex (Sperry and Mesibov, 2005). Future research could use focus group outcomes and commonly reported difficulties (e.g. understanding hidden rules of social interaction, rigidity, empathy) to develop appropriate 'social skills' interventions for young adults. This could involve piloting and devising programmes

collaboratively with individuals with HF-ASD. For those in established relationships, access to social support from friends and family was cited as one of the most important buffers to maintaining harmonious marital relations (Renty & Roeyers, 2007). However, little else is known about other dynamics that allow partners with and without HF-ASD to flourish in their relationships. Future studies could use qualitative methods to interview couples in long-term partnerships to find out about their strategies used to manage conflict or solve problems. This data could then be used to support HF-ASD couples reporting difficulties with their relationships. Although there is interest in supporting couples to have satisfying relationships, it is also important to note that not all HF-ASD individuals may seek partnerships. Therefore, the teaching of the 'hidden curriculum' (i.e. how to have safe sexual relationships) to school-aged children with HF-ASD needs to be included in social education classes so that individuals can make informed choices regarding their sexual and relationship preferences, later in life.

Sexual Selfhood: the right knowledge at the right time

Individuals with HF-ASD display poorer sexual knowledge compared to their typically developing peers (Mehzabin & Stokes, 2011). However, contrary to historically reported 'asexual' stereotypes (Konstantereas & Lunsky, 1997), HF-ASD participants reported positive attitudes towards sexuality, and when compared to typical peers were significantly more positive in their attitudes towards male homosexuality. In one study, increased knowledge was related to negative attitudes toward sexuality in young high-functioning adults (Konstantareas & Lunsky, 1997). Carers had previously discussed risks associated with sexual behaviours with the young people in their charge therefore it is possible that this had influenced their attitudes towards certain sexual activities. With regards to research on sexual orientation, a greater prevalence of bisexual and homosexual orientation was found in individuals with ASD compared to the general population (Gilmour et al., 2012).

These findings should encourage researchers to reflect on the role that sexual education might have in shaping young people's attitudes. Access to knowledge is especially important for members of a vulnerable, minority population such as ASD. The evidence suggests that HF-ASD individuals are more likely to be open to alternative sexual experiences therefore it is crucial that they have access to knowledge which familiarises them with their rights and the subtle social rules pertaining to such circumstances.

Sexual Socialisation: who should be providing the education?

Evidence regarding where young people with HFA source sexuality information was contradictory and sparse. One study stated that individuals with HFA relied on conversations with their peers (Mehazabin & Stokes, 2011), whilst another found that television and the internet were their main sources of sexuality information (Browne-Lavoie et al., 2014). Most neurotypical individuals rely on their friends to discuss sexuality skills and rules, but HF-ASD adolescents often lack a peer group, and therefore may be at increased risk of being abused. Indeed, lower levels of sexual knowledge were related to increased likelihood of sexual victimisation in HFA individuals (Brown-Lavoie, et al., 2014). Parents were other sources of sexuality information. However, parents often reported feeling unsure of which topics to discuss with their children, and at what time, resulting in little to no sexuality information being shared with adolescent children (Nichols & Blakely-Smith, 2010). Research on interventions are sparse, but the outcomes of those evaluated show that parents are more willing to face taboos related to their ideas of sexuality and as a result, were able to speak more openly with their children. Professionals also voiced similar hesitations; for many clinicians, confidence in providing sexuality information was dependent on how much prior experience they had of working with sexuality and HFA clients.

Educating individuals with ASD on sexuality is also a complex and delicate subject for caregivers, both in professional and familial contexts. There is often the wish to protect the young person in their charge but historically, measures put in place to protect have become barriers to those wishing to access sexuality education that is healthy and developmentally appropriate (Hingsburger, 1995). One young person with HF-ASD thought that often professionals based their opinions on relationships and sexuality based on their knowledge of lower functioning individuals with ASD (Koller, 2014). At other times they came to biased conclusions based on people's facial expressions (or lack thereof) in a clinical appointment (Rosqvist, 2014). Therefore, there is a need to strike a balance between protecting and prohibiting the expression of sexual behaviours. Koller (2014) suggests that there needs to be a collective appraisal of professionals' attitudes and values towards sexuality education for individuals with special needs, before provision can be seen to be helpful. Finally, it is not only the responsibility of adults to provide information, but to also support safe social opportunities for HF-ASD individuals to learn about sexuality from their peers.

Context of sexuality research and values to consider for future investigations

In order to contextualise the current findings, it is important to note that a large proportion of the early research on sexuality in autism focussed on problematic narratives of sexuality. Previous studies pathologised unusual or 'deviant' behaviours, which were often interpreted without full consideration of the context from which they were borne. Researchers have often relied on carer-reports of institutionalised, intellectually impaired participants who had no access to sexuality education. Although there were some individuals in Hellemans and colleagues' (2007) study who had genuinely problematic behaviours (e.g. paraphilias involving young children) others were often behaviours expressed in a problematic way, which could have been addressed with appropriate support (e.g. masturbation in

public). As a result, an unhelpful caricature of asexual or deviant individuals on the autism spectrum has been created.

Changes in research methodology have allowed researchers to better understand the sexual interests and behaviours of high-functioning individuals. Whilst early research was more concerned with quantifying of behaviours (e.g. how many times a person masturbates), recent studies are more drawn to understanding the social and psychological aspects of sexuality and relationships. The use of self-report methods has been one factor that has helped to dispel the impression of the 'deviant' and 'asexual' individual, by allowing researchers to gain opinions directly from HF-ASD individuals. There have also been benefits to using a comparative group of NT individuals as comparing groups has demonstrated that individuals with HF-ASD are similar in many respects with regards to their interest in relationships and sexual behaviours. However, using this methodology may be problematic as it inherently classifies sexual behaviours found in the general population as acceptable and anything that deviates from this model of behaviour, as inappropriate or, pathological. Mesibov, as cited in Koller (2014:133) encourages reflection on how researchers and professionals might approach the complex task of providing support to individuals who might not be interested in pursuing traditional sexual unions such as marriages whilst bearing in mind the needs of the individuals to find appropriate sexual outlets against commonly held societal morals and values.

To conclude, sexuality education is an area in autism research that still requires academic theory to be translated into practical, clinical and educational interventions in order to support the individuals who are most vulnerable to abuse and exclusion of having a fulfilling adult life. It is important that the agenda of sexuality education is not that of teaching those with HF-ASD to behave in a more 'normal' way. Rather, it should be seen as an opportunity for HF-ASD individuals to gain knowledge that supports them to make informed, safe decisions on their sexual behaviours and relationships. As part of a wider consideration, researchers could

also be advocates that promote accurate illustrations of HF-ASD and the extent to which it does, and does not, affect relating to others, including in a sexual context.

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Part 2: Empirical Paper

Young women's experiences of having Autism Spectrum Disorder

Abstract

Aims

This qualitative study explores some of the challenges that young women with autism spectrum disorder (ASD), (DSM code 299, APA, 2013) have encountered during their childhood and adult life.

Methods

Fourteen women aged between 18 and 30 with a clinical diagnosis of ASD were recruited via snowball sampling and interviewed using a semi-structured interview. Qualitative data was analysed using a framework analysis approach. Standardised, quantitative measures of autism, depression, anxiety, IQ and psychological distress were used to situate the sample.

Results

The framework analysis yielded four main themes that described elements of the participants' experiences specific to being a woman with ASD. These themes were 'You're not autistic', Pretending to be Normal, Passive to Assertive and Forging an identity as a woman with ASD.

Conclusions

Female-specific difficulties and coping strategies related to their experiences of ASD include delays in diagnosis, vulnerability to abuse and 'camouflaging'. Future investigative research could build on themes identified in this study. Surveying professionals' knowledge of female ASD would be useful to triangulate findings, and map the signs they might be missing in females. The development of a quantitative measure of 'camouflaging' could also be useful as a screening tool by clinicians.

Young women's experiences of having Autism Spectrum Disorder

Introduction

Autism Spectrum Disorder[2] (ASD) is a neurobiological condition with a proposed complex aetiology involving both genetic and environmental factors (Hallmayer, Cleveland, Torres et al., 2011). A diagnosis of ASD is made when a person has impairments in social communication and restricted, repetitive behaviours (APA, 2013). The prevalence of ASD in the general population is currently thought to be approximately 1 in a 100, with some estimates as high as 1 in 68 (CDC, 2014). Male-to-female ratios in ASD samples range between 2.5:1 and 10:1 (Baio, 2014). The variability in gender ratios between studies suggests that prevalence estimates of females with ASD may be inaccurate. In particular it is notable that, in clinically ascertained samples, the gender ratio is generally at least four to one in favour of males (Fombonne, 1999). Furthermore, this male-to-female ratio is even more pronounced in samples of people without intellectual disability, sometimes as high as 10 to 1 (Honda, Shimzu, Imai, et al., 2005). However, in studies where researchers do not rely on clinical referral to identify cases, the gender ratio drops to 3, or even 2.5 to 1 (Baird et al., 2006; Kim, et. al., 2011). Taken together, these observations suggest that some females who have ASD are at risk of being missed by clinical services, and that this ascertainment bias is especially pronounced for those without an intellectual disability (Lai et al., 2015). The possibility that females are at greater risk than males of having their autistic difficulties unrecognised is also implied by other findings. First, females need more autistic traits than males to achieve a clinical ASD diagnosis (Russell, 2010). Second, compared to males with similar levels of autistic traits, girls need to have more co-occurring behaviour difficulties and lower IQ to receive an ASD diagnosis (Dworzynski, Ronald, Bolton and Happe, 2012). Third, on average females receive their ASD diagnoses later

[2] The terms 'ASD' and 'autism' are used interchangeably throughout this Empirical Paper.

than equivalent males (Giarelli et al., 2010). One explanation proposed to explain this bias against identifying females with ASD is that there may be a distinctly female manifestation of ASD, a 'female autism phenotype' that differs from our current conceptualisation of the disorder, which is largely based on male cases (Mandy et al., 2012; Lai et al., 2015).

Is there a female specific ASD phenotype?

The growing literature of first-hand accounts of ASD presents a rich picture of the female phenotype. Accounts published by women with Asperger Syndrome (now considered under the umbrella term of ASD) describe how female ASD may differ from men with ASD. Liane Holliday-Willey, a best-selling American author argues that women on the spectrum are not different to men in terms of core characteristics of autism; rather, the differences lie in male and female *reactions* to having ASD. According to Holliday-Willey, females use coping strategies to mask their uncertainty in social situations and pretend to be normal by copying others or escaping into 'a world of fantasy or nature' (Holliday-Willey, 2012:11). Another influential author, Rudy Simone, who has a diagnosis of Asperger's, proposes subtle gender differences in the manifestation of ASD. She maintains that women are more expressive in face and gesture; have autistic obsessions which are not as unusual in subject matter as those of their male counterparts, and are less likely to have taste and food texture issues compared to men (Simone, 2010). Robyn Steward highlights topics that are pertinent (but not exclusive) to keeping women with ASD safe, such as managing sexual relationships (Steward, 2014). Relationships can often require the reading of nuanced behaviours and as highlighted by other research (Cridland, et al. 2013) women with autism can struggle to identify when they are placing themselves in high-risk situations with prospective sexual partners, or in abusive relationships.

Clinical Observations

Qualitative differences in social connectedness and reciprocity have been found in clinical observations of girls and boys with ASD (Attwood, 2007; Kopp and Gillberg, 1992; Gillberg and Coleman, 2000). Gillberg and Coleman (2000) noticed that females displayed better superficial social skills compared to males and that these skills were used to 'mask' their autistic features. The use of such compensatory strategies could be considered as one of the factors contributing to girls with ASD remaining undetected for longer. Cridland et al.'s (2013) qualitative findings of high-functioning females with ASD, contrast with clinical observations. High-functioning adolescent females with ASD reported significant difficulties in socialising with neurotypical girls.

Empirical findings comparing core symptoms of ASD

Researchers have attempted to go beyond anecdote and clinical observation, to study gender differences using quantitative methods, but the results of this work have so far been inconclusive. A recent meta-analysis summarising this work found females with ASD show fewer repetitive and restricted behaviours and interests (RRBI) but similar levels of social communication difficulties when compared to males (Van-Wijngaarden-Cremers et al., 2014). However, there are contradictory findings in social communication studies. In one study of high-functioning adults with ASD, females presented with less obvious autistic behaviours in social contexts when interacting with others (Lai et al., 2011). In contrast to this, a more recent study found females reported greater social-communication difficulties when compared to males, as well as poorer adaptive and cognitive functioning (Frazier et al., 2014). Similar contradictions were found regarding empathising abilities. Three different studies found that males and females with ASD were equal in their emotion perception, mentalising abilities (Lai et al., 2012) and empathising abilities, as measured using the Empathy Quotient (Auyeung, Allison, Wheelwright & Baron-

Cohen, 2012). Lai and colleagues (2011) found that females with ASD *displayed* fewer but *perceived* more autistic features when compared to males with ASD. The authors hypothesised that this could be related to females being able to 'camouflage' their difficulties better than males and internalise their problems.

Co-occurring conditions

Comparisons of female and male children with autism show high rates of internalising symptoms in females and more externalising behaviours in males (May et al., 2014). However, no differences are found between genders when comparing high-functioning adults (Hofvander et al., 2009). There is also evidence that 'social relational difficulties' are more closely related to psychopathology in females than in males (Crick & Zahn-Waxsler, 2003). Females of all ages with ASD have been found to experience greater sleep problems, depression and anxiety (Hartley & Sikora, 2009), more emotional problems (Mandy et al., 2012) and more 'attention' and 'thought' problems (Holtmann, Bolte & Poutska, 2006) when compared to males with ASD.

