SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

MAJOR RESEARCH PROJECT

'I didn't fit the stereotype of autism': A qualitative analysis of women's experiences

relating to diagnosis of an autism spectrum condition and mental health

Submitted by Hazel Elizabeth Went to the University of Exeter in part fulfilment for the

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I certify that all material in this thesis that is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

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LITERATURE REVIEW

Experiences of adults on the autism spectrum: A systematic review of qualitative research evidence

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Abstract

Recent estimates suggest that approximately 1% of the population are on the autism spectrum. With the majority of research focussing on behavioural and medical interventions for children with autism and those with comorbid learning disabilities, the question of what happens to children with autism who grow up to become adults with autism has been largely overlooked. This review explores the qualitative literature about the experiences of adults with autism.

Keyword searches of two online databases resulted in the inclusion of twelve articles from 1925 retrieved journal articles, following the application of inclusion and exclusion criteria. The findings outlined experiences of diagnosis of autism, both as children and adults, and barriers to obtaining a diagnosis as an adult. The emotional experiences of those on the spectrum were identified, in addition to compensatory strategies adults employed to manage their autism-related difficulties, and support that had been received. The findings also provided insight into the increased social isolation experienced by adults on the autism spectrum, and the effort required to engage in social interaction; in addition to the sensory experiences of adults with autism. There is a clear need for further qualitative research into the experiences of adults on the autism spectrum, in particular of women and older adults; and the physical and mental health related experiences of adults with autism. The studies highlighted a need for greater understanding of autism in adults across healthcare professionals to enable timely identification and intervention; and timely, targeted emotional interventions.

Keywords: Qualitative; autism; Asperger's; review; experiences; voice; adult

Introduction

Autism Spectrum Conditions

Autism is a lifelong developmental disability characterised by impairments in communication and social interactions, and repetitive and stereotyped activities; these are known as the "triad of impairments" (Wing, 2002). It is estimated that the prevalence of autism in the UK is greater than 1% (Brugha et al., 2012). Individuals with autism and cognitive impairment (IQ<70) usually receive their diagnosis of autism in early childhood and are supported throughout schooling and adulthood by specialist services (Frith, 1994); however those with higher cognitive ability can often be recognised as different but their idiosyncrasies misunderstood. Such children may be appraised by school staff and family as eccentric, idle, gifted, shy or obstinate (Georgiou, 2005). Thus, the process of diagnosis for people without learning disabilities may not commence until adolescence or even adulthood, which can result in a lack of appropriate support and can impact on the person's identity and self-esteem.

Considerable research has been undertaken into autism spectrum conditions (referred to as ASC from hereon). Much of the research published concerns managing behaviour and 'symptoms', perhaps due to the higher risks and greater need for intervention for people with autism who display behaviour that challenges (Jordan, Robertson, Catani, Craig, & Murphy, 2012; Matson, Sipes, Fodstad, & Fitzgerald, 2011). Additionally, there is considerable interest in the literature in searching for causes of autism and improving diagnostic procedures, tools and screening measures, facilitating a more accurate process of autism diagnosis, and

earlier access to support (Garcia-Primo et al., 2014; Harris, Barton, & Albert, 2014; Falkmer, Anderson, Falkmer, & Horlin, 2013).

Amongst this research, however, it appears that the voice of the person with autism is missing. We know that adults with autism are at significantly increased risk of mental health problems, with over a quarter experiencing severe and multiple problems (Moss, Howlin, Savage, Bolton, & Rutter, 2015; Buck et al., 2014; Joshi et al., 2013). It appears that loneliness, as a secondary consequence of the social difficulties experienced by people with autism, is associated with increased depression and anxiety, and decreased life satisfaction and self-esteem (Mazurek, 2014). In addition to mental health problems, most physical health, central nervous system and sensory conditions are more common in adults with autism than the general population (Croen et al., 2015) resulting in greater cost to health services. As people with autism experience difficulties with social communication, they often find it difficult to access health services and communicate their symptoms, resulting in accessing health professionals at a later stage than people without autism and often having greater treatment needs as a result (Nicoladis et al., 2012; Potvin, Snider, Prelock, Wood-Dauphinee, & Kehayia, 2015).

Research also tells us that the economic consequences of adult autism are significant, with only around 15% of adults with autism being in full-time paid employment (Mavranezouli, Megnin-Viggars, Cheema, Howlin, Baron-Cohen, & Pilling, 2014) and significantly more being in unskilled, part-time and poorly paid jobs irrespective of ability (Howlin et al., 2013). This underemployment, in addition to loss of productivity for families and carers on whom individuals with autism are reliant, contributes to a cost of supporting adults with autism estimated at £25 billion in 2006 (Knapp, Romeo & Beecham, 2009).

While this research can tell us about the impact of autism on adults and society, an understanding of the experiences of adults with autism could enable clinicians to explore the factors which contribute to the issues discussed and develop interventions which could help reduce the economic and psychosocial consequences of autism.

Objectives

This review aims to answer the question: "what are the lived experiences relating to autism of adults on the autism spectrum, as reported by the adults themselves?" This review seeks the voice of people with autism, and so qualitative literature will be sought; quantitative research predominantly involves participants choosing from options dictated by the researcher. The review does not include literature on the experiences of families, carers or educators, nor papers which relate the experiences of children with autism.

Methods

Participants sought were adults with autism and Asperger's Syndrome. Inclusion criteria for articles included in the review are outlined in Table 1. Articles were sought which were published up to 18th December 2015, the search date.

Table 1.Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
1	Primary research	Book reviews, books,

		commentaries, literature reviews, policy documents
2	Qualitative studies	Quantitative studies
3	Published in English and in countries where English is the first language	Published in other languages, or in countries where English is not the first language
4	Peer reviewed paper	Non-peer reviewed publications
5	Includes individuals over 18 years old	Participants are under 18 years old
6	Participants have a diagnosis of autism or Asperger's Syndrome	Participants do not have a diagnosis of autism or Asperger's Syndrome
7	Studies include participants' own account of their own lives	Studies which do not report on participants' accounts of their own lives

A search was carried out on the PsycArticles via OVID and EBSCO databases up to 18th December 2015; a full electronic search strategy is included in Appendix A.

Keyword search terms were "autism", "Asperger's Syndrome", "Asperger Syndrome" or "pervasive developmental disorder", combined with "qualitative", "phenomenological", "discursive", "discourse", "grounded theory", "thematic analysis", "conversational analysis", "IPA", "narrative" or "semi-structured interview".

On retrieval, duplicates were first removed; subsequently, titles and abstracts were read for eligibility according to the inclusion criteria. Finally, the full text was read for the remaining papers.

Studies included in the literature review were scored according to the CASP (2013) checklist for qualitative research. The CASP checklist provides a structure by which to appraise a report of qualitative research (Appendix B), asking questions such as whether the research methodology was appropriate, whether ethical issues have been taken into consideration and whether the data analysis was sufficiently rigorous.

Themes from each of the papers were identified and listed along with the paper's CASP score, based on the CASP checklist in Appendix B. Appendix C outlines the themes arising from the papers. A thematic synthesis of the themes arising from the papers was utilised (Barnett-Page & Thomas, 2009) to draw out common themes from the papers' findings. Stronger emphasis was given to the themes from the higher quality papers; where a theme from a lower quality paper was not replicated in other studies, it has not been included.

Results

1925 papers were retrieved by the search, screened and assessed for eligibility for inclusion. The study selection strategy is illustrated in Figure 1.

Records identified through database search (n=1925)

EBSCO (785)
PsycArticles (1140)

Records after duplicates removed (n=1913)

Records screened (n=1913)

Records excluded from title and abstract

(n=1889)

Bases for exclusion (title and abstract)

(n=1889)
Participants under 18 years   103
No diagnosis of autism   1621
Study does not report on participant's own accounts   95
Study not qualitative   70

Full-text articles assessed for eligibility (n=24)

Full-text articles excluded

(n=12)

Bases for exclusion (full-text)

(n=1889)
Participants under 18 years   1
Study does not report on participant's own accounts   9
Study not qualitative   2

Studies included in literature review (n=12)

Figure 1. Study selection strategy.

Twelve papers were included in the literature review. Table 2 summarises the included studies, their CASP scores and their findings.

Table 2. Papers included in the systematic review.

Reference	Aim	Method	Analysis	Limitations	Findings	CASP Score
Smith & Sharp, 2013 #1	Explore unusual sensory experiences in adults with AS	Semi-structured interviews via internet messaging N=9 (6M, 3F)	Grounded theory	Only small range of sensory experiences explored Small sample size	Both positive and negative unusual sensory experiences described; most have coping strategies for negative experiences	9/10
Jones, Quigney & Huws, 2003 #2	Explore the sensory experience of people with ASC	Individual websites N=5 (3M, 2F)	Grounded theory	No information on background of participants Some websites very brief	Descriptions of hypersensitivities which cause discomfort, and sensory distortions Participants have developed their own coping strategies, and some of the sensory differences are enjoyable and comforting	9/10
Kronenberg, Slager-Visscher, Goossens, van den Brink, & van Achterberg, 2014 #3	Identify the everyday life experiences consequences of substance use in people with ASC	Individual interviews N=12 (12M, 0F)	Descriptive phenomenology	Only male participants Did not explore co-existing mental health conditions	Executive functioning impairments associated with co-occurring substance use and ASC, with significant consequences for daily life functioning and social interactions	8/10
Linton, Krcek, Sensui, &	Explore feelings of	Discussion	Phenomenological analysis	Used self-identification	People with ASC have significant concerns	8/10

Spillers, 2014 #4	people with ASC on DSM-V classification of autism	forum dialogue N=76 (42M, 34F)		of spectrum Used only one internet forum, limited generalisability	about the DSM-V classification, including potential for exacerbation of gender bias in diagnosis	
Griffith, Totsika, Nash, & Hastings, 2012 #5	Understand the experiences of people with ASC in middle adulthood	Individual interviews N=11 (7M, 4F)	Interpretative phenomenological analysis	Small sample size, including some not yet diagnosed with ASC Open-ended nature of interviews caused difficulties for some participants resulting in limited data from some interviews	Difficulties with employment identified, need for autism awareness amongst employers Practical living difficulties and limited support for people with autism	8/10
Trembath, Germano, Johanson, & Dissanayake, 2012 #6	Explore anxiety and coping strategies in young adults with ASC	Focus groups N=11 (9M, 2F)	Thematic analysis	Small sample size Focus group methodology can limit participation and expression for some people with ASC	High levels of anxiety among individuals with ASC Triggers include unexpected change, social interactions, fearful anticipation and disappointments Lack of understanding about solutions	8/10
Krieger,	Gain insight	Individual	Developmental	Very small	Parental support,	8/10

Kinebanian, Prodinger, & Heigl, 2012 #7	into contextual factors contributing to employment participation in adults with ASC	interviews N=6 (3M, 3F)	and hermeneutic narrative approach	sample size Not all participants had official diagnoses of ASC	adapting to the cultural context, sensory issues and timing of diagnosis impact on capacity to participate in employment	
Jones, Zahl & Huws 2001 #8	Explore the emotional experience of people with ASC	Individual websites N=5 (4M, 1F)	Thematic analysis	No information on background of participants Some websites very brief	Feelings of alienation, depression and apprehension are common in people with ASC	8/10
Muller, Schuler, Burton, & Yates, 2003 #9	Understand perspectives of people with ASC on strategies for improving vocational placement and job retention services	Individual interviews N=18 (13M, 5F)	Thematic analysis	Participants from small geographic area and very similar cultural backgrounds	Appropriate job matching important , support for social interactions important to overcome barriers to employment	8/10
Muller, Schuler, & Yates, 2008 #10	Understand social challenges and supports for people with ASC	Individual interviews N=18 (13M, 5F)	Thematic analysis	Small sample Participants all receiving psychological support; potential for greater insight and social	Descriptions of social isolation and difficulties with social interaction, but all expressing a desire for increased connectedness. A variety of social supports suggested	7/10

				motivation		
Williams, 2004 #11	Explore theory of mind of people with ASC	Interrogation of published autobiographies of adults with ASC N=10 (6M, 4F)	Interpretative phenomenological analysis	No mention in analysis of clear bias of paper authors with respect to autism Participants all highly literate.	With difficulties in social understanding, people with ASC have to use theorising to negotiate social world but strategies are flawed	6/10
Townson et al., 2007 #12	Examine difficulties in accessing advocacy by people with ASC	Individual interviews, focus groups N unstated	Thematic analysis	Participants from small geographical area	Barriers to accessing advocacy include late diagnosis, poor communication and sensitivity towards people with ASC, lack of awareness, and difficulty fitting into services already available	5/10

Method, Data Analysis and Study Limitations

Methods. Individual interviews were most commonly used as a data collection method, by six of the twelve studies. Although talking with unfamiliar people can be challenging for people on the autism spectrum, this method is likely to be less anxiety provoking than focus groups, which involves greater social interaction and social skills. Even so, one of Griffith, Totsika, Nash and Hastings' (2012) participants ended their interview after only nine minutes due to high levels of anxiety. Two studies: Trembath, Germano, Johanson and Dissanayake (2012) and Townson et al (2007) employed focus groups as a method of data collection, which appears to have been a successful data collection strategy. However, it is difficult to ascertain whether their participants would have been able to relate their own experiences if another individual described different ones; it is likely that participants could have self-silenced if their account differed.

