

**The Impact of Socio-Cultural Values on Autistic
Women: An Interpretative Phenomenological Analysis**

Portfolio Volume 1: Major Research Project

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Abstract

The experiences of autistic females, particularly those of adult women are not well understood. The way that autism has been conceptualised traditionally has contributed to knowledge being largely extrapolated from experiences of autistic men and children. Lived experience research provides a valuable resource for understanding hard to reach voices, such as those of autistic women without intellectual disabilities. Existing research has examined the impact of “autism” on the person diagnosed with it, the impact of autistic people on others, and how culture may impact on how autism is understood. However, we have rarely questioned how culture has impacted on autistic people. This becomes more pertinent as the aetiology for sex differences in autism remain unclear, and we start to consider the role of gendered socialisation on how autistic women may present.

This study aimed to examine how autistic women have made sense of their lived experiences in the context of the culture they are embedded within. This was achieved through an Interpretative Phenomenological Analysis with eight autistic women with no diagnosis of intellectual disabilities. Three core themes emerged highlighting the pervasive impact of socio-cultural values on participants, followed by how they have individualised as autistic women, and finally reflecting on the importance of staying connected with society for them. By understanding autistic women in their contexts, a more representative portrayal of their relationships with others, strengths and needs was also offered. These have implications for the continued need to shift attitudes in society through dissemination of knowledge; and clinical implications for cultivating identity development and the building of meaningful connections with society for autistic women.

Chapter One: Introduction

For a long time, it was taken for granted that what was understood about autistic women was representative of their experiences. However, explorations of the conceptual and methodological flaws in autism research has highlighted the potential gap in our knowledge. To understand the current situation, this introduction started with thinking about how autism has been traditionally conceptualised, and how this has shaped current thinking about sex differences in autism. We then move towards thinking about the less explored territory of social contexts that may provide useful insight. Preceding all this, I reflected on my epistemological position as the principal researcher.

1.1 Note on language

This study will use the term “autistic” to refer to people diagnosed with Autism Spectrum Disorder (ASD), Asperger’s Syndrome (AS) and the relevant umbrella of conditions. “Autism” was used to describe the phenomenon that these diagnoses denote. These terms were most endorsed by autistic adults as descriptors (Kenny et al., 2016), and were therefore chosen to reflect those preferences.

1.2 Personal reflections

Reflecting on the inspiration behind this research, I instinctively thought of the challenges experienced by my younger autistic sister in making sense of her experiences, and navigating education, work, and relationships. As her sibling, I was equally confused when trying to simultaneously learn for myself and convey to others her spectrum of abilities and needs when seeking support for her. This research was in many ways an extension of an on-going process between my sister and me in trying to understand the impact we have on each other. Having worked clinically with autistic children, adolescents, and adults across the spectrum in different mental health services as a (pre-qualified and trainee) psychologist has only increased my curiosity. My personal and clinical involvements with autism provided me with a degree of insight into this research topic, such as the challenges that they may experience. However, it was reflecting on the presumptions that came with my knowledge that allowed me greater reflexivity throughout this research (Appendix K contains extracts of

reflections relevant to different aspects of this research). For example, listening to experiences in the form they were presented and not unduly framing them in concepts such as theory of mind. This was necessary for ensuring that I honoured what was shared by the participants.

1.3 Ontology and epistemology

My understanding of autism to date, developed from my clinical and personal experiences, has left me cautious of thinking about autism as a diagnostic construct. At the same time, I recognised its existence as a socio-cultural phenomenon that warranted more exploration and understanding. This led me to approach this research from a critically realist ontological position, where I believed the reality of autism exists, but one could never fully understand it because of the imperfect mechanisms in grasping another person's lived experience, as well as the complex nature of this phenomenon. I believed that this research would bring us closer to an understanding of autistic women under critical examination, but would never be able to make any claims about fully comprehending their experiences (Moon & Blackman, 2014). Subsequently, I drew on a constructivist epistemological position for this research, which was premised on the idea that the lived experiences of autistic women would only be made apparent because *we* (in this case, autistic woman and researcher) were there to actively try and understand it meaningfully within its context (Larkin et al., 2006).

1.4 Autism and diagnosis

Mainstream research and understanding of autism has been arguably embedded within a different ontological and epistemological position, exemplified through the continual attempts to find biological causes for autism (Hassall, 2016; Verhoeff, 2013). These demonstrated a more positivist understanding (Moon & Blackman, 2014), whereby autism was perceived as measurable deficits (Smukler, 2005). However, an ontological and epistemological shift has been emerging in the conceptualisation of autism (Hollin, 2017; Runswick-Cole et al., 2016).

Autism was first identified within a medical context and was understood as a disorder of deficits in the person, specifically children (Asperger, 1944/1991; Kanner, 1943). The idea

of autism was further quantified as a triad of deficits, and expanded to a spectrum of presentations (Wing, 1981a). In the latest editions of diagnostic manuals, the historical triad of deficits have been combined to become two core domains of traits. Social interaction impairments and communication difficulties have been merged to become a domain of persistent social communication and interaction difficulties. Restrictive, repetitive and inflexible patterns of behaviours and interests have remained a domain of its own. Diagnostic criteria further differentiates autistic people along a spectrum of intellectual functioning and expressive language abilities (American Psychiatric Association [APA], 2013; World Health Organization [WHO], 2018).

The conceptualisation of autism has changed over time as could be seen by the revisions in diagnostic criteria and the recognition of it as a more heterogeneous condition (Happé & Ronald, 2008). However autism has remained conceptually unstable (Hollin, 2017), and empirical evidence has yet to make any definitive claims about the underlying causes of autism (Lord & Jones, 2012; Rutter, 2013; Timimi & McCabe, 2016). Debates have ensued as to whether autism is a nosologically distinct entity at all (Hassall, 2016; Verhoeff, 2012). Alternative conceptualisations have moved more towards relativist positions of understanding autism. One such example would be the social model perspective; which argued that autism is a social group, with its own distinct identity and culture (Straus, 2013). This perspective challenged the locating of pathology within an autistic person, and highlighted that the main difficulties experienced by autistic people were often relational (Straus, 2013). Related ontological examinations of autism included the debate of whether autism is a 'disability' or a 'difference' (Kapp et al., 2013; Latif, 2016). As it stands, research has stimulated much debate about autism, and generated more questions about this phenomenon than it has answered.

1.5 Autism and Sex

One aspect of autism that has remained relatively constant since it was first documented has been the idea of a male preponderance in this phenomenon (Asperger, 1944/1991; Kanner, 1943). However, this has also been challenged more recently; with

questions around the possible under-recognition of autism in females, particularly amongst those without Intellectual Disabilities (ID, Trubanova et al., 2014). Traditionally, the average male-to-female ratio in autism has been recognised as 4:1 (APA, 2013; Fombonne, 2003). However, collations of prevalence studies that measured sex ratios in autism found that male-to-female ratios ranged from 1.33 to 15.7 (Fombonne, 2009). Studies that have used ascertainment sampling methods also reported a smaller sex ratio estimate ranging from 1.11 – 3.5: 1 (Loomes et al., 2017; Zwaigenbaum et al., 2012). These inconsistencies may have resulted from a variety of theoretical and methodological problems (Fombonne, 2009; Kreiser & White, 2014).

Several models have theorised the sex ratio observed in autism from biological perspectives. These have looked at differences in brain structures and functioning (Baron-Cohen, 2002), greater genetic vulnerability in males (Skuse, 2000) and greater protection in females for developing autism (Robinson et al., 2013). The evidence for these theories have remained inconclusive, and they have been critiqued for insubstantially explaining the range of autistic traits and for the considerable overlaps of characteristics between the sexes (Kreiser & White, 2014; Rivet & Matson, 2011; Skuse, 2007). Despite so, studies have shown an inclination to validate and explain the sex differences observed (Rivet & Matson, 2011), rather than interrogate whether there is a sex difference, exposing research to risks of theoretical confirmation biases.

Methodologically, Kreiser & White (2014) highlighted the potential sampling and information biases in this area of research. These included the use of diagnostic methods and tools that were unequally validated across sexes, generalising from unrepresentative samples and selection biases against autistic females. Understandably, autism research has mostly been conducted with autistic males as there have been more males diagnosed than females (Thompson, Caruso, & Ellerbeck, 2003). However, a reciprocal bias is generated when the development of diagnostic instruments depend largely on these male samples (De Bildt et al., 2009; Kamp-Becker et al., 2011; Oosterling et al., 2010). In turn these instruments would only become less sensitive and specific to identifying autistic females (Young et al., 2018).

Passive approaches of identifying autistic people with pre-existing diagnoses in databases were also prone to missing out participants who were not known to clinical services already. Where active case ascertainment was employed, the sex ratio was reduced which suggested that autistic females were less frequently identified for autism in clinical settings (Loomes et al., 2017). This was demonstrated by a study that found autistic females with ID and/or behavioural differences were more likely to be diagnosed than those without amongst a large cohort of school-aged children (Dworzynski et al., 2012). Correspondingly, active case-ascertainment studies with large cohorts of pre-school and school-aged children without ID reported smaller male-to-female ratios of 1.65–1.9:1 (Kim et al., 2011; Zwaigenbaum et al., 2012). These findings suggested that autistic females without ID were at risk of false negative diagnostic outcomes, and there may be more autistic females with average or above intelligence than estimated, who were more likely to be overlooked clinically.

Relatedly, most research on autism have focused on children and adolescents (Pellicano et al., 2013). This has been problematic since autistic females were more likely to go undiagnosed as children (Kim et al., 2011), and when they were diagnosed they were more likely to be identified at an older age than male peers (Begeer et al., 2013). Hence, our knowledge about adult autistic women have mostly been extrapolated from males and children. Research with autistic adults has been recognised as an important clinical issue (Lai & Baron-Cohen, 2015), especially as outcomes research for autistic adults (with and without ID) have shown that they are significantly disadvantaged in employment, relationships, physical and mental health, and have poorer quality of life (Howlin & Moss, 2012).

These critical evaluations confronted a longstanding and widely accepted view that autism was more prevalent amongst males compared to females. More importantly, they have drawn attention to the possible misconceptions about autistic females based on these assertions. Research has begun to recognise these limitations and have started to consider the impact of socio-cultural variables on autism (Kreiser & White, 2014).

1.6 Gendered Differences

Cheslack-Postava & Jordan-Young (2012) proposed three plausible scenarios in which gendered socialisation may have interacted with biological predispositions to produce the observed sex differences in autism. Socialisation by way of gender has been theorised extensively, and has been underpinned by thinking about the complex relationship between socio-cultural influences and individual dynamics that may influence gender identity and gender role formations (Stockard, 1999). For autistic females, gendered socialisation may impact on how their behaviours have been interpreted, and how they may express themselves, including the part of them that is autistic.

The first scenario posited that biological predisposition to autism was randomly distributed between male and females, however gendered socialisation would lead to a differential expression of autism resulting in the observed male-to-female ratio. The second scenario also considered how gendered socialisation would impact on the sex ratio, but only as an amplifier to the higher predisposition for males to be autistic. Finally, the third scenario proposed that males were more predisposed to being autistic than females, and this was unaffected by gendered socialisation. It was asserted that extant literature about autism has been over-represented by the third scenario, where the male prevalence in autism has been assumed to reflect intrinsic sex differences without legitimate consideration for gendered socialisation (Cheslack-Postava & Jordan-Young, 2012).

Examining this in more detail, research based on the view that there is an innate male predisposition for autism will first be summarised, followed by looking at research that has also considered the impact of socialisation.

1.6.1 Biological influences

Hypotheses that place the aetiology of sex differences innately within the person have looked for differences in genetics, cognition, and neurology. An influential model on brain differences has been the Extreme Male Brain Theory (Baron-Cohen, 2002, 2010), which hypothesised that cognitive profiles of autistic people reflected an extreme version of a 'male' brain that 'systemises' (e.g. analytic capacity for systems) better than it 'empathises' (e.g.

intuit others emotions). Relatedly, it was suggested that prenatal testosterone levels may lead to autism by the masculinisation of the brain, and thus developing an extreme male brain (Auyeung et al., 2009; Ingudomnukul et al., 2007; Knickmeyer et al., 2006). There has been much criticism surrounding these ideas, chiefly aimed at the weakness of inferential evidence drawn from the general population to autistic populations (Barbeau et al., 2009; Kreiser & White, 2014; Rivet & Matson, 2011).

It has also been proposed that epigenetics influence the reported sex ratio in autism. Key hypotheses included the Greater Variability Model (Wing, 1981b), the Female Protective Effect model (Jacquemont et al., 2014; Robinson et al., 2013), and the Liability/ Threshold Model (Tsai & Beisler, 1983). These suggested that the higher prevalence of autism in males resulted from genetic vulnerabilities in the male sex. The reduced vulnerability and increased protective factor of female genes was used to explain why fewer autistic females were diagnosed, and often had more severe co-occurring pathologies. An issue with this line of investigation was the potential mediating effect of ID with sex and autism; where the significance of findings were reduced once ID was accounted for in the samples (Lord et al., 1982; Volkmar et al., 1993).

The epigenetics of the X-chromosome has also received a lot of attention, as it was suspected to carry the relevant genes for autism expression and explain the sex ratio. Research into the mechanisms of genes have speculated that autism may be transmitted on the X-chromosome (Skuse, 2000); or that autism is linked or inactivated on the X-chromosome (Loat et al., 2004, 2008). While these lines of research have been innovative they have also yet to be substantiated by empirical evidence (Kreiser & White, 2014; Rivet & Matson, 2011).

Research into the biological causes of autism have been important for probing the biological component in Cheslack-Postava & Jordan-Young's (2012) hypotheses for explaining the asymmetrical sex ratio in autism. However, findings from these perspectives have remained inconclusive (Hull & Mandy, 2017; Kreiser & White, 2014; Lord et al., 1982; McLennan et al., 1993; Rivet & Matson, 2011; Timimi & McCabe, 2016). Despite so, there has

been an uneven distribution of autism research that leans towards these areas of 'Biology, Brain & Cognition', followed by 'Causes' and 'Treatments' (Kirkovski et al., 2013; Pellicano et al., 2013).

1.6.2 Social influences

Research that examined potential gendered phenotypic differences in autism has provided an important bridge between thinking about biological and social causes for the sex ratio. In studies where age and intellectual ability were matched, sex differences were not found in core autism traits as measured by gold standard assessments (Holtmann et al., 2007; Lai et al., 2011; McLennan et al., 1993). However, perceptions of difficulties by parents and autistic women were mismatched with the measures, indicating that gendered expectations may play a role in phenotypic differences.

Parents of autistic girls (compared to parents of autistic boys) reported more problems in socialising, attention and thinking (Holtmann et al., 2007). Similarly, parents reported significantly less reciprocal social interaction difficulties before age 5, but this reversed for the same group of females as adolescents and adults where their parents subsequently reported greater reciprocal social interaction difficulties (McLennan et al., 1993). These inconsistencies were discussed in the context of gendered socialisation, where parents may have expected more socially desirable behaviour of their daughters and therefore saw them as having more difficulties despite similar levels of autistic traits (Holtmann et al., 2007). Interpretations of autistic girls having less social difficulties at a younger age may reflect greater efforts by parents to shape their daughter's behaviours early on, but the effect correlated negatively with age (McLennan et al., 1993). In a study with adult autistic men and women, childhood autistic traits were similarly comparable, but autistic women reported more autistic traits than men, despite being observed to have fewer socio-communication difficulties (Lai et al., 2011). It was concluded that these findings pointed towards autistic women making greater progress in compensatory socio-communication skills as compared to autistic men (Lai et al., 2011).

Following this line of thought, clinical observations have led to a hypothesis that autistic females use imitation and modelling more to mask their difficulties in social situations (Attwood, 2006). These behaviours have been coined “camouflaging” (Hull et al., 2017); defined by conscious and unconscious masking and compensatory strategies, which may have developed implicitly or explicitly to minimise the appearance of autistic traits in social settings (Hull et al., 2020). For example, adolescent autistic girls have described coping with social challenges by learning to take on other people’s perspectives, inconspicuously observe peers in verbal and non-verbal social interactions, and covertly imitate facial expressions and topics of conversations (Tierney et al., 2016). Camouflaging allowed autistic individuals to stay connected with society, but it also threatened their sense of authenticity and left them feeling exhausted (Hull et al., 2017; Tierney et al., 2016). Although camouflaging behaviours were not unique to autistic females, it was speculated that it may represent a significant part of the female phenotype of autism.

To further contextualise how camouflaging may lead to under-recognition of autism in females, it was observed that for children without ID, gendered social norms affected the way social challenges transpired. It was noted that the male social landscape in the playground was marked by more play behaviour (e.g. structured games), and in this context, autistic boys were noticeably more solitary and easier to identify. In contrast, the female social landscape involved more unstructured joint engagement (e.g. talking), and this was more conducive for autistic girls to camouflage. Autistic girls were observed to be more inconspicuous (at least to adults but not necessarily to their peers) by keeping close proximity with peers and interweaving between social and solitary activities (Dean et al., 2017).

Similarly, in a study that attempted to compare social masking between autistic men and women, matched for age and IQ, found that autistic women “camouflaged” significantly more than autistic men (Lai et al., 2017). The study suspected that gendered socialisation was likely to have contributed to this increased inhibition of dispositional responses and engagement with behaviours perceived as socially desirable (Lai et al., 2017).

These findings on the role of gendered expectations contribute to probing the gendered socialisation aspects of Cheslack-Postava & Jordan-Young's (2012) hypotheses. However, research in this area is still in its infancy, and requires further exploration.

1.7 Culture

An anthropological perspective of culture was used in this research, where culture was understood as the implicit and explicit beliefs, values, attitudes and behaviours in a social group, and are passed through relationships between people (Beldo, 2010; Hudelson, 2004). Culture exists as a dynamic process between individuals and their contexts, where beliefs are socially constructed and have an impact on individuals; but individuals are also agents who can interact and reinterpret their experiences (Hudelson, 2004; Krause, 1995). This broader understanding of culture was used to foreground the universal day-to-day social interactions that affects everyone, including autistic women. The term “socio-cultural values” was used to emphasise this more universally social perspective of the term culture that everyone has, as opposed to locating culture in specific social groups that one may not belong to. For example, literature that has explored culture and autism have mostly focused on the impact of cultural beliefs on diagnosis and help-seeking behaviours amongst families of autistic people and professionals (Ennis-Cole et al., 2013; Ravindran & Myers, 2012), or within cross cultural comparisons (Bernier et al., 2010; Kim, 2010). The impact of a dominant social culture on autistic people has rarely been considered. Yet, research on identity has shown how social groups (Tajfel, 1974) and gender (Carter, 2014) play significant roles on people’s identity-formation. Autistic women do not exist in isolation of their contexts and are intrinsically part of it. Therefore, the socio-cultural values around them will also impact on the development of their sense-of-self. Our understanding would be incomplete if we were to only think about how autism affects autistic and non-autistic people, and how others perceive their autistic traits, but not earnestly explore how *others have affected them*, from their perspectives.

Gendered beliefs and values are inextricably tied to culture in the way it exists within immediate family systems and extends into people’s roles within society (Carter, 2014). In

questioning the impact of gendered socialisation on the current state of knowledge about autistic women, it has also become apparent that gendered beliefs were likely to have played a role within the culture of families, clinical and research practices. These have affected autistic girls and women in terms of identification (Dworzynski et al., 2012; Loomes et al., 2017), gendered expectations on how they behave (Holtmann et al. 2007, Kanfischer et al., 2017) and their camouflaging behaviour (Hull et al., 2020). An unquestioning stance towards the gender disparity in autism has also been nurtured within research, and it remains unclear how much gendered beliefs about autism have affected this (Cheslack-Postava & Jordan Young, 2012). Furthermore, the research community has shaped much of what society understands about autistic women, yet their perspectives from lived experiences have rarely been used to enrich our understanding. A more contextualised exploration of autistic women's experiences from their perspectives would bring us closer to understanding the sex ratio in autism, and conceptualising them in a more holistic way that will impact on supporting their needs.

Chapter Two: Literature Review

2.1 Introduction

Research highlighting the lived experiences of autistic women can provide insight into the impact of socio-cultural values on them, however such research has been limited. In a meta-synthesis of qualitative literature that captured the lived experiences of autistic children, adolescents and adults, only 33 studies were identified (published between 1980 and 2014). Fifteen studies explored the perspectives of autistic adults, in which autistic women were under-represented and no studies specifically aimed to unearth their views. Where autistic females (children, adults, older adults) were part of a study, they were generally a small subset of the sample (DePape & Lindsay, 2016). Fortunately, in recent years there has been a shift towards recognising the gendered impact of living with autism. This chapter aimed to systematically review the evidence on the lived experiences of autistic women and capture any insights into socio-cultural impact.

The review was framed by the following questions a) How have autistic women perceived their lived experiences? b) How has culture shaped those experiences? An outline of the search strategy will be detailed, followed by a summary and discussion of these studies, including a critical evaluation of the literature. The key findings in relations to the review questions were then synthesised and the implications were considered. The chapter concludes with the rationale, the aims and specific research question for the current research project.

2.2 Literature Search Strategy

The primary focus of this literature review was on the lived experiences of autistic adults (aged over 18 years old), who were cis-gendered females (henceforth referred to as autistic women). Qualitative, quantitative and mixed-methods studies were considered given the paucity of literature in this area.

Search terms (Table 1) were developed in accordance with the PICO strategy for literature searches (Santos et al., 2007). The population was identified as autistic women, and the outcomes that the review was looking for were socio-cultural experiences. Questions

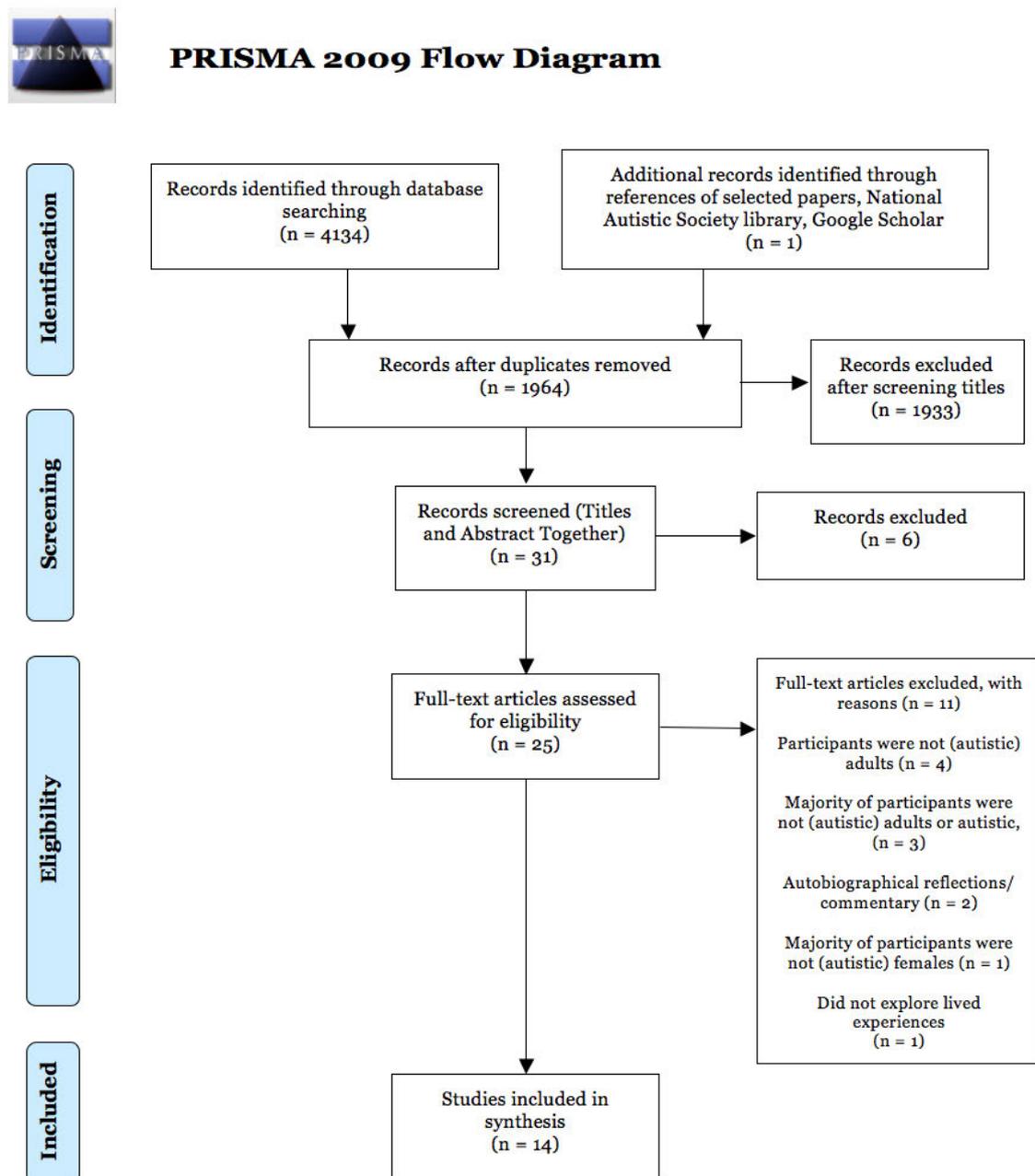
relating to interventions and comparison populations of the PICO strategy were excluded, as they were not relevant to this review. Terms relating to the socio-cultural experiences of autistic women were generated directly and indirectly. Terms such as “social” and “culture” were used to capture any literature that has conducted research from this perspective directly. Terms such as “norms”, “camouflaging” and “late-diagnosis” were indirect keywords drawn from literature that has thought about social influences on the experiences of autistic women (See 1.6.2). The term “experience” was searched for jointly with terms relating to culture to return specific results to lived experiences. These terms were applied to titles, abstracts and keywords of four databases: Scopus, EBSCO host, APA PsychNET and PubMed. Additional searches were made to the National Autistic Society’s research library, Google Scholar and reference lists of all the selected studies for review. There were no date restrictions on the searches, and the search included articles published until May 2020.