Anecdotal accounts (Holliday-Willey, 2012; Steward, 2014) and clinical observations (Attwood, 2007; Gould & Ashton-Smith, 2011) of people with ASD have suggested important differences in how males and females with ASD present. However, to date the empirical literature is contradictory with a lack of replication of previous findings. This may reflect the following methodological limitations of work in this area. First, most quantitative studies to date have not tested specific ideas about gender differences, but have rather sought to compare males and females in terms of their core ASD symptoms and co-occurring conditions. This broad-brush approach fails to address specific questions raised by the clinical literature, and may miss key ASD gender differences. Second, the measures used in studies were mainly developed using male participants, and so may be biased against capturing

aspects of the female ASD phenotype, leading to underestimation of gender differences (Mandy & Tchanturia, 2015). Therefore, in order to advance the study of ASD gender differences, a systematic inductive investigation of the female phenotype is required to yield specific, testable hypotheses about the female ASD phenotype; and to promote the development of measures that capture 'female' as well as 'male' manifestations of ASD. As such, a qualitative approach will allow for an exploration of female-specific ASD markers, with a longer-term view of contributing to the development of standardised measures that are sufficiently sensitive to capture the female ASD phenotype. Specifically, this study used semi-structured qualitative interviews (Appendix 8) with women to address the following questions:

(1) How do young women with ASD view their diagnosis and the process of obtaining it?

(2) What kinds of difficulties do young women with ASD experience *and*

(3) What kinds of coping strategies do they use to manage: at home, socially, in education and at work?

Method

Overview

Young women who had been diagnosed with high-functioning ASD in the past ten years were invited to contact the researcher via online adverts to take part in semi-structured interviews (Appendices 3 and 4). The interviews consisted of questions that explored the experiences of being a woman on the autism spectrum, including challenges and coping strategies used in daily life.

Service User Consultation

During the design of this study, Robyn Steward, an autism consultant and young woman with a diagnosis of high-functioning autism, served as a voluntary consultant to this project. Robyn contributed to the content of the interview, information and consent sheets and helped to pilot the interview schedule. However, her data was not incorporated in the analysis, as she did not meet the criterion of having received a diagnosis in the past ten years.

Ethical Approval

Ethical approval was sought and granted via the UCL Research Committee only, as participants were not recruited via any NHS sites or through clinicians. (Research code: **5339/001**; Appendix 2).

Recruitment Procedure

Young women were recruited via snowball sampling, through use of a small pool of initial informants including Robyn Steward and the first couple of participants who then passed on the research study details to friends of theirs. A research website with recruitment information on the study and links was created. The website link was then placed on social media sites and forums frequented by young women with ASD including Facebook. Women with HF-ASD who were interested in the study contacted the researcher directly. All participants resided in the UK, however, the majority lived outside of London, including cities in the West Midlands, North West England and the Scottish border, which required the researchers to travel to carry out some interviews.

Participants

Young women were eligible to participate in the study if they met the following criteria:

i) they had received a diagnosis of ASD from a UK based clinician in the past 10 years
ii) they were aged between 18 and 35;
iii) they lived in the United Kingdom;
iv) their level of functioning was above 70 on an IQ measure (to reduce group heterogeneity as the experiences of those with an IQ below 70 may be partly conditioned by their intellectual difficulties).

Table 1. Participant Details

Participant No.	Age at time of interview	Age at diagnosis	WTAR scaled scores	AQ-10 *(cut-off=6)*	Employment
P01	24	22	122	9	Creative
P02	23	15	115	6	Student
P03	28	27	110	8	Professional
P04	25	16	113	10	Support Worker
P05	25	23	122	10	Volunteer
P06	30	26	124	9	Student
P07	22	21	124	9	Creative
P08	24	20	85	10	Professional
P09	27	22	108	8	Administrator
P10	28	26	117	9	Volunteer
P11	28	27	108	8	Full-time mother
P12	27	19	115	8	Student
P13	26	19	92	10	Volunteer
P14	28	26	110	9	Athlete

Seventeen young women contacted the researcher asking to participate in the study. Three did not meet eligibility criteria: one young woman was outside of the qualifying age range (51) and two lived outside of the UK (USA and Australia). Only UK residents were interviewed in order to control for cultural factors that might influence the findings. Young women who had received an ASD diagnosis more than 10 years ago, may have reported different coping strategies, compared to

those with a more recent diagnosis. Accessibility was taken into consideration and depending on the social anxiety concerns expressed by the participant, the researcher made the appropriate adjustments at the interview stage. Although the researcher's preference was to interview participants face-to-face, she sought to meet the needs of each participant and used internet-based video calling (via Skype), Skype instant-messenger and telephone. Ten of the young women were seen in a face-to-face interview, one of which was completed over the telephone as time ran out. Three participants were interviewed using Skype video calls and one was interviewed using Skype messenger. The mean age of the participants was 26.7 years, (SD = 2.30). Diagnoses of high-functioning ASD had been made in the past 10 years, and the mean age of diagnosis was 21.3 years, (S.D. = 4.79). All participants' level of functioning was >70 on an IQ measure.

Design

The research design for this study was qualitative and allowed for the generation of new ideas from the in-depth accounts of each woman's personal experience of ASD. Quantitative screening measures for anxiety, depression, autism and IQ were used to situate the sample.

Measures

(1) Semi-structured interviews. Participants were interviewed using a semi-structured interview developed specifically for this study (Appendix 8) in consultation with the supervisor and the project consultant, Robyn Steward. Smith, Harré and van Langenhove's' (1995) observation regarding the flexibility of semi-structured interviews led us to conclude that this method is well suited to young women with ASD as the interview items do not need to be read out in a set order, thus allowing

the interviewer to freely follow the participant's line of response. The community psychology principles outlined in Barker and Pistrang (2005) also apply to this study, especially those of 'Giving Voice to Traditionally Under-represented Populations'. Consultations with Robyn Steward shaped the interview process. Robyn outlined that individuals with autism do not necessarily tell stories in a chronological order: rather, they make connections according to a process of visual or verbal association. Therefore, we ensured that each woman's narrative dictated the line of questioning, instead of rigidly pursuing the pre-prepared order of questions on a card. Robyn also highlighted certain questions that were not clear or explicit enough in their intention and therefore risked being misunderstood by someone with ASD.

Face-to-face interviews were chosen as an especially productive method as they were thought to capture in-depth and thoughtful responses from the participants as opposed to only using quantitative measures, which might elicit closed, narrow responses. The option of non-face-to-face interviews was offered as an alternative to increase accessibility and allow voices of socially isolated or anxious individuals to be heard. The topics identified in the interview schedule were based on previous research findings discussed in the introduction, and on discussions with Robyn Steward who had recently published a book on areas of concern for women with ASD (Steward, 2014). Questions in the interview were focussed on gaining an understanding of young women's strengths and difficulties in a range of situations, and the types of coping strategies that they used to manage them. Questions included topics such as diagnosis, friendships, relationships, sensory sensitivities and interests. Interviews were designed to last up to an hour. This is a relatively short period of time considering that this is a new topic of research with many issues being addressed in a short interview. However, we were mindful that participants might find it tiring or challenging to talk for longer than an hour, especially to a person they had never met before. Participants were also asked about their timing

preferences, and if they needed breaks between questions or a copy of the questions in front of them to act as a prompt during the interview. The opportunity to split the interview into two parts, should the session run over an hour, was also offered. These options were presented with a view to giving all participants an equal opportunity to express their experiences, bearing in mind that participants had a range of communication styles, abilities and needs.

(2) Autism Quotient-10 is a ten item, brief version of the Autism Spectrum Quotient-50 (50 items), used to correctly classify individuals as having or not having ASD (Woodbury-Smith, Robinson, Wheelwright & Baron-Cohen, 2005). In our study, the AQ-10 was chosen as a screening measure to ensure all participants met the criteria for an ASD diagnosis. Participants rate items by selecting one of four statements. Depending on the statement and its relevance to autism symptoms, the ratings are scored as '1' or '0'. Higher scores indicate higher levels of autistic symptoms. A score of 6 or above indicates possible ASD caseness and is the suggested optimal cut-off (Murray, Booth, McKenzie et al., 2013).

(3) General Health Questionnaire -12 (GHQ-12) is a twelve-item, brief version of the GHQ-60. It is used as a screening device to assess the respondent's current mental state (Goldberg & Williams, 1988) and is a reliable and valid measure of severity of psychological morbidity (Goldberg, Gater, Satorius et al., 1997). Participants in this study were asked to complete the measure for the researcher to gain an overview of the mental wellbeing of the sample. The GHQ-12 comprises six items that describe positive mood states and negative mood states (Appendix 11). Participants are asked to rate them according to a scale from '0 = better than usual' to '3 = much less than usual'. In young adults, a cut-off score above two thirds of the total outcome yields the highest possible sensitivity rating of 64% and specificity of 79% (Makowska, Merecz, Mosicicka et al. 2002).

(4) Hospital Anxiety and Depression Scale (HADS) is a fourteen-item self-assessment scale used to detect depression and anxiety over a one week period (Appendix 10). Participants are asked to respond to statements that best describe their state of mind. Respondent select answers on a four point Likert scale of severity ranging from 'Not at all = 0' to 'Most of the time = 3'. Higher levels indicate greater severity of symptoms. The fourteen items are divided in half: seven items measuring anxiety and seven measuring depression. Respondent receive a score between 0 – 21 for each domain. A recent review of the HADS, indicated specificity and sensitivity ratings for anxiety were 0.78 and 0.9; and specificity and sensitivity for depression were 0.79 and 0.83, respectively (Bjelland, Dahl, Haug & Neckelmann, 2002).

(5) Wechsler Test for Adult Reading (WTAR) is a neuropsychological assessment tool, which provides a measure of premorbid intelligence (Holdnack, 2001). The demographic prediction tables of the WTAR are co-normed with the widely used Wechsler Adult Intelligence Scale (WAIS). The participant is presented with 50 irregularly spelt words and asked by the examiner to pronounce each in turn. Each correct word pronunciation is scored as '1', with a maximum raw score of 50. This raw score is standardized by age and compared to the scores predicted for the participant's demographic classification. Examiners can assess the participants' vocabulary by their ability to pronounce the irregularly spelled words, and by extension, estimate their premorbid IQ. In this study, researchers used the WTAR in order to offer a quick estimate of verbal IQ, to establish whether participants were able to easily verbalise their experiences and to situate the sample.

Procedure

Information Sheets were provided in the first instance, to the young women who had requested to take part in the research (Appendix 5). These were posted or emailed at least 24 hours before consent was requested, in order to allow participants time to read the relevant information and to consider whether they wanted to take part in the study (Mental Capacity Act, 2005). Young women who decided to participate then arranged a time to be interviewed. Interviews were conducted and audio recorded in a setting such as a community centre or at the university base, depending on participants' wishes. For the five participants who were interviewed on Skype, interviews were carried in a private room at the university base (Appendix 6). Consent forms were given at the start of the interview and the participant was informed about the recording of the interview, confidentiality and their freedom to withdraw from the study at any point (Appendix 7). Participants were also reminded that they could decline to answer any questions and could terminate the interview at any time. They were given £15 as compensation for their time at the end of the interview. Participants completed all quantitative assessments (HADS, AQ-10, GHQ, and WTAR) prior to the audio-recorded interview. The whole process lasted one hour and thirty minutes for each participant.

Analytic Procedure

Qualitative data. All but two interviews were transcribed by S.B. The remaining two were transcribed by research assistants. Transcriptions were later analysed using a Framework Analysis approach (Ritchie and Spencer, 1994; 2003). Framework Analysis was chosen as an analytic approach because it offers a systematic process that allows the researcher to be transparent in the analytic stages of the procedure. This method is considered appropriate for the current study, as it is

inductive and data-driven, whilst also allowing the researcher to consider predetermined research questions (Ritchie et al., 2014).

The five key stages of Framework Analysis (Ritchie & Spencer, 1994; 2003) are outlined below:

- *Familiarisation* – At this first stage, each transcript is read and the audio-recorded interviews are listened to several times to become familiar with the data.
- *Identification of a thematic framework* – Interesting parts of the data are identified using codes. The researcher then begins to underline interesting parts of the data and uses codes or labels to describe the content of each passage.
- *Indexing* – At this stage the researchers convene and after discussion agree on an initial set of codes, each with a brief definition. This forms the initial analytical framework. The iterative process of refining-applying-refining the analytical framework is repeated until no original codes are generated.
- *Charting* - Once all the data has been coded using the analytical framework, it is summarized in a thematic matrix. The data is coded using the analytical framework and summarised in a thematic matrix. Data is abstracted from transcripts for each participant, coded and summarised using verbatim quotes and finally inserted in the corresponding cells in the matrix.
- *Mapping and interpretation* - In the final stage, themes are generated from the data set by reviewing the matrix, through associations made between the participant's responses and categories. Themes are generated, explored and discussed within the research team.

In this study, the interview transcripts were read closely to ensure that the researcher became familiar with the data. Following this, transcripts were re-read by the researcher (S.B.) and the supervisor (W.M.) and ideas that appeared to be

relevant to the research questions were coded. From the list of codes, groups of potentially relevant themes were generated. The interview transcripts were uploaded to QSR International's NVivo 10 software (QSR, 2014), in order to highlight particular coded passages and organise the codes more efficiently. The codes were then reviewed, grouped into themes and subthemes, which formed an initial conceptual framework. Participants and the research supervisor acted as consultants, and gave feedback with regards to whether the themes were grounded in the data. Successive discussions took between the researcher and supervisor in order to ensure that the data was fairly represented in the final framework.