Four studies utilised the internet to collect their data: Jones, Zahl and Huws (2001) and Jones, Quigney and Huws (2003) by accessing personal web pages, Linton (2014) through accessing online forums and Smith and Sharp (2013) by carrying out semi-structured interviews using internet messaging. These methods are frequently preferred as lines of communication by people with autism as they generally provoke less anxiety around social interaction, and enable individuals to interact freely (Jones, Quigney & Huws, 2003).

The final study, that of Williams (2004), collected already existing data in autobiographical accounts of people with autism. Capturing data which are already in the public domain results in an analysis of the experiences of autism

which is pertinent to the authors with autism. In this way, no external values or themes are imposed on the individuals.

Data Analysis. The most common data analysis method used in the literature was thematic analysis, used by five out of the twelve studies: Jones, Zahl & Huws (2001), Townson, Muller (2003), Muller, Schuler & Yates (2008), Muller, Schuler, Burton and Yates (2003), and Trembath, Germano, Johanson and Dissanayake (2012) to identify common themes in the participants' responses. Jones, Quigney and Huws (2003) and Smith and Sharp (2013) utilised grounded theory as a method of analysis, Smith and Sharp in particular using the interpolative method to inform data gathering such that later interview questions were based on participants' previous responses.   Krieger, Kinebanian, Prodinger and Heigl (2012) utilised a narrative approach to analysis, inferring a core narrative for each interview, clustering meaningful experiences of the core narrative and analysing the structure of the narrative and its plot. The primary concern about this approach, and approaches using phenomenological analysis, is the inference made by researchers without ASC of meaning based on language used by participants with ASC. As differences in communication and use of language is one of the diagnostic criteria for autistic spectrum conditions, despite intact grammatical ability (Bartlett, Armstrong & Roberts, 2005) there is a possibility that the resulting analysis identifies meaning which is very different to the meaning attributed by the participants.

Limitations. None of the authors discussed the consideration of the biases of those involved in the analysis prior to undertaking data analysis. This was particularly noticeable in Williams's (2004) report, where autism is described as

a "devastating developmental disorder" (p. 704), and the authors or people with ASC in general frequently called "these people", indicating significant bias of the author. As expected, coming from such a bias, the conclusion of Williams is that people with ASC are flawed in their compensatory strategies, and lacking in a "wisdom" that people without ASC appear to have.

Main findings and implications

Common themes amongst those drawn out by the papers' authors were identified and are discussed below. These themes are: sensory experiences, emotional experience, social isolation, social interaction, support and services, diagnosis, compensatory and coping strategies, and employment; themes are listed in order of strength of the contributing evidence.

Sensory experiences

Altered sensory experiences were described in four studies, including three papers scoring most highly on the CASP, as being an important part of the autistic experience. Heightened sensory experiences are common, and while mostly causing stress, anger or discomfort could also be a source of fascination. Where the sensory experiences caused fear, anger or panic, this resulted in a need to escape the situation or strike at the source of stress. Sensory overload was described as a feeling of being so overwhelmed by sensory input that it could be difficult to concentrate on anything.

Heightened sensory experiences have a significant impact on the day-to-day functional ability of adults with autism in addition to contributing to their experience of social isolation. Everyday situations and environments can cause considerable levels of distress resulting in escape or avoidance.

Emotional Experience

The emotional experience of autism was described in four of the studies, one of which achieved a score of 9/10 on CASP. All studies concurred regarding the emotional experiences of adults with autism as being negative, consisting of anxiety, depression, fear and anger. Sources of these negative emotional experiences were wide ranging. External causes of negative experiences include the person's environment, interacting with people, reports in the news and other media, the workplace and crowds. Internal causes of negative emotions include anticipation and disappointment, uncertainty, self-perception and fear for/of other people.

The negative emotional experience of adults with autism has an impact on their ability to function in daily domestic activities, socially and occupationally. Most strategies used by adults with autism to manage their emotional experience are reactive, not pre-emptive, and thus their negative emotional experiences are unlikely to persist.

Social isolation

Six of the papers, with CASP scores evenly distributed between 5/10 and 9/10, described an intense social isolation as part of the experience of adults with autism. Primary causes of the social isolation, particularly those described by the studies with higher CASP scores, include social interaction difficulties and avoidance of social situations.

Most adults with autism have a yearning for a meaningful relationship, whether romantic or platonic; however for some, the social isolation is less distressing and these adults find comfort in the social distance from others.

Social interaction

Difficulties with social interaction were described in six of the studies as being a significant part of the experience of adults with autism. Social communication impairments is a core component of the difficulties with social interaction, including frequent miscommunications and difficulties picking up on non-verbal or emotional cues in communication. Adults with autism related that they need to make a conscious effort to understand the unwritten rules of social interaction, which results in exhaustion and anxiety. This affects all social interactions including those with family, friends and colleagues.

Difficulties with social interaction can contribute to the feeling of social isolation in adults with autism, in addition to contributing to a negative emotional experience.

Support and services

Experiences of support and services as part of the experiences of adults with autism were described in four papers, three of medium-high quality and one of lower quality as scored according to CASP. Support and services for adults with autism relate to mental health issues arising from their negative emotional experiences in addition to practical support services. Adults with autism frequently do not fit into services which are not designed specifically for people on the autism spectrum, and therefore often experience being passed from service to service. Adults with autism also experience difficulties in services

with healthcare professionals not having understanding of, or training in, autism. Many adults with autism are unaware of the support services available to adults on the spectrum, and so have not accessed any support.

Support required by adults with autism included a need for practical help in undertaking everyday tasks including undertaking paperwork and structuring each day, in addition to help in developing social skills in order to improve social interactions and decrease social isolation.

Some adults with autism seek support from the internet in order to access peer support and advice, primarily from other people on the autism spectrum.

Diagnosis

Diagnosis was included in three of the papers: two with CASP scores of 8/10 and one with a CASP score of 5/10. Individuals who have been diagnosed with autism during adulthood have generally sought a diagnosis themselves, and the outcome of autism assessment came as a relief, facilitating both self-understanding and self-acceptance and enabling them to connect with others with autism. However, they often find that non-specialist professionals' lack of knowledge about autism creates barriers in the diagnostic process such as not being referred in a timely way. Most adults with autism diagnosed in adulthood have been diagnosed with one or more additional neurodevelopmental conditions or mental health issues prior to an autism diagnosis.

Adults with autism who received their diagnosis in childhood have received support during childhood/adolescence, which had led to a greater feeling of being able to seek and access support during adulthood.

In one study, participants discussed the issue of gender discrepancy in autism diagnosis (Linton, Krcek, Sensui, & Spillers, 2014). They highlighted the gender bias, citing females being more likely to mimic social skills, and expressed concern about the criteria for the diagnosis of autism in the new Diagnostic and Statistical Manual of Mental Disorders (5th ed.) (American Psychiatric Association, 2013).

Compensatory and coping strategies

Adults with autism develop strategies to overcome difficulties as a result of their ASC, and these compensatory and coping strategies are discussed in three of the studies with scores of 9/10, 8/10 and 6/10 on the CASP. Strategies include maintaining constant control over their behaviour through the use of imposed rules, hiding their real self, mimicking the behaviours of their peers, controlling the environment to make it more predictable, and developing their self-awareness and understanding of ASC. All of these strategies are effortful and are thus not possible to utilise for long periods of time.

Other coping strategies employed by adults with autism include withdrawal and avoidance to manage distressing sensory situations

In order to manage the emotional experience of autism, adults employ other coping strategies including relaxation, use of computers or other special interests, joining a support group or spending time alone. Some adults with autism use less successful strategies for coping with their emotional experience including use of alcohol and drugs.

Employment

Three studies discussed the employment experiences of adults with autism. Many adults with autism experience periods of unemployment or underemployment, and tend to experience specific difficulties within the work environment.

Factors which impact on an individual's ability to settle into a job include the knowledge and understanding of employers and colleagues, matching the job to the person's skills and interests, and the structure, hierarchies and procedures of the workplace.

Periods of unemployment and underemployment adversely impact on individuals' emotional experience and their self-perception.

Discussion

The aim of this review was to appraise and integrate qualitative research findings of the experiences of adults with autism which relate to their autism. The findings suggest that unusual sensory experiences are a common experience of adults with autism, and are predominantly a source of stress, although some sensory experiences can have pleasurable qualities. The evidence for unusual sensory experiences was strongest. Adults with autism often experience depression and/or anxiety as a result of their autism; these often developed as a result of other difficulties associated with ASC. Social isolation is very common in adults with autism, partly due to difficulties with social interaction and also due to avoiding anxiety-provoking social situations. Difficulties with social interaction is also a part of the experience of adults with

autism; although people with autism made a conscious effort to understand social interaction, they still experience difficulties picking up on non-verbal communication, initiating and participating in social interactions. The support and services available for adults with autism is variable, with adults falling between services. Healthcare professionals' lack of understanding of autism can lead to difficulties providing appropriate services. This can also lead to adults not being referred for diagnosis of autism. Receiving a diagnosis of autism as an adult comes as a relief, facilitating both self-understanding and self-acceptance; however receiving a diagnosis in adulthood could result in a longer period of distress prior to assessment. Adults with autism use compensatory and coping strategies to overcome difficulties as a result of their ASC. These strategies apply across all areas of life including social interactions, controlling the environment and managing high levels of depression and anxiety. While most strategies have their utility, some strategies can make the problems worse such as drug and alcohol use. Adults with autism experience difficulties with employment, in finding and keeping appropriate employment. Many experience multiple periods of unemployment and underemployment. Although the evidence for employment issues is relatively weaker than the other themes, this is partly due to the scarcity of the evidence overall.

Limitations

Due to the paucity of qualitative literature, the scope of the review was wide-ranging, exploring literature reporting on any autism-related experiences of

adults with autism spectrum conditions. Thus, the topics discussed were broad and there was little depth to the available data.

Although in Linton's study participants highlighted a gender difference in the diagnosis of autism, the majority of participants across all studies were male (118 vs. 63 females). Kronenberg, Slager-Visscher, Goossens, van den Brink and van Achterberg's (2014) study involved no female participants at all. In initially undertaking the review, an additional criterion of the review was that of gender, i.e. studies were initially sought which explored the voices of adult women on the autism spectrum only. This resulted in no papers being accessible. Thus, there appears to be a lack of female voice which makes it difficult to determine whether the results of this review are generalisable to women with autism.

Only one study provided details of participants' ethnicity; the other studies did not. It is particularly important to consider ethnicity where there appears to be a variability in diagnosis of autism among different ethnic groups (Emerson, 2002; Rosenberg, Daniels, Law, Law, & Kaufman, 2009), whether due to differences in identification or referral is unclear. All studies took place in Europe, USA or Australia, suggesting that results might reflect the experiences of individuals within western culture; however this is likely to be due to the inclusion criterion that studies are published in English.

Many of the studies included details of participants' ages, and all participants were under 63 years of age perhaps due to the method of recruiting participants in the studies. This yields a result which may not be generalisable to the older adult population.

