Exploring the Lived Experiences of Autism Spectrum Conditions

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Declaration

This thesis has not been submitted to any other institution, or for the purpose of obtaining any other qualifications

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Overall Abstract

When individuals are diagnosed with Autism Spectrum Conditions (ASC), the whole family is affected. Recently, qualitative research has investigated the experiences of siblings of autistic people. A literature review was undertaken to identify and evaluate the research investigating siblings' experiences. Six databases were searched, resulting in seventeen studies meeting criteria for the review. Data was analysed using Thematic Synthesis. Results described the roles and responsibilities participants undertook which were different to those normally expected by siblings. Themes also explored the impact of their siblings' behaviours, experiences of acceptance and empathy and interpersonal relationships. Participants expressed love for their siblings. But, several factors, including their siblings' diagnosis of ASC affected participants' mental health. Results found participants wellbeing was improved if they had control over how they supported their siblings, understood more about ASC, had alone time with parents and had the opportunities to meet with other siblings of autistic people.

A research project was conducted. ASC diagnoses often occur later for females than for males. So, many females' needs are not understood until later life. Research investigating the lived experiences of autistic females is limited. The study aimed to investigate the experiences of females diagnosed with ASC at forty years old or over. Data was gathered and analysed using Interpretative Phenomenological Analysis. Eleven females were interviewed. Results revealed that ASC was misunderstood by professionals and many participants used strategies to try to 'fit in' with peers. The consequences of this included poor mental health. Participants described experiences of grief and adaptation to diagnosis. This was affected both positively and negatively by other people and many participants experienced positive changes to their identities and psychological wellbeing after diagnosis. Services require training to understand ASC in females to prevent it being under recognised.

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Literature Review

A Thematic Synthesis of Siblings' Lived Experiences of Autism

Abstract

Objectives

Despite increased understandings that the whole family system is influenced by diagnoses of Autism Spectrum Conditions, the experiences of siblings can be overlooked. However, recently understanding of siblings' experiences has begun to develop via qualitative studies. This review aimed to systematically identify, appraise and review this literature, to facilitate understanding of siblings' lived experiences.

Design and Methods

Six databases were systematically searched for studies reporting empirical qualitative data on the lived experience of neurotypical siblings of autistic people. Seventeen studies met inclusion criteria and were analysed using Thematic Synthesis.

Results

Synthesis of the data revealed four superordinate themes; *Roles and responsibilities,* different to what may be expected typically*; Impact of behaviours,* particularly aggressive behaviours*; Process of adjustment,* including learning and developing empathy and acceptance; *Interpersonal experiences* with others and between siblings.

Conclusions

Whilst a narrative of love and empathy was present throughout, several participants experienced significant difficulties affecting their mental health. Findings suggest a sense of agency, understanding ASC, time spent alone with parents, supportive environments and the chance to relate to other siblings as protective factors in facilitating positive psychological wellbeing for siblings of autistic people.

Practitioner Points

- Neurotypical siblings can be supported in several ways including, via parental psychoeducation, psychological therapy, connection with other siblings
- Future research may consider a systemic approach to recruitment to provide a broader insight into sibling experiences

Keywords

Autism, ASC, siblings, systematic review, thematic synthesis, qualitative research

Introduction

Autism Spectrum Condition[1] (ASC) is a neurodevelopmental condition present from early childhood. Individuals experience difficulties in several areas defined by the diagnostic criteria as pervasive and “persistent deficits in social communication and social interaction” as well as “restricted, repetitive patterns of behaviour, interests, or activities” (American Psychiatric Association, 2013).

A body of literature provides insight into the experiences of parents of autistic[2] people, particularly children. Parenting an autistic child can be stressful as parents are required to navigate their child’s needs and interactions with multiple services alongside juggling family life and relationships with often limited or no respite (Hastings & Johnson, 2001; Myers, Mackintosh & Goin-Kochel, 2009; Vasilopoulou & Nisbet, 2016). Many also experience financial difficulties due to the limited work opportunities that fit flexibly alongside caring responsibilities (Buescher, Cidav, Knapp & Mandell, 2014). However, several parents also develop a sense of strength and resilience as a result of caring for their much loved child suggesting a range of adjustment experiences dependent on several contextual variables (Myers, Mackintosh & Goin-Kochel, 2009).

Individuals rarely exist in isolation and those living within a family influence, and are reciprocally influenced by, the systems surrounding them (Bowen, 1995). Recent research has included the experiences of siblings of autistic people due to an increasing interest in understanding the family system as a whole in relation to ASC (Cridland, Jones, Magee & Caputi, 2014; Meadan, Stoner & Angell, 2010). However, results relating to the impact of growing up in a family with an autistic sibling are mixed. Many neurotypical[3] siblings can experience positive levels of self-concept and similar psychosocial ‘adjustment’ to their peers (Macks & Reeve, 2007). However, some

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[1] This term is used in line with the preferences of the autistic community, removing the word ‘disorder’ (Kenny, Hattersley, Molins, Buckley, Povey & Pellicano, 2016). Autism Spectrum Disorder is the official diagnostic term

[2] ‘Identity-first’ term based on research findings and preferences of autistic people

[3] Term used to describe individuals who are developing typically neurodevelopmentally

findings suggest an increased pressure placed upon siblings as they adopt a 'parentification' role of additional responsibility (Bowen, 1995; Seligman & Darling, 2007). Nevertheless, several demographic factors may be influential in mediating the risks of experiencing difficulties with emotional wellbeing (Macks & Reeve, 2007; Meaden et al., 2010).

Overall, the literature is typically focused on the specific adjustment experiences of siblings, rather than the broader lived experiences of neurotypical siblings (Dempsey, Llorens, Brewton, Mulchandani & Goin-Kochel, 2012; Griffith, Hastings & Petalas, 2014). To the knowledge of the researcher, just one previous review by Mandleco & Webb (2015) focused on sibling perceptions of living with a 'young person' (defined as below twenty-one years) diagnosed with ASC in a review of twenty-eight articles. The review resulted in themes relating to knowledge of ASC, impacts on relationships and perceptions of their autistic siblings (older siblings provided more descriptions that were positive, as did those whose autistic sibling was more able to communicate and siblings found the presence of aggressive behaviours stressful). Neurotypical siblings experienced emotions including anxiety, but also increased empathy. Positive adjustment experiences were affected by understanding ASC and receiving support. However, the paper combined both quantitative and qualitative data and also reviewed the experiences of siblings of individuals with Down Syndrome. Whilst providing an important insight into the lived experience of neurotypical siblings, authors only focused on experiences of siblings of children living with their autistic siblings. Thus, the review leaves several siblings not represented, including the ongoing experiences of adults and those living away from their autistic siblings. Since the review was published, an initial search revealed additional qualitative papers that focused on the lived experiences of siblings of both autistic children and adults. Therefore, the aim of this review was:

1. To systematically identify the qualitative research that investigates the lived experience of neurotypical siblings of autistic people
2. To critically appraise qualitative research that investigates the lived experience of neurotypical siblings of autistic people
3. To generate a thematic synthesis of the themes evident in the extant literature on experience of neurotypical siblings of autistic people

Method

The protocol for this review was registered on the international prospective register PROSPERO (reference: CRD42018105823).

Search strategy

The databases Web of Science, PsycINFO, PsycARTICLES, Medline (all via OvidSP), Scopus, CINAHL (via EBSCO) were systematically searched in October 2018. A combination of the following search terms were entered into the databases; (Autis* Spectrum OR Autis* OR Asperger* OR Pervasive Developmental Disorder) AND (Sibling* OR Sister* OR Brother*) AND (Lived experience* OR Qualitative) OR (Lived experience* OR *Qualitative method*). Names of specific qualitative methods were included in the searches to ensure rigor of systematic searching (Dixon-Woods, Fitzpatrick & Roberts, 2001; Shaw, 2012). The symbol * was used for truncation. The additional qualitative search terms input across searches were; grounded theory, interpretative phenomenolog*, thematic, template, narrative, content, discourse.

Study selection. Based on initial searches, titles and abstracts of identified studies were screened and unsuitable articles excluded based on a number of criteria. All duplicates were removed. Articles were included if they were qualitative in design (for both data collection and analysis) and included empirical data focusing on experiences of siblings of autistic adults or young people. Articles including data collection from parents or professionals as well as siblings were included if the sibling data comprised a clear section of the analysis or was easily extractable. Only sibling data was synthesised from these articles.

Studies were excluded if they were not written in English. Articles described as qualitative that did not provide sufficient narrative information in the findings or provided largely codes were excluded. On obtaining the full article, studies that did not focus on the experiences of siblings of autistic people were excluded. References from book chapters and thesis articles were excluded. Citation and ancestry searches were undertaken on the remaining papers.

Data extraction. Core data was extracted from articles meeting inclusion criteria. This included, author, year and country of study, available sample demographics, autistic sibling characteristics, recruitment, data collection and methodology and summary of key findings.

Quality appraisal. The quality of each study included in the review was assessed using the Critical Appraisal Skills Programme qualitative research checklist (Appendix A; CASP, 2018). The purpose of this was to facilitate an understanding of the strengths and weaknesses of the articles for synthesis. Articles were not removed based on this process, rather a critique of the articles is included as part of the review. The checklist includes ten questions, with additional prompt questions to allow the researcher to consider the validity of research, rigor of analysis, clarity of results and the influence of findings. For each question, the reviewer is given the option to answer ‘yes’ (item considered adequately), ‘no’ (item not considered adequately) or ‘unsure’ (not possible to ascertain this information). The checklist was adapted for the purposes of the review to include the option of ‘partial description’ (when information was partially stated but not evidenced or elaborated upon). A random selection of articles (20%, n = 4) were appraised by a second reviewer, a researcher independent to this review. Discrepancies were minimal and were resolved via discussions between reviewers.

Data synthesis. Data was reviewed using Thematic Synthesis, following the stages described by Thomas & Harden (2008). Firstly, verbatim text from the 'results' or 'findings' sections of each study were transferred into a table in Microsoft Excel to undertake 'line by line' coding of the text. Codes were created to identify the content and meanings within each line for each study. As this inductive process continued per study, codes were translated and a 'bank' of themes developed. Descriptive themes were developed by comparing codes across the studies, resulting in a grouped hierarchical structure which was further interpreted to yield analytical themes. The process resulted in superordinate and subthemes.

Results

Summary of included papers

The literature search yielded 417 records. Removal of duplicates resulted in 392 records. Following review of citations and application of inclusion and exclusion criteria, seventeen studies were included in this review. This includes nine studies additional to the studies reviewed by Mandleco & Webb (2015), seven of which are newly published. The process of study selection is shown in Figure 1. below.

Studies included a total of 246 participants with a range of between 2-65 neurotypical participants in each study (M = 14.47). In eight of the studies, additional data was included from parent(s), professionals and/or autistic siblings. This data was excluded from the review. Four studies stated that the autistic siblings had a comorbid intellectual disability. Participants ranged in age from 4-67 years and their autistic siblings were between 4-65 years old. All but one study collected data via interviews. One study used data from online blogs. Additional data collection methods included photo and video elicitation, observations and focus groups. Several types of methodology were employed for design and analysis. See Table 1. for a summary of the main characteristics of each study.

Quality appraisal results. Appendix B provides detailed information about the results of quality appraisal. Briefly, all studies were assigned an answer of ‘yes’ more frequently than the other response options suggesting an overall moderate to good standard of study based on the checklist criteria. Two were assigned a ‘partial description’ for ethical considerations. Studies receiving a ‘no’ mostly related to the question about relationship consideration and reflexivity. Several studies provided limited information about the potential impact of bias and only three explicitly described a reflective or reflexive process.

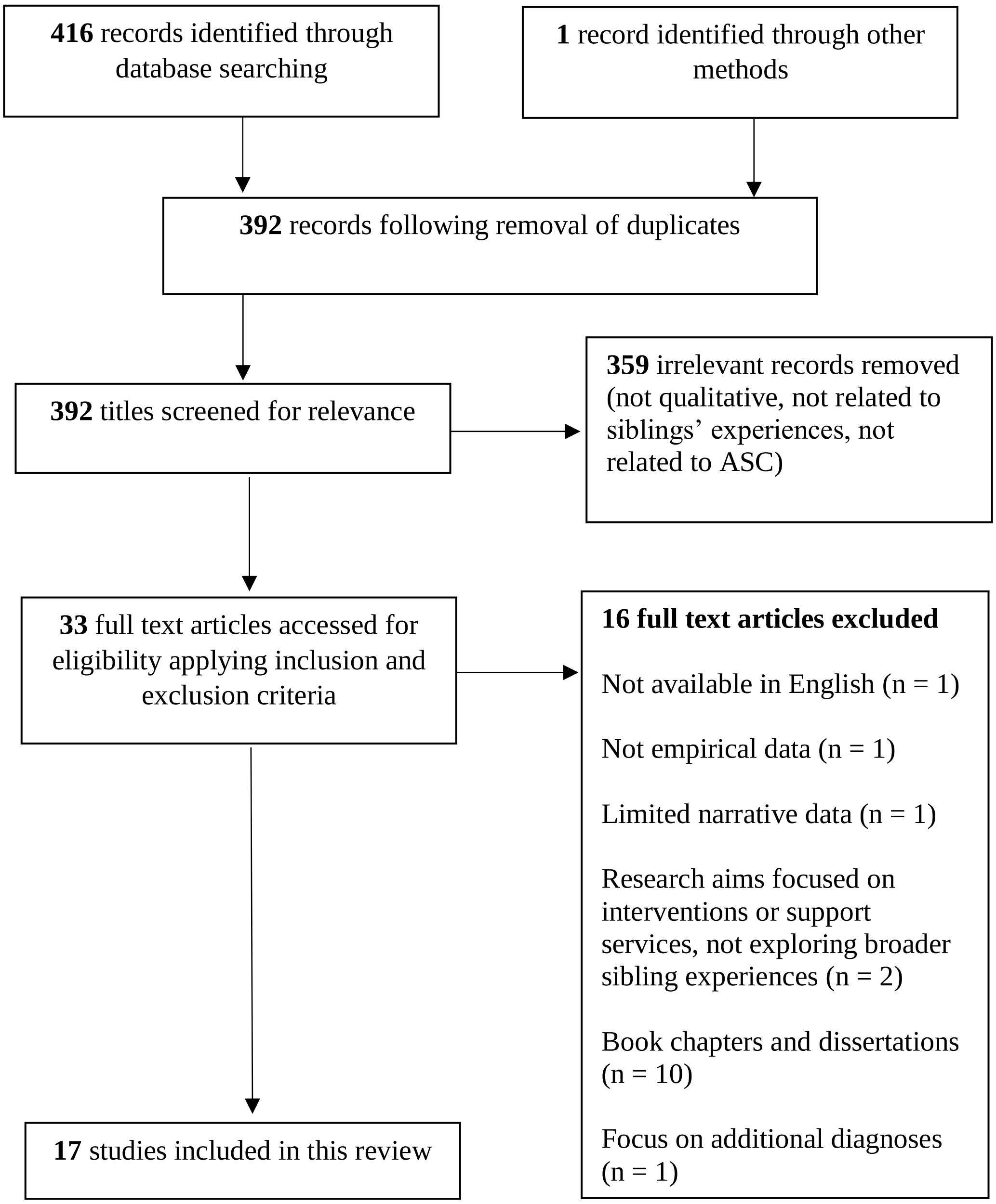

Figure 1. *Search strategy and study inclusion criteria (October 2018)*

Table 1.
Main characteristics of included studies

Authors (year)	Country	Participant characteristics	Autistic sibling characteristics	Recruitment	Data collection and methodology	Key findings, themes
Mascha & Boucher (2006)	UK	N = 14 4 males, 10 females Aged 11-18	Diagnoses: ASD[a] AS[b] Aged 7-20	West Midlands Autistic Society newsletter	Semi-structured interviews Content Analysis	Difficult behaviours, aggression, embarrassment, supporting parents Enjoying times with sibling, having fun Discussing difficulties with parents Benefits of understanding autism Future concerns for sibling, self, responsibilities
Benderix & Sivberg (2007)	Sweden	N = 14 8 males, 6 females Aged 5-29	Diagnoses (all): ASD & moderate-profound ID[c] Aged 10-11	Taken from broader study sample	Interviews Thematic Content Analysis	Precocious sense of responsibility Feeling sadness for their sibling, having empathy Experiencing violence leading to fear and anxiety Impact on friendships
*Bachraz & Grace (2009)	Australia	N = 3 3 females Aged 4-6	Diagnoses: ASD Aged 5-9	Early intervention organisation	Naturalistic observations Photo-elicitation Semi-structured interviews from dimensions of EFI[e] Collective Case Study	Bonds between the TD[f] children in the family Connections with autistic sibling depending on 'severity' Different standards and treatment of their sibling Taking 'big sister'/caring roles Understanding autism
*Hwang & Charnley (2010)	Korea	N = 9 5males, 4 females Aged 7-15	Diagnoses: ASD Aged 6-18	Parent support groups	Video elicitation and interview Visual ethnography	Negative attitudes and language use by others Shame induced by others Influence of culture Reframing autism

Authors (year)	Country	Participant characteristics	Autistic sibling characteristics	Recruitment	Data collection and methodology	Key findings, themes
*Sage & Jegatheesan (2010)	USA	N = 2 2males Aged 7	Diagnoses: ASC Aged 4-5	Taken from broader study sample	Semi-structured interviews Draw-and-tell technique Naturalistic observations Case Study	Differing awareness of autism Mixed emotions Doing what their sibling wants Positive play and mixed relationship experiences Cultural differences
Moyson & Roeyers (2011)	Belgium	N = 17 7 males, 10 females Aged 6-14	Diagnoses: ASD Aged 5-16	Parents association Family support service Rehabilitation centre Special schools	Interviews Focus groups Descriptive	Autism invisibility Nine sibling QoL[g] domains Aggression and behavioural difficulties Understanding each other Shared activities Wellbeing Acceptance of ASD Support
Angell et al. (2012)	USA	N = 12 6 males, 6 females Aged 7-15	Diagnoses: ASD Aged 6-15	Local support groups Children's ASD services	Semi-structured interviews Collective Case Study Grounded Theory	Themes related to family systems theory Varied relationship experiences including shared activities, friendships, challenging behaviours and embarrassment Bonds and cohesion Adapting and coping strategies
Petalas et al. (2012)	UK	N = 12 6 males, 6 females Aged 14-17	Diagnoses: ASD AS ID Aged 4-18	NAS[d] website Local parent group, school, newspaper, charity Subsample from larger study	Semi-structured interviews Interpretative Phenomenological Analysis	Impact on themselves and the family Impact of reactions of others Acceptance of their siblings/wishing things to change Positive experiences Future concerns