A thematic table was constructed and used to identify quotes in the transcripts representative of each theme (Table 3). Example quotes extracted from the interviews are shown in the Results section as evidence of quality of the analysis, and participant validity checks were implemented (Ritchie and Spencer, 2003). This involved participants being sent a summary of themes and related quotes (Appendix 16). Reliability of the coding process was ensured by frequent consultation between the supervisor and the researcher before consensus was reached on the final framework.

Quantitative Data. Descriptive statistics were used to summarise data from the three quantitative measures, the GHQ, HADS and AQ (Table 2, Results Section).

Disclosure of Researcher's Perspective

I am a White British female researcher completing this research as part of my Clinical Psychology Doctorate in London, UK. I have a background of working with young adults and children with ASD, both in a professional capacity (support worker, assistant psychologist) and as a researcher. I have an interest in improving the quality of life for individuals with ASD. During my role as an assistant psychologist in a CAMHS service I noticed that a number of young girls did not meet the current

criteria for an ASD diagnosis. This ignited my interest in understanding why certain girls were not receiving a diagnosis, and as a result, the support they required. I am a feminist and subscribe to a strengths-based view of autism, which I consider as a *difference*, not a *disorder*. I anticipated that the analysis would highlight some differences between ways in which young men and women cope with having ASD. I attempted to set these expectations aside during the interview process by avoiding leading questions. Similarly, during the analysis stage, I was encouraged to remain reflective on my position and how this might influence my analysis by taking a transparent, systematic approach to data analysis and by engaging in regular discussions with my supervisor.

Results

Results from the HADS and GHQ

All fourteen participants completed the HADS and GHQ measures (Table 2). The mean HADS-A (anxiety) score was 13.5 (SD 3.7, range 7-20), which is above the recommended cut-off for caseness. All but one participant (P09, score 7) scored above the cut-off score, indicating a high prevalence of anxiety-related difficulties in this sample of young women. The mean HADS-D (depression) score was 5.3 (SD 4.8, range 1-15), below the recommended cut-off score for caseness. Three participants scored above the cut-off score, indicating some difficulties with depression were present in the sample. The mean GHQ score was 15.4 (SD 4.4, range 9-27), above the lower cut-off indicating psychological distress. Three participants (P03, P09 and P14) scored in the 'distress' range, indicating that they were currently experiencing some form of psychological distress. Two participants (P05 and P08) fell in the 'severe' range of distress, indicative of severe psychological difficulties at the time of interview.

Table 2. HADS anxiety and depression scores and GHQ-12 scores

Participant No.	**HADS – A** *(8 = cut-off)*	**HADS – D** *(8 = cut-off)*	**GHQ** *>15 = distress; >20 = severe*
P01	13	7	13
P02	14	2	11
P03	11	2	16
P04	20	8	17
P05	18	15	27
P06	11	1	14
P07	13	3	15
P08	18	14	21
P09	7	3	16
P10	15	9	12
P11	17	1	9
P12	12	1	14
P13	10	7	15
P14	10	1	16
Mean	13.5	5.3	15.4
SD	3.7	4.8	4.4

Results from the Interviews using Framework Analysis

The transcripts of the interviews with young women with ASD were analysed using Framework Analysis (Ritchie and Spencer, 1994; Ritchie et al., 2003). The final thematic framework is outlined in Table 3.

The four major themes identified from the data are as follows:

(1) 'You're not autistic' recognises common barriers to gaining a diagnosis as a woman;

(2) Pretending to be Normal identifies strategies that young women employed to try and fit in with their peers;

(3) Passive to Assertive explores how passivity and social naivety impact on young women with ASD and how they have learnt to be assertive;

(4) Forging an Identity as a young woman with ASD outlines social difficulties associated with being a young woman with ASD and how they have chosen to forge their identities through their interests.

Table 3. Framework analysis and frequency of themes

Theme	Subtheme	Frequency (out of 14)
1."You're not autistic"	a. Labelled with non-autistic diagnoses	12
	b. Unhelpful professional stereotypes of autism	12
	c. Quiet at school, so went unnoticed: 'I should have burnt more cars'	6
	d. Misunderstood, unsupported or blamed by teachers	8
	e. The costs of a late diagnosis	8
2. Pretending to be Normal	a. 'Wearing a mask'	8
	b. Learning social behaviours from TV, books and magazines	6
	c. Social mimicry	5
	d. The costs of masking	5
3. Passive to Assertive	a. Please, appease, avoid conflict	7
	b. Entrapment in abusive relationships or risky situations	8
	c. Victim of sexual abuse	9
	d. Learning to be assertive	8
4. Forging an identity as a woman with ASD	a. Societal pressures: what is expected of young women	11
	b. Friendships: uncertainty and intensity	12
	c. Hard to be friends with neurotypical girls	8
	d. Easier to be friends with boys	7
	e. Friendships and support online	7
	f. Interests define identity and self-confidence	7

Within these four themes, nineteen subthemes were identified. Quotes were labelled as 'P' followed by a unique identifier for each participant. To preserve confidentiality, unique identifiers (e.g. P01) are not related to those listed in Tables 1 or 2.

(1) 'You're not autistic'. This theme explored young women's experiences of a delayed diagnosis of autism. The first two subthemes discuss perceived biases held by GPs and mental health professionals; the following two subthemes consider reasons for being 'missed' and 'misunderstood' in school. The final subtheme considers the implications of having a late diagnosis.

(1a.) *Labelled with non-autistic diagnoses***.** Almost all the young women reported having experienced one or more mental health difficulties: mainly depression and anxiety, with some having experienced eating disorders. However, many commented that health professionals treating them had never suggested that their difficulties might be related to autism.

> *"Four to five years of depression and anxiety treatment. Five different antidepressants taking to maximum dose and back down again with no effect…years of talking therapy… and not once did anyone suggest I had anything other than depression". (P05)*

In some cases, family members or friends had suggested that they might be on the autism spectrum. After having researched ASD and decided to pursue a diagnosis from their GP, five participants reported that their GPs did not recognise how they presented as 'autism' and failed to act (i.e. referral for further assessment) on the information they were given. Others reported being misdiagnosed:

> "*You go to your doctor…and you get diagnosed with multiple personality disorder which is completely opposite to what you are". (P07)*

One participant adopted a strategic approach to gaining a referral. After an initial dismissal (her GP suggested that her difficulties related to hormones), she returned to her GP, with a view to getting a social anxiety diagnosis to use as a 'stepping stone' to an autism assessment. In contrast, there were two exceptional cases of a speedy diagnosis: both young women had been immediately referred for assessment after presenting to their GPs who had recognised signs of autism in their behaviours.

(1b.) Unhelpful professional stereotypes of autism. Twelve participants thought that a delay in diagnosis was partially due to a lack of professional knowledge of autism in females:

> "*When I mentioned the possibility to my psychiatric nurse she actually laughed at me...I asked my mum, who was a GP at the time,*

> *she's retired now, if she thought I was autistic. She said, 'Of course not'. At the time, a good 10 years ago now, there just wasn't much information about how girls presented, and from what she knew I was nothing of the sort". (P05)*

Other young women suggested that autism stereotypes such as '*The Rain Man'* (P03) and the extreme social impairments associated with classical autism added to professionals' reluctance to diagnose a woman who showed some capacity, albeit superficial, to socialise with others. Young women reported that other professionals also held male-biased stereotypes of autism. During a diagnostic interview, the assessing psychologist appeared to be taken aback when he found that she was a literature student and not an engineer. Similarly at school, she was not referred for a diagnosis:

> "*I'll always remember my special needs teacher saying I'm too poor at maths to be autistic". (P04)*

(1c.) Quiet at school, so went unnoticed: 'I should have burnt more cars'. Teachers were other significant professionals who, according to six participants in the current study, had little knowledge of how ASD presented in females. Indeed, young women reported that their passive and compliant behaviours where often misinterpreted as being 'shy' or 'good'. Four participants described being regarded by teachers as "teacher's pet" (P04) or the 'model pupil'. Despite being quiet and well-behaved girls in school, three young women talked about being disruptive and having regular 'meltdowns' at home:

> "*I was unbearable with my mother, but at school I was perfect". (P09)*

Eight young women suggested that their quiet and passive behaviours were seen as socially acceptable for girls, and had they been more disruptive, they might have been noticed sooner.

> *"The reward for trying hard to be normal was to be ignored because you were acting normal and I look at stories online of kids who were going off the rails and I think, I should have just burnt more cars". (P09)*

(1d.) Misunderstood by teachers. Four young women spoke about teachers misinterpreting their behaviour as rude or lazy, when in fact their behaviours were related to difficulties with social rules or processing difficulties:

> "*I was often accused of being rude when I had absolutely no intention of being so… he started saying I wasn't trying and that I was a waste of his time and he yelled that at me in front of the entire class". (P04)*

Other poignant examples of being misunderstood came from four other young women who were bullied. Upon complaining to their teachers, they recalled that *they* were blamed and told that they should try and 'act more normal'.

> "*When I was being bullied, I was told not to antagonise these girls and actually I was only antagonising them by being myself*". (P03)

(1e.) The costs of a delayed diagnosis. Most of the interviewed young women had been diagnosed between the ages of 20 and 30. Eight participants shared how they thought a delayed diagnosis had impacted on their wellbeing and education:

> "*I think women tend to be diagnosed later in life when they actually push for it themselves…when you're a child, you don't realise that you're anxious and depressed… [that] your education is going to suffer because of that and I think that if I had known, and if people had helped me from earlier on, then life would've been a whole lot easier". (P07)*

Women also talked about their emotional reactions to having a late diagnosis, and shared their regret and anger at having 'tried to be good' for so long, and as a result being missed. Women said that being diagnosed sooner would have helped them to understand their difficulties with making friends. Knowing about their diagnosis may also have protected against the social vulnerabilities associated with having autism:

> "*Had I known about Asperger's, I think I'd have known that I'm more suggestible…and I might not have ended up in the situations that I did". (P14)*

(2) Pretending to be Normal. This theme describes women's experiences of being perceived as 'different' by their peers and the strategies that they used to 'fit in'. The first three subthemes describe the strategies that women learnt from various media and other people and the final subtheme reflects on the costs of pretending to be someone else.

(2a.) 'Wearing a mask'. Socialising as part of a large group was reported as challenging by all the women. To cope, eight women described putting on a 'mask' or acting as a certain 'persona', which allowed them to blend in and socialise:

> "*I honed something of a persona which was kind of bubbly and vivacious, and maybe a bit dim, because I had nothing to say other than adult novels. So I cultivated an image, I suppose, that I brought out to social situations as my partner's girlfriend, that was not 'me'". (P09)*

Young women described how their masking was something they used to hide their autistic traits in order to appear normal. One woman described using her 'mask' as a 'double-bluff' technique to openly joke about an aspect of her behaviour that a peer might have labelled as autistic:

> "*I'll mask if I act weird, which is typical of ASD, I'll make a joke about it". (P02)*

Another woman described using alcohol as a way to *"free me up to maintain my neurotypical mask" (P03)* in situations where she needed to pretend to be interested in conversation topics, such as television programmes that she did not like.

(2b.) Learning social behaviours from TV, books and magazines. Six of the interviewed women described learning how to 'mask' from different media sources

including characters in American sit-coms, magazines, books on body language and novels. Using the actors as a guide, one woman studied emotional expressions from her favourite series and would later re-enact the facial movements in order to practice how she might react in a specific social situation. Teenage girls' magazines also acted as a resource from which to learn about hidden meaning in body language and how to behave to get a specific reaction from others:

> "*They'd have the right behaviour for certain things, so 'If you want this, you should do this'". (P02)*

Another woman learnt phrases and facial expressions from fictional literature in order to manage more unpleasant situations, such as bullying.

> *"When I was being bullied, there's this book by Ellen Montgomery and the character Emily, whenever somebody is horrible to her…she just looks at them, and because of her expression they go away, and I thought that I could do the same…it didn't work at all and I was aghast". (P04)*

*(2c.) Social mimicry***.** Women reported that their social mimicry was something they did 'automatically' and therefore was interpreted by the researcher as distinct from 'masking' behaviours, where women consciously learnt to 'put on a front'.

> *"I honestly didn't know I was doing it until I was diagnosed, but when I read about it, it made perfect sense. I copy speech patterns and certain body language". (P05)*

Two women had noticed that they would quickly pick up accents from other people. They thought that this happened because they were trying to be as similar as possible to the person they were socialising with:

> "*I automatically mimic what other people are doing, what people are saying, how people say things, I went on [Girl Guide] camps…and I would come back with strong accents. But I can't consciously put on an accent...my way of coping is that I mimic". (P06)*

(2d.) The costs of masking and mimicking. Despite having acquired superficially adaptive strategies for coping in social situations, women also identified some significant costs related to 'masking' and 'mimicking'. Four women found that the effort required to consciously process people's behaviours and later act them out, was exhausting:

> *"It's very draining trying to figure out everything all the time, everything is more like on a manual, you've got to use one of those computers where you have to type every command in". (P01)*

Participants also talked about confusion with their own identity as a result of masking and pretending to be someone else. One reflected that she did not know who she was unless it was in relation to others, other women had *"acted neurotypical" (P07)* so convincingly that at times they had doubted whether they even had ASD. Women also reported having masked to fit in with social expectations of other women. This had, in one case led to situations where she felt pressured to behave in a way she knew was wrong, but felt unable to protest.

(3) Passive to Assertive. This theme describes the effects of passivity and eventual assertiveness in women's behaviours. The first three subthemes explore how women's passivity had led to entrapment in unhealthy relationships, high-risk situations and in many cases, to sexual abuse. The final subtheme discusses how women had learnt to assert themselves.