Implications for research

There are a number of gaps in the literature which suggest areas for future research. These include research exploring the experiences of women and older adults with autism, the experiences of people with different ethnicities on the autism spectrum, and research into how adults on the autism spectrum experience health conditions and access health services. Methodologically, further research could explore other sources of data such as use of internet forums, to access participants who might find face-to-face contact difficult.

Clinical implications

An issue arising from the review is that of professionals' understanding of autism, which appears to impact on the diagnostic process and the support and services available for adults with autism. A lack of expertise can result in adults not being referred for diagnosis, and subsequent to diagnosis not receiving the needed support. Healthcare professionals could receive training in order to understand the presentation of autism in adults, to enable them to identify signs of autism in addition to enabling them to ascertain support needs. This is particularly important due to the high reported rates of mental health difficulties in adults with autism.

Conclusion

This review has explored the qualitative literature about the experiences of adults with autism. Although the literature is sparse, it covers a number of clinically relevant themes including experiences of diagnosis, social isolation and sensory experiences, suggesting areas for clinical intervention such as training for health, education and social care professionals, and post-diagnostic

support. Further qualitative research could substantiate these tentative results.

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Appendix A: Search Strategy

Search Strategy

EBSCO

AB (autism OR asperger* OR ASD OR ASC)

AND AB (qualitative OR discurs* OR phenomenological OR discourse OR grounded OR thematic OR conversational OR IPA OR narrative OR semi-structured interview)

PSYCarticles via OVID

(autism OR asperger* OR ASD OR ASC).ab

AND (qualitative OR discurs* OR phenomenological OR discourse OR grounded OR thematic OR conversational OR IPA OR narrative OR semi-structured interview).ab

Appendix B: Critical Appraisal Skills Programme (CASP) Checklist

Screening Questions	Answer
Q1 Was there a clear statement of the aims of the research? HINT: Consider • What was the goal of the research? • Why it was thought important? • Its relevance	Yes / No/Can't tell
Q2 Is a qualitative methodology appropriate for the authors' stated aims? HINT: Consider • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal?	Yes / No/Can't tell

Is it worth continuing?

Q3 Was the research design appropriate address the aims of the research? HINT: Consider • If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)	Yes / No/Can't tell
Q4 Was the research design appropriate to address the aims of	Yes /

the research?

No/Can't tell

- If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

Q5 Was the data collected in a way that addressed the research issue?

Yes / No/Can't tell

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Q6 Has the relationship between researcher and participants been adequately considered?

Yes / No/Can't tell

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during

(a) Formulation of the research questions

(b) Data collection, including sample recruitment and choice of location

- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Q7 Have ethical issues been taken into consideration?

Yes /

HINT: Consider

No/Can't tell

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Q8 Was the data analysis sufficiently rigorous?

Yes / No/Can't tell

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Q9 Is there a clear statement of findings?

Yes / No/Can't tell

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Q10 How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C: Common Themes Arising From the Papers

Reference/CASP score	Primary themes	Secondary themes
Smith & Sharp, 2013 9/10	Heightened stress	
	Sensory stress	Fear/anger Attack/escape Avoidance
	The stress avalanche	
	Coping strategies	Blocking out other inputs Dampeners Creating order Calming strategies
	Other people	Source of sensory stress Negative interactions with others Positive interactions with others
	Isolation	
	Self-acceptance	
	Fascination	Pleasurable/calming Skills/abilities Long-term pursuits Distracting
Jones, Quigney & Huws, 2003 9/10	Turbulent sensory perceptual experiences Coping mechanisms Enjoyable sensory perceptual experiences Awareness of being different	
Kronenberg, Slager-Visscher, Goossens, van den Brink, & van Achterberg, 2014 8/10	Jumble of thoughts and emotions Overload of stimuli Feeling lonely Structure helped function	
Linton, Krcek, Sensui, & Spillers, 2014 8/10	Reliability of autism diagnosis PDD-NOS Validity of autism diagnosis Neurobiological research High functioning Reciprocity: "I could fake conversations" Gender	
Griffith, Totsika, Nash, & Hastings, 2012 8/10	"Some days I do struggle" Employment issues Experiences with mainstream support Raising awareness – future steps towards	

	supporting people	
Trembath, Germano, Johanson, & Dissanayake, 2012 8/10	Sources of anxiety	Interactions with others Fearful anticipation Concern for others Disappointment Environment
	Living and coping with anxiety	Avoiding anxiety Managing anxiety
	Experience of anxiety	Dynamics Impact on self Impact on others
Krieger, Kinebanian, Prodinger, & Heigl, 2012 8/10	Social context	To feel socially secure To be familiar with social environments
	Cultural context	To achieve cultural competence
	Physical context	To feel protected or offended
	Temporal context	Receiving and accepting diagnosis
Jones, Zahl & Huws 2001 8/10	A sense of alienation A sense of frustration Depression as central emotion A pervasive sense of fear/apprehension	
Muller, Schuler, Burton, & Yates, 2003 8/10	Workplace experiences	Diverse vocational interests Patterns of unemployment and underemployment Work generally negative Exceptions to the rule
	Obstacles to successful employment	Mastering job application process Adapting to new routines Communication Social interactions with coworkers and employers
	Recommendations	Job matching Individualised ASD-specific supports Communication support Autism awareness training Attitudinal supports
Muller, Schuler, & Yates, 2008 7/10	Features of social experience	Intense isolation Difficulty initiating social interactions Communication difficulties Desire for intimacy and social connectedness Desire to contribute to one's community Effort to develop greater self-awareness

	Recommended social supports	External supports Communication supports Self-initiated supports Attitudinal supports
Williams, 2004 6/10	Feelings of distance from other people	Detached scientist Alien Onlooker
	Inaccessibility of social and emotional cues for interaction	The enigmatic nature of social interaction Difficulty in picking up cues that are 'hidden' Difficulty in picking up cues due to sensory problems Development in the ability to read emotional cues
	Coping strategies	Studying other people's behaviour as a guide Imposing rules Using a 'visual library'
	Limited success of coping strategies	Failure of strategies in new/unexpected social situations Difficulties in generalising
Townson et al., 2007 5/10	Late diagnosis and lack of support services Unfortunate experiences within the system of care Feelings of not belonging and issues with identity Barriers to communication and sensitivity	

SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

EMPIRICAL PAPER

'I didn't fit the stereotype of autism': A qualitative analysis of women's experiences relating to diagnosis of an autism spectrum condition and mental health

Trainee name:	**Hazel Went**
Primary research supervisor:	**Dr Janet Smithson**
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Target Journal:	Autism
Word Count	7821 (excluding abstract, tables, references, footnotes and appendices)

Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter

Abstract

Autism spectrum conditions are generally perceived to affect males, with the majority of studies quoting the ratio of four males being diagnosed with autism for each female.   The potential implications of this for women on the spectrum or seeking a diagnosis are wide-ranging, including healthcare professionals' disbelief in autism in women leading to difficulties obtaining a diagnosis and misdiagnosis of other mental health conditions. In this study, a grounded theory methodology was applied to data from fifteen online blogs to explore the experiences of adult women on the autism spectrum of diagnosis of autism, and of mental health issues. The study yielded two grounded theory models: of diagnosis of autism and of mental health, which are linked through misdiagnosis of and comorbid mental health conditions. The findings suggest that there is a need for clinicians to be aware of the unique presentation of autism in women, and of the additional mental health issues which women with autism commonly experience. Additionally, targeted autism-specific interventions may be required, focussing on the core difficulties of autism as opposed to the resultant emotional and mental health difficulties.

Keywords: Internet; blogs; autism; Asperger's; women; diagnosis; mental health; voice

Introduction

It is estimated that the prevalence of autism spectrum conditions (ASC) in adults in the UK is approximately 1% (Brugha et al., 2011). With the significant proportion of adults with autism facing social isolation and healthcare, educational and economic exclusion, in addition to severe mental health difficulties and other physical health problems, it is important that their needs are recognised and met (National Institute for Health & Care Excellence, 2012;Lugnegard, Hallerback, & Gillberg, 2011; Hofvander et al., 2009; Gray et al., 2014; Ghazziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998).

It has historically been accepted that women with autism are in the minority, with literature quoting male to female ratios between 1.9:1 and 16:1 (Mills & Kenyon, 2013; Van Witngaarden-Cremers et al., 2014). Generally, the higher ratios are quoted for people who have higher levels of cognitive functioning (Attwood, 2003). There have been few challenges to these ratios until recently; indeed, autism has been described as the expression of the "extreme male brain" (Baron-Cohen, 2002, p. 248), and this term has become popular within both academic and non-academic literature.

The concept of autism as the extreme male brain, and a male condition, can become a self-fulfilling prophecy, in that clinician bias towards the male model of autism results in greater referral of boys and men for assessment, contributing to the gender difference in diagnosis (Kreiser & White, 2014). Additionally, screening tools and research are generally based on a male population, resulting in preferential identification of males as autistic.

In the past fifteen years, clinicians and researchers have identified that girls and women with autism spectrum conditions display different characteristics to boys

and men on the spectrum, which is likely to result in under-diagnosis of females (Attwood, 2003; Howe et al., 2015; Lehnhardt et al., 2016). In particular, Attwood (2003) notes the greater use of imitation of behaviour in girls and women with ASC which results in effortful copying of successful behaviours, such that they are less likely to display behaviours which might cause sufficient concerns for parents to seek support from health professionals. Additionally, Nichols, Moravcik and Tetenbaum (2009) highlighted other differences in clinical presentation between males and females on the autism spectrum at higher cognitive abilities, including differences in expression of play, the greater distractibility of boys than girls, and the differences in parental and social expectations of males and females which could be responsible for the gender differential in the identification and diagnosis of autism. Thus, whilst a male might obtain a diagnosis of autism spectrum condition, a female experiencing similar difficulties could receive one or more diagnoses of other mental health conditions such as generalised anxiety disorder or schizophrenia and autism may never be considered (Geurts & Jansen, 2012).

While there is a slowly growing acknowledgement that girls and women on the autism spectrum can present differently to boys and men with autism, research into the experiences of women is scarce. For example, while it has been reported that in general women tend to be diagnosed later than men, and that women are more likely to have a pre-existing diagnosis of an anxiety, mood or psychosis-related disorder (Geurts & Jansen, 2012), there are few reports of exploration of women's actual experiences in these areas. There is some attempt to analyse the autobiographical reports of women such as Temple Grandin, Liane Holliday-Willey, and Donna Williams through their books (Davidson, 2007), but it is acknowledged that these single case studies are

edited by third parties and in some cases co-authored, and thus may not be the primary authors' own words (Hacking, 2009).

More recently, the National Autistic Society has been engaged in a European project "*Autism in Pink*" aiming to increase the understanding of the experiences of women with autism. Twelve women from the UK participated in a focus group also attended by parents, carers and professionals (Mills & Kenyon, 2013). The project authors explored the lives of their participants through this group along the eight themes of the Personal Wellbeing Index – Adult (International Wellbeing Group, 2006), which are: community connectedness; personal safety; personal health; personal relationships; future security; standard of living; achievements in life; and spirituality and religion. Although the project provides a valuable insight into the lives and experiences of a limited number of women in the UK with Asperger's and autism, there are a number of areas of particular interest which are not included in this and other research, including the experiences of the identification and diagnostic process, and women's experiences of mental health issues prior or subsequent to diagnosis of autism spectrum conditions. A study by Bargiela, Steward and Mandy (2016) explored the female autism phenotype and its impact on women with autism without a learning disability. It identified a number of issues relating to the female phenotype, including a later diagnosis due to being misunderstood and not fitting the professional stereotypes of autism and developing a new identity as a woman with autism, often accessing support from others online.

Internet Research

The growth of the internet and internet discussion forums over the past decades has resulted in the creation of a new social world for people with autism

spectrum conditions. The internet provides a space for people with ASC to interact, with fewer of the anxiety-provoking social challenges of face-to-face interactions (Romano, Truzoli, Osborne, & Reed, 2014); indeed it has been suggested that a significant proportion of adults with autism use social networking sites for social connection and to gain information (Mazurek, 2013). Online communication has been shown to be empowering to people with ASC, enabling them to find a voice (Brownlow & O'Dell, 2006).

