‘You don’t know what the future is going to hold’:
Experiences of growing older with an autism spectrum condition
- A participatory research study

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Table of Contents

Abstract 8
Chapter 1: Introduction 10
1.1. Part I: Understanding Autism 10
  1.1.1. Historical definitions 10
  1.1.2. Medical definitions 11
  1.1.3. Diagnostic criteria 11
  1.1.4. Social and alternative definitions 12
  1.1.5. Prevalence 13
  1.1.6. Theories of autism 14
    1.1.6.1. Theory of Mind Theory 14
    1.1.6.2. Central Coherence Theory 15
    1.1.6.3. Executive Dysfunction Theory 15
    1.1.6.4. Extreme Male Brain Theory 16
    1.1.6.5. Social Motivation Theory 16
    1.1.6.6. Critiques of common theories 17
  1.1.7. Legislation, policy and guidance 18
    1.1.7.1. Autism Act 18
    1.1.7.2. Think Autism 19
    1.1.7.3. NAS Report 19
    1.1.7.4. Report for the Welsh Assembly Government 20
    1.1.7.5. NICE Guidelines 20
  1.1.8. Autism across the lifespan 21
  1.1.9. Experiences of adults with ASC 22
1.2. Part II: Understanding Ageing 23
  1.2.1. Definitions of ageing 23
  1.2.2. Theories of ageing 24
    1.2.2.1. Erikson’s Stages of Psychosocial Development 24
    1.2.2.2. Disengagement theory 25
    1.2.2.3. Activity theory 25
    1.2.2.4. Selection, optimisation and compensation 25
    1.2.2.5. Dynamic Integration Theory 26

1.2.2.6. Convoys Model of Social Relations 26
1.2.3. The experience of ageing 27
1.3. Part III: Participatory Research 28
1.3.1. Definitions 28
1.3.2. Participatory research and autism 30
1.4. Part IV: Systematic Review 31
1.4.1. Article identification 31
1.4.2. Review procedure 33
1.4.3. Critical appraisal 33
1.4.4. Findings from Systematic review 34
1.4.4.1. Theme 1: Diagnosis 35
1.4.4.2. Theme 2: Being different/self-identity procedure 36
1.4.4.3. Theme 3: Social difficulties 38
1.4.4.4. Theme 4: Mental health difficulties 40
1.4.4.5. Theme 5: Support and coping 40
1.4.5. Phenomenological considerations 42
1.4.6. Summary 43
1.5. Part V: Ageing with autism – the research picture to date 43
1.5.1. Ageing in autism research 43
1.5.2. Qualitative studies of ageing with autism 46
1.6. Part VI: Focus of the present study 48
1.6.1. Gaps in the literature 48
1.6.2. Aims and research question 51

Chapter II: Method **51**
2.1. Chapter Overview 51
2.2. Research Paradigm 52
2.2.1. Epistemology and ontology 52
2.3. Qualitative framework 53
2.3.1. Choice of method 53
2.3.2. Theoretical underpinnings of IPA 55
2.3.2.1. Phenomenology 55
2.3.2.3. Hermeneutics 55

2.3.2.4. Idiography 56
2.3.2.5. Epistemology and ontology of IPA 56
2.3.3. IPA in this study 57
2.4. Participatory Research 58
2.5. Reflexivity 59
2.5.1. Researcher background 60
2.5.2. Researcher position 63
2.6. Participants 64
2.6.1. Inclusion 64
2.6.2. Exclusion 65
2.6.3 Sampling 65
2.7. Design 66
2.7.1 Participatory research design 66
2.7.2. Method of data collection 67
2.7.3. Development of interview topic guide 68
2.8. Analysis and methodological rigour 69
2.9. Ethical considerations 70
2.9.1 Obtaining permission to complete the research 70
2.9.2. Informed consent 71
2.9.3. Reducing distress 72
2.9.4. Confidentiality and anonymity 73
2.10. Dissemination 74
2.10. Chapter summary 74

Chapter III: Results 74
3.1. Overview of results 74
3.2. Recruitment 75
3.3. Demographics 75
3.4. Themes 76
3.4.1. Growing older 78
3.4.1.1. ‘Not a bad little future’: Thinking about the future 79
3.4.1.2. ‘It’s better not to think about it’: Concerns for the future 83