Authors (year)	Country	Participant characteristics	Autistic sibling characteristics	Recruitment	Data collection and methodology	Key findings, themes
*Chan & Goh (2014)	Singapore	N = 5 3 males, 2 females Aged 9-13	Diagnoses: ASD Aged 9-13	Autism centre and online support group	Semi-structured interviews Thematic Analysis	Double standards in parenting and differential treatment Empathising with parents and taking on parenting roles Making do and wishing for time with certain parent Enjoying time alone with parents
**Tozer & Atkin (2015)	UK	N = 21 7 males, 14 females Aged 25-67	Diagnoses: ASD Severe ID Aged 24-65	National carer support networks newsletters	Semi-structured interviews Thematic Analysis	Responsibilities and complicated family life Adapting to siblings needs Commitment to sibling and feeling protective Mixed emotions Mixed experiences of services, some positive, some marginalisation
*Corsano et al. (2016)	Italy	N = 14 9 males, 5 females Aged 12-20	Diagnoses: ASD ID Aged 40-52	Day care centres	Semi-structured interviews Qualitative Content Analysis	Mixed attitudes towards their siblings Conflicting emotions Positive self-perceptions, some contrasting with expected perceptions of parents Precocious sense of responsibility Supporting parents and masking own needs Future concerns Impact on friendships
***Cridland et al. (2016)	Australia	N = 3 3 females Aged 16-17	Diagnoses: AS Aged 13-15	Local secondary schools Community groups	Semi-structured interviews Thematic Analysis	School roles and responsibilities to protect and advocate for their sibling More responsibility at home Conflicting motivation to engage with the family system Adjustment to their siblings diagnosis and impact

Authors (year)	Country	Participant characteristics	Autistic sibling characteristics	Recruitment	Data collection and methodology	Key findings, themes
Ward et al. (2016)	USA	N = 22 11 males, 11 females Aged 7-18	Diagnoses: ASD Aged 4-23	Word of mouth Special education classes Taken from a larger study sample	Semi-structured interviews Descriptive	Contradictory and conflicting experiences Positive experiences and learning from sibling Difficult experiences and limited attention Extra responsibilities Difficult and aggressive behaviours Age, gender and birth order differences
Dansby et al. (2017)	USA	N = 65 Details unknown (approximately aged 17-31)	Diagnoses: ASD Details unknown	Online blog posts written by siblings of autistic people	Collated from pre-written blog posts Phenomenological Content Analysis	Family relationships, including difficult experiences with parents Role of parenting Humour Range of emotions Impact on future life personally and professionally Adaptive and maladaptive coping used
Gorjy et al. (2017)	Australia	N = 11 8 males, 3 females Aged 12-17	Diagnoses: ASC HFA[h] AS Aged 6-12	Via parents who had participated in previous research	Semi-structured interviews Thematic Analysis	‘Meltdowns’ and aggression A sense of ‘normality’ Siblings as ‘different’, participants as ‘different’ Responsibility for sibling Impact on relationships and parental attention Adapting and coping strategies Love and pride for siblings
Noonan et al. (2018)	Ireland	N = 8 3 males, 5 females Aged 18-37	Diagnoses: ASD Mild-moderate ID Aged 22-30	Services for adults with ‘disabilities’	Semi-structured interviews Interpretative Phenomenological Analysis	Overarching theme of being in limbo Overcoming barriers to enter their sibling’s world, distance and closeness Balancing their own needs and family needs, feeling unseen Feeling protective, threat from others Feeling distant, future concerns

Authors (year)	Country	Participant characteristics	Autistic sibling characteristics	Recruitment	Data collection and methodology	Key findings, themes
*Tsai et al. (2018)	UK Taiwan	N = 14 (7 from each country) 6 males, 8 females Aged 9-17	Diagnoses: ASC AS Aged 5-18	Via email from a sample taken from a wider study	Semi-structured interviews Interpretative Phenomenological Analysis	Positive and negative impact of siblings Resilience and coping Family experiences and different expectations Support options and friendships

Note. ^{a} = Autism Spectrum Disorder (American Psychiatric Association, 2013); ^{b} = Asperger Syndrome, diagnosis based on previous diagnostic criteria; ^{c} = Intellectual Disability; ^{d} = National Autistic Society; ^{e} = Ecocultural Family Interview; ^{f} = typically developing (neurotypical); ^{g} = quality of life; ^{h} = High Functioning Autism, a term used by some clinical services to describe level of cognitive ability; *parents included in the sample (data removed from review); **siblings and professionals included in the sample (data removed from review); *** parents and siblings included in the sample (data removed from review)

Thematic synthesis

Analysis of the data resulted in the superordinate and subthemes shown in Table 2. below. The themes do not represent an exhaustive list of participants' experiences. Rather, they summarise the prevalent themes described across the data. Some aspects of experience overlap across themes. When using the term 'participant(s)' in the narrative below, this refers to the neurotypical sibling. To support clarity for the reader, '….' is used to edit quotes.

Table 2.
Superordinate and subthemes

Superordinate themes	**Subthemes**
Roles and responsibilities	Caregiving and parenting
	A protective role
	Future concerns
Impact of behaviours	Aggression, idiosyncratic behaviours and unpredictability
	Embarrassment and being 'different'
Process of adjustment	Acceptance, empathy and learning
	Strategies and support
Interpersonal experiences	Negotiating 'outside' relationships
	Fitting in the family and being seen
	Sibling connections

Roles and responsibilities

Caregiving and parenting. In several studies participants adopted different roles to those which may usually be expected of a sibling. For some, this included a prominent role, akin to parenting, including support with self-care, school work, running of the home, emotional and financial support (Bachraz & Grace, 2009; Cridland, Jones, Stoyles, Caputi & Magee, 2016; Dansby, Turns, Whiting & Crane, 2017; Gorjy, Fielding & Falkmer, 2017; Mascha & Boucher, 2006; Ward, Tanner, Mandleco, Dyches & Freeborn, 2016) and "*keeping the show on the road*" (Tozer & Atkin, 2015, p.365).

In some studies, participants of an older age held an internal sense of responsibility for their siblings driven by concern or worries for their sibling (Benderix & Sivberg, 2007; Tozer & Atkin, 2015). However, this was also seen in children even at a young age (Bachraz & Grace, 2009), including adult participants recounting their childhood and describing the impact of such responsibility (Tozer & Atkin, 2015, p.346):

> *"....so I decided I was an adult by the time I was twelve because I was parenting the whole family. I was really scared, I mean many years of sleepless nights."*

Some participants adopted a parentified role in additional settings. In adolescent girls at school, many supported teachers and students to understand ASC and their siblings' needs (Cridland et al., 2016). Many also felt the need to support their parents or relieve parental pressure (Benderix & Sivberg, 2007; Chan & Goh, 2014; Corsano, Musetti, Guidotti & Capelli, 2016; Tozer & Atkin, 2015). For example, one teenager said of their parents:

> *"....when I think my parents need to rest, I go and try to comfort him."*
>
> (Benderix & Sivberg, 2007, p.414)

Many participants adopted these roles somewhat naturally and care was driven by affection towards their sibling, as well as obligation (Angell, Meadan & Stoner, 2012; Tozer & Atkin, 2015). Although present across genders, findings from some samples raise questions about whether a parentified role was more typically adopted by females and highlight worries female participants expressed more frequently about their siblings' wellbeing (Bachraz & Grace, 2009; Cridland et al., 2016; Ward et al., 2016).

Many understood the reasons for supporting their families and found this fitted with their values (Noonan, Donoghue & Wilson, 2018). However, this did not mediate the feelings of unfairness or burden experienced by some (Benderix & Sivberg, 2007; Cridland et al., 2016; Ward et al., 2016). It also made it difficult for some to develop an identity of their own, separate from their sibling (Dansby et al., 2017).

Additionally, those continuing to support and care for their siblings into adulthood experienced dilemmas about balancing their own lives (including parenting their own children) with the needs of their sibling, leading to guilt (Tozer & Atkin, 2015). Studies that included data from adult participants suggest that many children do what is needed in the moment, but some on later reflection experience ongoing emotional effects. For example, in Dansby et al. (2017) and Tozer & Atkin's (2015) studies, some participants experienced resentment about their earlier lives.

A protective role. Alongside adopting the aforementioned additional parenting role, many felt a duty to protect their autistic sibling from both emotional and physical harm, some based on negative reactions from strangers or peers (Hwang & Charnley, 2010; Noonan et al., 2018). As well as by love and affection and an intrinsic need, this was often driven by concerns about vulnerability, safety and the potential negative reactions of others, such as bullying (Angell et al., 2012; Benderix & Sivberg, 2007; Cridland et al., 2016; Dansby et al., 2017; Moyson & Roeyers, 2011; Noonan et al, 2018; Petalas, Hastings, Nash, Reilly & Dowey, 2012; Tozer & Atkin, 2015; Tsai, Cebula, Liang & Fletcher-Watson, 2018; Ward et al., 2016).

Recalling the experiences of feeling responsible for protecting their sibling from childhood, an adult participant described living "*in a state of being on alert*" in order to protect her sibling (Tozer & Atkin, 2015, p.346). This experience of living with fear and sadness about protecting their sibling was also expressed by children and adolescents (Cridland et al., 2016) in the samples suggesting an intense sense of responsibility to keep their siblings safe. For example:

> *"….it is scary, because if someone would try to kidnap him, he wouldn't know what to do….I get nervous if he is swimming by himself….I do have occasional bad dreams about him drowning or dying because I cannot help him."* (Angell et al., 2012, p.6)

Although some found it positive that they could support and protect their sibling, and some experienced pride in this role, participants experienced feelings of frustration that their siblings did not always accept their support or advice and feelings of pressure and burden (Cridland et al., 2016; Gorjy et al., 2017).

Future concerns. Whilst many acknowledged that supporting their siblings was something they would continue, for some, this sense of responsibility was experienced as a "*job*" (Angell et al., 2012, p.6; Noonan et al., 2018, p.1149). For some participants, they had noticed things had become easier as their siblings reached adulthood, due in part to the care they had received from an early age (Noonan et al., 2018). However some, particularly older, children raised concerns about their future protective or caring role, with some feeling concerned that this may be burdensome or too difficult to manage into adulthood (Dansby et al., 2017; Ward et al., 2016). However, others (adults) stated that this was something they wished to do as their choice and also enjoyed, rather than something they felt they had to do (Dansby et al., 2017; Noonan et al., 2018). Others wished to support their sibling whilst retaining their own independent lives (Corsano et al., 2016). Some expressed intense sadness about what needing ongoing care meant for their sibling:

> *"….it's heartbreaking because it's somebody who is going to be dependent on you for the rest of your life".* (Noonan et al., 2018, p.1150)

Descriptions included fears and apprehension, not solely about participants' own role in providing support or parenting, rather about what support would be available for their sibling's needs to be nurtured, for example in clinical services, in education and in navigating relationships, as well as concerns about their development and wellbeing (Dansby et al., 2017; Moyson & Roeyers, 2011; Petalas et al., 2012).

Impact of behaviours

Aggression, idiosyncratic behaviours and unpredictability. The experience of the potential for aggression influenced the willingness of some participants to continue to support their siblings in more of a caregiving role to adulthood (Dansby et al., 2017). For many, these experiences had been intense, stressful and upsetting to witness or be subjected to (Angell et al., 2012; Benderix & Sivberg, 2007; Gorjy et al., 2017; Mascha & Boucher, 2006). The quote below highlights an upsetting experience of one sibling being fostered due to ongoing aggressive behaviours:

> *"....that incident with the knife was what tipped it over the edge. That's when they decided that he couldn't stay at home."* (Petalas et al., 2012)

Some younger children described reacting unhelpfully to their siblings' behaviours, whilst older siblings recognised ignoring certain behaviours led to more successful outcomes (Moyson & Roeyers, 2011). In Tozer & Atkin's (2015) study, behaviours that were challenging led some to experience their childhood home life as chaotic. Despite their siblings' lives requiring predictability, some participants own lives were experienced as contradictory to this. Behaviours often felt unpredictable, leading to a sense of anxiety as to how they would progress (Petalas et al., 2012), with some waking each day not knowing what to expect:

> *"It's not always predictable....you wake up every morning thinking, 'please don't be a bad morning'."* (Gorjy et al., 2017, p.1491)

Some experienced self-blame about what they had done to deserve the behaviours (Gorjy et al., 2017). The unprovoked and unpredictable nature of aggression or violence was very difficult for participants to cope with, especially when they were the target with some experiencing this as very frightening and physically hurtful (Benderix

& Sivberg, 2007; Mascha & Boucher, 2006). Others experienced destructive behaviours, leading to property being broken (Angell et al., 2012, Ward et al., 2016)

With behaviours that were more related to the core features of ASC (e.g. repetitive behaviours or routines), some participants experienced conflicting emotions of both "*irritation*" and "*empathy*" (Petalas et al., 2012, p.307).

Embarrassment and being 'different'. Several participants expressed their own embarrassment that they struggled to navigate experiences with others outside of their family due to their siblings' (aggressive or non-aggressive) behaviours (Mascha & Boucher, 2006; Petalas et al., 2012). For some, this included wishing to keep peer relationships or certain other children and their siblings separate due to behaviours that may appear different to the societal 'norm':

> "*He'll just go up to people and start tapping them and pushing them out of the way, and then he walks out of the shop without paying for stuff….It can be embarrassing because everyone's watching.*" (Petalas et al., 2012, p.307)

This included fears for their sibling that they may be judged or bullied, but also concern that attention would be drawn to participants by their sibling's behaviours, perhaps representing a desire to 'fit in' (Angell et al., 2012; Dansby et al., 2017; Hwang & Charnley, 2010; Mascha & Boucher, 2006; Petalas et al., 2012).

Process of adjustment

Acceptance, empathy and learning. Several participants described acceptance of their sibling and of ASC itself (Moyson & Roeyers, 2011). However, for some in the sample, this was difficult due to the complex impact of their siblings' presentation and some participants expressed a desire for their siblings to not be autistic (Dansby et al., 2017; Petalas et al., 2012). Although at times this desire was driven by the difficulties associated with their siblings' behaviours, for some, this related to a compassionate wish for their siblings' lives to be easier or to a yearning to be able to connect with them further (Petalas et al., 2012).

Descriptions highlighted a sense of maturity in many participants, alongside resilience, compassion, empathy and patience based on their life experiences with their sibling (Benderix & Sivberg, 2007; Chan & Goh, 2014; Cridland et al., 2016; Mascha & Boucher, 2006; Noonan et al., 2018; Petalas et al., 2012; Ward et al., 2016). This included positive effects, such as developing an understanding of what it is to love "*unconditionally*" (Ward et al., 2016, p.72). For some, this acceptance appeared to be influenced by cultural narratives about ASC, with UK participants being more accepting of their autistic siblings than their age matched counterparts from Taiwan in one study (Tsai et al., 2018). Additionally, many described having increased empathy for people and being more accepting of *"difference"* (Gorjy et al., 2017, p.1491) in all individuals as a result of having an autistic sibling:

"....a great education in empathy." (Noonan et al., 2018, p.1149)

Some used this increased understanding and empathy to educate others and normalise ASC, whilst others expressed a wish to change the understanding of others. (Angell et al., 2012; Cridland et al., 2016; Gorjy et al., 2017; Hwang & Charnley, 2010). Others chose to work or volunteer in settings with autistic people (Gorjy et al., 2017) suggesting a need to develop a realistic public perception of ASC and support others. Alongside empathy, many participants felt pride and love for their autistic siblings, their skills and their many positive qualities (Angell et al., 2012; Petalas et al., 2012; Ward et al., 2016). However, this perspective had taken time for some as their relationships with siblings and understandings evolved over time (Dansby et al., 2017; Gorjy et al., 2017; Hwang & Charnley, 2010; Moyson & Roeyers, 2011; Ward et al., 2016). Additionally, this acceptance required many to adjust to fit the needs of others, something that became easier with an understanding of the reasons for this as they got older (Cridland et al., 2016). This was also present in younger children, particularly when an open dialogue was shared within the family about ASC (Bachraz & Grace, 2009).

Strategies and support. Participants expressed several ways to adapt to their life with their sibling. For some, this included developing preferred coping strategies, including spending brief periods alone, talking with peers, exercise and taking a proactive role in teaching their siblings skills (Angell et al., 2012; Dansby et al., 2017; Gorjy et al., 2017; Moyson & Roeyers, 2011; Tsai et al., 2018).

Several participants shared their feelings and sought support, for example, from parents (Cridland et al., 2016; Moyson & Roeyers, 2011). Despite some having not done this, several participants expressed a desire to access support outside of the home. For example, in the form of support "*networks*" with other neurotypical siblings of autistic people (Corsano et al., 2016, p.8) suggesting a need to connect with others they could relate to. Some did this face to face or online, providing them with opportunities to share with others who could relate to their experiences:

> *"….it just makes me feel better that somebody else has someone that shares these kinds of experiences."* (Angell et al., 2012, p.6).

Additionally, some younger participants enjoyed having the opportunity to spend time away from home and away from ASC for a time to play and have fun with others who weren't autistic (Moyson & Roeyers, 2011).

Other participants (adults) described seeking therapeutic support which was invaluable in supporting their adaptive coping skills (Dansby et al., 2017). However, others did not due to conflicting feelings, with some experiencing guilt and feeling they had failed as a sibling for needing support (Dansby et al., 2017). Some adolescents expressed a desire to access therapeutic support outside of their family in order to speak openly without associated judgement or guilt (Cridland et al., 2016).

When discussing support options, some participants were able to speak with their parents about their needs. However, others did not have an outlet to process their emotional needs, leading to isolation and an unmet need to connect with others who had similar experiences (Dansby et al., 2017, p.10):

"I cried myself to sleep sometimes and didn't know who to speak to about it."

In one study, some participants via blog posts also described using unhelpful methods to cope, including misusing substances (Dansby et al., 2017). Positively, some participants experienced a sense of agency in learning about strategies that supported their siblings (Angell et al., 2012; Chan & Goh, 2014).

As well as support for themselves, some described a complex process and stress that the families experienced in accessing appropriate services for their siblings (Petalas et al., 2012; Tozer et al., 2015). Despite adopting additional caring roles as children, participants described often feeling left out of discussions by professionals (Tozer et al., 2015). Furthermore, some adult participants, now with their own additional caring roles (of children and older age parents), felt they were judged by professional services for not taking full caring responsibilities for their siblings (Tozer et al., 2015).

Interpersonal experiences

Negotiating 'outside' relationships. Negotiating relationships, including friendships outside of the home and in a sense away from ASC was complex for many across the studies. Some needed an escape from their home and found this by spending time with friends, many of whom were supportive and understanding (Gorjy et al., 2017; Moyson & Roeyers, 2011). Others found comfort and connection in making friends with others with an autistic sibling or family member (Angell et al., 2012; Corsano et al., 2016; Gorjy et al., 2017). However, many participants found friendships difficult to navigate (Benderix & Sivberg, 2007; Corsano et al., 2016; Petalas et al., 2012). Some missed out on opportunities for social connection, with some younger children expressing concern that their parents wouldn't have time to spend with them and their friends so did not invite them home:

> *"I don't bring friends home when my brother is there because then Mum doesn't have any time to help us."*(Benderix & Sivberg, 2007, p.416).