Weblogs, or blogs, are web pages typically run by an individual or small group, which are informal in style and typically updated regularly. They are frequently written in the style of a diary, with individual entries being termed 'posts'. Blogs serve as a source of information and support for many people with mental health problems, providing an opportunity to learn from other people with the same diagnosis (Kalckreuth, Trefflich, & Rummel-Kluge, 2014). The process of creating blogs, "blogging", and gaining reader feedback has been shown to be associated with an improvement in authors' wellbeing (Rains & Keating, 2015).

Internet research has seen a considerable increase commensurate with the growth of internet use. The internet can provide naturalistic information on a variety of topics including personal experiences of physical and mental health and other sensitive issues, and is becoming recognised as a legitimate source of valuable data (Seale, Charteris-Black, MacFarlane, & McPherson, 2010). One of the advantages of using data already existing in blogs is that these data are naturally occurring, reducing the likelihood of the response biases which can arise in other qualitative methods such as interviews and questionnaires (Whitehead, 2007).

To date the majority of quantitative and qualitative online research in autism has focused on the online experiences of parents of children with autism, usually with accompanying learning disability, as opposed to individuals with ASC themselves (Fleischmann, 2005; Green et al., 2006). This research concerns the spontaneously described experiences of people with ASC.

Research Aims

The aim of this research is to explore the experiences of adult women with autism or Asperger's Syndrome through analysing naturally occurring posts on their online blogs. In particular, as the general consensus is that females with autism are in the minority, one of the focuses of exploration will centre on women's experiences of the identification and diagnostic process. This process includes the period prior to referral to specialist services when the individual first became aware that they might have an autism spectrum condition, and subsequent responses by the individual and by others.

 Additionally, it has been shown that in general women receive diagnoses of autism spectrum conditions later than men (Geurts & Jansen, 2012), and that a lack of self-understanding and support can result in the development of mental health issues such as depression and anxiety (Ghaziuddin, 2005). Therefore, an additional focus of the study will be women's experiences of previous and current diagnoses of other mental health conditions.

Research Question

There are two research questions:

1. What are the reported personal experiences of the ASC diagnostic process for adult women identifying with autism spectrum conditions, as described in their online blogs?

2. What are the reported mental health experiences of adult women identifying with autism spectrum conditions, as described in their online blogs?

Method

Participants

As the research interaction took place between the researcher and the blogs, the participants in this study were considered to be the blogs themselves.

Identifying Blogs

The blogs were identified by entering the search terms "autism blog" and "asperger's blog" into the Google search engine, each with the terms "gender", "woman", "girl" and "female".

Blogs retrieved in the first five pages of each google search were accessed in order to determine the suitability of the blog for inclusion, i.e. blogs written by adult women (age 18+ years) who state that they have a diagnosis of, or identify with, an autism spectrum condition. Table 1 lists the inclusion and exclusion criteria.

Table 1.Inclusion and exclusion criteria for blogs.

Inclusion	Exclusion
Web page is a blog	Other forms of web pages
Written by adult women describing themselves as having an autism spectrum condition	Written by men
Written by adult women (as above) about their own experiences	Written by family members or other third parties about a person with an autism spectrum condition
Written in English	Not written in English

Blogs

Fifteen blogs were chosen in order to provide credibility to the study through triangulation of multiple data sources (Long & Johnson, 2000; Shenton, 2004).

Table 2 lists the blogs identified, along with demographic information of the blog authors. Blogs were written spontaneously by their authors, and there was no external moderation or third party editing of the content.   The blogs were not necessarily primarily about autism, although the majority of the blogs were described on their home pages as documenting the life of a woman with autism.

Although it was not possible to confirm that the blog authors had a diagnosis of an autism spectrum condition, there was no reason to suspect otherwise. As blogs were not written for monetary gain, nor for the purpose of gaining an online following, there seemed to be no incentive to disclose a diagnosis where there was none. Demographic information was sought from each blog by first

accessing the 'About' page on each blog, then by reading through all posts in the blog for missing information. For two blog owners, the marital status changed during the blog's lifetime, from 'in a relationship' to 'single', and two authors' employment statuses changed. In fact, one author experienced several changes of employment and periods of unemployment for the duration of blogging.

Where possible, authors' countries of origin were identified; however this information was not available for four bloggers. However, it is possible to infer probable country of origin by analysing spelling, language and cultural references; by these indicators, it is most likely that these four blogs originated in the USA.

Table 2. Details of the blogs used in the current research.

Blog	Age at diagnosis	Employment status	Marital status	Living situation	Country of origin	Schooling
B01	22	Full-time education	In relationship	Not stated	UK	Mainstream
B02	>30	Unemployed	In relationship / single	Supported living	Holland	Mainstream
B03	30s	Employed/part-time education	Single	Living independently alone	USA	Mainstream
B04	Adulthood	Full-time employed	Not stated	Not stated	UK	Not stated
B05	38	Self-employed	Married	Living independently with husband and children	USA	Mainstream
B06	17	Employed	Not stated	Not stated	USA	Mainstream
B07	Self-	Unemployed;	In a	Not stated	Not stated	Not stated

	diagnosed	frequent changes of employment	relationship			
B08	Not stated	Employed	Not stated	Living with parents	Not stated	Mainstream
B09	40	Self-employed	Single	Living independently with children	UK	Mainstream
	36	Stay-at-home Mum	Married	Living independently with husband/children		Not stated
B10	Self-diagnosed	Not stated	Single	Not stated	Not stated	Not stated
B11	25	Self-employed	Not stated	Not stated	UK	Not stated
B12	Adulthood	Not stated	Not stated	Not stated	Australia	Mainstream
B13	Adulthood	Not stated	Not stated	Not stated	Not stated	Mainstream
B14	Adolescence	Unemployed	In a	Living with	UK	Mainstream

			relationship / single	parents			
B15	30s	Self-employed	In a relationship	Not stated	USA	Mainstream	

Once the blogs were identified, all posts on the blog were scanned for
relevance to the areas of interest: diagnosis and mental health. If a post was
identified as relevant due to the inclusion of a keyword (for a list of keywords,
please see Appendix C) or other content, it was copied in its entirety and pasted
into a Word document. All Word documents were imported into NVivo software
for organisation of analysis. Figure 1 illustrates a flowchart used by the
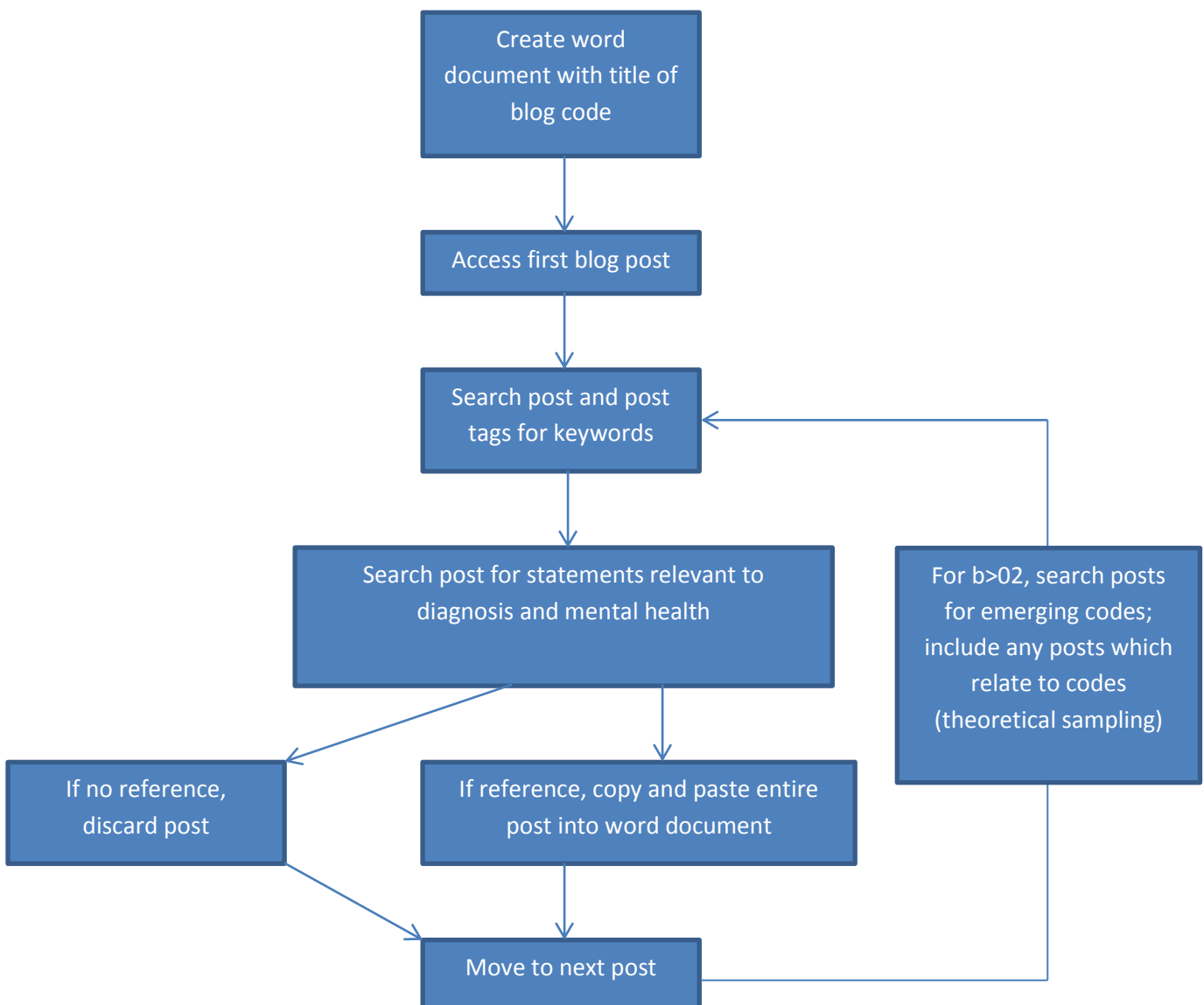researcher to process each blog.

Figure 1. Blog post flow diagram.

Ethical Considerations

This research was approved by the University of Exeter School of Psychology Ethics Committee (Appendices A and B). The original ethics proposal and approval involved accessing online support forums for people identifying with the autism spectrum; however forum moderators were not happy to allow their forums to be utilised for research purposes. Therefore, an alternative data source, that of blogs, was chosen.

The British Psychological Society's Ethics Guidelines for Internet-mediated Research (BPS, 2013) was accessed for the purpose of carrying out ethical research. Blogs are written in the public domain with the intention of informing all visitors to the website; it is therefore, according to the BPS, reasonable to assume that there would be no expectations of privacy of the data. Additionally, it has been suggested that the ability for anyone to retrieve the contents of the blog without interaction with the site or author contributes to its public nature (Eastham, 2011). For these reasons, and as some of the blog authors did not provide any method of contacting them, consent for use of blog material was not sought. However, on accessing blogs, copyright and permission information was sought. One author stated that she did not wish for her blog to be used for any purpose other than providing information for other women on the autism spectrum, and therefore her blog was not included in the current study.

Risk

Most of the blog posts were written at a time prior to data collection and by individuals; it was not possible to identify or contact in the case of disclosure of

risk to self or other people. As blogs are generally written in the past tense, in a similar manner to a diary, it was very unlikely that authors would disclose risk of self-harm or suicide. None of the blogs accessed discussed self-harm or suicidal thoughts in the present or future tense, instead relating past episodes and how authors coped.

It was considered that there was minimal risk to blog authors as a result of the research, as downloading, reading and analysing the blog requires no interaction or intervention with the blog author, and the research can therefore be considered non-intrusive (Eastham, 2011).

Confidentiality

Although blogs can be considered as being in the public domain, the blog titles have been anonymised to protect authors' identities. In the online domain, a pseudonym can be considered as an identity (Eastham, 2011) and therefore it was necessary to protect online identities as much as authors' own offline identities. Quotes have also been altered in a minor way which does not change meaning, to prevent blogs being identified by searching quotes on the internet, in line with the BPS guidelines.

Analysis

The data were analysed using grounded theory following the methodological guidance of Charmaz (2006). A full glossary of terms used in grounded theory is included in Appendix C. I was aware of the paucity of research and theory in this area, which is why grounded theory was considered more appropriate for

this study (Tweed & Charmaz, 2012; Strauss & Corbin, 1998). Additionally, the epistemological position taken throughout this research was social constructionist, i.e. the research sought to explore how people subjectively understood and made sense of their experiences (Andrews, 2012). Grounded theory is suited to such an epistemological position (Strauss & Corbin, 1998).