3.4.1.3. 'That's my ambition': Hopes and plans for the future 86
3.4.1.4. 'I've completely changed' versus 'self as stable': Change with age . 88
3.4.1.5. 'Therapy or practical support or maybe both': Suggestions for support 91
3.4.2. Contemplating difference 93
3.4.2.1. 'My brain is wired up slightly differently to everyone else's': Feeling different 94
3.4.2.2. 'I feel quite normal': What is normality? 97
3.4.2.3. 'Autistic people even become brilliant in that': View of autism 98
3.4.2.4. 'There must be people with worse problems than me': Social comparison 101
3.4.2.5. 'A wonderful release … now trapped': Diagnosis, self-identification and disclosure 102
3.4.3. Relationships 105
3.4.3.1. 'I feel friendships were these random things': Relationship difficulties 106
3.4.3.2. 'I can bounce stuff off him': Positive experiences of relationships . 108
3.4.3.3. 'One can't get too close': Need for distance.................................. 110
3.4.4. Life so far has been a challenge... 112
3.4.4.1. 'I was bullied by all the bullies': Negative experiences 112
3.4.4.2. 'I just get walked over': Poor treatment and being taken advantage of 115
3.4.4.3. 'I'm talking from a different plane': Not being understood 116
3.4.4.4. 'How do you deal with a really low place?': Difficult feelings....... 117
3.4.5. Resources and Resilience: Managing difficulties 119
3.4.5.1. 'I pursue things I'm better able to do': Self-help and meeting needs another way 120
3.4.5.2. 'I'm sort of bluffing my way through': Having a veneer 122
3.4.5.3. 'It's one of my Asperger interests': Special interests and advocacy 124

Chapter IV: Discussion **126**
4.1. Overview of findings 126
4.1.1. Growing older 127

- 4.1.2. Contemplating difference 132
- 4.1.3. Relationships 136
- 4.1.4. Life so far has been a challenge 139
- 4.1.5. Resources and Resilience: managing difficulties 143
- 4.1.6. Summary of study aims and findings 146

4.2. Methodological strengths 148
- 4.2.1. Novelty 148
- 4.2.2. Participatory framework and impact for analysis 148
- 4.2.3. Quality Assurances 150
- 4.2.4. Reflexivity 151
- 4.2.5. Sample 151

4.3. Limitations 151
- 4.3.1. Sampling issues 151
- 4.3.2. Participant demographics 152
- 4.3.3. Analysis 153

4.4. Clinical implications 154

4.5. Future directions 156

4.6. Summary and conclusions 157

4.7. Reflective account 158
- 4.7.1. Reflective account of main researcher 158
- 4.7.2. Reflective account of participatory researcher who analysed one transcript .. 161

References **163**

Appendices **193**

A. Literature review search strategy 193
B. Quality appraisals of reviewed articles 196
C. Extract from reflective log 199
D. Interview topic guide 203
E. Visual representation of themes 204
F. Health Research Authority approval letter 207
G. University of Essex ethics approval letter 215
H. Participant information sheet 216
I. Participant consent form 219
J. Table of excluded themes 220
K. Extracts of annotated transcripts showing coding and emergent themes……..……221

Abstract

Background. Autism spectrum conditions (ASC) have traditionally been viewed as disorders of childhood and research, policy and practice have reflected this. As a relatively new diagnostic category, individuals with ASC are only now reaching older adulthood and little is known about the experience of ageing in people on the spectrum. Qualitative research that includes the voices of individuals with ASC has been a particularly neglected area, and no studies have been published which use a participatory research approach with older people with autism.

Aims. The current study aimed to explore the lived experience of older people with an ASC with a focus on interpersonal relationships. It also aimed to meaningfully include individuals with ASC in the research process.

Method. The present study uses a qualitative design with a participatory research framework. Volunteer participatory researchers, with lived experience of ASC were included in all aspects of the research process. Semi-structured interviews were conducted with seven male participants (mean age 62.1 years), and the data analysed using Interpretative Phenomenological Analysis (IPA).

