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University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

‘It’s a Challenge, but I’m up for it’: Exploring the Life Experiences and Self-Concept of Autistic Adolescents

by

Stacey Louise White BSc

Thesis for the degree of Doctorate in Clinical Psychology

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University of Southampton

Abstract

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The first chapter of this thesis is a systematic review of the available qualitative literature exploring the life experiences of autistic adolescents. A thematic synthesis of the findings of 11 qualitative studies was completed. Three themes pertinent to the lived experiences of autistic adolescents were identified: 'social experiences', 'personal experiences' and 'working out what helps me'. Supported by the literature, these findings offer insight into the shared experiences of autistic individuals during adolescence; highlighting factors that may impact autistic adolescents' wellbeing, and identifying possible support options. Further research is required in this field to enhance the understanding of life experiences of autistic adolescents from first-hand perspectives. This chapter concludes with clinical and educational recommendations.

The second chapter of this thesis is a qualitative empirical study exploring the self-concept of adolescent females diagnosed as on the autism spectrum in adolescence. Individual semi-structured interviews were completed with six participants, aged 14-18 years old. Interview transcripts were analysed using Interpretative Phenomenological Analysis, identifying four themes: 'belonging', 'struggling sense of self', 'outsider support' and 'moving towards the authentic self'. Participants in this study appeared to journey through experiences of belonging, struggling sense of self and outsider support before moving towards a sense of authenticity. This was discussed in relation to the literature. In addition to this, factors enhancing participants' sense of self were discussed. This chapter concludes with consideration of directions for further research and clinical recommendations which may enhance the support provided to this population.

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Research Thesis: Declaration of Authorship

Print name: Stacey Louise White

Title of thesis: 'It's a Challenge, but I'm up for it': Exploring the Life Experiences and Self-Concept of Autistic Adolescents

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: Date:

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To my littlest loves, I am dedicating this thesis to you in the hope that it encourages you to follow your dreams, believe in yourselves and never give up. I will always be here cheering you on.

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With the oversight of my main supervisor, editorial advice has been sought. No changes of intellectual content were made as a result of this advice.

Chapter 1 Exploring the Life Experiences of Adolescents on the Autism Spectrum: A Systematic Review of the Qualitative Evidence

1.1 Introduction

In line with the evidence base and preferences of the autistic community, this thesis will draw upon the endorsed terminology of *autistic* and *on the autism spectrum* throughout (Kenny et al., 2016).

1.1.1 What is autism spectrum disorder?

Eugen Bleuler, a German psychiatrist, first coined the concept of ‘autism’ as a symptom of severe schizophrenia in 1911 (Evans, 2013). Over 100 years later, autism is now recognised in both the “International Classification of Diseases, Eleventh Revision” (ICD-11) and the “Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition” (DSM-5) by the term *autism spectrum disorder* (ASD) (American Psychiatric Association, 2013; World Health Organization [WHO], 2019a). ASD is widely understood as an umbrella term for a spectrum of neurodevelopmental differences initially characterised by a ‘triad of impairments’ model: difficulties with (i) communication, (ii) behaviour or social interaction and (iii) social skills (Wing & Gould, 1979). Recently, changes to the ASD diagnostic criteria, reflected within the DSM-5, has seen an adjustment of this ‘triad of impairments’ model to a dyad of behavioural criteria; (i) continued difficulties with social communication and social interaction, and (ii) patterns of fixed and repetitive behaviours, activities or interests (American Psychiatric Association, 2013). These areas of difficulty impact on “how a person communicates with and relates to other people, and how they experience the world around them”, resulting in the unique and differing presentation of each autistic individual (National Autistic Society, 2016).

Societal awareness around ASD has significantly increased over the last 30 years, with the diagnosis now being recognised as a disability, entitling those diagnosed to apply for social care benefits. In addition, the introduction of the Autism Act (2009) confirms a commitment by the UK Government to support the needs of autistic individuals through ‘The Autism Strategy’. This strategy includes statutory guidance for the NHS and social care services. ‘Think Autism’

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(Department of Health, 2014) is the current strategy, which proposes a five-year plan to improve the lives, service and support available to autistic adults. It includes financial investments into ASD community awareness and innovation projects as well as a commitment to providing ASD training to frontline staff.

1.1.1.1 Prevalence

The information available about the prevalence of ASD varies. WHO draws on the findings of Elsabbagh et al.'s (2012) systematic review to report a global ASD prevalence of 1 in 160 children. The estimated number of children with ASD is reported to have increased over a 50-year period. This has been attributed to the changes made to the ASD diagnostic criteria in 1994 and increased contact with secondary outpatient services (Hansen et al., 2015) improving monitoring and diagnosis, as well as a lack of standardised prevalence surveying measures (Fombonne, 2018). It is widely recognised that current ASD research, which underpins prevalence estimates, is heavily skewed towards generation by Western countries, which are reported to make up less than 20% of the global population (de Leeuw et al., 2020; Elsabbagh et al., 2012; WHO, 2019b).

Conversely, prevalence within the UK is estimated to be significantly higher and reported to be about 1 in 100 people, equating to approximately 700,000 people (National Autistic Society, 2018a; National Institute for Health and Care Excellence [NICE], 2011). Similar to the data underpinning the estimates provided by WHO, this estimate is generated from a dataset which could now be considered somewhat outdated, the 2011 UK Census. More recent figures, reflected by the Department of Health in Northern Ireland, suggest the prevalence of ASD continues to increase, concluding 3.3% of school-aged children in this area are reported to have ASD between 2018 and 2019, an increase of 2.1% since figures captured between 2008 and 2009 (Waugh, 2019).

1.1.1.2 Barriers to diagnosis

NICE guidelines recommend an ASD diagnostic assessment for a child or young person should be started within three months of the referral being received; however, data collected about referrals to NHS Trusts for ASD assessment between October and December 2018 evidence only 18% of referrals meeting this recommendation (NHS Digital, 2019; NICE, 2011). The National Autistic Society conclude the current monitoring of autism assessment waiting times "simply isn't good enough", highlighting how long waiting periods can be a traumatic experience for the individual and their families (National Autistic Society, 2019).

Once at the point of assessment, barriers to receiving a diagnosis have been found to include the challenge of anxiety about attending appointments, cost of assessment, access to adult specialist assessments, fear of not being believed, difficulty describing symptoms, mistrust of health professions, lack of emotional support, stigma, complexity and inconsistent routes through assessment process, and lack of value of formal diagnosis (Crane et al., 2018; Lewis, 2017).

With this in mind, it is not surprising that self-diagnosis is becoming increasingly more common (Lewis, 2016, 2017).

1.1.1.3 Comorbidities

Comorbid diagnoses are common for autistic people and have a significant impact on the quality of life of individuals (Lai et al., 2019). NICE guidelines recommend clinicians consider the presence of coexisting conditions when completing an ASD diagnostic assessment (National Autistic Society, 2018b; NICE, 2011). The most common coexisting condition for autistic people is an intellectual disability, with up to 70% of sample populations reporting this comorbidity (Matson & Goldin, 2013). Physical or mental comorbid conditions have been reported for over 50% of autistic people (Catalá-López et al., 2019). Physical health comorbidities include epilepsy, bowel disorders, type 1 diabetes, muscular dystrophy and sleep disorders (Kohane et al., 2012). When considering mental health comorbidities in this population, attention deficit hyperactivity disorder is thought to be the most prevalent, with an estimated 28% (range 25 – 32%) reporting the diagnosis, followed by 20% (range 17 – 23%) reporting an anxiety disorder (Lai et al., 2019). Comorbid challenging behaviour is recognised to have a significant impact on autistic people; however, research into this area is lacking (Matson & Goldin, 2013).

1.1.2 Adolescence

WHO defines an adolescent as an individual aged between 10 and 19 years old and considers this period to fall between childhood and adulthood, making up approximately 16% of the world's population (UNICEF, 2019; WHO, 2014). Due to the variety of cognitive, psychosocial and emotional changes an individual experiences during this stage of life, adolescence is often considered as two or three distinct but overlapping stages (Garrison & Felice, 2009; UNICEF, 2005; WHO, 2010). Table 1 displays the differences in areas and stages of development throughout the adolescent period (WHO, 2010).

Adolescence is recognised as a challenging and complex period of life requiring management of both personal and educational pressures (O'Reilly et al., 2018). Autistic individuals appear to

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experience further challenges with college students reporting poorer academic performance and ill health (McLeod et al., 2019; Sedgewick et al., 2018). Evidence suggests that autistic adolescents reported higher rates of bullying and lower levels of happiness in comparison to their peers (Lung et al., 2019). It is important to understand the challenges autistic adolescents face to ensure proper support is implemented.

Table 1: *Stages of adolescent development defined by the World Health Organization (2010)*

	Early 10 – 15 years	Middle 14 – 17 years	Late 16 – 19 years
Growth of body	<ul style="list-style-type: none"> -Secondary sexual characteristics appear -Rapid growth reaches a peak 	<ul style="list-style-type: none"> -Secondary sexual characteristics advance -Growth slows down -Has reached approximately 95% of adult growth 	<ul style="list-style-type: none"> -Physically mature
Growth of brain		<ul style="list-style-type: none"> -Brain growth occurs -Influence on social and problem solving skills 	
Cognition	<ul style="list-style-type: none"> -Uses concrete thinking -Does not understand how a present action has results in the future 	<ul style="list-style-type: none"> -Thinking can be more abstract but goes back to concrete thinking under stress -Better understands results of own actions -Very self-absorbed 	<ul style="list-style-type: none"> -Most thinking is now abstract -Plans for the future -Understands how choices and decisions now have an effect on the future
Psychological and social	<ul style="list-style-type: none"> -Spends time thinking about physical growth and body image -Frequent changes in mood 	<ul style="list-style-type: none"> -Creates their body image -Thinks a lot about impractical or impossible dreams -Feels very powerful -Experiments with sex, drugs, friends, risks 	<ul style="list-style-type: none"> -Plans and follows long-term goals -Usually comfortable with own body image -Understands right from wrong
Family	<ul style="list-style-type: none"> -Struggles with rules about independence/dependence -Argues and is disobedient 	<ul style="list-style-type: none"> -Argues with people in authority 	<ul style="list-style-type: none"> -Moving from a child–parent/guardian relationship to a more equal adult–adult relationship
Peer group	<ul style="list-style-type: none"> -Important for their development -Intense friendships with same sex -Contact with opposite sex in groups 	<ul style="list-style-type: none"> -Strong peer friendships -Peer group most important and determines behaviour 	<ul style="list-style-type: none"> -Decisions/values less influenced by peers in favour of individual friendships -Selection of partner based on individual choice rather than what others think

Sexuality	-Self-exploration and evaluation	-Forms stable relationships	-Mutual and balanced sexual relations
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1.1.3 Life experience

Life experiences are generated through events that hold meaning to us. Life experiences can differ in duration, magnitude and the severity of change required in response to the experience (Olaya Guzmán and Essau, 2011). The meaning we give to our life experiences can influence not only our thoughts about ourselves, others and the world around us but also our behavioural responses in the future (Westbrook et al., 2011). Life experiences or lived experiences are of particular interest to phenomenological psychological researchers, who aim to explore these from the perspectives of the people who have lived them using qualitative methodologies (Smith, 2003).

Currently, research into the life experiences of autistic people tends to focus on the perspective of systemic stakeholders, mainly parents, siblings and professionals who lack the lived experience of being autistic (Nicolaidis, 2012), with few studies involving autistic individuals directly (Jivraj et al., 2014). The reason for this approach does not appear to be reported within the literature; however, the need for autistic individuals to be recognised as “autism experts” is growing (Gillespie-Lynch et al., 2017).

Of the research generated through stakeholder involvement, parents or caregivers have been found to experience higher levels of emotional stress and strain in comparison to the general population, as well as perceived stigma and isolation in all contexts of life (Besette Gorlin et al., 2016; Broady et al., 2017; Corcoran et al., 2015; Daniels et al., 2017; Saccà et al., 2019). Gobrial (2018) reports mothers also experience a negative impact on their social life.

Siblings of autistic individuals recognised extra responsibilities and less parental attention through their childhood, and in adulthood a sense of responsibility for the welfare of their sibling if their sibling is marginalised by services (Ferraioli & Harris, 2009; Tozer & Atkin, 2015; Ward, 2016).

1.1.4 Previous reviews

DePape and Lindsay (2014) completed a qualitative meta-synthesis of the literature exploring lived experiences from the perspective of autistic individuals. Synthesising literature published between 1980 and 2014, this review captured the perspectives of autistic individuals aged between 7 and 62 years old. Using a narrative synthesis approach to analyse data from the 33 included studies, this review identified four themes related to the lived experiences of autistic

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individuals across the lifespan. These themes were ‘perception of self’, ‘interaction with others’, ‘experiences at school’ and ‘factors related to employment’.

To the best of our knowledge, DePape and Lindsay’s systematic review is the first to explore lived experiences from the perspective of autistic individuals. As such the findings offer a significant contribution to the field, however, replication of this review may be challenging. This is due to the limited detail provided about the reasons for excluding full-screened studies, how the authors applied the narrative synthesis approach in practice, and how bias was addressed during the narrative synthesis. This review also excluded unpublished studies, which introduces a publication bias threatening the validity of the findings (Boutron et al., 2019). In addition to this, DePape and Lindsay draw attention to the underrepresentation of the autistic adolescent population within the included literature. For this reason, the identified themes are likely to be more greatly influenced by autistic adults’ life experiences and may not fully reflect the experiences of the autistic adolescent population.

1.1.5 Purpose of current review

Adolescence is a challenging and complex period of life for many (O’Reilly et al., 2018). It has been suggested that autistic adolescent individuals experience even more challenges than their peers during this period (McLeod et al., 2019; Sedgewick et al., 2018), including increased experiences of bullying and lower levels of happiness (Lung et al., 2019). However, literature exploring the first-hand life experiences of this population has been identified as lacking (DePape & Lindsay, 2014). As a result, the findings of the previous qualitative systematic review exploring the lived experiences of autistic individuals across the life span may not fully represent experiences for the adolescent population. With this in mind, there may be benefit to completing a systematic review focusing purely on the life experiences of autistic adolescents.

In addition to this, since DePape and Lindsay’s systematic review was completed in 2014 the ASD diagnostic criteria have been reviewed and the Think Autism Strategy has committed to enhancing awareness through community projects. These changes may have a significant impact on the life experiences of autistic adolescents from the point of assessment, as well as promoting research in this field. DePape and Lindsay (2014) recognise the need for continued review of the evidence base as societal understanding changes over time. For this reason, it would be beneficial to complete a new systematic review of the literature base.

Finally, there were several limitations to DePape and Lindsay’s (2014) systematic review which could be addressed through the methodology of a new review which will enhance the validity of

the findings and the transparency and replicability of the review. This could be achieved by searching grey literature databases, providing greater detail about the exclusion of full-text papers, providing greater detail about the application of the synthesis methodology, and explaining how bias was addressed throughout the review.

With this in mind, the purpose of this review is to synthesise the qualitative literature available about the first-hand experiences of autistic adolescents. This review addresses the question ‘what are the life experiences of autistic adolescents?’

1.2 Methodology

The protocol for this review was published on the PROSPERO register of systematic reviews from 5th November 2019, under the registration CRD42019155605.

1.2.1 Project team

A project team of three researchers completed the systematic review. The ‘primary researcher’ led on all aspects of the systematic review and write-up of this project. The ‘second researcher’ undertook all aspects of dual screening and also held the role of main supervisor of the systematic review. The ‘third researcher’ offered a deciding view when consensus could not be reached between the primary and secondary researcher and also held the role of secondary supervisor of the systematic review. Reference to ‘project team discussions’ in this methodology reflects a meeting between all three project team members. All members of the project team were actively working in the field of clinical psychology within NHS settings at the time of completing the systematic review. All researchers had clinical experience of working with autistic individuals.

1.2.2 Search strategy

A systematic search of the literature was initially conducted on 14th November 2019 by the primary and secondary researcher. Prior to analysis, the search was rerun on 11th January 2020, to ensure the systematic review reflected all available literature. Four electronic bibliographic databases were searched for relevant articles. These databases were PsychINFO via EBSCO, MEDLINE via EBSCO, Cumulative Index to Nursing Allied Health Literature (Plus with Full Text) via EBSCO and Web of Science. The three databases hosted by EBSCO were searched using a ‘title’ and ‘abstract’ search. The Web of Science database was searched using a ‘topic’ search.

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Grey literature is the term given to material that has not been published by mainstream publishers and can include leaflets, theses and conference proceedings. The importance of including grey literature resources in a systematic review search strategy has been recognised (Paez, 2017). Four grey literature databases were searched. These were PubMed, Autism Data, OpenGrey and The British Library. PubMed was searched using the search terms in a 'title' and 'abstract' search. Autism Data, OpenGrey and The British Library were searched using the key words 'adolescent', 'autism' and 'life experiences'.

No date or language restrictions were imposed, and the bibliographic software EndNote X9.2 was used to store and manage the results of this search.

1.2.3 Search terms

The search terms were developed by the primary researcher with support from a Research Engagement Librarian, and confirmed by the second researcher. The search terms were developed around the four key words relevant to the systematic review question, formulated using the SPIDER tool (Cooke et al., 2012). Methley et al. (2014) suggest the SPIDER tool is an appropriate framework for systematic narrative reviews of qualitative literature. Table 2 depicts how the search terms were prepared for use on a database hosted by EBSCO.

Table 2: *Search terms for PsycINFO via EBSCO*

Search tool	Key words	Search terms
Sample	Adolescent	teen* OR youth* OR "young person*" OR "young people" OR adolescen* OR 1* N3 year* OR student*
Phenomenon of Interest	Autism	ASD OR autis* OR Asperger* OR ASC OR "pervasive developmental disorder*" OR PDD
Design and Research type	Qualitative	qualitative* OR interview* OR semistructured OR "semi structured" OR unstructured OR structured OR "open ended" OR "case stud*" OR "focus group*" OR narrative* OR discourse* OR phenomenolog* OR "grounded theory" OR thematic* OR IPA OR theme* OR ethnograph*
Evaluation	Life experiences	experience* N4 (life OR lived OR personal OR past OR earl*) OR perspective* OR expectation* OR "life event*" OR transition* OR narrative* OR stor* N1 (personal* OR individual* OR own)

1.2.4 Eligibility criteria

As this systematic review aimed to explore the life experiences of autistic adolescents, the inclusion criteria for this systematic review reflected the key words identified by the SPIDER tool. To ensure included papers aligned with the aim of the systematic review, factors for exclusion were also considered. Table 3 captures the generated eligibility criteria.

Table 3: *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Adolescents, aged between 10 and 19 years, • Formal ASD diagnosis, • Life experiences, • Qualitative and mixed-methods studies. 	<ul style="list-style-type: none"> • Sample included participants under 10 years of age, • Sample included participants over 19 years of age, • Participants' age not stated, • Study not focussed on autistic adolescents (10 – 19 years old), • Diagnosis is unclear or not confirmed, • Study focussed on multiple diagnoses, • Study included mixed stakeholder sample, • No direct involvement of adolescents, • No quotes from autistic adolescents included, • Study not focussed on life experiences, • Study focussed on future experiences, • Intervention studies, • Secondary data reviews, • Quantitative studies, • Audio files, books and conference proceedings, • No English version available.

1.2.5 Data selection

Figure 1 depicts the full data selection process using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher et al., 2009). The initial search yielded 2,174 papers sourced from PsychINFO (n=666), MEDLINE (n=247), Cumulative Index to Nursing Allied Health Literature (Plus with Full Text) (n=238), Web of Science (n=827), PubMed (n=22), Autism Data (n=88), OpenGrey (n=1) and The British Library (n=85). At the point of inclusion, a further 145 papers were sourced through citation searching using Google Scholar. Duplicate papers (n=908) were removed before the first phase of screening; title and abstract screening.

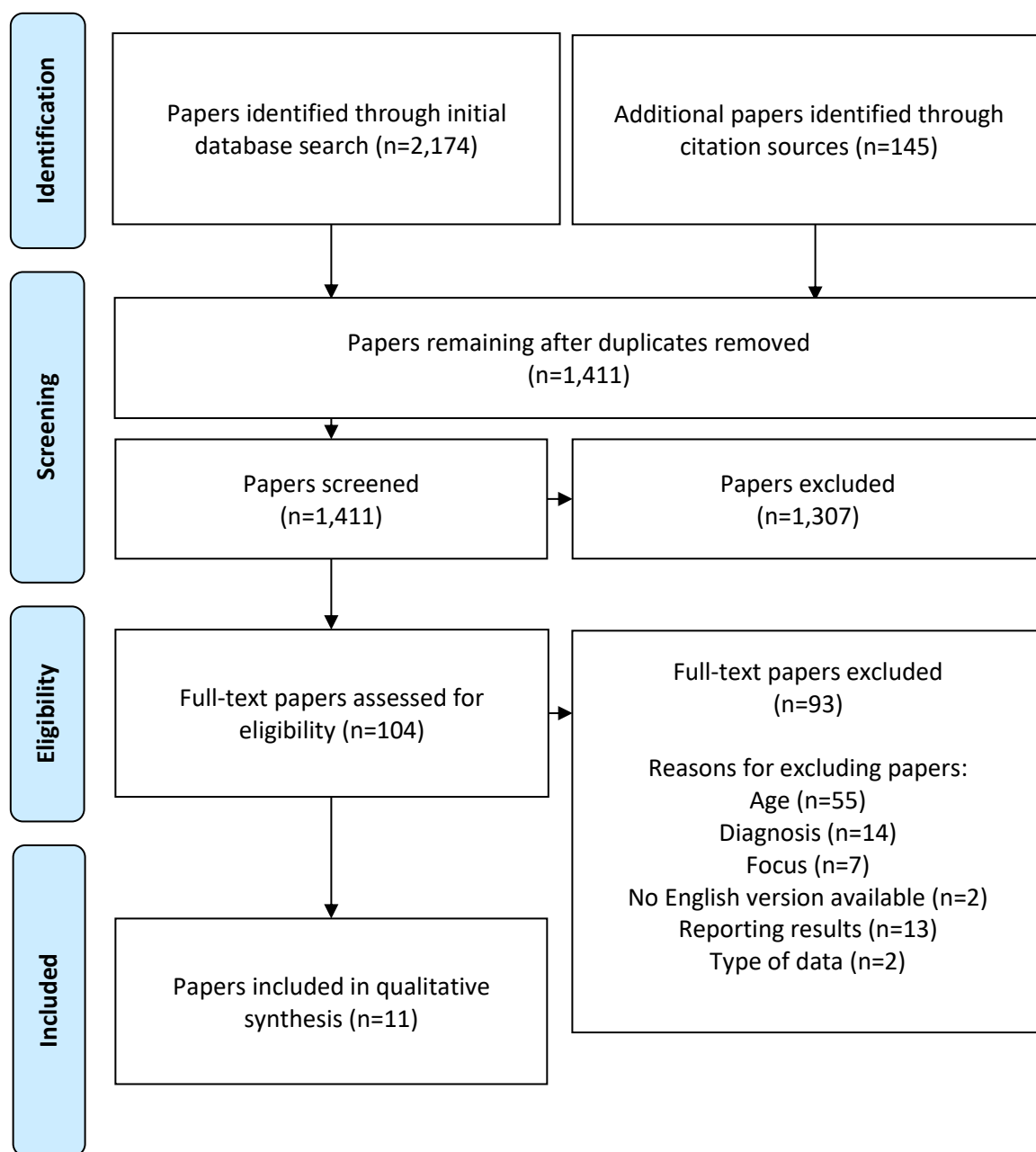
A total of 1,411 papers were screened by title and abstract; 1,307 papers were excluded through the title and abstract screen and 104 papers proceeded to the second phase of screening; the full-

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text screening. Ten per cent of the papers were dual-screened, by the second researcher, at each stage of screening to ensure consistency with the exclusion criteria. Any discrepancies identified through the dual screening were discussed, and if a consensus could not be agreed, the third researcher determined if the paper should be excluded.