*(3a.) Please, appease and avoid conflict***.** Seven women spoke about pleasing others and, at times, acquiescing to what others wanted from them in order to receive affection from others or feel socially accepted. There were also concerns with wanting to do the 'right thing' as expected by society:

> "*I almost feel pressured by society to do it because you get told this is what is expected of you to make to be a good girlfriend and you think, if I don't do it, then I am not fulfilling my duties". (P08)*

Five women spoke about going to great lengths to avoid conflict. One woman reflected that she used to feeling very uncomfortable about having an argument or debate with another person, because she had viewed this as 'having a fight'. In some situations where women had avoided conflict and later over-asserted themselves, it had ended friendships or caused lasting damage: "*When it finally comes out I can be a bit too blunt*" (P10). However, there were two exceptions to women being passive. One woman in particular made it clear that she had never appeased if she knew something was wrong, on the contrary, it is likely she would be very vocal about this.

*(3b.) Entrapment in unhealthy relationships and dangerous situations***.** Eight women gave two overarching reasons to explain how they had become entrapped in a situation where their safety was compromised. One young woman commented that when engaged in social mimicry:

> *"There's potential for you copying a guy's flirtatious behaviour without realising that's what you're doing". (P05)*

Secondly, many women reported finding it difficult to 'read' other people's intentions and discerning if someone was being friendly or was attracted to them. In contrast to their neurotypical female peers, who would share skills to keep themselves safe, women reported feeling isolated as teenagers and lacking a point of reference from which to learn these skills.

> *"Because we don't sense danger and can't. That's one reason, I think you not reading people to be able to tell if they're being creepy, you're that desperate for friends and relationships that if someone is showing an interest in you, you kind of go with it and tend not to learn from others safety skills". (P07)*

Women's uncertainty regarding social rules in a particular setting was also mentioned. For example, some women had not known that they *could* say 'no' when they had wanted to refuse sex or other people's advances. At times when they had

known they could refuse, women reported that they had not known *how* to say 'no' or how to leave a situation until it was too late. Five women talked about being trapped in unhealthy relationships that they could not escape where they were being manipulated by their partners:

> "*I kept trying to break up with him and whenever I did he would say I didn't know my own feelings…I was at my wit's end I felt so trapped*". *(P04)*

*(3c.) Victims of sexual abuse***.** Nine of the 14 women reported having been victims of sexual abuse at one point in their lives. Women commented that their social naivety (related to their ASD) had led them to being manipulated and taken advantage of by others. Only half of the accounts of sexual abuse happened in abusive relationships with boyfriends. Two women spoke about feeling obliged to have sex, as they felt this was what was expected of them in a girlfriend role. One participant commented that arguments would *"end up in us having sex even if I didn't want to" (P11).* Three women reported "*gradually being pestered"* (P14) into sex when in a relationship. Three other women spoke about having been raped by people they did not know. One particularly distressing incident involved a young woman who was groomed by a peer, pretending to be a friend:

> *"She tricked me into thinking that she was being nice and took me to this house where these three men raped me". (P07)*

(3d.) Learning to be assertive. This final subtheme explores women's increased assertiveness. The findings suggest a link between self-awareness and assertiveness. Eight women who had reported difficult relationship and interpersonal experiences were later able to reflect and understand how they had been manipulated. As a result, many described feeling able to recognise and 'read' other's intentions and used this knowledge to leave situations where they felt uncomfortable: for example, *"[there were] times when guys pushed for it, so I just walked away" (P05).* Other women used skills they had actively learnt, such as *"a*

guide to being assertive" (P02) provided by a counsellor and skills learnt in the workplace to manage children with challenging behaviours.

> "*I've become quite good at resolving conflict in order to avoid it…it just made her more and more angry because she would ready to have this massive argument and I'd diffuse the situation". (P11)*

Four women explained how they had used their diagnosis of Asperger's as a tool to give them more confidence asserting their opinion. Women commented that before having a diagnosis they would have *"just kept quiet" (P10)* but now they were able to ask people for clarification or explanations when they were unsure of a situation. One participant reflected that in the past she had used her diagnosis as a means of excusing herself from an activity, however, now she no longer felt the need to provide an explanation, and felt confident enough to refuse activities she did not enjoy.

(4) Forging an identity as a woman with ASD. The creation of this final theme involved more inference on the part of the researcher. This theme related to women's perceptions of social gender stereotypes that they had felt pressured to, struggled to, and at times refused to fulfil. It is a pertinent topic, as their ASD diagnosis might have impacted on their ability to fulfil these perceived expectations. The first and last subthemes discuss women's views of gender-stereotypical roles and how their identities were more likely to be defined by their interests. The remaining four subthemes discuss friendships.

(4a.) Societal expectations of how to be a woman. Eleven women talked about their perceptions of gender-stereotypical roles and how these had influenced aspects of their lives, and sometimes clashed with their ASD. One woman declared that she didn't *"really accept the validity of gender stereotypes" (P04)* and openly rejected gender-based theories of behaviour. Regarding romantic partnerships, two women

were aware of having made choices outside of the 'status quo' and were comfortable with having partners many years their senior:

> "*He's 50, err so what, such conventions never bothered me before". (P07)*

This compared to the views of three other women who had tried to abide by social conventions, with various outcomes.

> "*From birth females are expected to take that mother role. They're expected to take that caring, nurturing, 'looking out for everyone', kind of role". (P08)*

One of the three women reflected on the difficulties that she had faced when attempting to 'fit' into a role that she did not identify with. She commented that she had spent the past eight years of her life trying to be the 'perfect wife' and had lost her sense of self and identity because "*I knew that I wasn't being me" (P10).* Further, three women thought that eccentricity was more accepted in males with ASD compared to females with ASD who:

> *"Often come across as brash or bossy…shy guys can be endearing to girls, but bossy girls are rarely attractive to guys so I do think guys have a slight advantage there". (P08)*

(4b.) Friendships and uncertainties. Women reported difficulties in discerning how other people felt and discussed how this affected their ability to navigate socially complex situations, such as making and maintaining friendships. This was an area where women felt that society expected them to be competent, being women, however, many found navigating companionships challenging. Eight women reported feeling uncertain as to what was expected of them and how to behave in a friendship. Where friendships had previously been formed, women reported that they had been unsure of how to behave:

> "*Not knowing what was expected of me, not being able to pick up on when to provide support or how often to get in touch". (P09)*

In established teenage friendships three women reflected that the main area of conflict would be around wanting to have the exclusive attention of a friend.

> *"A lot of my problems came about with them having other friends that I didn't like or I didn't get on with…I didn't really want to share them". (P10)*

Women also found it difficult to 'define a friend'. Three women said they would have to consciously think of situations, such as being helped in the past or recalling how a person had reacted to a specific event to know if someone was a friend.

> *"This person sort of dealt with this and was still my friend afterwards, [so] they must be good friends". (P11)*

Despite reported difficulties with friendships, nine women also talked about having retained a small number of long-lasting friendships from school or university, where they had been accepted for 'who they were' by others.

*(4c.) Harder to be friends with girls***.** Eight women reported challenges in forming friendships with neurotypical women. This was another area where women found it challenging to meet what they perceived to be socially expected skills of a typical female. During teenage years, women commented that many of the girls were often more sophisticated in their social abilities: *"girls…socially are a lot quicker" (P02).* One woman recounted being bullied when she had tried to apply the same strategies to approach people when she had been younger: *"My name is Rosie, will you be my friend?" (P11).* Other challenges with socialising related to lack of interest in teenage girl activities such as getting dressed up, wearing make-up and short skirts. Women also said they found gossip and competition amongst females difficult to navigate.

> *"The gossip as well in women that can be quite hard…if they're talking about someone sometimes it's hard to know whether they are… [being] mean...you know you worry that if you say the wrong*

> *thing with other women that you're going to be talked about behind your back". (P10)*

One woman commented that at times, girls would notice someone who was vulnerable and *"they'll generally put her down" (P02)*. Other women felt intimidated by neurotypical girls and had experienced rejection for being seen as "*one iota different from them". (P03)*

*(4d.) Easier to be friends with boys***.** In contrast, women said they felt more at ease in their friendships with males. However, one young woman highlighted that relating to men better was not necessarily related to gender, but to society 'allowing' men to be more straightforward, and this being a communication style that she felt more at ease with. Seven participants described boys as easier to relate to because they were more honest in their communication style.

> "*I just feel so much more comfortable with men because they're more, you can take them at face value and its not that fear of them judging you or having alternative motives and thoughts and they kind of say things straight". (P07)*

One woman said that if her male friend was not interested in a line of conversation, he would *"would literally just turn to me, and just be like, 'Shut up you are going on about that too much, I want to talk about this now' " (P08).* She thought this was helpful, as she did not have to decipher if he was bored by having to read his facial expression, because he would just tell her. Neurotypical boys were also seen as less judgemental and more accepting of differences and understand them as *"Well, she's a girl, she not going to be like me because she's a girl" (P14).*

(4e.) Online friendships. Seven women spoke of the importance of friendships that they had made or maintained using online media. Friendships with other 'Aspie' women from online forums were particularly important. One woman described her friends as a: "*gang of fellow Aspie women who I think of as my family" (P10).* Some

had found that their visits to online forums had increased their pride and confidence in having a diagnosis:

> *"It's a difference not a disorder...it was really helpful because it made me feel good about myself". (P02)*

Other women used blogs as a way of hearing other women's stories and sharing their own, and as a result felt accepted and understood by others who have been through similar experiences.

> *"Something that I really appreciate about having the diagnosis is actually being in this club now where people talk about their experiences and having so many echoes of my own". (P03)*

Four women also commented on how using an online platform had made communication easier. For example, in normal face-to-face communication, one would be expected to 'read' body language, tone of voice and facial expression, so *"If all we have is typing for each other, then it's completely equal" (P10).* Women talked about being able to express themselves more clearly when they didn't have the pressure and anxiety to respond immediately, as with a face-to-face conversation. Further, use of messaging was also an easier and less awkward medium to express difficult emotions and access support from their friends.

*(4f.) Interests define identity***.** The final subtheme explored the importance of interests as being a defining feature of ten women's identities and '*raison d'etre'*. Women's current interests varied enormously, and included animals, in particular dogs, international boat racing, sexuality, physics, literature, The Middle East, autism and events organising. Three women also spoke about how their interests had provided them with structure and given them a sense of achievement.

> "*It's very good…for my self-belief, to see that that I can do something that's recognised by other people as beneficial and productive*". *(P04)*

Four participants, whose interests were their full-time occupation explained how their activity defined them as people, gave them a focus in life and provided a sense of personal wellbeing.

> "*I was very obsessed, and still am, with creative writing and that kind of provides the entire focus of my life…I would say I forge most of my identity on that and the degree…they allow me to express myself in different ways, they form the basis of my identity". (P09)*

Respondent validity

All participants were sent a summary of the themes identified in their interview (Appendix 16) and were invited to comment on the interpretations and themes outlined by the researcher. Eight participants commented on the analysis. Young women's perspectives on the themes were taken into consideration and two quotes were placed under different theme heading in response to feedback.

Discussion

To our knowledge, this is the largest and most in-depth qualitative study of young women's experiences of high-functioning ASD. This study applied Framework Analysis to narratives elicited through semi-structured interviews in order to gain a rich account of: i) social difficulties, ii) coping strategies and iii) strengths in a group of young women with high-functioning ASD. The most notable areas of reported difficulty were: delays in diagnosis, vulnerabilities related to social naivety, and social and cultural challenges associated with being a female with a social communication disorder. Camouflaging through 'masking' or mimicking' was a commonly described strategy adopted by young women to cope in social situations through the course of their teenage years and early adulthood. The role that camouflaging may play in making it harder to detect females is also discussed. The most noticeable strength manifested by the young women was their attempt to forge

an identity independent of societal expectations, and based instead on their interests. Discussion of these select findings aims to map features of the female autism phenotype that could provide an explanatory model for under-detection in females with ASD.

Delays in Diagnosis

The majority of the young women in this study reported delays in receiving a diagnosis, the average age of diagnosis being 21. Recent studies of high-functioning females with ASD confirm they are more likely to be misdiagnosed, have a delayed diagnosis or remain unidentified compared to males (Kreiser & White, 2014; Begeer et al., 2013; Giarelli et al., 2010). The findings of the current study suggest some possible mechanisms that underlie such delayed or missed diagnoses. The researcher proposes a model of multiple determinants, including internal and external factors. An internal factor reported by young women was co-occurring mental health difficulties. Among external factors, lack of knowledge in health and educational professionals, resulted in unhelpful biases regarding autism or misinterpretation of subtle signs manifested by females with ASD. Young women's compensatory strategies, such as 'camouflaging' also contributed to their being 'missed'.

Mental Health Diagnoses. In some cases young women had suspected they might be on the autism spectrum, but their worries had been dismissed by their GP. Participants gave examples of clinicians having either attributed their symptoms to hormonal changes or mental health difficulties. Indeed, almost all of the young women in the study reported having experienced mental health problems. Therefore it is possible that presenting mental health problems may 'overshadow' autistic traits (Kopp & Gillberg, 1992; Trubanova et al., 2014). Previous studies have proposed that females who present with overlapping symptoms, such as social avoidance,

which is common to both ASD and depression, could result in their ASD remaining undetected for longer (Kreiser & White, 2014).

Lack of Knowledge and Biases. Another factor that may have contributed to delayed diagnosis was clinicians' limited awareness of female ASD. Some young women also reported having witnessed clinicians expressing unhelpful, 'male-biased' stereotypes of how ASD should present, which participants believed had delayed their referrals for a diagnosis. Expectancy bias has previously been suggested as a hypothetical influencing factor (Rutter et al., 2003). If a given disorder is believed to occur more frequently in one gender, there is an increased risk of biased diagnostic patterns. Therefore, the likelihood of a clinician referring a young woman for ASD assessment could be lower compared to a male presenting with the same difficulties (Giarelli et al., 2010; Russell et al., 2011).