The initial search generated 4134 articles. Duplicates were removed, after which the remaining papers were screened by title and abstract to identify potentially relevant papers. This resulted in 31 studies that were deemed relevant. After retrieving full texts, 14 studies were identified as suitable for the current review and synthesis (Figure 1).

Table 1

Search terms used in systematic literature review

Focus	Search Terms
Population: Autism	(autism OR autistic OR asperger OR asperger’s)
Population: Female	(female OR females OR women OR woman)
Outcomes: Socio-cultural experiences	((social* OR cultur* OR stigma* OR expect* OR norm* OR mask* OR camouflag* OR “late* diagnos*” OR late-diagnos*) AND experienc*)

Figure 1*PRISMA Flow Diagram of systematic literature search*

2.2.1 Inclusion and Exclusion Criteria

The inclusion criteria for this review were as follows: 1) all peer-reviewed original research articles that focused on understanding the lived experiences of autistic women, 2) participants aged over 18 years old. Lived experiences of autistic women with and without ID were included for a thorough overview.

Literature that was not pertinent to lived experiences were excluded, this included studies that aimed to evaluate psychometrics or draw inferences from assessments alone, and studies that focused on genetic and neurocognitive functioning. Studies that reported experiences of siblings, carers and professionals to autistic women were excluded, as they were not first-person perspectives. Studies that focused on gender dysphoria or transgender people amongst autistic populations were excluded as they introduced an added layer of complexity to understanding autistic women that would warrant a separate investigation to the current literature review.

2.3 Overview of findings

Of the 14 papers included in the evidence, 12 employed qualitative methodologies, one used quantitative and another used a mixed-methods approach. Seven of the qualitative papers collected data through semi-structured interviews, while two studies used focus groups, and another two collected indirect data. The quantitative and mixed-method studies collected data using questionnaires/surveys with closed and open questions. A broad range of analyses was used for these studies; the most common was thematic analysis, which was used in five studies. The mixed-methods study also used thematic analysis for their qualitative data, and descriptive statistics for their quantitative data. Three studies interrogated their data with narrative analysis, and another two studies with interpretative phenomenological analysis (IPA). One study used framework analysis and one study conducted a feminist geographical analysis on their data. A summary of the studies and their findings can be found in Appendix A.

2.4 Summary and critical evaluation of papers

The Critical Appraisal Skills Programme (CASP, 2018a, 2018b) were used as a guiding framework for the critical evaluation of both qualitative and quantitative studies (See Appendices B and C for tabular summary of all studies under CASP framework). Additional qualitative research assessment features were also incorporated (Elliott et al., 1999; Tracy, 2010; Yardley, 2000). Most studies were of reasonable to good quality in terms of methodology and reporting of findings. A common shortcoming was the lack of reporting

on how the relationship between researcher and participants were considered within qualitative studies (CASP, 2018b; Elliott et al., 1999). Summaries of each study and key evaluations were categorised under four areas below.

2.4.1 Literature on the lived experiences across the lifespan of autistic women

Three studies explored the lived experiences of autistic women across their lifespans. Each study demonstrated coherency between using a qualitative methodology and their objectives, through to data collection, analysis and interpretation choices (CASP, 2018). The studies differed in the specifics of their aims, approaches as well as sample selected, but the results were broadly consistent with each other. Each offered different insights to the experiences of autistic women, which added richness to the findings.

Baldwin & Costley (2015) had the broadest aims of the three studies in their attempt to address the gap in research of understanding the lived experiences of 82 autistic women with no diagnosis of ID. This research was nested within a larger study that included autistic men. In line with the exploratory nature of this study, a questionnaire was used to obtain both quantitative and qualitative data on experiences relating to diagnosis, autism symptomatology, physical and mental health, education, employment, social experiences, and support needs. An advantage of this mixed-methods approach was that the range of quantitative data helped to thoroughly situate the sample, while the open comments (qualitative data) added depth to the experiences captured by the descriptive statistics.

Baldwin & Costley (2015) reported a persistent view amongst autistic female participants that an earlier diagnosis would have improved their experiences in life. This was reflected in the high prevalence of anxiety and depression. Many reported feeling unsupported and underestimated within education and employment. Relational difficulties were also prevalent in both settings. Many participants reported wanting more support with social relationships, and at the same time 80% of participants reported being satisfied ('very' and 'fairly' levels) with their social lives. Qualitative comments indicated challenges with implicit social rules and conscientiousness over other people's responses. These would have been interesting areas for a deeper probe into the interrelatedness between autistic women

and their environments and highlighted the limitations of a more exploratory qualitative approach within mixed-methods. In being able to compare the findings with a parallel male sample, Baldwin & Costley (2015) concluded that their findings were more reflective of the difference in how autistic women experience the world, rather than a unique female profile of autism.

Baldwin & Costley (2015) had focused on autistic women without ID, because of their susceptibility to being under-recognised. Contrastingly, Kanfiszler, Davies, & Collins (2017) included autistic women with ID in their study because their perspectives have rarely been captured, despite being more likely to be diagnosed with autism (Dworzynski et al., 2012). All seven participants were diagnosed in adulthood (≥ 18 years old) to capture those who were more likely to have been overlooked in childhood (Kanfiszler et al., 2017). The study aimed to explore the lived experiences of autistic women through narrative analysis with semi-structured interviews that covered four broad areas of adulthood, diagnosis, childhood and hopes for the future (Kanfiszler et al., 2017). The study demonstrated rich rigor and credibility (Elliott et al., 1999; Tracy, 2010) through detailing the process of analysis, including participant validation. While the study situated the sample in their contexts, there were no statements locating the principal researcher's cultural or theoretical positions. This could be particularly problematic for showing philosophical congruence in narrative analysis since researchers with different underlying assumptions could use this method for data analysis (Dominique & Shenhav, 2014).

Nonetheless, the findings in this study conducted by Kanfiszler et al. (2017) were grounded in examples, and delivered coherence and resonance, which were important features of qualitative research (Elliott et al., 1999). Gender identity emerged as one of two key findings and highlighted how differing from gender norms impacted on the participant's self-perception. Social relationships were the second key finding, which focused on interpersonal difficulties impacting on self-esteem and feeling vulnerable to victimisation. Interestingly, participants with ID attributed their risks of victimisation primarily to a

concrete lack of social skills. Participants without ID, on the other hand, ascribed their risks of victimisation to their deviation from gendered social norms (Kanfischer et al., 2017).

Webster & Garvis (2017) provided a balance to the predominant focus on narratives around hardship and victimisation, by investigating perceptions of success in the lives of 10 women diagnosed with autism (≥ 18 years old). This study also used a narrative approach underpinned by a social constructionist lens that was congruent with their methodology. A strength of the study was in how it demonstrated theoretical consistency by allowing the participants to define “success” for themselves.

The findings were presented with an evocative and coherent narrative (Elliott et al., 1999; Tracy, 2010). The subsequent discussion also made a compelling case for interpreting the results through self-efficacy theory. Success was influenced by a range of intrapersonal and interpersonal factors that helped with developing self-efficacy. Intrapersonal factors included developing agency to respond to different life challenges; and interpersonal factors included having others believe in their capabilities and seeing themselves as having positive influences on others. Notably, interpretations of success by the participants ranged from raising children to academic achievements. These emphasised the everyday successes of autistic women and challenged unrealistic expectations of needing to have savant-abilities in order to be considered successful (Webster & Garvis, 2017).

2.4.2 Literature on the lived experiences of late-diagnosed autistic women

The potential diagnostic biases (see Chapter One) against autistic females has led to interests in the experiences of late-diagnosed women. The following three qualitative studies (Bargiela et al., 2016; Kock et al., 2019; Leedham et al., 2020) were conducted with the primary aim of understanding the lived experiences of autistic women who were *late-diagnosed* – the definition of which varied across studies (detailed below). All three studies showed congruity between their methodology and their aims, data collection, analysis and interpretations (CASP, 2018b). All three studies had performed credibility checks in line with their methods and used some form of analytical ‘auditor’ to review the plausibility of their findings (Elliott et al., 1999). The framework analysis study (Bargiela et al., 2016) used

participant feedback to enhance credibility. The IPA studies used discussions and audits by peers instead (Kock et al., 2019; Leedham et al., 2020) and did not use “member-checking” due to it being theoretically incompatible with the approach (McConnell-Henry et al., 2011). The findings across the studies were largely consistent and will be discussed together. The summary and evaluation of methodologies will be discussed separately.

In a framework analysis study with 14 women, late-diagnosis was defined as receiving a diagnosis aged 15 or older (Bargiela et al., 2016). The age cut-off was arbitrary, but the study believed that those who were diagnosed after early adolescence better reflected the underrepresented sample of autistic women who were likely to have been missed by clinical services earlier in life. Semi-structured interviews focused specifically on topics relating to their perception of gender on autism and diagnosis, as well as of life experiences. The sample was situated by quantitative screening measures that looked at autism traits, general health, mood and verbal intellect, and identifying their professions and employment statuses (Elliott et al., 1999).

Leedham et al. (2020) expanded on the work of Bargiela et al. (2016) by using IPA to focus on the lived experiences of 11 autistic women who were diagnosed in middle to late adulthood (≥ 40 years old). Semi-structured interviews focused on participant’s reflections of their diagnosis over time, their perspectives of how the diagnosis has impacted their self-representation and relationships. None of these three studies had discussed the potential influence of the researcher’s cultural and theoretical positioning on the analysis of the data (CASP, 2018b; Elliott et al., 1999). However, Leedham et al.’s (2020) study provided the strongest indicator that the researcher’s influence was considered through reporting the use of reflective notes that were referred to throughout the research process.

Kock et al. (2019) also conducted an IPA study, interviewing eight autistic women who were diagnosed in adulthood (20-40 years old). This study focused specifically on the impact of late-diagnosis on autistic women’s intimate relationships. This carried face validity of being a worthy topic (Tracy, 2010), however the rationale was arguably underdeveloped in depicting the importance of this topic. It was unclear as to how the gaps highlighted in the

introduction came together to form the research question. The descriptive nature of the findings in this study also lacked the thick description desired of an in-depth interpretative analysis (Smith, Flowers, & Larkin, 2009). Furthermore, the presentation of the findings lacked aesthetic merit and meaningful coherence (Tracy, 2010) in addressing the question of how a late-diagnosis *impacted* on autistic women's experiences of intimate relationships. The concluding claim that difficulties relating to autism and the meaning participants assigned to the diagnosis had an impact on the nature and sustainability of their relationships (Kock et al., 2019) were debatably overstated from the results. Nonetheless, the findings from this study supported existing evidence on experiences of late-diagnoses amongst autistic women, and also gave descriptive insight to the experiences of intimate relationships for autistic women.

In exploring the lived experiences of autistic women in relations to having a late-diagnosis, there was consistency in how they experienced being perceived as not autistic. This was attributed to them not looking like the stereotypes that people expected of autism, as well as the camouflaging strategies autistic women used (Bargiela et al., 2016; Leedham et al., 2020). There were also similarities across the studies in finding that late-diagnosed women reconstructed their identities in light of their diagnoses (Bargiela et al., 2016; Leedham et al., 2020). This included renegotiating relationships and making sense of how others responded to their diagnosis, as well as changing their views of themselves, including having more self-acceptance (Kock et al., 2019; Leedham et al., 2020). Relatedly, autistic women also reflected on their earlier experiences of victimisation in light of their diagnoses. These reflections generated shifts from passivity to assertiveness through understanding themselves differently (Bargiela et al., 2016). Specific to the findings of intimate relationships, autistic women also reported difficulties with the spontaneous nature of sex and relationships, as well as sensory challenges that can happen during sex (Kock et al., 2019). There were also difficulties reported with the compatibility of interpersonal preferences and interests amongst autistic women and their partners, as well as concerns and considerations about the progression of intimate relationships. However, the majority of

participants also highlighted positive experiences in intimate relationships (Kock et al., 2019).

2.4.3 Literature on specific lived experiences of autistic women

Six studies aimed to examine specific lived experiences of autistic women. Four studies were focused on experiences unique to women, these included childbearing, motherhood (Gardner et al., 2016; Pohl et al., 2020; Rogers et al., 2017), and menopause (Moseley et al., 2020). Two studies focused on the specific experiences of autistic women relating to service-use (Tint & Weiss, 2018) and transitions in life (Pesonen et al., 2015). Both qualitative and quantitative methodologies were used for studies within this category, and a range of exploratory and probing methods were used to analyse the data obtained.

A notable difference amongst these six studies was whether they included self-identified autistic women. This brought to the foreground important questions around how best to include autistic women who were likely to have been undetected or denied a diagnosis due to diagnostic deficiencies or phenotypic differences (Kirkovski et al., 2013; Rivet & Matson, 2011). Recruiting self-identified autistic women can add complications to the validity of studies. Chiefly, it can be hard to determine whether formally diagnosed and self-identified autistic women are talking about the same experiences, when they talk about 'autism'. Different studies have gone to different lengths to address this challenge when recruiting self-identified women. One study merely mentioned the potential limitation in its discussion (Gardner et al., 2016), and another explicitly used autism screening questionnaires in attempt to corroborate self-identification (Moseley et al., 2020). The plausibility of using autism screening questionnaires to identify autism in adults has remained debatable (Baghdadli et al., 2017; Hirota et al., 2018). Hence, the dilemma of including self-identified women in research remains inadequately addressed. I would argue that to do so would require a substantially improved understanding of autistic women, re-examining the specificity and sensitivity of existing formal diagnostic measures for autistic women and learning more about self-identified autistic women. I contend that unless this

dilemma is adequately addressed in research studies, it would be more methodologically sound to recruit formally diagnosed autistic women.

Gardner et al. (2016) originally intended to conduct a quantitative study to assess the childbearing experiences of autistic women. The overwhelming feedback to their questionnaire during the consultation and design period resulted in the data being approved for a standalone qualitative study. While the change in approach was appropriate for the unexpected qualitative data, other aspects of the design were evidently less thought through. There was no clarity on the theoretical positioning and lens for analysing the data (Willig, 2001). Similarly, the study failed to outline what was explored in their questionnaires, which made it hard to determine the appropriateness and replicability of the method. Despite the shortcomings of its methodological reporting, the researchers had astutely taken the opportunity to be the first study to qualitatively explore the experiences of childbearing amongst autistic women. Hence the study was relevant and timely demonstrating the worthiness of the topic (Tracy, 2010). Moreover, the presentation of findings carried resonance and was a significant contribution to understanding this uniquely female experience from an autistic perspective (Tracy, 2010).

Rogers et al. (2017) intended to elaborate on the study by Gardner et al. (2016) with a narrative analysis of the issues experienced by autistic women with no ID during their perinatal period. In a reversal of circumstances, Rogers et al. (2017) adapted the study into a single case study thematic analysis, due to only one participant responding to recruitment. Data collection spanned over a period of months, through emails, pre- and post-birth, and through one post-birth interview. The lack of transparency in locating the research culturally and theoretically was a noteworthy limitation in this study. Considering the intensity and prolonged period of engagement with just one participant, it was important for the study to have demonstrated reflexivity (CASP, 2018b; Elliott et al., 1999).

On a considerably larger scale, Pohl et al. (2020) conducted a quantitative study comparing the perinatal and early motherhood experiences of 355 autistic and 132 non-autistic women. This was designed to be a mixed-methods study but the qualitative data was

not published in this study. A comprehensive and accessible survey was co-constructed with six autistic mothers. This was used instead of existing measures so that it could better capture relevant issues of pregnancy, childbirth and early motherhood, self-perception of parenting, communication with professionals and disclosure of autism in parenting contexts. Mothers of both samples had to have at least one autistic child to control for the effects of parenting autistic children, but this reduced the representativeness of the non-autistic sample to the general population of mothers. A range of confounders were also not matched, including mothers of male sex, non-female gendered mothers and education, marital statuses, and co-morbid psychiatric diagnoses. These were in addition to the already discussed issues pertaining to inclusion of self-identified autistic women. Since the current literature review was interested in the lived experiences of autistic women, the summary of the results focused more on said experiences rather than the comparison with non-autistic women.

The findings from these three studies on childbearing and motherhood were broadly consistent with each other (Gardner et al., 2016; Pohl et al., 2020; Rogers et al., 2017). Autistic women reported heightened sensory experiences during their perinatal, intrapartum and post-partum periods that were often experienced as added challenges compounded by hospital environments and contact with professionals (Gardner et al., 2016; Rogers et al., 2017). A more disturbing commonality across the studies were the reported experiences of feeling dehumanised by professionals, and feeling a lack of control over childbirth (Gardner et al., 2016; Rogers et al., 2017). Autistic women in all three studies experienced difficulties with early motherhood, such as breastfeeding. While some autistic women found their own mothers to be an invaluable resource for support (Gardner et al., 2016), all the studies reported insufficient support with parenting. This was made worse by experiences of feeling unfairly judged by professionals as being incompetent (Gardner et al., 2016); and suspecting that the disclosure of their autism negatively impacted on how they were judged as parents (Pohl et al., 2020; Rogers et al., 2017). This often resulted in higher levels of anxiety and interpersonal conflict with professionals (Gardner et al., 2016; Pohl et al., 2020; Rogers et

al., 2017). In the face of these challenges, autistic women in all three studies reported a determination to do their best for their child. This included breastfeeding despite experiencing sensory discomfort (Gardner et al., 2016); being more thoughtful and assertive with parenting decisions (Rogers et al., 2017); and the majority of autistic women reported that motherhood was a rewarding experience, despite many of whom also reporting high levels of isolation, fear of judgement, lack of support and self-doubt (Pohl et al., 2020).

Autistic women who were either navigating or had experienced menopause, reported similar challenges to those expressed by autistic mothers (Moseley et al., 2020). Seven autistic women, who were natal females, participated in an online focus group that concentrated on exploring how autistic women perceived the extant state of knowledge around menopause for autistic people, and whether they believed that menopause posed specific challenges for autistic women. The qualitative data were suitably analysed with thematic analysis. The researchers acknowledged their roles in the process of analysis, and addressed this with triangulation, iterative coding and reflexive notations for quality assurances (Tracy, 2010). Moseley et al. (2020) reported how their participants found that most professionals lacked knowledge about autistic women and their experience of menopause. Experiences included an exacerbation of, and/or new issues to existing challenges with masking, relationships, sensory experiences, and executive function. They reported a scarcity of resources along with increased low mood and anxiety relating to the unpredictable nature of menopause. In terms of thinking about barriers to progress, diagnosis was again raised as important for understanding their own needs better and being more compassionate towards themselves. A spotlight was also cast on the fact that menopause was a taboo subject in their contexts, and this further complicated their attempts to communicate or search for information and help (Moseley et al., 2020).

Tint & Weiss (2018) also used thematic analysis on data derived from focus groups. Twenty women with formal diagnoses of autism and no diagnoses of ID participated in focus groups of two to six people. The focus groups aimed to explore autistic women's perceptions of service-use and identify what they considered to be unmet service needs and barriers. The

definition of *service* was broad and ranged from general practitioners to educational services. Many of the participants were single, and lived independently or with spouses, had secondary education or higher qualifications, and were employed or attending full-time education. These contextual factors were useful in reflecting the sample's level of independence and integration with society. Participants found it challenging to effectively convey their needs to professionals, who also appeared to lack understanding of autism and some perceived the participants as not autistic because of their ability to mask certain difficulties. Common issues included professional's lack of awareness with sensory overstimulation and being overly focused on pain; and finding themselves ineligible for the support they requested (Tint & Weiss, 2018).

Finally, a narrative study was conducted through semi-structured interviews with two autistic women to examine their sense of belonging and life transitional issues that occurred in the absence of appropriate social support (Pesonen et al., 2015). The topic of belonging, defined as feeling accepted and socially connected to others, was interesting and noteworthy (Tracy, 2010). The method design was robust (CASP, 2018b), and the rationale for the study was theoretically sound. The study rendered one participant's sense of belonging as "faded" along with their lack of self-determination due to exclusionary experiences. The other participant was described as having a "simmering sense" of belonging. Consequently, the study concluded that a sense of belonging could fade or simmer depending on whether there was appropriate social support during the importance transition to adulthood between the ages of 18 and 25 years old (Pesonen et al., 2015). Although this hypothesis had good evidence-base for exploring, the interpretations of the two interviews in this study lacked the credibility, resonance and meaningful coherence that would substantiate this conclusion (Tracy, 2010). Furthermore, the absence of any statement to the theoretical or cultural positioning of the researchers added uncertainty around how reflexive the researchers were in applying their hypothesis to the analysis (Yardley, 2000).

These six studies accentuated the challenges experienced by autistic women across their lifespan with different services (Gardner et al., 2016; Moseley et al., 2020; Pesonen et

al., 2015; Pohl et al., 2020; Rogers et al., 2017; Tint & Weiss, 2018). Autistic women reported challenges with communicating their needs, and their interactions with professionals compounded some of those difficulties when seeking support. There were also positive encounters with professionals who were supportive and helpful peppered across these studies.

2.4.4 Literature that explored lived experiences of autistic women indirectly

Two studies looked to foreground the experiences of autistic women through indirect research approaches (Davidson, 2007; Haney & Cullen, 2017). These studies obtained their qualitative data through analysing existing publications/posts made by autistic women who talked about their experiences.

From a feminist geographical perspective, a qualitative analysis was conducted on 16 autobiographical accounts that contained first-hand accounts of experiences published by autistic women (Davidson, 2007). Of the literature in this review, this was one of the earliest explorations of autistic women's lived experiences, which reflected the innovation of this approach in attempting to give voice to autistic women in research. The value of analysing the written word of autistic women was also persuasively presented, arguing that autobiographical writing allowed autistic women to express their lived experiences without the restrictions of social interactions and research agendas. A clear depiction of Davidson's (2007) feminist stance was offered along with her hypothesis that gendered conceptualizations of autism and being a woman were likely to have exacerbated the feelings of alienation experienced by autistic women. In contrast, the particulars of how the research was conducted were less transparent. The criteria for selecting the 16 published texts used in the analysis were undefined, which made it difficult to contextualise and evaluate the relevance of the sample (Elliott et al., 1999). It was indicated that the paper would explore specific themes that focused on a sense of alienation and socio-spatial strategies used to cope with expectations from neurotypical others. However the study lacked clarity on how the analysis was conducted and failed to demonstrate rigour and reflexivity (Yardley, 2000). It was also ambiguous whether the findings were a result of selecting extracts that corroborated

the hypothesis or if they were derived from an inductive approach to partial or whole readings of the autobiographies.

Nonetheless, Davidson (2007) presented the results evocatively and grounded it in quotations. Autistic women reported feeling alienated by social exclusion, because of not fitting in, and feeling exhausted by compensating with intellect and behavioural conformity (Davidson, 2007). The findings also provided insight into the impact of perceptual differences and sensory distortions on the behaviours of autistic women, bridging the gap of what might be perceived by others as bizarre, but internally experienced as understandable reactions. The framing of how autistic women controlled their environments because of trying to cope with chaotic experiences further substantiated this. There was also a strong emphasis on confuting the notion that autistic women lacked emotional experiences, instead, it was suggested that emotional experiences and expression was simply different (Davidson, 2007). The study convincingly concluded that involving autistic women's perspectives in research would be crucial in making sense of their experiences, which would be otherwise easily misunderstood.

In another indirect study, 1636 posts from 212 women on a public online autism discussion forum were analysed thematically through a phenomenological lens (Haney & Cullen, 2017). The study aimed to understand how autistic women described their experiences and used online autistic communities (Haney & Cullen, 2017). The "ethical grey areas" of using data without explicit informed consent were outlined and considerations into how the research would attempt to uphold ethical practice by protecting the participant's privacy were sufficiently detailed and in line with ethical guidance (Eysenbach & Till, 2001). However, the limits of indirect data meant that some important demographics were unidentifiable. For example, approximately a third of posts were from women diagnosed with autism, another third were from self-identified autistic women, and the remaining belonged to the unspecified category (Haney & Cullen, 2017). Other than limiting how much the sample could be situated in their contexts, the differentiation of this would also have

been potentially useful in exploring qualitative similarities and differences between diagnosed and self-identified autistic women.

Haney & Cullen (2017) presented their findings through four major themes, which focused on diagnosis, symptoms associated with autism, impact of autism on relationships and employment. It appeared that autistic women used online forums to share and validate each other on the challenges experienced with diagnosis and managing symptoms. A perception that these challenges may have arisen due to their ability to assimilate with social mimicry were consistent with findings from other lived experience research (Baldwin & Costley, 2015; Bargiela et al., 2016; Kock et al., 2019; Leedham et al., 2020). In terms of how autistic women described their experiences, the predominant themes posted online focused on a range of relationships with other people, including socialising at work. These reflected how autistic women perceived themselves in relations to others, specifically neurotypical women and how they experienced others (Haney & Cullen, 2017). Interestingly, underscoring these descriptions of experiences where not issues specific to diagnostic characteristics of autism, but issues pertaining to the reciprocal interaction between autistic women and neurotypical men and women, as well as autistic men (Haney & Cullen, 2017). This revealed the confines of viewing autism as an entity of diagnostic traits, and the importance of understanding the experiences of autistic women situated within their socio-cultural interactions.