Of the 104 papers included in the full-text screening, 93 papers were excluded. Of these, 55 papers were excluded on the grounds of age of the participant sample: a sample including participants over 19 years of age ($n=40$), a sample including participants under 10 years of age ($n=4$), and a sample where the age of participants was not reported ($n=11$). Fourteen papers were excluded on the grounds of diagnosis: the diagnosis was not confirmed ($n=13$) and the paper included a mixed diagnosis population ($n=1$). Thirteen papers were excluded due to the reporting of results: papers reported on mixed stakeholder data ($n=7$) and papers did not include the quotes of adolescents with ASD ($n=6$). Seven papers were excluded due to the focus of the research: future-orientated focus ($n=3$), not focussed on life experiences ($n=3$), and not focussed on adolescents with ASD ($n=1$). Two papers were excluded due to the type of data: secondary data ($n=1$) and intervention study ($n=1$). Two papers were excluded because there was no English version available.

Eleven full-text papers were found to meet the inclusion criteria.

Figure 1: *PRISMA flowchart*

1.2.6 Quality assessment

The quality of the included papers was critically appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP, 2018). This is a 10-question appraisal tool which aids the consideration of whether the results of a study are valid, what the results are and whether the results are useful. Nine of the 10 questions allowed for a “yes”, “no” or “can’t tell” response. The 10th question, “how valuable is the research?”, implies a quantitative response is required; however, there is no guidance to apply this systematically, and for this reason only the

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first nine of the questions have been included in this quality assessment. There is no suggested scoring criteria for this appraisal tool (CASP, 2018).

As the CASP Qualitative Checklist does not offer guidance about the application of “no” or “can’t tell”, the project team discussed how these terms would be used for this quality assessment. “Can’t tell” has been applied when the paper does not capture enough information within the document to conclude an answer. “No” has been applied when the paper indicates the question has not been met. The only exception to this approach is for question six, “has the relationship between research and participant been adequately considered?”, where the project team agreed this question requires either a “yes” or “no” response.

Currently there is little evidence to support excluding papers from qualitative systematic reviews, based on their quality assessment (Thomas & Harden, 2008). For this reason the quality assessment will not influence the exclusion of papers in this systematic review.

1.2.7 Data extraction

The extraction of data from included papers was completed by using the highlighting and copy function to duplicate the relevant text from the PDF version of the paper. This text was entered into a data extraction document created on Microsoft Word using the paste function. When copying and pasting the intended data was not possible, the text was entered manually into the Word document and thoroughly checked by the primary researcher to ensure accuracy. The extracted data was used to support synthesis and develop the extraction table (Table 5).

Data extracted from included papers reflected the author’s/authors’ name/s, year of publication, country of origin, sample size, gender of sample, age of sample, diagnosis of sample, aim of study, method of data collection, method of analysis, full results/findings section including quotes, and themes or categories identified.

When extracting results data, one paper presented separate results sections for findings from an adolescent sample and parent sample. For this paper, only the results from the adolescent sample was extracted.

1.2.8 Data synthesis

The data extracted from the results sections of included papers was analysed using the thematic synthesis method described by Thomas and Harden (2008). Each stage of the thematic synthesis

was confirmed by the second researcher to reduce the presence of bias. Table 4 summarises the application of the three steps of thematic synthesis to this systematic review.

Table 4: *Application of the three steps of thematic synthesis (Thomas & Harden, 2008)*

Step	Aim of step	Application of step to this study
1.	Inductive coding	The primary researcher used the results/findings captured on the data extraction document of each paper. The primary researcher hand-coded each line of the results sections of the first paper by reading one line at a time and noting a short description of the meaning of each line beside the line itself. This researcher repeated this for each line of the results section of the first paper. The second researcher reviewed the coding of the first paper. Any differences about codes were discussed and amended. The primary researcher repeated this process for each of the remaining included papers.
2.	Construction of descriptive themes by organisation of codes	The primary researcher listed all of the codes from the results section of the first paper onto a piece of coloured paper, before cutting them into individual codes. This was repeated for each of the included papers. Each paper was allocated a colour to support identification of the themes origin. The primary researcher organised codes into descriptive themes by looking for similarities and differences between the codes. Where groups of themes held a central meaning a new overarching theme title that captured the central meaning, was developed. The second researcher was provided a typed version of the draft code organisation to review. Following a discussion between the primary and secondary researcher, the organisation of codes was confirmed.
3.	Development of analytic themes	The primary researcher considered how the groups of descriptive themes and the associated quotes connected with the review question. This supported the development of analytic themes. The primary researcher did this independently before discussing with the second researcher, to further extend the themes. Following both researchers having some time to consider the proposed analytic themes, a second discussion supported confirmation of the final analytic themes.

1.3 Results

1.3.1 Characteristics of included studies

In total, 2,319 papers were reviewed for this systematic review. Eleven papers remained following application of exclusion criteria (see Table 3). These papers consisted of journal articles published between 2014 and 2019 (n=10) and a Doctoral thesis (n=1) and captured research studies conducted in a range of countries: UK (n=3), USA (n=3), Sweden (n=1), Australia (n=1), Republic of Ireland (n=1) and Singapore (n=1).

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The studies included an adolescent population of 169 participants aged between 12 and 19 years old and sample sizes of four to 38 participants. Of the participants involved in the included studies, 135 participants were male adolescents and 34 female adolescents. One study had solely male adolescent participants, and one study had solely female adolescent participants. Six studies commented on the specific diagnosis of their participants. Of the 48 participants reflected by these studies, diagnosis of Asperger's syndrome (n=26), ASD (n=16) and high-functioning autism (n=6) were reported.

Studies adopted a qualitative approach (n=10) and a mixed-methods approach (n=1). Of the qualitative methods employed, all studies included 1:1 interviews within their methodology (n=11), drawing upon semi-structured interviews (n=9), structured interviews (n=1) and not specified (n=1). For one study, the semi-structured interview also formed part of a Photovoice methodology alongside additional participatory activities. Finally, data analysis was completed through thematic analysis (n=4), IPA (n=3), content analysis (n=2), grounded theory (n=1) and phenomenology approach (n=1).

Table 5: Data extracted from included studies

No.	Author, year (country)	Sample characteristics	Diagnosis	Focus	Method	Analysis	Main findings
1.	Acker et al., 2018 (UK)	Number: 14 Male adolescents (n=14) Age: 13 – 18		Anxiety	Qualitative study Semi-structured interviews	Interpretive Phenomenological Analysis	Six themes and six subthemes identified: <ul style="list-style-type: none"> • A wish to belong and feel connected to others • An ambivalent and delicate relationship to help <ul style="list-style-type: none"> -The fine balance of help from others -The unmet longing to help others • Internal pressure and self-criticism • Taking life steadily or spiralling into meltdown <ul style="list-style-type: none"> -The calming effect of life at a gradual pace -Raging meltdown • The mediating effects of sensory environments on anxiety <ul style="list-style-type: none"> -Anxiety caused by aversive sensory stimuli -Sensory-based calming strategies • Using fantasy and role-play to escape
2.	Arnell et al., 2018 (Sweden)	Number: 24 Male adolescents (n=17) Female adolescents (n=7) Age: 12 – 16		Physical activity	Qualitative study Interviews	Content analysis	One theme and five subthemes identified: <ul style="list-style-type: none"> • Conditional participation <ul style="list-style-type: none"> -Competence and confidence -Motivation -Adjustment to external demands -Predictability -Freedom of choice

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3.	Berkovits et al., 2020 (USA)	Number: 38 Male adolescents (n=33) Female adolescents (n=5) Age: 15 – age at point of interview		Perceptions of ASD diagnosis	Mixed-methods Semi-structured interviews WISC-IV; CBCL/YSR; CHS; SRS	Thematic analysis	<u>Qualitative findings</u> Two themes and seven subthemes identified: <ul style="list-style-type: none"> Negative perceptions of ASD <ul style="list-style-type: none"> -Social difficulties -Related symptoms and comorbidities -Cognitive deficits -Burden of diagnosis Positive perceptions of ASD <ul style="list-style-type: none"> -Cognitive benefits -Social benefits -Positive related factors
4.	Danker et al., 2019 (Australia)	Number: 16 Male adolescents (n=15) Female adolescents (n=1) Age: 13 – 17	Autism spectrum disorder (n=13) Asperger's syndrome (n=3)	Wellbeing	Qualitative study Photovoice including 1:1 semi- structured interviews	Grounded theory	Three themes and nine subthemes identified: <ul style="list-style-type: none"> Domains of student well-being <ul style="list-style-type: none"> -Emotional well-being -Social well-being -Academic well-being -Well-becoming Barriers to student well-being <ul style="list-style-type: none"> -Sensory barriers -Social barriers -Barriers associated with learning Supporting students with ASD to enhance their well-being <ul style="list-style-type: none"> -What helps with a good life in school -Who helps with a good life in school
5.	Fisher & Taylor, 2016 (USA)	Number: 30 Male adolescents (n=26)		Bullying experiences	Qualitative study Interview questions of ADOS – Module 4	Content analysis	Three themes and 11 subthemes identified: <ul style="list-style-type: none"> Types of victimization <ul style="list-style-type: none"> -Verbal victimization -Physical victimization -Relational victimization -Unspecified victimization

		Female adolescents (n=4)					<ul style="list-style-type: none"> • Reasons for bullying <ul style="list-style-type: none"> -Personal attributes -Other's opinions of them • Reactions to victimization <ul style="list-style-type: none"> -Own actions in the moment -Own actions after the fact -Retaliation and intimidation -Minimizing -Changes in relationships
		Age: 17 – 19					
6.	Goodall, 2019 (UK)	Number: 15		Educational experiences	Qualitative study	Thematic analysis	Three themes and seven subthemes identified:
		Male adolescents (n=12) Female adolescents (n=3)			Semi-structured interviews		<ul style="list-style-type: none"> • Mainstream school education: <ul style="list-style-type: none"> -Overwhelming environment -Curriculum and homework -Bullying -Unsupportive teachers -Improving school • Alternative Education Provision: <ul style="list-style-type: none"> -Supportive environment -Supportive teachers • Ideal school
		Age: 13 – 16			Participatory methods – beans and pots activity, diamond ranking, good teachers, bad teacher, me at school, design your own school activity		
7.	Kelly et al., 2018 (Republic of Ireland)	Number: 5	Asperger's syndrome (n=5)	Social communication skills	Qualitative study	Thematic analysis	Four themes and eight subthemes identified:
		Male adolescents (n=3) Female adolescents (n=2)			Semi-structured interviews		<ul style="list-style-type: none"> • Difficulty with components of communication <ul style="list-style-type: none"> -The school setting -Unfamiliar conversation partners • Managing challenging feelings <ul style="list-style-type: none"> -Anxiety • Limited opportunities for social communication <ul style="list-style-type: none"> -Rejection -Self-segregation
		Age: 15 – 17					

							<ul style="list-style-type: none"> -Use of the internet and social media for communication • Desire to improve social communication skills -Wish for help with social communication skills -Communication strategies
8.	Petalas et al., 2015 (UK)	Number: 12 Male adolescents (n=11) Female adolescents (n=1) Age: 12 – 15	High-functioning autism (n=4) Asperger's syndrome (n=8)	Sibling relationships	Qualitative study Semi-structured interviews	Interpretive Phenomenological Analysis	Two themes and eight subthemes identified: <ul style="list-style-type: none"> • Typical sibling experiences <ul style="list-style-type: none"> -Conflict in the sibling relationship -Positive regard and enjoyment -Acceptance, tolerance, or wishing for change -Beliefs and values on siblinghood • The presence of ASD in the sibling relationship <ul style="list-style-type: none"> -Reduced emotional control and increased impulsivity -The impact of ASD on social interactions -Atypical sibling interactions: the subtle presence of ASD -Social comparisons in the context of ASD
9.	Poon et al., 2014 (Singapore)	Number: 4 Male adolescents (n=3) Female adolescents (n=1) Age: 12 -17	High-functioning autism (n=2), Asperger's syndrome (n=2)	Experiences of Singapore secondary schools	Qualitative study Semi-structured interviews	Interpretive Phenomenological Analysis	Three themes identified: <ul style="list-style-type: none"> • Construction of HFA • Peer relationships • School perceptions
10.	Rossello, 2015 (USA)	Number: 4	Asperger's syndrome (n=4)	Disclosure of ASD diagnosis	Qualitative study	Phenomenological approach	<u>The adolescent interviews findings</u> All adolescents were glad they had been told about their diagnosis and being informed of their

		Male adolescents (n=1) Female adolescents (n=3) Age: 13 – 17		Semi- structured interviews		diagnosis did not negatively impact on their views of their future.
11.	Vine Foggo & Webster, 2017 (Australia)	Number: 7 Female adolescents (n=7) Age: 13 – 17	Asperger's Syndrome (n=4) autism spectrum disorder (n=3)	Social experiences and relationships with female peers.	Qualitative study Semi-structured interviews	Thematic analysis Two themes and five subthemes identified: <ul style="list-style-type: none"> • Social interactions are important -<i>Having friends</i> -<i>Friendship qualities</i> -<i>Sharing experiences</i> • Social interactions are difficult -<i>Managing conflict and group interactions</i> -<i>Perceptions of others</i>

1.3.2 Quality assessment results

Although the CASP Qualitative Checklist does not offer scoring criteria for the overall assessment of the quality of a study, the number of standards met by the 11 included studies varied significantly, with one study achieving two “yes” ratings and one other study achieving nine “yes” ratings (see Table 6). There was a clear statement of aims in most studies (n=10), and because of this it was possible to conclude a qualitative methodology was appropriate for these studies. Similarly, it was possible to conclude the majority of studies used an appropriate research design (n=10), and most studies also described appropriate recruitment strategies (n=8) to address the aims of their research. Some studies did not provide enough information about the recruitment strategy used to establish if this is the case (n=3). The majority of studies collected data in a way that addressed the research issue (n=10); however, only a few studies adequately discussed the relationship between the researcher and participants (n=2). Ethical issues were found to be considered in most of the studies (n=10); however, not all studies offered comment (n=1). Finally, most studies were found to use a sufficiently rigorous data analysis (n=10), but only some of these studies presented a clear statement of findings (n=7).

Table 6: *Quality assessment of included studies*

No.	Study	Q1. Clear aims	Q2. Appropriate methodology	Q3. Appropriate design	Q4. Appropriate recruitment strategy	Q5. Appropriate data collection	Q6. Adequate consideration of relationship between researcher and participants	Q7. Ethical considerations	Q8. Rigorous data analysis	Q9. Clear statement of findings
1	Acker et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓
2	Arnell et al. (2018)	✓	✓	✓	✓	✓	✗	✓	?	✓
3	Berkovits et al. (2020)	✓	✓	✓	✓	✓	✗	✓	✓	✓
4	Danker et al. (2019)	✓	✓	✓	✓	✓	✗	✓	✓	✓
5	Fisher and Taylor (2016)	✓	✓	✓	✓	✓	✗	?	✓	?
6	Goodall (2019)	?	?	?	?	?	✗	✓	✓	?
7	Kelly et al. (2018)	✓	✓	✓	✓	✓	✗	✓	✓	✓
8	Petalas et al. (2015)	✓	✓	✓	✓	✓	✗	✓	✓	✓
9	Poon et al. (2014)	✓	✓	✓	?	✓	✗	✓	✓	?
10	Rossello (2015)	✓	✓	✓	?	✓	✓	✓	?	?
11	Vine Foggo and Webster (2017)	✓	✓	✓	✓	✓	✗	✓	✓	✓

Key: ✓ = yes ? = can't tell ✗ = no

1.3.3 Thematic synthesis results

The thematic synthesis identified three main themes: ‘social experiences’, ‘personal experiences’ and ‘working out what helps me’. Each theme encapsulated either three or four subthemes incorporating the lived experiences of autistic adolescents. The findings are reflected in Table 7 and will be discussed in detail, including example quotes.

Table 7: *Thematic synthesis results*

Theme	Subtheme	Studies included in the subtheme
Social Experiences	School Experiences	1, 2, 3, 4, 6, 7, 8, 9, 10, 11
	Feeling Connected	1, 2, 3, 4, 5, 7, 9, 10, 11
	Social Adversity	1, 2, 3, 4, 5, 6, 7, 8, 9, 10
Personal Experiences	The Perception of Difference	3, 4, 5, 6, 7, 8, 9, 10, 11
	Experiences of Heightened Emotion	All studies
	The Worry of Getting Things Wrong	1, 2, 3, 4, 5, 8, 9, 10
	Sensory Experiences	1, 2, 3, 4, 7, 8
Working Out What Helps Me	Personal Strategies	1, 2, 4, 5, 6, 7, 8, 10
	Support from Others	1, 2, 4, 5, 6, 7, 8, 9
	Practical Support	1, 2, 4, 7, 8, 11

1.3.3.1 Social experiences

All 11 included studies involved themes related to the social experiences of individuals.

1.3.3.1.1 Subtheme: School experiences

‘School experiences’ were present in nearly all of the included studies. For many, the school experience was reported to be enjoyable, enhanced by the social opportunities with friends and school staff in different settings within the school environment. Danker et al. (2019) suggest “preference for school was due to the increased opportunity to learn, obtain support from school community members and socialise with their friends” (p. 134). In addition to this, how enjoyable individuals found the school experience was associated with perceptions about how useful a subject was deemed to be. For some individuals, attending lessons that were not considered useful to them was described as frustrating and boring. There was a preference for having choice and flexibility around lessons to support engagement:

“I have no PE in school, I’ve ruled it out... I thought it was unnecessary and it would be hell... but as long as it is theory, I’m in” (Arnell et al., 2018, p. 1796)

The school experience was also associated with experiences of internal pressure to achieve for some individuals. Motivation to try hard in lessons was fostered by eagerness to avoid letting key figures down, such as teachers or parents, as well as anxiety about failing and the impact this may have on their future.

“I really cared about Maths because I didn’t want to let the Maths teachers down because they had done a great job in terms of teaching me, and...[...] It would have been heart-breaking” (Acker et al., 2018, p. 14)

However, the school experience also included negative social experiences of bullying, judgement and exclusion. This will be discussed further in ‘social adversity’.

1.3.3.1.2 Subtheme: Feeling connected

Feeling connected to others was important for individuals, with Acker et al. (2018) reporting a “strong urge to make and maintain social connections was apparent in nearly all participants’ narratives” (p. 12). Individuals highlighted the impact of feeling connected to friends, peers, siblings and teachers on their general wellbeing, and in generating feelings of inclusion, security, support and understanding.

“I think having friends around to make you happy is awesome. If you didn’t have friends around, which was the case with me for a while, you feel all alone and feel as though the whole world is against you” (Vine Foggo & Webster, 2017, p. 78)

From some, interacting with others who had a similar diagnosis promoted feelings of connection though shared experiences.

“You can feel a connection through everybody because everybody is here for a reason” (Goodall, 2019, p. 26)

When trying to form connections with others, the value and importance of feeling connected to others could foster feelings of anxiety about future social opportunities, whilst strained or disconnected experiences resulted in some individuals feeling they were not understood by others.

“Sometimes she doesn’t really like understand me that well and she just and she doesn’t really understand how I feel” (Petalas et al., 2015, p. 42)

1.3.3.1.3 Subtheme: Social adversity

'Social adversity' reflects autistic adolescents' experiences of bullying, exclusion, rejection and judgement. This theme was present in ten of the 11 included studies. Experiences of social adversity were described as distressing and frustrating, contributing to an individual's dislike of school and in some cases resulting in school refusal. For some, experiences of bullying were frequent and by a range of peers:

"I did get bullied quite severely by most of the school actually, well by most of my grade in school" (Fisher & Taylor, 2016, p. 6)

Bullying experiences ranged from "comments" to physical assault (Arnell et al., 2018, p. 1796). For some, experiences of social exclusion were reported and enhanced by individual's perceptions that peers did not want to involve them. This was most noticeable in group interactions:

"Yes, when you are sorting of sitting there and you feel like everyone else is good friends with each other and you are just sitting there" (Vine Foggo & Webster, 2017, p. 80)

Finally, judgement from others was also captured within 'social adversity'. Some individuals identified that judgements about the person were related to difference through diagnostic labels, such as ASD or a disability.

"I am kind of more known as Damon's brother or his, his you know retard..." (Petalas et al., 2015, p. 45)

However, for some, these formal diagnoses acted as a protective factor from social adversity, with peers supporting and shielding individuals. Experiences of social adversity encouraged social withdrawal and a preference for isolative experiences, avoidance of activities or contexts, and distrust of others.

1.3.3.2 Personal experiences

All 11 studies involved themes related to the personal experiences of autistic adolescents.

1.3.3.2.1 Subtheme: The perception of difference

'The perception of difference' was present in nine studies. This sense of difference was connected to having an ASD diagnosis or disability and enhanced by experiences of social adversity and considered a negative for some individuals. For some, such as participants in Danker et al. (2019), receiving an ASD diagnosis helped to "understand why they felt different from their peers without

ASD” (p. 137). However, for others seeking further understanding of this difference, trying to pinpoint what exactly made them different was challenging:

“With higher functioning autism you really don’t notice a difference, really. You just know that, you know that by definition you’re different, but you yourself are not sure how, because... you don’t see anything wrong with yourself.” (Berkovits et al., 2020, p. 837)

For some individuals trying to make sense of this difference, the difficulties they experience and the reason why they are treated differently to others can be frustrating and confusing. This experience can result in a reluctance to share personal information that might highlight a difference.