A further benefit of grounded theory over other methods of analysis, such as thematic analysis, is that, while thematic analysis can enable researchers to identify common themes relating to an issue, grounded theory can encourage the researcher to take a further step, building links between emerging categories, identifying category boundaries and developing explanatory theory (Floersch, Longhofer, Kranke, & Townsend, 2010).

Reflexivity

In qualitative research the researcher's position and biases, and the interaction between the researcher and the data, cannot be entirely ignored (Long & Johnson, 2000; Hall & Callery, 2001). At the outset, I created a memo (Appendix D) detailing my interaction with the research questions and position in relation to the data. I had worked with adults with autism for over a decade, and whilst undertaking the analysis had recently begun a placement in an autism diagnostic service for adults. This position may have affected the results due to my awareness of the prevalence of mental health issues in women with autism, and understanding of some of the difficulties in seeking a diagnosis as an adult. I may have been more likely to attend to statements relating to difficulties with the diagnostic process, or negative emotional and mental health experiences.

Analysis Procedure

Figure 2 is a visual representation of the process of the grounded theory

analysis used in this research.

```
                    ┌─────────────────────────┐
                    │   Research Question      │
                    └─────────────────────────┘
                                 │
                                 ▼
                    ┌─────────────────────────┐
                    │   Data identification    │
                    └─────────────────────────┘
                                 │
Initial memo    ▲                ▼
                │   ┌─────────────────────────┐
                │   │   Data collection        │ ◄──┐
                │   └─────────────────────────┘     │
                │                │                   │
Memo-           │                ▼              Theoretical
Writing         │   ┌─────────────────────────┐  sampling     Constant comparison
                │   │   CODING                 │
                │   └─────────────────────────┘
                │                │
                │                ▼
                │   ┌─────────────────────────┐
                │   │ FOCUSED CODING AND       │
                │   │ CATEGORISING             │
                │   └─────────────────────────┘
                │                │
                │                ▼
                │   ┌─────────────────────────┐
                ▼   │   THEORY BUILDING        │ ──┘
                    └─────────────────────────┘
                                 │
                                 ▼
                    ┌─────────────────────────┐
                    │   Writing-               │
                    │   up/dissemination       │
                    └─────────────────────────┘
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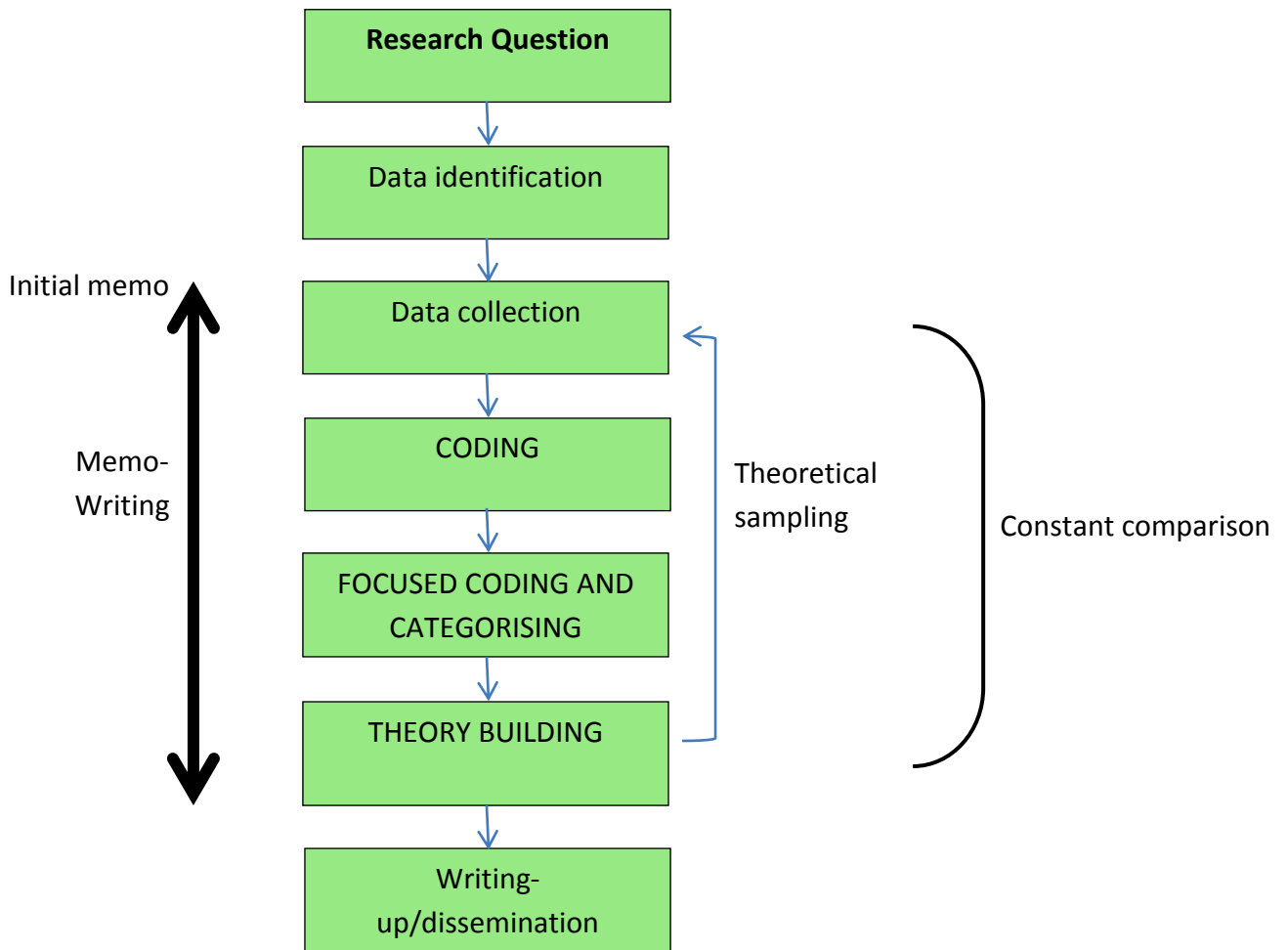
Figure 2. Process of analysis used in the current research.

NVivo 10, by QSR International (2012) was used to facilitate the analysis.

All blogs were read through by the researcher. In the first initial coding stage of

the analysis, primary codes were created from the first blog which attached a

label to fragments of the authors' descriptions of their experiences. Primary codes were as close to the bloggers' original words as possible. Only those elements of the blogs which were relevant to the research questions were analysed. In the next stage, the primary codes were combined under common themes: secondary codes, or concepts (Charmaz, 2006). These stages were repeated for the remaining blogs.

Theoretical sampling was achieved, as indicated in Figure 1, through identifying blog posts which related to emerging codes and, later on in the process, categories.

In line with qualitative guidelines for evaluating the quality and reliability of qualitative research (Long & Johnson, 2000; Elliott, Fischer, & Rennie, 1999; Treharne & Riggs, 2015), close to the beginning of the process, two additional independent researchers (both trainee clinical psychologists) each coded the data from one blog chosen at random. In discussing the three sets of results, similar codes were identified.

Memos were used to define the codes and record links and differences between codes, as well as posing sensitising and theoretical questions to facilitate the emergence of categories from the codes. The codes were represented visually using Inspiration 10 software (2010) to group the codes and begin to identify overarching categories. Theoretical sampling was utilised: the process of returning to the data to refine the emerging categories, identifying data which is in accord with, or is an exception to, the emergent categories (Tweed & Charmaz, 2012). As a further triangulation check, according to Long & Johnson (2000), towards the end of the process two additional independent researchers (a trainee clinical psychologist and an assistant psychologist) with differing

levels of experience with autism each analysed an additional randomly chosen blog and the results compared. Codes and categories were similar to those identified in the current study.

Results

The blogs yielded a wide range of life experiences of the authors. Overarching categories relevant to the research questions are represented visually in Table 3. Five overarching categories were identified, two of which overlapped between the diagnosis and mental health research questions. Further concepts are discussed below, and a full table of sub-themes is included in Appendix E.

Table 3. Categories and codes relevant to the research questions.

Question	Category	Code
Diagnosis	Being different	Different experiences to peers
		Wasn't like anyone else
		Always knew I was different
	Hiding self	Passing for normal
		Study behaviour
		Copy behaviour
		Try to behave normally
		Hid the real me
	Misunderstood	Nothing visibly wrong

	Being misunderstood
	Thought I was making it up
Different presentation in girls and women	Didn't fit the stereotype of autism
	Gender expectations – behaving like a girl
	Girls suffer on the inside
	I wasn't like the boys with autism
Discovery of autism	Became aware of autism
	Told about autism
Researching autism	Reading books about autism
	Reading website about autism
	Found out all I could
Ongoing struggle for diagnosis	No measures to diagnose adults
	Process took so long
Disbelieved by professionals	Questioning my motives for seeking diagnosis

	Diagnosis transformational	Relief at diagnosis
		Life changing diagnosis
		Autism was the answer to my questions
	Self-diagnosis	I know I have autism
		Don't need a professional diagnosis
	Still hiding self	Still copying people
		Getting harder to behave normally
	Questioning everything after diagnosis	Looking back after diagnosis
	Positive identity	Autism is who I am
		Now understand
		Difference not negative
		Advantages of autism
		Feel positive about autism
Mental health	Misdiagnosed with	Mental health diagnosis didn't make sense
		Label removed after autism diagnosis
		Misdiagnosed with
		Women don't have

		autism
Co-morbid mental health		Mental health all pervasive
		Mental health plus autism
Emotional experience		Emotions experienced
		Meltdown
Coping strategies		
Experiences of treatment		Medications
		Therapy

These categories will be discussed below. The authors' voices are represented as quotes, preceded by the blog number.

Diagnosis

Being different: all of the bloggers related feeling different when they were younger.

> B02: "Growing up I knew that I was different to the rest of the world."

None of the bloggers described being different in a positive way; their difference was a source of distress and isolation.

Hiding self: the women described hiding their real selves when they were younger to fit in with their peers and society.

B07: "I've spent my entire life carefully observing how neurotypical people behave, so I could act like them… and not stand out from the crowd like a weirdo. I became so good at hiding over the years that I didn't even realise what I was doing."

The women learned through experience and through observation to behave as others behave, despite this often being contrary to their nature.

Misunderstood: when younger, the bloggers related that they had been misunderstood, which had a significant impact on their self-esteem and anxiety levels.

B06: "These people didn't see me when I nearly dropped out of school because I was SO overwhelmed and overstimulated. They didn't see me struggling not to kill myself because I felt SO misunderstood."

The women had been misunderstood by those closest to them as well as professionals and peers, resulting in an intense isolation from all others.

Different presentations in girls and women: the bloggers described their autistic symptoms as being different from those of boys and men, partly because of the expression of autism in girls and women, and partly because of the differing social expectations of girls and women.

B01: "Girls *are* often expected to be quiet more than boys and if you have an aspie girl who is working her frilly socks off to be the same as the other girls, she'll learn that people want her to be compliant."

The differing presentation of autism in girls and women resulted in their autism not being recognised in childhood.

Discovery of autism: the first time the women became aware of autism was a pivotal moment, and usually involved another person suggesting the possibility of an autism spectrum condition.

> B01: "I wasn't even aware about Asperger's until a year previous, when it came to the attention of my exceptionally observant Art Therapist that I didn't seem to process emotions how other people do."

Some of the bloggers reacted with shock and disbelief, while others felt that the news was a revelation to them.

Researching autism: after becoming aware of autism, all of the women undertook to discover as much as they could about autism.

> B05: "The more I learned about autism, the more I needed to know. I researched, and read – a lot"

The bloggers accessed information from books, websites and online forums; the more information they gained, the more they wanted to learn.

Ongoing struggle for diagnosis: irrespective of their disclosed nationality, the bloggers experienced a continuing struggle to obtain a diagnosis.

> B13: "Eventually I grew so impatient with the wait to get an NHS diagnosis that I called the clinic to see just how long the estimated wait was, and I was told that I'd have to wait at least another five months."

Obstacles to diagnosis included difficulties finding a diagnostician, particularly a clinician who specialised in autism in adults, waiting times, and not being referred for diagnosis.

Disbelieved by professionals: the women experienced scepticism from healthcare professionals when they raised the topic of autism.

B09: "When the doctor calls me back she keeps questioning my motive for wanting an evaluation. If I'm working and living with others, I must be doing pretty well, she says."

Some of the women appeared to be functioning too well to be taken seriously, whilst others were disbelieved due to other diagnoses or their gender.

Diagnosis transformational: when they did finally receive a diagnosis, the women described feelings of relief and an overall transformation in how they saw themselves.

B09: "I was diagnosed with ASD earlier this year, and it has literally been a life saver for me. Everything in my life is improving since the diagnosis and I feel like I'm getting a second chance to live by having this new understanding."

The autism diagnosis provided the women with an understanding of their difficulties and confirmation that their concerns had been valid.

Still hiding self: despite the positive transformation all the women underwent following diagnosis, they continued to utilise the strategies they had developed over the years to hide many of their autistic characteristics.

B15: "A good percentage of what I do is based on a series of 'scripts' in my head that I still use."

These strategies were used to help the bloggers negotiate the social world, although the women found it exhausting and stressful to hide their real selves.

Questioning everything after diagnosis: after receiving the diagnosis, the women experienced a period of uncertainty when they revisited their lives and incidents that had happened and wondered how the situation may have happened had they known they had autism.

> B01: "I started questioning the everyday things, whether or not they were 'autistic' things or just me."

The questioning allowed the women to come to terms with their past, or process the events of their past with a new understanding.

Positive identity: overall, the diagnosis of autism enabled the women to develop a positive identity.