Others felt trepidation about inviting friends to their home or introducing partners to their sibling (Dansby et al., 2017). At times, this included fears about unpredictable or aggressive behaviours (Benderix & Sivberg, 2007; Corsano et al., 2016). Some participants ensured they had primed their friends with information about ASC prior to meeting their siblings (Gorjy et al., 2017), possibly as a means of reducing anxiety about potential peer reactions.

However, several participants decided not to talk to their friends about their siblings due to concerns about a lack of understanding and the offer of misguided sympathy that was not appropriate and devalued their siblings (Petalas et al., 2012). For some, this concern about receiving "*pity*" related to dominant cultural narratives about ASC (Hwang & Charnley, 2010, p.585).

Fitting in the family and being seen. Many found it difficult that different standards appeared to be held for their autistic siblings than for them (Chan & Goh, 2014; Gorjy et al., 2017; Tsai et al., 2018) and for some, this raised conflicting feelings, for example, of "*annoyance and empathy*" (Corsano et al, 2016, p.6). Several participants expressed the experience of their own needs or wishes being adapted or disregarded in favour of those of their siblings or that they did not receive similar attention (Corsano et al., 2016; Cridland et al., 2016; Dansby et al., 2017; Gorjy et al., 2017; Petalas et al., 2009; Sage & Jegatheesan, 2010; Ward et al., 2016). However, some felt guilt for expressing these feelings due to their love for their sibling and understanding of their needs (Dansby et al., 2017). Some participants experienced feeling overlooked, jealous or dismissed as their parents were preoccupied by the needs of their autistic sibling, leaving some feeling "*unseen*" (Dansby et al., 2017, p.9; Noonan et al., 2018, p.1149), "*neglected*", "*unloved*" (Dansby et al., 2017, p.9) or always attended to later:

> "*he's always taken care of first before we are taken care of*" (Ward et al., 2016, p. 72)

The title of a 17 year old's blog post in the study by Dansby et al. (2017, p.9) highlighted this experience further:

> *"My little brother is special needs. My parents gave him all their time and energy and have forgotten about me."*

In some participants, needs being unnoticed included participants masking their true feelings. At times, participants did not wish to burden their parents by sharing their feelings (Tsai et al., 2018). Others suppressed their feelings in order to meet explicit parental requirements. For example, Sage & Jegatheesan (2010) found that one participant drew images of himself and his sibling with "*angry eyes and a big smile*" (p.99) due to feeling angry but always smiling as expected by his parents.

Conversely, some participants were accepting of this need to adapt to their siblings' needs, appearing to see this as the norm for their family or recognising themselves how this may lead to successful sibling interactions (Bachraz & Grace, 2009; Cridland et al., 2016; Moyson & Roeyers, 2011). However, some expressed a wish for an additional sibling to "*do the things they could not do with their brother with ASD*" (Moyson & Roeyers, 2011, p.49), or of the opportunity to spend time away from their family, for example, by moving away (Dansby et al., 2017). This was associated with feelings of guilt. Furthermore, many found value in spending time alone with their parents, something that was reduced compared with their siblings (Chan & Goh, 2014; Cridland et al., 2016; Moyson & Roeyers, 2011) and in sharing their feelings with parents (Moyson & Roeyers, 2011). Both suggest a role of open communication and dedicated parent-participant time in supporting adaptive coping for participants.

Sibling connections. Sibling connections included a range of experiences and emotions with some conflicting experiences within samples. Some longed for a connection with their sibling but found this to be limited and frustrating (Corsano et al., 2016; Moyson & Roeyers, 2011). For some, this related to difficulties with communication and interaction and at times, the aforementioned aggression (Angell et al., 2012; Dansby et al., 2017; Sage & Jegatheesan, 2010; Ward et al., 2015). Others felt sadness that their siblings did not appear to want to connect with them (Moyson & Roeyers, 2011).

However, despite several challenges across the data, the presence of a strong emotional "*bond*" (Tozer & Atkin, 2017, p.346), love and affection was expressed in several samples. For example, one teenager said:

> *"He's a very sweet boy….he has brought a lot of joy into our family".* (Ward et al., 2015, p.72).

Many commented on the things they enjoy about spending time with their siblings including sharing play experiences and laughter (Angell et al., 2012; Mascha & Boucher, 2006; Noonan et al., 2018; Sage & Jegatheesan, 2010), with some making a deliberate effort to share their autistic siblings' interests in order to connect which continued into adulthood (Noonan et al., 2018; Tozer & Atkin, 2017). Others expressed admiration of skills that evolved out of their siblings' 'special interests' (Petalas et al., 2012; Tsai et al., 2018), including their "*quirks and inventive ideas*" (Dansby et al., 2017, p.9) or broader positive qualities and "*good nature*" (Mascha & Boucher, 2006, p.23). One participant described her brother as "*one of the coolest people I know*" (Angell et al., 2012, p.6).

Some participants experienced strong connections with their siblings, so much so that they felt they were able to interpret them for others when communication was difficult (Sage & Jegatheesan, 2010). Ohers experienced these powerful connections with other members of their family, most notably with their additional neurotypical sibling(s). At times, this included one neurotypical sibling taking a supportive role to the other when their parents were otherwise occupied, potentially satisfying a need for participants to feel nurtured and attended to more consistently (Bachraz & Grace, 2009).

Discussion

This review aimed to systematically identify, appraise and thematically synthesise the qualitative literature investigating the lived experiences of neurotypical siblings of autistic people. Synthesis of the literature generated four superordinate themes; *Roles and responsibilities, Impact of behaviours, Process of adjustment and Interpersonal experiences*. These are discussed below. However, results will not be repeated as detailed synthesis can be found in the results section. A critique of the included studies, of this review and implications for clinical practice are considered below.

The experiences of neurotypical siblings varied across the sample. Some participants experienced a need to protect their siblings with several feeling a strong sense of responsibility for them. This was influenced in some samples by their parents and several participants were responsible for processes of care, akin to the ‘parentification’ stated in previous literature (Bowen, 1995; Seligman & Darling, 2007). This was most consistently stated across all data samples and was still present in adult samples. Several participants undertook these responsibilities, not only out of duty, but also with a natural need to support and nurture their siblings. However, it was also burdensome for many and some existed in a state of hypervigilance driven by their need to protect their siblings. This review extends previous understandings by providing insight into the longitudinal experience of adults with some experiencing ongoing emotional difficulties resulting from their childhood and longstanding feelings of resentment about their role within the family. Some adults described things becoming easier as they aged, choosing to take on caring roles for their siblings, something they enjoyed. Others battled with guilt and maintenance of independence and some adult participants felt judged by professionals in relation to their caring responsibilities suggesting an ongoing burden associated with this for some.

Some of the more difficult experiences for neurotypical siblings centred around the potential for aggression within the household because of their siblings' needs leading to an impact on overall wellbeing within samples. This was also seen in the articles reviewed by Mandleco & Webb (2015), suggesting this to be a consistent feature across previous and newly reviewed studies. In the studies, aggression was seen in many samples where siblings had more significant additional needs (e.g. additional communication difficulties, severe intellectual disability). This is consistent with the literature that suggests behaviour that is challenging can be associated with several variables, including communication and cognitive difficulties and environmental factors (Coiffait & Leedham, 2016). Additionally, prevalence of such behaviours is more common in individuals with both an ASC and intellectual disability (National Institute for Health and Clinical Excellence, 2015). Extending the themes from the previous review, this review also found that not only aggressive behaviours, but also idiosyncratic behaviours were a source of distress for several participants, particularly those trying to 'fit in' socially and this included descriptions by several older participants.

As is consistent with the previous Mandleco & Webb (2015) review, alongside difficult experiences, many participants felt they developed additional empathy and improving their understandings of ASC with age supported increased compassion.

Some participants used this to develop other people's understandings of ASC. This review extends the understanding of the things participants found helpful in coping with their experiences. As well as talking with parents and peers who were understanding (as shown in previous findings), some adult participants described having found formal therapy helpful. Additionally, in a new study, adolescents expressed a desire to access therapy. Furthermore, some sample findings suggest that online support may provide a helpful supportive outlet. This may be the case especially for those concerned with contributing to parental burden or for neurotypical siblings experiencing guilt associated with accessing support as seen in some samples.

This review highlights issues about public perceptions of ASC. Several children described feeling anxious or tentative about how their siblings would be perceived by others and some of these anxieties continued into adulthood. Many participants understood their siblings' needs and recognised a rationale for differing parental care between siblings. However, many also experienced feelings of being unseen and their needs being overlooked or ignored leading, in some samples to an internalised feeling of being unloved and neglected. Many found it valuable to talk with parents and spend time alone with them. Nevertheless, certain descriptions do raise concerns about the ongoing psychological wellbeing of some participants. Theoretically, from an Attachment theory perspective (Bowlby, 1980), those not consistently provided with attention or with their needs inconsistently met are at risk of long term psychological and relational consequences that may be experienced later in life. Additionally, participants who were (unintentionally) unprotected from aggressive behaviours were left feeling anxious and unsafe without an appropriate attachment figure to facilitate regulation of their emotions.

Many participants described warmth, love, affection, admiration and a strong bond with their siblings as seen in Mandleco & Webb's (2015) review. For those in older childhood or adult samples from the newly sourced articles, the understanding of this was extended. Several participants described important ways they maintained these bonds by making deliberate efforts to share in their siblings' enjoyed activities and continuing to make time to spend with them.

It is important to note that all themes in this review relate to a specific sample of participants and their siblings and all autistic individuals are different. Thus, the aim of the review is to understand the lived experiences of the available samples of siblings of autistic people, not to simplify the complexities associated with family systems or of ASC. In simplifying such complexities, findings have the potential to locate the problems within the autistic child and create a negative narrative that further marginalises autistic individuals. It is clear that many autistic siblings in the samples had significant needs that directly or indirectly affected their neurotypical siblings' wellbeing.   Therefore, it is imperative to validate and acknowledge the siblings' experiences alongside creating a balanced narrative that considers the broader variables that interact to exacerbate these difficulties, (e.g. parental support, demographic factors, presence of additional siblings and the influence of peers and friendship).

Critique of included studies

Although providing a clear description of the data analysis process, some authors did not offer a description of the theoretical or epistemological standpoint of the study, making it difficult to accurately understand the underlying theory influencing some studies. All authors clearly stated their study aims and methods were replicable in the majority of included studies. Ten studies included clear statements of the use of multiple independent coders and an audit process to ensure rigor of analysis and the additional studies clearly stated a rigorous and detailed analytical process. Although several studies did state the ethical considerations, these were not included in enough detail in several studies. Inclusion of this information would provide the reader with a clear picture of how participant safety was ensured and what steps were taken to undertake an ethical study. In one study (Benderix & Sivberg, 2007) additional ethical considerations were raised based on statements made by participants (for example, 'locking up' siblings due to aggressive behaviours). Some of these statements raise potential safeguarding and deprivation of liberty concerns and it is not stated how these were addressed.

Reflexivity and reflective processes to consider potential researcher influences and biases were only described explicitly across three of the studies limiting the transparency of findings and conclusions overall. Additionally, some studies provided helpful examples of interview questions or references to those developed from additional sources. This provides the reader with a clear idea of how questions asked may influence responses. Although studies largely used open-ended questions, it is not possible to know how the nature of these questions influenced study findings in those that do not provide example questions. Authors acknowledged study limitations including biases in gender samples, limited cultural variability, lack of longitudinal data and self-selected samples.

Limitations of the review and future directions

The quality of included studies was assessed to identify strengths and limitations. Additionally, this process was conducted independently on a selection of papers by an independent reviewer. Systematic searching was undertaken in a range of databases in order to identify appropriate papers and provide sufficient detail for replication of the methods. Databases that typically include qualitative studies (e.g. CINAHL) were also included as recommended by guidelines (Boland, Cherry & Dickson, 2017). However, the researcher did not search the grey literature and future studies may wish to address this limitation, for example by using the database Open Grey.

Data was synthesised following the stages recommended by Thomas & Harden (2008) and this process was completed thoroughly and rigorously. However, no audit was undertaken on the analytical process. It was appropriate to only include neurotypical siblings in the analysis due to the scope of this review. However, some papers included data from other people in the participants' lives. Experiences do not exist in isolation from the systems around them and individuals are likely influenced by the views and beliefs of their parents. For example, in studies by Sage & Jegatheesan (2010), Hwang & Charnley (2010) and Tsai et al. (2018), cultural beliefs relating to ASC potentially affected neurotypical siblings' experiences and own narratives. In the Tsai et al. (2018) study, some siblings had fewer positive narratives about ASC than their UK matched counterparts and cultural narratives were postulated by the authors to have influenced these differences. Articles were derived from a large range of countries, including those where cultures are individualist or collectivist. This may have affected the experiences of siblings. For example, in families from collectivist cultures, the emphasis on family as a shared entity with the needs of all prioritised over the needs of the individual may have affected how some siblings experienced their roles within the family. It is possible that the additional roles and responsibilities participants adopted to care for their autistic siblings would be seen as more the norm than would be expected in Western or more individualist cultures. Therefore, combining studies for review from a wide range of countries has the potential to introduce biases that are based on cultural norms which should be considered when interpreting the findings.

Additionally, on reading the full studies that included additional participants (e.g. parents), it was notable that many views were conflicting. Therefore, future research may wish to consider a systemic approach to participant recruitment to provide a broader insight into the factors influencing sibling experiences. This is important in considering how siblings are supported, particularly if their views are not corroborated by their parents and therefore may be misunderstood or unintentionally dismissed leaving needs unmet.

Many studies employed small samples. This is often appropriate in qualitative research which is focused on gaining a rich insight into individual experiences, rather than generalising findings or providing prevalence data (Polit & Beck, 2010; Thompson & Harper, 2012). However, whilst this review provides valuable insight into the lived experiences of siblings of autistic people, the size of samples does limit the transferability of these findings to broader sibling samples. Some studies explicitly stated that participants had varying levels of intellectual disability whilst others did not. It would be beneficial for future research to provide clear data about the cognitive ability of participants to support reviewers to make clear comparisons of findings. Although the current review provided data from adult participants, the voices of adults were relatively underrepresented, as is the case more generally in ASC research. Future research would benefit from understanding more about the experiences of adult siblings of autistic people to provide a more longitudinal picture.

Clinical implications

The data suggested that all siblings had differing experiences. Thus, a ‘one size fits all’ approach to support is inappropriate. However, several implications are evident. Firstly, clinicians working with parents may support siblings by providing sensitive and compassionate psychoeducation about the needs of neurotypical siblings, whilst recognising the potential guilt that parents may feel in relation to these experiences. Several in the samples clearly benefited from dedicated time with their parents and the importance of this may be shared as appropriate with parents to support neurotypical sibling wellbeing.

Some participants found value in having control over the support they offered their siblings. Therefore, clinical services may consider ways to support siblings to have some agency over their involvement in their autistic siblings' lives and support plans. Many also enjoyed connecting with their autistic siblings where possible and clinicians may consider ways to help siblings to facilitate this. Some siblings may benefit from accessing support groups, particularly ones alongside other neurotypical siblings of autistic people. This is likely to differ dependent on several factors. Younger siblings may benefit from a place to play or be creative, whereas older siblings may benefit from support that is more psychological. Sharing with others is likely to support siblings to recognise that their thoughts and feelings are valid and to normalise experiences to reduce feelings of guilt and shame. As was evidenced in the samples, some neurotypical siblings may wish to access a more traditional therapy and support could be provided in facilitating and normalising this. Given that participants in one sample accessed support forums online, modern support groups or interventions in clinical services may consider the use of technology to support open communication. This would be dependent on ethical and safety considerations.

Conclusions

The results of the synthesis provided an in depth insight into the range of experiences of neurotypical siblings of autistic people. Whilst a narrative of love, affection and empathy was present throughout, several participants experienced significant difficulties that affected their mental health. It is clear that extra pressure is placed on neurotypical siblings to undertake a caring or parental role and at times this leaves participants own needs overlooked or secondary to their siblings, affecting overall wellbeing. Additionally, the presence of aggressive behaviours led to anxiety in the sample. This review provides insight into the experiences of adults and older children as well as younger participants. Many developed great empathy for their siblings as their understanding developed with age. However, many resented the difficult experiences of their childhood and some accessed therapy that was beneficial.

Findings suggest a sense of agency, understanding ASC, time spent alone with parents, supportive and inclusive environments and the chance to relate to other siblings as protective factors in facilitating positive psychological wellbeing for siblings of autistic people.

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Appendix A. Critical Appraisal Skills Programme qualitative research checklist (adapted)

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Yes	Can't tell	Partial description	No

2. Is a qualitative methodology appropriate?

HINT: Consider
- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- is qualitative research the right methodology for addressing the research goal

Yes	Can't tell	Partial description	No

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Yes	Can't tell	Partial description	No

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Yes	Can't tell	Partial description	No

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

HINT: Consider

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

Yes	Can't tell	Partial description	No

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Yes	Can't tell	Partial description	No

Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

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

Yes	Can't tell	Partial description	No

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account

- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Yes	Can’t tell	Partial description	No

9. Is there a clear statement of findings?

HINT: Consider whether

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

Yes	Can’t tell	Partial description	No

10. How valuable is the research?

HINT: Consider

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

Yes	Can’t tell	Partial description	No

Appendix B. Quality appraisal results

Authors (year)	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship & Reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research
Mascha & Boucher (2006)	✓	✓	✓	✓	✓	✗	◥	?	✓	✓
Benderix & Sivberg (2007)	✓	✓	✓	?	✓	✗	✓	✓	✓	?
Bachraz & Grace (2009)	✓	✓	✓	?	✓	✗	◥	✓	✓	✓
Hwang & Charnley (2010)	✓	✓	?	✓	?	✗	✓	?	✓	✓
Sage & Jegatheesan (2010)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Moyson & Roeyers (2011)	✓	✓	✓	?	✓	✗	✓	✓	✓	✓
Angell et al. (2012)	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓
Petalas et al. (2012)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓

Authors and year	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship & Reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research
Chan & Goh (2014)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Tozer & Atkin (2015)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Corsano et al. (2016)	✓	✓	✓	✓	✓	◥	✓	✓	✓	✓
Cridland et al. (2016)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Ward et al. (2016)	✓	?	?	✓	✓	✗	✓	✓	✓	✓
Dansby et al. (2017)	✓	✓	✓	✓	?	✓	✓	✓	✓	✓
Gorjy et al. (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Noonan et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Tsai et al. (2018)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓

Note. ✓ = Yes; ✗ = No; ? = Unclear; ◥ = Partial description

Section 2

Research Report

Exploring the Lived Experiences of Females Receiving an Autism Diagnosis in Middle Adulthood: A Phenomenological Study

Abstract

Objectives

Females often receive Autism Spectrum Condition (ASC) diagnoses later than males, leaving needs misunderstood. Prevalence of autism diagnosis in females in middle adulthood is increasing but understanding of the lived experiences of such individuals is currently poor. This study aimed to explore the lived experiences of female adults diagnosed with an ASC in middle adulthood.