“The reason why I don’t like it is because like when people find – they’ll treat me normally but when they find out, they’ll like treat me like differently. Like, than before. And it really bothers me” (Berkovits et al., 2020, p. 836)

For some individuals, however, identifying as being different was a positive experience.

“I think, [I’m] special, I am different from others . . . and this marks me out of the crowd. Just like Albert Einstein, Hitler, Newton, Stalin” (Poon et al., 2014, p. 1075)

1.3.3.2.2 Subtheme: Emotional experiences

‘Experiences of heightened emotion’ was identified in all included studies. Many studies highlighted how anxiety can be overwhelming and debilitating for some individuals.

“Anxiety seemed to cause overwhelming physiological symptoms: ‘I was just trembling physically and mentally, it was like...mentally and, and erm, yeah. I just thought oh god’” (Acker et al., 2018, p. 14)

In addition to anxiety, individuals also shared experiences of anger, frustration, shame and envy. For some, strong emotional experiences were linked to struggling to understand others, technology not working as it should, making mistakes and academic failure. Frequently, experiences of anxiety could escalate to feelings of anger, and Petalas et al. (2015) highlighted how individuals experience a “sense of reduced emotional and behavioural control” (p. 44). Some individuals acknowledged instances of self-harm and aggression to others during this time.

“It [ASD] can have a really big impact on it [sibling relationship] because I can be a bit violent and unintentionally hurt her... that really makes me feel guilty... There are times

when you think ah my god is she going to end up bruised because I am in a bad mood”
(Petalas et al., 2015, p. 44)

These emotional experiences can be confusing and heighten an individual’s anxiety further. Developing self-understanding through receiving an ASD diagnosis can help individuals make sense of their emotional experiences and reduce some of the distress they may have been experiencing.

“If I didn’t know, I’d still be angry because I’d want to know why I cried so much”
(Rossello, 2015, p. 66)

1.3.3.2.3 Subtheme: The worry of getting things wrong

‘The worry of getting things wrong’ was present in eight studies. Individuals identified difficulties with the volume of their voice, literal interpretations and misinterpretations of what others were saying, difficulty knowing what to say and making academic errors.

“Concern about what happens ‘if I, mess up’ (Tom) built up around exams which epitomised an unknown future” (Acker et al., 2018, p. 14)

Many identified anticipatory anxiety about knowing what to talk about in conversations, and this acted as a barrier to confidence in initiating conversation or building new relationships and a worry about getting it wrong.

“I’m a bit shy to meet other people, because I don’t really know what to say after saying, ‘Hello, nice to meet you.’ I don’t know how to keep the conversation going fully, so it’s difficult to meet new people” (Danker et al., 2019, p. 135)

Associated with a worry about making mistakes was a fear of peer or family reactions, potential repercussions within the school context, ruining friendships, ruining their own future and feelings of embarrassment.

“Alongside the drive to maintain close attachments was a worry that treasured relationships would be lost by ‘messing things up with people’ (Peter), causing an argument (Sam) or ‘ruining a friendship’ (Peter)” (Acker et al., 2018, p. 12)

1.3.3.2.4 Subtheme: Sensory experiences

For some individuals, sensory experiences had a significant impact on engagement with day-to-day experiences. When individuals were overwhelmed by sensory input, they found it difficult to concentrate, becoming distracted by their sensory experience, and this could increase anxiety and

discomfort as well as generating physiological symptoms such as migraines. Noise was a significant sensory experience that caused individuals difficulties within the school environment, with Danker et al. (2019) noting that “noise and echoes in school posed a barrier to half of the participating students” (p. 135).

In addition to this, visual stimulation was also identified by some individuals:

“I don’t know why, every time when I see like some kind of corner... Like if for example, butts like out, like more out pointing, I get distracted. Like I start rubbing my eyes to just like get some kind of pressure off” (Berkovits et al., 2020, p. 837)

However, Acker et al. (2018) and Berkovits et al. (2020) highlighted that for some individuals sensory experiences offered opportunities for self-soothing and regulation which was enjoyable and calming.

“Spike felt relief from anxiety when deep pressure was administered. These participants’ anxiety seemed to be regulated to some extent by these external, sensory objects” (Acker et al., 2018, p. 15)

1.3.3.3 Working out what helps me

Ten of the studies included themes related to autistic adolescents working out what helps them. This theme reflects the trial and error and developing awareness of what helps individuals within and during social and personal experiences.

1.3.3.3.1 Subtheme: Personal strategies

‘Personal strategies’ was identified in eight studies. This theme reflected the strategies individuals use to support them day to day with social interactions and school experiences. Some individuals utilised cognitive strategies to reduce the impact of experiences, such as ignoring others, counting down time and minimising experiences. Whilst for others, engaging in fantasy play was a way of exploring interactions by role-play scenarios and making mistakes in a non-judgemental, safe environment.

“Six participants described fantastical ‘ideal universes and utopias and dystopias’ (Fraser) which seemed to reduce their anxieties by creating a buffer between participants and a reality which could feel too threatening.” (Acker et al., 2018, p. 15)

In addition to this, preparing for and planning ahead of an event proved to be a useful personal strategy. This included thinking of topics that might interest others, scripting conversations, establishing all the information needed ahead of an event and planning game plans for sports

activities. Kelly et al. (2018) reported that “Maria and Hannah use scripting to plan for conversations that may occur the next day” (p. 327). However, these strategies can be time consuming for individuals, resulting in them staying up late into the evening preparing. For some individuals, choosing to remain on the periphery of social situations, playing truant or withdrawing to a quiet location after a period of time, such as their bedroom, for time alone were personal strategies they utilised.

“Both participants three, [sic] and five expressed a need for time alone to ‘de-stress’, whilst participant two claimed ‘I can only be with my friends for so long and then I want to be by myself’ (Vine Foggo & Webster, 2017, p. 80)

Personal strategies supported individuals to manage their mental wellbeing, relax and maintain friendships.

1.3.3.3.2 Subtheme: Support from others

Experiences of receiving support from others had helped individuals identify what types of support might help and when they may need this. This support can be provided by family members, school staff, friends and people who individuals feel similar to. For some individuals, having the chance to try things by themselves whilst knowing support is there should they need it was identified as important to them.

“When I used to get into trouble he always used to be there for me and step in but I didn’t really used to like it that much but it did help me a lot... he has always been there” (Petalas et al., 2015, p. 43)

Useful support from others included listening to the individual, understanding the individual’s experience, supporting a reduction in distress and helping the individual to understand challenging situations.

“Most participants valued support from others when they felt worried or anxious. This could be to ‘have someone explain’ confusing situations (Tom), or to reassure: ‘...if they explain it to me and I find out it’s not meant to be offensive, then, I can understand’ (Acker et al., 2018, p. 13)

By experiencing non-judgemental, timely support from others, individuals felt understood by them and trusting of the support they could receive when they are experiencing difficulties.

“You know me and what to do to help. If I had to keep this in all day I would explode. You know when I am annoyed or not” (Goodall, 2019, p. 27)

1.3.3.3 Subtheme: Practical support

Finally, 'practical support' was identified in six of the included studies. Individuals identified ways in which their environment could be adapted to support them to engage successfully, allowing for positive experiences. This theme was particularly orientated around the school context. For some individuals, this involved creating timetables to support a routine, developing familiarity with the environment and opportunities for regular or flexible breaks.

"Jason used timetables to avoid 'mess[ing] up' (Acker et al., 2018, p. 14)

These forms of practical support were identified as ways of enhancing an individual's wellbeing by increasing predictability and facilitating self-regulation through respite from overwhelming sensory experiences. Goodall (2019) found "five boys wanted more breaks and areas to go to de-stress within school to recalibrate and refocus" (p. 24). This could allow for positive experiences for the individuals. In addition, individuals also valued being provided the required stationery, having opportunities to use technology, receiving support from teaching assistants and parents with schoolwork and completing activities with a preferred peer, which supported the individual to overcome some of the academic and social challenges they experienced.

"Students enjoyed having access to laptops and deemed computers fun to use, and a tool that helped overcome their writing issues as it was quicker to type than write. Additionally, a few students enjoyed having access to Smartboards and Google classrooms. Technology was also a means for students' social interactions" (Danker et al., 2019, p. 136)

1.4 Discussion

Using a systematic review methodology, this study aimed to explore the qualitative literature to address the question "what are the life experiences of autistic adolescents?" Thematic synthesis was used to synthesise the extracted data from 11 included studies, resulting in the identification of three themes related to the life experiences of autistic adolescents: 'social experiences', 'personal experiences' and 'working out what helps me'. Although the quality of the included studies varied significantly, given the identified themes were found within most of the studies, and align with previous research, this supports confidence in the findings.

1.4.1 Social experiences

'Social experiences' revolved around three important factors about the lived experiences of autistic adolescents: the school experience, feeling connected and social adversity.

Chapter 1

The school experience was viewed as an enjoyable one by some individuals, with the usefulness of lessons being an important factor for engaging with lessons. Literature around positive school experiences for autistic students is sparse; however, there is evidence suggesting individuals report preference for and positive experiences in secondary school settings more frequently than primary school settings (Neal & Frederickson, 2016), which is reflective of the stage of education the population of this systematic review will be completing. However, currently the majority of the evidence base identifies the negative experiences and challenges autistic individuals experience within the school setting, with Jahromi et al. (2013) concluding autistic individuals are less likely to enjoy school and as such are likely to be less cooperative within the school environment. This study identified that autistic individuals could feel bored if school lessons were considered not to be useful. This finding aligns with previous research, which has also highlighted that poor work materials and a high level of academic ability contributed to autistic adolescents' boredom within the school environment (DePape & Lindsay, 2016). Finally, this theme also identified an internal pressure to achieve academically; however, the literature involving autistic adolescent students in the field of academic achievement has been identified as lacking (Keen et al., 2016).

'Feeling connected' highlighted the importance of social connections for autistic individuals, which challenges the common misconception that autistic individuals are not socially motivated (Ahlers et al., 2017). Evidence is growing in support of some autistic individuals being socially motivated (Livingston et al., 2019) with a wish to connect with others (Hickey et al., 2018), and the positive impact connection with others can have on feelings of wellbeing and inclusion for autistic individuals, enhancing school participation (Daniel & Billingsley, 2010) and reducing anxiety (Robertson et al., 2018). This theme recognised the importance of shared experiences and connecting with people who autistic individuals consider similar to themselves. This is supported by the literature, with Daniel and Billingsley (2010) identifying that autistic individuals recognise the significance of shared experiences with others. This is reported to be further enhanced when others are accepting and appreciative of the individual's social differences (Sosnowy et al., 2019). These experiences not only increase the sense of connection but also offer relief to the autistic individual (Sosnowy et al., 2019).

Social adversity was also a significant life experience for autistic adolescents. This theme is supported by a wealth of literature which highlights that autistic individuals are more likely to experience bullying and exclusion than peers (Humphrey, 2008; Lung et al., 2019; Sterzing et al., 2012; Symes & Humphrey, 2012). Experiences of being ignored, rejected and excluded were more common for autistic individuals receiving a mainstream education than that of their peers attending special educational settings (Mandy et al., 2016; Zablotzky et al., 2014), which is

significant as more autistic students are now attending mainstream schooling (Richter et al., 2019). For this cohort, experiences of verbal bullying and exclusion have been found to impact on school enjoyment, feeling safe within the school environment and academic achievement (Adams et al., 2016). In addition to this, experiences of bullying have also been identified within the family context (Milton & Sims, 2016), which supports this theme not solely being associated to the school environment.

1.4.2 Personal experiences

‘Personal experiences’ was generated around four significant personal experiences for autistic adolescents: the perception of difference, the experience of heightened emotion, the worry of getting things wrong and sensory experiences.

‘The perception of difference’ highlighted the sense of difference autistic adolescents can experience often associated with an ASD diagnosis, perception of disability and related experiences of bullying. This personal experience is supported within the literature, with individuals often having an awareness of difference (Hickey et al., 2018; Huws & Jones, 2015). Humphrey and Lewis (2008) emphasise that for some autistic individuals the school context requires constant negotiation of feeling different to peers, resulting in autistic individuals feeling forced to adapt to fit in. This is further supported by evidence that autistic individuals have the ability to show concern about their reputation (Cage et al., 2016), which may further enhance feelings of difference. Coleman-Fountain (2017) highlight how autistic individuals often identify awkward social situations being the result of ASD, which may support why this theme found an association between feelings of difference and an ASD diagnosis. This may also reflect why the evidence base and understanding about compensation strategies which aim to enhance social presentations and mask difficulties is growing (Livingston & Happé, 2017). Compensatory strategies have been found to require significant and sustained effort to maintain and as such can impact negatively on an individual’s wellbeing (Livingston et al., 2019; Milton & Sims, 2016). However, this theme also highlights how for some autistic individuals feelings of difference was a positive experience. This is again supported by the literature, which finds some autistic individuals feel proud of who they are, inclusive of the way they may differ from others (Cage et al., 2016; Humphrey & Lewis, 2008). Interestingly, similar to the findings of this theme, evidence suggests receiving a diagnosis allowed a greater understanding of self and others; however, for some autistic individuals it can be a personal journey to move towards having pride in an individual’s autistic identity (Milton & Sims, 2016).

Significant attention has been given to the difficulties autistic individuals experience with recognising (Uljarevic & Hamilton, 2013) and processing emotions (Weiss et al., 2017) and internalising experiences (Sarabadani et al., 2018). However, 'experiences of heightened emotion' draws attention to how autistic individuals are often able to identify and share their emotional experiences, contributing to identification of an important and possibly unexpected theme to some. Evidence suggests autistic adolescents are more likely to experience greater levels of emotional distress (Robinson, 2018), and clinically significant difficulties with anger, anxiety or sadness in comparison to peers (Totsika et al., 2011) with a high prevalence of anxiety disorders within the autistic population (Lai et al., 2019). In line with this, experiences of anxiety were significantly present within this theme, which for some individuals resulted in feelings of anger and behavioural responses including self-harm and aggression towards others. This is recognised within the literature, with autistic individuals being found to experience emotional regulation difficulties (Weiss et al., 2017) and have inadequate coping strategies to manage difficult experiences in comparison to peers (Jahromi et al., 2012). In addition, evidence is starting to emerge about increased anger-focussed rumination within the autistic adolescent population which has been associated with emotional and behavioural dysregulation, symptoms of depression and poorer functioning (Patel et al., 2017). For this reason, and in line with the findings of this theme, it is important that autistic individuals are supported by others to identify new emotional regulation coping strategies to increase independence (Torrado et al., 2017).

'The worry of getting things wrong' captured the significance of social communication difficulties experienced by autistic individuals and the impact of this. In this study, individuals identified challenges with knowing what to say, which has been identified by Carter et al. (2005) as a common difficulty for autistic individuals who struggle with initiation and maintenance of conversations. During the period of adolescence, greater demand is placed on social relationships with peers (Block, 2011), which alongside the increasing complexity of social interactions is likely to compound the difficulties autistic individuals experience (Burgess & Turkstra, 2010). Sosnowy et al. (2019) describe how uncomfortable this experience can be for autistic individuals, experiencing a pressure to adhere to social expectations but not knowing how to act. As a result, higher levels of social anxiety symptoms have been observed in autistic individuals as a result of social communication difficulties (Pickard et al., 2017), which reflects the concerns about reactions of others to autistic individuals making mistakes identified in this study.

'Sensory experiences' identified in this review is recognised within the DSM-5 and supported by a wealth of literature. The school environment is recognised to be a challenging environment for individuals with sensory difficulties (Fernández-Andrés et al., 2015; Humphrey & Lewis, 2008) with individuals experiencing anticipatory anxiety and physical reactions to noise and touch, impairing

their ability to concentrate (Howe & Stagg, 2016; Humphrey & Lewis, 2008), which is reflective of the findings of this review. When sensory experiences impact on an individual's concentration, they have been found to result in academic underachievement for autistic individuals (Ashburner et al., 2008; Howe & Stagg, 2016). There is evidence to suggest sensory-based interventions can support self-regulation within the school environment, enabling academic and social success for autistic individuals (Benson et al., 2019), and the theme 'working out what helps me' of this review may offer an insight into autistic individuals' perspectives about what meaningful interventions could be.

1.4.3 Working out what helps me

The final theme, 'working out what helps me', evolved around three different support domains that have been identified as useful or being utilised: autistic individuals' personal support strategies, support from others and practical support strategies. With regard to this theme, Tamm et al. (2019) proposed that additional support strategies are required due to the executive functioning difficulties autistic individuals experience.

'Personal strategies' is supported by a strong evidence base exploring the compensatory strategies of autistic individuals to enable them to navigate the demands of the social world (Hull et al., 2017; Livingston & Happé, 2017; Tierney et al., 2016). Cognitive compensatory strategies, similar to the personal strategies identified in this theme, may also be used as an attempt to mask difficulties (Livingston & Happé, 2017). One of the personal strategies identified by some autistic individuals was the use of fantasy play. Ke and Moon (2018) identified how reality-based virtual play can enhance the social interaction performance of individuals, with Vera et al. (2017) recognising that the controlled and structured environment of virtual play allows for repetition and generalisation to the real world. For autistic individuals, computer or video gaming is one of the most common circumscribed interests (Harrop et al., 2019), which might offer further explanation of this being identified as a useful supporting aid by some individuals in this study. Although the benefits of this strategy have been identified within this study and the literature, currently few support interventions utilise fantasy play (Harrop et al., 2019); however, Vera et al. (2017) suggested reality-based virtual play could be a useful tool for classroom learning. Similar to the benefits of virtual or fantasy play, Tamm et al. (2019) showed how the planning and scripting strategies identified in this study offer opportunities to support executive functioning difficulties by allowing preparation time for planning, prioritising and organising.

This study identified 'support from others' as a positive support strategy, pinpointing others listening, explaining and reducing distress as being beneficial to autistic individuals. This aligns

with the literature, with Ahlers et al. (2017) emphasising how providing social emotional support to autistic individuals requires a teaching–learning process to support personal growth and acts as a protective factor against suicidality within this cohort (Hedley et al., 2017). Within the classroom, positive experiences with tutors and mentors have been found to be highly valued by autistic individuals, with meaningful relationships significantly supporting mental health difficulties in this cohort (Milton & Sims, 2016) whilst the quality and level of teaching support can also have a positive impact on academic success (Tamm et al., 2019). Evidence suggests it can be challenging for others to identify when this support is needed, with compensatory strategies masking the individual’s need for support (Livingston et al., 2019) and individuals experiencing barriers to prevent them seeking support from others (Camm-Crosbie et al., 2019; Crane et al., 2019). This idea is not reflected in this systematic review but is an important consideration when individuals identify the benefit of support from others as reducing experiences of distress.

Finally, ‘practical support’, which captured practical strategies that autistic individuals have found useful, is well supported by literature related to the current understanding of the needs of autistic individuals. The identification of access to required equipment in this study aligns with Tamm et al’s. (2019) conclusion that autistic individuals experience difficulties with the behaviours needed to independently complete school and homework, such as organisation. This was considered to include planning how to approach large tasks, independent organisation of materials and studying effectively, which can be a barrier to academic success, requiring varying levels of support to overcome. This mirrors the findings of this study’s theme, which found the availability of these types of practical support allowed for academic progression.

1.4.4 Strengths and limitations of the included studies

With an increase in self-diagnosis (Lewis, 2017), efforts to confirm participants’ formal diagnosis as part of the recruitment strategy was a strength of the included studies, allowing for a relatively homogenous participant sample. Given that the majority of literature about the lived experiences of autistic adolescents is captured through stakeholders (Nicolaidis, 2012), another strength of the included studies was the use of participants’ quotes to support findings to disseminate the voice of this cohort. Limitations included varying quality between the included studies and a significant lack of consideration to the researcher–participant relationship during data collection within nearly all included studies.

1.4.5 Strengths and limitations of the review

This is the first systematic review to look solely at the life experiences of autistic adolescents.

By investing time into the development of a detailed protocol, the systematic review included studies that provided meaningful data to help answer the systematic review question. The search strategy used for this review was comprehensive, searching grey literature databases and forward citation chaining, without date restrictions. This could be considered a strength because it supported consideration of a wider selection of literature. Dual checking throughout the systematic review process enhanced the validity of this review and reduced any potential biasing.

A limitation of this study was the failure to complete backward citation chaining. A further limitation of this systematic review is the limited amount of literature included that looks at the hobbies of autistic adolescents, which may offer insight into further important life experiences and the varied primary focus of the included studies. In addition to this and although identified as a strength, dual screening was also a limitation of this study as only a percentage of data was dual screened at each stage of the process. Finally, it should be acknowledged that a further potential limitation of this research may be found in the identified themes. It is acknowledged that within any piece of qualitative research the project and findings are influenced by the world view of the researchers (Austin & Sutton, 2014). As the project team all work in the field of clinical psychology, it should be acknowledged that researchers from other fields may identify different synthesis results.

However, given the comprehensive search strategy, robust inclusion and exclusion criteria, the range of database platforms searched and the transparency of the review protocol, the research team has confidence in this review including all relevant literature and the conclusions reached through thematic synthesis of the extracted data.

1.4.6 Directions for future research

Much of the research in this field, and included in this systematic review, has generated literature about the life experiences of autistic adolescents through a focus on specific topics, such as ASD diagnosis or social relationships. More high-quality research is needed to explore the more general life experiences of autistic adolescents to further support the themes identified in this systematic review and potentially highlight additional life experiences. This research should ensure adequate consideration of the relationship between the researcher and participants to reveal any biasing that may influence the study findings. In addition, there would be a benefit to future systematic reviews, when this literature is available to reflect the potential changing life experiences of this cohort.

The researcher has also identified the need for further research into two areas. Firstly, the factors and experiences that contribute to autistic adolescents' enjoyment of school is currently an

under-researched area, with the majority of research focussing on the challenges of education, and further research may identify opportunities to enhance individuals' experiences. Secondly, there is a need for exploration into autistic individuals' personal experiences of academic pressure. Again, the literature capturing autistic adolescents' experiences of this topic is sparse, and further research could offer insight into the support for and impact of these experiences.

1.4.7 Clinical and educational implications

The findings from this review offer a range of implications for stakeholders supporting autistic adolescents.