Females need to present with more impairments to be recognised. High-functioning women need to present with more difficulties in order to receive a diagnosis compared to males (Dworzynski et al., 2012). In this study, young women remarked that because they were able to hold superficial conversations, their GPs did not suspect autism. This was consistent with recent observations of clinicians (Hiller et al., 2014) who had found it difficult to detect subtle communication difficulties in women who appeared 'normal' in conversation.

Camouflage. Due to females' ability to compensate for social communication difficulties through 'camouflaging', women may be less likely to be diagnosed (Dworzynski et al., 2012). Camouflaging or 'masking' was the predominant coping strategy used in social situations by over half of the participants. Young women spoke about learning to 'mask' by studying people's behaviours or characters in literature, television and films as a guide on behaviour. Clinical observations, anecdotal accounts and case studies support the current findings. They report women with ASD imitating behaviours and often use the information they have

gleaned from observing socially able peers (Attwood, 2006; Kalafarski, 2010, Lai et al., 2011; Kopp and Gillberg, 1992).

Although masking/camouflaging could be considered an adaptive response to managing social situations, the young women interviewed also spoke about some significant implications related to 'pretending to be normal'. The two main concerns were confusion around their own identity, where some reported feeling unsure of 'who they were' when acting as someone else. Secondly, they mentioned mental exhaustion at 'keeping up a persona', which lead to experiencing more frequent meltdowns and counterproductively, avoiding social situations.

Participants also spoke about 'automatically' mimicking other people's behaviours without realising that they were doing so. Extant literature is not specific about the processes by which females with ASD mimic 'automatically', and how, if at all, it is different to conscious 'masking'. Quantitative investigation would be required to identify whether the two processes are distinct and how they compare to social behaviours found in neurotypical women. It would also be of interest to compare young males and females with ASD, to ascertain whether camouflaging is a trait exclusive to females. Further, it could be useful to develop quantitative measures of 'camouflaging' to aid clinicians with the diagnostic process.

The 'good girl' in school. Young women reported that their teachers perceived their passive behaviours as 'normal for a girl' or 'good', leading to them being undetected in their early years. This builds on previous findings where girls were reported to be 'coping reasonably well' in school settings and their passivity was misinterpreted as shyness and therefore ignored (Attwood, 2006). The interviewed participants also hypothesised that because they were often well-behaved and displayed superficial social skills, teachers failed to notice any problems. These findings support results obtained by Mandy and colleagues (2012) and Hiller and colleagues (2014) where teachers raised fewer concerns about girls' behaviours compared to boys. Indeed, sociocultural influences affect how people

perceive gendered behaviour (Kreiser & White, 2014) therefore, this could be an important external factor contributing to girls with ASD being missed, or their behaviours misinterpreted.

Impact of delayed diagnosis. Participants also spoke about the impact of receiving a delayed diagnosis. To the author's knowledge, there is no existing literature on this topic. Young women reflected on how receiving an earlier diagnosis might have been beneficial and might have helped them to understand why they were different from others, especially during school years when they felt acutely different from their peers. In addition, an earlier diagnosis could have provided a platform to access support from health services and in school, as well as reduce the likelihood of bullying or manipulation by others. These findings suggest that there is a need for training of GPs and other professionals in spotting subtle signs of ASD in females. However, it is also advisable to further test the hypothesis that later diagnoses have a negative impact on individuals' well-being, especially given that this is the first study reporting such findings. This could be achieved through quantitative research that investigates the relationship between age of diagnosis, functional impairment and well-being in a representative sample of males and females.

Vulnerabilities

Vulnerability in social situations was another theme cited in the accounts of many participants. Whilst difficulty with reading other people's intentions is inherent to a diagnosis of ASD (APA, 2013) it is proposed that the social naivety of ASD amplifies the vulnerabilities that are associated with being a young woman. Many participants shared experiences where they had been trapped in risky situations or unhealthy relationships. Interviewees reported having been unaware of hidden 'social rules', which meant that they were unsure of how to react in potentially dangerous situations. At times when they had known to be at risk, they did not know how to

react, or if they did, they were unsure whether their behaviour was appropriate. One woman suggested that teenage girls on the spectrum were unlikely to take part in conversations common to adolescent neurotypical girls regarding relationships where hidden social rules and safety skills might be learnt. Further, a passive presentation combined with conflict avoidance manifested by many of the participants, meant that they were unlikely to be able to express what one participants described as 'don't mess with me vibes'. These findings extend clinical observations by Attwood (2006) who suggested that females with ASD might be more likely to exhibit 'passive personalities' in order to avoid committing social faux pas and being noticed for social blunders. Indeed, almost all of the young women reported wanting to 'fit in'. At times, they had been so desperate for affection or companionship that they had succumbed to behaving in particular ways which hadn't 'felt right' for the sake of appearing 'normal'.

The participants also talked about being victims of sexual abuse. Risk of sexual victimisation is hardly discussed in the literature; in fact, it has only been reported in a single case study of a young woman with ASD (Kreiser & White, 2014). A recent publication by Steward (2014) responds to the need for sexual educational material for women on the autism spectrum, providing practical advice on how young women can keep themselves safe; however, further development on interventions is necessary. The vulnerabilities highlighted in the research identify a need for social and relationship skills awareness for young women on the spectrum, carried out in school or by family members in order to protect them from grooming and manipulation. Preliminary research and the current findings also point to the need to assess the level of victimisation present in this population, in order to better quantify the extent and nature of the problem.

Sociocultural challenges of being a woman with a social communication disorder

Social norms are implicit or explicit rules that define societal expectations of appropriate behaviour between individuals (Christensen, Rothgerber, Wood & Matz, 2004). Within social norms, gender norms dictate behavioural expectations. Common gender stereotypes of females include the expectation to be sociable and caring (Christensen et al., 2004). The young women in this study reflected that the expectation to be sociable, which they had perceived to be implicitly linked to their gender, presented them with difficulties in social situations. As girls many of the participants reported attempts to navigate neurotypical female friendships had been met with repeated rejection or resulted with them becoming the victims of bullying. Overall, they had found it difficult to manage complex social interactions. This is partly in keeping with findings by Trubanova and colleagues (2014) who observed that teenage girls on the spectrum found it harder to be intimate, to conform to group interest or to interpret subtle cues; however in these cases, girls were ignored or overlooked as opposed to being overtly rejected by peers.

There is evidence that young women with ASD are more aware of their symptoms, therefore more likely to be affected by rejection and isolation from peers (Gould & Ashton-Smith, 2011; Head, McGillivray & Stokes, 2014). Indeed, most of the participants reported feeling ‘different’ to their classmates and work colleagues. Young women also spoke about having attempted to comply with stereotypically female roles to their own detriment: many reported feeling depressed for ‘trying to be someone they were not’. Previous findings support the observation that socialisation processes and pressure to conform to gender stereotypes contribute to internalising problems commonly found in females (Keenan and Shaw, 1997). Although not directly related, research needs to consider the interactional process between autistic difficulties as they present in females, and societal expectations about femininity, and how this could result in missed diagnoses and mental health problems.

Other participants faced a dilemma of whether being 'true to themselves' (being a young autistic woman) compromised their ability to meet perceived societal standards set for girls and women. Many sought to forge an identity that often intentionally rejected socially constructed female roles. Young women spoke of having gained a sense of well-being and purpose from the pursuit of interests that defined them as a person, including research, creative endeavours and athletic achievements. To the author's knowledge, no research on social identity in young women with ASD exists; this is a topic that would warrant further investigation as a means to understanding the potential protective function of special interests in females on the spectrum.

Methodological strengths and limitations

To the author's knowledge, this is only the third qualitative study of this population therefore it is necessarily broad in its scope as it aimed to identify a range of themes representative of the female experience of living with ASD. The findings from this thematic interpretation offer an original contribution towards developing a systematic and comprehensive understanding of how ASD might manifest in young women and why they are often being missed by professionals. Quantitative measures were used to situate the sample and to contextualise some of the responses given by the participants. Standardised measures of depression and anxiety provided useful data on psychological distress, which tallied with the qualitative experiences of mental health problems that women reported. In the future, it would also be useful to obtain qualitative data from teachers, parents, and clinicians, which would afford a comprehensive perspective on how autism is experienced by all parties, thus addressing some of the weaknesses of previous studies, and gaining an understanding of how women with ASD are viewed. The triangulation of current findings could confirm which mechanisms might contribute to females being missed, e.g. teachers holding 'male-biased' views of ASD.

Methodological limitations were related to recruitment criteria and study design. Given the exploratory nature of the investigation and the small sample recruited, it was beyond the scope of this study to seek to map the full extent of the phenomenon of female ASD. It is therefore possible that we have missed out on other relevant themes. The use of snowball sampling was helpful as it allowed quick location of young women with autism. As yet, no such established database of this difficult to reach population exists. The disadvantages of such a method include community bias, whereby the first participants have a strong influence on the definition of the sample, it being reliant on their ability to find further participants deemed to be suitable. This type of study might also have attracted participants who were especially reflective. The recruited sample may also present a biased view of high-functioning females with ASD, as the criteria only allowed participants who had been diagnosed in the past ten years. It is possible that young women diagnosed during their childhood might have had different experiences, thus making delayed diagnosis a non-relevant topic. Separate investigation of low-functioning young women with ASD (excluded from this study) is also required, as different themes pertinent to their specific experiences could have emerged. It is important to consider that all participants were recalling events that had happened to them at different points in the past, and might have been affected by recall difficulties, especially when disclosing traumatic events. The impact of reported mental health problems was also considered. The two participants who had the highest reported anxiety were not interviewed face-to-face. The difference in interview method may have impacted on what topics the interviewees were comfortable or willing to share with the researcher and this could have influenced the themes generated from the collective analysis.

Future Research

Further investigations need to be carried out on larger female populations to ascertain the relevance of the aforementioned subthemes and how they might describe aspects of the female phenotype. Two themes also highlighted in Lai and colleagues' (2015) most recent review of the literature warrant further investigation: the mechanisms of 'camouflaging' using both quantitative and qualitative methods, and the role that co-occurring conditions play in the delayed identification of ASD in females. Further qualitative research on the experiences of young women who were diagnosed earlier could also yield interesting comparative data and would address whether themes identified in this study are relevant to high-functioning females who receive a diagnosis earlier during childhood. The development of interventions based on the current study and previous research findings on social naivety to support young women who already have a diagnosis of ASD are also needed (Lai et al., 2015). In particular, future investigations could focus on social vulnerability and naivety, social rules and relationships. All participants highlighted the importance of an early diagnosis, and given the higher level of insight present in females compared to males (Kreiser & White, 2014) it may be that their awareness of difficulties also contributes to higher rates of internalising problems in young women with ASD. Preventative measures should be taken to ensure that the appropriate support is provided. Future research could also investigate differences between young women who are diagnosed in early childhood compared to those diagnosed in adolescence and adulthood.

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Part 3: Critical Appraisal

Critical Appraisal

Introduction

This appraisal reflects on a number of conceptual and practical challenges arising during the process of this research project. The first section discusses the implications of designing and conducting qualitative research with women with diagnosis of ASD. This includes considerations made regarding access to the sample population and making the research accessible to them; use of language during the recruitment and interview process and development of an appropriate interview schedule. The importance of rapport with participants, including ethical issues and service user involvement in measure development and piloting stages, is also examined. The second section concerns how these findings reflect on current service provision and how they might translate into further development of services that support young women, their families and professionals involved in their care.

Methodological challenges

Conducting qualitative research with young women with ASD

Extant qualitative research on ASD (published in English) is very limited, with only one study focusing specifically on the experiences of adolescent women on the autism spectrum. The current research project furthers Cridland and colleagues' (2013) qualitative findings by broadening the scope of enquiry regarding features that may be investigated further as potential descriptors of the female autism phenotype. The paucity of qualitative research in the field of ASD research could be due to the overwhelming interest in research on genetic and biological models to explain autism, leading to a neglect of research using direct experiential enquiry. This could also have been based on the assumption that people on the autism

spectrum may be unable to reflect on and describe their own experiences. However, based on the sample in my research, this was resoundingly not the case. On this basis, I had to explore new approaches in qualitative research that were best suited to answer the research questions in hand, using previous studies that had adopted this approach as a model (Huntley, unpublished DClinPsy thesis, 2013).

Accessing the participants and making the research project accessible

Accessing a group of young women with high-functioning ASD was not as difficult as might have previously been predicted, however it did require flexibility. Given that I did not have access to any pre-existing databases of women with ASD, the chosen method of recruitment was creative and opportunistic in its approach. Most of the recruitment advertising was done through an open invitation online via written advertisements posted on forums frequented by young women with ASD on social media sites including Facebook. This was a high-risk method as there was no guarantee that this would have generated responses. Despite this, a number of individuals expressed an interest and fourteen young women were recruited. Once the young women had agreed to participate in the interview, flexibility was required on my part, to arrange interviews. Of the ten face-to-face interviews carried out, only four were carried out in London, the rest involved me travelling to the participant's hometowns in the UK, some living near to the Scottish border. Flexibility in the choice of interview location was a necessary factor for many participants who would have otherwise been unable to access and contribute to the research project. The remaining four women were interviewed over Skype, all but one using the video. These women found it too difficult to meet in person due to high levels of anxiety but expressed a keen interest to participate and asked for alternative modes of interviewing. In future research, it will be important to consider participants' anxieties in relation to visiting new places, and how adjusting to respondents' needs might

impact on the overall time schedule of the project.