2.5 Synthesis of findings and Implications of Review

A growing number of research studies have emerged in the past five years that have tried to better understand autistic women through their perspectives. This stemmed from better recognition that females have been generally under-represented, especially adult women. While this move towards more qualitative studies on lived experiences has been valuable, there was a clear need to increase the quality of reporting in terms of transparency and coherency of the relationship researchers can have on participants. These were frequently absent, but critical for evaluating the potential influence of researchers in qualitative research (CASP, 2018b; Elliott et al., 1999).

Thinking about how autistic women have perceived their lived experiences, these studies showed that the continued lack of understanding about autism in others has contributed to delayed diagnoses and access to support. The conflict in understanding included a mixture of not appearing autistic as others would expect and being misinterpreted for masking behaviours (Bargiela et al., 2016; Leedham et al., 2020; Tint & Weiss, 2018). This has in turn led to adverse experiences of isolation and self-criticism (Baldwin & Costley, 2015; Bargiela et al., 2016; Kanfischer et al., 2017; Leedham et al., 2020; Moseley et al., 2020; Webster & Garvis, 2017). For women with a diagnosis of autism, they continued to face challenges such as stigma and challenges to their abilities; these were experienced as patronising and sometimes dehumanising (Davidson, 2007; Gardner et al., 2016; Rogers et al., 2017). Some autistic women suspected that the unpleasant interactions they experienced may have resulted from disclosing their autism (Kock et al., 2019; Pohl et al., 2020; Rogers et al., 2017).

There was a striking commonality across these studies of how autistic women were affected by interpersonal relationships with others. The belief in an autistic woman's capability by another could contribute to their self-efficacy to succeed (Pesonen et al., 2015; Webster & Garvis, 2017). Conversely, isolation, bullying and victimisation was commonly reported across the lifespan of autistic women, which had a profoundly negative effect on how they perceived themselves (Baldwin & Costley, 2015; Bargiela et al., 2016; Gardner et al., 2016; Kanfischer et al., 2017; Kock et al., 2019; Leedham et al., 2020; Rogers et al., 2017). Only one study focused on the successes of autistic women, highlighting their sense of agency and desire to have a positive influence on others (Webster & Garvis, 2017). Logically, a lot of research has implications for improving support for autistic people, and identifying areas of difficulties may take priority, to highlight relevant needs. However, this may also be the potential legacy of predominantly thinking about autism in terms of deficits and challenges.

One study that was able to make comparisons with a corresponding autistic male sample concluded that their findings suggested there was not so much of a unique female

profile amongst those without ID. Rather it indicated that subtle and subjective factors might have influenced how autism manifested, and were experienced by women as compared to men; alluding to socio-cultural influences (Baldwin & Costley, 2015). Other studies supported this with their findings that suggested nonconformity to cultural expectations of females may play a role in the challenges reported (Bargiela et al., 2016; Kanfiszler et al., 2017). Nonetheless, most research has focused on thinking about how autism *impacts* on the challenges experienced by autistic women, which may have underplayed the impact that relationships could have on them as well. For example, in the case study by Rogers et al. (2017), the participant provided a context of abusive childhood experiences, which she felt was interacting with heightened autism-related traits (e.g. sensory issues) during her perinatal period. However, the study's focus and conclusion were orientated towards thinking about the challenges of how autism related traits, such as communication, decision making and sensory overloads affected her experience. While the findings were important, it also risked reducing the experiences to predefined concepts, and underemphasising the impact of the perceptions and interactions with others. The current research would argue that a more holistic perspective of investigating the interconnected relationship autistic women have with the people around them would provide more insight into the unique experiences of autistic women.

2.6 Research Aims and Questions

Though research on autistic women has gained momentum in the past few years, and qualitative methods have advanced as a useful method of enquiry, there is still a need to strengthen understanding of their lived experiences. In particular, for autistic women without ID who were less likely to be diagnosed (Dworzynski et al., 2012; Kim et al., 2011), and more frequently mislabelled as not autistic due to stereotypes (Bargiela et al., 2016; Tint & Weiss, 2018). There is a lack of literature on the impact that socio-cultural influences conveyed through relationships, have on autistic women, as opposed to the predominant focus of how 'autism' affects the woman. The primary aim of the current study was therefore to investigate how autistic women have understood their life experiences in the context of

their socio-cultural settings. A secondary aim was to try and capture a more holistic understanding of autistic women that included challenges as well as strengths and successes. These aims underpinned the overall research question: *How has autistic women made sense of their experiences in the context of the culture they are embedded within?*

Chapter Three: Methodology

3.1 Overview

The methodology adopted for this research was Interpretative Phenomenological Analysis (IPA), and this chapter aims to address the various methodological principles involved. It will start with an introduction to the research design, and the methodological approach, along the relevant theoretical underpinnings, before presenting the rationale for using IPA. This will be followed by a detailed summary and discussion of the specific procedures taken, as well as the ethical considerations and quality assurances that were thought about throughout the study.

3.2 Design

The aim of this research was to examine how autistic women made sense of their lived experiences in the context of socio-cultural values. This was a relatively unexplored ‘insider’ perspective that necessitated a more in-depth exploration. To do so required drawing out reflections of participants, detailing their thoughts, feelings, as well as the history of their beliefs, rich data what would be easily lost if quantified. Hence, a qualitative design was most suited to addressing the current research objective, given the ability for qualitative methods to encapsulate and contextualise lived experiences, with depth through inductive (data-driven) analytic processes (Padgett, 2016).

3.3 Interpretative Phenomenological Analysis

IPA was used because of its particular interest in phenomena as is meaningfully experienced by people within their contexts (Willig, 2013). It draws together the phenomenological process of “giving voice” and interpretative process of making sense with participants (Larkin & Thompson, 2012). The following section will detail the theoretical aspects of IPA that make it suitable for the current research aims.

3.3.1 Phenomenology

Phenomenology is a philosophical practice rooted in a number of ideas that endeavour to illuminate the experiences of the experiencer in the way it manifests through consciousness (Moran, 2000). Husserl believed in going “back to the things themselves”

(Moran, 2000; p. 9) and was concerned with the processes of conscious reflection that allows us to recognise a phenomena as they present themselves (Smith et al., 2009). However, he also believed that we were prone to being obscured from doing so, by our tendency to try and fit new experiences into our preconceived categories of experiences. As such, he believed that phenomenological inquiry required *bracketing* aside these taken-for-granted perceptions of the world in our consciousness in order to isolate and fully engage with a phenomenon. To do so would require adopting a *phenomenological attitude* through a series of *reductions* aimed to direct the inquirer away from their interfering preconceptions acquired through life, towards the essence of their experience of a phenomenon (Smith et al., 2009).

In practice, this transcendent practice of bracketing is never fully achievable, as a person is always a *person-in-context* (Larkin et al., 2006). That is to say that one cannot be meaningfully detached from their contexts filled with language, objects, culture and history. Heidegger proposes the concept of *Dasein*, commonly known as 'being-in-the-world' (Eatough & Smith, 2017; Larkin et al., 2006) to reflect our relatedness with the world with which we are immersed within, and always interacting with (Heidegger, 1962). The acknowledgment of this intersubjective relationship we have with the world raises the importance of meaning-making through interpretations that place people within their social and historical contexts (Smith et al., 2009). This idea of a more contextualised phenomenology was further expanded by Merleau-Ponty who was concerned with the subjectivity of the embodied lived experience (Merleau-Ponty, 1962). An individual's experience can never be fully shared or conceived by another, because we are always perceiving from our own embodied positions (Moran, 2000; Smith et al., 2009). As such, empathy only provides us insofar with a proximal understanding of another's experience of a phenomenon.

From phenomenology, IPA has inherited from Husserl the ambition to understand phenomena in its own terms, as far as is possible. To do so would require bringing the phenomenon to consciousness through reflection of the lived experience (Larkin et al., 2006). Heidegger and Merleau-Ponty broadened our view to seeing the person within their

embodied social, historical and linguistic contexts (Moran, 2000). This shaped both the way meaning is expressed by participants and perceived by researchers. As such, IPA is a humbling commitment and on-going process to systematically reflect and interpret meanings attributed by people of their experience, while acknowledging that we are only ever conducting “experience close” research, rather than reaching the essence of a lived experience (Smith et al., 2009).

3.3.2 Hermeneutics

The theorising of interpretation is the second major theoretical foundation of IPA. Schleiermacher emphasised the availability of meaning for interpretation delivered by the linguistic techniques and intention of a person describing an experience (Schleiermacher, 1998). The interpretative analysis can in turn offer meaningful perspectives to this description that exceeds the explicit claims of the original description through systematically bringing to consciousness what may have been unconscious to the experiencer. It is also believed that understanding occurs alongside the emergence of the phenomena into consciousness (Heidegger, 1962). Therefore, there is an interconnected relationship between what ‘shows itself’ and that which ‘lies hidden’, which would necessitate interpretation for making visible the latent, invisible meanings in a description of phenomena (Smith et al., 2009).

Considering the person-in-context, Heidegger highlighted the inevitability of interpreting through a lens shaped by the analyst’s own prior experiences, assumptions and preconceptions (Heidegger, 1962). To prioritise the experience of the phenomenon as it is, requires the analyst to be aware of their preconceived ideas. However, this awareness may precede the interpretation, or may become more apparent as the analyst engages with experience that is being interpreted. This adds a cyclical dimension to the process of interpretation and bracketing that connects it to reflexive practices (Smith et al., 2009).

A major influence of hermeneutic theory on IPA is the idea of the hermeneutic circle (Schleiermacher, 1998), which brought attention to the co-dependent relationship between the part and the whole across multiple levels in research (Smith et al., 2009). For example,

the moving from a word (part) to the sentence (whole) to contextualise meaning; moving from a sentence (whole) to analysing specific words (part) to illuminate a deeper meaning. This process reflects the iterative process of interpretation and analysis used in IPA (Smith et al., 2009). IPA has also been described as a double hermeneutics process, whereby the researcher is always trying to make sense of what the participant is trying to make sense of (Smith & Osborn, 2003). This process involves the researcher both trying to understand from the perspective of the participant, as well as reflexive use of the self to gain a perspective from a slightly different angle.

3.3.3 Idiography

The third major foundation for IPA is the idiographic focus on specifics and the particulars, as supposed to things in general (Eatough & Smith, 2017). This refers to the focus of the specific individual experiencing a specific phenomenon, as well as the depth of analysis achieved through systematic and thorough attention to the data provided by the individual (Larkin et al., 2006). This has meant that IPA tended to use small, carefully selected purposive samples, in order to achieve this intense commitment to the particulars on both levels of detail and meaning by the person. Idiography does not however shy away from generalisations, rather it takes on a more meticulous approach to reaching them through grounding them in the aforementioned particulars (Smith et al., 2009). The immersion of people within their contexts in phenomenology has offered us a more nuanced and complex view of experience, where the experience is both uniquely embodied and intrinsically relational to the world around them (Smith et al., 2009).

3.3.4 Rationale for using IPA

The experiences of autistic women have been relatively unexplored. The prevailing conceptualisation of autism as a disorder and deficits has affected the recognition of autistic women (Gould & Ashton-Smith, 2011), especially for those without ID (Dworzynski et al., 2012). Not appearing autistic, as others would expect has been reported by autistic women to be a barrier for recognition (Bargiela et al., 2016; Leedham et al., 2020; Tint & Weiss, 2018). The behavioural and aesthetic similarities with non-autistic women are part of what

contributes to this tension in being not recognised, and camouflaging may partially explain this (Hull et al., 2017). Nonetheless, autistic women are different to non-autistic women in the ways they experience and perceive the world, such as in areas of social interaction, patterns of thinking and sensory perception (APA, 2013; Fenton & Krahn, 2007; Robertson, 2010; WHO, 2018). The differences of autistic women without ID and non-autistic women are less visible and harder to determine, which necessitates a more nuanced, contextualised and in-depth exploration.

In this context IPA was most suited to the current research with autistic women without ID owing to its idiographic approach, which provided opportunities for the lesser-heard and unique perspectives of autistic women by foregrounding their sense-making. The interpretative process and phenomenological attitude further enhances this endeavour by encouraging a systematic, contextual and reflexive joint meaning-making process between researcher and participant. Furthermore, these theoretical underpinnings of IPA complemented my critical realist ontological, and constructionist epistemological position to this research.

The double hermeneutic approach provided a meaningful attempt to address the *double empathy* problem; which proposed that non-autistic researchers may have difficulties empathising with the experiences of autistic individuals, as much as autistic people may find it hard to understand non-autistic people (Milton, 2012). This naturally posed concerns about ethical and validity issues in autism research. IPA enabled this research to stay respectfully grounded in the participant's perception of their experiences, by reminding the researcher that they are constantly trying to make sense of what the participant has made sense of. The rigorously systematic and reflexive interpretation process then encouraged an analysis that stayed as close to the participants' intended meaning as possible. Reviews of studies using IPA to explore autistic people's experiences have also argued for its usefulness. It can provide a balance in power between autistic participants and non-autistic researchers by centring the participants as experts of their experience (Howard et al., 2019; Macleod et al., 2018).

3.3.5 Limitations

There were several limitations regarding IPA that were considered in the process of selecting this method. A critique of IPA is its focus on language as a medium (Willig, 2013), and called into question the validity of it as a tool to convey experiences. The use of language in itself can carry meaning and construct a version of the experience rather than describes it. Additionally, the repertoire of verbal language a person has, can shape the way the experience is categorised, and therefore limit the expression of one's perception and experience of phenomena (Willig, 2013). Specifically, for this research with autistic women, I needed to ensure that there was a shared understanding of abstract concepts such as "culture". The flexible use of the interview schedule, and reflective explorations with participants, mitigated the shortfalls for using language as a medium to a degree.

Another limitation of IPA was the potential pitfalls of re-describing, instead of critically examining and interpreting the data (Howard et al., 2019). To achieve a higher level of abstraction in light of concerns with the double-empathy problem added to the tentativeness in approaching the data. Furthermore, the quality of the interpretations depended significantly on the reflexivity of the researcher to engage with their own preconceptions. My clinical experience and personal interest in autism meant that there was an abundance of preconceptions that required bracketing. On the other hand, the demand for reflective practice within clinical psychology training (British Psychological Society, 2017) has provided me with skills and rehearsal in reflexive practices.

3.3.6 Consideration of Alternative Approaches

The exploration of lived experience can be achieved through other qualitative methodologies other than IPA, but alternatives such as Narrative Analysis, Thematic Analysis and Discourse Analysis lacked the idiographic focus desired for this research. The hard to reach views of autistic women and the diversity within the target population would benefit from IPA's idiographic attention to particular experiences in particular contexts (Smith et al., 2009).

The most notable contender to IPA for this research was Grounded Theory (GT), which was a more established approach (in comparison to IPA), with multiple versions that directed research in different directions. GT also aimed to understand experience and capture a degree of essence about the phenomenon of interest, through inductive cycles of analysing information in the form of language. Where the two approaches diverged was in GT's focus on understanding the fundamental processes in social interactions that account for phenomena. Whereas, IPA focused more on gaining insight into the psychological world of the participant (Willig, 2013). As such, IPA was more suited to the current research, in that it would stay rooted in detailed analysis of a small sample, whereas GT may be more likely to push towards a conceptual explanation (Willig, 2013).

3.4 Consultation

There is a need for research to better capture the perspectives of autistic people through meaningful engagement and consultation (Milton, 2014; Pellicano et al., 2013). The challenge for the current study was thinking about how to recruit for consultation without detracting from the small existing pool of autistic women available for participating in this research. The study originally aimed to seek consultation on the research aims and procedure through an autism charity that facilitated paid participation of autistic people in research. Unfortunately, an appropriate sample of autistic women could not be identified after an extended period of recruitment for consultation. Subsequently, consultation was had with different professionals with significant research and clinical experience with autistic people. Furthermore, the first participant of this research was also recruited as a pilot interview and was consulted regarding her experience of the interview afterwards. The interviewing process was constantly refined through reflecting on the feedback of the interview experience provided by each subsequent participant.

3.5 Participants

IPA requires reasonably homogenous samples to examine convergence and divergence in detail (Smith et al., 2009). It was necessary for the sample to be homogenous in terms of being autistic women, but there were no restrictions placed on socio-cultural

contexts. A purposive sampling method was used to recruit six to ten autistic women as recommended for sufficiently rich data analysis within a professional doctorate (Smith et al., 2009).

3.5.1 Inclusion criteria

The main inclusion criterion was being an autistic woman (adult woman over 18 years old) with a formal diagnosis of ASD (American Psychiatric Association, 2013; World Health Organization, 2018). The inclusion of self-identified autistic women was considered due to the high risks of being undiagnosed or misdiagnosed as an adult or woman (Kirkovski et al., 2013). However, it was outside the remit of the current study to substantially validate self-identified autism and therefore only women with formal diagnoses were included.

3.5.2 Exclusion Criteria

The observed systematic bias against diagnosing autistic women without ID (Dworzynski et al., 2012; Kim et al., 2011) has meant that we know relatively little about their experiences. This would benefit from further investigation into what may be culturally contributing to this. Hence, autistic women with a diagnosis of ID were excluded from the current study.

Autistic women presenting with acute symptoms of mental health difficulties, such as substance dependence, psychosis and suicidal intent were excluded from this study. Acute symptoms were likely to impact on how they perceived their experiences. However, a history of mental health difficulties was not an exclusion criterion. The high prevalence of mental health difficulties within autistic populations (Crane et al., 2019), and autistic women (Baldwin & Costley, 2015) would suggest that this was likely to represent common experiences of the current sample.

Transgender autistic women were excluded from the current research. Although this was a valuable perspective, it was likely to add significant heterogeneity to the sample in terms of differences in how they may have experienced and interacted with their socio-cultural contexts compared to cis-gendered autistic women.

3.5.3 Recruitment

As autistic women without ID were less likely to be found within clinical samples (Loomes et al., 2017), three recruitment strategies were used to maximise reach. Staff and students at the University of Hertfordshire were recruited through their online news bulletin. The study was also advertised through a charity that supported autistic adults in the community and through an online forum for autistic women. Permission was sought to distribute recruitment advertisements in all three settings.

A summary and contact details (email) were provided in the advertisement for interested parties to approach the principal researcher. All participants were provided opportunities to discuss (via email or video-link) queries or concerns, as well as adjustments that may be helpful for the interview.

3.5.4 Participant Information

Fourteen autistic women responded to recruitment, all but one was from the university. Eight cis-gendered women participated in this study; seven responded to recruitment from the university, and one from the charity. Two women decided not to participate and prioritise their mental health needs, two women decided not to go ahead after the initial response to the advert, and two women were not autistic. All participants had a formal diagnosis of autism. All participants stated a preference for face-to-face interviews, however this was not geographically viable for one participant, and the interview was conducted via video-link instead. Table 2 outlines demographic data and pseudonyms of participants.

Table 2

Pseudonyms and Demographic Data of Participants

Participant ID	Participant Pseudonym	Age	Age at Diagnosis	Gender Identity	Current Profession
1	Lola	34	30	Female	Psychology degree student
2	Ambie	48	40	Female	Published poet and Charity Volunteer
3	Marion	53	50	Female	Senior scientist and

4	Trinity	25	9	Female	professional doctorate student Performance and Production degree student
5	Sarah	20	16	Female	Media and Communications degree student
6	Lauren	20	12	Female	Student at university
7	Rebecca	24	22	Female	Engineer and part time degree student
8	Emma	18	16	Female	Nursing degree student

3.6 Ethical Considerations

This study was granted full ethical approval by the University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee. The protocol number was aLMS/PGT/UH/03787(1) (Appendix D).

3.6.1 *Informed consent*

Informed consent was crucial to ensure that this research respected the autonomy, privacy and dignity of participants (British Psychological Society, 2014). The Consent Form (Appendix E) was forwarded to all participants prior to the interview alongside the Participant Information Sheet (Appendix F). This was to ensure that they had sufficient time to consider participation and ask questions via email or in person. All participants provided signed consent and there were no reasons to suspect that anyone lacked capacity to consent.

3.6.2 *Confidentiality*

Protecting the identity and privacy of each participant was upheld in recruitment, data collection, analysis and post-participation stages. The participants were anonymised with numbered IDs, which were later replaced by pseudonyms of the participant's choice. Reasonable changes that retained the context of information were made to person-identifiable details within the transcripts. Audio copies of the interviews, along with the original transcripts were stored-securely on digitally encrypted and password-protected

devices. Hard copies of signed consent forms were transferred into electronic copies and stored with the other confidential participant information. Only anonymised transcripts were shared with supervisors in the research team.

3.6.3 Potential distress

The specific needs, preferences and values of working with autistic research participants at all stages of the study were considered (Gowen et al., 2017; Howard et al., 2019). At the pre-engagement stage, participants were asked for their preferred terminology for autism that would be used throughout their interview. They were also asked to share any specific needs or requests that may make the interview more comfortable, and accommodations were made where possible. Example requests included larger rooms, dimmer lights and reviewing a copy of the interview schedule in advance. The definition of culture, as well as the interview questions were printed to support those who may benefit from processing the questions visually. An adjacent room was always booked next to the room of the interview, to provide the participant a space before, during or after the interview should they wish to use it for settling in or relax with privacy. All participants were offered the choice of video-link or face-to-face interviews.

It was emphasised to participants, in the information sheet and at the interview, that they did not have to talk about anything they did not feel comfortable with. The limits of confidentiality were explained to participants in person. If serious concerns for the safety of the participant or people around them became apparent, they would have been discussed with the participant, and the protocol stated in the information sheet would have been followed. This did not occur for any participant.

At the end of the interview, participants were provided the opportunity to feedback their experience. Relevant signposting for mental health support was provided on the debrief sheet, and I was prepared to pause/discontinue interviews and discuss seeking mental health support if that became necessary. No direct signposting was required for any participant.

3.7 Interview schedule

IPA interviews are intended to be conversational (Biggerstaff & Thompson, 2008), and encourage participants to tell their own stories using their own words (Smith et al., 2009). Keeping this in mind, a semi-structured interview schedule was designed to map out the relevant territories that would lead to a more in-depth exploration of the participant's experiences. This was used flexibly in response to the participants, prioritising the sense-making process. Prompts were provided in places where the participants found the question too broad. Culture was defined as the values, beliefs, attitudes and behaviour of a particular social group or society in the interview. This was first shared with the participant and discussed if necessary. The interview schedule started with an exploration of the participant's perception of their culture, followed by a conversation of their experiences, and ended with thinking about how these may have impacted them (Appendix G). This interview schedule was rehearsed and refined with professionals with clinical and research experience working with autistic people. This also increased the researcher's confidence in conducting the interview, which ultimately had an impact on the participant's engagement in the process (Smith et al., 2009).

3.8 Interviewing procedure

Information about the location and time of the interview was provided in advance. All interviews, including the video-link interview was conducted in private and quiet study rooms. Interviews lasted between 60 minutes and 139 minutes; the average interview length (including introductions) was 90 minutes.

3.9 Analysis

3.9.1 Transcription

All the interviews were audio-recorded and transcribed verbatim by the principal researcher to aid with immersion in the data and analysis. Although the focus of analysis in IPA were the content of the interview, significant pauses, and non-verbal expressions (e.g. laughter) were noted in the transcripts to aid with interpretation.

3.9.2 Data analysis

A number of stages have been outlined for conducting analysis in IPA research (Smith et al., 2009), and the specific process utilised in the current study is detailed in Table 3. This was by no means a linear process. The underlying principles of hermeneutics meant that the analysis was cyclical and iterative in moving back and forth between words and sentences, individual transcripts and overall findings - the part and the whole (Smith et al., 2009)

Table 3

Stages of IPA analysis used in this research

Stage of Analysis	Details of Process
Phase 1: Listening and Reading	After each interview, the audio-recording was listened to individually and again after each transcription to try and capture the essence of what was shared. Any initial thoughts or comments noted from the interview were recorded in a reflective research journal in attempt to bracket these distractions as much as possible from what was said by the participant.
Phase 2: Initial exploratory commenting	Initial exploratory thoughts of the transcript were formed under the categories of <i>Descriptive</i> (content-focused), <i>Linguistic</i> (use of language), and <i>Conceptual</i> (more interrogative and conceptual ideas and questions about the data) content (See Appendix H for example extract of analysis).
Phase 3: Developing emergent themes	The aim was to produce a more concentrated understanding of the text in the form of concise statements – emergent themes. This was achieved through analysing the exploratory ideas alongside the transcript and moving from specific parts (words) to the whole (sections of text) in a circular hermeneutic manner (See

<p>Phase 4: Searching for connections in emergent themes – developing Superordinate themes</p>	<p>Appendix H for example extract of analysis). Listing all the emergent themes, a range of strategies (e.g. abstraction, subsumption, polarization, contextualization, numeration, and function) was then used to think about how these emergent themes fit together. Not all the emergent themes develop into master themes, and were discarded in this process (See Appendix I for example list of themes and clustering)</p>
<p>Phase 5: Moving to the next case</p>	<p>Phases 1 to 4 were then repeated for the next interview and transcript. In keeping with the idiographic commitment of IPA, the researcher attempted to bracket any conceptions formed from the previous interview. When thoughts about a previous interview came up while analysing the existing one, I would record these comments separately, again in attempt to bracket them off and return to focusing on the interview at hand.</p>
<p>Phase 6: Looking for connections across all transcripts.</p>	<p>Once all the interviews were analysed individually, the aim was to then look for patterns across the interviews. Again, in a circular hermeneutic manner, master themes for all participants were brought together, moved around, reconfigured and labelled in attempt to reach higher-order concepts. This eventually created the final Superordinate Themes, and related Subordinate Themes (Table 4 in Chapter Four)</p> <p>See Appendix J for a list of all the master themes across all participants</p>

3.10 Quality Assurances in Qualitative Research

The aims and assumptions of qualitative research are vastly different to that of quantitative research, therefore traditional evaluations of research in terms of

representativeness of the sample, reliability and replicability of findings and objectivity in procedures would be unsuitable for the current research (Yardley, 2000). At the same time, there were some fundamental aspects of quality research that applied to both quantitative and qualitative methods, such as having an explicit statement of purpose, ethical and respectful practice, clarity and contribution to knowledge (Elliott et al., 1999). These have been integrated into the reporting of this research throughout. The following addresses the quality assurances that were more pertinent to qualitative research.