Results. The analysis yielded five superordinate themes each with several subordinate themes. The higher-order themes included ‘growing older’, ‘contemplating difference’, ‘relationships’, ‘life so far has been a challenge’ and ‘resources and resilience’. They provided a narrative of paradoxes in that experiences related to growing older were in many ways ordinary; however, they occurred within a context of relational estrangement. The concepts of difference and normality, and the social construction of disability, were prominent themes throughout the data.

Conclusions. Data from the analysis highlighted the interpersonal struggles older people with ASC face, despite a sense that experiences were not all unique to people with autism, or to older people on the spectrum. Implications for services and future research are discussed with a particular focus on how participatory research can be further developed in the area of autism.

Chapter I: Introduction

This study explores experiences of growing older with an autism spectrum condition (ASC). It considers the narratives of what it is like for an individual to enter into older adulthood in the context of their experiences with autism with a particular focus on interpersonal relationships. This chapter will offer definitions of autism and ageing respectively as well as consider theoretical underpinnings and models. It will conclude with a review of the relevant research in the field and identify gaps in the literature.

The terms autism spectrum condition (and its abbreviation ASC) and autism will be used interchangeably in this paper, but both should be considered to refer to the whole spectrum of the conditions and to include Asperger's Syndrome.

1.1. Part I. Understanding autism

1.1.1. Historical definitions

Autism was first described in 1943 by Leo Kanner who studied eleven children and wrote about what he observed to be a distinct syndrome of unusual behaviours including delayed communication, need for sameness and a desire for aloneness. He named this presentation 'early infantile autism'. The symptoms described were included in the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM; APA, 1952) under the term 'childhood schizophrenia'. Not until the publication of the DSM-III in 1980 (APA, 1980) was the term 'schizophrenia' replaced by infantile autism.

Just one year after Kanner's first case studies, Hans Asperger (1944) described a similar set of difficulties in children, though focussing on those with high IQ. He conceptualised this as a personality trait which he labelled 'autistic psychopathology'. This was later named Asperger Syndrome (AS) by Lorna Wing, who translated the case descriptions of Hans Asperger. She suggested AS and other autism conditions lie on a continuum of autistic difficulties (Wing, 1988). Asperger Syndrome was not included as a separate diagnostic category until publication of the DSM-IV in 1994 (APA, 1994).

1.1.2. Medical definitions

The dominant framework for understanding autism is the medical model. Within this, diagnostic frameworks often offer the most widespread definitions. The latest edition of the DSM (DSM-V; APA, 2013) defines ASC under the broader term of neurodevelopmental disorders. They are characterised by difficulties in functioning, which used to be referred to as the 'triad of impairments' (Wing & Gould, 1979); social interaction, communication and social imagination. About 70% of individuals with autism also have a diagnosis of an intellectual disability (Fombonne, 2003).

The National Institute for Health and Clinical Excellence (NICE) defines autism as:

> "qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems." (NICE, 2012).

1.1.3. Diagnostic criteria

Until the latest edition of the DSM (DSM-V; APA, 2013) five diagnostic labels were grouped under the umbrella term of ASC. This most recent edition, the DSM-V, synthesised these under one single diagnostic label of 'autism spectrum disorder'. Controversially, Asperger's syndrome is no longer included as a distinct diagnosis. Prior to this change in criteria, difficulties in all three areas of functioning (triad of impairments) were needed to warrant a diagnosis. More recently, social interaction and communication difficulties have been combined into a single category (DSM-V, 2013) and assessment of severity of symptomology is required for diagnosis.

1.1.4. Social and alternative definitions

The National Autistic Society (NAS) defines autism as “a lifelong developmental disability that affects how people perceive the world and interact with others” (NAS, 2018). They go on to state that “autism is a spectrum condition” and “all autistic people share certain difficulties but being autistic will affect them in different ways”, highlighting individual differences in how ASC may present.