Design and Methods

The study employed a qualitative design, using Interpretative Phenomenological Analysis (IPA). Eleven autistic females diagnosed over the age of forty years were interviewed using semi-structured interviews.

Results

Four superordinate themes emerged: *A hidden condition; The process of acceptance; Post diagnostic impact of others; A new identity on the autism spectrum.*

Conclusions

Findings highlight several factors affecting late diagnosis in females, including widespread limited understandings of others. Diagnosis was experienced by several participants as facilitating transition from being self-critical to self-compassionate. Participants experienced a change in identity that enabled greater acceptance and understanding of the self. However, this was painful to adjust to at such a late stage.

Practitioner Points

- Autistic females should be assessed by skilled clinicians approaching this process critically

- Training of service providers to support earlier recognition needs to be widespread. Autistic females should be encouraged to participate in providing this training
- The participants in this study were of average to above average intellectual ability, hence findings may not be transferable to females with intellectual disability

Keywords

Autism, ASC, autistic female, Interpretative Phenomenological Analysis, qualitative

Introduction

Autism Spectrum Condition[4] (ASC) is a lifelong neurodevelopmental condition. To meet diagnostic criteria, individuals present with persistent deficits with social communication and interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). Approximately 50-70% of autistic[5] individuals have an associated intellectual disability (Matson & Shoemaker, 2009). Prevalence rates of ASC are estimated at approximately 1% in the United Kingdom (Brugha et al., 2016).

Receiving a diagnosis of ASC can be an arduous process. The issues faced are likely to differ between genders (Gould, 2017; Lai & Baron-Cohen, 2015) and approximately three times more males than females are currently diagnosed (Loomes, Hull & Mandy, 2017). Furthermore, diagnosis typically occurs later in females compared with males, particularly females presenting with average cognitive ability (Begeer et al., 2013; Siklos & Kerns, 2007).

Several theories contribute to understanding the male bias in the diagnosis of ASC. One theory is a potential female autism phenotype, with characteristics in the core domains presenting differently in females to the widely understood conceptualisations of ASC, based on evidence from largely male samples (Gould & Ashton-Smith, 2011; Kreiser & White, 2014; Mandy, Chilvers, Chowdhury, Salter, Seigal & Skuse, 2012). Findings suggest autistic girls are significantly more likely to engage in pretend play than boys and demonstrate more competence with non-verbal interactions, leading to potential underdiagnosis based on traditional assessments (Knickmeyer, Wheelwright & Baron-Cohen, 2008; Rynkiewicz et al., 2016). Females are more likely to 'internalise' their difficulties, presenting as anxious, passive,

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[4] Term used increasingly within the autism population, removing 'disorder'. This term is used henceforth in line with such preferences (Kenny, Hattersley, Molins, Buckley, Povey & Pellicano, 2016). Autism Spectrum Disorder is the official diagnostic term.

[5] Dominant 'identity-first' term used in modern autism literature based on research findings and preferences

depressed or with eating difficulties (Attwood, 2007; Mandy et al., 2012). Furthermore, girls often use compensatory strategies to ‘mask’ or ‘camouflage’ their difficulties, allowing them to ‘blend in’ to social situations with several hypothesised functions including, aiming to reduce shame, bullying and attempting to cope with the social world (Bargiela, Steward & Mandy, 2016). This can take significant cognitive and emotional effort and impact negatively on mental health (Bargiela et al., 2016). In friendships, girls with average intellectual ability may compensate for interpersonal difficulties which may relate in part to the dominant societal expectations of girls as sociable and nurturing (Goldman, 2013). Compared with autistic boys, girls appear more socially motivated and despite experiencing more conflicts, have similar social experiences to neurotypical[6] girls (Segdewick, Hill & Pellicano, 2018). Additionally, their interests may appear similar to their neurotypical peers, differentiated by the intensity of such interests in autistic girls (Gould et al., 2011). Thus, based on historical understandings of ASC, the needs of girls are often difficult to recognise and may appear subtle to those responsible for referring for assessment (e.g. teachers).

For autistic adults of all genders, the literature is limited, and little research specifically focuses on the experiences of individuals growing older receiving diagnoses (Happé & Charlton, 2012). Historically, much of the literature has focused on experiences of autistic children, adolescents and their parents (Abbott, Bernard & Forge, 2012; Cridland, Jones, Caputi & Magee, 2013). However, recently, the experiences of autistic adults have gained increasing interest in research. When interviewing adults diagnosed with Asperger syndrome (AS), Punshon, Skirrow & Murphy (2009) found participants described the impact of societal views, negative life experiences and beliefs about AS on their adjustment to diagnosis. Griffith, Totsika & Hastings (2011) interviewed individuals aged over thirty-five. However, many participants received

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[6] The term used to represent a neurodevelopmentally typical development (without autism)

their diagnosis up to sixteen years prior, providing limited insight into specific experience of diagnosis at this age. Hickey, Crabtree and Stott (2018) and Elichaoff (2015) used Thematic Analysis to investigate the experience of autistic adults. Although Hickey et al. (2018) recruited a sample over the age of fifty, providing insight into growing older with needs unmet, both studies recruited mostly male participants overall. Thus, there remains a scarcity of research that investigates the specific experiences of adult females, especially those in middle and later adulthood.

Bargiela et al. (2016) began to address the female gap in the literature using Framework Analysis to investigate the experiences of adult females diagnosed between nineteen and thirty. Females described misunderstood needs and ongoing mental health difficulties and findings suggested camouflaging behaviours, internalising and stereotyped understandings influencing later diagnosis.

To date, no qualitative studies have specifically focused on the experiences of females receiving their diagnosis in middle adulthood. Given what is known about the likelihood that females' needs are under recognised (Gould, 2017) and their support needs often misunderstood and misattributed to different diagnoses (Attwood, 2007; Eaton, 2018), this represents an important gap in the literature. Thus, the rationale of the study is to better understand how to meet the needs of autistic females who receive a diagnosis in middle adulthood.

A qualitative methodology was deemed to be appropriate to gain an in depth understanding of autistic females' experiences. The methodological and analytical approach of Interpretative Phenomenological Analysis was most appropriate, allowing detailed exploration and interpretation of how individuals make sense of lived experiences within a particular context (Larkin & Thompson, 2012; Pietkiewicz & Smith, 2014).

Aim

The aim was to investigate the individual lived experiences of females receiving a diagnosis of ASC in middle adulthood. The desire was to understand reactions to diagnosis, the meaning of diagnosis, how individuals make sense of their experiences and the impact on their lives. It is anticipated that the outcomes of this study will form an important basis for clinicians to inform future practice.

Method

Methodological approach

The study employed a qualitative design, using Interpretative Phenomenological Analysis (IPA) with semi-structured interviews. IPA was chosen as it the only qualitative idiographic case study approach which is focused on the ‘particular’. Therefore, it aims to explore the specific lived experiences of people with shared characteristics within a particular context relating to specific phenomena. With the specific participant sample in mind, it was appropriate to select IPA as participants were all autistic females who had received a diagnosis at a specific time point (middle adulthood). Additionally, IPA allows the researcher to develop an in depth understanding of lived experiences (Pietkiewicz & Smith, 2014; Smith, Flowers & Larkin, 2009) in line with the aims of the project. The interpretative element of IPA is routed in hermeneutics (the theory of interpretation). Therefore, the researcher analyses data via an in depth process, with the aim of ‘making sense’ of how individuals make sense of their own world. IPA was the appropriate methodology to understand not only how individuals made sense of their own experiences, but also how psychologically, these experiences could be understood, in order to provide a more in depth insight into their inner world with the aim of informing both understandings and clinical practice.

Ethical considerations. Ethical approval was obtained via the Integrated Research Application System (IRAS, 218102) and from Sheffield Health and Social

Care NHS Foundation Trust for governance. Additional information about ethical considerations and participant safety can be found in Appendix A alongside approval documentation.

Participants

Participants were 11 female adults recruited via purposive sampling. They were included if they had received an ASC diagnosis at or over the age of 40 years. Demographic information was collected from participants at interview. All participants were White British. See Table 1. for demographic information.

Participants were excluded from taking part in the study if they:

- Lacked capacity to provide consent
- Were born male (i.e. they were not be included if they identified as female or had transitioned from male to female)
- Were unable to speak English
- Were under the age of 40 years when receiving their diagnosis

The above criteria were explicitly stated on the information flyer provided to participants in advance of them signing up for the study.

Materials and service user involvement.

The interview schedule was developed based on the aims of the project. Previous research findings and interview questions from Punshon et al. (2009) were used to create the original schedule. The researcher met with three autistic women who volunteered via Sheffield Adult Autism and Neurodevelopmental Service (SAANS). The researcher had created a draft list of questions at this stage and discussed these with the service users (SU). On discussion, SU advised the researcher on things that they felt were relevant based on their experiences. They provided advice about how to use prompts to support participants by making questions clearer or more concrete (e.g. prompts for emotions). The researcher added several prompts and updated the questions based on the SU views. She shared the final questions with all SU via email for their consultation and agreement. No additional changes were then required at this stage.

The schedule was semi-structured and used to guide the interview (see Table 2.) but deviated from to allow participants to share their personal stories. Adaptations were made on a case by case basis. Participants were given the opportunity to ask for clarification or for any questions to be reworded. The researcher aimed to ask clear and concise questions, restating these if they were unclear. She used additional exploratory prompts to ask for further information throughout (e.g., "can you tell me more about x").

Table 1.

Participant demographics

*Participant	Age	Age at diagnosis	Diagnosis	Education level	Employment status	Additional current diagnoses	Preferred terminology
Lily	50	45	AS[a]	UG[d]	Employed	ADHD[e]	Asperger’s
Hannah	43	40	ASD[b]	UG Undertaking Masters	Self-employed Student	ADHD Dyslexia	Autistic
Marie	53	50	HFA[c]	Participant unsure	Student	Dyslexia	Not known
Elizabeth	43	40	HFA	GCSE	Unemployed	Epilepsy	Autistic
Alice	47	40	AS	UG	Unemployed	None	Autistic
Olivia	51	48	AS	UG	Employed	PTSD[f]	Aspie ASC
Merrell	64	62	HFA	Masters	Self-employed	Learning difficulties	Autistic/Asperger’s OTS[g]
Celia	53	48	AS	UG	Employed	Dyspraxia	OTS
Mia	60	51	AS	UG	Self-employed	ADHD	OTS
Ruby	44	44	ASD	GCSE	Employed	None	Asperger’s
Kate	51	49	ASD	None	Employed	Depression	Autism

Note. * = pseudonym; [a] = Asperger Syndrome, diagnostic description based on previous diagnostic criteria; [b] = Autism Spectrum Disorder (American Psychiatric Association, 2013); [c] = High Functioning Autism, a term used within the clinical service to describe level of cognitive ability; [d] = Undergraduate Degree; [e] = Attention Deficit Hyperactivity Disorder; [f] = Post Traumatic Stress Disorder; [g] = on the spectrum.

Table 2.
Interview Schedule

Interview questions	Prompts
1. What was the exact diagnosis you were given from SAANS/other place?	*I want to use the words that you identify with the most. What name would you use to describe the diagnosis?* *Is it autistic, or something else?* *What do you call your diagnosis?*
2. What was your experience of receiving the diagnosis? Can you tell me about that day?	*What was that like? How did you feel? [if you know],* Why did you feel that way? *Did you do anything as a result of receiving your diagnosis? What did you think?* *[If need more prompts - Sometimes people say they feel (options). Is this right or is it something else? Additional prompts with example emotions if needed]*
3. How were you with the diagnosis of (use their name for it) in the first 3 weeks after you had received it?	*How were things for you? What did you think? How did you feel? Why did you feel this way? What did you do about it? [use prompts from emotions described earlier if needed]*
4. Since that first few weeks, has anything changed?	*How/What is different about them? How have you felt since then? What have you done since then? What have you thought since then/what has gone through your mind?* *[if described an emotion, thought, concern, in question 3] – Has this gone? Has this changed? Do you still x, y, z? What is it like now?* *Health and wellbeing? [if so, in what way?] Any effect on work, home life, getting out and about [if so, in what way?]*
5. How has receiving the diagnosis affected your life in any other ways that we have not yet spoken about?	*Anything that diagnosis changed? Was there any effect on hobbies, other activities [if so, in what way?] Any effect on your health, wellbeing? [if so, in what way?] Any effect on work, home life, getting out and about [if so, in what way?]*
6. What does the diagnosis mean to you now?	*Any effect on who you are? [Any effect on] why you do the things you do?*
7. Has receiving the diagnosis affected how you see yourself?	*Any change in how you think about yourself or your past?*
8. Has receiving the diagnosis of (whatever name they use) affected your relationships with other people?	*Which relationships? How? How have others reacted to you? Any impact on work relationships? Any impact on family, friends, romantic relationships?*
9. Is there anything else that you feel would be important for me to know about your experience of receiving a diagnosis of (whatever name they use)	-

Procedure

Participants were recruited in two ways from SAANS:

1. Clinicians provided newly diagnosed females with information about the project and an information flyer (Appendix B).
2. Using records kept within the service, a SAANS clinician posted the information flyer to 40 females who had previously received a diagnosis.

The flyer asked participants to visit a research webpage that provided further information about the study. Participants clicked a link and entered a password, opening an online form through Qualtrics to input their contact details. The researcher contacted participants via their preferred method to arrange an interview time. A confirmation letter, longer version of the information sheet and a consent form were then sent to participants (Appendix C, D and E).

Participants attended SAANS on one occasion. Confidentiality and exceptions to this (e.g. safety concerns) were explained at the start of the interview. The interview was recorded using an encrypted digital audio recorder. Interviews lasted between 35-95 minutes. Participants were debriefed at the end of each interview.

Quality control

The researcher took several steps to support quality control in line with guidance (Elliot, Fischer & Rennie, 1999; Yardley, 2000). This included, ongoing process discussions with supervisors and practising interview style prior to recruitment and throughout. Furthermore, an independent audit of each stage of the analytic process was conducted on three of the transcripts by a peer to ensure a high standard of rigor. See Appendix F for the audit form.

Analysis

Following each interview, field notes were made by the researcher as part of the reflexivity process (described below). These notes were referred to when undertaking the analysis to support transparency. An external person hired to undertake this task transcribed the interviews verbatim. Interview transcripts were analysed in line with IPA guidance (Larkin & Thompson, 2012; Smith et al., 2009). Transcripts were read alongside recordings and ideas noted down 'line by line' on the transcript in the right hand margin. Notes focused on linguistic processes, conceptual ideas and descriptive comments made by participants.

Next, tentative emerging themes were noted in the left hand margin of each transcript. See Appendix G for example transcript. Then, themes were grouped together with the use of notes and conceptual maps (see Figure 1.), based on their characteristics and given initial codes for all transcripts. A conceptual map was created for each participant to explore initial ideas and formulations about their experiences. Data was then analysed as a whole. This process included, exploring overlapping themes across each individually analysed transcript, looking for similar concepts within the transcripts, themes and conceptual maps, exploring exceptions within the data and clustering themes together alongside theory and literature to understand them further. This continued until a list of overarching 'superordinate' and subthemes were developed.

Reflexivity

Reflexivity is an important component in qualitative research (Berger, 2015; Biggerstaff & Thompson, 2008). It allows the researcher to consider, bring awareness to and evaluate their position and ideas, both personally and professionally. Throughout this project, the researcher kept a diary to engage with reflexivity proactively (see Appendix H for diary excerpt). This allowed her to consider what she 'brought' to the project (e.g., age, gender, preconceptions, previous knowledge about autism). As well as considering the impact of these factors on the credibility of research findings, they allowed the researcher to continually reflect on how to approach research processes.

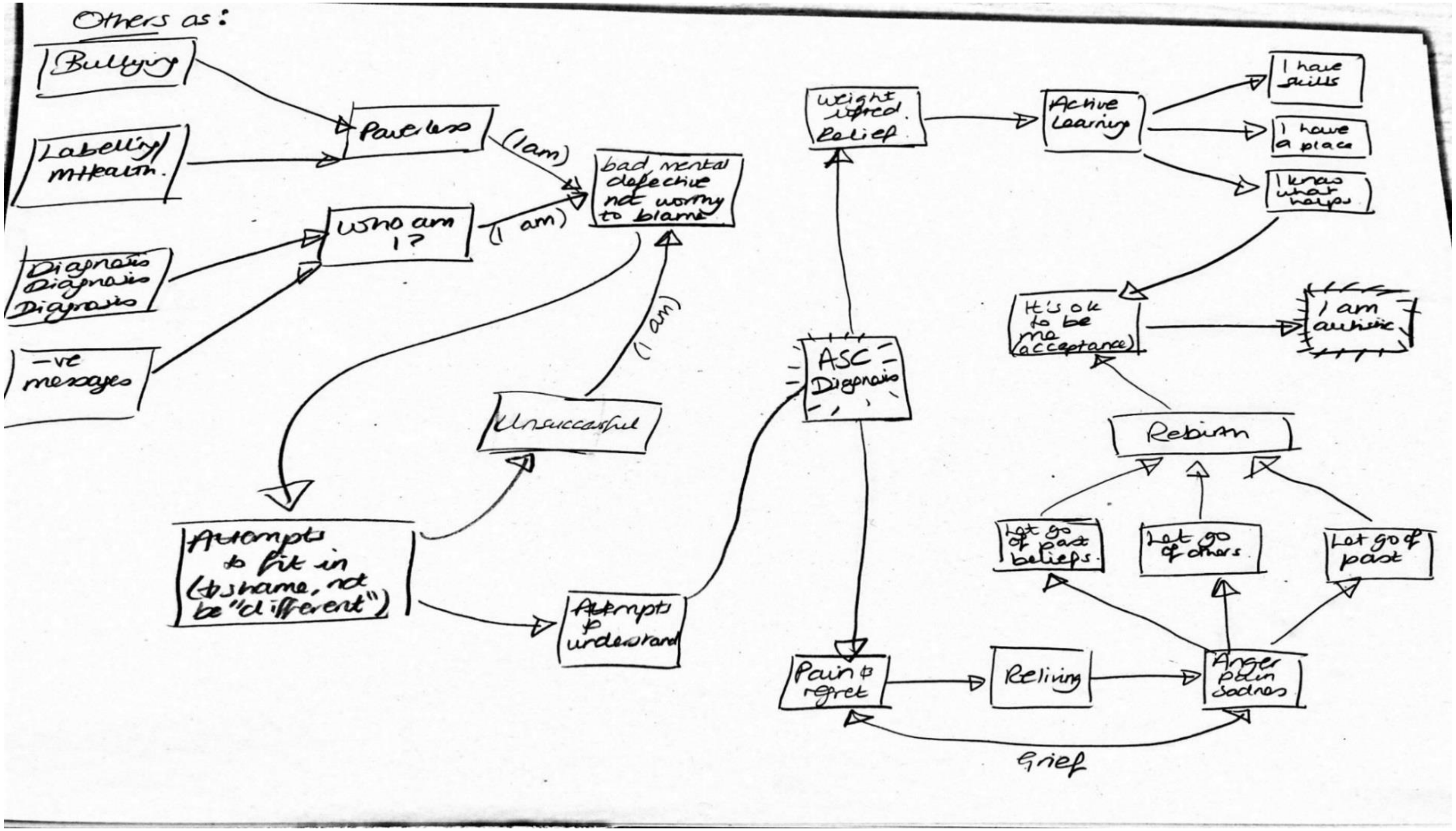

Figure 1. *Example conceptual map*

Results

Analysis of the data produced four superordinate themes, each comprising several subthemes as shown in Table 3. below. The themes are discussed below alongside illustrative participant quotes. All participant names are pseudonyms used to maintain anonymity. Some quotes have been edited to support clarity for the reader and missing data is represented by the use of '….'. Additional explanations of participant points are included within '[ ]'.