3.10.1 Sensitivity to context

Yardley (2000) suggested that there should be an awareness and understanding of contexts in qualitative research from a theoretical and methodological position, as well as the socio-cultural influences around the participants, and how this may impact the researcher-participant relationship. The current study has tried to achieve this through conducting a systematic literature review to explore the history and landscape of research regarding autistic women. This provided an indicator of how relevant and timely the research questions were (Tracy, 2010). The very aims of the current research were to understand autistic women in their socio-cultural contexts, and therefore the interview questions and the demographic data collection were fundamental to *situating the sample* (Elliott et al., 1999).

Attention was also paid to the individual needs and preferences of each participant, from language to process, through to environment. This was important for ensuring that the experience for participants was accessible, respectful and dignified (Tracy, 2010). The interview schedule was also used flexibly to help put participants at ease, which was important for building the necessary rapport for a positive experience and collecting good quality data (Smith et al., 2009). The power dynamics between experiential expert and researcher was also carefully considered. The participant's storytelling and experience was always at the fore, but it was also necessary to think about when to take more of a lead as researcher and guide the interview so that the data collected in the time available was relevant.

3.10.2 Commitment and rigour

The selection of IPA as a methodology was arguably a show of commitment to rigour, given that the methodology was rooted in ideas of hermeneutics. The demand for immersion and iterative analysis, led to a prolonged period of engaging with the data in attempt to transcend superficial interpretations (Smith et al., 2009). As will hopefully be apparent in the results, the study also strived to be attentively idiographic by grounding the results in examples from the data (Elliott et al., 1999).

3.10.3 Transparency and coherence

This study has attempted to provide transparency through detailing all relevant aspects of the data collection and analysis and presenting the findings in a clear and coherent manner. Transparency was also offered in the form of acknowledging my theoretical positions, experience and presumptions as the principal researcher (Tracy, 2010; Yardley, 2000). At the interview and analysis stage, there were underlying experiences reported by participants that I resonated with, such as feeling misunderstood by others. These were areas I paid attention to reflecting and recording in my reflective log (Appendix K) to take ownership of my beliefs and biases. Sometimes these offered more depth to the analysis, and sometimes reflection helped me move away from my assumptions and recentre the participant.

3.10.4 Impact and importance

The reach and utility of a piece of research ultimately defines its value, and is perhaps the most important evaluation in terms of quality (Yardley, 2000). Extant narratives around autistic people have a tendency to 'other' or 'alienate' them, placing them in a world of their own (Davidson, 2007), and research has reflected this by frequently exploring autistic people in isolation rather than in relation to the people they live with and around. The voices of autistic women are even less heard within the research community due to the way autism has been conceptualised and researched (Kreiser & White, 2014). Hence, an in-depth exploration of their experiences situated within their contexts is an important perspective for better understanding them, and why their voices have been so marginalised.

Chapter Four: Findings

4.1 Overview of themes

From the analysis, three superordinate themes emerged, which encapsulated experiences of all eight participants within each (See Table 4 for superordinate and subordinate themes). The phenomenological aspect of the analysis addressed the “objects of concern” and the “experiential claims” made by the participants; these were the experiences they chose to talk about and how they made sense of them. The interpretative aspect was achieved through positioning those descriptions in their socio-cultural contexts and critically examining the meaning of what the participants have made sense of (Larkin et al., 2006). The reader of this chapter would also add an additional layer of interpretation by bringing their fore-conceptions with them into the participants and researcher’s sense-making process (Smith et al., 2009).

Table 4

Superordinate Themes and Related Subordinate themes

Superordinate themes	Subordinate themes
Pervasive influence of socio-cultural values	Power in the unsaid
	Trapped under the weight of socio-cultural norms
	Expectations to change and conform
Individualisation as an autistic woman	Differentiating from others
	An integrated sense of self
Staying connected with society	Feeling disconnected
	Wanting meaningful connections
	Relational healing

4.2 Pervasive influence of socio-cultural values

Within this superordinate theme, socio-cultural values were apparent in multiple areas of participant's lives, ranging from family values about relationships and manners, to wider societal values about expectations on women's behaviours. These values had positive and limiting impact on participants, and their power were most felt when participants felt excluded from the unwritten rules shaped by these values. Participants experienced the weight of norms created by socio-cultural values when they deviated from how others expected them to behave. Furthermore, participants became aware of the pressures to change and conform in multiple aspects of their lives.

4.2.1 Power in the unsaid

Socio-cultural values were embedded within beliefs, attitudes and behaviours of families and wider society. These values were powerful in how they transcended generations and could be as empowering for participants, as they were restrictive when participants wanted to be different to conventions. Part of the power in these values was in its implicit nature, where a lack of shared understanding with wider society of unwritten rules exposed participants to certain risks and vulnerabilities.

The family was evidently an immediate system where autistic women assimilated values from their parents. These values may have been consistent or disparate to wider cultural values, but reflected what values were learned from their immediate culture. These values were often enacted within the scripts or the behaviours of the family, rather than explicitly relayed. An example would be a family's values of marriage:

There was very much a belief of, sort of, once you're married, you stay married. That kind of came up a lot, which I think is the only reason my grandparents stayed together, obviously. Yeah, once you're married, you stayed married. You're supposed to marry young, that's something as well, you're supposed to marry young, you're supposed to have produced kids, and everything was supposed to be overseen, sort of by God. (Lola)

Lola's description reflected how she came to understand a collection of behaviours from previous generations, as values and expectations placed on her to fulfil. This collection of behaviours perhaps spoke to a less explicit belief around the institution and sanctity of marriage, and Lola alluded to an overarching link with religion. Sarah demonstrated how family values imbibed in scripts and behaviours influenced her perceptions and interactions with others:

I've always looked at what's going on through the lens of my core values my parents instilled in me, which was...self-fulfilment, but it was also like, be critical of others, I'd say, 'cause my dad's a very critical person...he'll come back and this, the vitriol that comes out of his mouth towards [other] people, it's like, "wow" [high pitched], but then obviously, if you're around that it kind of filters in so you end up looking at people like "I can't believe they done that." (Sarah)

When family values clashed with personal values, the former could feel imposing. Both Lauren and Lola described being expected to have children in their family culture, and experienced varying pressure to do so. Lauren held "a strong belief that [she] will not have children [laughs]" and would "slip [her belief] into conversations", where her parents would respond with "No, no, you'll change your mind". The indirect exchanges reflected the tentativeness with which Lauren tried to express an alternative belief, and also how strongly held and resistant to change that family belief was for her parents. For Lola, a similar belief relating to marriage and childbearing was held so strongly that her mother signed her up to a dating website without her knowing. Lola found "this very interfering '...I want grandchildren' kind of view...quite difficult to deal with". Lauren and Lola's experiences alluded to how values passed down in families operated forcefully within the unsaid.

Likewise, family values that instilled empowering beliefs had a positive influence on how challenges were viewed and approached in life. Lola, Marion, and Rebecca specifically highlighted how they inherited from their mothers, beliefs that being a female meant being

strong and capable. Sarah learned from her parents that “there was no shame about talking about what you’re interested in” and “women, just do what they want, you know, they don’t have to be like, housewives, they don’t have to be, earners...” It is worth noting that the emphasis on an empowered female culture within their immediate families, was often juxtaposed with how this was not the norm in the wider societal context. Marion succinctly explained “if you’re looking at the real average woman in this country, they probably don’t have that role model of someone as powerful as my mother, on which to, kind of, instil that they could be strong”. This showed the potential tension between immediate family values with wider societal cultures.

While there was a degree of tacit understanding within families of what the values were, this was not always the case in wider socio-cultural contexts. The implicitness in which values were communicated could leave them feeling vulnerable. In a general context, Ambie stated, “I’m always unsure of my behaviour. So, I ask people have I upset them all the time. And half the time, they say I haven’t, and why do I think I have, I say because I can’t tell.” Repeated experiences have suggested to Ambie that she may have violated a social etiquette, but not being able to confirm this has fostered uncertainty for her. Furthermore, Lola felt that she was more exposed to being mistreated in relationships, from not being able to interpret other’s intentions:

...Growing up, I didn’t have the diagnosis, it was very easy to be taken advantage of by partners and friends, it was very difficult to gauge exactly what partners wanted from you...I ended up in a relationship at 18 [years old]...and he steadily became more and more abusive...it got to a point where, it actually did end up with him being arrested for domestic violence...I kind of look back on it now, and I think, had I been able to see the signs of him getting annoyed, and I know it still wouldn’t be my fault, but, if I was able to see the signs of him getting annoyed, I probably could have kept myself safer. (Lola)

There was a sense that social rules served a function of providing people with schemas in how to act in specific situations. However, these rules were often unspoken, and therein lay the risks against autistic women who may initially feel excluded from this knowledge:

I feel like there's an expected kind of social etiquette that you have to follow...it's kind of like the unwritten social rules of society...people are brought up into, and you're kind of expected to...adhere to there, but without being told, really, what they are. (Emma)

The power of knowledge and the risks of not having a shared understanding with others also increased the likelihood of behaving in a way that avoided offending others and developing assumptions that they needed to endure certain experiences if the problem was in them. Lola demonstrated this in explaining how she inductively concluded that her sensory difficulties reflected some weakness in her as a result of the way others misinterpreted and reacted to her behaviours:

I remember there being lessons where I was having a sensory nightmare, the lights were too bright, or there was a buzzing noise or something that no one else could hear, and I remember sitting there just thinking 'it will be so much worse for you, if you walk out, because then there will be a huge argument' and just thinking 'it would be so much worse if you put your hands over your ears because then you're going to get teased by the other students' so you're just going to have to sit and endure it. And obviously without the context of knowing I was autistic at the time, part of me was like "oh well everyone is going through this as well, so like, they're all coping with it, why aren't you coping with it?" And like, it wasn't until, I was, a lot later "Oh, actually these people don't go through this, this is why they're sitting there fine and not flinching, it's because they're not going through it, not because I can't cope with it and they can" (Lola)

4.2.2 *Trapped under the weight of socio-cultural norms*

Following on from how powerful socio-cultural values could be for the autistic women in this study, this subordinate theme explored the restrictions and limitations experienced by them as they talked about the impact of differing from socio-cultural norms shaped by these values.

Many of the participants reflected on how they were not recognised as being autistic by certain stereotypes that they did not fit in with. Their autism was sometimes hidden in plain sight under the mainstream narratives that often associated autism with being male, exhibiting behaviours stereotyped as autistic, and having ID. Trinity explained, “Like for me as an autistic woman, extremely difficult, in certain aspects it can be to do with that a lot of people just think of it ‘Oh it’s only men that are autistic and not women’”. Emma expanded on this with her observations from experience, and highlighted how others often expected to be able to observe something tangible to characterise autism by, such as behavioural differences:

Since being diagnosed, [she has noticed that] there's definitely the view that girls aren't autistic. There's still that view that girls aren't really autistic it's more of a male thing or that there's definitely a view that “Oh, you're not autistic because you have friends or you can make eye contact” or...they're like “you don't *seem* autistic.” (Emma)

Limiting stereotypes about autism also came with how frequently autism was thought about in conjunction with ID in the wider socio-cultural context. Marion described how such stereotypes prevented professionals from identifying her needs:

My mother used to work at [a renown therapeutic institution] and some of her eminent colleagues used to work on autism [laughs]. But... and they knew there was something... an issue, there was an issue with me, but because autism in those days was, you know, with people with intellectual disabilities, not, non-verbal, et cetera, more the classic

Kanner's autism and not Asperger's, that they just, didn't think that that was me, at all.

(Marion)

These stereotypes of autistic behaviour could be so prevalent, and removed from how these women saw themselves, that it prevented them identifying with autism in the first place when looking for support or an explanation for their experiences. Before Emma was diagnosed, she did not think that she could be autistic because: "... to me, autism, was kind of like kids who struggle to speak, or like couldn't move properly or like flap their hands a lot and stuff." Comparably, Ambie "used to work with autism, you know; with children and all that...I never thought it'd be me". These experiences brought to the fore of how autism was less often recognised as a spectrum in their socio-cultural contexts. Instead, the end of the spectrum where autistic people had high levels of needs had become the dominant representation of autism.

Many participants described how their needs in relations to autism were more complicated than how abilities and difficulties were typically categorised – often in a binary and mutually exclusive way. Lola described how trapped she felt between such extremes, when her needs were in fact much more nuanced than that:

There's such a misunderstanding about it, that it's really really difficult to pin down really, because it's almost like, my work would have wanted me to have a letter saying that I'm high functioning, whereas PIP or something would have wanted a letter saying that I'm low functioning, and the reality is I'm both. So, what do you do in that situation? You're kind of set up to fail. (Lola)

This became frustrating for participants when their ability to do one thing was further used to challenge the authenticity of them finding something else difficult. In such cases, it appeared that others overestimated how well they could cope:

It gets a bit annoying, most of the time, like - yes, some of the things that I can't do, you can't visually see it...when people really annoy me and they say, "Well, you can do this, you can, that and that."...I always say, "Well, hold on a second. Let me just cut my brain out. And I'll show you my brain. I'll show you where the autism is." I just automatically say that to think, look, I cannot show you it. I can tell you about it. I can tell you how I'm feeling. But I can't show you that. (Trinity)

Trinity's comment reflected the weight of responsibility she had for justifying her needs and why they defied other people's expectations, and this was not always easy given that the differences were not always visible or in line with what people expected to see. The consequences for participants who could not meet this implicit demand for visible and convincing *proof* of their needs were twofold. There was the obvious risk of having their requests for support denied, but also the additional invalidation of being misjudged for why they may make such request. This was shown in Rebecca's experience, where her apprentice managers were provided with a letter, and explained in person what her needs and difficulties were. However, these were repeatedly dismissed. Rebecca explained that she "didn't seem stereotypically - there's no stereotypical autistic person, as they would imagine need to be autistic - that actually 'oh, she'd be fine', 'she's...' not making it up, 'but...she's making it seem a lot worse than it is.'"

Reflecting on group activities, unexpected demands and presenting in front of crowds at work, Rebecca explained that in the moment, she could feel like "at the time, it does, it feels like the world is ending [laugh]". These stressful experiences also have the impact of draining her emotional and physical resources for days afterwards at home, which were invisible to her colleagues. Rebecca reflected on how her description of how she truly felt may be perceived as "incredibly dramatic" by others, but she was also clear that how she felt in the moment was separate to her ability to rationalise retrospectively that "what [she's] asked to do really isn't that big a deal in the grand scheme of things". Rebecca's comments revealed the imbalance between how much effort she put in to understanding and meeting

other people's expectations despite the personal costs, and how misunderstood she was in return.

Conversely, stereotypes about autism also generated stigma that led to an underestimation of abilities. These demonstrated how the autism diagnostic label, categorised under disabilities, overshadowed observable abilities in participants. Trinity described her experiences of seeking employment instead of going to university after college:

I said to [the people at the job centre], "something to do with radio or maybe photography or video editing." They said, "Right, we've got these websites for these volunteering roles, charity shops, really good idea." But they never, ever, like gave me links to any radio or anything to do with video editing or photography, they just kept constantly saying charity shops. (Trinity)

The lack of interest in Trinity's skills, and the insistence of her taking up unpaid employment pointed towards how societal norms appraised and capped her abilities. For Lauren, she was more explicitly excluded from joining the military because of her autism:

I couldn't join [the military] because of my disabilities. They don't accept any disa-..., well they don't accept autism. I sort of knew it, and I was appealing the decision...I think something really annoyed me in particular, and I was gonna fight for it, and I sort of gave up afterwards, was the fact that you have to write a letter. And that letter isn't you. It's sort of, you basically write what your disabilities are, how they affect you. And I think, you, they don't meet you. If they met me, I think it would be a bit different. They wouldn't see the disability, they wouldn't sort of characterise it. And they just see the disability for me, I think. (Lauren)

Lauren's account showed how she experienced the presumption that being autistic meant she would be deficient in some way for the role. Her only option was to justify how

limiting her disabilities were, and there was no interest in what she could do, or how her diagnosis may not affect her ability at all. Her deflated response to the process of appealing also conveyed a powerless sentiment against the established norm in seeing autism, purely as a disability.

Sarah, on the other hand, was all too aware of the stigma attached to autism from observing how her autistic father was marginalised at work despite being an “extremely qualified” engineer. This awareness transformed into such a threat for her that she was determined not to disclose her autism to even her extended family members (the exceptions being partners, autistic friends and anonymous situations like this study). Sarah did not appear to reject the part of her identity that was autistic and saw the benefits of her differences such as being logical. Nonetheless, she described feeling discouraged to share that part of herself that was autistic with others, and in fact actively feared that it would result in discrimination. In this sense, it was less of a choice to not disclose, but rather a socio-cultural constraint from showing a part of who she was to society. These could be seen in her reflections on what she feared the most about people knowing she was autistic:

Not being able to make connections with other people, without being immediately screened through “Oh, they have autism.” So, literally it's like a screen in front of you. It's like, they interact with you, but it's like “Oh, we treat them differently because they're autistic; We'll talk to them differently; We'll think of them as lesser”. Whereas, actually I'm just as capable as the rest of you, my brain just works differently. (Sarah)

Most the participants described how knowledge and understanding of autism in society has improved overtime. However, they also felt that there was still a lot of progress to be made. In particular, Emma took issue with the superficiality of acceptance in society:

...Even like there's like, all that campaign; it's like, “Oh, it's okay to be different”. But I feel like it comes with like hidden terms and conditions. Like it's okay to be different *if* we

can meet your support needs. Or it's okay to be different *if* like we're able to put in those accommodations. Or *if* you're different in *this* way, but not in *that* way. Or *if*, you're not too different. (Emma)

This was best echoed by the experiences of Trinity who continuously struggled to find any paid employment and decided to study at university instead. She made numerous applications for low-skilled roles that she had voluntary experience of working in (and was arguably overqualified for). She had been rejected for jobs with the reason that she was autistic before, which she only realised was a violation of equality laws much later. Trinity had up until very recently always stated that she has autism on her application forms. While Trinity was aware that there could be multiple reasons for why she has not gained paid employment, the culmination of her experiences led her to suspect that she was victim to covert discrimination:

I have seen a few times on social media, especially one [supermarket chain] in particular, they put a poster up a couple of months ago saying about "This is one of our colleagues, he's autistic." And it kind of made me think, okay, *he's* autistic, and I've been turned down by [the same supermarket chain] four times. And they were known, that I have autism. (Trinity)

Emma made an important point of distinguishing between statements about accepting difference and actually acting on them. For her, the latter would mean, "people have to accept other people and not make out like, 'Oh, it's a big inconvenience'". Sarah also contemplated that "it's normal to be discriminated or bullied, and it's because people don't accept that other people are different. I don't think they ever will. I think it's just because they are such a minority. It will always happen, I guess" These experiences and reflections hinted at how they experienced society's resistance to true attitudinal changes.

Instead, participants described how problems were often projected onto them, which then justified their being marginalised. Their behaviours and experiences were often not seen in context by those who would locate the issue in them, which they were susceptible to internalising over time. This had the possible effect of absolving people from the relational responsibility to making any changes on their part. This could be seen in the aforementioned examples in the way Rebecca felt the need to manage how others “assumed [she was] making a fuss for no reason” when she tried to explain her needs and difficulties at work. Similarly, Marion described how “[professionals she saw as a child] knew that there was something wrong with *me*”, all the while her simultaneous traumatic experiences at home and signs of autism at school went unnoticed. Further to these examples, Lauren described how she was “constantly getting into trouble” for her behaviours that included walking out of class, and “lying” to teachers and therapists. She recalled that she was admonished weekly for her “misbehaviours” and that they “basically stood [her] out as a target” in school. Lauren reflected on these experiences, “I don't know if I'd categorise [them] as lying because I think, at the time, I didn't realise what my issues were. I was being told these were my issues”. The repeated attempts to change something in Lauren, in order to resolve her arguably non-conforming and inconvenient behaviours showed how easy it was to locate the problem in her. With hindsight, her behaviours could be contextualised as possible reactions to sensory and executive functioning difficulties, as well as finding a way to protect herself from overwhelming realities. However, it was striking that these considerations were largely absent.

For some autistic women, it was clear to them the way they were perceived, were just other people's perception, and was not necessarily a reflection of how they were. For others, the way they were treated for being different had a profoundly damaging impact on them. This was most poignantly demonstrated when Ambie reflected, “I just thought I was bad. I just thought, I just thought I was no good. I just thought, I still sometimes think that, I just feel like ‘why me?’”

4.2.3 Expectations to change and conform

For many participants, socio-cultural values set a norm with which they were expected to conform to. These were apparent for different aspects of their lives and often were noticed from a young age. For those who differed from the normative values, they experience the pressure to change.

Marion felt patronised and confused by the frequency with which she was advised, “all you’ve got to do is be yourself” – because she believed that she was already being authentically herself. Overtime she came to understand that the underlying message of this advice was “I think what they were actually really saying is – *change* – and be something that we can handle, please.” The expectation to change and conform became increasingly evident through the discussion about the implicit power of social-cultural values. This current subordinate theme focuses in more detail on how the intolerance to difference also came with the implicit message of change and conform.

There was a prevailing sense amongst this study of autistic women that they were expected to be *quiet* and *pleasant* for others. When Ambie reflected on how girls were expected to behave in her culture, she stated, “I was to be seen and not heard. Speak when you’re spoken to.” Similarly, many of the autistic women in the study spoke of expectations to be “quiet”, “good” and “well behaved”; to be “polite” and have good manners. Good behaviours were often juxtaposed with “bad” or “rude” behaviours as unacceptable, highlighting the incorporation of morality into shaping behaviours. The universality of this experience alongside how “good” was translated as behaviours that were desired of participants, demonstrated the powerfully implicit message which encouraged conformity to a norm. Lauren was taught that being good meant, “meeting [her parents’] values...communicating with other children [as opposed to adults]...I’d sort of be rewarded for that”. For Emma “good” meant that she “always did exactly what [her parents] said. [Emma] always got good grades. [Emma] was always like, responsible.” Conversely, for Sarah, she learned in her childhood that it was not acceptable to cry because it was “seen as putting on the water works, being manipulative”. So for a long time, she disallowed herself to

cry at home or at school. Lola described how she was raised to be “very very polite, and very quiet, and to follow the rules really strictly”. She reflected that being very literal contributed to her complying with this, but it was also necessary for her because she “found being polite the easiest way to kind of get through things.” The involvement of rewards, praises, reprimanding and sometimes, an absence of conflict, indicated how reinforcement mechanisms were involved with shaping behaviours to the accepted norm from a young age.

The roots of such expectations to be agreeable for most of the participants could be understood from the wider socio-cultural narratives about women. From a young age at school, Lola observed, “girls were socialised to be a bit more careful with who they were”. More broadly, Sarah described how she understood that “women are meant to be like, nice, fluffy, everything”, and deduced that because her interests deviated from those descriptors, this contributed to her struggling to fit in with her peers at school. On an individual level, Rebecca reflected on the stark contrast of how she was treated compared to men, while working in a male-dominated environment:

What I find is that, I am perceived to be rude a lot more quickly than my male counterparts would be. So I could say the same thing, but if I’m saying it as bluntly as they’re saying it, then I’m perceived as being rude. (Rebecca)

Although Rebecca was conscious that she was not rude in how she communicated with others, she nonetheless adapted her behaviour by “treading” more carefully with the way she worded or suggested things to her colleagues in order to reduce confrontations at work. The expectation to conform was also reinforced more broadly, such as when she explained to other people “so-and-so said exactly the same thing.” And she would be advised, “well, you should probably word it a bit differently then”. Ultimately, the message many of the autistic women received was that they were expected to behave in line with gendered stereotypes of women. This proved challenging for many of the autistic women in this study,

not because they were rude or unfeminine, but because not everything they wanted to do or be, was aligned with the current stereotype for women in their socio-cultural contexts.