As such, qualitative findings are not intended to be generalised to the wider population, however it is important to acknowledge that the views of the women represent a particular group of individuals, namely high-functioning and articulate women on the spectrum. Nonetheless, it is important to consider that biased samples are also present when using quantitative approaches where participants are recruited from clinical settings, such methods automatically excludes individuals living in the community who are functioning well.

Use of language

Careful considerations were made regarding the use of suitable written and spoken linguistic expression throughout the research. Social interaction difficulties are inherent in ASD and I was aware of the need to use clear and precise language, especially in the first approach to the potential participants.

Written Language. The development of an advert, information and consent sheets that provided enough detail, but that were also clear and concise, was aided by regular consultation with a service user consultant to the project who proof-read and made suggestions. The development of the interview schedule was challenging, as it required balancing open-ended questions whose implicit meaning might have been missed, with closed, direct questions. This was managed by developing questions with the supervisor versed in qualitative methodology and the service user consultant. The consultant's feedback regarding questions that were too vague or abstract was also useful and later implemented. The final schedule began with one closed question and then continued with open-ended questions. I had pre-prepared clarifying prompts for participants who might not understand the initial intention of question. Overall, participants who at first appeared to be 'stuck' with a question were able to ask when they did not understand and clarifications were provided.

Spoken Language and Cues. The use of a semi-structured interview

schedule allowed for flexibility in the choice of questions asked and the order in which they were asked. This approach enabled participants to feel more comfortable in constructing and sharing narratives that they thought were important, in the order they chose. The interview itself was set up as an informal meeting with participant and myself sitting diagonally opposite. I avoided using technical or academic terminology during the meetings and outlined the stages of the process in order to orient the participant. Participants were given the option to have the interview questions in hand during the interview, so that they could follow the text of the questions as the interviewer read them aloud, or refer to them during the interview. My previous work with individuals with ASD had taught me the importance of different methods of communication and use of visual cues; indeed, the women who used the cards reported that they had found them helpful to organise their answers and understand where my line of questioning was going.

Use of interviews

Interviews are a valuable method of qualitative research as they provide access to primary data sources and directly capture the experience of the participant. However, there are always bound to be challenges related to time management during semi-structured interviews. A number of women told me that they would have liked to continue talking after an hour had lapsed. On reflection, I was aware that due to her focus on building rapport and being guided by the women's stories, she had found it difficult to interrupt participants' narratives. However, this resulted in later topics being under-explored. In order to manage this in the future, perhaps the task of time keeping could be given to the participants. Other qualitative methods such as focus groups would have been unlikely to glean the same information, i.e. intimate disclosures; besides, group dynamics might have proved somewhat difficult to manage with an ASD population and I, as a researcher, would have had less control over the choice of topics discussed.

Piloting the questionnaire

Two women with ASD assisted in piloting the interview schedule, one contributor being Robyn Steward, the project and service-user consultant. The piloting phase helped to develop a clearer sense of which topics were important to women; new ones were flagged up that the draft schedule had not initially included. Further, it was useful to trial the interview to see if questions were too long or complicated to understand. A number of questions were shortened or rephrased as a result of feedback from both Robyn and the other participant, and the final schedule was agreed by all. Despite the helpful feedback from the two participants, the need for a wider piloting group became apparent as interviews proceeded with the remaining twelve participants. There were two topics, 'school' and 'compensation' that arose as important themes in women's experiences, however, they had not been previously captured in the piloting phase, and therefore, in the final interview schedule. In hindsight, had the researcher been able to access a wider pool of women with ASD to pilot the schedule, she might have gained a fuller understanding of the most pertinent topics that described women's experiences on the spectrum.

Service user consultation

Having access to Robyn Steward, a service user consultant, was very helpful for the development of measures and to ensure the research questions used were accessible to the women being interviewed. However, it is also acknowledged that Robyn may have influenced many of the topics chosen as a point of focus for the interview schedule, which may have therefore excluded others from being explored. For example, an area of particular interest for Robyn was that of women's safety in sexual relationships and this featured as a one of the main topics in the interview schedule. On the other hand, if the service user consultant had been closer to some of the other participants in terms of their experiences of diagnosis (not

diagnosed until late adolescence, early twenties) then it is possible that other topics may have featured more heavily in the final questionnaire. The choice of service user consultant is therefore important to bear in mind for similar qualitative research.

Relationships in qualitative research: continuity of rapport

A qualitative method of enquiry helped to establish a safe rapport with participants, which, by proxy also encouraged women to disclose intimate and at times, traumatic material during the interview. Whilst this was not totally unforeseen, given that one of the questions asked about abuse, at times it still remained a challenge for the researcher to manage because it required her balancing between taking a 'clinical'/'research' stance to contain participants who talked about being in distress whilst enabling them to tell their story. After the first disclosure, it was useful to reflect on how this might be managed with the research supervisor. It was agreed that risk to the women should be checked and support offered as needed.

A further aspect of the relationships established with the interviewees involved the definition of boundaries, which other researchers had found difficult to manage. I wanted my interviewees to feel that they were active participants in the research, and entitled to contribute in ways that they felt relevant to their experience (respondent validity). Once interviews had completed I told them that I would consult them on their responses and the themes that had emerged from the analysis. Many young women responded positively and insightfully, and where no adjustments needed to be made, they were satisfied by how I had described their experiences.

I also wanted to feel I was approachable should they require signposting for further support. A number of women contacted me with various enquiries, one asking about support with an application for a clinical psychology course, others regarding research, or to view their artist portfolio. All of the relationships ultimately felt contained and well founded; however, future research could look more

specifically at how I might position myself. For example, openness and control should be balanced to protect both interviewees and researcher) whilst still affording privileged access to invaluable experiential material.

On reviewing the project, it was noted that good practice includes offering each interviewees access to their recording, should they wish to edit the contents prior to transcription. On this occasion, I did offer to stop the recording on request but this measure was never invoked during this study.

Ethical considerations

The women interviewed in this study could be argued to be a vulnerable population. As discussed in the research findings many women expressed being conflict avoidant and passive in social interactions. Notwithstanding, there were some exceptions. A few women voiced their disagreement or corrected me when they thought something had been misunderstood or misinterpreted. They expressed themselves either during the interview process or via email, when they asked for clarifications. This happened with a small minority of interviewees therefore it was assumed that the majority of the other women were genuinely satisfied with the participation in the project.

Knowing that women may have been more likely to appease, highlights the need for a platform to be able to comment openly on experiences of the research process. Although I provided a feedback sheet to gain some insight into their experience of the research process, participants were asked to complete the form in the interview session, which may have prevented them from providing more critical comments. It may have therefore been more helpful to have provided the participants with an anonymous method (i.e. online survey) where they could have expressed any concerns they had with the research in an honest and unpressured manner.

It is also pertinent to ponder on the vital role that women played in this study. The research could not have been completed without them, and the answers they provided were intended to help their community of women. Their ownership of the project should be acknowledged, and, as a tangible recognition of their participation future projects could consider the creation of a network through which women with ASD may support each other.

Finally, this project has further raised my awareness of the impact that talking about traumatic experiences might have had on my participants, and whether further support could have been put in place for them, for as example, as a follow-up interview. One woman had never told anyone about her abuse, and had disclosed this to me for the first time. This was a concern; however, I ensured that she had support elsewhere, and she assured me that this was something she was working up to sharing with her therapist. Future projects could have further 'protective' measures built in as follow-up tools.

Influence of previous experiences of working with ASD

Previous experience of having worked with a young girl who displayed symptoms of ASD, but failed to 'score up' on the ADOS, inspired further study into the experiences of young women on the spectrum. This was a story that was shared to give the participants context to my reasons for conducting research on female ASD. It is apparent that I would have been sensitive to stories about being 'missed' or 'not diagnosed', and to some extent this will have influenced the questions asked during interview and the focus of the themes generated from the subsequent data analysis. Another compelling reason to research this population relates to their relatively obscured position in society, cited as a 'minority within a minority' by Rudy Simone. During the research process, listening to women's experiences placed emphasis on areas that required further attention in clinical and research settings. Indeed, given that I occupy the position of both clinician and researcher, some stories were

especially poignant: accounts of internalizing difficulties and trauma that drew me to a position where I felt compelled to be more active in an immediate and therapeutic sense. Despite this initial urge, I was able to reflect that the outcome of this research could contribute to equally supportive actions, and arguably, impacting individuals lives on a larger, longer term scale, i.e. the development of new diagnostic measures.

Implications of the current findings for service provision and future research

A recent paper by Pellicano, Dinsome and Charman (2014) summarises the current concerns of professionals, women and parents of women on the spectrum and where they would like future gender related research to be focussed. Feedback included: a focus on why women 'slip through the net', further research on the best approaches for working with girls with ASD and assessing whether the current diagnostic measures capture the female profile of ASD. Two areas that require further investigation which are implicitly suggested by findings from this study, build on those made by the participants in Pellicano et al.'s, (2014) study. Firstly, there is a need for further training for professionals in health and education settings as both were identified as contexts where women had reported being 'missed' or 'misunderstood'. Secondly, female-specific services are required to provide social and relationship skills that increase personal safety and wellbeing and decrease their social naivety and vulnerability.

Professionals in health settings. Women reporting their experiences in Pellicano and colleagues (2014) study reported that professionals had 'been blind' to signs of autism when they presented as adults. Similar experiences were shared by the young women interviewed in this study. One possible solution could be the delivery of training to health professionals, in order to better understand how the female phenotype in autism presents, including common co-occurring symptoms that might

obscure ASD. This could help clinicians differentiate between internalizing problems that present commonly in women and problems that are related to ASD. Keifer and White (2014) made suggestions for GPs to build into their assessment interviews should young women present in their clinics with internalising problems such as anxiety or depression. In depth interviews should establish where the anxiety originates from and whether it is socially related. Assessments could also include questions on friendships and other relationships. The responses would afford insights into the social communication difficulties experienced by young women with ASD, and provide opportunities to better understand compensation and camouflage, which have on recently started to being investigated.

Professionals in school settings. During school years, the young women in this study reported being 'missed' or having their behaviour misinterpreted by staff who thought they were quiet and well-behaved. It is proposed that through the provision of training, teaching staff could be guided to notice a number of behaviours that are indicative of autism in girls. In social situations, such as unstructured play of playground, researchers recommended that teachers compare play activities of 'quiet' girls with other girls their age (Head, 2014). Previously research has found that teachers had used boys with autism as a 'measure' of whether a girl might be autistic, and dismissed the possibility. One hypothesis for this is because males and females with ASD present in different ways; i.e. boys are more likely to have problematic externalising behaviours. Attention could also be paid to friendships between girls with ASD and their peers and how they engage (or not) with group activities. Further, girl's capacities to understand instructions and excessive apologizing could also be monitored, as the literature indicates that girls appear to be more prosocial and therefore, less of a hindrance in classroom situations.

Services for women with ASD. Finally, services that are responsive to the immediate

needs of women and girls are required. In a number of cases, both in the current study and others (Pellicano et al., 2014) women have retold experiences of being diagnosed and then discharged from mental health teams, due to lack of resources to support them. As such, the female community of women on the autism spectrum has been creative in its response to the 'gap' in provision and opened online forums and groups, which were recognized by the young women in this study as important source of support. Other sources of information have included personal websites, such as 'The Curly Hair Project', which take an autobiographical approach to supporting other women. However, the approach to service provision needs to be accessible to women and include women with ASD in their design, creation and delivery. This could be carried out through the creation of a consultation group of young women, similar to that created by Autism in Pink, which could help to identify future areas of research and to evaluate current services. To conclude, the direction of future research in women with ASD needs to genuinely collaborative, where academic investigation is responsive to the priorities of service-users and theory is translated into practice.

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Appendices

Appendix 01: Studies excluded from the literature review
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Appendix 01: Studies excluded from the literature review

Studies Excluded from the Psych Info and OVID Medline search

Exclusion Reason	Frequency
Gender Identity	6
Sexual Deviance	4
Book chapter	15
Book review	5
Dissertation	1
Parenting	13
Genetics or physiological	16
Psychiatric study	7
Intellectual Disability	13
Interventions	8
Child study	5
Non-ASD	15
Animal study	3
Language	1
Other	12

Appendix 02: Ethical Approval

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE

Dr Will Mandy
Research Department of Clinical, Educational and Health Psychology
UCL

24th March 2014

Dear Dr Mandy

Notification of Ethical Approval
Project ID: 5339/001: Experiences of women with Autism Spectrum Disorder (ASD)

In my capacity as Chair of the UCL Research Ethics Committee (REC) I am pleased to confirm that your study has been approved by the UCL REC for the duration of the project i.e. until September 2015.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: http://www.grad.ucl.ac.uk/ethics/ and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

   Reporting Non-Serious Adverse Events
   For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

   Reporting Serious Adverse Events
   The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for your research.

Yours sincerely

[redacted]

Professor John Foreman
Chair of the UCL Research Ethics Committee

Cc:
Sarah Bargiela, Applicant
Professor Peter Fonagy, Head of Department

UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building
University College London Gower Street London WC1E 6BT
Tel: +44 (0)20 7679 7844 Fax: +44 (0)20 7679 7043
ethics@ucl.ac.uk
www.ucl.ac.uk/gradschool

Appendix 03: Recruitment information on the website

Retrieved from: https://sites.google.com/site/womenandautismspectrumdisorder/

Researchers at University College London want to learn more about women's experiences of autism spectrum disorder (ASD)

Who are we looking for?