It is important to recognise the unique presentation and expertise of every autistic adolescent by inviting their thoughts and opinions at all times rather than making assumptions about their experiences. This review has identified the importance of asking the autistic adolescent what meaning their ASD diagnosis holds for them and if they would want others within the environment to know about this diagnosis. Similarly, it is important to work with the individual to identify their sensory needs, possible triggers to overstimulation and individualised strategies to support and maintain engagement within different contexts. This approach should also be utilised to identify and individualise the practical support needs and support strategies of autistic adolescents in different contexts. Given the barriers autistic adolescents often experience accessing support, it could be of benefit to document this information, in collaboration with the individual, and share with the wider system to enhance the support received.

As part of the preparation for academic assessments, additional time should be invested into supporting autistic adolescents to understand the range of possible outcome scenarios and the impact of these on future goals. This may support a reduction in experiences of anticipatory anxiety related to academic achievement. Similarly, consideration of the use of fantasy play within clinical and educational settings could support the development of social interaction skills for autistic adolescents, potentially reducing experiences of anticipatory anxiety related to some social interactions.

It is important for all contexts to offer a safe, non-assuming and non-judgemental space for autistic adolescents to talk about experiences they find distressing. This opportunity should be offered in a timely manner. Support should also be provided to help autistic individuals make sense of what may have triggered their emotional reaction, and when maladaptive behavioural responses are present, discuss and support the development of more adaptive emotional regulation strategies.

More widely, it is important for the systems around the autistic adolescent to engage with autism community awareness projects to enhance the knowledge and understanding of professionals, peers and family members. This is particularly important within mainstream school environments as it may reduce experiences of social adversity, facilitating an inclusive environment for autistic individuals enhancing individuals' wellbeing.

1.5 Conclusion

This is the first systematic review to solely explore the life experiences of autistic adolescents from the perspectives of the individuals themselves. The findings identified three main themes pertinent to the lived experiences of autistic adolescents: 'social experiences', 'personal experiences' and 'working out what helps me'. These findings can enhance understanding about the shared experiences of autistic individuals during adolescence, the impact these experiences can have on wellbeing and ways in which to support individuals during this period. The findings can support the development of meaningful support aligned to the perspectives of autistic individuals (WHO, 2006). Finally, this review concludes with a call for further research in this field, enabling greater understanding of the life experiences of autistic adolescents and how these experiences may change over time.

Chapter 2 ‘What If I Just Want to Be Me?’: Exploring the Self-Concept of Autistic Adolescent Females Using Interpretative Phenomenological Analysis

2.1 Introduction

An introduction to the topic of ASD is presented in Chapter 1. This chapter will specifically focus on autistic females and self-concept.

2.1.1 Autistic females

2.1.1.1 Disparity of diagnosis within the female population

More males than females receive a diagnosis of ASD, with a ratio of four to one being widely reported (Lai et al., 2015). However, further research suggests a more varied picture; a meta-analysis concluded the male:female ratio differential as being closer to 3:1 retrospectively (Loomes et al., 2017). This ratio is reported to differ depending on the cognitive abilities of the population sample, with a ratio of closer to 2:1 being reported in an intellectual disability population and a greater male representation in high-functioning populations, with ratios of between 5.7:1 and 11:1 (Lehnhardt et al., 2016; Loomes et al., 2017; Yeargin-Allsopp et al., 2003). In addition, females also tend to be misdiagnosed and/or receive a diagnosis at a later age when compared to males (Lai & Baron-Cohen, 2015; Loomes et al., 2017; Rutherford et al., 2016). With the exact cause of ASD still unknown, it is hard to fully understand this gender disparity (Shefcyk, 2015) however there are a variety of schools of thought about why it may occur.

2.1.1.1.1 The female phenotype

One school of thought proposes that there are different gender phenotypes and argues that the current diagnostic assessment has been developed on the presentation of a male population, which may account for the diagnostic imbalance (Bargiela et al., 2016; Kirkovski et al., 2013; National Autistic Society, 2018). Currently, the knowledge and conceptualisation of ASD is largely derived from research into a male-dominated population, which is considered problematic as it fails to recognise differences in the female manifestation (Gould & Ashton-Smith, 2011; Kreiser & White, 2014; Mandy et al., 2012; Mandy & Lai, 2017). An example of the difference in gender phenotypes is proposed by Webster and Garvis (2017), who suggests females hold a greater interest in social interaction, than males, and this may support females in learning to mask their

social difficulties. This contributes to current thinking about the female phenotype involving 'social camouflaging', which Mandy (2019) describes as the "monitoring and modifying [of] their behaviour to conform to conventions of non-autistic social behaviour". Hull et al. (2017) considers the concept of camouflaging to involve two elements; 'masking' of difficulties through the development of different social personas and 'compensation' strategies to support the bridging of social and communication differences (Hull et al., 2017). Attwood (2006) highlights how additional coping mechanisms and camouflaging may make it more challenging to diagnose females, which could offer an explanation for under-diagnosis in the female population.

2.1.1.1.2 Female protective effects

Evidence is growing in support of the female protective effects theory which offers another explanation for the sex differential in a range of diagnoses, ASD (Jacquemont et al., 2014; Robinson et al., 2013). This theory suggests that females may require greater exposure to genetic and environmental factors to present with traits of ASD than males (Robinson et al., 2013) which may result in fewer females requiring an ASD diagnosis and/or diagnostic overshadowing.

2.1.1.1.3 Socially constructed stereotypes

A final school of thought considers how our socially constructed views about gender presentations may influence our perception and recognition of ASD symptomology (Cheslack-Postava & Jordan-Young, 2012). When considering gender differences within the triad of impairments, a recent meta-analysis found females present with lower severity of repetitive and stereotyped behaviour (Van Wijngaarden-Cremers et al., 2014). In addition to this, Attwood (2006) highlights how autistic females tend to display intense interests around people and animals rather than objects, which are considered more age and gender appropriate. It is argued that the socially accepted context of which autistic females' repetitive behaviours occur could make it appear less unusual and result in misinterpretation or failure to recognise these behaviours, impacting on the diagnostic outcome (Gould & Ashton-Smith, 2011; Halladay et al., 2015).

2.1.1.2 The presentation of females on the autism spectrum

Pellicano et al. (2014) draw attention to the significant consequences of this gender differential on the health and wellbeing of autistic females. Webster and Garvis (2017) suggest females hold a greater interest in social interaction and this may support them in learning to mask their social difficulties; however, this can be exhausting to maintain. It can impact on an individual's mental wellbeing and perceptions of self, resulting in an altered clinical presentation, comorbidities and difficulties eliciting support (Hull et al., 2017; Kirkovski et al., 2013). Bargiela et al. (2016) investigated the experiences of late-diagnosed autistic females, revealing a theme of "you're not

autistic”, describing how their difficulties were not being believed or were misunderstood by others, resulting in a delayed diagnosis. Leedham et al. (2020) highlight how the mislabelling of a female’s presentation can result in self-criticism, although after receiving a diagnosis this can evolve to self-compassion and increased agency.

Autistic females report higher levels of emotional difficulties, which are more likely to present as anxiety, depression or eating difficulties when compared to autistic males and neurotypical females (Mandy et al., 2012; May et al., 2014; Solomon et al., 2012). Solomon et al. (2012) identified higher rates of social isolation during the adolescent period in the autistic female population.

Difficulty in recruiting autistic females to research has led to little being known about this population’s specific experiences or stories (Davidson, 2007; Goodall & MacKenzie, 2019; Kirkovski et al., 2013). Research into this area has been identified as a key priority by the autism community (Pellicano et al., 2014).

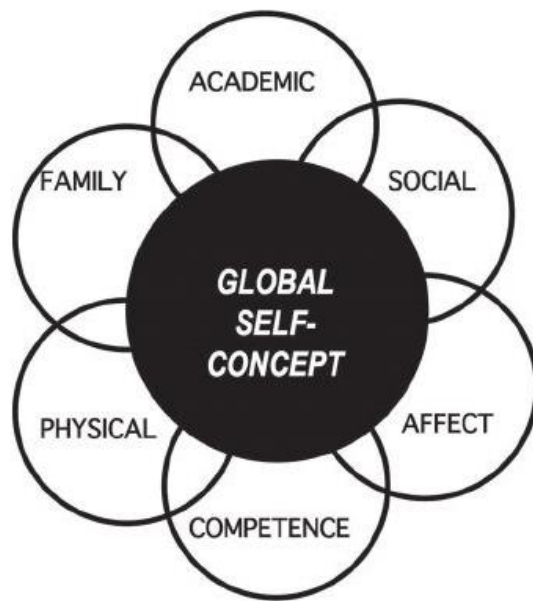
2.1.2 Self-concept

2.1.2.1 What is self-concept?

Who am I? Although no one single or simple definition can be identified (Côté, 2009), self-concept is widely recognised as the view an individual holds about themselves in relation to this question (Myers, 2010) and has been defined as “the totality of an individual’s thoughts and feelings having reference to himself as an object” (Rosenberg, 1979).

Initially, theorists viewed self-concept as a single stable conceptualisation of the self (Demo, 1992). However, in recent years, self-concept has been recognised as a multifaceted and hierarchical phenomenon (Bracken, 2009; Markus & Wurf, 1987). An example of this can be seen in the Multidimensional Self-Concept Model (Bracken, 1992, cited in Bracken, 2009), which argues that six self-concept domains contribute to an individual’s “global self-concept”: social, competence, affect, physical, academic and family (Figure 2).

Figure 2: *Multidimensional Self-Concept Model* (Bracken, 1992 cited in Bracken, 2009)



Alongside the multifaceted conceptualisation of self-concept, evidence has emerged supporting the active, flexible and responsive nature of an individual's self-concept to environmental feedback and change (Demo, 1992; Markus & Wurf, 1987) which influences an individual's behaviour in different contexts (Bracken, 2009).

2.1.2.2 Development of self-concept

Although the drafting of attributes of self-concept starts in early childhood, adolescence is considered a critical period for the development of self-concept, which becomes the foundation for the remainder of an individual's life (Erikson, 1963). Erikson (1963) proposed that between 12 and 19 years of age an individual works through a stage of "identity vs role confusion" to develop a sense of self and personal identity. This involves establishing a "sexual, political, moral, religious, and vocational identity" (Block, 2011, p. 785) which is achieved through the appraisal of values, beliefs and goals in the search for a sense of self and personal identity. Gender differences have been recognised within this period, with females focussing primarily on interpersonal relationships and males more invested in ideologies and occupations (Archer, 1989).

Success through this period allows an individual to arrive at "a phenomenological wholeness, or integrated self" in late-adolescence (Foster, 2011, p. 776) supporting an individual's wellbeing (Waterman et al., 2010). Erikson (1963) suggests failure to reach a resolution through this period will result in feelings of inadequacy. Evidence suggests adolescents can struggle with identity commitment and achievement if they experience high levels of anxiety (Crocetti et al., 2008) and

may later present with psychosocial adjustment difficulties, higher depressive symptoms and involvement in criminal activities (Meeus et al., 2012).

2.1.3 Self-concept in the autistic population

Of the research available in this area, most considers the challenges an autistic individual faces in developing self-concepts or the impact of life events on a person's view of their self-concept. When specifically considering the self-concept of autistic females, the majority of evidence focuses on gender identity, which is a specific area of an individual's self-concept. This evidence suggests autistic females experience more negative feelings towards gender conformation (Cooper et al., 2018; Dewinter et al., 2017; Lemaire et al., 2014). Due to the lack of evidence in this topic area, the remaining discussion of this section will reflect the research completed with both genders.

Little attention has been given to the identity formation of autistic individuals (Bagatell, 2007); however, queries have been raised about how self-concept develops in autistic people, given their social difficulties (Ratner & Berman, 2015). Huang et al. (2017) suggest autistic individuals experience an impairment in the "psychological self" whilst Ratner and Berman (2015) identified that individuals with a higher prevalence of autistic traits tend to experience greater difficulty forming an identity, which is reported to result in higher levels of distress and anxiety.

When considering the impact of receiving an ASD diagnosis, evidence has reported varying findings. Tan (2018) proposes the concept of 'biographical illumination', an "enrichment and cultivation of self" that occurs after receiving an ASD diagnosis, whereby individuals experience a transformation in self-concept, specifically the autistic self and identity. Lewis (2016) offers supporting evidence for this by identifying that for some individuals, receiving a diagnosis in adulthood has been found to have a positive impact on self-concept (Lewis, 2016). When exploring the lived experience of females, Leedham et al. (2020) reports a more varied conclusion through the theme of "changing wellbeing and views of the self". For some participants, receiving a diagnosis facilitated greater understanding and acceptance of the self, whilst for others they felt a loss of self-concept.

Through the exploration of cultural identity, Cresswell and Cage (2019) identified that marginalised autistic adolescents had a poorer self-concept than that of assimilated autistic adolescents. This study concluded that with support to explore and commit to a preferred group identity, autistic individuals' mental health and self-concept may benefit.

2.1.4 The role of narratives in sharing self-concepts

Through the growth of socio-cognitive skills and a motivation to make sense of who we are, adolescents begin to narrate their own life stories (Habermas & Bluck, 2000). Polkinghorne (1991) argues that stories about the self are developed through “linking diverse events” of an individual’s life into a meaningful whole, which creates a narrative identity. This narrative identity is generated through the organisation of memories and other relevant information about ourselves which evolves from adolescence over the course of adulthood, reflecting an individual’s self-concept, priorities, changing concerns and roles (Habermas & Bluck, 2000; Singer, 2004). Huang et al. (2017) suggest that using a self-narrative approach with autistic individuals allows for the individual’s “own voice” to be heard more clearly. This approach has been utilised in other research into the self of autistic individuals (Tan, 2018).

2.1.5 Rationale for the current study

Erikson (1963) suggests adolescence is a critical period for the development of self-concept, however, it has been recognised that little attention has been given to the identity formation of autistic individuals (Bagatell, 2007). Chapter 1 brings awareness to the increased challenges autistic individuals face, in comparison to their peers, during this complex period (McLeod et al., 2019; O’Reilly et al., 2018; Sedgewick et al., 2018). However, there is recognition within this field that much of our understanding of autism is derived from the perspective of stakeholders (Nicolaidis, 2012) and male-dominated populations, which fail to reflect the differences for the female autistic population (Gould & Ashton-Smith, 2011; Kreiser & White, 2014; Mandy et al., 2012; Mandy & Lai, 2017). As such little is known about the first-hand experiences, stories (Davidson, 2007; Goodall & MacKenzie, 2019; Kirkovski et al., 2013), and self-concept of autistic females.

It is widely recognised that autistic females may have significantly different life experiences to autistic males; with an increased likelihood of misdiagnosis and/or late-diagnosis (Lai & Baron-Cohen, 2015; Loomes et al., 2017; Rutherford et al., 2016), and the presence of masking and compensation strategies which can alter their clinical presentation, result in comorbidities and introduce barriers to eliciting support (Hull et al., 2017; Kirkovski et al., 2013). These experiences have been found to impact autistic females' self-concept (Leedham et al., 2020; Lewis, 2016), however the findings about this impact vary. The autism community recognise the importance of these experiences and suggest research into the field of autistic girls and women is a key priority (Pellicano et al., 2014). However, of the literature currently available, there is very little exploring

the impact of these life experiences and the global self-concept of autistic females from a first-hand perspective, during the critical time where self-concept is being developed.

With this in mind, it is of interest to the researcher to explore the self-concept of autistic adolescent females who have received an ASD diagnosis during adolescence, a crucial identity formation period, to add to the limited evidence base and to support the individual's voices to be heard.

2.1.5.1 Research aims

This research aims to explore the self-concept of adolescent females diagnosed with ASD in adolescence, through the following research questions:

- What life events and experiences do autistic females identify as important to them?
- How do important life events and experiences influence autistic females' self-concept?
- How does receiving an ASD diagnosis influence autistic females' self-concept?

2.2 Methodology

2.2.1 Qualitative approach

Qualitative research methods attempt to answer 'how' and 'why' questions through exploration of participants' experiences, and the meaning given to these, from the perspectives of the participants and therefore lends itself well to the aims of this study (Chamberlain, 2000; Hammarberg et al., 2016).

2.2.2 Interpretative Phenomenological Analysis

Careful consideration was given to a range of qualitative methodologies when designing this study. The researcher recognised that much of the published literature in the field of self-concept utilises a Narrative Inquiry methodology. As such, this approach was considered in-depth, however, the phenomenological approach of Interpretative Phenomenological Analysis (IPA) was eventually deemed as the most meaningful for this study.

As IPA aims to understand how individuals make sense of major personal and social life events, and the meaning these hold, in rich detail (Smith, 2003), this approach aligns with the aims of this study and compliments the epistemological stance of the researcher. IPA has been highlighted as a useful qualitative methodology in the field of autism research as it is underpinned by a commitment to "illuminating" participants' experiences (Howard et al., 2019). This commitment is

supported by a step-by-step analysis framework (Smith et al., 2009), which enhances the transparency and coherence of this study and offers something that did not appear to be as clearly defined by a Narrative Inquiry methodology. Through this analysis framework, the individual voices of participants can be heard, how the group of individuals' experiences intertwine can be identified and the researchers' interpretation of the participants' experiences can be presented. Capturing the voice and experiences of the individual participants and making sense of this through an interpretative lens was particularly important to the researcher and this was supported by an IPA methodology.

IPA is strongly influenced by three underpinning theoretical orientations: phenomenology, hermeneutics and idiography (Smith et al., 2009). Table 8 describes the influence these theoretical approaches have on an IPA methodology.

Table 8: *Influence of theoretical approach on Interpretative Phenomenological Analysis*

Theoretical approach	Area of concern	Influence on Interpretative Phenomenological Analysis
Phenomenology	Experience	From a phenomenological perspective, IPA aims to examine what the human experience is like through an individual's personal perception and expression of the meaning these experiences hold (Smith et al., 2009). It is recognised that an individual's experience is influenced by their relationship with the world, and as such an IPA researcher should aim to become close to participants' experiences (Smith et al., 2009).
Hermeneutics	Interpretation	Hermeneutics questions if it is possible to fully uncover the meaning of another perception and understand the context and relation of this perception, acknowledging that a text is shaped by historical, cultural and personal experiences and contexts of an author (Smith et al., 2009). It is recognised that in attempting to understand participants' experiences, the researcher is engaging in 'double hermeneutics', a two-staged interpretation process whereby the research is attempting to make sense of the participant making sense of their own experiences (Smith & Osborn, 2003; Smith et al., 2009). For this reason, it is important in IPA to consider the wider context of both the participant and researcher that may be influencing the meaning made by the researcher (Smith et al., 2009).
Idiography	The "particular" (Smith & Osborn, 2003).	Within IPA, this theoretical approach is committed to "understanding how particular experiential phenomena (an event, process or relationship) have been understood from the perspective of particular people, in a particular context" as well as a detailed and thorough approach to analysis (Smith et al., 2009, p. 29).

2.2.3 Epistemology

The primary researcher is approaching this study from a social constructionist epistemological stance, which accepts there is an objective reality which is constructed through active involvement of language and social interaction (Andrews, 2012). Such an approach encourages curiosity in the process itself and a recognition that knowledge about the topic of interest is constructed between participant and researcher through a balanced power dynamic (Losantos et al., 2016). A social constructionist stance fits well with the study's topic of interest, with the self being identified as a social constructed concept (Gergen, 2011) and the theoretical underpinnings of IPA as this methodology "subscribes to social constructionism" (Smith et al., 2009, p. 196).

2.2.4 Ethics

This study was developed in line with the "Code of Human Research Ethics" (BPS, 2014) and ethical approval was obtained from the University of Southampton Ethics and Research Governance Team on 16th October 2019 (Appendix A). Given this study aimed to recruit participants from a "vulnerable" sample (BPS, 2014, p. 13), significant consideration was given to issues of consent, risk of harm, confidentiality and debriefing (Appendix B).

2.2.5 Study design and development

2.2.5.1 Methodological procedure

A semi-structured interview design of open-ended questions was used to elicit the life stories of participants. Such a design is the most frequently used and widely recognised for use in an IPA study (Smith, 2003). This method lets the researcher hold an area of interest in mind whilst allowing for flexibility to modify questions and probe areas of interest in light of the information participants share. In addition, this approach allows the researcher and participant to build rapport, essential when inviting participants to share rich accounts about their lived experiences (McGrath et al., 2019; Smith, 2003). One further benefit of this design compared to others is that it positions the participant as the expert of their lived experiences (Smith, 2003), offering challenge to the inherent power imbalance that occurs within research interviews (Råheim et al., 2016). Within this study, the semi-structured interview was designed to elicit the participants' narratives, identified as a meaningful way for autistic individuals to be heard and to reflect an individual's self-concept (Habermas & Bluck, 2000; Huang et al., 2017).

2.2.5.2 Participant sampling

Purposive sampling was used to recruit participants. This method is widely utilised within qualitative research as it seeks a homogenous sample of participants who are likely to find the research question significant to them (Palinkas et al., 2015; Smith, 2003). Inclusion and exclusion criteria were developed to further support the self-identification and recruitment of a homogenous participant sample (see Table 9). Additional consideration was given to inclusion and exclusion criteria relating to the assigned sex and identifying gender of participants to reduce the potential focus on gender identity.

Table 9: *Inclusion and exclusion criteria*

Inclusion	Exclusion
<ul style="list-style-type: none"> Assigned female sex at birth Identifies as female Aged between 13 and 18 years old Diagnosed with ASD between 12 and 17 years old Received the diagnosis at least 12 months prior to the interview date Able to provide evidence of diagnosis Able to understand a basic level of spoken and written English Has a good level of verbal expression If under 16 years old, has consent from a parent or guardian 	<ul style="list-style-type: none"> Assigned male sex at birth Identifies as male or non-binary Outside of age range a time of recruitment Diagnosed with ASD outside of age range Diagnosed within 12 months of the interview date Not able to provide evidence of diagnosis Unable to understand a basic level of spoken and written English Non-verbal or unable to adequately express themselves through spoken English If under 16 years old, does not have consent from a parent or guardian

2.2.5.3 Sample size

There is differing guidance about the number of participants required for a doctoral level qualitative study, ranging from five to 10 participants (Polkinghorne, 1989; Smith, 2003; Turpin et al., 1997). After consideration of this guidance, this study aimed to recruit between six and eight participants.

2.2.5.4 Pilot interviews

Two pilot interviews were conducted prior to data collection, firstly with a research colleague to identify any difficulties with the practical and procedural aspects and secondly with an eligible participant in the study to ensure the interview schedule was accessible. The interview schedule

was revised following feedback and observations from these pilot interviews. Appendix C presents the finalised schedule.