Themes do not represent an exhaustive account of participants' experiences; rather an interpreted account of several descriptions. Some aspects of experience overlap within themes due to their fluid nature. The contribution of participants to each theme was recorded (see Table 4.). Additional quotes evidencing each subtheme can be found in Appendix I.

Table 3.
Superordinate themes and subthemes

Superordinate themes	**Subthemes**
A hidden condition	Pretending to be 'normal' and fitting in
	Mental health and mislabelling
The process of acceptance	Initial reactions and search for understanding
	Reliving life through a new lens
	Grief and reflections on the past
Post diagnostic impact of others	Initial reactions of others
	Stereotyped assumptions
A new identity on the autism spectrum	Negotiating relationships, connections and community
	Changing wellbeing and views of the self
	The meaning of diagnosis

Table 4.

Participant contributions to subthemes

Superordinate and subthemes	**Participants**										
	Lily	Hannah	Marie	Elizabeth	Alice	Olivia	Merrell	Celia	Mia	Ruby	Kate
A hidden condition											
Pretending to be ‘normal’ and fitting in	✓	✓		✓	✓	✓	✓	✓	✓	✓	
Mental health and mislabelling	✓		✓		✓	✓	✓	✓	✓	✓	✓
The process of acceptance											
Initial reactions and search for understanding	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Reliving life through a new lens	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
Grief and reflections on the past	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Post diagnostic impact of others											
Initial reactions of others	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Stereotyped assumptions		✓	✓	✓	✓	✓		✓		✓	✓
A new identity on the autism spectrum											
Negotiating relationships, connections and community		✓		✓	✓	✓		✓	✓	✓	✓
Changing wellbeing and views of the self	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓
The meaning of diagnosis	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓

A hidden condition

This superordinate theme considers the hidden nature of ASC in females, including attempts to make sense of themselves in a world comprised of a myriad of 'norms' and expectations.

Pretending to be 'normal'[7] **and fitting in.** Efforts to 'fit in' were influenced by several factors, including confusing social interaction attempts and perceived failures. For some, 'unsuccessful' connections led to internalised beliefs that they were "*wrong*" "*broken*" or "*bad*" (Alice, Olivia, Lily). This appeared to relate to a need for acceptance that at times was so strong, some participants took on a persona that was ego dystonic in order to fit in:

> *"….it started at school and it went on to college as well….[I wore] different clothes to everything that I wore at home…., I hated this person that I put on."(Hannah)*

Women had several motivations for disguising their true selves. These included attempts to develop relationships. For others, the aim was to blend in and not appear 'different':

> *"I never felt like I fitted in anywhere….other people just seemed so – like their lives have always seemed much easier….they've just seemed to do things without the whole thought process that I have to go through."(Ruby)*

Strategies were developed to try to cope in a social world. Some appeared to be unconscious or less deliberate. Others were practised with the aim of learning social rules and appearing 'normal' when making comparative evaluations to people who appeared to be part of the social norm or 'ingroup'. These strategies were effortful and sometimes avoidance of social contact was reported as being a preferable strategy:

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[7] Use of the word 'normal' by some participants refers to 'neurotypical' or non-autistic people

> *"….ok, need to remember to kind of get it in there and say how are you, at least, back. So, I remember then going out and thinking, right, I have to be prepared for these times when you bump into people and they expect these things. But sometimes if people didn't see me I would actually just hide."(Hannah)*

Merrell describes a distressing awareness that she experienced abject difficulty relating to others:

> *"I've never really understood how I'm supposed to be, and so I've had to copy other people to fit in."(Merrell)*

Her used of the word "supposed" suggests a self-perception influenced by societal ideology where some fit and others do not.

For many, pre-diagnosis, hiding or mimicking served a survival function. However, the consequences of doing so were complex, with some feeling deeply unhappy and exhausted. In part, this was as many attempts didn't appear successful, leaving participants feeling on the periphery despite considerable efforts.

Mental health and mislabelling. Experiences of mental health difficulties were expressed and for some, this was associated with complex family histories, trauma, struggling in school, and bullying. Participants often reported that their experience was not understood by professionals. Lily described seeking support within mental health services leading to several diagnoses which did not explain her experiences. Failure to find an appropriate understanding or formulation added to the sense of confusion. This appeared to factor in her exhaustion with life, and attempts to end her life:

> *"[Clinician] would say 'oh, you've got borderline personality disorder'….I explained to him exactly why I wasn't BPD….I wasn't getting any answers, I just stopped going. I just stopped asking for help, I just stopped, you know, looking for answers."(Lily)*

> *"I was exhausted trying to figure it out….why things were so different for me, and….by the time I had got to that diagnosis, I was already half dead, I was already in a functioning depressed state."(Lily)*

Participants described not only significant ongoing battles with their mental health, but this being entwined with a battle to understand themselves. Within their descriptions is an implied power imbalance where labels were enforced upon them. When receiving (non-autistic) diagnoses, some described self-doubt, struggling to trust their own judgements even when they knew the suggested diagnoses did not adequately describe or help them

Some recalled upsetting experiences at key developmental stages. For example, during education of being misunderstood and their needs not recognised or supported, leaving them vulnerable to interpreting these experiences as their fault:

> *"….I couldn't stop sobbing….I was really, really upset and they couldn't calm me down so I was taken to the headmistress's office and she slapped my legs and told me to stop."(Ruby)*

As well as resulting in missed support opportunities and misattributed blame, participants' experiences likely resulted in ongoing confusion about identity. Many appeared to have internalised unhelpful messages, leading to a devalued sense of self and strongly helped beliefs of being fundamentally "*mental*" (Kate) "*wrong*" (Alice, Olivia, Celia) or "*defective*" (Lily, Alice, Mia).

The process of acceptance

This superordinate theme describes participants making sense of their diagnosis, grieving and adjusting, alongside re-experiencing memories with a new understanding.

Initial reactions and search for understanding.

The experience of the diagnostic process was described. The assessments were often intensely emotional, "*sad*" (Ruby) and even "*harrowing*" (Olivia). Many experienced anxieties about the unexpected and fear that they may receive no further answers. For others, it was painful to re-experience emotions associated with past experiences.

Some had spent a long time considering what the outcome may be and their initial reactions acted as confirmation about what they had been researching pre-diagnosis, providing a sense of relief, calm and validation:

> *"....I suppose the calm kind of comes with the relief....'what can I do now?' It stopped the obsessive thoughts of 'am I? Am I not?'"(Hannah)*

For some, this was coupled with a sense of "*vindication*" (Alice), that experiences they were ashamed of could be explained. The relief described across the data included a "*eureka*" (Lily) moment for some, a realisation that diagnosis allowed them to end the arduous search to understand how they experienced the world:

> *"....it was a sigh of relief....I don't have to do that anymore, we don't have to be searching for something that was never there, which was a great relief."(Mia)*

Some described conflicting feelings initially. One, of relief and at times, "*elation*" (Olivia). But also, frustrations about what this might mean for their sense of identity and the potential for diagnosis to be limiting, forced them to question themselves:

> *"....I thought 'am I just anything other than these symptoms?' Um, that really upset me....I sort of started doubting my ability to do my job".(Celia)*

For Elizabeth, one of the more difficult emotions was a feeling of shame and fear about what being diagnosed at her age might mean. This may be exacerbated by the fact that, being autistic was never something she had considered and seeking a diagnosis was instigated by others. Thus, receiving a diagnosis required a significant shift to a new way of thinking about who she now was.

For many, the diagnosis created a springboard for learning and understanding with several participants describing an active process of researching what autism meant for them:

> *"….I got to work….learning everything I could….reading everything…I know everything there is now, ha, I read everything."(Lily)*

Lily's description suggests a focused approach. For Olivia, the process of understanding the diagnosis provided her with a sense of purpose and possibly control over developing a new understanding of herself in the world:

> *"….it gave me a sense of purpose, it was….that's why I don't understand all of this, now I can go and research why I don't; understand that.' And there was that sense of something new and something new to research."(Olivia)*

Alongside researching, some found connecting with others helped to develop their understanding. This included accessing groups with other autistic adults. For years, the understanding of the self had been limited and at times negatively prescribed by others. Research and connections provided concrete information participants could relate to and autonomy in this meaning making process.

Reliving life through a new lens. Several participants described a process of looking back, reliving their lives with a new perspective after diagnosis. For many, this happened almost instantly and for others, continued several years later. The metaphorical lens that participants had previously viewed their lives through had been coloured in part by the fact that they did not understand their experiences. For some, this included looking back at idiosyncrasies from their life:

> *"….why I had to have the same seat on the bus all the time, and I'd get annoyed if I didn't get it. It's all the little things that it's given an answer to."(Kate)*

Although Kate describes her new understanding as seemingly minor with the use of "the little things", they were all things that prior to diagnosis were not understood and contributed to a feeling of difference.

Some participants described reliving past experiences as a process that was somewhat out of the conscious awareness in a way that took them back to that time and magnified those memories:

> *"….your life flashes before your eyes….thousands of memories coming back, constantly of 'oh, I remember when this happened….that's why I had a meltdown and couldn't understand why.'"(Alice)*

In the moment, a different understanding of themselves had likely shaped participants' reactions to those experiences and to how they thought of themselves in the social world. To experience this and to describe it during the interview was emotional for several participants:

> *"It's good….at least now I understand why I've felt the way I have a lot of the time and why I've been the way I am a lot of the time as well. Sorry, it's making me really emotional."(Ruby)*

Although these revelations in light of diagnosis felt positive, both quotes suggest a sadness and pain associated with not having these understandings earlier. With those, these life experiences may have been more manageable and provided answers to things that in the moment were confusing and at times devastating.

For some participants, reliving the past allowed them to shape interpretations and of others in the present:

> *"….taking my daughter to clinics…I'd say, 'I think it's because of this' and I'd explain round it and they'd be like, 'wow, oh, that's really interesting and I think that you're absolutely right'."(Hannah)*

For Hannah, reflecting on her childhood helped her to express to professionals what her daughter (also autistic) may be experiencing. Hannah was experiencing an ongoing battle for her needs to be recognised by certain services. Feeling powerless, increasing the knowledge of others allowed her to elicit some control over how her daughter was interpreted and supported.

Grief and reflections on the past. Although the expression of grief was unique to each participant, the experience included several common emotional elements. Many participants explicitly referenced their experience post-diagnosis including a grieving process. Most portrayed a sense of sadness for their pre-diagnosis self and the significant struggles which may have been easier had their needs been understood:

> *".... I felt really bad for myself as a child....blaming myself for things....not being good enough....or being slow and not like everybody else."(Hannah)*
>
> *"....to think that's how that child was treated. It's really sad."(Ruby)*

Some described current feelings of "*anger*" (Marie) that their difficulties were not understood earlier. For Elizabeth, learning that others had suspected she was autistic, exacerbated this anger about what might have been with an earlier understanding:

> *"[she said] 'I always kind of thought you might have autism.' And I didn't say to her, but I thought, so why didn't you do anything?"*

Many participants felt that through learning and understanding what autism meant for them, and through new experiences, they had moved overall to a place of self-acceptance. However, grief was a fluid and ever changing process including many experiencing fluctuations in mood and periods of loss and fear about the lifelong nature of autism:

> *".... you sort of realise that you're stuck like this forever really, so that's a bit....It's a bit overwhelming....I'm going to struggle with things for the rest of my life, that's hard."(Celia)*

For some, this related to a process of looking back, with the intensity of the grief attributed to a loss of a past that could have been:

> *"....that's the grieving process....it is incredibly painful....because you've lost half your life, you really have".(Lily)*

Post diagnostic impact of others

This superordinate theme explores participants interpersonal experiences post-diagnosis and the impact on their lives in several interpersonal settings.

Initial reactions of others. Some shared their diagnosis immediately, with others more cautious about potential reactions. Some had positive experiences, leading to a feeling of gratefulness about being finally accepted for who they are. This included continuing to be treated as individuals by the important people in their lives. For others, this highlighted a contrast to their earlier experiences:

> *"....blessed to have such lovely people around....care enough about me not to be bothered by my weird quirks and funny ways....It makes a change after years of bullying and being penalised for being odd."(Merrell)*

For some, an openness of important others to understand what it meant for them to be autistic provided opportunities to develop communication. For Celia, this allowed for positive relationship changes as her husband became more attuned to her needs:

> *"....he got really into researching it....it's really improved our relationship because he's realised now that a lot of the arguments we had were me misunderstanding what he'd said and him misunderstanding how I'd reacted."*

In contrast, some participants found others being unsure what to do with the information or feeling let down by unhelpful and "*patronising*" reactions (Olivia, Marie). Mia's ex partner's approach had the potential to leave her feeling self-conscious or that her behaviour somehow needed modifying to meet the societal ideal:

> *"....if he considered I was talking too much if we were with other people he would like kick me to tell me to shut up....I just found it difficult."*

For Ruby, she felt most supported and validated by others online, or by her work colleagues. However, she experienced family members as dismissive with them not appearing to recognise the magnitude of what it meant to receive the diagnosis:

> *"....I just expected him [husband] to say something....or realise how massive this was for me and he didn't for ages, and about two weeks later I just said, 'look, this is huge for me....to you I'm no different, but to me I'm completely different'."*

Elizabeth received several helpful and positive reactions. However, she described an ongoing fear of disclosing. Some reactions highlighted the potential for invalidation, leading her to be selective when seeking support:

> *"....when I told my dad....he was....'You don't have autism, you're perfect. There's nothing wrong with you.'....he thinks I'm his perfect little girl....who's got nothing wrong with her, so I can't talk to him about if I've had a bad day."*

The narrative, of being "perfect" suggests a neurotypical ideal with the implied opposite being 'imperfect' and autistic. It is possible that this message contributed to the difficulty Elizabeth described with integrating autism as a part of her identity and fear of judgement.

Stereotyped assumptions. For many, the aforementioned need to 'mask' or develop a persona changed post-diagnosis. However, some participants experienced inner conflicts, wanting to show their true selves, but being fearful of reactions. For some, stereotyped assumptions about ASC, likely based on pre-existing schema led to frustrations about meeting the expectations of others:

> *"....it makes me a little bit cross, that they think I should fit into some sort of stereotype. Sometimes I feel that I'm letting them down because I don't act how they think I should do!"(Celia)*

Some transitioned from a psychological position of seeking to hide their true selves to feeling invisible and dismissed, fighting for their true needs to be recognised (for example, in the benefits system). Some postulated that the amount of effort placed on previously camouflaging their behaviours directly affected how they were viewed post-diagnosis:

> *"….anyone who's got to middle age with undiagnosed autism has had to basically do Olympic level training in how to be a normal person….[when I] appear sort of normal, that is because of the years of actual effort that I've put into it."(Alice)*

Several participants experienced tailored and helpful support, with many describing supportive adaptations at work. However, some had continuing battles for these adaptations to be made. Others volunteered to offer training within their workplaces to add to knowledge.

Some experienced the diagnosis limiting the options for support that was individualised as people made assumptions about how they fit into a label based category. At times, this included a loss of mental health support. For Marie, this approach to supporting her in college felt oppressive and narrow in its view of who she is as an individual:

> *"Just stop looking at that damn word; that damn word doesn't make me, me."*

A new identity on the autism spectrum

This superordinate theme describes participants navigating relationships and changing relationships, alongside an ongoing process to understand how autism relates to who they are.

Negotiating relationships, connections and community. Many participants described ongoing changes in relationships post-diagnosis. Some included familial relationships and old friendships evolving supportively in light of new understandings:

> *"....he'll [husband] now take the lead in situations where he knows I'm not comfortable, whereas before he just thought I was being awkward."(Celia)*

Others made life-changing relational decisions. Previously stuck in a passive position based on others' expectations of her as a woman, Lily took control and ended the relationship with her husband. Some had experiences where they recognised friendships that weren't supportive:

> *"....the implication....I was automatically wrong, because I had this Asperger's thing....So that was unexpected, and I had to walk away."(Alice)*
>
> *"....one person that I talk in confidence to....and they treat me the same as everybody else. The people that have ignored me I don't want to know."(Kate)*

The ability to make these changes signified a newfound confidence to live shaped by their values. It represented a parallel 'letting go' of an old life, pre-diagnosis, one where they no longer needed to assimilate to meet the social norm.

For some, connecting with others included making links with other autistic adults, particularly females, via supportive groups and online. Alice was able to communicate in a medium where she felt skilled, describing the internet as a place where she "*really shines*" compared with "*in real life*" which she still found difficult to navigate:

> *"....the moment I go out and I try to mix with so called normal people I immediately feel completely isolated."*

For many, these new associations provided the opportunity, not only to learn, but also to identify with others, suggesting an ongoing value to many in social connectedness:

> *"there's a tremendous amount of power....in being diagnosed and being a part of a community....the social media age that we're in....'oh, my gosh, this has happened, does anyone relate?' And have people say 'yes, I understand.'"(Hannah)*

Descriptions suggest, an intrinsic need for belonging, where participants found positives and validation in relating to others and recognising strengths, many of whom found friendships ‘offline’ difficult. For some, they found a shared value and identity, contrasting with past self-beliefs, and at times devaluation by others:

> *“I’ve never fitted in that jigsaw puzzle….[now]I fit somewhere, I belong somewhere with other people somewhere who are like me. Yes, it’s good.”(Ruby)*

Conversely, Elizabeth, engaged in ongoing camouflaging behaviours:

> *“I won’t always tell him [husband] that I don’t understand, to make it less embarrassing, but then obviously that makes things ten times worse….”*

The description suggests a belief that accepting support from others may mean accepting she is autistic, something she is not ready to do. In not doing so, she recognises this contributing to relational difficulties.