Expectations to conform also occurred for other socio-cultural beliefs. Rebecca's experience of being persuaded to make a different academic decision to the one she wanted to make exemplified the demand on her to be an intellectual or academic in a certain way. She recalled the frequency with which she was told by her educators that she was making "a mistake" by choosing an engineering apprenticeship over attending university:

So certainly knew that there was a pressure there, to sort of change my mind, to follow this predefined set of steps to this predefined end goal...Just because of, the amount of times it was discussed and brought up, and how strong the beliefs were that, you know, "you should be going to a university, you should be doing this". It would certainly make me question whether I was making the right choice. (Rebecca)

Rebecca described how others repeatedly shared their vision of how she would live her life, and she had no desire for some of these ideas such as travelling: "Yeah, most definitely. Go traveling, yeah, experience the world, study in a posh university, some sort of high level degree that I suppose they considered to be an intellectual degree..." The disparity between what she wanted to do, and what some people in the wider society deemed best for her to do, reflected the conviction with which people held their socio-cultural beliefs. Her experiences of self-doubt demonstrated the persuasion of these dominant beliefs, and with hindsight, she was pleased that she made the right decision for her against the tide of opposing opinions:

So, certainly if I had a less supportive family, I might have caved and thought okay I'm making a mistake here.... So, it wouldn't be the emotional pressure as such I think, but it would be more of a, if everyone's saying this, why are they saying it? What's their reason behind it. Which often I'm not so good at picking up on. So I would start wondering if

actually there's something that - because I haven't done it - I'm missing something. And there's something that inherently makes it better to go down that path... I think if I'd had sort of decided, actually, no they're right, I'll go along and do it [go to university], I think I probably would have ended up quite isolated, in quite a difficult place in terms of that.

(Rebecca)

Conversely, Lola experienced the opposite scenario where she was expected to show that she was less able than how she saw herself in order to receive support. Lola recalled “I came out of those PIP assessments, so demotivated and so upset that, because I literally just spent an hour with someone telling me how useless I was, and there was no backup from that”. Lola remembered how she could not afford to live without this support at the time. She was also not going to receive the help she needed unless she sufficiently demonstrated incompetency. This showed how the way support is shaped in society could force a person to comply with expectations that they do not fully identify with.

4.3 Individualisation as an autistic woman

In this second superordinate theme, the participants shared how they broke away from socio-cultural beliefs that did not fit in with how they saw themselves or the world. This provided the necessary space for them to embark on journeys of self-discovery and develop more coherent and authentic narratives about their identities.

4.3.1 *Differentiating from others*

Surrounded by implicit and invisible socio-cultural values that sometimes imposed themselves on autistic women with expectations, the autistic women in this study started differentiating who they were expected to be from who they wanted to be. Ambie reflected on the contradictory behaviour of her parents who imposed certain rules on her: “But they were just as rude, if anything - more. So basically ‘do as I say, not do as I do’”. As Ambie started to evaluate the values she has been taught, she started to individuate and decide what her own values were: “Sometimes I don’t know who I am, but yeah, I know, I got a strong sense I

don't want to be my mum". Sarah also described the process in which she developed her own sense of self and values, which involved self-reflection, social analysis and experimentation:

Growing up, it was like, "You can't cry, you can't do this, you can't do that!" And then it was like, once I was old enough to form my own views about the world and like, you know, sometimes, it is okay to cry, you can do that, you can be a person and have emotional responses to things. It's not just your parents that get to have that, it's like you get to have that as well. But I only figured out through a lot of Googling, a lot of reading Reddit in particular, to kind of measure my experiences against theirs, and learn what's acceptable and what isn't. (Sarah)

Trinity utilised mainstream media to help her understand herself better, through movies and video streaming platforms. She was able to study in detail about emotional experiences, and obtain different perspectives on experiences that others also shared. The variety of ways that mainstream media and social media were used casted a spotlight on how the portrayal of culture in these various mediums could provide a more candid insight into socio-cultural experiences and beliefs that were typically less explicitly discussed. With access to typically unspoken knowledge through media platforms, Trinity started externalising what was deemed *her* bad behaviour, into sensory overloads that involved an interaction between her environment and her:

I've started to watch Youtubers talk about little videos or movies or TV shows that kind of think, oh, so that *wasn't* bad behaviour. It was a sensory overload. I've only just started to realise that now. So back then, because I didn't know what it was, and they didn't know what it was, they automatically assumed "bad behaviour, you get excluded". (Trinity)

For some autistic women, they differentiated from their parents' behaviours and values much more consciously, especially when they did not want to repeat patterns of relational traumas with others:

You know how some people say that if you come from an abusive background you end up being the abuser – for me, that's totally the opposite, you know, because of where I came from, I was just like, this is not going to happen [laughs]! And it's not going to happen in [Marion's child's] life. (Marion)

Other than differentiating from values that filtered through families, some participants also had to distinguish themselves from wider socio-cultural ideas that they also did not identify with. One such disempowering stereotype was the conflation of autism with ineptitude. Lauren received her diagnosis of autism later than her siblings who were diagnosed with other disabilities. There was an initial hypothesis that the way Lauren presented was due to difficulties with transition during the adoption. She explained how she found it “harder for [her] to come to terms with [her diagnosis of autism]” at first because by that point she understood having a diagnosis as having a disability that defined the rest of her future. This idea also had its roots from early narratives during her adoption where she was aware her adoptive parents were told “you know what, these children [Lauren and her siblings] probably won't get a decent job” because of the delayed development they presented with. In turn she grew dispirited thinking “You know what? It's not much expected of you.’ So I think in my view, I sort of took a slack. GCSEs I was like, ‘you know what, I don't really care about it.’” The most evident marker for Lauren in differentiating from this internalised idea that she was destined for a nugatory life was her decision to attend university, which surprised everyone including herself.

For Trinity, after she overcame some of those internalised doubts about her general abilities, she also had to prove herself in order to separate herself from other people's beliefs about her. Alas, trying to individualise from other people's perception was not as simple or

easy as changing her own belief, since she was part of a culture of people whose recognition was consequential to her:

If I talk about it, she [Trinity's mother] won't believe me. If I showed her it, she will. I mean, it's the same one for everyone really, like, if it's my friends or my boyfriend, I say, "Look, I'm not gonna say. I'm going to show you that I can do it." Like do it and then they see it and think, "Look, look, I can do it. I can do this." (Trinity)

Hence, for participants to separate from values and beliefs that did not, or no longer fitted in with their identity was not always an individual matter. The differentiation of how the autistic women saw themselves and how others saw them also led to awareness for some to manage the expectations of other people who may see them differently. Two polar examples came from Trinity and Sarah, where Trinity tried to offer more knowledge about her autism, and Sarah obscured her autism from others. Trinity pre-emptively informed people about how she may experience sensory overloads, be it with university peers or prospective employment, in attempt to reduce the likelihood that they would be shocked and respond judgementally if she was to experience one with them. Although she knew that her sensory overloads were not indicative of "bad behaviour", she was cognisant of the fact that the society around her was unlikely to share that understanding:

... I'll just walk into a room and they just think, "Oh, just there she is, normal person." But then when I have sensory overload, they're like, "Wait, what's happening? What's going on?" And then I have to make them aware. That's why I like to make people aware in advance, just so, if it ever did happen, they'll be like, "Oh. Okay, this is a sensory overload or something". (Trinity)

Sarah took a completely different approach to managing other people's expectations by keeping her autism in the shadows and not disclosing it publicly, so that she could

foreground who she was as a person. She shared her thoughts on managing her appearance to others:

I wanted to be, like, not like the other girls, but like, learn how to blend in, to like succeed later on in life, I guess. So, I can do things like go to university and not be seen as, like, have to be like handled with like gloves or something. Or I can get a job and be seen as really quite successful in what I do, and I don't stand out as someone with autism, because it's definitely a stigma. (Sarah)

Sarah's initial back and forth hinted at the complexities involved with sustaining an authentic sense of self that was separate to other people's ideas; all the while keeping in mind that there was a part of them that needed to be less visible because others were unlikely to appreciate it. Rebecca also indicated a similar differentiation between how she saw herself, and how she managed other people's perception of her: "because my mum's very good at teaching me coping mechanisms, ways to sort of – *not hide* how I am, but just to, maybe, *lessen* what other people see." This statement reflected the integrity demonstrated by the participants, whether they chose to share or conceal parts of themselves, they all held onto a strong sense of self against a current of often unsympathetic socio-cultural beliefs. Reflecting on their experiences, the autistic women in this study talked about how they separated dominant socio-cultural views that impacted them, from who they believed they were. This was arguably a necessary process that preceded the next subordinate theme, whereby, they had to first differentiate from the values they were surrounded by, in order to redefine and integrate a more coherent narrative of themselves.

4.3.2 *An integrated sense of self*

It was common for the autistic women in this study to talk about how the hardships they experienced prompted them to reflect about their identity, moreover, that within these reflections, autism was sometimes the missing piece of the puzzle. This was best demonstrated when Ambie described her curiosity to understand herself:

I identify with the autism; I identify with the mental health as well, but with the autism, it's me. Actually, it's when I was about my late 30s, I kept thinking, it's not right. There's something not right. Why do I keep biting myself and hitting things? And why do I get angry so quickly? And why do I do this? Why do I get that? And why do I have, them call them tantrums, but they're not tantrums, they're meltdowns? (Ambie)

This was not always the case, as with Rebecca who sought a diagnosis out of necessity for her work, rather than for an exploration of herself. Nonetheless, the experience of feeling different to others was still present, along with the problems that arose from other people's intolerance of her differences. The distinction for Rebecca was in the way she described her mother encouraging her to understand, value and manage her differences early on without a diagnosis.

Reflection inevitably led to a curiosity about themselves and a journey of self-discovery. Trinity initially became interested in YouTube videos from watching other people's videos that helped her feel more uplifted when she was experiencing low moods. It was through these videos that she was also able to learn more about autism, and later on propelled her to learn new skills:

I made a YouTube channel. And I then realised I had a skill. So using my visual skills, and through their videos and because I watch a lot of movies and TV shows, I thought, "Okay, I'm going to make videos." And through that, I realised that I had video editing skills, and that's why I'm here, because I'm doing Film and TV production, because I want to be a video editor. (Trinity)

On the other hand, Lauren talked about developing a more balanced perspective of herself that integrated different aspects of her:

I count myself as an *ambivert*, in the fact that when I'm with my friends, quite a outgoing loud person...and that's something I've had to hide a lot. I think growing up, parents always saw me as an introvert. Everyone told me I was an introvert. But now, it's very obvious I'm not fully an introvert. I quite like being an introvert sometimes, but it's that culture of having to adapt to different situations. I'm a very different person with, around my family as well. And that culture is different from what I have had to experience at university. (Lauren)

This drawing together of new and old identities was an important point. The participants did not just become a different person after reflection and further insight of themselves. It was instead more intricate, involving differentiating, retaining, and embracing new things about themselves. This was also suggested in Lola's reflections on deciding to take on a completely new career after the devastating experience of discrimination after disclosing her diagnosis at work, and leaving her job of many years. She shared that from "this really hellish situation has risen like a whole new life's purpose." However, "there's a part of [her] that's, well, this shouldn't have happened in the first place. You know, nothing's about me changed, other than having a diagnosis."

Self-discovery included both finding out things they didn't know about themselves, and not limiting themselves to fit into any particular stereotypical categories. This provided agency for some of the autistic women in this study, to adapt in order to achieve what they wanted:

I kind of have a lot of different, I don't want to call them personalities, they're not big enough to be personalities. I have a lot of different, roles, that I pick depending on the context of where I am, what I'm doing at the time, who I'm speaking to. So, if I was, completely left to my own devices, and was just allowed to behave in the way that was most comfortable for me, I probably wouldn't say much to anyone at all [laughs]. I certainly

wouldn't do things like, be sitting here or going to work. Or, if I did, I would not be as productive. (Rebecca)

Many of the autistic women also talked about staying true to their own values, which guided them in making decisions for themselves. Emma described an expectation and some pressure to choose a subject to study at university that was deemed academic by her grandmother. Reflecting on what helped her make a decision that felt right for her, even though it was against the hopes of people she cared about, she explained, “because I really wanted to do it [mental health nursing]. And I knew that was gonna really help me as well.” This intuition to make decisions guided by their own beliefs was emphasised for other autistic women as well, for other areas of their lives. Sarah stated, “I do what I want” when it came to her interests, she elaborated that “when [she] was younger, [she'd] kind of hide it, but at this point, it's like, if people want to have a problem with it, they can have a problem with it.” The forcefulness of her statement may give off the wrong impression that she does not care for what others think anymore, however, this was also not the case. Sarah explained, “It's like, it hurts that they judge it, sometimes, like, you know, being a woman in falconry, it's not marginalised, but it's like you are, sometimes, a bit looked down upon.” Rebecca also emphasised this on several occasions that “It's not that I don't care what people think. But I'm not going to let it stop me doing things I want to do” or conversely “I wasn't going to put myself in a situation where I was uncomfortable for the sake of people that, not that I didn't care about, but, that, they'd be quite happy whether I was there or not”. The ability to distinguish how they positioned themselves in relations to others increased their agency to be themselves.

The participants in this study were homogenously adult autistic women without ID. Other than that, their lives were vibrantly diverse, just like non-autistic people. Participants talked about different life events that contributed to their experiences in life, such as childhood abuse, sexual assaults, and physical abuse, bereavement, having albinism and visual impairments, adoption and relational traumas - in addition to being autistic. In that

sense, autism was entwined with their identities rather than being a separate entity that could be clearly delineated. As Marion succinctly pointed out:

I don't think you can separate [being autistic and being me] out really, being *autistic* is about your behaviours, well the behaviours and traits are you, so, it's really, I'm not saying that your whole identity is being autistic, but they're kind of meshed in, so when someone, says "Oh do you do that because you're autistic?" Er, yes and no. I do that because I do that. (Marion)

4.4 Staying connected with society

This final superordinate theme explored the impact of feeling disconnected from people and society and the longing for meaningful connections with others. These two subordinate themes were then brought together by thinking about the restorative impact that meaningful relationships had for participants.

4.4.1 Feeling disconnected

Feeling misunderstood in some shape or form, was a prevailing occurrence for all autistic women in this study. Examples of such have been interspersed across the superordinate themes, from being misperceived as rude, unintelligent, arrogant, lying or unkind. At the core of which, was a feeling of being seen in a light they did not identify with. These experiences have left many of the participants feeling hurt, alone and disconnected. Ambie shared the invalidation that came with experiences of disconnection during some of her holidays, which were important to her:

Sometimes when I go somewhere, if I have a misunderstanding with someone, I find it hard to connect with them again... and sometimes if that happens, I feel so isolated. Because, you see, I've taken me with me, you know, I'm taking the damaged part away on holiday with me, which is quite challenging. And I can't, I wish I could be someone else, but I'm not, I'm just Ambie. (Ambie)

Ambie referred to the integrated nature of her mental health difficulties and experiences of sensory overload that were as much a part of her, as her creative and personable qualities. As such, feeling misunderstood for how she might behave, for example in reaction to feeling overwhelmed, have left her feeling vulnerable to personal rejection.

Understandably, for some participants who have felt isolated and ostracised, they did not have limitless supplies of psychological resource to keep on trying to connect with others. In that sense, disconnection became a vicious cycle, where they may feel the necessity to guard their emotional wellbeing and create a distance with others. An example of which could be seen in Lola's thought processes behind disclosing her autism to other people:

If I'm disclosing to people, I either want to do it straight away or not at all, because I think once you get past a certain point, if they don't know you're autistic, then you can get too invested in them, and then they come out with some hateful overlay rhetoric." (Lola)

Experiences where Lola found messages from others to be confusing, or where she experienced mixed signals about the interaction, had led her to conclude that there were times when she was rejected dishonestly. She suspected on occasions, that the real reason was a stigma towards her being autistic. These experiences have affected her deeply, to the extent that they have shaped some of her interactions, where she felt such a strategy was necessary to prepare her mentally to be either pleasantly surprised, or expectantly disappointed.

Relatedly, for those who had other qualities that were prized in their socio-cultural contexts, it was easy to operate under a certain illusion that those other qualities could compensate for the lack of relatedness with others. Rebecca gave a candid reflection regarding her secondary school years that alluded to this:

[Speaking about her experiences of depression] Generally it was related to sort of struggles getting on with people at school, pressure of achieving good grades, of performing

well because that was what I perceived myself as being good at. So, to me, it didn't matter so much if I didn't have friends as long as I was getting good results. And then if there was something that knocked my grades down, for example, then that would become a much bigger issue than in reality actually was. (Rebecca)

The investment in one aspect of her life became much larger (i.e. her intellectual ability) when it was also responsible for the lack of connectedness with her peers. This was not always the case for every autistic woman, not even Rebecca, but it highlighted the possible psychological mechanisms involved with justifying the undesirable experiences of being disconnected with others at a deeper level. Marion shared a similar reflection on a time period where she embodied certain confident, glamorous characters through how she looked:

I mean it didn't really work that well because I still wasn't confident, and I still didn't talk to people. But I *could*, not talk to people and, not get on with people, and not be understood, but I felt sexy and looked good, if you get what I mean [laughs], so that was okay. So it was their problem, you know? (Marion)

Not wanting to be discriminated from others could also come from a position of wanting to survive in the socio-cultural context in which they existed within. Exploring with Sarah her fears of not fitting in with the people around her she reflected that “you'd be the outcast; you'd be the weird one. And you don't really see a lot of success stories or anything about people who are very obviously autistic, unfortunately”. Sarah had observed this not only with her father's experiences, but also with autistic peers at university who were seen as “weird” and were often “alone”.

Many participants talked about experiences of loneliness from not having someone who understood them. Trinity explained the kind of rumination that occurred for her when relationships broke down. There was a striking similarity between Trinity and some of the

other participants in their spontaneous assumption of responsibility that they may have done something wrong. That was not to make a judgement on whether they had or not, but it highlighted the universality of an implicitly received message that they were at fault for relational disconnections. When in reality, relational breakdowns were rarely one-sided:

Sometimes we [autistic people] don't like to be lonely. We don't like to be alone. We like to be around people. And then sometimes when we do something wrong, or if we lose a friend or, if somebody stops talking to us, we feel like we've done something wrong. And we're like, I don't understand what have I done wrong? What have I said wrong, or they start to laugh at me and they start to, just bully me for no reason. (Trinity)

This was separate and different to the fact that many autistic women wanted and enjoyed time alone too. This spotlighted the multiplicity of relationships and connections as experienced by participants. It was not all or nothing and could be quite nuanced in not wanting too much, but not, none at all; as clarified by Rebecca:

Friendships wise. I tended to have one friend at a time. I found it difficult to cope with demands from multiple friends. Not that they were being demanding, just standard social, sort of d'you want to go out, d'you want to do this, d'you want to come around my house, whatever. (Rebecca).

Rebecca made a clear distinction between what were her preferences for socialising, and how that differed from socio-cultural norms around her, of what was perceived as standard. Lauren further expanded on how exhausting she could find social interactions and demonstrated the fine balance between wanting to remain connected and needing more resources required for social communication:

I was in a flat with other people. And so I'd interact all day at University and then come home. And there were other people saying, "Oh, do you want to hang out in the evening?" And I was so exhausted from - it's not putting a pretence, but, it's watching how people communicate, and I have to put extra effort in to make sure that I'm communicating in the right way and thinking about what I say before I blurt it out, basically. (Lauren)

Lauren's emphasis on not *pretending* to be a different person also showed the way she did not want to disconnect from her authentic self and from others.

Experiences of involuntary socialising also led some participants to actively disengage from people they did not choose to spend time with. Lola described the dissonance she experienced as a child with her mother on this issue:

There was huge pressure from my parents to, make this friend...and they would introduce a lot of random people to me, and try and make them befriend me. And that kind of never really worked out. So there was an expectation going to a lot of social events, social clubs and things like, I was a Rainbow...Brownie...Guide, and I hated all three of them and I dropped out of all three of them. But every time I hit a new age bracket, I was taken back to do the next one, to try and socialise. (Lola)

It was not difficult to understand why Lola would want to disconnect in these situations, after being relentlessly made to socialise with peers that she could not connect with. It also emphasised the difference between relational and physical connections. Lola could be physically placed amongst other children, but her experiences suggested a simultaneous relational disconnection with those children. However, wanting time to themselves was not a permanent state for participants. Even for those who had strong foundations of relational connection with others, physical connections were still important, as demonstrated by Rebecca, "I've come to sort of realise that actually, if I don't have people around me that I can spend time with, talk to, just have fun with, that actually, it does get

quite lonely now.” As such, disconnection appeared to provide the necessary contrast for appreciating deeper connections. Marion talked about feeling a certain void and alienation at her workplace due to staffing changes. For the first time in 20 years of working there, she did not have that “one special person” at work that she “really click[s] with”. She described missing “you know, if something, if you feel you need to talk about something, or they feel they need to talk about, that you can rush to say ‘Oooh! Guess what just happened!’ or whatever.”

4.4.2 *Wanting meaningful connections*

It was evident that all the autistic women in this study longed for meaningful connections with other people. Such connections were important for feeling accepted as who they were. While some autistic women in this study had strong bonds with parents and siblings, many relationships were also complicated, not unlike the experiences of non-autistic people. The strength of familial loyalty and the desire to stay connected was perhaps most conspicuous for those who had experienced abusive relationships with their parents. Ambie showed the mixed and complex feelings that motivated her to persevere with trying to stay connected with her family following a conflict after she came out as gay to them:

I didn’t speak to him [her dad] for about two to three years. There’s a couple of times in my life where I didn’t talk to them for a few years, but after that one, I got back in contact with them, and said that we should try and get on. (Ambie)

Ambie described a relationship with her parents that was marked with physical violence and neglect early on, this was further complicated by the fact that she recognised her parents had their own mental health needs, and that not all her memories with them were bad either. The fact that Ambie would cut-off communication with her parents at times suggested that she wanted more than just their physical presence. Her repeated attempts to communicate with them through her poems and conversations indicated that she was striving for an understanding from them.

On the end other of this spectrum of relationships, was Rebecca's strong connection with core family members. In particular, the secure attachment she had with her mother and grandmother acted as a guiding compass for her independence. It provided her with a supportive foundation to explore and make her own decisions. Rebecca demonstrated this as she reflected on the impact of her grandmother's values on her:

...It also means that I know that I've got support if ever I feel I'm in trouble, or if there's something that I'm really struggling with. And it gives me the confidence that I'm not just making a big deal of nothing most of the time. I've sort of learned to judge what is important and what isn't if you like. (Rebecca)

Having meaningful connections with the wider society was also important for the participants. For example, Marion shared that "what interested me is talking about, you know, life and what people feel about things and, sort of deeper conversations". Her wanting "deeper conversations" with others highlighted the depth she sought for in interactions. This was also shown through her "embracing the biker culture" (which she was introduced to through her husband). She highlighted the "revelation" she experienced of finding that "you really have to go beyond first impressions to find out the real people, and to click". It was interesting how many participants attempted to connect meaningfully and understand others, which was juxtaposed with how they also felt misunderstood by others or lost with their identity at times.

Romantic relationships were an area that most participants talked about. The intimacy of such relationships exposed the relational risks involved for some participants in disclosing that they were autistic. The contemplation of sharing something that felt vulnerable to the participants suggested that the potential for a meaningful relationship was worthwhile for them. Sarah explained her trepidation in disclosing: "I guess it's difficult because you don't know how they're gonna react to you, as a person with Asperger's...So, it's a bit of a scary one. The mortifying ordeal of being known, I guess." Lola expanded on some

of the thinking behind this concern: “if I get with someone, are they going to be like, ‘you know, I really care about you, but I don’t want autistic children, I don’t want to risk that.’” The types of anxieties associated with rejection in romantic relationships, of who they were intrinsically, suggested that this demanded a certain degree of trust and courage for participants, many of whom had experienced relational distress such as bullying.

Interests were often an important subculture that provided participants with the opportunity to connect with others who recognised them for something they chose to be recognised for. Trinity detailed the benefits of meeting others with the same interest as her, because: “they don’t care if I’m autistic, we just have a laugh, we talk, we talk about anything”.

For Lauren, she discovered her enjoyment for socialising once it became meaningful for her. Like Lola, Lauren’s parents managed most of her social calendar when she was younger, and she played a passive role in socialising. This was to the extent that she did not initially learn to drive because she associated this with people wanting to socialise. When Lauren gained relative autonomy and independence at university, she was able to actively engage and enjoy being with others:

I will also count one my hobbies as socialising... When I came to university, I was getting all into the societies... I was doing, all these things that I had to do myself. That was different because it was always my parents, I did girl guiding for 13 years, and that was just something that was expected of me because my parents would take me to them. And now it’s something, it just felt something different, to be able to do it myself and be able to socialise. (Lauren).

4.4.3 Relational healing

The restorative impact of supportive relationships was evident for most autistic women in this study. From the formation of new relationships, to rebuilding existing relationships. Finding a place within society was also part of that relational healing to feeling

ostracised. The autistic women in this study were often able to use qualities they knew they had all along or developed along the way to find how they belonged with others.

This was most notable with Lauren talking about the relational risks she took in order to be comfortable with being herself. She talked of having “built up a lot of walls” for “survival” as a “child”, and her adoptive “parents spent 10 years trying to knock them down”. A combination of family therapy and newfound independence at university helped her to “be able to communicate things that [she] need... to be able to build a relationship”. Lauren explained how she had created personas as a child because she did not believe that she was a “generally likable person”, and through learning to communicate her vulnerabilities and her needs rather than “pretend that everything was normal” helped her “realise, actually, you don’t need to be that person, you need to be yourself.” Lauren’s earlier beliefs about herself, that she was fundamentally unlovable, were formed in relation to her early experiences with her family of origin, as well as feeling out of place with her adoptive family who had a very different culture in terms of socio-economic background, geography and religion. It was therefore unsurprising that for Lauren to learn to appreciate her own “wacky” character, it also involved relating differently with the significant people around her.