2.2.6 Procedure and data collection

2.2.6.1 Recruitment

In line with purposive sampling, this study was advertised through ASD voluntary sector services between October 2019 and January 2020. Permission to approach potential participants within voluntary sector networks was sought from the service administrators (Appendix D). Once written consent was obtained, administrators circulated the study advert (Appendix E) in the way they considered most appropriate for their service. This included advertising on social media platforms, printing in a newsletter, circulating by email and handing out the advert in group sessions. The study poster included the contact information for the researcher encouraging interested parties to request further information.

Interested participants were given a study overview, Participant Information Sheet and, where appropriate, Parent Information Sheet via email. They were contacted again a week later and practical arrangements then made for conducting the interviews.

2.2.6.2 Expression of interest

Fifteen requests for additional information about the study were received: four from adolescents, 10 from parents/guardians and one from a wider family member. Following this, seven interviews were arranged (one pilot study and six included interviews). Four of the expressions of interest made no further contact after receiving the Information Sheets, one expression of interest had conflicting education pressures and three expressions of interest met exclusion criteria: two diagnosed in prior 12 months, and one identified as male.

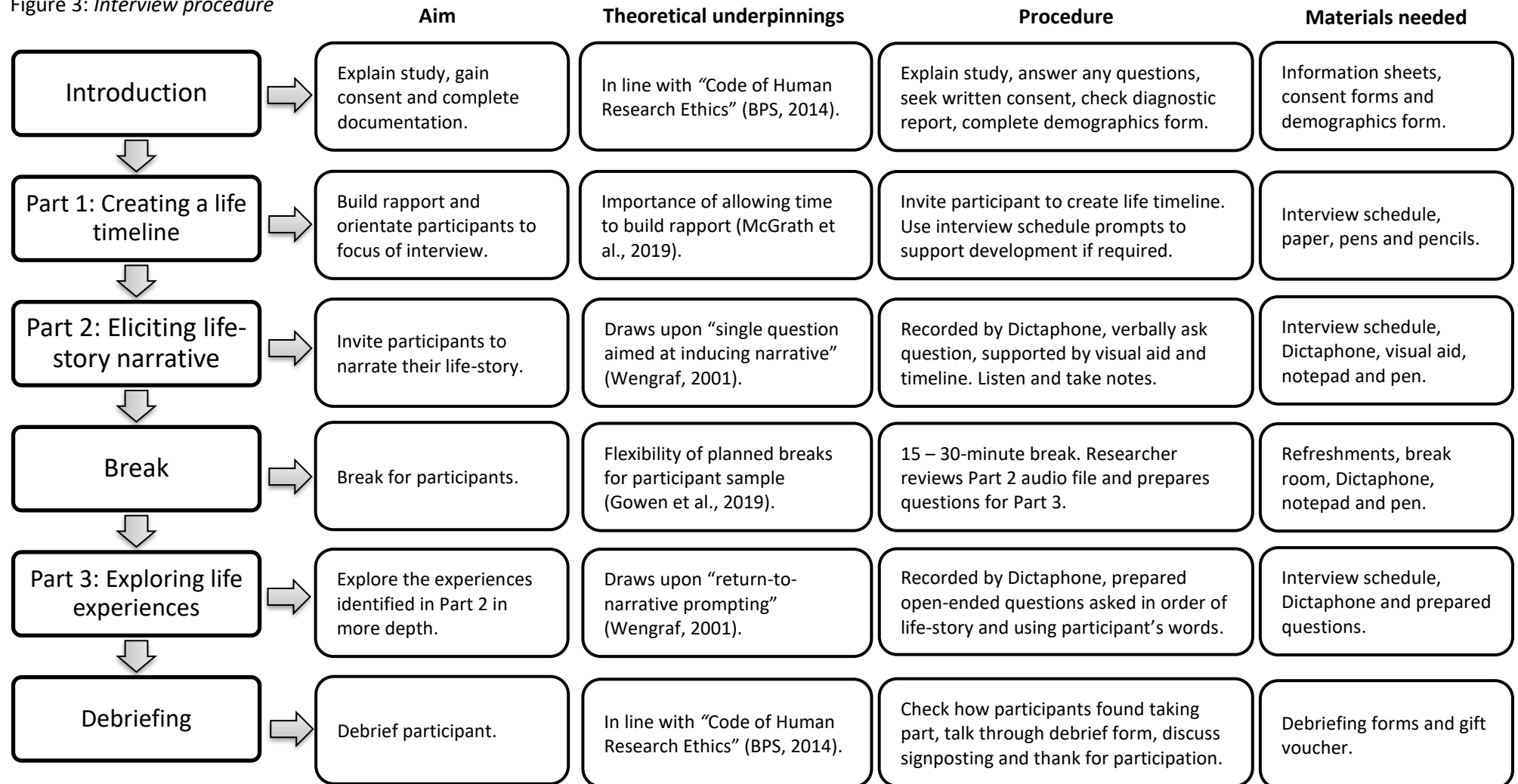
2.2.6.3 Interview venue

The venue of the interview was directed by participants with the intention of choice and familiarity bringing some comfort in an unusual context. The pilot interview was completed at the participant's home address. Four interviews were conducted at the participants' home address, one in an education setting and one in a library.

2.2.6.4 Interview Process

An overview of the interview process is provided in Figure 3. Supporting materials can be found in the appendices (Appendix G – O).

Figure 3: Interview procedure



2.2.6.5 Adaptations to procedure

For one participant, shifting between Part 1 and Part 2 of the interview was challenging. The participant found this repetitive and confusing. To support engagement, adaptation of Part 2 was required, and it was agreed the participant would use a scrapbook to talk about a more specific topic: her experience of visiting London to watch the Paralympic Games and visit Harry Potter World.

2.2.6.6 Participant demographics

Six female adolescents aged between 14 and 18 years old participated in the study. All participants had received their ASD diagnoses 12-48 months prior to interview. Participants' demographics, including religion and ethnicity, are introduced in Table 10.

Table 10: *Participant demographics*

Name	Age	Age at point of diagnosis	Additional diagnoses	Ethnicity	Religion	Education setting	Lives with
Annie	17	14	Hypermobility, Connective tissue syndrome	White	No religion	State	Mother, Father
Beth	14	13	Dyspraxia	White	Christian	Private	Mother, Father, Brother
Claire	14	13	ADHD, Dyspraxia, Hypermobility, Cancer	White	No religion	Home schooled	Mother, Father, Sister, Brother
Danielle	15	13	None	White	No religion	State (Reduced hours)	Mother, Father, Sister
Ellie	16	12	Coeliac	White	No religion	Private	Mother, Father, Sister
Felicity	18	17	Anxiety, Depression, Slow growth	White	No religion	Private	Mother, Father, Sister

2.2.7 Data analysis

2.2.7.1 Data management

Each interview was recorded by Dictaphone, and the audio files were uploaded to a password-protected computer which only the researcher had access to. A professional transcription service, which held a confidentiality agreement with the University of Southampton, transcribed the files. The researcher compared the transcripts to the audio files to ensure accuracy of transcription and deleted the audio files from the computer following completion of Step 1 of the data analysis. The researcher removed any identifiable information from the transcripts before commencing analysis.

2.2.7.2 Interpretative Phenomenological Analysis

This study followed the six steps of IPA defined by Smith et al. (2009). Smith et al. (2009) identify a step-by-step analysis structure to support novice researchers through the analysis process though acknowledge there is no standardised way of working with the data. Table 11 reflects the application of this analysis structure to this study. Data analysis was completed by hand.

Table 11: *Six steps of IPA (Smith et al., 2009)*

Step	Aim of step	Application of step to this study
1.	Immersion in original data through reading and re-reading of a transcript	When ensuring the accuracy of the transcription, the researcher listened to the audio file of the interview whilst reading the transcript. The researcher repeated this one further time before reading the transcript in isolation.
2.	Initial noting of the transcript	Initial noting captured descriptive, linguistic and conceptual comments about the participants' narratives (Appendix M) and were recorded on the right-hand side of transcription data.
3.	Identifying themes through the transcript	The researcher then moved to identifying themes by analysing the initial noting (Appendix M). Identified themes were noted to the left-hand side of the transcription data.
4.	Searching for connections between the themes within the transcript	For this step, the researcher wrote out each of the identified themes on separate sheets of paper and considered how themes may connect with each other, by moving them around. This supported development of a map of how the themes connect.
5.	Repeating step 1 to step 4 on the next transcript	
6.	Looking for patterns across all transcripts	A meeting was held to allow the project team to complete this step together. This was to support consideration of higher-order concepts shared collectively between the transcripts. A map of

superordinate themes and subordinate themes was generated (Table 12).

2.2.8 Quality assurance

Yardley (2000) proposed four essential criteria to judge quality of qualitative research, which have become widely utilised within this field (Lyons & Coyle, 2016; Smith, 2003) and have been drawn upon within this study.

Sensitivity to context was achieved through completing a systematic review of the lived experiences of this cohort and consideration of the psychological theories underpinning the research topic. *Commitment and rigour* has been demonstrated through the project teams' wealth of clinical experience with the research population and topic of interest and the robust and detailed recruitment and data analysis processes. *Transparency and coherence* is evident through the complementary nature of the study's research aims, the chosen research design and methodology, the researcher's epistemological stance and chosen analysis approach, the detailed description of all aspects of the research process, including data collection and analysis, and the evidencing of themes with quotes from all participants. Additionally, given the interpretive nature of IPA methodology, a continual process of reflexivity supports the quality of the approach and transparency of data collection and analysis (Brocki & Wearden, 2006). The researcher completed a reflective diary (Appendix N) and a bracketing interview (Appendix O) as tools to notice how historical and cultural influences may have influenced the researcher's behaviour and reporting throughout the research process. Finally, the *importance and impact* of this study is established through the generation of evidence which can contribute to a sparse literature-base capturing the voice of autistic females and offering clinical implications to enhance support for this cohort.

2.3 Findings

2.3.1 Introduction to participants

2.3.1.1 Annie

Annie was the first participant to be interviewed. Annie is a 17-year-old female who lives at home with her mother and father. Annie came across to the researcher as an optimistic, gentle natured individual with a good sense of humour, which she wove into her story.

Annie shared a narrative about the challenges she faced and the ways she coped with transitioning between academic environments until other life events shattered the stability of her home life. Annie identified receiving an ASD diagnosis as allowing her access to the right support,

from the right people. This supported her to reach the point she finds herself at now; growing in confidence, developing meaningful friendships, attending college regularly, and doing well on her course.

2.3.1.2 Beth

Beth, a 14-year-old female, met with the researcher in an educational setting to take part in the interview. Beth lives at home with her parents and older brother. Beth spoke with a sense of maturity as she shared her life story; a story of relational challenges and a longing to be accepted, before concluding with the positive impact of finding the people she considered to be true friends. Thinking about her ASD diagnosis, Beth recalled how she was assessed twice, explaining that in the first assessment she felt unable to be herself. Beth reflected on how it was hoped receiving an ASD diagnosis would enable her to access the support she needed. Including support at school, in PE lessons as coordination is difficult for her, and access to therapy, to help her anxiety and understanding of the challenges she had faced within friendships.

2.3.1.3 Claire

The third interview allowed the researcher to meet Claire, a 14-year-old female, in a library setting. Claire lives at home with her parents, younger sister, and younger brother. Claire spoke with wisdom and knowledge that made her appear older than her biological age, sharing a story grounded in a love of her family, home schooling, Disneyland, standing up for others, and hospital visits. For Claire, her ASD diagnosis was something her mother had previously wondered with her about and felt to Claire as just another item to be added to her “list” of diagnoses. Claire wondered if feeling unfazed by her life experiences was actually part of her ASD.

2.3.1.4 Danielle

Danielle, a 15-year-old female, met with the researcher at Danielle’s home address where she lives with her parents and younger sister. Danielle received an ASD diagnosis at the age of 13 however has since been having difficulty accessing the support she needs at her school. As a result, Danielle was attending school on a reduced timetable. Danielle presented as a quiet and shy individual on meeting the researcher, however, grew in confidence as the interview progressed. Using a scrapbook, Danielle shared a story about her weekend away to watch the Paralympics in London and a visit to Harry Potter World with her family.

2.3.1.5 Ellie

The fifth interview was completed with Ellie, a 16-year-old female. Ellie lives at home with her parents and older sister. Ellie presented herself as engaging, warm, and charismatic, sharing a story grounded in funny family tales that resulted in accidental physical injury.

For Ellie, the playful rivalry within her family has encouraged her to challenge herself to try new things and fostered a strong connection with her parents and sister. Ellie was given an ASD diagnosis when she was 12 years old and spoke eloquently about the “gift” of ASD, the positive meaning this has for her, and her view of special interests being a defining characteristic.

2.3.1.6 Felicity

The final interview was completed with Felicity, an 18-year-old female who received a diagnosis 12 months before the interview. Felicity lives at home with her parents and younger sister. Speaking with a sense of bravery and honesty that moved the researcher, Felicity shared a story about the challenges she had faced; bullying within friendships, the pressures of academic achievement, a determination to do well, and the strategies she used to persevere. Felicity identified her ASD diagnosis as a positive; giving her a word to explain how she was feeling that others could understand and allowing access to the right support for her.

2.3.2 Summary of findings

With an aim of exploring self-concept, six autistic adolescent females who had received an ASD diagnosis in adolescence were invited to share their life stories during individual semi-structured interviews. Using IPA to analyse the interview transcripts a journey clustering around four superordinate themes (and 12 subordinate themes) was identified; ‘belonging’, ‘struggling sense of self’, ‘outsider support’, and ‘moving towards the authentic self’. Participants shared experiences of becoming closer to and distanced from a sense of belonging, the struggle of making sense of who they are and integrating these different elements of themselves into a cohesive narrative, and experiences of eliciting and receiving support from others. These experiences appeared to precede and enable movement towards exploring and accepting their authentic selves.

Table 12: *Identified themes*

Themes	Prevalence	Participants reflecting theme
Belonging		
Friendships	6	All
Family	6	All
Connection	6	All
Reference Points	6	All
Struggling Sense of Self		
Autistic Self	5	Annie, Beth, Claire, Ellie, Felicity
Presentation of Self to Others	6	All
Abilities and Achievements	6	All
Personal Strategies	6	All
Outsider Support		
Accepting Others' Support	5	Annie, Beth, Claire, Ellie, Felicity
Eliciting Support	5	Annie, Beth, Claire, Ellie, Felicity
Moving Towards the Authentic Self		
Personal Growth	6	All
Adjusting Reference Points	5	Annie, Beth, Claire, Ellie, Felicity

2.3.3 Belonging

This superordinate theme reflects participants' experiences of becoming closer to, and distanced from, a feeling of belonging. For all participants, a sense of belonging appeared to develop through a foundation of security and emotional depth in relationships with family and friends, however, this experience was fluid and fragile. 'Family' provided a subtle but essential foundation to support the development of a sense of belonging for participants, which some participants shared their appreciation for, whilst 'friendships' held a more powerful and central role which did not appear to offer the same sense of stability as the family context. For participants seeking, initiating, and maintaining friendships introduced a range of challenges which had the power to impact on their sense of belonging in these contexts. Participants identified the importance of 'connection' with others, experienced through shared experiences, in enhancing a sense of belonging and support during times of difficulty. Participants also shared the longing that could ensue when a connection was not present. Participants also shared how they make sense of ways they may belong and what they may need to do to enhance their sense of belonging, by using family, friends, and peers as 'reference points' to evaluate themselves and their abilities against. As well as the impact losing these reference points can have on their sense of belonging.

The following extract captures Beth's experience of moving towards a sense of belonging within her friendships, a closeness she had not experienced within these relationships until this point:

"Friends are just medicine for you really. They can really make you feel good about yourself" (Beth, 519-520)

Beth uses the word "medicine" metaphorically to depict not only the therapeutic impact her new friendships have on her self-esteem, but also the essential nature of this treatment to cure her of a feeling of never quite fitting in, something she has tried but struggled to achieve before.

2.3.3.1 Subordinate theme: Friendships

In this extract, Claire shares a memory of her plan to build a friendship with a cool kid in primary school:

"So, it was like, if I stand up for him, he'll be friends with me and then I'll be a cool kid [...] But then I had to stay in over break, but he also stayed in over break. Didn't end up being friends with him but you know I tried" (Claire, 104-108)

Claire creates a logical plan about how she can initiate a friendship that will enable her to become "a cool kid", however, this plan proves unsuccessful. As Claire shares this experience, she laughs lightly highlighting her acceptance of this outcome.

Felicity echoes Claire's acceptance of the outcome, sharing her experience of becoming the fifth friend within a friendship group at school:

"Five people don't work in a friendship group, so I sort of got pushed out because there's always that one person who doesn't sit on the table of four" (Felicity, 55-57)

In a passive tone, Felicity shares her understanding of the rules of her friendship group and the impact of these rules on her position within the group. Interestingly, Beth also comments on the difficult dynamics of a new person joining a friendship group for lunch:

"Those other three girls who I thought were my good friends, they didn't offer to move so I could sit with them. They stayed there kind of under control of this other girl" (Beth, 398-400)

Beth recalls a moment of confusion followed by a growing sense of distress when she experiences a shift in her position in her friendship group. For Beth, this experience later evolves into an experience of being bullied by people she once considered "good friends".

Chapter 2

Although Annie shared similar challenges within friendship groups, she shared a reflection of how things had started to improve when she became friends with people she identified with:

“You see teenagers going round, having fun, taking pictures and stuff like that. And that was what it was like and I’m not usually the kind of person that does that. But I was then, and I was able to do that and it felt good, yes” (Annie, 457-459)

Annie constructs an image of her perception of how teenagers spend time with their friends. Annie identifies the meaningful shift from previous friendship experiences where she felt on the outside, lacking in ability to be one of the ‘teenagers you see’, to feeling included.

Building on feelings of inclusion, Danielle and Ellie share a sense of stability within their friendships:

“Yes, I don’t know anybody that’s favourite colour is pink. None of my friends, it’s all black and blue, yes, dark colours” (Danielle, 395-396)

Danielle identifies a sense of harmony and exclusivity within her friendship group, through shared preferences. Similarly, Ellie uses the context of time to share the stability of her position within one of her friendships:

“I’ve been friends with Maria for years” (Ellie, 364)

Noticeably, Ellie does not comment further on this friendship, suggesting an acceptance of this friendship being just as easy to maintain as the comment itself.

2.3.3.2 Subordinate theme: Family

Both Ellie and Beth shared their recognition and appreciation of their parents, by introducing a comparison with others:

“My parents were... A lot of parents wouldn’t be that accommodating and that considerate and engaging in conversations about it, and I... Yes, they are very, very good parents” (Ellie, 322-324)

In this extract, Ellie acknowledges her parent's investment in participating in experiences that are meaningful to her. This highlights her recognition that others may not have the same experience. Repeating the word “very”, Ellie emphasises how grateful she feels to be supported in this way. Similarly, Beth uses repetition of the word “care” to highlight the many ways her parents show they care about her.

“I’m lucky to have parents who care about me, and you know I have good accommodation if that makes sense. My parents cook for me, they care a lot about me, and they care about how I’m doing at school. They care about my happiness and mental health” (Beth, 227-230)

Beth describes feeling “lucky” to have parents who are invested in providing these elements of care to her. Felicity also introduces the role of care when talking about her relationship with her sister:

“I think that reflects on how she cares for me in a sense. So, from that, she’s the bigger sister in a lot of senses, except for the fact that I’ve done more stuff than she has” (Felicity, 162-164)

Felicity describes the changing dynamic between her and her younger sister, recognising the different roles they take and a sense of stability within these roles. Similarly, Danielle chooses to report her enjoyment of activities through a description of shared experience with her sister, building a sense of closeness between them:

“Me and my sister found it fascinating” (Danielle, 184)

Claire shares her experience of developing a relationship with new family members:

“I wanted to get home so I could spend more time with him but, also, I was just enjoying being there. I was also looking out for things that he could do, next time he came and what he might like. So, I was like, oh yes, Sam would like that” (Claire, 201-203)

Claire describes the period shortly after meeting her brother for the first time. Although Claire was on holiday in Disneyland with her family, something very important to her, she recalls making plans about how the next holiday could offer a shared experience for her and her brother, broadening her connection with Sam and her family.

In contrast to Claire’s experience of broadening connections, Annie describes the impact of unexpected changes within the family system, during a time where she was already struggling:

“My granddad died and my sister was in hospital that’s what... It just put me over the edge” (Annie, 325-326)

Describing two emotional experiences occurring at the same time, Annie uses the words “it just put me” to indicate her lack of control over the impact of these experiences, before using the

phrase “over the edge” to highlight a sense of plummeting into difficulty. For Annie, stability in her family foundations offers a form of protection and support through times of difficulty.

2.3.3.3 Subordinate theme: Connection

Danielle describes how she shares information about experiences she feels others with be impressed by, to build a connection:

“I remember someone in my class said, oh, I went to the Olympics, and then I said, well I went to the Paralympics. I remember people were like, did you? Because, everybody watched it on TV, and it was a very big thing for, obviously, it to be in London” (Danielle, 216-219)

As Danielle recalls this experience, she adjusts her tone of voice to reflect the surprise of her classmates, sharing the building sense of excitement within this moment.

Annie and Ellie use “we” to describe a collective experience that occurs during periods of connection. In this extract, Annie recalls being asked to complete a scavenger hunt on her first day at college:

“It was good because we were able to laugh about how on the tour one of the things they told us was that we were at a college now [so] we’re going to be treated like adults” (Annie, 391-393)

Whilst Ellie recalls a holiday:

“We’re in Cornwall, we’re having an amazing time. We discovered gluten-free Cornish pasties and that was our favourite joint food before the diagnosis, so it was brilliant. Having a great time” (Ellie, 112-114)

Both extracts highlight the shared enjoyment of these experiences, which Ellie continues to enhance through the use of “amazing”, “favourite”, “brilliant” and “great”, driving forward the impact of this experience for her. However, through connection also comes support during times of difficulty, which Claire emphasises in the following extract:

“Wasn’t that fazed, again, because Jasmine is... It’s just the normal, for my family. So, normal” (Claire, 294-295)

Claire highlights how this connection acted as a protective factor to the emotional impact of receiving a diagnosis of cancer, normalising this experience to some extent for her.