This research study is looking for:

- **Young women aged between 18 to 30 years**,
- who received **a diagnosis of Autism Spectrum Disorder** (ASD, including high-functioning autism and Asperger Syndrome) ***after*** **January 2004**

What would happen if I took part in the study?

If you decide to take part in the research study, you would:

- Be asked a some questions on your general health, mood and ASD
- Be interviewed by a female researcher on your experiences of ASD as a woman

Will I get paid?

Participants who take part will get £15 in cash to thank them for their time

There may be possible benefits if you take part in the study.

1. You could find out more about yourself and how your ASD has influenced who you are
2. You would be contributing to scientist's knowledge of female ASD and could help with future diagnosis of women

To take part in this research study or for more information, please contact Sarah Bargiela at sarah.bargiela.12@ucl.ac.uk

The principal researcher for this study is Dr Will Mandy at University College London

About the Researchers

The 'Experiences of Women with ASD' study is being lead by Dr. Will Mandy, a senior lecturer on the Clinical Psychology Doctorate at UCL. His main research interests are Autism Spectrum Disorder and Eating Disorders.

Sarah Bargiela is a second year trainee on the UCL Clinical Psychology Doctorate. This study forms the main part of her thesis. Her research interests are Autism Spectrum Disorders and Community Psychology.

Robyn Steward is a consultant for the 'Experiences of Women with ASD' study. Robyn is the author of '*The Independent Woman's handbook to super safe living on the Autistic Spectrum.*' She also has a diagnosis of Asperger's syndrome. Robyn is an Autism and Asperger's trainer to professionals working in education, children's services and social care.

Appendix 04: Recruitment flyer posted on forums

Appendix 05: Information Sheet

Information Sheet for UCL Research Studies

Title of Project: Experiences of being a woman with ASD

Ethical Approval: *This study has been approved by the UCL Research Ethics Committee (Project ID Number): 5339/001*

Researcher Details

Sarah Bargiela, Trainee Clinical Psychologist
Research Department of Clinical, Educational and Health Psychology, UCL, 4th Floor, 1-19 Torrington Place, London, WC1E 7HB

E: sarah.bargiela.12@ucl.ac.uk

T: 07880801618

Who are we looking for?

We would like to invite women aged between 18 – 30, who have been diagnosed with autism spectrum disorder (ASD), including high-functioning autism and Asperger Syndrome, by a clinician, after the year 2003, to participate in this research project.

Details of Study

Aims of the research and possible benefits

The aim of this research is to find out about the experiences and coping strategies of women who have a diagnosis of autism spectrum disorder (ASD). The benefits of participating are that you will be contributing to helping researchers to better understand female ASD and help women in the future be diagnosed more accurately.

What will happen if you agree to take part?

Once you have got in touch, I will give you a copy of this information sheet and my contact details and you will be welcome to call me or email me with any questions. After this, if you decide you would like to take part we will arrange a date and time to meet up.

The meeting will involve me asking a number of questions on different topics. These will be about your general health, mental health, ASD traits, verbal abilities. I will then we ask you some questions about your life experiences in different contexts (e.g. school, home, socially). Your responses for this part will be audio recorded on an MP3 player so that I can listen again and write up the responses. All your answers will be kept private and your name will not be one any of the answers that are written up. Refreshments will be provided and you can have a break any time you need.

The whole process should last about an hour and a half, although it may take slightly longer depending on how much you choose to say. The interview can take place at UCL or somewhere else of your choosing where you feel comfortable (e.g. in your home). If you

decide to be interviewed at UCL a map will be provided with the location and public transport details. If you would more comfortable to have an interview over Skype this can also be arranged.

Any risks you need to be aware of?

As mentioned before, the information from your interview will be anonymised and kept confidential. There could be a few questions on intimate relationships that you might find uncomfortable. I will let you know when I am about to ask them, and you do not have to answer any questions you do not feel comfortable answering. We will agree at the start of interview how you would like to show me when you do not want to answer a question (hand signal, saying "no comment", showing a card).

Possible benefits to taking part?

Your answers will contribute to research on women with ASD with a view to improving quality of life for other young women with a diagnosis and providing information on coping strategies and other women's stories of daily life. In the long term this research hopes to inspire further research on how women with ASD are recognised, diagnosed and supported at an earlier stage in life.

Arrangements for ensuring anonymity and confidentiality

You may withdraw your information from the project at any time up until it is transcribed for use in the final report. Recorded interviews will be transcribed (written up) and the MP3 recorder will then be wiped clear. The MP3 recorders will be kept in a locked cabinet, within UCL and the interviews will be transcribed on the premises. Your data will be anonymised and kept confidential.

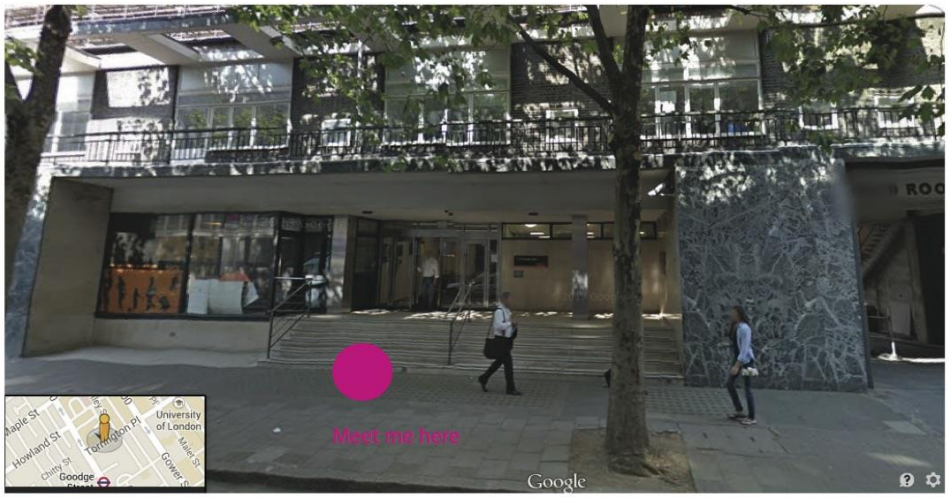
If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

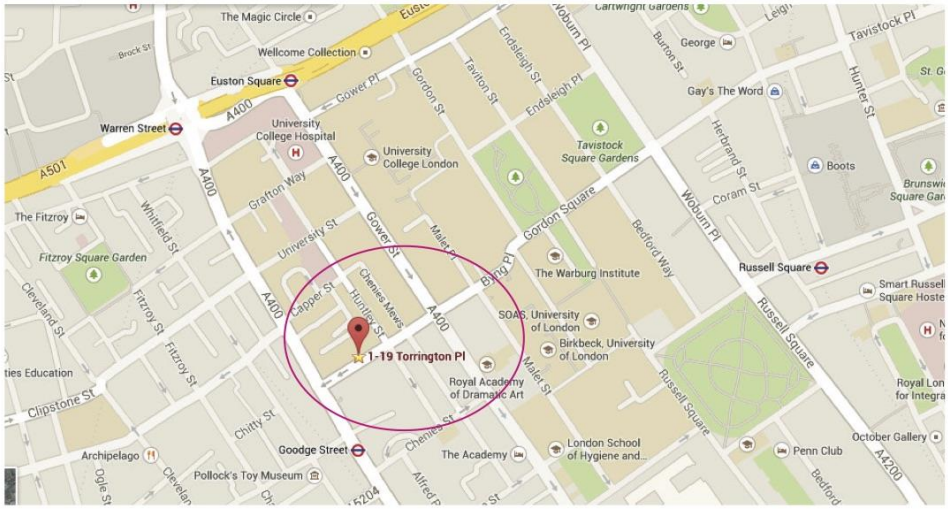
- If you do not understand any of the information above, or something is not clear, please feel free to ask me either face to face, on the phone or via email.
- It is your decision to take part in this study. If you choose not to take part, it will not affect you or disadvantage you in any way.
- If you do decide to take part, and then later change your mind, you are free to withdraw from the study at any point. You will not have to give me a reason if you do decide to withdraw.

All data will be collected and stored in accordance with the Data Protection Act 1998

Appendix 06: Directions for getting to the Interview Venue

This is the UCL building, 1- 19 Torrington Place





If you have any problems at all regarding transport or finding your bearings, feel free to give me a ring on 07880801618.

See you soon,
Sarah

Appendix 07: Consent Form

Informed Consent Form for UCL Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: **Experiences of being a woman with ASD**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 5339/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research (Sarah Bargiela) must explain the project to you.

If you have any questions after having read the information sheet, please ask the researcher before you decide whether you want to take part in the study.

You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

Please initial on the lines below:

.....I have read the notes written on the Information Sheet and I understand what the study involves.

.....I understand that if I decide at any time that I no longer wish to take part in this project, I can let the researcher know by email (sarah.bargiela.12@ucl.ac.uk) and she will withdraw my answers immediately.

.....I consent to my answers and personal information being used for the purposes of this research study only.

.....I understand that the researcher will be treating my information as strictly confidential and it will be handled in accordance with the Data Protection Act 1998.

.....I agree that the researcher has clearly explained the research project named above to me and that I agree to take part in this study.

.....I understand that my answers to the interview of experiences will be audio taped and I consent to the research using my answers as part of the project.

.....I understand that the information the research will gather from me will be published as a draft report and I will be sent a copy. If I am not happy with what is written in a draft report, I can tell the researcher and ask them to change it or take it out. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

.....I understand that I am being paid £15 for taking part in this research and that some of my personal details (WHICH) will be passed to UCL Finance for administration purposes.

Signed:
Name Printed:
Dated:

Appendix 08: Interview Schedule

Interview Schedule for Women's Experiences of ASD

"During this interview, I will be asking you questions on topics that other women with autism think are important. These include friendships, intimate relationships, sensory issues, interests and diagnosis. But I am also interested in any other topics you think may be important for women with autism. At the end I will check with you and find out if there are any topics you think we have missed that you might like to tell me about. It is important for you to know that you don't need to answer any questions that you don't feel comfortable with and that there are no right or wrong answers, only your answers. This interview will last about an hour."

TOPIC
Main questions
- Follow up and prompt questions (dependent on responses given)

DIAGNOSIS

Who referred you to get a diagnosis?
- How old where you found out that you had ASD?
- Why do you think you were diagnosed?

What changed in your life after you were diagnosed?
- How did you react when you received the diagnosis?
- How did other people react when you received the diagnosis? (family, friends, teachers)

What is good about having ASD?
- What about having ASD is difficult?
- Have you ever used any strategies to hide your ASD?
- How would I know that you had ASD?

Do you think it is difficult for women to get a diagnosed with ASD? Why?

INTERESTS

What are your main interests at the moment?
- What do you like about this area of interest?
- How has having this interest helped you?
- How has having this interest caused you problems?

Do you think any of your interests are particularly 'female' and why?
(It might help to think about any male friends with autism that you know who might have special interests and how your interests might compare)

FRIENDSHIPS

Do you have someone you would call a friend?
Could you give me an example of a friendship you have?
- What do you like about that friendship?
- What do you find difficult about that friendship?
- If you have ever been involved in an argument or disagreement could you tell me what happened and how it was resolved?
- How do you think your views of friendship have changed over the years?
- How do you know if someone is a friend or not?

How do you see your friendships with males compared to your friendships with females?

How, if at all, do you think your friendships with people who have ASD are different to your friendships with people who do not have ASD?

INTIMATE RELATIONSHIPS

"This card has questions about intimate relationships and sex. Remember, you do not have to talk about anything you are not comfortable with. I will ask the questions and you can say 'PASS' or show me the PASS card if you would like to move to the next question."

Have you ever had a sexual relationship? (such as a boyfriend or girlfriend / a one night stand / a 'friend with benefits' / someone you have casual sex with / a fling)
What was good about this relationship?
What was difficult about this relationship?

Have you ever been in a situation where you have had sex and you did not want to?

Do you think being taken advantage of is an issue that other women with ASD might also experience?
- Why do you think this might be?
- How do you think men with ASD find relationships?

SENSORY SENSITIVITIES

Do you have any sensory sensitivities?
What is good about having these sensitivities?
- Have these sensitivities ever got in the way or been difficult to manage?
- How do you think these sensory sensitivities help you?

Do you think there are any sensory sensitivities that are specific to women with ASD?

Do you think your interests might be related to your sensory sensitivities in any way?

ALCOHOL AND SUBSTANCES

Do you drink alcohol?

Do you use any substances? (By this I mean legal substances like rescue remedy, paracetamol as well as illegal substances like marijuana, ecstasy and cocaine)
- In what situations might you find yourself using (alcohol / substance)?
- How might (name of substance / drinking) be helpful?
- How might (name of substance / drinking) be unhelpful?

Do you know if there are any substances that women with ASD might use more than men with ASD?
- If so, why do you think that might be?

MENTAL HEALTH

Have you ever had any mental health difficulties?
What are you like when you are experiencing (name of mental health difficulty)?
- What makes you (your answer)?
- How do you cope with (your answer)?

What mental health difficulties do you think particularly affect women with ASD?
- Why do you think that might be?

WOMEN & MEN with ASD

Are there any things you have noticed that might be different between men with ASD and women with ASD?
- What do you notice is different in your male friends with ASD compared to your female friends with ASD?
- What do you think is similar?

Do you think women with ASD have different coping strategies to men with ASD?
- What are the similarities?

Is there anything else we have not had a chance to discuss?

Do you have any questions?

Appendix 09: Interview Feedback Form

Women with ASD Interview Feedback Questionnaire

What was your experience of being interviewed? (put a cross on the line)

Easy to engage in — Challenging to engage in

Relaxed — Anxious

I felt I was listened to — I felt I was not listened to

Overall, I felt (tick appropriate face) about the interview process

I would change .....