> B11: "I know that many may disagree, but I actually don't mind being defined by my Aspergers. I enjoy it. I see it as a strength and something that makes me unique and amazing."

The autism diagnosis provided the women with an explanation of their difficulties and access to a supportive community of others with autism who shared the same traits.

Self-diagnosis: some of the women went through a process of self-diagnosis, during which they declared themselves to have autism.

> B13: "I'm an adult woman with Asperger's Syndrome. I have not yet received a professional diagnosis, but in my research and speaking with other people with Asperger's I am very certain I have this condition."

Most of the women who self-diagnosed went on to seek a clinical diagnosis; however some bloggers questioned the utility of requesting a professional diagnosis once they believed themselves to have autism.

Misdiagnosed with

The authors described a variety of mental health issues with which they had been misdiagnosed, and whose diagnosis was rescinded following the accurate identification of an autism spectrum condition. Some of these misdiagnoses appeared to relate to the bloggers' gender. These issues included bipolar disorder, psychosis and personality disorder:

> B05: "It took 38 years to learn that I am *not* crazy, depressed, agoraphobic, or bipolar (only a couple of labels I lugged around over the years). I am autistic."

Misdiagnosis was distressing to the individual, and the diagnoses they had received appeared not to fit with their experiences; the diagnosis of autism made sense to the women.

Co-morbid mental health

All of the bloggers discussed experiencing mental health conditions in addition to their autism. Anxiety disorders, including panic and phobias, were described by the bloggers as occurring frequently and in a variety of situations. Anxiety was depicted as being all-pervading and resulting from a lifetime of being misunderstood and not fitting in:

B08: "Sometimes, I get really anxious in a new situation, and I don't know how to talk. There are NO words that I can form, because I don't know how to apply things I've already learned to current situations."

Depression was another mental health condition with which authors had been diagnosed:

B08: "Yes, I have Aspergers. I also have depression. They are two separate things. I see my Aspergers as being something that I can work with and it can be positive. With depression, I honestly don't see the "good" of it."

The mental health conditions were identified as separate conditions to the autism spectrum conditions, even if they were believed to have occurred as a result of the difficulties encountered as an autistic adult.

Emotional experience

Emotions experienced: the authors described a range of negative emotions which they experienced regularly, such as worry, fear, anger, loneliness, shame and stress.

B05: "Loneliness is a returning thing in my life (just like it is for many people, and autistic people in general (sometimes it's a big black hole, sometimes it's just a cloud passing by)."

Most of the described emotions were negative, and pervasive.

Meltdown[1]: when their emotions became overwhelming, bloggers would experience "meltdown", a state in which they were unable to function physically or mentally and might lose behavioural control:

> B01: "Comparing crying with a meltdown is like comparing a puddle to a tsunami. It builds inside like an angry volcano, I snap at all those around me, I swear, I shout, I accuse. If I had any propensity to violence I would probably hit walls and break doors. Then comes a wave of tears and shaking, which feel like they'll never stop. They go on and on and on, they do not end when someone comforts me or when the problem is solved. They will stop when they are finished only, maybe minutes, but maybe hours. I am desperate and vulnerable and totally raw."

'Meltdowns' were described as uncontrollable and almost inevitable in some situations.

Coping strategies: bloggers described strategies they used to cope with emotional pain, which included self-harm and suicide attempts, constant checking of self, and asking for help:

> B15: "Additionally, I understand that a medication will not solve all of my problems. I still am in the process of forming better coping strategies for the stress in my life, and have committed myself to this goal."

Strategies varied in their short- and long-term utility to the individual. The authors had begun to develop coping strategies prior to their diagnosis; however receiving a diagnosis of autism gave permission to the women to seek help, and identification of the difficulties with which they were trying to cope.

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[1] *Meltdown is a term used within the scientific literature relating to autism (e.g. Bedrossian, 2015; Linn & Smith Myles, 2004; Iver, 2012; Ryan, 2010) and is a known construct for children and adults on the autism spectrum.*

Experiences of treatment

The treatments described by the bloggers were either medications or psychological therapies, with varying responses.

Medication: while some bloggers explained that they were compelled to take medications by doctors who just wanted to prescribe, some authors felt able to refuse to take medications, either directly to the prescriber or by ceasing their medicines without informing medical practitioners:

> B14: "I was offered anti-depressants and I did end up with the pills but I never took them and I didn't feel I was bad enough for them."

Medication was viewed as helpful by some of the bloggers, but for others it appeared to make their symptoms worse.

> B05: "Although I feel I am more irritable and less tolerating of interruptions—especially when the medication is wearing off at the end of the day. I feel better overall taking the meds than not."

Medication was not perceived as the answer to their difficulties by any of the authors; instead it enabled some women to better tolerate events and emotions.

Therapy: Psychological therapy had appeared to be helpful for a number of the authors, but others described having experiences of numerous different types of therapy and therapist without deriving any benefit. In fact, for a small number of bloggers therapy was depicted as harmful:

> B01: "My first taste of therapy came at the age of 16, and came in the shape of a small wiry middle-aged cognitive behavioural therapist who

was allergic to radiators, and insisted I join the local Buddhist Centre …

My second experience of Cognitive Behavioural Therapy (CBT) came in

a much friendlier package, and a woman I got on with incredibly well.

However, looks can be deceiving and because my Aspergers was

unknown, this therapist was more destructive than beneficial."

Neither medication nor therapy described related to the core difficulties of autism, rather to associated mental health difficulties and emotional experiences. Without addressing the core difficulties, medication and therapy could only be a temporary solution at best.

In this section, the categories relating to diagnosis of an autism spectrum disorder and mental health issues emerging from the women's words have been identified. In the next section, the grounded theory and relationship between emergent categories will be discussed.

Discussion

The first question I aimed to explore in this research related to the experiences of women on the autism spectrum relating to diagnosis, as described in their blogs. The grounded theory arising from the data is illustrated in Figure 3.
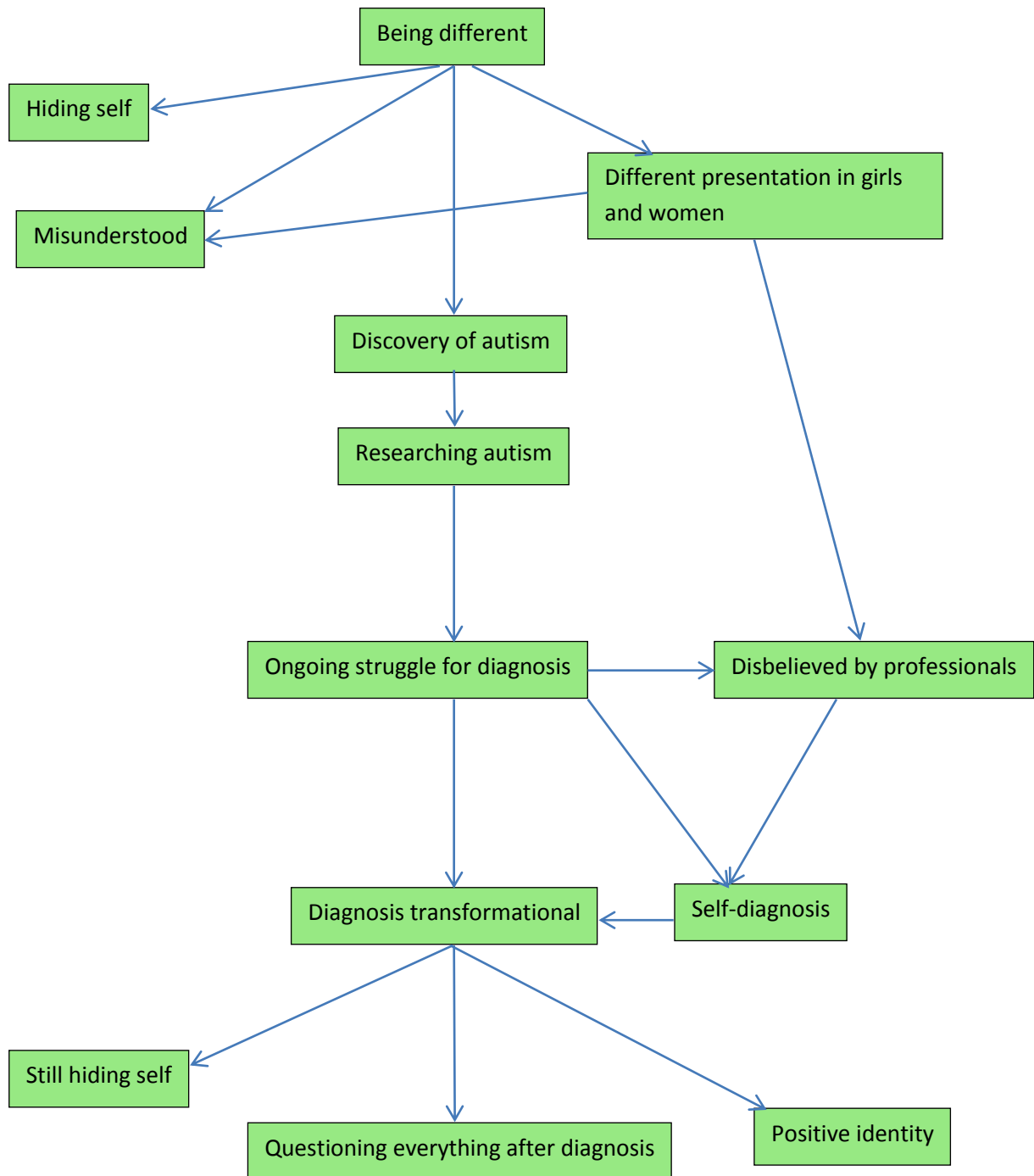
Figure 3. A grounded theory model of diagnosis.

All women were diagnosed in their late teens or later, possibly due to their gender and the expression of their autism; this is in accord with research in the Netherlands (Begeer et al., 2013) which suggested that the differing presentation of girls and women on the spectrum might contribute to a later identification. The authors did not seem to fit the stereotype of autism, describing that they often mimicked the behaviours of those who appeared to be socially successful, in order to appear "normal". This had been suggested as a hypothesis by Attwood (2006). Attwood and others (Kreiser & White, 2014) observed what they believed to be mimicking behaviour, but it was unclear whether this was an explicit strategy undertaken by their participants or behaviour of which the females with ASC were less aware. Despite the imitative behaviour described by the bloggers, appearing to be neurotypical, i.e. not autistic, on the surface did not overcome the core difficulties of autism; this corroborates quantitative research of Lai et al. (2011) who reported a superficial socio-communicative ability in females with autism which contributes to their delayed identification.

As children, women were aware of *being different*, knowing they were not the same as their peers. They spent a lot of time and effort *hiding self*, studying others and trying to copy their behaviour in order to appear "normal". This led to the women being *misunderstood,* as it was not clear to others why they were different, and they women were perceived negatively by others. Some of the women experienced considerable bullying as children. A factor which contributed to the women being misunderstood was the *different presentation in girls and women*. The women did not fit the typical stereotype of autism, and often internalised their distress which resulted in others believing they were shy or depressed. *Discovery of autism* occurred when the women first became

aware of autism, either through being told by someone close to them or seeing something in the media. This led to the women *researching autism*, predominantly through reading books or websites about autism. The women attempted to find out as much as they could about autism. On searching for a diagnosis, the women experienced an *ongoing struggle for diagnosis.* In some cases there were practical difficulties to diagnosis such as clinicians not having access to the right diagnostic tools, but in all cases the process took a very long time. The struggle for diagnosis was perpetuated by the women being *disbelieved by professionals*, and questioned as to their motives for seeking diagnosis. The professionals were also reportedly influenced by the *different presentation in girls and women,* generally not being aware of the presentation of autism in girls and women. Some women went on to a state of *self-diagnosis,* in which they made a decision that they had autism and declaring this to themselves and to others. A small proportion of these women chose not to proceed to clinical diagnosis, being content in their self-diagnosis. The *diagnosis* was *transformational* for the women, and in some women was life changing. Autism was the answer to the questions they had been asking for many years about the reasons for their difference, and the transformational diagnosis led eventually to the development of a *positive identity*. The women came to understand themselves better and to accept that autism is who they are. They developed positive feelings about autism, and began to see the advantages of autism. However, some women were *questioning everything after diagnosis*, a short period of time in which they re-visited their lives prior to the diagnosis through a new lens of autism. This could result in a period of distress during which the women remembered incidents in their lives which could have been different had they known about their autism at the time. Even

though the women generally felt positive about autism, they still had times when they were *still hiding themselves.* They continued to use the strategies they developed when they were younger in observing others' behaviour and copying it.

The second research question was: what are the self-described experiences of mental health of women with autism? Figure 4 illustrates the mental health experience model arising from the data.
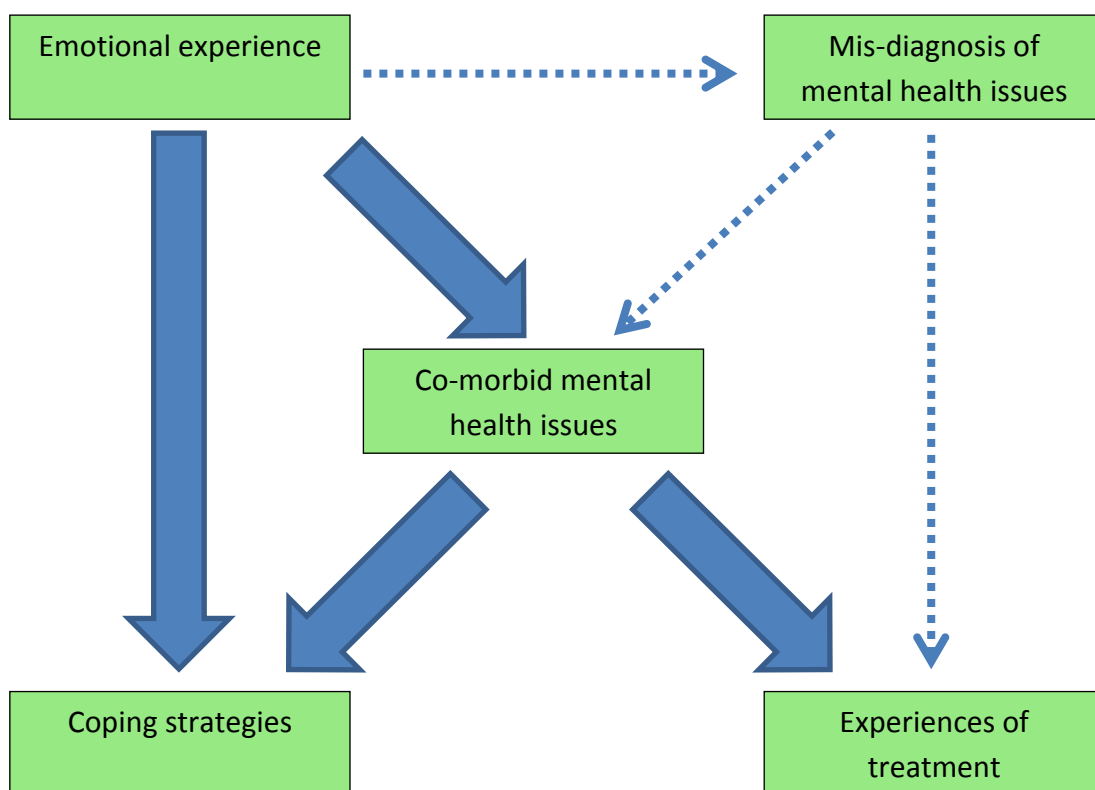

Figure 4. A grounded theory model of mental health experiences.

Emotional experience is the description of the feelings commonly experienced by the women with autism, and consisted of negative emotions. A number of feelings were described as contributing to the bloggers' emotional experiences: including constant worry, fear, isolation, anger, stress and shame. Despite the

women's difficulties with socialisation, and the levels of anxiety caused by interacting with others, they described feeling lonely and isolated. Isolation has been connected with increased depression and anxiety in people with ASC (Mazurek, 2014). This feeling was exacerbated when amongst others. When talking about their experiences in relation to autism, no positive feelings were described, perhaps due to the emphasis in the blogs on the difficulties relating to autism.