Felicity and Beth continue to expand the experience of connection by bringing into awareness that connections can be lost:

“My best friend, the girl who I literally thought was my soul mate, got very distant from me” (Felicity, 93-94)

As Felicity shared this experience, a tear ran down her cheek, bringing to light the pain of losing connection with a key figure in her life. This was shared by Beth:

“I’d lost that bond with her I’d had when I was a baby. So hence why we had attachment issues, I guess” (Beth, 370-371)

Beth highlighted how a connection can take time to build, or rebuild, even with key figures and also how this early life experience can influence how you form connections with people in the future. Beth spoke openly about how she uses strategies to help her form the types of connections she wants with others:

“I feel because they don’t know the real me of my autism stuff they don’t treat me differently, so we can just get on as normal people and it’s really nice” (Beth, 562-564)

Through her narrative, Beth shares a longing to be accepted by others and to develop deep and meaningful connections; however, she identifies that she feels she would not be treated in the same way as others if her friends became aware of her ASD diagnosis. Beth noted how camouflaging her “real” self from others allows her to connect in a way that she wants and builds a sense of belonging, something she has struggled to find before.

2.3.3.4 Subordinate theme: Reference points

Ellie shares how positioning her sister as a reference point encourages competition between them:

“She comes up and she’s like, oh yes, I did it. Oh, yes, you did. And then I go, I can’t let her do it” (Ellie, 198-199)

Ellie uses examples of conversation to build a picture of how her sister will often take the lead in activities and how this can push Ellie into trying to match her sister’s achievements. Similarly, Claire uses her siblings as reference points for her recent hospital visits:

“She was in and out of hospital all the time, when I was younger. So, that’s just normal. So, with me being in and out of hospital, it’s like Jasmine’s had her turn, Sam’s had his turn, and it’s my turn now” (Claire, 283-285)

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Claire identifies how her current experiences are in line with her sibling's past experiences. This offers an element of containment and a sense of acceptance around the challenges she is presented with.

For Danielle, her friends offer a point of reference:

"Yes. It's a friend's thing as well, everybody in your year likes the colour pink, and you get pink things, you go with it" (Danielle, 392-393)

Danielle highlights how through evaluation, she has accepted the need to adjust her personal choices to align with the preferences of her points of reference. This further facilitates Danielle's sense of belonging; however, Felicity and Beth introduce how comparing themselves to the wider school year can have a detrimental impact on their sense of belonging:

"Even though I did fine, I realised I wasn't doing fine because I would look at girls who got 90% and I only got 80%" (Felicity, 352-353)

Felicity's outlook on her academic achievements shifted as she developed an awareness of the achievements of her reference points. Through this comparison, Felicity internalised this as a failure, becoming critical and dismissive of her academic position within her year. Beth echoed a similar experience of perceiving herself as not as good or the same as her reference points. Through evaluation against school peers, Beth became aware of how she differed to others and shared a sense of fear of being confronted with rejection for being herself:

"I guess, because I don't have the outgoing personality that lots of people do, and I just didn't like the same things that people did [...] I was scared that someone would say something nasty if I said the wrong thing, or they would say, they just wouldn't want me involved with them, or to be around them" (Beth, 260-265)

Annie considers the impact of her friends finishing college:

"Steph and Lauren had left college and it just took a toll I think" (Annie, 87)

Annie positioned Steph and Lauren's friendship as points of reference for her sense of belonging at college. By using "took a toll", Annie conveys the impact this loss had on her. Similarly, Felicity highlights the discomfort caused by the loss of her reference points and her preference to have points of comparison to evaluate herself against:

"I mean, I've finally reached the top of the school, and I feel like I didn't enjoy that feeling. I preferred the feeling of always having someone to look up to. Always having someone to just like refer back to" (Felicity, 180-182).

2.3.4 Struggling sense of self

This superordinate theme captures how participants struggle with the sense of who they are and how they integrate the multidimensional elements of their life, to create a cohesive narrative about who they view themselves as.

For participants, trying to make sense of who they are involved acknowledging the presence of their 'autistic self', which often emerged at the point of formally receiving an ASD diagnosis. This appeared to allow participants to view the meaning of their life experiences through a new lens, as well as the many struggles they have faced until this point. The experience of acknowledging the autistic self also supported growth in understanding for participants. Participants shared how they may hide this struggling sense of self from the outside world by altering their 'presentation of self to others'. Participants shared the pressure of attempting to hide any differences or difficulties they may be experiencing from others and how returning home can be a safe space to relax this presentation and express the struggles they were experiencing. Participants shared how this sense of self is influenced by comparisons against others and the views of others which impacts their 'abilities and achievements'. For many participants, abilities and achievements were centred on academic success or personal skills. When participants perceived this as going well, it appeared to enhance their self-esteem however, when this was not going well, it acted as a barrier to accessing support. Finally, participants shared an insight into the 'personal strategies' they use to protect themselves from the impact of this internal and external conflict that supported them to persevere through this struggle. These strategies included cognitive and behavioural strategies that develop and change over time.

For Beth, the responses of others make her question the validity of her emotions during times of difficulty:

"I'm being essentially punished for something, for the way I feel and for feeling this down and for trying to explain to tell someone. I guess showing them my true side, whether that's a bad thing or not. Which evidently they seem to think it was a bad thing" (Beth, 501-504)

Beth identifies she has a sense of self, by commenting on "showing them my true side", yet the response of others makes her feel rejected and introduces doubt about showing her true side when she is struggling.

2.3.4.1 Subordinate theme: Autistic self

Felicity shared her experience of receiving an ASD diagnosis:

“The more they explained, the more I was like, yes, this could be me, but in the back of my head I was like, what if I just want it to be me?” (Felicity, 530-531)

Felicity shared a sense of hope that the ASD diagnosis may provide her with a new way of understanding herself, however she starts to question herself, using “could” to introduce a sense of doubt about whether the diagnostic summary truly reflects her understanding of who she is.

Annie shares how receiving a diagnosis of ASD acted as a pivotal point to developing a greater understanding and clearer narrative about herself:

“Since the diagnosis, I learned more and more about it, about myself and about autism” (Annie, 490-491)

Annie uses the repetition of “more” to show how she is building on the foundations she had in place before receiving a diagnosis. Similarly, for Ellie growth in understanding comes from being given the wording to describe parts of her autistic self, at the point of diagnosis:

“It’s like you’re given a box, but you already have all the stuff, you’ve just got all the names for the stuff” (Ellie, 856-857)

In this extract, Ellie emphasises her acceptance of the elements that make up her autistic self but also acknowledges its existence before receiving a formal diagnosis. Ellie shares a sense of the significance of receiving a diagnosis by likening this experience to receiving a gift that allows you to understand who you are more clearly.

For Beth, a diagnosis offered a sense of validation for the continual battles she had faced trying to find where she belongs:

“Essentially saying that I’m different, it made me put it all in retrospective [sic] that I’m, no matter how normal you try to come across you were always, inside you were always going to feel like a different person and you don’t belong here. You just feel emotions which other people would never get, over such small things. I guess I have lots of weird habits like, for example, I do this jumping thing” (Beth, 416-421)

Until this point, Beth has experienced a significant internal battle of feeling different from others but not wanting to be. Noticeably, Beth changes from initially using “I” to describe the impact of this new way of understanding herself, to “you”, building a sense of distance from this personal

experience and the emotional impact of this change in understanding. Similarly, Claire also distances herself from the impact of an ASD diagnosis on her sense of self by creating a list of diagnoses:

“It’s just another thing. It’s like it’s just another thing on my list” (Claire, 444)

2.3.4.2 Subordinate theme: Presentation of self to others

Ellie reflects on how her mother feels schoolteachers don’t believe her because of Ellie’s presentation at school:

“My mum’s got this theory that they think she’s making everything up because, at school, I don’t show a lot of the stuff and I wait until I get home and then it’s like, wah” (Ellie, 837-839)

In this extract, Ellie conveys the release of emotional pressure on returning home from school, something she suppresses so others are not aware of how much she is struggling. Annie echoes the pressure of suppressing elements of herself and her behaviour around people at school:

“It was worse at home because all of these weird little things that I did, I hid them. I guess you could say the autistic side” (Annie, 171-172)

Annie recalls making a concerted effort to hide her autistic self because her “weird” behaviours may not be accepted by her peers, but notices how this suppression make her behaviour feel “worse” when she returns home.

Similarly, Danielle recognises how the attitude of her peers differed to her own, implying a conflict with her values around education and her view of herself as a student:

“Secondary school, I feel like it’s hard, because people, they don’t want to learn, they see school as a waste of time and a terrible place” (Danielle, 417-418)

Felicity builds on the conflict Danielle identifies, by sharing how she felt the need to hide what is important to her around others, things that she orientates her sense of self around:

“Like with the dance friends, they more particularly didn’t enjoy academia, as I used to really love it. So, I think I found it really hard to find a balance between not obsessing over schoolwork, but also obsessing over schoolwork for teachers” (Felicity, 238-241)

Felicity uses the word “obsessing” to build a sense of the meticulous attention she wants to give to her schoolwork and the consuming nature of this experience. Felicity shares her struggle with recognising she cannot achieve this if she wants to fit in with her friends.

Beth also felt like she needed to present differently to others to create the interactions she desired:

“I felt like I had to come across as an ordinary teenager who’s completely fine. I don’t want to ever be seen as someone with difficulties and special needs because I feel like people will treat me differently if they knew that kind of thing” (Beth, 443-446)

Beth shares the conflict between the self she wants others to reinforce and the felt sense of her autistic self that others may reinforce should they find out about her ASD diagnosis. Beth illustrates the energy that she puts into presenting the way she feels she needs to for others to interact with her as “an ordinary teenager”.

Claire highlights how she worked through a similar conflict to the one Beth describes, and the choice she made:

“Literally like, I never really fit in anywhere. So, now I just make the most of it, so I’ll go as weird as possible but then I still tried to fit in, when I was younger. And it just didn’t work so then I get bullied” (Claire, 77-79)

Similar to Annie, Claire uses the word “weird” to describe her behaviour in front of others. Claire introduces this “weird” presentation as a protective response to feeling like she does not really fit in anywhere outside of her family.

2.3.4.3 Subordinate theme: Abilities and achievements

Beth reflects on the challenges she faced academically:

“I was slow academically at first. I struggled with the work, I don’t know why. I think I was just a lot slower to process everything than other children” (Beth, 23-25)

As Beth compares her progress to those around her, she talks in the past tense, which implies she may have since noticed a difference in her academic ability. Connecting with Beth’s academic struggles, Felicity highlights how others’ perceptions of her achievements can become a barrier to accessing the support she may need:

“I was never a red flag. Like even if I did no revision, I’d still be like on the average or a bit above that. So, no-one really noticed because there was no cause for concern. [...] But for me that was a failure because I measured everything by what I have done, not what I could do, if that makes sense” (Felicity, 286-291)

Within her narrative, Felicity describes the importance of her academically achieving self. For Felicity, “average” achievements had a detrimental impact on her self-esteem, rocking her sense of self; however, to those around her “average” was completely acceptable. This created a barrier to Felicity accessing support.

In contrast, Ellie shares a sense of confidence in her academic ability and reflects on the adjustments made by her school to help her to continue to challenge herself:

“I was in the top for all of them, and they had to create special lessons for the top, those people, because they were above. And that’s great and that came quite naturally to me”
(Ellie, 691-693)

For Annie, achievement was measured by familiarity within the school environment, rather than her academic progress:

“Yes, it was a bit of an achievement. Again I’d made my friends, I knew where I was coming because our classes were in the same building, the same room pretty much apart from some that were in another building” (Annie, 440-442)

Smiling as she shared this experience, Annie builds on the sense of the pride she feels about settling into another new school environment. This experience started to provide evidence to Annie that she could adjust to transitions and challenge the view she held of her ability to be able to navigate this.

For Danielle, her view of her ability and her value to others is clearly defined by her baking:

“Baking, that’s my thing, you know, someone’s birthday coming up, I’d make a cake for them” (Danielle, 506-507)

Danielle shares the personal meaning this activity holds for her, enabling her to show care for others through something she feels she can do well. Similarly, Claire tells of the impact of feeling she can do something well:

“It’s just nice to be good at something. That you can consistently be good at something”
(Claire, 226-227)

Claire brings to light the importance of this sense of achievement being consistent for her, supporting the development of self-esteem and a positive sense of self.

2.3.4.4 Subordinate theme: Personal strategies

Claire shares how her personal strategy involves changing her behaviour to help her when interacting with others:

“Well, I wasn’t being me. That wasn’t me. That was some dunno, like mouldable putty”
(Claire, 114-115)

Referring to “mouldable putty”, Claire likens the personal strategy she uses to something with an adaptable property that is shaped by those around her. For Claire, this strategy is not authentic to her sense of self. Similarly, Annie shares how she would mimic the behaviour of her friends and sister:

“I didn’t really understand what the problem was. If I’d see them doing something that seemed pretty normal, I’d do it as well. I guess after a while they’d start to notice that I was copying and stuff like that” (Annie, 187-189)

Annie highlights how she would assess the actions of those around her before deciding whether she should copy them.

In comparison Beth draws upon cognitive strategies as a way of protecting her self-esteem during times of difficulty:

“Your mind builds up a wall that, to block out being in contact with such cruel situations and things to make you feel bad about yourself” (Beth, 351-352)

Although Beth perceives herself as holding quite a passive role in the implementation of her personal strategy, she uses the metaphor “builds up a wall” to describe the strength and impenetrable properties of it. However, Beth later indicates that this strategy does not always work for her, and so she has other strategies she may use:

“I don’t see what’s wrong in expressing to everyone my feelings and my emotions by showing them self-harm, because that shows a lot of how you’re feeling. And you want people to understand. Lots of people think its attention seeking and I did get a lot of people saying that. But it’s nothing like that” (Beth, 470-474)

Beth identifies the function of this strategy as communicating the distress she feels as a result of others’ actions, and shares how others often misunderstand what she is trying to achieve.

Danielle identifies a strategy of cognitive avoidance to protect herself when reflecting on difficult experiences:

“It’s just, I don’t want to think about stuff like that too much” (Danielle, 249)

Danielle acknowledges a limit to what she will allow herself to think about. Danielle builds a sense of discomfort in allowing herself to think about emotive topics or experiences and uses “too” to suggest a frequency of this action.

After trying a range of strategies to help her through a period of significant academic pressure and personal struggles, Felicity finds solace in one final personal strategy, making a plan to end her life:

“To me, the only thing that kept me calm throughout that period of no revision and just feeling very sad, was planning an attempt... That kept me really calm, and every time I thought of it I just like... It’s like a deep breath” (Felicity, 83-87)

As Felicity recalls this experience, she shares a sense of struggling for a long time and, for her, how this strategy offered her the chance to persevere for a little longer. By comparing the reassurance of this strategy to “a deep breath”, Felicity deepens the sense of calm it offered her, a word Felicity repeats twice within this extract. Whilst sharing this experience, Felicity leaves the word “attempt” hanging in the air, appearing to lose herself in thought for the briefest of moments whilst tears flowed freely, sharing the serious intention behind this strategy.

For Ellie, experiencing a period of great difficulty resulted in her developing a greater awareness of herself and her needs, allowing her to recognise what personal strategies she needs to draw upon and when, during times of challenge:

“If you try and push through that distracted phase, if you’re really stressed, if you’re really distracted and you’re trying to work, if you try and push through it, that’s, like, the worst thing you can do. The best thing to do is stop, take a break and then come back to it when you’re relaxed” (Ellie, 733-736)

Ellie shares her learning with others, highlighting her confidence in the benefit of this strategy during times of difficulty.

2.3.5 Outsider support

This superordinate theme, ‘outsider support’ captures five participants’ experiences of seeking and receiving support from others. Participants shared their experiences of ‘accepting others’ support’, how the support offered to them differed, what support was meaningful to them, and the impact of receiving the right support. For participants, receiving the right support resulted in a sense of collaboration and progress, leading to increased confidence and feeling more able to

cope with some of the challenges they faced. However, 'eliciting support' from others presented its own challenges for participants and required determination to persevere. When trying to seek the individualised support they needed, participants had to draw upon a range of approaches to support their requests, from reminding others, providing reading materials, visual information, and support from others.

The following extract captures one of Annie's first experiences of being offered the right outsider support for her:

"One of the options she gave me was she would wait at the reception every morning and then she'd walk me in with regards to the class and stuff like that. And then she'd pop in every now and then make sure how I was doing. And she said that she was always there if I needed to talk. And she was just brilliant; she actually got to know me and was able to help me" (Annie, 432-436)

It was important for Annie to have access to both physical and emotional support, from someone who could be available if needed. Annie builds a sense of how this support differed to previous experiences through the word "actually" when explaining the relationship they developed. Annie acknowledges the significance of being seen as an individual by the support provider, to make the support meaningful.

2.3.5.1 Subordinate theme: Accepting others' support

Both Felicity and Ellie consider how the approach of others can influence whether the support offered is meaningful to them:

"She also used the thing, we. So, I'd be like obviously she didn't even know me, and she'd be like, sometimes we get depressed. But obviously she's not depressed" (Felicity, 404-405)

Reflecting on the support she had received from a therapist, Felicity recalls the power of the therapist using "we" when talking about Felicity's experiences. Similarly, Ellie also experiences a sense of support through the mutual respect shown in contexts where everyone is having comparable experiences:

"So, everyone is experiencing some kind of stress and worry, so there's a respect you don't really get anywhere else" (Ellie, 300-301)

Annie reflected on the support she received from a member of support staff at her college:

“So, for the first couple of weeks I’d go up and I’d meet this lady called Mary who was amazing [...] and eventually after a couple of months I was able to go in by myself” (Annie, 97-100)

Mary’s support acted as a scaffold to allow Annie to grow in confidence. Through the use of “eventually”, Annie conveys a sense of improvement over time, highlighting the need for continued support but also the achievement of reaching a point where she could complete this independently. Beth echoes a change over time in the way she copes with experiences that challenge her, as a result of the support she receives from a therapist:

“This woman also gave me coping mechanisms for my anxiety and how to deal with certain things, friendships within school, which were actually quite helpful. I think that’s helped get me where I am today” (Beth, 93-95)

In contrast, Claire shares why offers of support from the wrong people can lead to it being rejected:

“To be honest, it’s kind of annoying because then I’ve got all these people like, I’m so sorry. Is there anything I can do for you? Things like that. And it’s people I don’t like and are particularly basic bitchy girls. Like the cool girls. The not very nice girls. They were like, I’m so sorry. What can I do for you? It’s just like, go away. I don’t like you” (Claire, 453-457)

Claire recalls her experience of sharing her cancer diagnosis on a social media platform for others to see, describing a sense of discomfort and annoyance as the girls she views as unkind suddenly offer her sympathy and support.

2.3.5.2 Subordinate theme: Eliciting support

Beth shared how she hoped the support she received at school would improve by telling others about her ASD diagnosis:

“It would allow me to do certain things or not do certain things. Because I would have special allowances with my issues” (Beth, 90-92)

Beth uses the word “special” to highlight the individualised response she needs and hoped she would be able to receive during times of difficulty. Building on this, Felicity notes the challenges of trying to access consistent individualised support:

“As soon as I tell people, people forget I’m autistic, and then teachers don’t give me help and I have to keep reminding them that actually I seem fine, but I’m really not” (Felicity, 558-560)

For Felicity, having to remind others she was struggling, even when she did not appear to be, was frustrating. Felicity shared how she continued to do this however, for Annie directly requesting support was a challenge:

“She finally came and was able to calm me down. But I don’t think I’ve ever forgotten that. Everyone else had left; I was the only one left. And then I didn’t know when she was coming, I didn’t know when I’d see her again” (Annie, 144-146)

Annie recalled her sense of panic in a situation where she was the only student left and her mother had not arrived to collect her. Annie shared how she was stuck in a prolonged internal turmoil, unable to elicit the help she needed to soothe her distress until her mother arrived and provided the support she needed.

For Claire, eliciting support from her Scouts group required providing additional written documentation:

“So... we even sent over reading materials” (Claire, 418)

As Claire started to describe her experience, she stated “so” before pausing and smiling, sharing a sense of determination to achieve access to the support she needs. Similarly, Ellie created a visual scale to not only help others know what support she needs but also to help herself recognise when she is struggling:

“Actually, I made a yellow book and it’s got this thing inside of it, which is like a spectrum [...] I showed my parents, once you get past this section, you’ve just got to let it ride out and hope it doesn’t get worse. You can’t really intervene” (Ellie, 720-724)

Developing this visual aid allows Ellie to elicit the support she needs without having to necessarily verbally request it.

2.3.6 Moving towards the authentic self

All six participants shared a sense of ‘moving towards the authentic self’ within their narratives, which appeared to be facilitated by reflecting on the challenges they have faced. For participants, this included experiences of finding a sense of belonging, struggling with who they view themselves to be, and eliciting and negotiating support from others.

Participants shared a sense of 'personal growth', which encapsulated moving towards the authentic self by accepting who they are and feeling as though others accept them for who they are. Participants shared how this promoted a greater understanding of themselves and their experiences, as well as increasing confidence in being who they are and increasing determination to achieve their goals. Participants also introduced the idea of 'adjusted reference points', shifting who they compare themselves against from peers, friends, and family members to people with similar experiences, and their own experiences. This change supported participants to build confidence in being who they are and doing things that are meaningful to them. Participants shared how this enhanced feelings of belonging and allowed them to start to challenge others' judgements about their choices.

The following extract from Ellie's interview captures the journey to this point and the sense of optimism this move can generate:

"It was really sucky and not fun but it was quite beneficial, in the long run [...] I've moved forward, and I feel like that was quite a nice little forecast for how my 2020 is going to be. I just want to try stuff and if I don't like it, I've tried it" (Ellie, 926-930)

2.3.6.1 Subordinate theme: Personal growth

For Felicity, growth came from accepting there is not a need to change who she is:

"My parents always think that anxiety and depression is something that I will get rid of, that it's something that will go away. Whereas I feel happy now because autism is something that won't, so it feels like I'm not under this pressure to be fixed" (Felicity, 581-584)

In this extract, Felicity shares the pressure she has felt until this point, a pressure to change and present differently to meet others' expectations. Felicity now recognises that she does not need to change and shares a sense of freedom and confidence that accompanies this experience. Similarly, both Annie and Beth acknowledge a growth in their confidence allowing them to embrace new experiences:

"It was just like this new feeling being able to go, it's a challenge but I'm up for it" (Annie, 478-479)

Beth associates her personal growth partly to the personal qualities of her new group of friends:

"I've become friends with people who are more outgoing and more extroverted than I am, so that's helps me get to grips with myself. They've just helped me gain confidence

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and self, more self-esteem, and made me feel good about myself all the time. I think I'm lucky with that" (Beth, 197-201)

Beth values her new friendships as they allow her to start to feel like she belongs, providing the safety to grow in confidence, rather than just survive.

Claire shares a growth of determination to protect others, as a result of the challenges she faced.