Olivia described being surprised by enjoying a new friendship with a work colleague, relationships she had previously separated from her home life. Success had been facilitated by a negotiated openness to understand her:

> *“….next day she said ‘oh, you really shut down, half-way through tea’….I said, ‘it was a bit much.’ She said, ‘….I’m starting to get the feel for….it’s either tea with the kids or walk with the dog, isn’t it, you can’t do both?....I like it, I do, because she is a nice person, and I like having a new person in my life.”*

Changing wellbeing and views of the self. Diagnosis and new understandings provided many with the opportunity to let go of blame. Recognition that it was ok to be who they were rather than meet some idealised version of the self was freeing:

> *“I feel free, very much more free.”(Lily)*

Many described ongoing anxiety and depression. However, others reported that adaptations they were able to make in their life meant that they experienced much less distress than previously:

> *"I don't get as much as anxiety as I used to…. because I've got better understanding of – and because I understand it better I'm actually able to deal with it better….So I build strategies around that really."(Merrell)*

Some, knowing mental health difficulties were still a fluctuating part of their lives, described finding ways to proactively develop "*coping mechanisms*" (Alice, Celia) to reduce the likelihood of becoming overwhelmed, experiencing elevated anxiety or "*going into crisis*" (Lily). This included managing social situations by doing the things that they could cope with and letting go of associated guilt. Descriptions suggest a newfound permission for participants to meet their own needs and a developing identity as someone who no longer needed to conform to be acceptable:

> *"I feel a lot better about myself….I can be happier being myself, rather than trying to fix myself and change myself and fit in."(Ruby)*

For many, understanding more about the ways autism affected them had reduced the intensity of emotions, with some describing reduced physical symptoms of anxiety and reducing medication. Over time, many described changing views of the self, one that was self-accepting and developing in confidence, but not limited by diagnosis and recognised strengths:

> *"I am still me….it's made me less hard on myself. I've given myself a bit of slack now….I think, there's some things….I'm never going to be able to do and that's just how things are. That's made me a happier person."(Celia)*
>
> *"I've got a phenomenal memory….people respect me for it. And some of my little quirks…I feel more relaxed now….because I know there's an explanation for them."(Kate)*

Many were kinder to themselves, signifying a progression from self-criticism to self-compassion:

> *"....to understand where those difficulties and stresses are coming from makes a difference in terms of how I think about myself."(Mia)*

This extended to engaging in soothing, often practical and enjoyable self-care activities, such as art, communicating online, spa days, learning and gardening.

The meaning of diagnosis. A minority of participants struggled to find overall value in the diagnosis whilst struggling with acceptance. However, others described it meaning "*everything*" (Lily, Ruby). Elaborations focused on newfound confidence to trust their own judgements, having a voice in society and recognising their contributions as valid and important:

> *"other people have been telling you for years you're wrong; now I trust that gut instinct because I know that I'm a grown woman and I know who I am now. So, it's more powerful."(Lily)*

For some, the fact that their experiences could be explained was a novel thing, having lived for so many years searching for understanding:

> *"....it means there is a logical reason for my irrational behaviour and I like that, I like there to be a reason for everything....I can prepare myself better"(Celia)*

The understanding was of profound importance, allowing several participants to make sense of a part of their "*identity*" (Hannah), one that identified part of who they were and provided a "*framework*" (Mia) for learning and improving their wellbeing. This extended to feeling there was power, strength and pride in diagnosis. Many experienced a changing view of themselves in society, one that was 'different' to some, but that difference was in fact neurodiversity and something to celebrate:

> *"we're just wired slightly differently, I don't think it's a defectiveness at all."(Mia)*

> *"Yes, I'm different, I accept that, but I'm proud to be."(Kate)*

Alongside pride participants felt in being individuals, some also recognised the resilience they had drawn from to overcome so much pre-diagnosis, a strength that they felt able to capitalise on with the support of diagnosis:

> *"….I've overcome so many things in my life, because of my inner strength….now I feel even more powerful now that I've got my diagnosis to back me up and to push me along to be even stronger still."(Ruby)*

Discussion

This study aimed to investigate the lived experiences of females being diagnosed autistic in middle adulthood using a qualitative methodology, Interpretative Phenomenological Analysis (IPA). The analysis revealed four superordinate themes: *A hidden condition; The process of acceptance; Post diagnostic impact of others; A new identity on the autism spectrum.* The themes are discussed below to consider how the current study relates to and extends existing knowledge.

Consistent with previous theorising, many participants referred to 'camouflaging' their characteristics (Bargiela et al., 2016; Hull, Petrides, Allison, Smith, Baron-Cohen, Lai & Mandy, 2017). This was motivated by a desire to 'fit in', to navigate social relationships and to behave as they 'should' by societal standards. These attempts to cope often exacerbated difficulties with mental health, consistent with previous literature (Cage, Monaco & Newell, 2017). In the current study, the need for acceptance into the social 'ingroup' pre-diagnosis was evident. Awareness of remaining on the periphery despite significant effort was intensely distressing. Consequently, several women developed an internalised view that they were intrinsically flawed.

Mental health difficulties were present across the data, with many still specifically experiencing anxiety and low mood post-diagnosis. Some had been frequently mislabelled and misdiagnosed, consistent with previous findings (Bargiela et al., 2016; Eaton, 2018). For some, mental health struggles included past suicide attempts and self-harm. One influence on declining mental health pre-diagnosis was the lack of agency women had in understanding themselves. This highlights that misdiagnosis and mislabelling was not only about a lack of understanding of autistic females across services. It also related to power issues, where others made overarching statements about who participants were. Whilst trying to understand themselves in a confusing world, this exacerbated self-doubt, shame and negative self-image.

Several participants expressed relief post-diagnosis. For some, this included a sense of "vindication" reducing long-standing shame associated with social misunderstandings. Others feared what diagnosis may mean for them, particularly at this stage of life. For many, diagnosis gave women the opportunity to commence a meaning making process as seen in previous findings (Baldwin & Costley, 2016). The current study provides more insight into this process. For many, this was the initial step in regaining control of self-understanding.

Many participants reflected back on their life, both during assessment and post-diagnosis, as reported in previous literature (Hickey et al., 2017). It was painful to interpret life experiences in a new light, one where they were not to blame. Adjustment experiences were not consistent with theories proposed by traditional grief models. For many, expression of grief related to the intense pain for all they had previously endured, leading to 'loss' of a life where they were understood by themselves and others. Thus, increasing self-acceptance highlighted the sense of pain of what they had endured. Some found this grief complicated to process, leaving them 'stuck' in a place of despair about how things could have been different.

Many participants experienced supportive reactions and adaptations post-diagnosis. The study highlighted the importance of reactions that were validating and provided opportunities for relationship development. Post-diagnosis, some participants recognised that camouflaging had unintentional consequences, with females being able to function ‘successfully’ in appointments, leading to ongoing unrecognised needs, as seen in findings by Tint & Weiss (2017). Additionally, previously held schemas of others about ASC potentially contributed to difficulties, including lost benefits and battles for support. This appears to be a particular area related to the experience of females, with their presentation not fitting previously male conceptualisations of ASC. Stereotyped understandings of ASC will likely influence referral biases for diagnosis at a younger age that rely on the reports of others, as highlighted previously (Dworzynski, Ronald, Bolton & Happé, 2012). Given the amount of emotional distress experienced by women, the study emphasises the importance of developing an understanding of ASC in females across educational, governmental and employment settings to reduce the likelihood of women enduring the same.

Previous findings suggest those viewing ASC as a form of ‘neurodiversity’ positively relate it to the self (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). Thus, unhelpful narratives experienced by two participants post-diagnosis may have partly influenced difficulties they experienced integrating diagnosis into their identity. Diagnosis in middle adulthood likely also shaped this experience. Participants had experienced many significant life-stages without a diagnosis. For several women, the prospect of a ‘new life’ at this age was psychologically daunting to contemplate.

Participants described changing relationships post-diagnosis. Some found comfort in identifying with others within the female autism community, suggesting, for some, a pull for relating and group membership. Previous findings indicate a sense of belonging to be of value to autistic women (Bargiela et al., 2016). This may relate to an increased motivation for social connection, as seen in child friendship studies (Sedgewick, Hill, Yeates, Pickering & Pellicano, 2016). Some still found social experiences difficult, but many found ways to navigate relationships, letting go of guilt associated with meeting their own needs. Several participants found power in diagnosis, relinquishing the need to assimilate to the societal norm, allowing them more choice in the trajectory of relationships. For many, this process took time. However, for several women, the diagnosis provided a sense of permission to develop an identity where they were acceptable as they were. This study extends previous understandings about what diagnosis can mean to individuals. For many, this signified transitions to a place of self-compassion which was proactively nurtured by engaging in activities consistent with their needs. Some also experienced a sense of pride in being an autistic female, emphasised by newfound beliefs that being ‘different’ was acceptable.

Strengths, limitations and future directions

The use of semi-structured interviews allowed for guided, but flexible data collection, providing individuals with the chance to freely make sense of and express their stories. Several steps were taken to assess rigor and allow for transparency when drawing conclusions from the data, including active engagement in reflexivity and independent audit. Despite these steps, it is not possible to negate all bias; therefore, all findings should be interpreted in the context of this understanding.

All participants received their diagnosis at or above the age of forty years, helpfully providing information about females’ experiences at a specific life stage post-diagnosis. Some participants were recently diagnosed, meaning their stories would likely differ in some respects to those who were diagnosed many years before. Further research may wish to investigate females’ experiences at additional time points post-diagnosis to understand the progression of adjustment experiences. Many participants described a psychological shift that allowed them to view themselves compassionately, rather than critically post-diagnosis. Greater understandings of this could be obtained by measuring levels of self-compassion and their impact in longitudinal investigations.

Participants in the sample presented with average to above intellectual ability[8]. Although this provided helpful information about a particular cohort, it leaves the voices of those with additional cognitive impairments underrepresented. Future research may wish to address this by considering supportive adaptations.

Furthermore, this research focused on females based on traditional understandings of gender. Future research may consider the role of gender more broadly, inclusive of participants with several gender identities.

Implications for clinical practice

Findings suggest the importance of flexible skills when undertaking assessments with autistic females. Assessments require skilled clinicians to consider diagnostic criteria critically alongside additional assessments to consider differing presentations. This may include supplementary interviews to help to access the subtleties of these differences, assessment of camouflaging behaviours, as well as considering alternative explanations for mental health presentations.

Individuals may require support to integrate their diagnosis into their identity, possibly dependent on age of diagnosis. Based on findings in the sample, these are areas that services may support individuals with, via groups, signposting and creating means for social connection alongside learning about ASC, exploring strengths and individuality. Services may wish to consider ways to support autistic women to foster self-compassion skills, likely to be supportive in emotional regulation.

To support early recognition and appropriate adaptations post-diagnosis, training is required to several services, schools and employers about autism in females and risk factors for mental health difficulties. This should aim to include training to broader mental health services to prevent misdiagnoses in autistic females. Development and delivery of training should include consultation with autistic females.

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[8] Intellectual ability was not assessed

Conclusions

Findings suggest widespread limited understandings of ASC in females influencing late diagnosis in the sample. They also highlight issues of power and control. Pre-diagnosis, misplaced labels and misdiagnoses were enforced upon participants contributing to ongoing battles with mental health, identity and a devalued sense of self. Post-diagnosis, participants overall had increased agency, allowing them to take control of and make sense of their own experiences. For many, this was an incredibly painful process as they re-experienced and grieved such a significant period of life. It is evident that diagnosis achieved in a timely manner would likely alleviate the distressing way life was experienced by the sample. It is paramount that training to mental health services, schools and wider agencies takes place to reduce the likelihood of unmet needs taking a significant toll on wellbeing in autistic women. Results emphasise the value of understanding oneself within a diagnostic framework where needs and strengths can be assessed, nurtured and supported.

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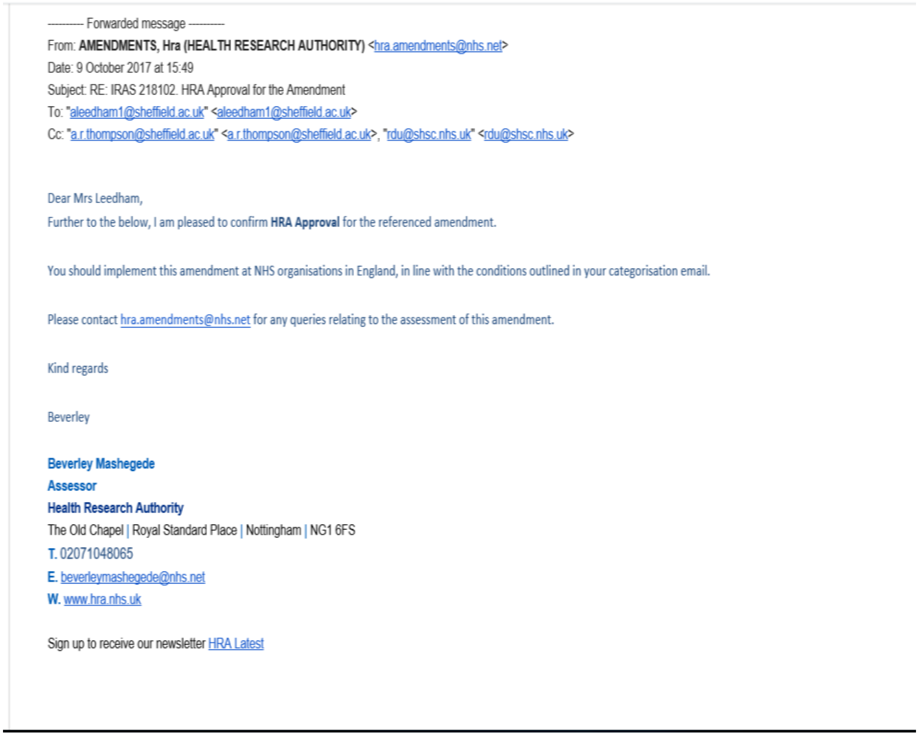
Appendix A. Ethical approval and considerations

Health Research Authority and Research Ethics Committee approval



---------- Forwarded message ----------
From: **AMENDMENTS, Hra (HEALTH RESEARCH AUTHORITY)** <hra.amendments@nhs.net>
Date: 9 October 2017 at 15:49
Subject: RE: IRAS 218102. HRA Approval for the Amendment
To: "aleedham1@sheffield.ac.uk" <aleedham1@sheffield.ac.uk>
Cc: "a.r.thompson@sheffield.ac.uk" <a.r.thompson@sheffield.ac.uk>, "rdu@shsc.nhs.uk" <rdu@shsc.nhs.uk>

Dear Mrs Leedham,
Further to the below, I am pleased to confirm **HRA Approval** for the referenced amendment.

You should implement this amendment at NHS organisations in England, in line with the conditions outlined in your categorisation email.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Beverley

Beverley Mashegede
Assessor
Health Research Authority
The Old Chapel | Royal Standard Place | Nottingham | NG1 6FS
T. 02071048065
E. beverleymashegede@nhs.net
W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest

Trust approval

Ref 218102 Amendment 1 approval - SHSC

Yiwei Harland <Yiwei.Harland@shsc.nhs.uk>
to me, m.freeth@sheffield.ac.uk, Andrew
Fri, 27 Oct 2017, 11:59

Dear Mrs Leedham

Re: Amendment to 218102 - Exploring the Lived Experiences of Females Receiving an Autism Diagnosis as an Adult: A Phenomenological Study

Sponsor's Unique Amendment Number: 1
Amendment date: 22 September 2017
REC Favourable Opinion date: 03 October 2017
HRA Approval date: 09 October 2017

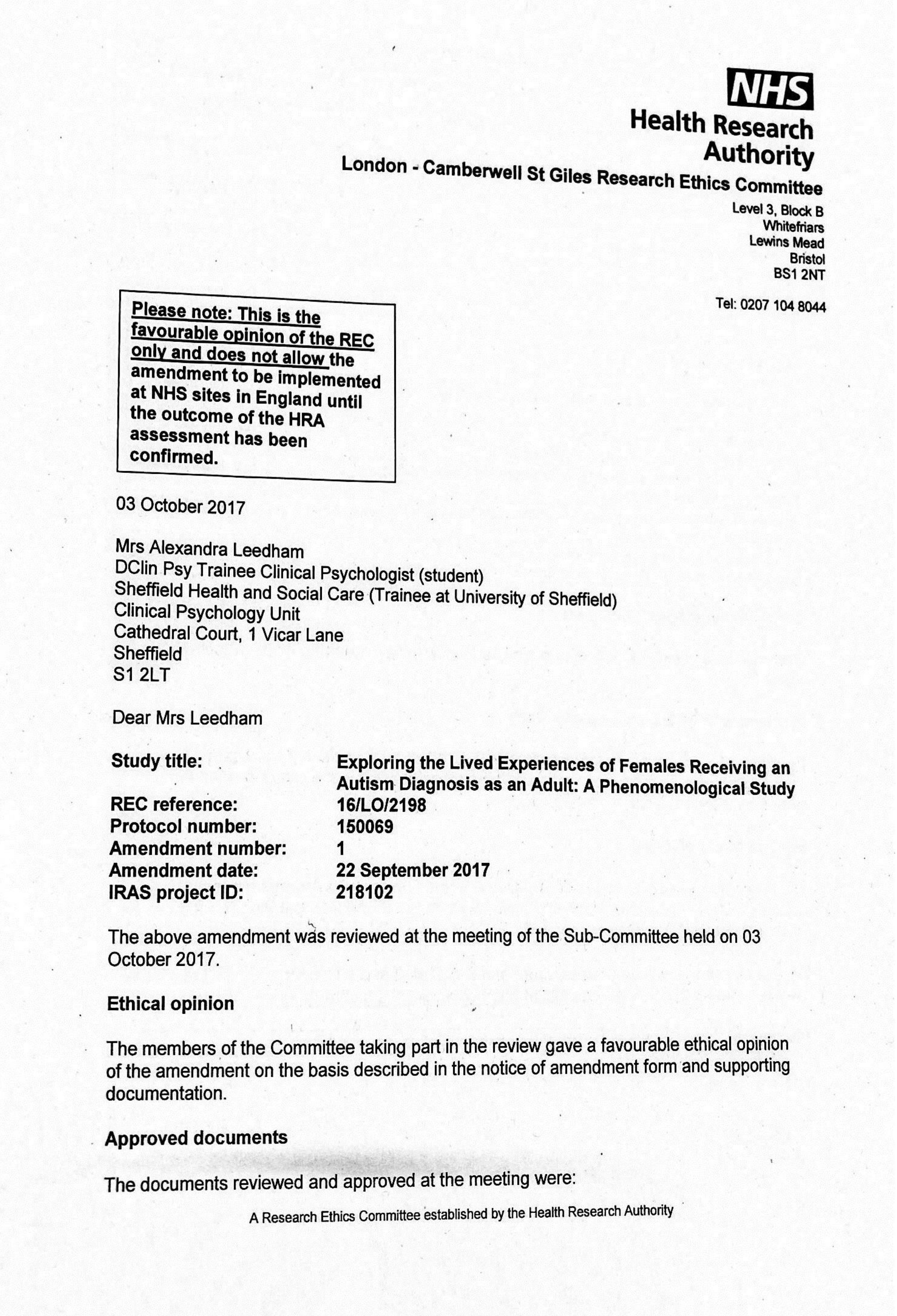
Following review of the above amendment, Sheffield Health & Social Care NHS Foundation Trust has decided to accommodate it. The amendment may therefore be immediately implemented at this site under the existing NHS Permission. Please note that you may implement only those changes that were described in the amendment notice or letter.