Friendships were also areas where some of the autistic women found relational healing. Lola had returned to study with the perspective of “I didn’t plan to make friends, I planned to work” As such she openly disclosed her autism to her peers with some expectation that she might be rejected for it, “I walked into my access course... and I basically turned to the other two ‘by the way, I’m autistic’... and I thought, if they’ve got a problem with that, I don’ care”. Lola was pleasantly surprised to find that “they were both fine with it, and they got to know me as a person, was fantastic” She remained close friends with these two peers and this unexpectedly strong and positive friendship helped her to feel “a lot more open about coming out about [her autism]”. This was a heartfelt example of how being accepted by her peers helped Lola to become more confident with who she was. There was also a validation that came with other people recognising the qualities that Lola knew

she had to offer in friendships. This in turn gave her confidence in herself, but also gave her a different narrative to add to her history of struggling to find mutual friendships in her youth.

For autistic women in supportive relationships, they talked about how these have helped them. Marion described a strong and enduring relationship with her husband, whom she met when she was 17 years old, helped her to communicate her emotions, which benefited her wellbeing:

He bought me out of my shell, yeah, so he sort of, liked told me, wanted me to express myself, so you know, when I was upset, and I would just, clam up, he would sort of, ‘No, come on, tell me, what’s the matter with you? Why? You’ve got every right to be angry. Tell me, tell me...’ you know, and eventually I would sort of spit it all out, so he was good for me in that way. (Marion)

The contrast between the tension with which Marion held onto her emotions, and the release that came with sharing this with someone, highlighted the significance of having someone who was willing to work through these with her. This was reminiscent of when Trinity recalled the significance of her friend saying to her during an unexpected sensory overload experience in public, “I’m here. It’s fine. You’re not on your own”. Again, there was this sense of not only overcoming a difficulty that was important, but also having someone who cared enough to offer help without asking. For Trinity, this was momentarily healing because it countered past experiences of facing challenges alone with very different and less desirable outcomes.

The healing aspect of relationships was not one-directional. By supporting others, it had the effect of empowering participants to see themselves as someone with the resources to bring about positive change for others. Of note, in the examples below with Trinity and Marion, was their intuitive and compassionate use of themselves to centre the needs of others:

The reason I came [to this university], not just because of the course, but I wanted to be closer to my boyfriend because he lost his mom a couple years ago. And I really wanted to support him. That's another thing of autism. I don't know if it's for women and men, but we can be quite caring. We can be very supportive. (Trinity)

Marion further exemplified this in describing the strong bond she has with her child, and the sense of agency she felt in making a positive impact to the life of someone important to her:

I wanted my boy to realise there's nothing wrong with being autistic and that doesn't stop you from doing anything. So, you know, it's like "Mum's autistic as well, so we can be autistic together" [laughs]. It's quite good, because he doesn't, he was saying the other day about people with disabilities, and he was like, saying, "God it must be really difficult to have disabilities, I'm so glad I don't have any". And I'm like [shake fists in air], he doesn't even realise he's got a "disability", you know what I mean, you know, with special needs, which is great, because he doesn't see it as a disability, "Yes! My work is done!" [laughs] (Marion)

For Emma, when talking about why she chose to go into her profession, she confidently responded, "because, I met some amazing nurses when I was in hospital. They really helped me, so I wanted to be able to help other people." It was touching illustration of Emma's intentions to share with others the same compassion she was given when she felt psychologically depleted. It also showed the shift in position from being helped to helping others.

Other autistic women also demonstrated how they wanted to make a positive impact to others around them and to the wider society. The fact that some of the autistic women volunteered to participate in this research study, despite rarely disclosing their autism publicly was testament to this. All of the autistic women were accomplished in their own ways within society. These achievements connected these autistic women to their socio-

cultural contexts, and was one of the ways that helped them position themselves amongst many people they have felt different to.

Ambie channelled her emotional pain into poetry, and this has had a far-reaching impact, where her writing has been published and she performed frequently. You could say that she has built for herself a very large platform to be heard from, which was something that was very important to her – genuine understanding. Ambie also thought about her successes in being able to raise large sums of money through her poetry, for the autism charity that has supported her. This suggested the importance of feeling like a contributing member of society and culture. Similarly, Lauren, who expressed ambivalence about her current choice of study, shared an experience where her different perspective to others was sincerely valued. The contentment she conveyed revealed the importance of feeling genuinely appreciated by others:

Someone I did a module with last term, she said, "the only reason I got a first was because of you"... I was able to give a perspective, from my own personal experience, and from experiences I've picked up from younger children. And that they were like, "Well, you know what, I wouldn't have thought about it this way." And actually, my lecturer actually said "Oh, you know, a couple people have put in their, they've quoted you."... It's crazy to think - it's brilliant, and I was like, just because I see the world slightly differently. I never thought about that... It's quite a cool thing. (Lauren)

In a different way, Sarah described how her job as a falconer was the perfect bridge for her to share her esoteric knowledge on her special interest with other people, at an intensity that was appropriate. Sarah spoke with humour about how in her job "I don't have to sit there and bore somebody like 'Well, let me tell you every detail about this specific bird!' I can tell the public that, and they think its education [laughs]." In return, Sarah also developed a much higher tolerance for social unpredictability because of her passion for what she does:

With the job that I do, you never know what you're gonna get. So it's like, I never know if I'm going to deal with people who are against the keeping of birds of prey. What questions am I gonna get? Am I gonna get kids? Am I gonna get family? Am I gonna get older people? It's an unpredictable environment, you just kind of, get thrown into it, you have to learn to deal with it. So I say like, maybe my professional experience is kind, of added into why I have a much higher tolerance. (Sarah)

Feeling supported by others and feeling able to support others have provided all the autistic women in this study strength in a multitude of ways. None of the autistic women saw themselves as existing in isolation to their socio-cultural contexts. The lack of give-and-take they experience have caused some autistic women difficulties, and even pain and distress. At the same time, having a relationship with others, and society has added to the variety of personal strengths and skills showcased amongst this group of autistic women.

Chapter Five: Discussion

This final chapter aims to discuss the findings of the study and to place them within the context of the broader literature. Following which, clinical implications will be considered, along with the strengths and limitations of this study. Suggestions for future research are discussed before closing with conclusions.

5.1 Summary of results

This research was driven by the question of how autistic women have made sense of their experiences within their socio-cultural contexts. Three key themes emerged from the interpretative analysis. The first theme centred around how the participants experienced socio-cultural values as having a pervasive influence on their lives. These values were often seen as implicitly and explicitly powerful and restrictive at times; part of which included the expectation to conform to cultural norms. The second theme showed how autistic women separated from some prevailing cultural expectations around them. This was often followed by or occurred concurrently with individualising and forging their own sense of self. Finally, the third theme explored the participant's desire to stay connected with society, in contrast to some of their experiences of feeling alienated from society. Their longing for meaningful interactions and connections with others were apparent. This was especially so in talking about the restorative impact of relationships where they have felt supported, accepted, and understood.

5.2 Socio-cultural impact

Culture can operate in the unsaid by being entrenched within beliefs, attitudes and behaviours, and is not always easy to think about consciously (Krause, 1995). For some of the participants, eliciting the impact of socio-cultural values on them was not always a straightforward process, and required exploring their reflections on experiences. This was also apparent on another level, where throughout this research, I noticed a reoccurring assumption from peers, professionals and participants from a mix of backgrounds that "culture" referred to beliefs and practices of ethnic minorities (in the UK). This was seen also in researching literature, where studies on culture and autism were predominantly in the

field of cross-cultural differences, again largely referring to how different cultural practices influence decisions on seeking diagnoses and support (Burkett et al., 2015; Ennis-Cole et al., 2013; Mandell & Novak, 2005). I was curious by this absence of examining the impact of occidental culture on autistic people, which mirrored how ubiquitous, yet unspoken “culture” was for participants. It has been suggested that people may be less consciously aware of cultural values and ideas until they raise issues, or become the focus of decision-making (Krause, 1995). This may explain why the normative position surrounding this research would locate “culture” in the other. It may also explain why we are able to think about autism as a culture (Straus, 2013), because it is still largely seen as a set of difficulties; yet the reverse of thinking about the impact of culture *on* autistic people has been missing.

The implicitness of socio-cultural values makes it hard to address them verbally when they clash with personal values; this had the undesirable impact for some participants to internalise conflict and problems as meaning they are intrinsically “bad”. Existing studies on the lived experiences of autistic women have described the difficulties they face when not fitting in with conventional constructions of being a “woman” or “autistic” (Baldwin & Costley, 2015; Bargiela et al., 2016; Kanfischer et al., 2017; Tint & Weiss, 2018). The current findings on how participants feel restricted by socio-cultural stereotypes and norms, and experience pressure to change and conform, complement those findings.

Limburg (2016), diagnosed with AS at 42 years, reflected on her performances of appearing non-autistic by behaviours such as taking on local intonations and making eye contact. However, the performative aspects of her identity also extended to her autistic self. Limburg (2016) reflected on how she felt inclined to perform her autism when the person assessing her for support was repeatedly surprised by her ability to communicate clearly and behave cooperatively. She contemplated how she had once again violated normative assumptions that gave rise to discomfort in others. Her not appearing “autistic” in line with the stigmatised views of it, was as disruptive to the social fabric as when autistic behaviours arrive uninvited to social situations. Limburg (2016) reflected on the subsequent necessity and effort involved with managing other’s perceptions in relations to her autistic identity;

such that enough understanding could be elicited from others without “engendering their alienation” (Nadesan 2, as cited in Limburg, 2016). Limburg’s (2016) experiences revealed how dominant cultural narratives about autism can leave autistic women feeling like they are in the wrong no matter how they act. Like the experiences of the autistic women in this study who encountered difficulties for their non-conformity with expectations about womanhood and autism, it reveals the flaws of stereotyped understanding, that reduce curiosity for diversity and dynamic differences.

5.3 Identity

Williamson (1981, 1991) describes the intimacy paradox, where many of us as adults, will want to live a life meaningfully shared *and* will want to simultaneously be self-determined. To achieve both, it is argued that a redistribution of power is necessary with one’s family of origin, requiring an individual to first differentiate from the family, before renegotiating a new relationship that balances autonomy with intimacy. Although this was theorised in the context of family systems, the concept also maps onto the familial and societal experiences of the autistic women here. The participants in this study demonstrated their differentiation from families, as well as dominant ideas around them. This appeared to be part of the process towards developing their sense of self and identity, rather than towards any goals of self-insulation. Following a shift in self-perception that often involved feeling more empowered about being themselves, this was often followed by a shift in their relationships with existing and new people in their lives.

Issues with identity formation were apparent in this study, consistent with previous lived experience research with autistic women (Bargiela et al., 2016; Haney & Cullen, 2017; Kanfischer et al., 2017; Pesonen et al., 2015; Webster & Garvis, 2017). In not identifying with externally imposed identities, all the autistic women reflected on their own values and being at some point. Some participants felt that having a diagnosis of autism helped them construct a more balanced picture of themselves, as was reported in past studies (Leedham et al., 2020; Webster & Garvis, 2017). However, some participants also reported ambivalence about the diagnosis. This was often in the context of having already developed a relatively

strong sense of self and understanding, and the diagnosis was seen as only contributing practically to their lives, rather than making any fundamental impact to how they saw themselves. Ultimately, it seems that the development of a sense of self and identity is important for autistic women's wellbeing; and a timely diagnosis can facilitate this but opportunities to do so are not limited to diagnoses. Research on autistic self-advocacy in the Netherlands supports this idea in concluding that self-understanding (along with social contact, and changing public image of autism) as their most important goals (Waltz et al., 2015). Similarly, in a thematic analysis of autistic narratives it was found that nearly all participants "wanted to be able to define themselves on their own terms" (Milton & Sims, 2016, p.527).

Identity can be seen as something that is externally constructed within culture, where its formation requires internalisation (Duveen, 2013). This line of thought applies to autistic people, as demonstrated by Macleod et al. (2013) who drew upon social identity theories to explore the identities of higher-education students who were autistic. The research was framed using Social Identity Theory, Social Categorisation Theory and marginal social identities (Breakwell, 1978; Tajfel, 1978; Turner, 1999, as cited in Macleod et al., 2013). Under these models, self-concept was seen as being affected by the way the social group perceives the person, and behaviours within specific contexts are influenced by how people position themselves in relations to the social groups. Furthermore, people are likely to resolve dissonances between self-perception and external norms by way of adjusting self-perception or instigating external change to achieve internal and external compatibility. Those ways of understanding identity for autistic people resonated with the findings in this study, where the participant's identities were influenced by socio-cultural constructions of norms about autism and womanhood. These were not the only two markers for identity, but were highlighted here only in relations to its relevance for this research. For the participants in this study, the battle with identity formation may have resulted from the dissonance with which they saw their abilities and limitations, such as being seen as incapable when they believe they are.

To demonstrate but a couple of possible scenarios under these theoretical frameworks, some participants may have understandably internalised negative external evaluations, and downgraded their self-image (at a point in their life) to match external perceptions. This may reflect the experiences of participants who at certain points in their life felt that they were “bad” or “wrong” or deficient in some way. Alternatively, instead of changing the internal self-image, participants may endeavour to bring about changes in the external perception. This could be seen in the way some participants have tried to change social perception of autistic women through their personal and professional lives. In a way, all the participants have contributed to broadening perspectives of autistic women by volunteering to share their experiences in this study. In doing so, they are fortifying a self-image that fits in more with how they see themselves, compared to more disparaging historical narratives in research and society.

5.4 Intrinsically connected with society

The word “autism” originated from the Greek work *autos* meaning ‘self’. Coined by Bleuler in 1911 (Stanghellini & Ballerini, 2004) it was intended to describe an immersion to inner life and indifference to the outer world. Although conceptualisations of autism has shifted greatly from this analytically derived notion, the idea that autistic people are intensely self-focused (Baron-Cohen, 2005) and detached to the extent of being in a world of their own (Huws & Jones, 2010) has become deeply rooted in beliefs about autism. However, Sinclair (2012) would argue that “autism is not an impenetrable wall” and autistic people are not incapable of relating, nor do they lack the desire to connect with others (Sinclair, 2010). The current findings from the participants in this study would agree with this view.

In fact, this study would argue that the autistic women in this study all had a longing to connect and belong. This is separate to the fact that they also enjoy and want time to themselves. This is most evident when for some participants, it is after they have gained relative independence (along with other factors such as internal resources) that they notice this longing and reach out to connect. Research has long theorised and evidenced that social belonging is a powerful and fundamental motivation (Baumeister & Leary, 1995). Although

the dominant narrative around autism infers otherwise, research has shown how connection with like-minded individuals, mutual acceptance and feeling understood are important for many autistic people (Milton & Sims, 2016).

Research with autistic women also add to this finding, where the belief from others of their capability contributed to their agency in making decisions (Webster & Garvis, 2017). The current study builds upon this in examining the damaging impact of being misunderstood in terms of strengths and limitations; as well as the restorative impact of forming meaningful relationships with others through a variety of cultural groupings. The relationship between belonging and autistic people is a relatively unexplored area of research. Such research may enrich our understanding of this concept. The duality reported by some autistic people of wanting to be alone and connected, may mean they can provide unique insight into ideas such as how relatedness can occur without interactions, or interactions can take place without an authentic connection (Baumeister & Leary, 1995). In claiming the need for belonging is fundamental for people, Baumeister & Leary (1995) also presented the argument that a deprivation of belongingness could lead to undesirable effects on wellbeing. More recent research looked into the relationship between autistic traits and suicidal behaviour would support this idea, and showed that thwarted belongingness mediated this relationship (Pelton & Cassidy, 2017). The evidence increasingly points towards the implication of meaningful social connections for the wellbeing of autistic people.

5.5 Role of gendered socialisation

There are a number of ways to conceptualise the observed sex ration in autism (Cheslack-Postava & Jordan-Young, 2012), and the current findings of this study tentatively lends support to the involvement of gendered socialisation. Theories on gendered socialisation extended from thinking about socialisation in general; they consider how people develop a sense of self and identity, by learning the roles and expectations associated with a socio-cultural group they belong to, in this case, gender (Stockard, 1999). In society, when people behave in ways that are concordant with gender ideals, others typically positively reinforce them from a young age. The reverse happens where gender discordant

behaviours are sanctioned. As such, gender is encouraged to play a role in individual and social identity formation (Carter, 2014). While many of the autistic women in this study have talked about challenging gender stereotypes, they were not immune to its effects and talked of their pressures to change their behaviours to reduce conflict with others. Camouflaging behaviours reported in this study included self-managing eye contact and facial expressions, observing and evaluating appropriate behaviour for specific social situations, and inhibiting themselves from talking excessively about interests. These were explored more from the perspective of how socio-cultural environments may encourage camouflaging, such as expectations for participants to conform.

Examples of gendered expectations in this study included reflections of behaving more passively or inconspicuously in some settings; the impact of which has included going undetected for autism. Where participants have behaved differently to gendered expectations, they experienced accusations of rudeness and marginalisation that felt unreasonable or illogical. These experiences are consistent with findings that looked into gender differences for expectations to agree with opinions and comply to requests. In an experimental study, 142 participants (32% males and 68% females) were asked to rate the responder's willingness to comply with a request and agreeableness to an opinion expressed by male and female actors on a telephone call. The same actors were used, but the conditions paired the male and female actors in all the possible combinations (e.g. male caller to female responder, male caller to male responder, etc.). There were also three conditions varying in silence gap length between request and response (no delay, 600ms delay, 1200ms delay) to simulate hesitancy. The results showed that in all conditions participants rated females as being less agreeable than males with the increasing lag times, which suggested a higher expectation for the female to be more agreeable. Females were rated as less compliant overall across time delay conditions, particularly when a male made the request. An unexpected finding was that females were judged more harshly for their uncooperativeness if they showed reluctance to help another female (Roberts & Norris, 2016). These findings complement qualitative evidence that highlights the complexity in female relationships, or

where autistic women felt more excluded and bullied by female peers (Cridland et al., 2014; Haney & Cullen, 2017). This was also found in the current study, where some participants perceived that female peers were more gossipy and male peer interactions were perceived as more straightforward. For the autistic women in this study who expressed differing opinions to their peers, or showed hesitancy to accept a request, there was a likelihood they were judged and treated more harshly because they were expected to agree and comply more than males.

Relatedly, the invisibility of autism was an issue for many women in this study. Disclosure often led to mixed response ranging from acceptance, to dismissal of needs, through to denying their capabilities. These experiences echo discussions around invisible disabilities that contend invisibility may alleviate experiences of obvious stigma, but the person is still likely to experience forms of rejection, humiliation and social disapproval (Davis, 2005). (I use the term “disability” to refer to the functional categorisation of autism as such in clinical settings, while acknowledging that autism is also *a difference* for many people rather than a disability.) Furthermore, the invisibility of needs may make it harder to secure support and require the person to exhaust more effort in seeking it. They may experience a necessity to prove or convince others of their needs; a demand that is less expected of people with visible disabilities (Davis, 2005). This was demonstrated by some of the participants who described being misperceived as exaggerating their needs at school and at work, and learning to pre-emptively let others know when they may need help. Many of the participants also appreciated that their spectrum of abilities and needs were not straightforward in the context of how society understands them. Socio-cultural norms may expect that someone who can make eye contact on an individual basis, or present in front of a crowd, translate to being able to do this in other contexts. In reality, for the participants in this study, this depended on a variety of variables, including rehearsal, relatedness to the person they interact with and internal resources.

5.6 Clinical Implications

There are a number of implications that can be drawn from this study, and broadly relate to the understanding of autistic women and how these findings could be applied clinically. I shall explore these now in terms of implications on an individual, societal and clinical point of view.

On an individual level, the participants in this study have identified the importance of disseminating more accurate portrayals of autistic women in society. Many reflected on how a paucity of information had delayed diagnosis and seeking relevant support. For the participants who sought to make sense of their experiences, many did not relate to the prevailing stereotype of autism, and therefore did not consider autism. This study would propose that more diverse representations of autistic women could increase access for autistic women who may benefit from a diagnosis in formulating their experiences (Bargiela et al., 2016; Haney & Cullen, 2017; Kock et al., 2019; Leedham et al., 2020).

On a societal level, the participants in this study recognised that understanding about autism has greatly improved over the years. At the same time, they emphasised that there is still a lot of room for improvement, especially when it comes to understanding autistic women. It is hoped that by sharing the diverse experiences and rich inner workings of these autistic women, they will contribute to attitudinal shifts in society. This is an area that has also been highlighted as a persistent challenge for the autistic community (Pellicano et al., 2013). The intended effect is twofold; firstly, to distribute more representative narratives about autistic women's strengths and needs, and secondly to counter narratives that depict autistic women as homogeneously isolated, unfeeling or helpless beings. As was repeatedly highlighted by the participants in this study, it was key for them that society better understands autistic women; and in doing so, they hoped for greater acceptance of their diversity and differences from others.

Clinical and research work hold influence over how autistic women are perceived individually and within society. On a research level, this study supports further developing conceptualisations of autistic women. This would have an impact on how autistic women are

perceived and understood by the different types of clinical settings they may access. This underlies more practical implications of ensuring clinical formulations contextualises autistic women and better captures their relationships, needs and abilities. This is important for when a diagnosis is sought for, but also when offering psychological support, where it can be hard to tease apart whether their needs are associated with autistic traits, other life experiences or both.

While the suggestion for more contextualised formulations is unlikely to be new for most specialist services working with autistic people, many autistic women do not reach autism services, especially as adults. Too often, autistic women have encountered difficulties with accessing mainstream services and have their needs recognised, including for mental health support (Tint & Weiss, 2018). A narrow understanding of autistic women continues to impact the support they seek in a range of clinical contexts. This is evidenced by the lived experiences of autistic women in this study, and in other studies where they were missed for a diagnosis of autism, or misdiagnosed with disordered eating, social anxiety or personality disorders (Baldwin & Costley, 2015; Davidson, 2007; Gould & Ashton-Smith, 2011; Haney & Cullen, 2017; Leedham et al., 2020). Specifically for autistic women, conflict or feeling prejudiced against by services involved with pregnancy, childbirth and menopause can exacerbate the predisposing stress of those experiences (Gardner et al., 2016; Moseley et al., 2020; Pohl et al., 2020; Rogers et al., 2017). Therefore, an improved understanding of autism in all clinical services would be beneficial for both the autistic woman, and the clinician trying to build a therapeutic rapport and deliver effective care.

This study would suggest particular caution with attributing relational difficulties to autistic traits too quickly within clinical practice. Reducing relational conflicts down to the autistic woman's social skills and deficits risks perpetuating a misguided perception of them as antisocial or asocial. It also places an unequal amount of responsibility on them to behave in line with convention. Skills that help autistic women adapt are still necessary and helpful, but it is essential that we also recognise the role of socio-cultural values on the relational difficulties they come across. As reported by the participants in this study, relational conflict

can come from an intolerance of their behaviours that deviate from socio-cultural expectations. As women, they can be judged more harshly when deviating from social norms (e.g. opinions and interests) compared to men. In such circumstances, it would be remiss to locate the problem and need to change in them; instead they could be encouraged to make sense of the conflict and reflect on how they could respond in line with their values.

Factors that have supported the wellbeing of participants in this study included communicating with significant others in their life, finding ways to make meaningful connections with others, and embracing their individuality. Clinical formulations and interventions should reflect such findings from this and other studies that attend more to their need for belonging and individual strengths and successes (Milton & Sims, 2016). This may involve thinking about how to support identity formation amongst autistic women, which could in turn help them form genuine like-minded connections.

5.6.1 Further research suggestions

There are many possible avenues for further research from this study that would add to the dearth of research about autistic women, and about the impact of socio-cultural values. Firstly, further research that looks at the impact of socio-cultural values on autistic men may provide useful comparisons for similarities and differences. There are also expectations on men to behave a certain way, and they are socialised differently; the impact of which has been largely unexplored. Secondly, this study has taken a broad stroke to looking at cultural impact on autism; recruitment was not limited to any cultural grouping, and participants were encouraged to talk about the cultures most salient to them. Some cultures reoccurred more often than others such as religion, sexuality and class, which may be worth further exploration. Thirdly, the current sample consisted of all White British autistic females, and a replication of this study with autistic women of different ethnic backgrounds could further enrich the current findings. Fourthly, (as will be discussed below in limitations,) this study did not include autistic women with ID. Depending on the degree of ID, their experiences of independence in society and support may vary greatly from those of the current sample. Adapting future research to include their perspectives in a meaningful

way would be essential for more a thorough understanding. Lastly, a suggestion that results more indirectly from the findings of this study, would be further exploring identity development in autistic women, which was significant to many participants' narratives.

5.7 Strengths and Limitations

To my knowledge, this is the first study that has explicitly examined the reciprocal relationship between autistic women and their socio-cultural contexts. It is important for autism research to try and take account of alternative narratives about autism, and think about their experiences in a meaningful way (MacLeod, 2019). This study tries to do this, by embracing the nuanced and multifaceted identities of autistic women and how these interact and are affected by dominant values in society. As such, I believe that this is a timely and significant (Tracy, 2010) piece of research given the increasing discussions around whether autistic women are inherently different or do they present with a different phenotype, or both (Hull et al., 2020). This research contributes to this on-going investigation by thinking about why autistic women may present the way they do. It also adds to research that considers the possible role of gendered socialisation as part of understanding the sex disparity within autism (Cheslack-Postava & Jordan-Young, 2012).