"I want to go on the Jamboree as a leader so other kids can have a better experience than I did. Somehow that's going to happen because you have to as a leader" (Claire, 483-485)

Throughout Claire's narrative, she introduced a sense of herself as a protector of others who have been treated badly; however, until now this has been a reactive response. Claire shares her plan of how she will protect others and uses "somehow that's going to happen" to reflect her commitment to carrying this out.

For Danielle, personal growth was shared by reflecting on past experiences:

"That was good, but then, like I say for everything, I didn't really understand it back then" (Danielle, 172-173)

Danielle uses "back then" to imply growth in her understanding of the significance of attending the Paralympics that has occurred since this experience. Similarly, Ellie also shares a growth of personal understanding by reflecting on challenging past experiences:

"You have to really sink to deep depths to understand how not to ever do that in the future" (Ellie, 756-757)

For Ellie, this growth was wider than just an understanding of the significance of her experience. This growth encapsulated an opportunity to learn to develop the strategies she feels she needs to protect herself from the same experience happening again.

2.3.6.2 Subordinate theme: Adjusting reference points

Annie and Beth share the positive impact of re-orientating their reference points to their new school group, people they feel have had similar experiences to themselves:

"You know everyone's in the same boat, people who've had struggles academically and mentally. So, there's other people with autism, there's people with ADHD, dyslexia. And then there were just people that had struggled academically and just need that extra bit

of support. And they were all there so no one's judging you. And if you need that bit of help, that's absolutely fine" (Annie, 462-466)

Interestingly, Annie's speech flows freely as she builds a sense of acceptance within her class, through shared experiences. Beth also values this:

"I found people who even had the same issues as me. It's interesting. They were people who I would never have guessed would have issues with self-esteem or anxiety; it was just really interesting. We helped each other out, I guess" (Beth, 166-170)

Beth shares a sense of surprise that others around her experience similar challenges and uses the repetition of the word "interesting" to reflect the different experiences she has now that she has adjusted her points of comparison.

Moving to comparisons between her own experiences, Felicity considers her achievements this year:

"I've seen friends over Christmas for the first time in years, so that was definitely good. So, I had people around for New Year's; I didn't just tag along with my parents somewhere. [...] So, I think in that respect it's definitely been one of the best, in the fact I've had a social life over Christmas" (Felicity, 653-659)

By using "tag along", Felicity creates a sense of lacking independence and choice about how she has previously spent her free time during the Christmas period. With these personal experiences as a comparison point, Felicity smiles as she shares "it's definitely been one of the best".

Similarly, both Claire and Ellie reposition their point of reference to their enjoyment of experiences:

"It probably wasn't cool to other people. They were probably like, why would you want to learn about dinosaurs? Why would you do marine biology? But I enjoyed it" (Claire, 161-163)

Using her new point of reference, Claire challenges the reactions of others, using "but" to show how meaningful this experience has been for her. Ellie builds on the importance of her internal experience:

"It's more important to me that an event is positive than what the event is itself" (Ellie, 917-918).

2.4 Discussion

This study aimed to explore the self-concept of adolescent females diagnosed with ASD in adolescence. Employing an IPA methodology of individual semi-structured interviews, the researcher explored what life events and experiences six autistic adolescent females considered important to them and the influence these experiences may have on participants' self-concept. Through analysis of the interview transcripts, participants' narratives clustered around four superordinate themes: 'belonging' (encapsulating 'friendships', 'family', 'connection' and 'reference points'), 'struggling sense of self' (encapsulating 'autistic self', 'presentation of self to others', 'abilities and achievements' and 'personal strategies'), 'outsider support' (encapsulating 'accepting others' support' and 'eliciting support'), and 'moving towards the authentic self' (encapsulating 'personal growth' and 'adjusting reference points'). These findings offer an insight into the events and experiences that influence the self-concept of the autistic adolescent females participating in this study.

2.4.1 Domains of self-concept

This study identified several themes relating to the self-concept of participants that could be considered to reflect the domains identified in Bracken's (1992) Multidimensional Self-Concept Model (cited in Bracken, 2009). 'Family' may map on to Bracken's 'family' domain while 'abilities and achievements', 'presentation to others', and 'reference points' may encapsulate elements of Bracken's 'competence' and 'academic' domains. In addition to this, 'friendships' may map on to Bracken's 'social' domain with participants in this study considering how their interactions with friends impact on their sense of belonging or acceptance within social situations. In this study, participants shared the impact of changes within their friendships, such as loss and rejection which appeared to distance them from a sense of belonging in this context. Within the literature, social rejection is recognised as a threat to a person's sense of belonging, which can impact on an individual's mood and self-esteem (Smart Richman & Leary, 2009) and interfere with identity development (Ragelienė, 2016). In addition to this, it is suggested that autistic adolescent females may find it harder to cope with conflict in friendships than their peers (Sedgewick et al., 2019).

Another potential aspect of participants' self-concept identified in this study was the 'autistic self'. This theme considers how participants may make sense of who they are by appearing to acknowledge the presence of their autistic self and the new meaning life experiences may hold in light of a diagnosis. This theme does not appear to be reflected by any of Bracken's self-concept domains. It could be proposed that the multidimensional domains of global self-concept may require expansion to encompass neurodiversity; however, due to the lack of literature in this field

it is not possible to consider this further. Tan (2018) proposes that for autistic individuals an ASD diagnosis transforms the autistic-self and global self-concept. However, this does not appear to reflect the experiences of the participants in this study, who received an ASD diagnosis during adolescence. Within participants' life-stories, the ASD diagnosis process was mentioned but was not central to participants' narratives, with some participants only adding this event to their timeline as they started to narrate their life stories. This is reflected by the 'autistic self' being identified as a subordinate finding of this study, rather than a superordinate theme. It is possible that for participants in this study, receiving an ASD diagnosis may not have had a significant impact on their self-concept when considered alongside other significant life events, but instead offered an alternative way of viewing the meaning of their life experiences. In this study, participants' experiences appear to align more with the findings of Leedham et al. (2020), who identified a theme of 'reliving life through a new lens', which concluded a more varied impact of an ASD diagnosis for autistic women who received an ASD diagnosis in later life. In addition to this, it has been suggested that an autistic identity may become a protective factor for individuals against mental health difficulties (Cooper et al., 2017). This is supported by Cage et al. (2018), who suggest greater acceptance of an ASD diagnosis was found to protect individuals from symptoms of depression. With this in mind, further research exploring the idea of an autistic self may be of benefit.

2.4.2 Struggling sense of self

'Struggling sense of self' was a theme woven through all participants' transcripts. This theme reflects the struggles participants experienced whilst making sense of who they are and integrating the different elements of themselves into a cohesive narrative. Considered against Erikson's (1963) psychosocial stage of development for adolescence, it may be suggested that this theme reflects the challenge required during the 'identity vs role confusion' crisis, during the adolescent period. However, evidence suggests autistic females may be challenged about the validity of their presentation and this can impact their sense of self (Bargiela et al., 2016).

For the participants in this study, all of whom had already received an ASD diagnosis, there continued to be an internal struggle which is reflected by 'presentation of self to others'. This theme highlighted the need for continued adaptation of their presentation in social contexts, the recognition of managing their presentation to others, and the effort required to maintain this presentation. The experiences participants described in this theme appeared to reflect the concept of masking, which Webster and Garvis (2017) suggest is used to conceal social difficulties. Cook et al. (2018) proposed masking is used to support an individual to fit in and appear to cope in social situations. However, masking can result in the internalisation of difficulties, with higher

levels of depressive symptoms being noted, a lack of acceptance of the autistic identity (Cage et al., 2018), and failure by others to access and offer the support the individual may need (Cook et al., 2018). In this study, Ellie shares how the pressure of suppressing and possibly masking her struggles at school can result in an emotional reaction upon returning home:

“My mum’s got this theory that they think she’s making everything up because, at school, I don’t show a lot of the stuff and I wait until I get home and then it’s like, wah”
(Ellie, 837-839)

2.4.3 Authenticity

For participants in this study, experiences of a ‘struggling sense of self’, trying to find a sense of ‘belonging’ and negotiating ‘outsider support’ appeared to precede a movement toward a sense of authenticity. Referring again to Erikson’s (1963) psychosocial stage of development for adolescence, it could be argued that the theme ‘movement towards the authentic self’ may reflect navigation of the ‘identity vs role confusion’ crisis arriving at an ‘integrated-self’, defined by Foster (2011) as occurring in late-adolescence. However, given participants age and levels of anxiety (Crocetti et al., 2008) it may also be beneficial considering this theme to research suggesting there may be an over-time movement towards an integrated self (Bracken, 2009; Meeus et al., 2012). Further research is needed into this experience for autistic adolescent females for further understanding to be reached.

2.4.4 Supporting positive self-concept development

By inviting participants to share the important experiences and events they have experienced, possible factors that may support the development of a positive self-concept for participants in this study can be discussed.

2.4.4.1 Belonging

‘Belonging’ reflects participants’ experiences of moving closer to and further away from a sense of belonging through the security and emotional depth of family relationships, friendships, connections, and reference points. Belonging is recognised as a basic human psychological need which individuals are motivated to meet once physiological and safety needs have been fulfilled (Maslow, 1943). Poston (2009) argues that individuals need to establish a sense of belonging otherwise they may experience low self-esteem and social anxiety. However, evidence has suggested that finding a sense of belonging in social contexts can be challenging for autistic females; although motivated to meet this need, they may experience higher rates of loneliness,

poor-quality friendships (Locke et al., 2010), and social isolation (Solomon et al., 2012) as well as pressure to adapt their behaviour to be accepted (Myles et al., 2019). This theme may introduce alternative challenges to the common misconception that some autistic individuals, in this case, autistic adolescent females, may not be socially motivated (Ahlers et al., 2017).

2.4.4.2 Shared experiences

The important role of shared experiences was present in building a sense of belonging through ‘connection’, ‘friendships’ and ‘family’, as well as in the role of support (‘support from others’) and healthier personal comparisons (‘adjusted reference points’) for participants. Yet many of the participants in this study experienced long periods of school non-attendance which may have impacted on their opportunity for shared experiences with peers and sense of belonging within peer groups. Research has shown that individuals are likely to think more about others when they share an experience together, associating the experience with the people present and resulting in a sense of connection (Boothby et al., 2014). Shared experiences within friendships have been found to enhance an adolescent’s self-worth, inclusion, sense of acceptance, and trust (Hamm & Faircloth, 2005). For this reason, the role of shared experience could be vital for adolescent autistic females. Participants in this study provide a brief insight into what may constitute meaningful shared experiences for them. These experiences may foster a sense of belonging and aid movement towards their authentic self, however there is currently no literature in this area.

2.4.4.3 Outsider support

Within ‘outsider support’ participants shared experiences that highlighted difficulty in requesting the support they need and accessing the individualised support that could help them. These experiences are reflective of the literature which suggests autistic individuals may experience barriers to seeking help, including challenges communicating distress and fear of stigma (Coleman-Fountain et al., 2020). In addition to this, ‘presentation of self to others’ introduced participants’ experiences of the difficulties others may have recognising when support is required. The literature notes the high level of suicidality in this population and recognises how unmet support needs and camouflaging are risk factors (Cassidy et al., 2018). ‘Accepting support’ highlighted that when support is offered participants made a choice about engaging with it, deciding if it was the right support for them. Importantly, support provided by people lacking experience working with this cohort and inadequate support have been found to leave individuals feeling like they need to manage by themselves (Coleman-Fountain et al., 2020; Griffith et al., 2012). However, support that enables an autistic adolescent to feel valued (Sagen et al., 2013) by celebrating them for who they are (Attwood & Garnett, 2019) promotes self-acceptance through

appreciating difference (Cage et al., 2016) and can aid the exploration of the sense of self (Sagen et al., 2013).

2.4.5 Strengths and limitations

The population this research study was interested in is recognised as a difficult population to recruit from (Kirkovski et al., 2013). As such, successfully recruiting six participants can be seen as a significant strength of this study. In addition, the homogeneity of the participant sample was also a strength as it ensured the research topic held meaning to participants through their own lived experience, allowing the aims of the research to be achieved. However, given the sample size and demographics of participants the findings of this study should be interpreted with caution.

The research design was also a strength of this study. The interview schedule allowed for rapport building which facilitated participants' comfort in sharing important experiences and enhanced the richness of data. The topics shared were not limited to, or restricted by, the researcher's preconceptions (constructed by the experiences of someone who would identify as non-autistic), and the use of participants' words when structuring questions allowed the identified events and experiences to be explored further.

Although autistic individuals were consulted about the content and process of the interview, it is possible that the lack of involvement from the autistic community in the initiation and development of this project means this research does not reflect the priorities of the autism community (Pellicano et al., 2014). In addition to this, the validity of the study findings could have been improved through the use of member checking (Smith et al., 2009).

Two further limitations of this study were identified through the data collection period. Although the timeline task was felt to be successful in building a rapport, this task also generated rich and detailed data about the important events and experiences which were not audio recorded. Therefore the information shared during this task was not included in the analysis. Finally, Part 1 and Part 2 of the interview schedule were possibly too similar, which meant the narrative-inducing question required adaptation for one participant, which limited the depth and richness of data collected in the interview.

2.4.6 Directions for future research

The researcher echoes the call for further research exploring the experiences of autistic adolescent females, especially what contributes to their self-concept, including further

understanding of the 'autistic self' and exploration of the self-concept of individuals from different cultural and ethnic backgrounds.

Additionally, during the recruitment phase of this study, a participant who was assigned female at birth and identifies as male expressed interest in participating in the study. The prevalence of autistic individuals in this community is high, and although there is some literature in the field of gender identity of autistic adolescents, there is very little information considering the global self-concept of this population. Research into this area could only enhance the development of positive self-concepts.

Finally, given the importance of shared experiences for participants in this study, it would be beneficial to explore contributing factors to meaningful shared experiences for autistic adolescent females. Research into this area could support the identification and development of such experiences, increasing opportunities for meaningful shared experiences further enhancing individuals' sense of belonging, positive self-concept and positive experiences of support.

2.4.7 Clinical implications

This study offers a range of clinical implications for clinicians and services supporting autistic adolescent females however, given the study findings cannot be generalised, the clinical recommendations are offered with caution.

- The theme of 'presentation of self to others' highlights how participants may hide their struggling sense of self from the outside world. When working with autistic adolescent females, it may be beneficial to hold in mind that the presentation of the individual may vary depending upon the environment they are in. Participants highlight how they feel able to relax this presentation at home. To gain a greater insight into the challenges the individual is currently facing, clinicians may wish to consider involving family members to gain a greater insight into the individuals' presentation at home, which may also support the identification of change over time.
- The theme of 'autistic self' highlighted the participants' individual experiences of receiving an ASD diagnosis. This may offer important learning to clinicians and diagnostic services about the individual needs of autistic adolescent females during this process and promote consideration of how services can support the individual after diagnosis.
- Participants highlighted the importance of shared experiences in supporting them to feel accepted and enhance feelings of belonging. It may be beneficial to consider how shared experiences can be fostered, for example, looking to use therapeutic group interventions.

- By reflecting on their life experiences, participants shared ‘personal strategies’ they use to protect themselves in times of difficulty and the ‘personal growth’ that can follow. It may be beneficial to invite autistic adolescent females to reflect on their personal experiences as it may support the identification of the individuals’ strengths and coping strategies.
- Through the theme ‘eliciting support’, participants shared experiences of difficulty gaining the individualised support they felt they needed. Whilst the theme ‘accepting others’ support’ highlighted participant’s experiences of accessing the right individualised support, which was enhanced by shared experiences. These themes may highlight the benefit of collaboratively developing therapeutic interventions, which can be individualised and flexible to the needs of autistic adolescent females.
- Finally, the themes ‘family’ and ‘friendships’ highlighted the importance of stability in these relationships for participants, as well as the impact of change. It may be important for clinicians to work systemically to promote the stability of these systems around the autistic adolescent female. In addition to this, although therapeutic relationships differ in nature, it may be worth considering how stability of this relationship can be supported and hold in mind the possible impact relational changes may have on the individual’s progress.

2.5 Conclusion

This study contributes to the under-researched field of autistic females’ experiences and the development of their self-concept during adolescence. Findings suggest that during adolescence participants appeared to work through a period of struggling with a sense of self, trying to find a sense of belonging and negotiating outsider support, before moving towards a sense of authenticity. This study found themes relating to participants’ self-concept in relation to friends and family, which align with domains of the Multidimensional Self-Concept Model (Bracken, 1992, cited in Bracken, 2009). However, this study also identified the theme ‘autistic self’. This does not appear to be reflected in current models of self-concept. Participants’ sense of self appeared to be enhanced through opportunities for shared experiences, developing in a sense of belonging, and receiving the right outsider support which may have enabled movement towards a sense of authenticity; areas that require further consideration and exploration. Finally, this study has informed the direction of future research and provided clinical recommendations to enhance the support provided to this population.

Appendix A Ethical approval

Approved by Research Integrity and Governance team - ERGO II 47628.A2

The logo of the University of Southampton, featuring the text "UNIVERSITY OF" in a small, sans-serif font above the word "Southampton" in a larger, serif font, all in white on a dark blue background.

ERGO II – Ethics and Research Governance Online <https://www.ergo2.soton.ac.uk>

Submission ID: 47628.A2

Submission Title: Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescents. (Amendment 2)

Submitter Name: Stacey White

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

Appendix B Ethical considerations

Informed consent

Initially participants were given written information about the study through the information sheet (Appendix G). For participants under 16 years old, a Parent Information Sheet (Appendix H) was also provided to the parent or guardian. The readability of the Participant Information Sheet was assessed and content adapted to support clarity and understanding. At the point of interview, information about the study was further explained orally and understanding was checked. In line with the British Psychological Society [BPS] (2014) guidelines, all participants completed a written assent/consent form (Appendix I). This form acted as consent for participants aged 16 and over and as assent form for participants under 16. If participants under 16 years old gave their assent, consent was sought from their parent or guardian (Appendix I; BPS, 2014).

Confidentiality

It is an expectation that any psychological research will ensure the confidentiality of participants, unless otherwise stated (BPS, 2014). For this study, the only time participant confidentiality could not be ensured was in relation to risk of harm to self or others. This was reflected in the Participant and Parent Information Sheet and discussed directly with participants prior to completing the assent/consent forms. Within this report, all identifiable information has been altered or removed to ensure confidentiality.

Risk of harm to participants

This study accesses participants from a vulnerable sample, due to their age, which is identified as involving more than minimal risk of harm (BPS, 2014). For this reason, the project team thoroughly considered potential risks, and conducted risk management and contingency planning. This planning was described in detail on the Participant and Parent Information Sheets.

Debrief

Following completion of each interview, the researcher talked with the participant about their experience of participating in the study. For interviews involving participants under 16 years old and interviews where the participants and researcher felt it appropriate, the participant's parent/guardian was invited to join the debrief. The researcher verbally debriefed participants and offered a Participant Debriefing Sheet (Appendix K) and Parent Debriefing Sheet (Appendix L).

Appendix C Interview schedule

Interview schedule

Part 1

Question What would you like to go on your timeline?

Part 2

Question Can you tell me your life story, talking to me about the event and experiences that are important to you? Begin wherever you like. I won't interrupt you. I'll just take notes.

Part 3

Example questions: Can you give me an example of when that happened?
 Can you remember any particular one thing that happened on that weekend?
 Can you tell me more about how that happened?

Additional probe questions: Why is that important to you?
 What does that mean to you?
 What makes you think XXXX?
 You used the word XXX, what does that mean to you?
 You said XXX, can you tell me more about that?
 What makes you think XXX?
 You said XXX and XXX, is one more important than the other?
 What does that mean to you?
 You said XXX has changed, how do you think it has changed?
 You said XXX, do you feel that is different to other people? How do you feel it is different?

Final question: What important events and experiences would you like to happen in your future?

Appendix D Email to voluntary sector services

Dear,

I hope you do not mind me contacting you.

My names Stacey White and I am a 3rd year Trainee Clinical Psychologist, studying at the University of Southampton. As part of my qualification I am completing a doctoral research project. For this project, I am interested in exploring the self-concept of adolescent females diagnosed with autism and am currently in the process of recruiting participants.

My project is an opt-in piece of research and I am hoping to interview between 6 and 8 adolescent females, individually, about what they consider important to their identity. I do not anticipate the interview causing the young person any distress but I will also provide appropriate debriefing and signposting if needed. Participants will be given a small token of thanks in the form of a £15 Amazon voucher.

I understand that you are the (title) of (service name) and I wondered if there was any chance I may be able to seek participants from your service? If you feel this would be appropriate, I can provide you with leaflets about the study. The young person and/or their parent could then make contact with me if they would be interested in participating.

Thank you for your time.

Best wishes,

Stacey White

Appendix E Study advert

UNIVERSITY OF
Southampton

Are you female?

Are you aged between 13 and 18 years old?

Have you received a diagnosis of autism spectrum disorder (ASD) between 12 and 17 years old?

*If the answer is **yes** to all three questions, you may be interested in taking part in a piece of research.*

What is the research about?

During our teenage years we start to make sense of who we are (this is called our identity). For some people it can be hard to make sense of what an ASD diagnosis means when thinking about who they are. For some people it is easy to make sense of what an ASD diagnosis means, when thinking about who they are. There is a very small amount of research around this topic so this study would like to find out more about how autistic females describe who they are and what is important to them.

Who can take part in this study?

This study is interested in talking to people who:

- are female (biologically female and identify as female),
- are aged between 13 and 18 years old,
- have been diagnosed with an autism spectrum disorder (ASD) between 12 and 17 years old,
- have received their diagnosis at least 12 months ago,
- can provide evidence of their diagnosis,
- can understand relatively basic spoken and written English,
- can express themselves verbally to a relative standard,
- have a parent/guardian who can give consent on your behalf – if you are under 16 years old.

What will I be asked to do?

This piece of research will be collecting information by talking to participants so you will be invited to a friendly interview. The interview will take place somewhere you are familiar with. The interview will last a maximum of two hours.

Why should I take part?

There is no direct benefit to taking part however you will receive a £15 Amazon voucher for completing the interview. This will be to thank you for your time.

Please contact the researcher, Stacey White (Slid1n17@soton.ac.uk) if you would like more information about the study or would like to take part.

November 19 – V1.3

47628

Appendix F Participant Information Sheet

Participant Information Sheet (Version 1.6; September 2019)

Study Title: Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescence.