Kind regards,

Yiwei Harland

Research Governance Officer
Research Development Unit
Sheffield Health & Social Care NHS Foundation Trust
Fulwood House
Old Fulwood Road

Research Ethics Committee approval



NHS
Health Research
Authority
London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Tel: 0207 104 8044

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

03 October 2017

Mrs Alexandra Leedham
DClin Psy Trainee Clinical Psychologist (student)
Sheffield Health and Social Care (Trainee at University of Sheffield)
Clinical Psychology Unit
Cathedral Court, 1 Vicar Lane
Sheffield
S1 2LT

Dear Mrs Leedham

Study title:	**Exploring the Lived Experiences of Females Receiving an Autism Diagnosis as an Adult: A Phenomenological Study**
REC reference:	**16/LO/2198**
Protocol number:	**150069**
Amendment number:	**1**
Amendment date:	**22 September 2017**
IRAS project ID:	**218102**

The above amendment was reviewed at the meeting of the Sub-Committee held on 03 October 2017.

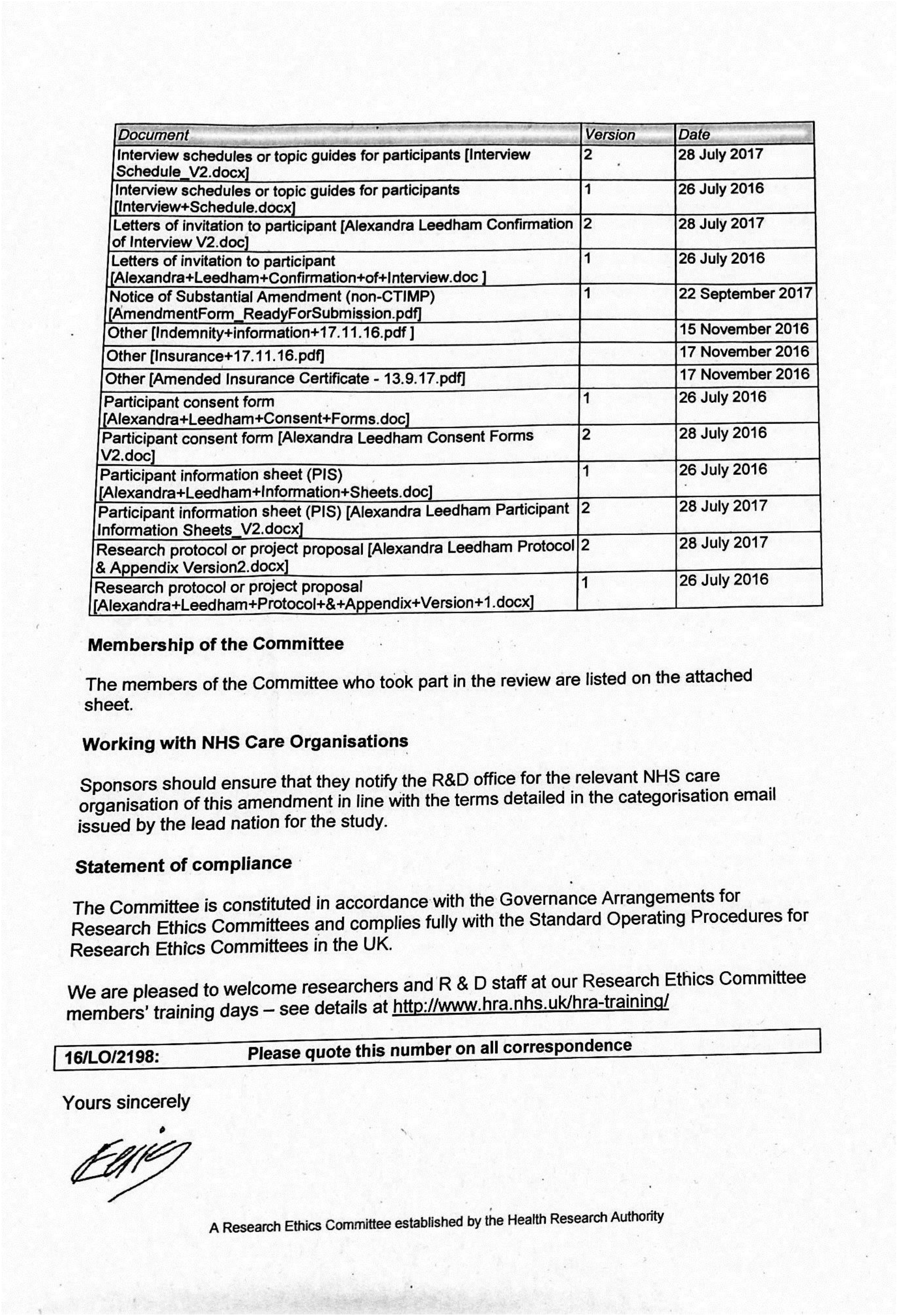
Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Research Ethics Committee approval continued



Document	Version	Date
Interview schedules or topic guides for participants [Interview Schedule_V2.docx]	2	28 July 2017
Interview schedules or topic guides for participants [Interview+Schedule.docx]	1	26 July 2016
Letters of invitation to participant [Alexandra Leedham Confirmation of Interview V2.doc]	2	28 July 2017
Letters of invitation to participant [Alexandra+Leedham+Confirmation+of+Interview.doc]	1	26 July 2016
Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_ReadyForSubmission.pdf]	1	22 September 2017
Other [Indemnity+information+17.11.16.pdf]		15 November 2016
Other [Insurance+17.11.16.pdf]		17 November 2016
Other [Amended Insurance Certificate - 13.9.17.pdf]		17 November 2016
Participant consent form [Alexandra+Leedham+Consent+Forms.doc]	1	26 July 2016
Participant consent form [Alexandra Leedham Consent Forms V2.doc]	2	28 July 2016
Participant information sheet (PIS) [Alexandra+Leedham+Information+Sheets.doc]	1	26 July 2016
Participant information sheet (PIS) [Alexandra Leedham Participant Information Sheets_V2.docx]	2	28 July 2017
Research protocol or project proposal [Alexandra Leedham Protocol & Appendix Version2.docx]	2	28 July 2017
Research protocol or project proposal [Alexandra+Leedham+Protocol+&+Appendix+Version+1.docx]	1	26 July 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

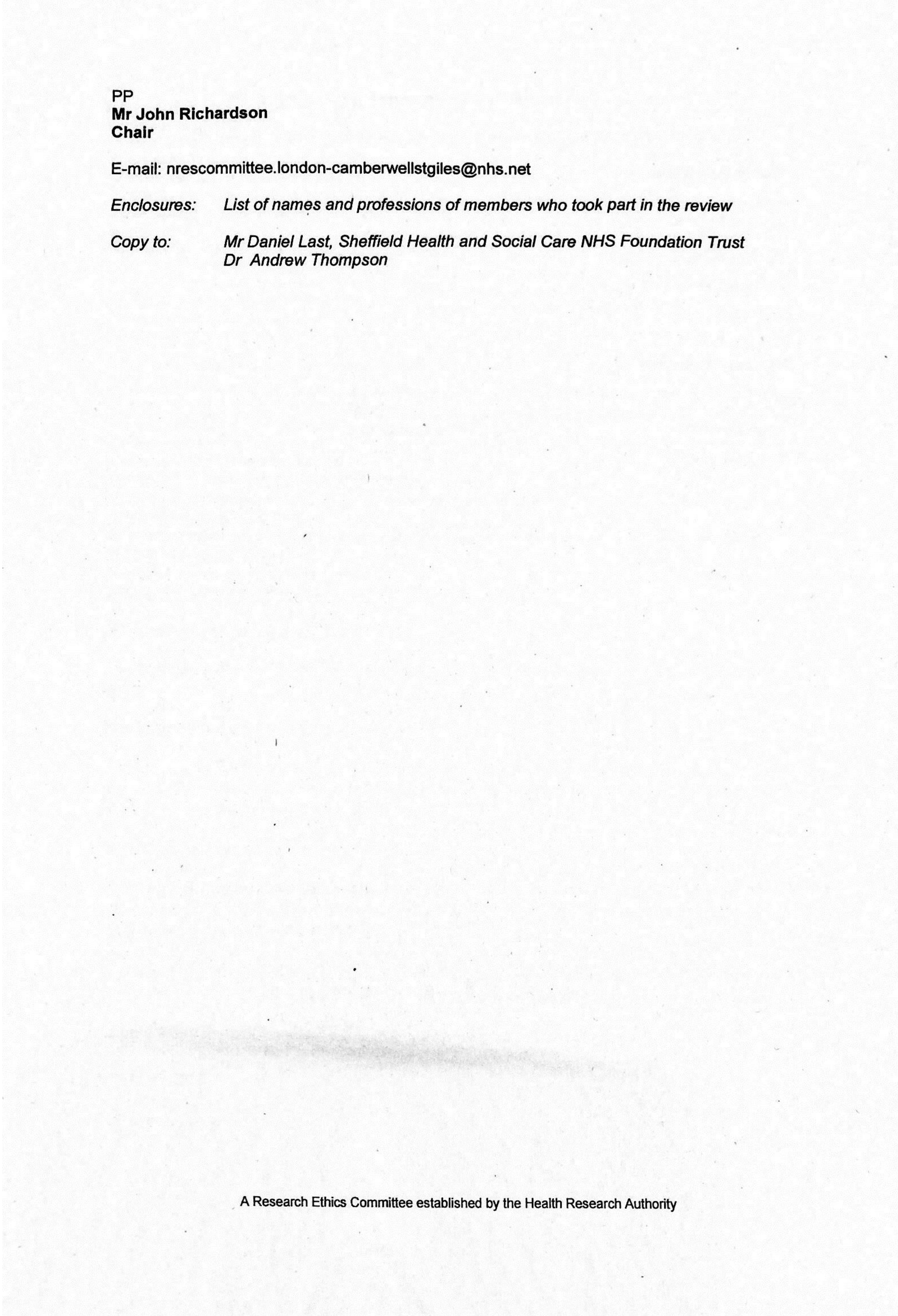
We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

16/LO/2198: **Please quote this number on all correspondence**

Yours sincerely

A Research Ethics Committee established by the Health Research Authority

Research Ethics Committee approval continued



PP
Mr John Richardson
Chair

E-mail: nrescommittee.london-camberwellstgiles@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Mr Daniel Last, Sheffield Health and Social Care NHS Foundation Trust*
Dr Andrew Thompson

A Research Ethics Committee established by the Health Research Authority

Ethical considerations

All encrypted data was transferred safely for transcription and password protected. Interview data was deleted from the recorder following analysis and all details in transcriptions were anonymised so that individuals cannot be identified. All electronic data files were deleted following completion of the study.

Participation in the research project was voluntary and participants were provided with clear written and verbal information in order to make an informed choice about participation. Participants had the option to withdraw from the project at any point and no questions were asked as to why this was the case. Participants were aware that they could refuse to answer any questions or stop the interview if they did not wish to continue. All participants were aware that choosing to withdraw would have no impact on their appointments within services they access.

As the researcher is experienced in undertaking therapy, the researcher followed IPA and supervision guidance about developing research interview skills that were flexible, whilst not undertaking therapy. This was to maintain client safety as well as being clear that clients had consented to participate in a research project, not a therapy.

All participants were given the option for a follow up appointment with a member of the Sheffield Adult Autism and Neurodevelopmental Service team or they could be provided with other support options (e.g. their GP or the Samaritans). During the interview, the researcher used her clinical judgement about the appropriateness of this, even if this was not openly expressed by participants, and responded to this as needed. It was not appropriate to conduct a detailed clinical risk assessment during a research interview, in line with IPA guidance. However, any concerns about the safety of a participant were discussed directly with them and with a member of the SAANS team.

Appendix B. Recruitment flyers

(Provided by clinicians)

The
University
Of
Sheffield.

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology
(DClin Psy) Programme
Clinical supervision training
and NHS research training & consultancy.

You are invited to take part in the following research project:

Exploring the Lived Experiences of Females Receiving an Autism Diagnosis in Middle Adulthood: A Phenomenological Study

Information Sheet

This research is being conducted by Alexandra Leedham, a Trainee Clinical Psychologist at the University of Sheffield.

She is interested in investigating females' experiences of being diagnosed with Autism in middle adulthood. She will be interviewing individuals one time and you are being invited to take part.

Alexandra will be supervised during this project by three supervisors. They are:

- Dr Megan Freeth, Lecturer in Cognitive Psychology, Sheffield Autism Research Lab, University of Sheffield

- Dr Andrew Thompson, Reader in Clinical Psychology, Clinical Psychology Unit, University of Sheffield

- Dr Richard Smith, Senior Clinical Psychologist, Sheffield Adult Autism and Neurodevelopmental Service

You have been invited as you have received a diagnosis of Autism at the Sheffield Adult Autism and Neurodevelopmental Service

What is the project's purpose?

The purpose of the research is to better understand people's experiences of receiving a diagnosis. Individuals have different experiences of receiving a diagnosis of Autism and react to this in different ways. This research aims to find out what people's experiences have been like, how they feel about their diagnosis and how this has impacted on their life. This can help services to learn more about how to support people with an Autism diagnosis.

To be included in the project you need to meet the following criteria:

- To be able to consent to participate
- To have been born female
- To speak English fluently
- To have received an Autism Spectrum Disorder diagnosis (it is ok to have received other diagnoses as well)
- To have been aged 40 years old or above when you received your diagnosis

How do I take part?

If you are interested in the study, please go to the webpage below and this will tell you more information about the project.

http://autismresearchlab.group.shef.ac.uk/Take_Part.html

Please click on the link titled **Female ASD Study** and enter the password **Female2017**

This will take you to an online form which asks you to register your interest in the study and provide your contact details. Alexandra will then contact you by telephone or email so that you can arrange an interview time together. She will send you a letter to confirm the date and time of the interview. She will also send you a paper copy of the information sheet from the webpage and a consent form.
You will be asked to attend an interview at Sheffield Adult Autism and Neurodevelopmental Service to talk about your experience of being diagnosed with Autism.

If you have any questions or any difficulty accessing the webpage, please contact Alexandra on:

aleedham1@sheffield.ac.uk

*If you feel it would be easier for your contact at the Sheffield Adult Autism and Neurodevelopmental Service to add your contact details to the webpage for you, they can do this for you. They will not then be told if you decided to take part or not.

This study is voluntary. If you decide you do not want to take part, please ignore this information sheet. This will not affect any support you receive from the Sheffield Adult Autism and Neurodevelopmental Service.

(Postal flyer)

The
University
Of
Sheffield.

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology
(DClin Psy) Programme
Clinical supervision training
and NHS research training & consultancy.

You are invited to take part in the following research project:

Exploring the Lived Experiences of Females Receiving an Autism Diagnosis in Middle Adulthood: A Phenomenological Study

Information Sheet

This research is being conducted by Alexandra Leedham, a Trainee Clinical Psychologist at the University of Sheffield.

She is interested in investigating females' experiences of being diagnosed with Autism in middle adulthood. She will be interviewing individuals one time and you are being invited to take part.

Alexandra will be supervised during this project by three supervisors. They are:

- Dr Megan Freeth, Lecturer in Cognitive Psychology, Sheffield Autism Research Lab, University of Sheffield
- Dr Andrew Thompson, Reader in Clinical Psychology, Clinical Psychology Unit, University of Sheffield
- Dr Richard Smith, Senior Clinical Psychologist, Sheffield Adult Autism and Neurodevelopmental Service

You have been invited as you have received a diagnosis of Autism at the Sheffield Adult Autism and Neurodevelopmental Service

What is the project's purpose?

The purpose of the research is to better understand people's experiences of receiving a diagnosis. Individuals have different experiences of receiving a diagnosis of Autism and react to this in different ways. This research aims to find out what people's experiences have been like, how they feel about their diagnosis and how this has impacted on their life. This can help services to learn more about how to support people with an Autism diagnosis.

To be included in the project you need to meet the following criteria:

- To be able to consent to participate
- To have been born female
- To speak English fluently
- To have received an Autism Spectrum Disorder diagnosis (it is ok to have received other diagnoses as well)
- To have been aged 40 years old or above when you received your diagnosis

How do I take part?

If you are interested in the study, please go to the webpage below and this will tell you more information about the project.

http://autismresearchlab.group.shef.ac.uk/Take_Part.html

Please click on the link titled **Female ASD Study** and enter the password **Female2017**

This will take you to an online form which asks you to register your interest in the study and provide your contact details. Alexandra will then contact you by telephone or email so that you can arrange an interview time together. She will send you a letter to confirm the date and time of the interview. She will also send you a paper copy of the information sheet from the webpage and a consent form.
You will be asked to attend an interview at Sheffield Adult Autism and Neurodevelopmental Service to talk about your experience of being diagnosed with Autism.

If you have any questions or any difficulty accessing the webpage, please contact Alexandra on:

aleedham1@sheffield.ac.uk

This study is voluntary. If you decide you do not want to take part, please ignore this information sheet. This will not affect any support you receive from the Sheffield Adult Autism and Neurodevelopmental Service.

Appendix C. Interview confirmation letter

The
University
Of
Sheffield.

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology
(DClin Psy) Programme
Clinical supervision training
and NHS research training & consultancy.

Research Project: Exploring the Lived Experiences of Females Receiving an Autism Diagnosis in Middle Adulthood: A Phenomenological Study

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Dear….

My name is Alexandra Leedham and I am a Trainee Clinical Psychologist at the University of Sheffield. Thank you for registering your details for this study. As we discussed (on the phone/by email), the study is interested in your experiences of receiving a diagnosis of Autism.

We arranged an interview date for:

Day, Date, Time

Please come along to the Sheffield Adult Autism and Neurodevelopmental Service (SAANS) for the interview.