Something I would keep the same would be.....

Appendix 10: Hospital Anxiety and Depression Questionnaire (HADS)

Hospital Anxiety and Depression Questionnaire

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your Clinician to know how you feel. Read each item below and then underline the reply, which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Do not take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought out process.

	I feel tense or "wound up"	**I still enjoy the things I used to enjoy**	
3	Most of the time	Definitely as much	0
2	A lot of the time	Not quite as much	1
1	From time to time, occasionally	Only a little	2
0	Not at all	Hardly at all	3
	I get a sort of frightened feeling as if something awful is about to happen	**I feel cheerful**	
3	Very definitely and quite badly	Never	3
2	Yes, but not so badly	Not so often	2
1	A little, but it does not worry me	Sometimes	1
0	Not at all	Most of the time	0
	Worrying thoughts go through my mind	**I can laugh and see the funny side of things**	
3	A great deal of time	As much as I always could	0
2	A lot of the time	Not quite as much as now	1
1	Not too often	Definitely not so much now	2
0	Very little	Not at all	3
	I get a sort of frightened feeling like "butterflies" in the stomach	**I feel as if I am slowed down**	
0	Not at all	Nearly all the time	3
1	Occasionally	Very often	2
2	Quite often	Sometimes	1
3	Very often	Not at all	0
	I feel restless as if I have to be on the move	**I look forward with enjoyment to things**	
3	Very much	As much as I ever did	0
2	Quite a lot	Rather less than I used to	1
1	Not very much	Definitely less than I used to	2
0	Not at all	Hardly at all	3
	I can sit at ease and feel relaxed	**I have lost interest in my appearance**	
0	Definitely	Definitely I do not take as much care as I should	3
1	Usually	I may not take quite as much care	2
2	Not often	I take just as much care as ever	1
3	Not at all		0
	I get a sudden feeling of panic	**I can enjoy a good book or radio or television programme**	
3	Very often indeed	Often	0
2	Quite often	Sometimes	1
1	Not very often	Not often	2
0	Not at all	Very seldom	3
	TOTAL A:	TOTAL B:	

Appendix 11: General Health Questionnaire Short Version (GHQ-12)

General Health Questionnaire

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Circle the response that best applies to you. Thank you for answering all the questions.

Have you recently:

1. been able to concentrate on what you're doing?

better than usual (0) | same as usual (1) | less than usual (2) | much less than usual (3)

2. lost much sleep over worry?

Not at all (0) | no more than usual (1) | rather more than usual (2) | much more than usual (3)

3. felt that you are playing a useful part in things?

more so than usual (0) | same as usual (1) | less so than usual (2) | much less than usual (3)

4. felt capable of making decisions about things?

more so than usual (0) | same as usual (1) | less than usual (2) | much less than usual (3)

5. felt constantly under strain?

Not at all (0) | no more than usual (1) | rather more than usual (2) | much more than usual (3)

6. felt you couldn't overcome your difficulties?

Not at all (0) | no more than usual (1) | rather more than usual (2) | much more than usual (3)

7. been able to enjoy your normal day to day activities?

more so than usual (0) | same as usual (1) | less so than usual (2) | much less than usual (3)

8. been able to face up to your problems?

more so than usual (0) | same as usual (1) | less than usual (2) | much less than usual (3)

9. been feeling unhappy or depressed?

not at all	no more than usual	rather more than usual	much more than usual
(0)	(1)	(2)	(3)

10. been losing confidence in yourself?

not at all	no more than usual	rather more than usual	much more than usual
(0)	(1)	(2)	(3)

11. been thinking of yourself as a worthless person?

not at all	no more than usual	rather more than usual	much more than usual
(0)	(1)	(2)	(3)

12. been feeling reasonably happy, all things considered?

more so than usual	same as usual	less so than usual	much less than usual
(0)	(1)	(2)	(3)

Appendix 12: Example coded transcript

Transcript for P04	Initial Codes	Framework
X: That sort of thing S: Yeah		
X: But then I don't know happened but he changed and he started saying I wasn't trying and that I was a waste of his time and he yelled that at me in front of the entire class	Teacher thought she was not putting effort into work, got into trouble	**2d. Misunderstood, unsupported or blamed by teachers**
S: oh my goodness that sounds very difficult	More insight now	
X: and I was, but the thing was, looking back I have some more insight into his motivations, but at the time I just didn't understand what I did wrong, but I was constantly losing things, being late for things, I couldn't concentrate, I can't work in a busy classroom, so I Just used to get my book out and not do my assigned work I just used to sit there and read cos that was one thing I could do. I would never finish an exercise in class, when it was PE I would come back late with my shorts on inside out	X not understand how her behaviour was 'wrong' Found it difficult to work in a classroom – sensory overloading? Dyspraxia?	
S: aww X: and he though and he got to think I was doing it on purpose S: Right X: So, his whole, his attitude to me changed like that and after that it became quite difficult for me to trust teachers, um, because they make a fuss of you at the beginning and then they think you're bad (laughs) it just, so I was very very aware that I was weird and I was bullied a bit as well by peers that really got worse in the teenage years	Teacher misinterpreting behaviour as deliberate Hard to trust teachers Bullied by peers Aware of being different Bullying badly during adolescence	**2d. Misunderstood, unsupported or blamed by teachers**
S: mm X: And one thing was that I was often accused of being rude when I had absolutely no intention of being so and that was a very very common recurring theme and nobody seemed to believe me when I said I didn't mean it and this used to absolutely exasperate me S: mm X: And oftentimes I wouldn't understood what I'd done S: Would people explain to you what they though was rude?	Accused of being rude by teachers and peers Unsure of why communications were thought of as rude	**2d. Misunderstood, unsupported or blamed by teachers**

X: Sometimes, sometimes for example, I remember this was when I was older when I was about 13 and I yawned and the teacher said 'is this lesson boring you X' and I said 'yes miss' it was and it was a very boring lesson and she said 'well in that case you can have a lunchtime detention' and I was very upset cos I didn't see what I had done, she asked me a question, I answered it. And the same teacher, that was a, she was a maths teacher and then one of the home works was about finding an equation to calculate how many patients could travel in a hospital lift or something and again I saw the word hospital and thought it must be relevant to the question so I wrote a paragraph in my maths book about how this is an atypical population and maybe you have amputees in there and critically anorexic peoples, I don't see what I'm supposed to do with this and the next thing I know I have another detention, just, just things like that S: yes X: And it, it's and I got very frustrated because my classmates would laugh and, err, some of them would try to explain to me 'that's rude you mustn't do that' I said, 'what do you mean?' I, the, the, and I see it now I I at least I still don't see the, the logic behind it but I can see I mustn't do it if that makes sense	Literal understanding of a question – lack of understanding of social rule Teacher misunderstanding response as rude Literal understanding of question meant it was difficult to understand the intended maths problem Teacher misunderstanding behaviour as rude / facetious Peers explaining why a social interaction was seen as rude Could only understand it logically	**2d. Misunderstood, unsupported or blamed by teachers** **2d. Misunderstood, unsupported or blamed by teachers**

Appendix 13: Extract from thematic analysis

2. Pretending to be Normal

ID N.	2a. Learning social behaviours from books, TV, magazines	*2b. 'Wearing a mask'*	2c. Social mimicry	2d. The costs of masking
P05			I do social mimicry against whoever I'm with. // I guess it's like a cloaking device - act like the person you're with, and then they'll like you. It's a way to avoid being singled out as different. I honestly didn't know I was doing it until I was diagnosed, but when I read about it, it made perfect sense. I copy speech patterns, certain body language etc. We had friends come to stay for a week when I was 8 and they were from Liverpool. I was flat out scouse for a fortnight after they left // I guess it's a defence thing, in that you're less likely to be treated badly by someone who likes the same stuff as you. I'm not sure. //	// It's exhausting, and I can't keep it up for long (if I try to hang out with someone for more than an hour, I start slipping up, and guessing wrong and making mistakes etc). //
P06		//...I cant keep up the bubbly and chatty for very long and I always felt that the minute I started to show me and the calmer side of me they were no longer interested //	// I automatically mimic what other people are doing what people are saying how people say things um which is has got me in trouble a couple of times (laughs) // I sort of went on camps with Guides and I would come back with strong accents from other camps from people Id met there and came back from one camp with an Irish accent // But I can't do it consciously that's what I find difficult I can't consciously put on an accent I just it's my way of coping is that I mimic //	
P07	// Like I've read books on body language and how to make people like you and things like that and if I follow then all, I'm actually a really good actress, so it's all an act//		// we're very good at mimicking social rights and wrongs, and we, I think a lot of us tend to study neurotypicals from a very logical stand point and then act it out...it takes an awful lot of effort so I only do it when I have to...if I'm meeting someone just as a one-off and I don't want them to think that I'm rude or not understanding them //	// I think the mimicking but that is extremely exhausting and ends up being more detrimental in the long run, particularly because you then have all these identity issues because, I can fake NT, that must mean I'm NT //
P04	// regarding literature when I was younger including as a teenager I used to try and use stories and books as a guide to how to behave //			
P09		// I honed something of a persona which was kind of bubbly and vivacious…so I cultivated an image that I brought out to social situations… that was not me, that required an awful lot [of effort] //		// for the first time I just don't have the energy to keep up that persona any more because I'm busy pursuing my own identity now, because before I was so busy pursuing this persona I didn't really have an identity of my own you see //

Appendix 14: Respondent validation form

Dear [Name of Participant],
I developed four main themes, within which, there were a number of subthemes. I have included one quote for the subthemes that describe your experiences.
If you see a quote that doesn't quite fit the subtheme heading, or I have misinterpreted it in any way, please do let me know by writing back to me via email and I will amend it accordingly.

Thank you for your feedback,
Sarah

Theme 1: 'You're not autistic'

Labelled with non-autistic diagnoses
You spoke about mental health difficulties that had affected you as a woman on the spectrum.

"Well definitely anxiety, and I would say that is the predominant and perhaps the only mental concern that I've had; so kind of general anxiety and just nausea and fear nothing particular in the form of a compulsion or anything like that just flat out fear and long term anxiety"

Quiet at school so went unnoticed
Teachers were other professionals that saw you a lot, but they did not have much knowledge on autism, and as you were quiet and well behaved in the classroom, the autism went unnoticed

"I was always socially reclusive, I was always very afraid of people…there's no problems there because you're conforming to what is the ideal in class which is quiet and not causing any trouble because you're reading a book...a very appropriate activity for a girl to do which is probably why I went undiagnosed for such a long time as well - I engaged in female oriented activities I suppose"

Theme 2: 'Pretending to be Normal'

'Wearing a mask'
You told me about having learnt to hide your true self and wear a mask to camouflage and become invisible amongst others in a social situation so that you wouldn't stand out as being different or unusual in any way

"I honed something of a persona which was kind of bubbly and vivacious and maybe a bit dim because I had nothing to say other than adult novels so I cultivated an image I suppose that I brought out to social situations as my partners girlfriend that was not me, that required an awful lot"

The costs of masking
After having spent a lot of time masking your true self, you told me that it had caused difficulties with how you saw yourself, your true identity.

"for the first time I just don't have the energy to keep up that persona any more because I'm busy pursuing my own identity now, because before I was so busy pursuing this persona I didn't really have an identity of my own you see"

Theme 3: 'From Passive to Assertive'

Please, appease, avoid conflict
You spoke about women on the spectrum, yourself included, being likely to be the types of people to please others and behave passively in difficult situations. Similarly, you talked about avoiding conflict, being more likely to agree in order not to upset other people.

"knowing how to handle that whether they have the right to say no or if they have been brought up to be quite passive, back to that school girl with the book again, being a passive girl that doesn't cause any trouble - you don't want to cause any trouble so…I feel very uncomfortable having an argument or even a debate with someone and it took me until my early twenties that having a debate with someone didn't mean you were fighting someone I'm very into keeping the peace"

Entrapment in abusive relationships or risky situations

You told me that women on the spectrum could be at greater risk of being in dangerous situations as they might not understand the subtle cues they might be communicating through behaving in a certain way

"if you are that kind of inward looking autistic person that's kind of doubtful of themselves you might end up complying to something based on an image that you're projecting that you do not understand the consequences of"

Theme 4: 'Forging an identity as a woman with ASD'

Societal pressures: what is expected of women

You spoke about the societal pressures that women experienced and how these were unhelpful aspirations or images for women on the spectrum

"p*erhaps girls either as a natural inclination or because that's what's expected of them because I think there's huge expectations on girls to be to you know kind of bottle it up and be a perfect hostess even when there's no party around um to kind of its ok to damage yourself and to hurt yourself inwardly as long as everything as long as all the china is there in place"*

Friendships: Uncertainty and Intensity

You told me about uncertainties regarding friendships, and what it was that made a friend and was expected of you as a friend. You also spoke about past experiences where you had been particularly intense with friendships and this had ended because you were unsure of what was expected of you.

"I would say…just plain avoidance of people is what makes friendship difficult but also not knowing what was expected of me, not being able to pick up on when to provide support or how often to get in touch… when I was a child I was very overbearing to one particular girl, as a friend...yeah, so I was since those early experiences of being too overbearing on people in my adult life I've moved away and tend to leave people alone"

Interests define identity and self-confidence

You talked about how your interests define your identity and self-confidence and gave you a purpose in life.

"they um define a structure to my life, certainly the degree has at the moment, they allow me to express myself in different ways, they form the basis of my identity, um, they are how I define myself, how I choose to look at the world and um all of my achievements, all of my sense of achievements, all my sense of wellbeing basically is linked to progressing or seeing myself progress in those two areas, so it forms the core of who I am, basically so yeah"