Researcher: Stacey White

ERGO number: 47628

This study would like to find out how autistic females define themselves, before and after their Autism Spectrum Disorder diagnosis. I would like to invite you to take part in a research study. This is because you have received a diagnosis of an Autism Spectrum Disorder. You have received this diagnosis between 12 and 17 years old.

This information sheet is to help you understand why this research is being completed. By reading this information sheet you can decide if you would like to take part in the study. Please take your time reading the information below. You can email the researcher, Stacey White, questions if anything in this information sheet is unclear.

What is the research about?

The researcher is a 3rd year Trainee Clinical Psychologist, studying at the University of Southampton. The researcher must complete a piece of research to finish her training. This is similar to completing coursework at school.

The researcher has found that some people find it hard to make sense of what an Autism Spectrum Disorder diagnosis means to who they are. During our teenage years, we all start to make sense of our identity (who we are). The researcher would like to find out how autistic females think about themselves after receiving a diagnosis.

Why am I receiving this Participant Information Sheet?

You are receiving this Participant Information Sheet because you have contacted the researcher to say you would be interested in taking part.

What will happen if I take part?

The researcher will arrange to meet with you somewhere you will feel comfortable. For example, at your GP surgery or at a community hall. If you are under 16 years old, you will need to bring a

parent with you. If you are over 16 years old, you may want to bring a parent with you. It is your choice.

At the meeting, the researcher will explain the study to you. You can then decide if you want to take part in the study. The researcher will ask you to sign a consent form if you want to take part. The researcher will then check your medical report. This will be to confirm you have a diagnosis of an Autism Spectrum Disorder. The researcher will ask you to answer some questions about yourself (questions like, how old are you? Who do you live with?).

The researcher will work with you to create a timeline of your life so far. You can decide if you want your parent/guardian to stay in the room for this.

After about 30 minutes, the researcher will start the interview. At this point, your parent/guardian must leave the room. The researcher will use a voice recorder and ask you one interview question. Once you have spoken about what you have been asked, you can take a break.

After the break, the researcher will ask you questions about what you said in the interview. These questions will help the researcher find out more about you.

Once the researcher has asked her questions, the interview will stop. The researcher will thank you for taking part. If you are under 16 years old, the researcher will ask your parent/guardian to join you and tell them the same information. You will receive a £15 Amazon voucher to thank you for taking part.

The interview should take up to a maximum of two hours.

Are there any benefits for taking part?

There are no direct benefits to you however after finishing the interview, you will receive a £15 Amazon voucher to thank you for taking part.

Are there any risks involved?

Talking about your personal experiences may cause you some distress. If this happens, the researcher will work with you to decide what support you may need. This support could include:

- Stopping the interview,
- Asking your parent/guardian to support you,
- Finding a service that can help you with how you are feeling.

What data will the researcher collect?

- Your contact details – This information will be collected to help the researcher arrange the interview with you. This information will be kept safe in a locked cabinet. After you have completed your interview, this information will be destroyed.
- Demographic information – You will answer some questions about yourself, like "how old are you?" This information will be kept safe in a locked cabinet. The researcher will keep this information until her coursework has been assessed. This information will be destroyed after the researchers work has been marked.
- Voice recordings – During the interviews, our voices will be recorded by a Dictaphone. After the interview, the researcher will upload the voice file to a password protected computer. The audio file will be deleted from the Dictaphone. The researcher will be the only person who has access to this computer.

Will my involvement be confidential?

Your involvement and any information the researcher collects about you will be confidential. The researcher will remove any information that could help others work out who you are. The researcher will do this before the project is handed in as coursework.

The researcher will need to share a small amount of information with the people helping her with the study (the project team). The project team must also keep your information confidential.

- The researcher will share the date, time and place of your interview with one member of the project team. The researcher will tell the person where they can find your contact information (in the locked cabinet). This is in case they cannot contact the researcher after the interview.
- If the researcher is worried about something you have said. This could be information about hurting yourself, someone hurting you or you hurting other people. The researcher will need to tell someone who can help you stay safe. The researcher will talk to you about this. Together you can think about any extra support you might need.

Does I have to take part?

No, it is entirely up to you whether you take part.

What happens if I change my mind?

You can change your mind about taking part at any time. You do not have to give a reason. If you decide you do not want to continue, you can tell the researcher. The researcher will delete the audio recording in your presence.

You might change your mind after the interview. If you do change your mind, you can contact the researcher by email. It may not be possible to remove your interview from the study if it has been prepared for analysis.

What will happen to the results of the study?

Your personal information will remain confidential.

Appendix F

The researcher will submit the results of the study as her coursework. After the coursework has been marked, the researcher hopes to write up the project for a research journal. This will be to help others find out about the results of this study. You can ask for a copy of this work if you would like.

Where can I get more information?

If you would like more information about this study, you can contact the researcher, Stacey White or the lead supervisor, Dr Melanie Hodgkinson by email.

What happens if there is a problem?

If you have a concern about any part of this study, you should speak to the researcher, Stacey White or the lead supervisor, Dr Melanie Hodgkinson by email.

If you remain unhappy or have a complaint about any part of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Contact information:

Stacey White (researcher) - Sld1n17@soton.ac.uk

Dr Melanie Hodgkinson (lead supervisor) – M.J.Hodgkinson@soton.ac.uk

Thank you!

Thank you for taking the time to read the information sheet and considering taking part in this study.

Appendix G Parent Information Sheet

Parent Participant Information Sheet (Version 1.6; September 2019)

Study Title: Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescence.

Researcher: Stacey White

ERGO number: 47628

In this information sheet, the term 'autistic' will be used. This terminology has been chosen as it is currently used by the National Autistic Society. The researcher recognises you may have your own preference about the terminology used. Please feel able to tell the researcher your preference if you decide to continue with the study.

Your daughter is being invited to take part in the above research study. To help you decide whether you would like your daughter to take part, it is important that you understand why this research project is being undertaken and what it will involve. Before giving consent for your daughter to participate, please read the information below carefully and ask questions if anything is unclear. You will be asked to sign a consent form on your daughters behalf however she will also be asked to sign an assent form to confirm she is willing to participate.

What is the research about?

The researcher is a 3rd year Trainee Clinical Psychologist studying at the University of Southampton. To fulfil the requirements of the Doctoral programme the researcher must complete a piece of research. Over her training, the researcher has worked clinically with several autistic females; many of whom have been trying to make sense of what this diagnosis means in relation to their identity.

Evidence suggests autistic females may be more socially aware of differences between themselves and peers, however research into the impact of a diagnosis on the view of oneself is limited. For this reason, the researcher is interested in the self-concept of autistic females receiving a diagnosis at a crucial point in their life, the adolescent period, to understand how this may shape how a person makes sense of who they are.

Why has my child been invited to participate?

You are receiving this Participant Information Sheet because you or your child has expressed an interest in participating in this study. This study is seeking participation from females who have

received a diagnosis of autism spectrum disorder during adolescence (between 12 and 17 years old).

What will happen if my daughter takes part?

The researcher will arrange to meet you both at a venue your daughter is familiar and comfortable with. The researcher will talk to you about the document/report you will need to bring with you to the interview, to confirm diagnosis.

At the meeting, the researcher will explain the study to you both. If you and your daughter are happy to continue, the researcher will ask for a consent form and assent form to be signed and check a medical report document confirming diagnosis. The researcher will ask your daughter to complete a demographics questionnaire. The research will then develop a life timeline with your daughter. Your daughter will be given the choice as to whether they would like you to stay in the room for this.

After about 30 minutes, the researcher will start the interview with your daughter. At this point, the researcher will ask you to sit in the waiting room. The researcher will turn on a Dictaphone to record the interview. The researcher plans to use an interview approach called Narrative Inquiry, which means she will ask one broad question to find out how diagnosis has shaped your daughters view of who she is, around the time of assessment and diagnosis. To do this the researcher will use subtle prompting to encourage your daughter to share this story. Once your daughter has finished sharing her story the interview will be paused. Your daughter will then be given a break before starting the second part of the interview.

The second part of the interview will again be recorded by a Dictaphone. In this part of the interview, the researcher will ask your daughter questions about what she shared in her life story (during the first part of the interview). This will allow the researcher to explore how your daughter distinguishes herself from others, how she may define herself and how this may have changed since diagnosis. The researcher will debrief your daughter and thank her for her time. You will be invited into the room for this debrief.

The interview should take up to a maximum of two hours.

Are there any benefits for my child taking part?

There are no direct benefits to taking part however your child will receive a £15 Amazon voucher at the end of the interview, to thank her for taking part.

Are there any risks involved?

Due to the nature of this research topic, there is a small chance that talking about personal experiences may cause your daughter some distress. If this happens, the researcher will work with your daughter to decide if the interview should be terminated. The researcher will make you aware that your daughter has become distressed during the interview and will spend time with you both considering if additional support may be required.

What data will be collected?

- Your contact details – this information will need to be collected to support with arranging the interview. This information will be stored securely in a locked cabinet. Once the data collection period is complete, this information will be confidentially disposed of.
- Demographic information – this will be collected at the start of the interview. This information will be stored securely in a locked cabinet. This data will be used when interpreting the interview transcripts. This information will be confidentially disposed of after the research has been marked.
- Audio recordings - An encrypted Dictaphone will be used to complete audio recordings throughout the two stages of the interview. The audio files will be uploaded to a password protected computer immediately after each interview. The audio files will then be deleted from the Dictaphone. The researcher will be the only person who will have access to this computer and the computer will be stored in a different location to the contact details. Once data collection is complete, the audio files will be transferred to an authorised transcription service, via secure channels. Once the transcription files have been returned to the researcher, the audio files will be permanently deleted from the computer.

Will my daughters' participation be confidential?

Your daughters' participation and the information collected over the course of the research will be kept strictly confidential.

During the interview period, contact details will be shared between the research team, as required by the University of Southampton Lone Working Policy. Only the researcher will be able to identify which interview transcript was developed during the interview with your daughter and any identifiable data will be removed before being shared with the research team for analysis. This allows for the maintenance of your daughters confidentiality. The signed consent and assent forms, required to proceed with the interview, will be stored in a locked cabinet, away from contact information and the password protected computer.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you. This will be shared for monitoring purposes and/or to carry out an audit of the study, to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out

the study correctly) may require access to your data. All of these people have a duty to keep your daughters information, as a research participant, strictly confidential.

Does your daughter have to take part?

No, it is entirely up to you and your daughter to decide if she takes part. If you decide you are happy for your daughter to take part, you will need to sign a consent form to show you have agreed for your daughter to take part, as she is under 16 years old. Your daughter will also be asked to sign an assent form to confirm she is happy to participate in the research.

What happens if we change our minds?

You have the right to change your mind and withdraw from the study at any time, without giving a reason and without participant rights being affected. If you decide you wish to withdraw consent during the interview period, you can inform the researcher and she will delete the audio recording in your presence. If you decide you wish to withdraw consent following the interview, again you can contact the researcher by email. This must be submitted before the audio files are transcribed as after this point, it will not be possible to identify which interview your daughter completed.

What will happen to the results of the research?

Your daughters' personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify your daughter without your specific consent.

To fulfil the requirements of the Doctoral programme the researcher must submit a written research paper. After formal assessment, this research paper may be prepared for publication in an appropriate research journal to add to the limited pool of data surrounding this topic. You are invited to request a copy of this should you wish.

Where can I get more information?

If you would like more information about this study, you can contact the researcher, Stacey White or lead supervisor, Dr Melanie Hodgkinson by email.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. You can contact either the researcher, Stacey White or lead supervisor, Dr Melanie Hodgkinson by email.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Contact information:

Stacey White (researcher) – Sld1n17@soton.ac.uk

Dr Melanie Hodgkinson (lead supervisor) – M.J.Hodgkinson@soton.ac.uk

Appendix H Consent/Assent Form

CONSENT/ASSENT FORM (Version 1.5; September 2019)

Study title: Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescence.

Researcher name: Stacey White

ERGO ID: 47628

Please initial the boxes if you agree with the statement(s):

The researcher has explained the project to me.	
I have read and understood the participant information sheet (September 2019/v1.6) and have had the opportunity to ask any questions.	
I understand the researcher will ask me questions and the answers will be recorded using a voice recorder.	
I understand that the researcher is a student and my interview will help her complete a piece of coursework.	
I understand my name or any other information that could identify me will be removed.	
I understand that I can tell the researcher if I do not want to take part. I can do this at any point and that is completely OK.	
I would like to take part in the interviews.	
I understand that I will receive a £15 Amazon gift voucher after finishing the interview.	

If you want to take part, you can write your name below:

Your name.....

Your signature.....Date.....

The person who explained the study to you needs to sign here:

Signature.....Date.....

Appendix I Parent Consent Form

CONSENT FORM (Version 1.5; September 2019)

Study title: Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescence.

Researcher name: Stacey White

ERGO number: 47628

Please initial the boxes if you agree with the statement(s):

I understand that I am giving consent on behalf of my daughter, as she is under 16 years old.	
I understand my daughter will be asked to sign an assent form to confirm she would like to participate in the study.	
I have read and understood the participant information sheet (September 2019/v1.6) and have had the opportunity to ask questions about the study.	
I understand that my daughter's participation is voluntary and that my daughter or I may withdraw consent at any time and for any reason without her participation rights being affected.	
I understand that personal information collected about my daughter, such as her name and age, will not be shared beyond the study team.	
I understand, for the purposes set out in the participation information sheet that my daughters interviews will be audio recorded, that the audio files will be transcribed, and then the audio files will be destroyed.	
I understand that my daughter may be quoted directly in the research reports but that she will not be directly identified (e.g. that her name will not be used).	
I agree for my daughter to take part in this research project and agree for the data to be used for the purpose of this study.	
I understand that once my daughter's personal information is no longer linked to the data it may not be possible to remove this data, if I decide to withdraw consent.	

Appendix I

Name of participant (print name)

Name of consenting adult Signature.....

Relationship to child..... Date.....

Signature of researcherDate.....

(Stacey White)

Appendix J Visual aid

Can you tell me your life story, talking to me about the events and experiences that are important to you?

Begin wherever you would like.

Appendix K Participant Debrief Form

Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescence.

Young Persons Debriefing Statement (August 2019 - V 1.4)

ERGO ID: 47628

Thank you for taking part in the interview with Stacey.

Your interviews will help Stacey to understand how you and other autistic females define your identity.

Some of the information you shared in your interview will be used in an essay. Your name and any other information that could identify you will not be included.

You can keep this document if you would like to. You can also have a copy of the essay, once completed, if you would like.

If you are upset or worried by something you have spoken about in the interview, you can tell Stacey now. If you feel upset or worried after the interview has finished, you can contact:

ChildLine

ChildLine is a confidential listening service which supports young people with any problem.

Website: www.childline.org.uk

Helpline: 0800 1111

Young Minds

Young Minds provides support about emotional wellbeing and mental health to both young people and their parents.

Website: www.youngminds.org.uk

Text: YM to 85258

Another support and advice service you may think about contacting is:

National Autistic Society

The National Autistic Society offer advice and support as well as providing a helpline for autistic people and their carers.

Website: www.autism.org.uk

Helpline: 0808 800 4104

If you have any further questions, please contact Stacey by email (Sld1n17@soton.ac.uk).

Thank you for taking part.

Signature:.....Date:.....

Appendix L Parent Debrief Form

Exploring the Self-Concept of Females Diagnosed with Autism Spectrum Disorder in Adolescence.

Parent/Guardian's Debriefing Statement (August 2019 - V 1.4)

ERGO ID: 47628

The aim of this research project was to explore the self-concept of females who have been diagnosed with autism spectrum disorder in adolescence. The data gathered, through interviewing your daughter, will enhance our understanding of how adolescent females diagnosed with autism spectrum disorder define themselves. The research project did not use deception and any information collected that could lead to your daughter being identified will be removed to ensure confidentiality. You can request a summary of the research findings which can be sent to you once the project is complete.

If you have any further questions please contact me, Stacey White, at sld1n17@soton.ac.uk.

It is hoped that participating in this study will not have caused your daughter any distress however if you feel she may need some additional support, you could contact:

Young Minds

Young Minds provides support about emotional wellbeing and mental health to both young people and their parents.

Website: www.youngminds.org.uk

Parental helpline: 0808 820 5544

National Autistic Society

The National Autistic Society offer advice and support as well as a helpline for autistic people and their carers.

Website: www.autism.org.uk

Helpline: **0808 800 4104**

Your daughter could also contact:

ChildLine

ChildLine is a confidential service that supports young people with any problem they may encounter.

Website: www.childline.org.uk

Helpline: 0800 1111

Thank you for giving consent for your daughter to participate in this research.

Signature:.....Date:.....

Stacey White

Appendix L

If you have questions about your daughters rights as a participant in this research, or if you feel that your daughter has been placed at risk, you may contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Appendix M Initial noting and coding of transcript excerpts

Emerging themes	Transcript	Exploratory comments
Achieving self	Felicity: So, I made it to secondary school at [name of school], and it was going well. The first thing I noticed that there was homework; I had never done homework before. I'd never done science before; I had never studied history. So, there was a huge change and I wanted to make a good impression, so I was very much a perfectionist because I had never done anything like that before so I would spend way too long on everything.	Describing how this school differed – adjusting to change. "I had never" repeated to list differences and build a sense of change being experienced Making an impression to teachers – proving self/not had to try before?
First experiences challenge achieving self		
Striving for recognition and investing to maintain achieving self construct		Committed to not showing struggling/focussed. Working hard to show doing ok.
Achieving self maintained by recognition		"way too long" to introduce awareness of difference to previous experiences and time investment.
First experience challenge achieving self	Yes, and then I did my exams... My first proper set of exams. I revised for the first time and I spent way too long. At that point the general consensus was that I had anxiety around exams and high-pressure situations because I used to cry sometimes and not go into dance because I was so scared of my teacher. It wasn't that she was that scary, I was just scared. I started therapy then the next year after my first set of exams, private therapy just for exam anxiety and dealing with things like that.	More firsts/changes Trying hard. Repetition of "way too long" building a sense of commitment/effort/investment of time.
Struggling/scared self?		First mention of anxiety – "general consensus" agreement by others around Felicity that this was her experience – not just her own interpretation. Feeling scared? Recognition of emotions and relation to actions - she wasn't scary but I was scared. Interpreted by others as anxiety – impacting on enjoyment.
Needing outsider support		Being helped to cope.

Appendix N Reflective diary excerpts

Interview with Beth

As Beth shared her life story, I noticed I wanted to interact with her and felt restricted by the interview schedule. I was drawn to wanting to respond to what she was sharing by offering encouragement and reminders that she only needed to share what she wanted to. In comparison to the timeline task, it felt like something had shifted for Beth as she started to share her life story through an uninterrupted narrative. I noticed a heaviness radiated around the room. I felt uncomfortable about how restricted I was feeling, and on reflection, I wonder about the power dynamic between us at this point - Did Beth feel like she had been instructed to share her painful life experiences with me? Was it my assumption that these experiences were painful or difficult for Beth to share? Was I actually the powerless one in this experience? During the break, I spent time checking in with Beth. I reminded her of her rights to take a break, stop, or terminate the interview. It felt really important to me to do this and I now find myself wondering how this influenced my curiosity in the final part of the interview. What did I avoid exploring because of my own experience?

Interview with Danielle

I noticed I had some preconceptions about what Danielle may be like from the email exchange with her mother, ahead of the interview. I anticipated having to work hard to build a rapport with Danielle and to help her to feel comfortable during the interview.

Danielle seemed to start to settle into the interview towards the end of the timeline task: becoming more animated and seeming to speak more freely. This quickly changed when I asked Danielle the life-story question. Danielle appeared to freeze in her chair and I noticed I started to feel anxious; I wonder whether I was picking up on my emotion or Danielle's. I found myself working really hard from this point. I wanted to make sure Danielle was ok and offered to stop the interview. I found myself regularly reminding Danielle we could stop the interview at any point. By narrowing the life-story question down to a significant life-event, Danielle decided she wanted to carry on with the interview. I noticed from this point I was reluctant to ask Danielle too many formal interview style questions and instead, we had more of a conversational interaction. I am frustrated that I had not anticipated a situation like this happening and I feel I have to prepare for this happening again in future interviews.

Before starting data analysis

Starting data analysis feels daunting. Prior to advertising for participants, I thought I would have a sense of at least some of the emerging themes at this stage but I don't – the participants' interviews were all so different. I wonder how the transcripts are going to come together and if the analysis is going to allow me to present the participant's stories in the way they deserve to be presented. I have noticed that when I think about how I will start the analysis I am drawn to coding the transcripts in the order I interviewed – I wonder why I am drawn to feeling there is a right way to approach the analysis.

Appendix O Bracketing interview excerpts

Interviewer: Why are you interested in this topic?

Stacey: Thinking back through my experiences, I have worked with three young autistic women who have really influenced my clinical experiences. One young woman before training and two during clinical training. I vividly remember a clinical session where one of the young women said something like “I don’t know who I am anymore, everything has changed since I got my diagnosis”. She had received a diagnosis when she was about 16 years old. That conversation has really stuck with me. I remember feeling sad for her about the conflict receiving an autism diagnosis had caused. When we were asked to start thinking of our thesis topics, that conversation kept coming back to me. I found myself wanting to understand more about that experience and wondered if all young women diagnosed on the autism spectrum in adolescence experienced a similar loss of self and internal conflict. Trying to recruit adolescent participants seemed to make sense because this is when we start to make sense of who we are. It seems like a really interesting age range to complete this study with. I know that autistic females are significantly under-represented in the research and can present differently to the view of what a ‘typical’ autistic presentation is, which has made me even keener to explore this topic. It just feels really important to me.

Interviewer: Why? What is it that is making it feel really important to you?

Stacey: I knew you were going to ask that! In some ways, it’s about giving marginalised people a voice. A lot of my background reading is about other people’s thoughts about autistic people’s experiences and in some ways that has really surprised me. I imagine there aren’t many research topics where that happens but that is my assumption. Before training, I worked with adults with a learning disability and this has made me passionate about everyone being given fair opportunities to express their own views, have choice, and to do so at their own pace. I feel, in some ways that I have a chance to allow the voice of my participants to be heard. I know though that the voice I present will also be influenced by my own positioning but I guess in some ways that is why we are doing this.

Interviewer: Do you have any thoughts about what the voice of participants might be saying in your research?

Stacey: I am really conscious of this at the moment. I am very aware, even just by telling you why I am interested in this topic, that I am anticipating others will have experienced a loss of who they

Appendix O

are or a struggle following receiving their diagnosis. In some ways, I worry that because of this I may be drawn to attending to the things that confirm this thought, like the struggles and conflict they have following their diagnosis. I also worry that because of this I may not be as curious about other experiences and themes that may come up within the interviews.

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