I have included an information sheet with this letter that tells you more about the project. I have also included a consent form for you to read. We can look at the consent form together at the interview and sign it on this date.

If the interview time is not convenient, please contact me to let me know. If you have any questions, please contact me on aleedham1@sheffield.ac.uk. Alternatively, you can contact your worker at SAANS and they will pass a message on to me.

Yours sincerely

Alexandra Leedham
Trainee Clinical Psychologist

Appendix D. Participant information sheet

The
University
Of
Sheffield.

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy)
Programme
Clinical supervision training and NHS
research training & consultancy.

Research Project: Exploring the Lived Experiences of Females Receiving an Autism Diagnosis in Middle Adulthood: A Phenomenological Study

Information Sheet

This research is being conducted by Alexandra Leedham, a Trainee Clinical Psychologist at the University of Sheffield.

She is interested in investigating females' experiences of being diagnosed with Autism in middle adulthood. She will be interviewing autistic individuals one time you have said that you would like to take part. You can read information about this study on the Sheffield Autism Research Lab webpage. The information in this form tells you more about the project.

Alexandra will be supervised during this project by three supervisors. They are:

- Dr Megan Freeth, Lecturer in Cognitive Psychology, Sheffield Autism Research Lab, University of Sheffield

- Dr Andrew Thompson, Reader in Clinical Psychology, University of Sheffield

- Dr Richard Smith, Senior Clinical Psychologist, Sheffield Adult Autism and Neurodevelopmental Service

The project's purpose

The purpose of the research is to better understand people's experiences of receiving a diagnosis. Individuals have different experiences of receiving a diagnosis of Autism and react to this in different ways. This research aims to find out what people's experiences have been like, how they feel about their diagnosis and how this has impacted on their life.

Why have I been chosen to take part?

Alexandra would like to interview between 10-14 individuals with a diagnosis of Autism for this research project. The information flyer was given to you as you have received a diagnosis of Autism at the Sheffield Adult Autism and Neurodevelopmental Service. You have indicated that you would like to take part in the research.

How do I take part?

Thank you for registering your interest in this project. You have agreed an interview time with Alexandra and you have been asked to attend this interview at Sheffield Adult Autism and Neurodevelopmental Service.

What will happen at the interview?

Alexandra will meet with you at the interview. You will be asked to sign a copy of the consent form. You will be able to talk about your experience of being diagnosed with Autism. Alexandra will ask you about yourself, including your name and diagnosis. She will also ask you questions about your experiences of receiving an Autism diagnosis and how these have impacted on your life. Alexandra would like to digitally audio record the interview so she can listen back to it. The interview will take between 60-90 minutes.

Do I have to take part?

No. You do not have to take part in this research study. Choosing not to take part will not affect any of the support you receive from Sheffield Adult Autism and Neurodevelopmental Service. Participation in this research study is voluntary. If you do decide to take part but then change your mind, you have the right to withdraw from the study **at any time**. You have the right to not answer any questions during the interview. You will not be asked why you have withdrawn as this is your decision.

What will happen to my information?

The information you provided on the website has been used to contact you. Alexandra is the only person able to access this information and this information will be deleted when the study is complete.

The consent form and paper copies of personal information we have about you will be locked in a cabinet at the University of Sheffield. Only Alexandra and the appointed person at the University responsible for this cabinet will have access to this information.

Information from the digital audio recorder will be used for analysis only. The recorder is encrypted, meaning only a person with a password can access this. This will be stored in a locked cabinet at the University of Sheffield. Recordings from the interview will be stored on a password protected computer. The digital folder on the computer will also be password protected and encrypted. This means only Alexandra and her supervisors will have access to this information.

When the study is completed, all files will be deleted from this computer. There will be paper versions of the interview transcripts. These will be stored for a maximum of 6 years in a locked cabinet at the University of Sheffield. They will be securely disposed of after this time.

What are the possible benefits of taking part?

Whilst there are no immediate benefits of taking part, people can find it helpful to talk about their experiences. Findings from the study will be shared with professionals who work with autistic people. It is hoped that this work will have a positive impact by helping individuals to understand your experiences and learn what things can be helpful in meeting the needs of autistic people. This will help clinicians to adapt their post-diagnostic services for people receiving a diagnosis in the future.

What are the possible disadvantages or risks of taking part?

Alexandra understands that talking about your experiences can be difficult or uncomfortable. She will be aware of this and if you are upset, she will ask you if you want to continue. If you do want to continue, Alexandra will allow you time and space to feel safe to continue. You can also take a break if you wish and leave the room. If you choose not to continue with the interview, Alexandra can help you to contact a friend or family member to support you. You may wish to bring somebody with you on the interview day so they can wait for you whilst you are talking with Alexandra.

If Alexandra is concerned about your wellbeing, she may ask you to contact your GP or speak to another professional at Sheffield Adult Autism and Neurodevelopmental Service.

What happens if the research study stops earlier than expected?

This would only happen due to unforeseen circumstances. If the research stopped earlier than planned, Alexandra or your contact at Sheffield Adult Autism and Neurodevelopmental Service would contact you to explain this.

What if something goes wrong?

If you are concerned about anything about the project, please contact Alexandra and she will do her best to address this. If you feel your concerns have not been answered, you may contact:

Dr Richard Smith
Sheffield Adult Autism and Neurodevelopmental Service
Michael Carlisle Centre
75 Osborne Road, Sheffield
S11 9BF

or

Dr Andrew Thompson
Clinical Psychology Unit
Department of Psychology
The University of Sheffield
Western Bank,
Sheffield,
S10 2TN

If you have a complaint and you feel it has not been dealt with to your satisfaction, you can contact the University Secretary Dr Andrew West via email on registrar@sheffield.ac.uk or telephone on 0114 222 1051. Dr West's Personal Assistant details are:

Mrs Sandra Ibbotson

s.ibbotson@sheffield.ac.uk
0114 222 1051

Will people know I have taken part in this project?

All the information that we collect about you during the course of the research will be kept strictly confidential. Only Alexandra will know the names of the people who were interviewed. You will not be able to be identified in any reports or publications. As explained earlier on this information sheet, if Alexandra has any concerns about your wellbeing, she may need to talk to somebody about this. When you meet with Alexandra for the interview, she can explain this further and you can ask any questions.

What will happen to the results of the project?

Alexandra plans to publish the findings from the research in the Journal of Autism and Developmental Disorders. She will also share the findings with individuals at the Sheffield Adult Autism and Neurodevelopmental Service and findings will be shared on the Sheffield Autism Research Lab webpage which you can access if you wish. You will not be identified in any report or publication.

Who has ethically reviewed the project?

The project has been reviewed by the University of Sheffield research governance and Sheffield Health and Social Care Trust research governance.

Research funding

This research project is funded by the University of Sheffield

If you have any questions, you can ask Alexandra these at your interview. If you have any before this time, she can be contacted on: aleedham1@sheffield.ac.uk

Thank you for taking part in this research

Appendix E. Participant consent form

The University Of Sheffield.

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Research Project: Exploring the Lived Experiences of Females Receiving an Autism Diagnosis in Middle Adulthood: A Phenomenological Study

Researcher: Alexandra Leedham

Participant identification number: …………………………..

Please read the information below and write your initials in the boxes if you agree to the statements.

1. I confirm that I have read and understand the information sheet dated *[insert date]* for the above study. ☐
2. The information sheet and the researcher explained the research project. Any questions I had about this information have been answered. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and with no negative consequences. ☐
4. If I do not want to answer any question or questions, I understand that I am free to decline. ☐
5. I understand that nothing will affect the support I receive from any services. ☐
6. I understand that I can contact the researcher, Alexandra Leedham on 0114 222 2000 or aleedham1@sheffield.ac.uk if I wish to withdraw. ☐
7. I understand that my participation and the information I provide during my interview will be kept strictly confidential. ☐
8. If, during my interview, I were to tell the researcher that I or someone else was at risk of harm, I understand that confidentiality may be broken to ensure my safety and that of other people (as outlined in the participant information sheet). ☐
9. I give permission for members of the research team to have access to my anonymised interview data. My name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
10. I agree for the data collected from me to be used in future research. ☐
11. I agree to take part in the above research project. ☐

______________________	________________	______________________
Name of Participant	Date	Signature
______________________	________________	______________________
Name of Researcher	Date	Signature

Appendix F. Audit form

1. Are field notes made by the researcher as part of the reflexivity process?

   Yes/Partially/No

2. Has data been sufficiently coded?

   Yes/Partially/No

3. Has data been systematically coded? (i.e. line by line in the right hand margin focusing on linguistics, concepts and descriptive comments, emerging themes in left hand margin)

   Yes/Partially/No

4. Has the researcher engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (evidenced by looking at different versions of the Excel documents, notes and changes to coding/themes).

   Yes/Partially/No

5. Looking at randomly selected excerpts from the data against the corresponding coding and themes recorded in Excel - are these consistent?

   Yes/Partially/No

6. Are quotes sufficient to provide evidence of the themes and subthemes?

   Yes/Partially/No

Appendix G. Example transcript with initial coding and emerging themes

Emerging themes		Descriptive Linguistic Conceptual	**Exploratory comments**
Research Search for understanding	P	Well, I kind of guess that I was expecting it anyway, because I'd done a lot of um.. a lot of research. I guess that's the way I am, if somebody tells me something I have to know everything there is to know about it, so um.. I'd done online testing as well, which um.. so I guess, I didn't know really. It was.. it – it kind of change – it changed – I seemed to recall saying it changed the way I saw things, at the time. Um.. didn't I? Do you remember?	Tentative language Had researched autism Changes the way saw things
	M	Hmm.	
	A	Can you say a bit – what does that mean, changed the way you saw things?	
Looking back on the past Fitting in before Feeling different to others before, isolated, weird	P	Well, because all my life I'd been told I was stupid and um, useless and.. I suddenly realised, I think it just … I think people have always – I've always felt that, that I was doing something wrong and that I shouldn't be doing it and suddenly I had validation for why I was doing it, it gave me that.. and I knew then that I wasn't alone, I wasn't the only one that was like it. I'd always felt so isolated – I mean I still feel isolated in that I mean – in some ways, because you kind of do when you – when you feel that you're weird and you're different and you see and hear and experience things differently to the way other people do. It's hard, I mean it – it's difficult to overcome those feelings I guess when you're my age, when you've spent your whole life feeling that way.	Emotive language Past – stupid, useless, isolated, weird, different Past – thought doing things wrong. Validation. Not alone (?fitting in) but still feels some of those things (different, weird) Hard to overcome especially at older age
	A	Yes. You said that there was validation, it felt like. Could you say a bit more about what that felt like?	

Diagnosis as validation Processing and adjusting Permission to be self Process of adjusting to accepting ok to be herself Identity	P	.. I think it's – and it's something that – I think that's something that, hmm.. has been kind of becoming more and more so. I'm and I think it probably will continue to , because it takes time to process these things, particularly being older, and as I said, this whole lifetime thinking one way, so it's a kind of – it's permission to be me rather than try to be something that.. I think that's a big thing, that I feel now that I have permission to be who I am, rather than trying to conform to something that I'm not, just because that's what everyone expects me to be, because that's the way everybody else is, and I don't – no, I don't feel – I'm beginning to sort of, 2 years on, I'm beginning to actually feel enough confidence to feel that actually I can be me and I don't have to be like everybody else. Would you agree with that? Because you've seen how I've changed.	Validation ?Moving through an adjustment process Takes time to process Lifetimes of thinking about self differently Permission to be self (?fitting in – with others/ok to be self). Idea that others are different to her Developing confidence ok to be herself (?process to get there - acceptance)
	M	Yes. I mean, when you received the diagnosis, you said at the time how you suddenly realised you weren't wrong being who you were.	
	P	Thanks	
	A	So you said there about conforming. Is that something that you feel you have done, up until then or on the past?	
Past copying others to fit in Aiming to conform, masking Positive to have diagnosis Past guilt about being self	P	Never completely, but yes, I kind of.. um.. well, yes, I guess I have, I never – um.. well, part of it is that I've never really understood how I'm supposed to be, and so I've had to copy other people to fit in, and now I've realised actually I don't need to do that, I can – particularly and that's one of the reasons why I think it's good to have – even when you're older – to have a diagnosis, because you can, when you're older, you kind of – well, you're not as fussed about what other people think anyway because you reach a point where – I think most people, when they get older, tend to become more individual, or a lot of people do anyway. Um, but I am actually now have got permission to do that,	Never completely conformed but didn't know how should be Copied others to fit in before (?Camouflage) Good to have diagnosis even when older Process of aging – less bothered about opinions Has permission to be self.

Permission with diagnosis to be self (acceptance)		which I didn’t have before, so I’ve always felt guilty about being me, and now I don’t.	Guilty about before. Now ok with being self.

Appendix H. Reflexive diary excerpt

Interesting interview today. Quite difficult to read as limited facial expressions. Made me feel awkward to not get any visual feedback especially when discussing some very emotive parts. Felt like an easier interview in a lot of ways to others as was more of a flow overall. Found myself feeling very warm towards her. Perhaps her age which was similar to my mum's made me feel quite drawn to her.

Participant appeared quite guarded at times with certain questions and I wondered about whether this related to her previous experience of professionals. She described having been misunderstood throughout her life from school onwards. This is still the case in many ways. ?if she is aware that certain things could be misconstrued.

Very positive descriptions of the impact of diagnosis on her wellbeing, self-esteem. Describing a lot of pride as an autistic woman. Really lovely to hear and aware myself in the room that I felt very interested in knowing more about this stuff – conscious of asking additional questions if it related to what I needed to know for my research questions, not just what I was interested in. I wonder if I have positive thoughts about how ASC diagnosis can be supportive based on clinical experiences that could bias my interpretation– something for me to be aware of and refer back to.

Interesting narrative around ASC. On the one hand, quite guarded, but then when describing pride in being autistic, very open to discussion and provided long descriptions. The participant provided almost an ASC versus neurotypical narrative at times, that autistic people are better and she knows this now that she has been diagnosed. Interesting and made me wonder if she was aware of this, or the impact on me of that narrative as someone who is neurotypical. Made me wonder if she had felt powerless pre-diagnosis versus the ability to be in control of her own experiences more so post diagnosis which made me feel happy for her.

Appendix I. Selection of illustrative participant quotes per theme

Superordinate themes	**Subthemes**	**Quotes**
A hidden condition	Pretending to be 'normal' and fitting in	*"It's like you pretend to be enjoying the conversations that you're in or the social situations that you're in and inside you're like – it's like being a duck, you know, your little feet are going like this underneath the water and you've got palpitations and everything and I just think…." (Ruby)*
	Mental health and mislabelling	*"I kind of collected labels of various sorts, until I reached the point where I got the Autism diagnosis"(Mia)* *"most of my adult life I was in the mental health system, being misdiagnosed, being mistreated, being drugged up to my eyeballs, being sort of blamed for not getting better" (Alice)* *"I thought I was going mad….I don't think I was an angry person before [diagnosis]; I was confused and frustrated and I was struggling to cope" (Olivia)*
The process of acceptance	Initial reactions and search for understanding	*"And then I thought that once I got the diagnosis that I'd be really happy, and I was surprised to find out that I wasn't; I went through a rollercoaster of emotions and just thinking 'well, you know, is this a good thing or a bad thing?'" (Ruby)* *"Because I was really starting to really spiral downwards, um, with coping, um, and oh, I was, I was so relieved and I thought 'that's it', and it was that sense that it made sense of things. And so it kind of – I was more elated, I was very elated for quite a long period of time, um, [husband] said I was like a spaniel, a spaniel that had been given two tennis balls. I was like 'yay!'"(Olivia).*

	Reliving life through a new lens	*“….things come back, if that makes any sense at all – I’m not – my conscious brain is not involved in it, it’s just a sudden recall of something and the realisation – it can be triggered by all sorts of things, probably by something….that feels similar in the present that has a hook back in the past that brings back a memory, I would imagine is what the trigger is.” (Merrell)* *“….like when I got married and then I had my kids and the failures as a parent, because I didn’t understand stuff or I wasn’t able to cope with the sensory overload of the screaming children and all of that, you go through the whole thing and you think about all of it with new glasses on, with that understanding. And that’s painful to do.” (Lily)*
	Grief and reflections on the past	*“I think if I’d been diagnosed then I’d have got the help I needed and then eventually when I became an adult I’d probably be more accepting of the situation” (Elizabeth)* *“….thinking back to the teenage years where my mother was telling me I was mental, going on the way I was.” (Kate)*
Post diagnostic impact of others	Initial reactions of others	*“So I found a book I found that very helpful, I found ‘Nerdy, shy and socially inappropriate’; it’s a very good read for people who want to – it’s most like myself, so um, my close friends, I bought them all a copy and said ‘here you go, that’s a handy read.’ And that actually was, you know, and really, we don’t sit down and talk about my autism, but they will be a lot more understanding of if we’re in somewhere loud, that I’ll just get up and walk off, they’ll understand that.” (Olivia)*
	Stereotyped assumptions	*“So, yes – I think from speaking to a lot of other women and adults, they have the same issues of people just um, looking at you and thinking ‘well, I don’t see what the issues are’, but you know, we spend our whole lifetime practicing and pretending to fit in to try and be accepted.” (Hannah)* *“because you know people are going to say ‘oh, well you don’t look like you have.’ ‘Oh, you’re very sociable.’ Well, yes, that’s because I’m acting half the time and I don’t – to be honest I’m not interested in half the stuff you’re saying to me and I don’t really want this conversation.” (Ruby)* *“the moment this idea that I might have Asperger’s came up, the support people I was with at the time just dropped me like a hot potato. It was like ‘oh, you’re in that category now, we don’t want you anymore.’”*(Alice)

A new identity on the autism spectrum	Negotiating relationships, connections and community	*"So I found some on Facebook, some adult autism places, who – so I talked to people about that, I'm struggling with this, this and this- you could kind of understand each other. So that really helped. And then I just did a lot of research on high functioning autism and one of the websites I found myself. And then I joined this, there's like a website autism thing, I joined that too. That really helped, because even though my husband has not got autism, and he tries to understand, I needed to relate to people who did have it. So I did that really and that helped. " (Elizabeth)*
	Changing wellbeing and views of the self	*"I'm no longer depressed, no longer on anti-depressants, don't take as much anti-anxiety medication as I used to…"(Lily)* *"Yes. I feel um, yes, I feel less anxious about things that I can't do anything about or that I know I'm not going to be able to do, so I suppose that's an improvement in mental health." (Celia)*
	The meaning of diagnosis	*"Well, there isn't an area in life, you know if you do – you know, work, relationships, family, there isn't an area of life, my life, that it hasn't touched." (Lily)* *"I'm glad that I have this diagnosis and the understanding is just crucially important." (Hannah)* *"And you know, the sort of coping mechanisms that any human being puts in to place, mine are ten-fold, to deal with the things I can't deal with." (Olivia)*