Overwhelming emotional experiences led to 'meltdowns' which began in childhood but which continued to occur frequently in adulthood, resulting in further shame but helping "clear the air" in regaining emotional balance. A range of coping mechanisms were discussed, including self-harm and suicide attempts as well as asking for help and developing strategies to manage their emotions.

The emotional experience, if sufficiently pervasive or intense, could contribute to a diagnosis of mental health issues; this could be an accurate diagnosis of a *comorbid mental health condition* experienced alongside the autism spectrum condition, such as depression or anxiety; or could be a *misdiagnosis* of a mental health condition.

Anxiety was the most commonly described mental health issue, and was pervasive and overwhelming, in accord with research with children (Mattila et al, 2010). Research with adult men with ASC suggested that depression was the most common mental health condition in males (Gillberg, Helles, Billstedt, & Gillberg, 2016). Other research which combines data from both genders also concludes that depression is the most common comorbid mental health condition (Barnhill, 2007); however given the dominance of males in such

research, it is perhaps unsurprising that depression was not the mental health condition discussed the most. There were some common triggers for increased anxiety, in particular socialisation and sensory sensitivities.

Depression was also experienced by the majority of bloggers. It was often described as a hidden condition due to the difficulties in communicating distress. The impact of both depression and anxiety was severe, affecting day-to-day function to the extent of being unable to get out of bed, leave the house or work.

Mis-diagnosis of a mental health condition appears to be a common occurrence for women on the autism spectrum, possibly related to difficulties obtaining an accurate diagnosis of autism because of their gender. While a number of authors had comorbid mental health issues, most described having been mis-diagnosed with other mental health issues ranging from psychosis to bipolar disorder; this is in accord with types of misdiagnosis described in the research (Van Schalkwyk, Peluso, Qayyum, McPartland, & Volkmar, 2015; Dossetor, 2007).

Whenever women had received a diagnosis of a mental health condition, whether accurate or a misdiagnosis, they all were offered treatment in the form of medication or therapy. The women had varying *experiences of treatment*, ranging from helpful to harmful. It appears that practitioners' experience of autism was pivotal in the outcome, particularly when delivering therapy (Gaus, 2011). Generally there was a feeling that doctors wanted to prescribe medications in the majority of situations, and some women found a real benefit of medications. However, others found that medications made their mental health much worse.

Coping strategies were the strategies adopted by the women with autism to manage their emotional experiences and mental health. These strategies had been developed over the years, and varied in their short-term and long-term usefulness to the women. This was particularly the case before the women had received their diagnosis; the coping strategies had been developed to manage an experience which they did not yet understand.

The mental health theory consists of a number of inter-related elements. *Co-morbid mental health issues* is a core element of this theory and relates to all other categories. While a late diagnosis and lack of self-understanding can contribute to the development of mental health problems, anxiety in particular can result from autism-related difficulties in predicting what will happen in the world. All women have developed coping strategies over the years of varying utility.

Gender

Some parts of the model in the pre-diagnostic stage appear to be specific to women:

Hiding self. Only a small minority of boys on the autism spectrum were thought to use hiding or masking as a strategy to navigate the social world (Hiller, Young, & Weber, 2016), whereas all bloggers described actively hiding their differences throughout their lives.

Misunderstood. As the women had spent their early years copying others' behaviour and hiding their autistic selves, they were more likely to be misunderstood than boys whose autism was more stereotypes and noticeable.

Different presentation in girls and women. Almost all of the bloggers related that a difference in presentation of autism in girls and women was core to their experiences. Although there is no research in boys and men's experiences of this, it is anticipated that this is less of a central feature in the male experience.

Disbelieved by professionals. The differing presentation of girls and women contributes to the difficulties in identifying autism in females. It has been shown that for girls the relative delay in obtaining a diagnosis compared to boys stems from difficulties gaining a referral for an assessment rather than delays from referral to diagnosis (Rutherford et al., 2016). It appears from this research that part of the difficulty in gaining a referral for girls and women could result from being disbelieved by professionals that they could have autism.

Limitations of the Current Study

Method: Ideally in grounded theory studies, researchers continue to collect data until theoretical saturation is reached, but in practice not always achievable (Charmaz, 2006); Strauss and Corbin suggest that saturation is "a matter of degree" (Strauss and Corbin, 1998 [1990] ; p136); Mason argues that it is "a rather elastic notion" (Mason& Mark, 2010). Where full theoretical saturation is not possible, for example in time- and resource-limited studies, grounded theory researchers are encouraged to "work towards theoretical saturation" (Bowen, 2008: p149) and demonstrate rigour and transparency. In the current study the sources of data were limited to the number of available blogs and it was not possible to reach saturation. With more data, it is possible that saturation might be reached.

Additionally, theoretical sampling was limited by the fact that blogs had already been written; it was not possible to generate further data as would happen in other data collection methods such as interviews. However, the substantial amount of data offered by the blogs allowed theoretical sampling in the choice of blog posts. From the elements of grounded theory in Figure 2, only theoretical sampling was affected by the constraints of the study.

Although the method allowed for data collection without direct contact with the bloggers, thus reducing the likelihood of the research affecting the authors' postings, it was also not possible to undertake respondent validation by contacting the bloggers for substantiation of the results. This was mediated by the triangulation exercises undertaking during analysis.

As a further method of checking the analysis, according to Long and Johnson (2000), the researcher undertook peer debriefing with colleagues within an adult autism service, gaining feedback on the categories and models. The models were subsequently presented in a regional network meeting of autism services, with positive and constructive feedback.

Participants: All blogs were written by those motivated to share their experiences, and authors were literate and articulate. Results may not be as generalisable to other women on the autism spectrum, particularly those with less access to online resources about autism. Equally, as far as could be determined, the authors were all from Western cultures with similar levels of awareness of the autism spectrum and diagnostic processes. These results may be less applicable in other cultures and countries.

It was not possible to confirm the diagnoses of blog authors; however there is no reason to doubt their personal accounts. Such blogs do not provide financial gain to authors, and in most cases there is no social incentive to describe themselves as autistic when they are not. Such social feedback would be more likely to occur in forums, where two-way interaction is expected. A blog is more likely to encourage an individual to be open about their diagnosis and their life. Indeed, it has been suggested that the invisibility offered by the blog interface can facilitate a more un-self-conscious narrative, enabling authors to offer an account which does not attempt to conceal negative aspects of their personality and lives (Hookway, 2008).

Clinical implications

The current stereotype of autism as a predominantly male condition appears to be impacting on the diagnostic process for women on the spectrum. They describe receiving a negative response from healthcare professionals with whom they discuss the possibility of autism, due to their gender and strategies they had used to appear "normal" and fit in socially; this had resulted in a longer time between identification of signs of autism and diagnosis. It would be beneficial to ensure that clinicians, including general practitioners and community mental health teams, are aware of autism and its presentation in women.

It would also be helpful to be aware of additional mental health issues which women with autism spectrum conditions are likely to experience; in particular depression and anxiety. The women describe the importance of a therapist's understanding of autism for successful therapeutic intervention; it could be

valuable for women with autism for therapists working with them to understand autism and how this can affect thinking and emotional processing.

Further Research

Further research could explore the gender-related experiences of women with autism in employment, particularly with regards to disclosure of their autism and support. Additionally, exploring the experiences of women with autism of healthcare providers could facilitate an understanding of the barriers to accessing timely services which can result in physical or mental health crisis. This is also the case for other poorly-researched populations with autism such as older adults and adults of varying ethnicities.

Conclusion

In conclusion, the results of the study highlight particular difficulties experienced by women seeking a diagnosis of autism due to their gender, over and above the lengthy diagnostic process. The findings of this study also support the suggestion that girls and women intentionally use mimicking strategies to fit in socially from a young age, and although these strategies are superficially successful, they do not overcome the core difficulties of autism. However, the core difficulties appear to manifest differently in women, such that even as children they do not fit the general male-based stereotype of autism. The diagnostic process is a challenging one, and the difficulties do not cease on receipt of a diagnosis. Subsequent additional challenges include coming to terms with their past life through a new lens of autism, and how to disclose the diagnosis to others. Additionally, the results demonstrate the high rate of

mental health co-morbidity with autism spectrum conditions, which is possibly due at least in part to delayed diagnosis. Finally, the findings highlight the high level of mental health mis-diagnosis in this sample prior to the final diagnosis of autism, suggesting that the female phenotype of autism is poorly understood.

These tentative results may be clinically relevant to a number of clinical practitioners from GPs and practice nurses, to community mental health team staff and specialist autism practitioners.

This study contributes to an emerging body of literature exploring autism in girls and women, and is novel in exploring the experiences of women through their spontaneous writings in blogs. The findings from the current study could be supplemented by further exploration of women's experiences using other sources of data such as forums, online messaging interviews which have been successfully utilised by Smith and Sharp (2013) or face-to-face interviews.

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Appendix A. Ethics approval.

This research was approved by the University of Exeter School of Psychology

Ethics Committee (Appendices A and B)

Your applications

2015/857	Hazel Went	The experiences of adult women on the autism spectrum.	conditional acceptance	16/03/2015	Track B

Your application (2015/857) entitled The experiences of adult women on the autism spectrum. has been conditionally accepted

Please visit http://www.exeter.ac.uk/staff/ethicalapproval/

Please click on the link above and select the relevant application from the list. The conditions are as follows:

An ethics reviewer raised the issue of how a user can decide on their agreement to have their post accessed without knowing in advance how their thoughts are going to be paraphrased, suggesting that a "verbatim" approach would remove all ambiguity and avoid deception. I can see the reviewer's point here, however given your desire to avoid individual forum posters feeling 'identified' through the publication of direct quotes (via direct quote google searching), I am happy to allow the intended 'paraphrasing', provided that this is made clear to participants that this is what will happen, and why. To this end, can you please be slightly more specific about this in your 'post to the forum' text, just to make it clear to participants how/why you not using direct quotations maintains their anonymity.