Webster & Garvis's (2017) research highlighted that the self-identified successful autistic women in their study did not have to be famous or have savant abilities. It was an important idea that provided a balanced narrative about autistic women. Inspired by so, the current study also tried to showcase the strengths and successes of participants alongside the challenges they experience throughout. The participants recognised their successes and strengths in their academic and professional achievements within their fields, from poets to scientists. They also talked about their contributions to peers, organisations, and wider society in the form of fundraising to being a governor for an NHS trust. Some strengths were demonstrated through the participants talking about their strong internal drive and focus, resilience to multiple challenges in life and applying courage to significant changes in their lives. More strikingly, was that all the participants showed curiosity for understanding other people, and persevered to build meaningful relationships.

Considering the closeness I have as the principal researcher to the research topic, this research benefited from IPA's reflexive approach. Keeping and referring to my reflective diary throughout the research offered me greater confidence to use my personal and professional experience to enrich interpretations in the analysis (Howard et al., 2019). All the while, remaining vigilant for them not to overshadow how the participants have made sense of their experiences. This was particularly valuable given that many socio-cultural values were experienced implicitly and making sense of them with the participants required talking through their thought processes and reading between-the-lines at times. IPA is uniquely suited to this task, by combining questioning and empathic hermeneutics to critically examine "Do I have a sense of something going on here that maybe the participants themselves are less aware of?" (Smith & Osborn, 2008). At the same time, the production of knowledge remains an inherently collaborative process that commits to giving voice to the participants' experiences (Larkin et al., 2006). This study also adds to the knowledge-base of using this methodology with autistic participants.

On the other hand, the exclusion of participants with ID in this study was a limitation that speaks to the broader challenges of including the voices of people with ID in qualitative research (Beail & Williams, 2014). The focus on socio-cultural values can be abstract or too broad a concept for some people, particularly when thinking about how implicitly they are often experienced. The method of using semi-structured interviews also requires a degree of verbal ability. Both of which can be barriers for people with ID in research (Beail & Williams, 2014). Future research could try to better capture the perspectives of autistic women with ID by using data collection methods that do not predominately rely on the spoken word, such as Photovoice (Jurkowski, 2008).

Similarly, while the current study has tried to represent the diversity amongst autistic women, most of the participants represented a group of White autistic women who were under 30 years old when diagnosed and at point of interview. It has been highlighted in reviews of research that looks at outcomes for autistic adults, most have included relatively young adults in their 20s to 30s (Howlin & Moss, 2012). Hence, much less is known about

autistic women later in life. Late-diagnosed and older autistic women represent a unique subgroup that can share insight into their experiences, which are likely to inform us more about the sex ratio and phenotype of autism (Bargiela et al., 2016; Kock et al., 2019; Leedham et al., 2020). By having a sample that leans towards the younger age group, the current study may not have captured some of the socio-cultural experiences of older autistic women. For example, issues relating to menopause (Moseley et al., 2020). Hence, socio-cultural experiences of autistic women older in age at point of diagnosis and research would also be worthwhile areas of further investigation.

Relatedly, this study was unable to fulfil its intentions to invite autistic women akin to the sample to consult on the development of the interview schedule. The challenges experienced by this study for finding a group of suitable consultants may reflect how inaccessible the research community are to autistic women with average or above intellectual ability who are not actively engaged with a clinical setting. Member-checking with participants or autistic consultants were also not used, as this conflicts with IPA underpinnings that believe truth is multiple and context-specific (McConnell-Henry et al., 2011). However, some research has attempted to adapt IPA to be more congruous with participatory approaches (Macleod et al., 2018; Maloret & Scott, 2018), and this area requires further consideration.

5.8 Conclusion

This research explored the lived experiences of autistic women, with a focus on the socio-cultural contexts they were each embedded within, and how these may have had an impact on different aspects of their lives. IPA facilitated this study by allowing me to immerse myself into the sense-making process with participants and deepening reflections with interpretations. The approach takes ownership of the fact that no absolute claims could be made about the phenomenon explored but can bring us closer to an understanding. Three key themes emerged in the findings which firstly reflecting the pervasive influence of socio-cultural values experienced by autistic women in this study. Secondly, the participants explored their role in shaping their sense of self, and how this interacted with society. Lastly,

their experiences were underscored by the desire to stay connected with society, and the positive impact of feeling genuinely connected with others. Their experiences speak to the intertwined relationship they have with society. Thus, understanding autistic women within their socio-cultural contexts has implications for broadening our conceptualisations of them in wider society, clinical and research settings.

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Summary of papers selected for literature review

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
Baldwin & Costley (2015)	<p>i) Exploration of gap in current research of adult autistic women's lived experiences</p> <p>ii) Identify note-worthy differences between autistic women and autistic men (both without intellectual disabilities)</p>	<ul style="list-style-type: none"> Adult autistic females With no co-occurring intellectual disabilities (ID) <p>N = 82</p> <p>Mean age: 32.7 years</p> <p>Age range: 18-64 years</p> <p>Mean age at diagnosis: 25 years</p> <p>Age range at diagnosis: 2-63 years</p> <p>58% diagnosed after 18 years old</p> <p>Australian study</p>	<p><u>Mixed Methods</u></p> <p>Data collected via Australian-wide survey using <u>questionnaire</u> with forced-choice responses and open comments covering the topics of:</p> <ol style="list-style-type: none"> 1) Health and wellbeing 2) Education 3) Employment 4) Social and community activities 5) Support needs 6) Future aspirations <p>Data analysed using:</p> <ul style="list-style-type: none"> <u>Thematic Analysis</u> of open comments <u>Descriptive statistics</u> <u>Chi-square statistical comparison</u> Analysis of over- or under-qualification for current job 	<ul style="list-style-type: none"> Participants believed that an earlier diagnosis of Autism would have reduced difficulties in life experiences There were high levels of stress and anxiety experienced by participants across all areas of life Participants struggled with executive functioning demands of education Mix of relationships experiences and goals by participants, who all sought to learn aspects of communication and social behaviour Participants reported that everyday life struggles were underestimated No discernible gender differences where compared with autistic males from original study 	<ul style="list-style-type: none"> Evidence supports the notion that there are a range of subtle and subjective ways in which autism manifests and is experienced by autistic women (compared to men); as opposed to the idea that is a unique 'female profile' of autistic females without ID Evidence highlights the high levels of difficulties experience, and unmet needs in multiple life settings Evidence supports masking hypothesis
Bargiela et al. (2016)	<p>i) How do late-diagnosed autistic women experience the female autism phenotype</p> <p>ii) How does the female autism phenotype influence their experiences of diagnosis, misdiagnosis and</p>	<ul style="list-style-type: none"> Adult autistic females Late-diagnosed (diagnosed at 15+ years) With no ID <p>N = 14</p> <p>Mean age: 26.7 years</p>	<p><u>Qualitative</u></p> <p>Data collected through <u>semi-structured interviews</u> covering the topics of:</p> <ol style="list-style-type: none"> 1) How were participants diagnosed 2) Exploration of their sense of how their gender impacted upon 	<p>Four themes derived from analysis:</p> <ul style="list-style-type: none"> Perceived as being not autistic – this included misdiagnoses, lack of knowledge amongst clinicians and costs of a late diagnosis Pretending to be “normal” – learning social behaviours and masking, 	<ul style="list-style-type: none"> Found that camouflaging was common but not universal in sample Camouflaging was associated with late-diagnosis and internalising difficulties experienced Some challenges experienced were not so much related to autism

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
	<p>missed diagnosis</p> <p>iii) How do late-diagnosed women adapt in response to challenges they face</p>	<p>Mean age of diagnosis: 21.3 years</p> <p>Age range: 19-30</p> <p>UK study</p>	<p>diagnosis</p> <p>3) Interests, social relationships, sensory experiences and mental health</p> <p>4) Perceptions of autism gender differences</p> <p>9 interviews conducted face-to-face; 4 via videoconferencing and 1 via telephone</p> <p>Analysed using <u>Framework Analysis</u></p>	<p>and the associated costs of these behaviours</p> <ul style="list-style-type: none"> • Experiences of being passive and assertive – reflections on past passive behaviours leading to victimisation, and learning to be assertive • Establishing identity as a woman with autism – gendered friendships, societal expectations on gender and person interest. 	<p>as they are to specific expectations for females in culture leading to a tension between autistic and gender identity</p>
Davidson (2007)	<p>i) Inform and enhance understanding of autistic women's experiences of the world</p> <p>ii) Foregrounding the experiences of autistic women who may struggle with obtaining a diagnosis</p> <p>iii) To understanding the variety of ways autistic women experience their encounters with the world</p>	<p>16 published autobiographical 'first-hand' accounts of autistic women's experiences</p> <p>Books written by autistic women from around the world</p>	<p><u>Qualitative</u></p> <p><u>Indirect data collection and analysis</u></p> <p><u>Feminist geographical analysis of autobiographical accounts from autistic women</u></p>	<ul style="list-style-type: none"> • Experiences of alienation and challenges with social interaction • Overwhelming experiences of perceptual differences and sensory distortion • A different capacity to express and experience emotions • Controlling emotions and environment to cope 	<ul style="list-style-type: none"> • Autistic women's experiences characterised by profound sense of alienation • Autistic women experience differences from autistic males and non-autistic women • There are similarities and unique differences in the experiences of autistic women • The behaviours of autistic women may appear unusual, but often make sense when considering how they experience the world
Gardner et al. (2016)	Exploring the childbearing experiences of autistic women	Autistic women who have given birth before	<p><u>Qualitative</u></p> <p>Data collected through a</p>	<ul style="list-style-type: none"> • Participants experienced enhanced sensory sensitivities during their 	<ul style="list-style-type: none"> • A range of sensory needs were experienced by autistic women in study

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
		<p>N = 8</p> <p>Mean age: 39 years Age range: 27-52</p> <p>United States study</p>	<p><u>questionnaire</u></p> <p>Analysed using open and <u>holistic methods of coding</u> leading to themes (analysis was not specified otherwise, but description is akin to thematic analysis)</p>	<p>prenatal and intrapartum period, as well as with breastfeeding</p> <ul style="list-style-type: none"> • Participants felt that they needed to have control of labour and birth experiences • Participants experienced difficulties and anxieties of being a new mother, and often wanted more information and support • Many participants found support from their own mothers in becoming a new parent • Participants felt there was an expectation of how to parent by people around them including professionals and this sometimes led to conflict 	<p>at different stages of childbearing</p> <ul style="list-style-type: none"> • There is a lack of understanding from professionals involved with childbearing regarding the needs of autistic women
Haney & Cullen (2017)	<p>i) How do autistic women describe their experiences of being females on the autism spectrum?</p> <p>ii) How do autistic women use discussion forums in online autism communities?</p>	<ul style="list-style-type: none"> • Autistic women (18+ years) • Formally or self-diagnosed with autism <p>N = 212</p> <p>Age range: 18-50+ years</p> <p>Posts in forum from US, UK and Canada</p>	<p><u>Qualitative</u></p> <p><u>Indirect data collection</u> and analysis, by identifying posts from autistic women on a public online forum</p> <p>Posts were published between 01/01/2014 to 31/12/2014</p> <p>Analysed using a <u>Phenomenological approach</u></p>	<p>Main themes of topics discussed in forum:</p> <ul style="list-style-type: none"> • Impact of diagnosis – challenges to being diagnosed and mixed reactions to receiving diagnosis of autism • Symptoms discussions seeking validation or advice for management of symptoms • Impact of autism on relationships – a range of experiences regarding preferences challenges in platonic and romantic 	<ul style="list-style-type: none"> • Evidence suggested that online community was a space where autistic women could form a cultural identity, and establish attachment and a sense of belonging • Suggested that greater awareness of autistic women is needed amongst professionals who refer, diagnose, offer intervention and support

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
				<p>relationships, as well as frequent reports of being bullied</p> <ul style="list-style-type: none"> Impact of autism on employment – a range of discussions around difficulties with interpersonal difficulties at work, work routines, environment and feeling unsupported 	
Kanfischer et al. (2017)	Exploring the lived experiences of autistic women	<ul style="list-style-type: none"> Autistic women Diagnosed in adulthood (18+ years) Excluded women in an acute phase of mental health condition or under the influence of substances <p>N = 7</p> <ul style="list-style-type: none"> 3 women were securely detained under Mental Health Act and had ID 4 women lived in community and had co-morbid diagnoses of Borderline Personality 	<p><u>Qualitative</u></p> <p>Data collected through <u>semi-structured interviews</u> focused on:</p> <ul style="list-style-type: none"> Stories of adulthood Diagnosis Childhood Hopes for the future <p>Data analysed using a multistage <u>Narrative analysis</u></p>	<p>Two main themes emerged from broad questioning:</p> <ul style="list-style-type: none"> Gender Identity – experiences described relating to feeling different to those around them, their perception of gender impacting on their friendships, identity, and motherhood Social Relationships – experiences of difficulties in social interactions, and feeling anxious and angry. As well as themes of victimisation in various forms at different stages of life 	<ul style="list-style-type: none"> Highlighted the diversity and individual differences amongst autistic women Definitions of “normalcy” affected the participant’s internalised self-representation Evidence suggests that autistic women camouflage their needs Participants with ID felt lack of social skills led to their victimisation Participants without ID felt that it was deviation from gendered social norms that led to victimisation

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
		Disorder, Schizophrenia, Bipolar, Depression and ADHD UK study			
Kock et al. (2019)	Explore the experiences of women who have been diagnosed with ASD in adulthood and impact this has had on their intimate relationships	<ul style="list-style-type: none"> • Autistic women • Aged 20-40 • Range of relationships statuses and sexualities • Excluded for active MH difficulties N = 8 UK study	<u>Qualitative</u> Data collected through face-to-face <u>semi-structured interviews</u> focused on: <ul style="list-style-type: none"> • Experiences of intimate relationships • Difficulties experienced in intimate relationships • Positive aspects of intimate relationships • Impact of autism diagnosis on their perception of relationships Data analysed using <u>IPA</u>	Four main themes emerged: <ul style="list-style-type: none"> • Response to receiving the diagnosis and information about autism – this included a range of emotions, self-reflection leading to more self-acceptance and improved understanding of the self • Factors influence the decision to date – including experiencing a range of response from partners to disclosing their autism • Experience of relationships as an autistic person – thinking about sexuality, difficulties relating to sex • Sex and sexual experiences – exploring positives and challenges, as well as the future in relationships 	<ul style="list-style-type: none"> • Meaning participants assigned to autism diagnosis have an impact on the nature and the sustainability of their relationships • Most autistic women have a desire to date and be in a romantic relationships • Discussion around sex was similar to that of non-autistic women • Suspected that autism increased vulnerability to being in relationships • Spontaneity of relationships can be particularly challenging for participants
Leedham et al. (2020)	Better understand the lived experiences of autistic women who receive a diagnosis in middle to late adulthood	<ul style="list-style-type: none"> • Autistic women • Late diagnosed (at age of 40+ year) Age range: 43-64 Range of age at diagnosis: 40-62	<u>Qualitative</u> Data collected through face-to-face <u>semi-structured interviews</u> focused on: <ul style="list-style-type: none"> • Experience of being diagnosed • Reflection after 	Four main themes emerged: <ul style="list-style-type: none"> • A hidden condition – participants often pretended to be ‘normal’ and tried to fit in with norms • Process of Acceptance – a range of initial reactions to diagnosis from frustration 	<ul style="list-style-type: none"> • Highlighted the diversity and individual differences amongst autistic women • Definitions of “normalcy” affected the participant’s internalised self-representation • Evidence suggests that

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
		N = 8 Co-morbid diagnoses included: <ul style="list-style-type: none"> • ADHD • Dyslexia • Epilepsy • PTSD • ID • Dyspraxia • Depression UK study	diagnosis <ul style="list-style-type: none"> • Impact of diagnosis on identity and relationships Data analysed using <u>IPA</u>	to relief, and reflection on experiences through autism lens <ul style="list-style-type: none"> • The impact of others post diagnosis – a range of reactions including improved relationships to feeling patronised • A new identity on the autism spectrum – including negotiating new relationships and changing views of the self 	autistic women camouflage their needs <ul style="list-style-type: none"> • Participants with ID felt lack of social skills led to their victimisation Participants without ID felt that it was deviation from gendered social norms that led to victimisation
Moseley et al. (2020)	Explore the extant state of knowledge around menopause in autism, how they navigate this transition <ul style="list-style-type: none"> • Whether autistic women think menopause poses particular challenges • What kind of support might be needed • What would be helpful to ask in this topic in the future 	<ul style="list-style-type: none"> • Autistic women • Formally or self-diagnosed with autism • Navigating or have navigated through menopausal transition N = 7 Mean age: 54.8 years Age range: 49-63 years British, Australian and South African participants participated online	<u>Qualitative</u> Data collected through an <u>online focus group</u> that discussed on <ul style="list-style-type: none"> • Knowledge of the menopause • Targets for research • Whether the menopausal experience would be expected to differ for autistic people • Extant support and ideas for optimal support Data analysed using <u>Thematic Analysis</u>	Three main themes emerged: <ul style="list-style-type: none"> • Lack of knowledge and understanding – participants often felt that professional lacked knowledge about autism • Cracking the mask and adaptive functioning – participants often felt that menopause amplified their autistic experiences such as sensory sensitivities and stress reactivity • Finding support – participants report a lack of support and advice 	Menopause can magnify existing difficulties experienced by autistic women, and generate new difficulties unique to autistic women, relating to sensory experiences, communication, emotional regulation in everyday living

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
Pesonen et al. (2015)	Examine sense of belonging and various life transition challenges that may appear in the absence of appropriate social supports	<ul style="list-style-type: none"> • Autistic women • Transitioned to further education or employment since comprehensive education • Living independently • Excluded if they had severe communication concerns <p>N = 2</p> <p>Aged 26 and 29 years old</p> <p>Finland Study</p>	<p><u>Qualitative</u></p> <p>Data collected through face-to-face <u>semi-structured interviews</u> focused on:</p> <ul style="list-style-type: none"> • Experiences of transition and support in childhood • Experiences of support in adolescence • Transitioning to adulthood • Experiences of transition and support in adulthood transition <p>Data analysed using <u>Narrative approach</u></p>	<p>The two participant's experiences were each framed under the following themes:</p> <ul style="list-style-type: none"> • Social support throughout life transitions – description of transition experiences of feeling supported to less supported • Disclosure – highlighted the challenges of finding work and preconceptions about their lack of ability • Sense of belonging – found that participant's sense of belonging either 'faded' or 'simmered' with the type of support they had young adult transitions 	<ul style="list-style-type: none"> • Sense of Belonging can 'Fade' or 'Simmer' • Social assistance and positive life experiences during emerging adulthood (18-25 years) seems to matter the most in forming a strong sense of belonging • Suggests a need to make social supports more visible to autistic people
Pohl et al. (2020)	Preliminary investigation into how autistic women experience the perinatal period and early motherhood, compared to non-autistic mothers	<ul style="list-style-type: none"> • Autistic mothers (formally and self-diagnosed) • Non-autistic mothers who parented an autistic child • Did not have to be biological parents • Autistic mothers were both formally 	<p><u>Quantitative</u></p> <p>Data collected through <u>online survey</u> focused on experiences of:</p> <ul style="list-style-type: none"> • Pregnancy • Childbirth • Postpartum period • Self-perception of parenting strengths and weaknesses • Communication with professionals in 	<p>Autistic mothers as compared with non-autistic mothers reported that they:</p> <ul style="list-style-type: none"> • Experienced significantly more difficulties in pregnancy and their child's early infancy than non-autistic mothers • Experienced significantly more difficulties with parenting than non-autistic mothers • Experienced significantly more difficulties in 	<ul style="list-style-type: none"> • There are several aspects of motherhood that autistic mothers find more challenging than non-autistic mothers • There were also positive aspects of experiences including overwhelming majority of autistic mothers finding parenting a rewarding experience • The combination of a lack of information

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
		<p>and self-diagnosed</p> <p>Autistic women n = 355 Non-autistic women n = 132</p> <p>Autistic mothers mean age: 42.7 years Non-autistic mothers mean age: 44.6 years</p> <p>Responses mainly from UK, US, Australia, France and Canada</p>	<p>relation to one's child</p> <ul style="list-style-type: none"> • Social experiences of motherhood <p>Data analysed using <u>descriptive statistics</u>, and <u>chi-square comparisons</u></p> <p>(This is part of a mixed-methods study, that also captured Qualitative data, not yet published at time of review)</p>	<p>communicating with child professionals</p> <ul style="list-style-type: none"> • Experienced worries about disclosing autism to professionals • Significantly more likely to find motherhood isolating and feel judged 	<p>about autistic women, and stigma involved with being autistic has impacted on these women's experiences</p>
Rogers et al. (2017)	Exploring the issues that autistic women without ID experience during perinatal period	Due to low response rate to recruitment, this Narrative study transformed into a Case Study of one autistic woman's experiences of pregnancy and motherhood	<p><u>Qualitative</u></p> <p>Case study</p> <p>Data collected through <u>emails</u> and post-birth <u>interview</u>:</p> <ul style="list-style-type: none"> • Experiences of transition and support in childhood • Experiences of support in adolescence • Transitioning to adulthood • Experiences of transition and support in adulthood transition <p>Data analysed using</p>	<p>Three main themes emerged:</p> <ul style="list-style-type: none"> • Communication and service difficulties – participant experienced significant difficulties in communicating with services through perinatal period • Sensory stress – participant experienced heightened experiences of sensory sensitivities • Parenting challenges – participant described significant challenges with services that appeared to easily presume her incompetence of parenting at multiple stages 	<ul style="list-style-type: none"> • Not being diagnosed with autism and disclosing autism both presented problems to accessing appropriate and respectful support • Autism impacted on pregnancy and mothering • Autism impacted on how natal professionals behaved towards her

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
			<u>Thematic Analysis</u>		
Tint & Weiss (2018)	i) How do autistic women perceive their service and support experiences i) What, if any, are the unmet service needs of autistic women ii) What, if any are the barriers to care that they identify	<ul style="list-style-type: none"> Autistic women Formally diagnosed Without ID Mean age: 35.46 Age range: 19-68 years Mean age of diagnosis: 26.25 years Age range of diagnosis: 2-65 years N = 20 (across 5 focus groups of 2-6 people in each) Canadian study	<u>Qualitative</u> Data collected face-to-face <u>focus groups</u> discussing: <ul style="list-style-type: none"> Service use Unmet service needs Barriers to care Data analysed using <u>Thematic Analysis</u>	Three main themes emerged: <ul style="list-style-type: none"> Masking service needs – participants found that masking their needs created obstacles to accessing support and also impacted on their self-perception Mis(communication) with service providers – professionals appeared to lack knowledge of autism and were concerned with different things to participants Accessing appropriate service “a constant struggle” – participants found that the system was problematic and misunderstands their needs 	<ul style="list-style-type: none"> There was a high level of unmet needs by services for autistic women in respects to mental health, residential support, vocational and employment Autistic women found that their needs were frequently eclipsed by their above average cognitive abilities, educational achievements and seeming social and communication abilities
Webster & Garvis (2017)	To explore the experiences of women with autism, since their diagnosis and the (internal and external) factors that enabled them to achieve success in different aspects of their life	<ul style="list-style-type: none"> Autistic women Diagnosed after 18 years old Age range: 28-55 years N = 10 Australian study	<u>Qualitative</u> Data collected through face-to-face <u>semi-structured interviews</u> focused on: <ul style="list-style-type: none"> Life experiences pre and post diagnosis Relationships Education Employment Success defined by	Four main themes emerged: <ul style="list-style-type: none"> Agents of change – participants did not see themselves as victims and felt in control of life decisions Experiencing the belief of others in their capability – this often had a significant impact on their self-efficacy Changed identity after diagnosis – many participants felt that their 	<ul style="list-style-type: none"> Experiences of overcoming obstacles enabled autistic women to develop self-efficacy and shape their own success Findings mapped onto Bandura’s model of self-efficacy where mastery, social persuasion and modelling of vicarious experiences, emotional and physiological factors

Author and Date	Research Aims	Participants details	Methodology	Summary of Key findings	Conclusions drawn from research
			women themselves in interview Data analysed using <u>Narrative approach</u>	diagnosis helped them construct a new identity • Seeing self as mentor to others – all women saw themselves as positive influence to other autistic women	all played a role • Diagnosis can be helpful for autistic women to construct a more positive sense of self

Evaluation of Qualitative Research Papers for Review using the Critical Appraisal Skills Programme (CASP)

Paper	Was there a clear Statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Baldwin & Costley (2015)	Yes	Yes, for qualitative part of mixed-methods	Yes	Yes	Yes	No Used an advisory group of autism specialists, autistic adults and parents of autistic adults on questionnaire	Non specified (Subset to a larger study)	Yes	Yes	Valuable
Bargiela et al. (2016)	Yes	Yes	Yes	Yes	Yes	No Multiple researchers involved with analysis and participants feedback on analysis	Yes	Yes	Yes	Valuable
Davidson (2007)	Apparent, but not clear stated	Yes	Yes	Rationale for choice of autobiographical accounts selected was not provided	Yes	No Statement locating the researcher's position but	Not specified or discussed, specifically around the use of indirect data	No Analysis process was not provided and therefore	Yes	Valuable

						did not discuss the potential relationship this had on the research		unclear how the results emerged from analysis		
Gardner et al. (2016)	Yes	Yes	Yes	Yes	Yes	Indicated Audit trail of coding decisions and triangulation of data	Yes	Yes	Yes	Valuable
Haney & Cullen (2017)	Yes	Yes	Yes	Yes	Yes	No Triangulation of data and use of journals to record coding process	Yes	Yes	Yes	Valuable
Kanfiszer et al. (2017)	Yes	Yes	Yes	Yes	Yes	Indicated Keeping of reflective memos promote authenticity of interpretations and completion of respondent validation by each participant	Yes	Yes	Yes	Valuable
Kock et al. (2019)	Yes, but rationale was less developed	Yes	Yes	Partially, but the decision to recruit women aged	Yes	Indicated Audit trail of coding	Yes	Yes	Yes	Valuable

				20-40 years old was unclear (stated for homogeneity, but why this age group)		decisions, and use of two coders				
Leedham et al. (2020)	Yes	Yes	Yes	Yes	Yes	Indicated Reflective notes in data collection and analysis	Yes	Yes	Yes	Valuable
Moseley et al. (2020)	Yes	Yes	Yes	Yes	Yes	Indicated Use of multiple coders and practice of reflexivity	Yes	Yes	Yes	Valuable
Pesonen et al. (2015)	Yes	Yes	Yes	Yes	Yes	No Multiple coders and member checking	Yes	Yes	Yes	Valuable
Rogers et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Tint & Weiss (2018)	Yes	Yes	Yes	Yes	Yes	No Multiple coders	Yes	Yes	Yes	Valuable
Webster & Garvis (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable

Evaluation of Qualitative Research Papers for Review using the Critical Appraisal Skills Programme (CASP)

	Did the study address a clearly focused issue?	Did the authors use an appropriate method to answer their question?	Were the cases recruited in an acceptable way?	Were the controls selected in an acceptable way?	Was the exposure accurately measured to minimise bias?	Have the authors taken account of the potential confounding factors in the design and analysis?	How valid were results?	Can the results be applied to the local population?	Do the results of this study fit with other available evidence?
Pohl et al. (2020)	Yes	Yes	Yes	Yes Not all matched Reason for selecting autistic mothers with at least one autistic child was indicated but the connection was not clearly stated in methodology	Yes	A range of confounders were not addressed	Reasonably valid	Limitedly	Yes



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Stella Mo
CC Shivani Sharma
FROM Dr Simon Trainis, Health, Science Engineering & Technology
DATE 18/11/2019

Protocol number: aLMS/PGT/UH/03787(1)

Title of Study: Exploring the Impact of Social Values and Culture on Autistic Women

Previous Title of study: Exploring the Successes and Challenges of women on the Autism Spectrum

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Amanda Ludlow
Nina Viljoen

Modifications:

Change of title
Change of supervisor
Additional locations

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 18/11/2019

To: 30/09/2020

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.

Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

**INFORMED CONSENT FORM FOR PARTICIPANTS
OF PROJECT:**

Exploring the Impact of Social Values and Culture on Autistic Women

Please read the Information Sheet before completing this Consent Form

Please retain a copy of the Information Sheet and this Consent Form to keep and refer to at any time.

Title of Study:

Exploring the Impact of Social Values and Culture on Autistic Women

Department:

School of Life and Medical Sciences, Doctorate in Clinical Psychology, University of Hertfordshire

Name and Contact Details of Principal Researcher:

Stella Mo, Trainee Clinical Psychologist, University of Hertfordshire

s.mo@herts.ac.uk

Details of Researchers involved:

Dr Shivani Sharma, Head of Psychology Division, University of Hertfordshire
Nina Viljoen, Clinical Psychologist, Hertfordshire Partnership NHS Foundation Trust
Dr Amanda Ludlow, Senior Lecturer, University of Hertfordshire

Approval for research:

This study has been approved by UH Research Ethics Committee

Ethics Approval Number: aLMS/PGT/UH/03787(1)

		Tick Box
1.	I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.	
2.	I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.	
3.	I have been assured that participating in or withdrawing from this study at any time will not benefit or disadvantage me financially, professionally or academically	
4.	In giving my consent to participate in this study, I understand that voice or video may take place and I have been informed of how/whether this recording will be transmitted.	
5.	I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself. In signing this consent form I accept that support might be sought for me, should circumstances require this.	
6.	I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.	
7.	I understand that my participation in this study may reveal findings that could indicate that I might require medical or mental health advice. In that event, I will be informed and advised to consult relevant third parties such as my GP or Student Wellbeing.	
8.	I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.	
9.	I have been told that I may at some time in the future be contacted again in connection with this or another study.	

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

.....
of *[please give contact details here, e.g. a mobile number or email address]*

.....
hereby freely agree to take part in the study entitled *[insert name of study here]*

... **Exploring the Impact of Social Values and Culture on Autistic Women**

UH Protocol number: aLMS/PGT/UH/03787(1)

Signature of participant.....Date.....

Signature of (principal) investigatorDate.....

Name of (principal) investigator *[in BLOCK CAPITALS please]*

.....

PARTICIPANT INFORMATION SHEET

1 Title of study

Exploring the Impact of Social Values and Culture on Autistic Women

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulations governing the conduct of studies involving human participants can be accessed via this link:

<http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

3 What is the purpose of this study?

You have been invited to take part in a research project that is trying to better understand the impact of culture* on women on the autism spectrum. The study aims to understand the successes and challenges faced by women on the autism spectrum in the social contexts they are situated within.

*'Culture' defined as the values, beliefs, attitudes and behaviour of a particular social group or society

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not disadvantage you in any way.

5 Are there any age or other restrictions that may prevent me from participating?

We are looking for adult women with a diagnosis of Autism Spectrum Condition/ Asperger's who do not also have a learning disability. It is preferable that you have had your diagnosis for at least two years, although this is not essential.

6 How long will my part in the study take?

If you decide to take part in this study, interviews will take approximately 30-60 minutes. It could be shorter or longer depending on how much you want to talk.

7 What will happen to me if I take part?

- You will be asked to sign a consent form to participate.
- You will be asked to complete a basic demographics form about yourself.
- The researcher will arrange a suitable time and place for an interview with you. This could be at the University of Hertfordshire, via telephone, or skype (with or without video).
- An outline of the questions could be forwarded to you before the interview if it would help you
- The researcher will ask you if there is anything that will make it easier for you to participate in the interview and accommodate where possible. For example, if regular breaks would help.
- If participating in the interview at the University, there will be time before and after the interview to settle in and relax; another room will be booked (adjacent where possible) for breaks.
- The interview will ask questions about different times in your life and ask for your reflections on being an autistic woman.
- It is possible to conduct the interview over more than one session, if the interview time is too long for you.
- There will be an opportunity to ask questions during and after the interview.

8 What are the possible disadvantages, risks or side effects of taking part?

You will be asked to take part in a relatively long interview and asked to share life experiences personal to you. You may also be asked to reflect on difficult life experiences you have shared in the interview. This can be distressing for some people. The researcher will be happy to speak to you about where to seek support for any distress experienced. It is very helpful for the research to hear about some of these difficult life experiences, however you have the choice to decline talking about anything that you find too difficult to share or reflect on.

9 What are the possible benefits of taking part?

There are no explicit benefits to participating in this project. However, we hope to contribute to the current understanding of autistic women. We anticipate publishing the findings of the completed study, and hope that this will have a positive impact on our understanding of, and service provisions to autistic women.

10 How will my taking part in this study be kept confidential?

All data, including the consent form, demographics form and interview data will be stored securely, in locked storage and password-protected electronic devices. All person-identifiable details will be changed in agreement with you to ensure your anonymity. The data will be stored for up to five years, to provide enough time for any subsequent reports and publication of the study. After which, the data will be disposed of securely. We would like to audio-record interviews with your permission so that they can be typed up and analysed. We will be looking for themes across all interviews. If you do not want your interview to be audio-recorded, the researcher will take notes instead. Audio-recordings will be password protected, and deleted after transcription. Only the researcher will access them and the supervisor will see anonymised transcripts.

Audio-visual material**11 What will happen to the data collected within this study?**

Audio recordings (if you have consented to this) will be deleted after transcription. The anonymised transcripts will be stored electronically, in a password-protected environment, for 5 years, after which time it will be destroyed under secure conditions. We will be analysing themes across the interviews completed and present this analysis in a doctoral thesis. The findings might also be published in an academic journal. This may include some direct, anonymised quotes from participants.

13 Will the data be required for use in further studies?

The data will not be used in any further studies.

14 Who has reviewed this study?

This study has been reviewed by:

The University of Hertfordshire Health, Science, Engineering & Technology Ethics Committee with Delegated Authority.

The UH protocol number is: aLMS/PGT/UH/03787(1)

15 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities.

16 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by email: s.mo@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Please keep a copy of this information sheet.

Interview Schedule

Exploring Culture

Providing definition of 'Culture' visually (Printed or screen depending on preference):

The values, beliefs, attitudes, and behaviour of a particular social group or society

1. What kind of values, beliefs and attitudes did you grow up around?

Prompts:

- a. *What expectations did the culture you grow up in have for girls and women?*
 - b. *What expectations did the culture you grow up have for autistic people?*
-

Experience of Culture

2. Could you tell me what it was like for you as an autistic woman [or alternative preferred term as stated in demographic form]?

Prompts:

- a. At home
 - b. At school
 - c. At work
 - d. At university
 - e. With friendships
 - f. With intimate relationships
 - g. On journey to obtaining autism diagnosis
 - h. To have the interests you had/have
 - i. To have the sensory sensitivities that you have
-

Impact of Culture

3. How do you think some of the beliefs and values around you have made it more difficult for you to be an autistic woman [or alternative preferred term as stated in demographic form]?

Prompts:

- a. *How do you think being an autistic woman and being part of a particular culture has been a disadvantage in your life?*
4. How do you think some of the beliefs and values around you have made it easier for you to be an autistic woman?

Prompts:

- a. *How do you think being an autistic woman and being part of a particular culture has been an advantage in your life?*
- b. *How has being an autistic woman contributed to your successes in life so far?*

Closing interview:

Is there anything that feels important or relevant to this study that you would like to add?

How have you found the interview today?

Example of analytic process (transcript, exploratory coding to emergent themes) – Anonymised participant

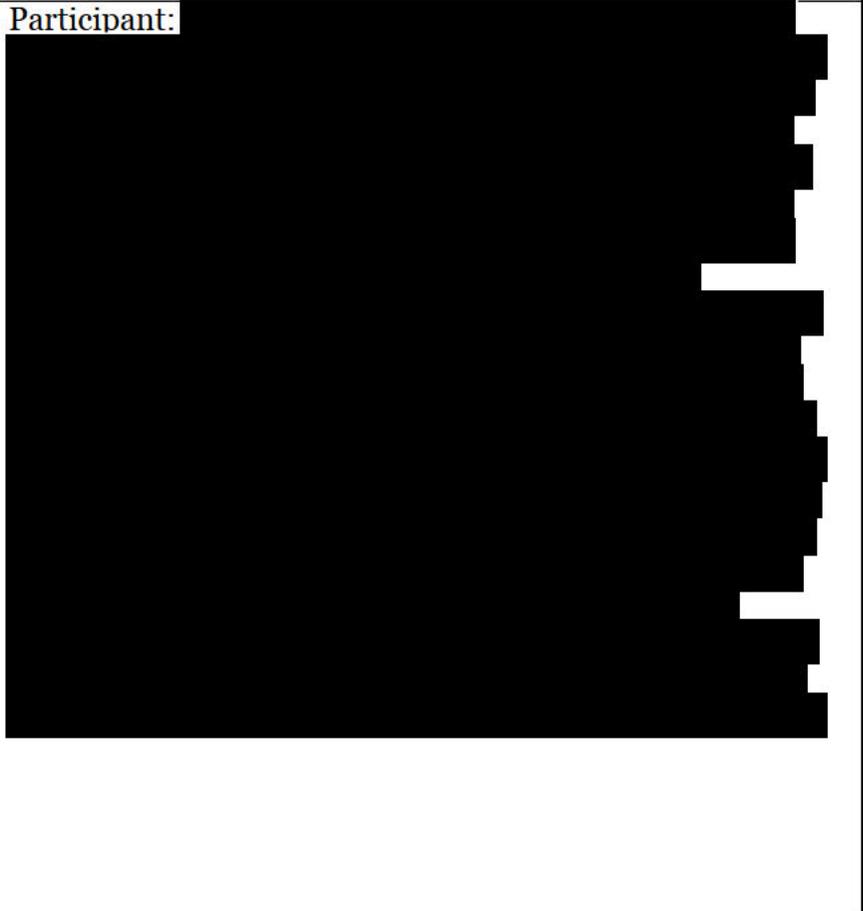
Exploratory coding key:

Descriptive: describing the content, subject of conversation

Linguistic: exploring the use of language

Conceptual: engaging data at more tentatively interrogative level

Exploratory Coding	Transcript	Emergent Themes
	<p><i>Interviewer: I would like to start by exploring how you have understood the culture that you grew up in. Here is a definition of culture that we are using for the study [show printed definition to participant and give time to read and think] the values, beliefs, attitudes, and behaviour of a particular social group or society.</i></p> <p><i>Could you tell me about what kind values, beliefs and attitudes you grew up around?</i></p>	
<p><u>First response to question about culture is thinking about family – family is an important part of thinking about culture for her? “we’ve always” – it’s a longstanding value, and it’s shared by [participant] with her family</u> Values of working hard <u>Being autistic is more than having a diagnosis – she’s the only one diagnosed</u></p> <p>Academic achievement associated with job success <u>What constitutes as job “success” for her and for family?</u></p> <p><u>Values turned expectations applied with pressure</u></p> <p><u>(Typical level of) sibling rivalry? To compare self with brother?</u></p> <p><u>What value is placed on “caring profession” and “special needs children”? Why is it juxtaposed with going to “university”?</u></p>	<p>Participant: </p>	<p>Strong influence of family beliefs</p> <p>Academia as a symbol of achievement</p>
<p><u>She had a quality of friendships, not quantity. Very quickly started and finished talking about friends, and returning to talk about her strengths</u> <u>Comparing self with others, self defined by comparison?</u> <u>An image of academic but more isolated child?</u></p>	<p></p>	<p>Intellectual identity</p>

<p><u>Was the “obvious” referring to the latter that she was not picked up for autism because she was in mainstream schooling? Be careful of potentially being presumptive here – re-listen to audio to see if tone elucidates more</u></p> <p>She was diagnosed when she was in her early- to mid-adulthood</p> <p><u>What is meant by “typical childhood upbringing” does she mean that she was treated in the same way, with the same expectations, and this is in some way related to not knowing she was autistic?</u></p>		<p>Unearthing of autistic self</p>
	<p><i>Interviewer: So, there’s some values around achievements, and work ethic. What kind of expectations did the culture you grew up around have for girls and women?</i></p>	
<p><u>The first person she mentions is her mother – was her mother significant in her gender identity formation? Socially learned about womanhood from mother?</u></p> <p>Socio-cultural value from her mother that Women can do anything/ Can achieve anything – her mother shared this value with her sister and her. <u>Empowering attitude for females</u></p> <p><i>“brought through” it’s carried through inter-generationally</i></p> <p>Family unit is her immediate culture. <u>Is there something about it’s immediacy that makes it more impactful/significant?</u></p> <p><i>Repeated use of the word “very much” when talking about her mother – does this reflect her presence for her too?</i></p> <p>Contrast of her mother’s “control” with her father’s “easy-going” character. <u>A picture is developing of how she experiences her mother and father very differently</u></p> <p><u>Her mother is more academic, like she is too – does she identify with her mother in some ways?</u></p> <p><u>Is there a pattern of portraying academic in comparison to someone else? If so, why?</u></p> <p><i>The language used for “her mother” feels more formal than when she refers to her father “my dad” (is that my assumption?). There s a closeness to dad (and mum) vs. the reverence of (father and mother)</i></p> <p><u>Is that the cost of support, there are demands made of you in return?</u></p> <p><i>She finds that her mother can be a bit demanding of her</i></p> <p><i>She’s sandwiched saying her mother as a loving parent between, what may be seen as critiques (demanding and placing a lot of expectations – why does the criticism need to be qualified with something positive?</i></p> <p><u>The relationship is both/and for her, she is loving and demanding</u></p> <p><u>Who has said “just because you’re a girl...can’t do this”? wider societal attitude?</u></p> <p><u>Her mother has expected her to be able to do/achieve things</u></p> <p><u>Pressure to get married and settle down (what does that mean for her culture?)</u></p> <p><i>Stereotypical – does she say this in contrast to the unsterotypical view of seeing women as being able to do anything?</i></p> <p><i>Marriage is tied to having grandchildren</i></p> <p><u>She is expected to bring the next generation into the world, for the generation above?</u></p> <p><u>This belief and expectation is held in the wider system. Does this add more pressure to the expectation?</u></p> <p><i>School culture of achieve if you wanted to does that imply if you worked hard enough for it? assuming ability and opportunity is similar.</i></p> <p><i>“In regards” – did she feel pigeonholed in other ways at school?</i></p>	<p>Participant:</p> 	<p>Mother’s legacy of female empowerment</p> <p>Wider cultural underestimation of female ability</p> <p>Cultural significance of forming families</p> <p><i>(Relationship between immediate family culture with wider society: beliefs are positioned as either congruent or clashing)</i></p>

Example of one participant's master themes developed from clustering emergent themes

List of emergent themes for a participant:

1. Heritage of empowered women
2. Unconditional family support
3. Family values as guiding framework to approach life
4. Heritage of culturally defiant women
5. Inheriting autonomous thinking
6. Heritage of women who proudly defied gender norms
7. Family fostered independence through secure attachment
8. Family values were a barometer for understanding herself
9. Valuing stability
10. Valuing relationships
11. Value of respecting difference
12. Inheriting mother's values
13. Family fostered independence
14. Differentiating from cultural perspectives around her
15. Prescribed path for her intelligence
16. Making decisions for herself
17. Doing what she wants
18. Breaking the restrictions of expectations
19. Having a family barometer she could trust
20. Societal expectations to perform her given identity as an intellectual
21. Restrictions of an intellectual identity
22. Differentiating from how others perceived her
23. Expectations to perform "being a successful woman"
24. Prescribed way of performing intelligence in culture
25. Making decisions that were *wrong* in other's eyes, but *right* for her
26. Pressure to conform to expectations
27. Societal expectations leading to self-doubt
28. Weighing decisions against her wellbeing
29. Overwhelming pain of a loved one dying
30. Illusion of compensating relational poverty with intellectual wealth
31. The solution became a problem
32. Accumulative effects of life stressors
33. Pedestal of being clever
34. Supported by her sister's strengths
35. Tolerating difference in family
36. Appreciating different achievements
37. Being different became harder with age
38. Stereotypes about autism
39. Stereotypes prevent people from recognising diversity in autism
40. Adapting to environment
41. Challenges with a binary perception of autism
42. Dismissed as being dramatic
43. Persuasive influence of stereotypes
44. Dismissed as over-exaggerating
45. It's hard to be candid and nice sometimes
46. I can – and - it's costly (*for my wellbeing*)
47. "I'll be fine in that I'll survival but that's about as fine as I'll be!"
48. Her turmoil was invisible to most people
49. Her emotional experiences were real
50. Coping looks different in different situations

51. Showing different sides of herself
52. Internalising weirdness for unshared assumptions
53. Having agency in choice to adapt
54. Costs of not adapting to norms
55. 'Autism' label made her an easy target
56. Ignoring her needs
57. Her needs used against her
58. Trustworthy guides for navigating social interactions
59. 'Autism' was an easy label to blame
60. Not trusting her own ability to recognise people's intentions
61. Finding friendships resource demanding
62. Learning to appreciate the benefits of being with others
63. Learning the necessity of being with others
64. Independence fostered her appreciation for being with others
65. Continuum of sociability
66. Maturity impacting on ability to respect difference
67. Differentiating self-care from irreverence
68. Autism diagnosis helped bridge understanding of her
69. She's still who she is
70. Gendered expectations of politeness
71. Additional effort required as an autistic woman
72. Expectation to change and adapt
73. Women expected to be quiet
74. Being able to prove herself face-to-face
75. Implicit pressure to conform
76. Tension between her values and expectations placed on women
77. People do not expect difference
78. Misconstrued by implicit assumptions
79. Inter- and intrapersonal reasons for under-diagnosis
80. Challenge of conveying she is capable *and* she needs support
81. Overcoming binary perception of ability
82. People misconstruing what they cannot imagine
83. Demonstrating how to be empathic
84. Bind of invisible consequences
85. Wanting reciprocal effort to understand
86. It's easier, but still not easy to be a woman
87. "It's not that I don't care what people think. But I'm not going to let it stop me doing things I want to do"
88. Determination to achieve what she wants
89. Assured of what she wants
90. Having qualities to survive in male-dominated profession
91. Multiplying autistic determination with empowering values to achieve self-fulfilment
92. Handicap of fearing social judgement
93. Becoming stronger by taking positive risks
94. Double-edged sword of defying gendered norms

Key:

Master themes

Temporary subordinate theme (for the clustered emergent themes)

Emergent themes from above

Grounded with family values

Heritage of empowered women

Heritage of empowered women
 Heritage of culturally defiant women
 Inheriting autonomous thinking
 Heritage of women who proudly defied gender norms
 Inheriting mother's values

Foundation of family values

Unconditional family support
 Family values as guiding framework to approach life
 Family fostered independence through secure attachment
 Family fostered independence
 Family values were a barometer for understanding herself
 Tolerating difference in family
 Appreciating different achievements

Secure attachments

Trustworthy guides for navigating social interactions
 Supported by her sister's strengths
 Having a family barometer she could trust

Valuing connectedness over time

Learning to appreciate the benefits of being with others
 Learning the necessity of being with others
 Independence fostered her appreciation for being with others
 Continuum of sociability
 Maturity impacting on ability to respect difference
 Demonstrating how to be empathic
 Wanting reciprocal effort to understand
 Valuing relationships
 Value of respecting difference
 Valuing stability
 Autism diagnosis helped bridge understanding of her

Loyalty to being herself

Balancing individualization with belonging

Differentiating from cultural perspectives around her

Differentiating from how others perceived her

Differentiating self-care from irreverence

“It’s not that I don’t care what people think. But I’m not going to let it stop me doing things I want to do”

Handicap of fearing social judgement

Inter- and intrapersonal reasons for under-diagnosis

Illusion of compensating relational poverty with intellectual wealth

The solution became a problem

Guided by her own values

Multiplying autistic determination with empowering values to achieve self-fulfilment

Making decisions for herself

Doing what she wants

Weighing decisions against her wellbeing

Determination to achieve what she wants

Assured of what she wants

Having qualities to survive in male-dominated profession

Becoming stronger by taking positive risks

Capable *and* needing support

I can – and - it’s costly (*for my wellbeing*)

“I’ll be fine in that I’ll survive but that’s about as fine as I’ll be!”

Finding friendships resource demanding

Challenge of conveying she is capable *and* she needs support

Overcoming binary perception of ability

Bind of invisible consequences

Overwhelming pain of a loved one dying

Accumulative effects of life stressors

She’s still who she is

Agency to adapt

Having agency in choice to adapt

Adapting to environment

Coping looks different in different situations

Showing different sides of herself

It’s hard to be candid and nice sometimes

Short-term costs; Long-term benefits

Breaking the restrictions of expectations

Making decisions that were *wrong* in other’s eyes, but *right* for her

Costs of not adapting to norms

Double-edged sword of defying gendered norms

Additional effort required as an autistic woman

The weight of socio-cultural norms and expectations

Expectations to conform to gender norms

Tension between her values and expectations placed on women
Gendered expectations of politeness
Women expected to be quiet
Expectations to perform “being a successful woman”
Being able to prove herself face-to-face
It’s easier, but still not easy to be a woman

Expectations to perform intellectual norms

Prescribed path for her intelligence
Societal expectations to perform her given identity as an intellectual
Prescribed way of performing intelligence in culture
Restrictions of an intellectual identity
Pedestal of being clever

Impact of not being stereotypically autistic

Stereotypes about autism
Stereotypes prevent people from recognising diversity in autism
Challenges with a binary perception of autism
Persuasive influence of stereotypes
‘Autism’ label made her an easy target
‘Autism’ was an easy label to blame
Her needs used against her

Impact of expectations to change

People do not expect difference
Being different became harder with age
Expectation to change and adapt
Pressure to conform to expectations
Implicit pressure to conform
Societal expectations leading to self-doubt
Not trusting her own ability to recognise people’s intentions
Internalising weirdness for unshared assumptions

Easily misconstrued

Her emotional experiences were real
Her turmoil was invisible to most people
People misconstruing what they cannot imagine
Misconstrued by implicit assumptions
Dismissed as being dramatic
Dismissed as over-exaggerating
Ignoring her needs

List of all master themes across all participants categorised under final Superordinate Themes

Pervasive influence of socio-cultural values

Power in the unsaid
Power within the Implicit
Feeling powerless
The weight of socio-cultural norms and expectations
Trapped under dominant cultural narratives
Absorbing socio-cultural expectations
Strong sense of responsibility
Expectation to conform to invisible social norms
Expectations to be someone else
Surrealism of her reality

Individualization as an autistic woman

Loyalty to being herself
Taking back control
Fight to be herself
Differentiation and Individualization
Journey to Individualization
Deciding who she is
Defining herself

Staying connected with society

Longing to Connect and Belong
Connecting with others
Sustained by connections
Grounded with family values
Staying connected
Staying Connected
Staying connected
Surviving

Extracts of Reflective Log

This is a selection of reflections that add to the reporting of this research project, and elaborate on some of the dilemmas and processes I thought about throughout.

Culture

[Redacted text block for Culture section]

Diagnosis

[Redacted text block for Diagnosis section]

Gendered differences

[Redacted text block for Gendered differences section]

[Redacted text block]

Methodological and ethical ideas

[Redacted text block]

Interpretation of results

[Redacted text block]

Clinical Relevance & Dissemination

[Redacted text block]

[REDACTED]