Appendix B. Letter of approval for blogs.

Hi Hazel,

I am happy to approve this use of blogs instead. Also, I do not think that you should have to ask bloggers permission to use their blogs as data. Blogs are, to my mind, completely 'public domain', in the same way that newspaper articles are. As such, I think you have the right to use them as research data in much the same way (i.e. you would not email a journalist to ask if you could use their articles as part of a data set).

Regards,

Tim.

_____
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Appendix C. List of keywords for identifying blogs

Diagnosis

- Diagnos*
- Assess*
- Test*
- Suspected
- Autism, Asperger's, ASC, ASD

Mental health

- Mental health
- Illness
- Stress
- Anxiety
- Depress*
- Bipolar
- *phobia*
- *disorder*
- Panic
- Psychosis
- Schizophrenia
- OCD
- *therapy*
- *psych*
- Counsellor

Appendix D. Grounded theory terms.

Category	A group of codes which share a (theoretical) property. Categories are more abstract than codes.
Code	A code is a label assigned to important/relevant words or groups of words within the data. Codes may be the participants' own words, or may represent them.
Constant comparison	Constant comparison is part of the process of simultaneous collection of data and analysis, which occurs all the time through the analysis process. Comparisons are made (and described in memos) within and between codes and categories to build the theory.
Memo	Memos are the written description and record of the researcher's thinking process during the process of research. Memos may describe the researcher's own thoughts and beliefs, but may be used to describe codes and categories, and how these are related.
Open coding	This is the first stage of data analysis, in which the data are read and codes assigned to chunks of text. Chunks may be individual words, phrases or sentences.
Saturation	Categories are theoretically saturated when further data analysis yields codes that fit within already existing categories, and no new categories are created.
Sorting	As memos are written, and codes and categories developed, sorting is the process of putting memos, codes and categories together which in turn can develop new ideas. The process of sorting builds the grounded theory.
Theoretical sampling	Theoretical sampling involves focusing in on the data in order to fill categories to reach saturation, or to identify exceptions and boundaries to categories. Theoretical sampling involves making a strategic decision to select appropriate data for analysis.
Theory	Grounded theory is described in literature as both the process and the product. As a product, the theory is a model which has arisen from the data which explores a phenomenon .

Appendix E. First memo.

30 March 16
First memo

My initial thoughts are the differences in experiences between males and females who are on the autism spectrum. Must remember the 3 different areas: diagnosis, mental health and sensory.

Why these questions? Why did I narrow my interests to these three questions? There were so many areas of interest to research with regards to autism, but from my work with women with autism I believe that this is an area which is lacking in the research. If you're going to begin some research, begin at the beginning: diagnosis is key! Without the diagnosis, we have no autism - i.e. with the exception of those who have been self-diagnosed, this is the common experience of all people who have been told they have autism. With the extreme male brain hypothesis, which has been reported in multiple media in a variety of ways, I suspect women will experience difficulties accessing a diagnosis. This has been the experience of working with women with autism. However, does this change according to area? Is it just this locality, and other places across the UK/world actually accept females with autism? What have been the positive experiences of diagnosis? With the advances in understanding of autism, are girls actually being diagnosed earlier now? My feeling is that this isn't the case, so I need to be aware of my thoughts when reading the blogs.

Mental health was a natural outcome of thinking about diagnosis: what happens when you don't receive a diagnosis of autism until adulthood? What is the effect on identity and self-esteem when you are misunderstood and perhaps don't understand yourself until adulthood? Exploring mental health in autism is highly relevant to clinical psychology, and important to understand as existing research suggests that about 80% of people on the autism spectrum have a mental health problem. I also remember a training years ago in which an adult woman described being diagnosed with psychosis for ten years before receiving her more accurate diagnosis of AS. Is this common, or was this woman's experience an exception? Do women pick up other diagnoses before coming around to autism?

Sensory experiences may seem distinct from both diagnosis and mental health, but now that DSM V includes sensory experiences, it appears that clinicians are paying greater attention to the well-known differences in sensory experiences in ASC. Do women experience additional sensory difficulties as a result of their gender, and gender expectations? Do women struggle with all the perfumed products and tight clothing, for example? Or do they simply choose not to conform? Or is this irrelevant?

My own beliefs: I believe that this study is so needed, as the voice of people with autism, and in particular women with autism, is missing in research. I believe that women do still find it harder to obtain a diagnosis of autism due to the extreme male brain theory and its frequent publications throughout the media - so I would expect the level of misdiagnosis to be high. From experience, I believe that a lot of the authors will describe experiencing mental health problems - but I also wonder whether they will describe experiencing strong positive emotional states as well? There's a suggestion that some people with autism can have high levels of optimism - is this borne out? I also believe that the women will describe a variety of different sensory experiences, and

will probably describe the negative or unpleasant experiences as these will have the greatest impact on their lives. There is so much importance placed by society on women's appearance, which involves so many smelly and slippery concoctions; I would expect this to be a problem and specifically for women.

Appendix F: Dissemination statement

The findings from this research will be disseminated to clinical psychologists through presentation at a South-West network meeting focusing on women on the autism spectrum.

Additionally, the findings will be disseminated to researchers and clinicians through publication of this study in a peer-reviewed journal. An edited version of the research will be submitted to the Autism journal after acceptance of the thesis by the Examiners' Boards.

This research originally consisted of three research questions, the third question involving the experiences of women on the autism spectrum with regards to sensory experiences. While it was deemed impractical to include the results in this thesis, the results of the third research question will also be disseminated in the same manner as the research within this thesis.

Appendix G: Instructions for authors

Autism submission guidelines for authors:

https://uk.sagepub.com/en-gb/eur/journal/autism#submission-guidelines

Autism provides a major international forum for peer-reviewed research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders. The journal's success and popularity reflect the recent worldwide growth in the research and understanding of autistic spectrum disorders, and the consequent impact on the provision of treatment and care.

*Autism*is interdisciplinary in nature, focusing on evaluative research in all areas, including:

- intervention
- diagnosis
- training
- education
- neuroscience
- psychological processes
- evaluation of particular therapies
- quality of life issues
- family issues and family services
- medical and genetic issues
- epidemiological research
- **4. How to submit your manuscript**
- Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.
- *Autism* is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

- IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

- All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

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- **5. Declaration of conflicting interests**

- Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. *Autism* does not require a declaration of conflicting interests but recommends you review the good practice guidelines on the SAGE Journal Author Gateway.

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- **6. Other conventions**

- We would prefer to use the term 'people with autism' or 'people with autism spectrum disorders or conditions'. We would also prefer the term 'typically developing' rather than 'normal'.

- **6.1 Research ethics**
  All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

- We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of

Helsinki http://www.wma.net/en/30publications/10policies/b3/index.html and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (at http://clinicaltrials.gov or other suitable databases identified by the ICMJE, http://www.icmje.org/publishing_10register.html). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

- **6.2 Patient consent**

  Authors are required to ensure the following guidelines are followed, as recommended by the International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published.

- Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note. When informed consent has been obtained it should be indicated in the submitted article.

- **6.3 Statistical analyses**

  Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually required. In research papers requiring

complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

- **6.4 Randomized controlled trials**

- *Autism* requires a completed CONSORT 2010 checklist and flow diagram as a condition of submission when reporting the results of a randomized trial. Templates for these can be found on the CONSORT website [www.consort-statement.com] which also describes several CONSORT checklist extensions for different designs and types of data beyond two group parallel trials. You should ensure that your article, at minimum, reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your trial report and may enhance its chances for eventual publication.

- **6.5 Prisma**

- *Autism* requires a completed PRISMA checklist and flow diagram as a condition of submission when reporting the results of a systematic review. Templates for these can be found on the PRISMA website www.prisma-statement.org. You should ensure that, at minimum, your article reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your systematic review and may enhance its chances for eventual publication.

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- **7. Permissions**
  Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

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- **8. Manuscript style**

- **8.1 File types**

  Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

- **8.2 Journal Style**

  Autism conforms to the SAGE house style. Click here to review guidelines on SAGE UK House Style.

- **8.3 Reference Style**

  Autism operates a Sage Harvard reference style. Click here to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

- **8.4. Manuscript Preparation**

  The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

- *8.4.1 Terms for Autism*

  UCL and NAS conducted a survey within the UK of stakeholders connected to autism, to enquire about preferences regarding the use of language. Based on the survey results, we have created guidelines on terms which are most acceptable to stakeholders in writing about autism here.

- *8.4.2 Keywords and Abstracts: Helping readers find your article online*

  The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online.

- ***8.4.3 Corresponding Author Contact details***

  Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

- ***8.4.4 Guidelines for submitting artwork, figures and other graphics***

  Artwork, figures and other graphics such as tables should be uploaded through SAGE's Online Submission System alongside the main body of the text, as a seperate file to ensure best quality in production. For further guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

- ***8.4.5* Guidelines for submitting supplemental files**

  This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

- ***8.4.6 English Language Editing***

  Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.