The neurodiversity movement (e.g. Singer, 1999) offers an alternative conceptualisation of ASC, proposing to view autism as a variation in human functioning. This paradigm suggests that there is no one ‘normal’ way of neurocognitive functioning and that different brains and minds should be accepted and respected, as other aspects of human difference are. The neurodiversity approach to autism was somewhat revolutionary as a first approach to challenge the dominant medical understanding of ASC. It has been embraced by many individuals on the spectrum, and their families.

Critics of the neurodiversity movement have highlighted that despite offering a useful alternative, such approaches do little to challenge the dominant medical model as they use the same paradigms as much of the medical and research professions (Runswick-Cole, 2016). Neurodiversity relies on the idea that there is a real and measurable difference in how brains of people with autism are structured (Runswick-Cole, 2014) and, according to critics, fails to contest the dominant discourse sufficiently (Davies, 2016).

Social constructionists view autism differently. Influenced by the social model of disability (Oliver, 1983), they contend that autism is purely a label which is constructed as a means of classifying, and pathologising, difference (Molloy & Vasil, 2002). They criticise the medical model's paradigm of conceptualising difference as disorder, and of locating this disorder within the individual (Molloy & Vasil, 2002). Analysing papers from the conception of the concept of autism, Timini & McCabe (2016) argue that ASC is a construct formed by ideologies rather than concrete scientific discoveries. Highlighting considerable diagnostic overlap, methodological flaws and contradictory findings in research and a lack of a universally-agreed aetiology, they stress the need to consider society's input and motivation in constructing a concept such as ASC (Timini & McCabe, 2016).

1.1.5. Prevalence

The Adult Psychiatric Morbidity Survey (Brugha, McManus, Meltzer, Smith, Scott et al., 2009) estimated the prevalence of autism in England to be at 1%. This figure was updated by a Department of Health study to include those with more severe learning disabilities, resulting in a figure of 1.1% (Brugha, Cooper, McManus, Purdon, Smith et al., 2012). Studies across different countries have reported varying levels of prevalence which have been combined to offer a conservative median estimate of 62 in 10,000 (Elsabbagh, Divan, Koh, Kim, Kauchali et al., 2012). The most recent UK estimate for prevalence of autism stands at 1.04% (MacKay, Boyle and Connolly, 2016). Considerable debate prevails as to whether incidence rates are increasing or whether changes in diagnostic criteria and practices as well as greater awareness amongst the public and professionals are the cause of the greater number of autism cases observed. Some studies suggest that improved diagnostic procedures have contributed significantly to the noted increase (up to one quarter of cases explained through this; King & Bearman, 2009). However, other epidemiological studies (Brugha et al., 2011) report that rates are stable across different age cohorts thus suggesting that autism prevalence has not been increasing over the past decades (Brugha, 2016).

1.1.6. Theories of autism

Theories of autism can be broadly classified into psychogenic (parent-child relationship), biogenic (biological) and cognitive frameworks. They aim to explain the aetiology, symptomatology and difficulties observed in individuals with autism. Despite causal explanations of the origins of autism not being the focus of this project, some of the theories are reviewed here briefly to provide a theoretical context. As this thesis is within the field of psychology, the emphasis will be on cognitive or psychological theories.

1.1.6.1. Theory of Mind Theory (Baron-Cohen, Leslie & Frith, 1985)

Theory of Mind (ToM) theories suggest that people with ASC lack a theory of mind which they argue explains social aspects of the condition, such as apparent lack of empathy. The main critique of such theories is the developmental trajectory of autism and the fact that it is often identified in early childhood before ToM may be developmentally expected. Similarly, research suggests that not all individuals who have a diagnosis of ASC fail ToM tests (Happé, 1995). On a more conceptual level, critics who question the concept of autism as a whole are concerned that suggesting a lack of ToM infers that the individual lacks empathy and thus lacks an essential part of being human. These voices thus brand the ToM Theory as ‘de-humanising’ and feel it adds to the oppression and marginalisation of those with difference (Davies, 2016).

1.1.6.2. Central Coherence Theory (Frith & Happé, 1994)

The Central Coherence Theory of autism proposes that a specific cognitive style underlies the difficulties observed in autism. It surmises that individuals with ASC have a greater ability to perceive detail but experience difficulties with seeing the bigger picture. Despite some empirical research which supports this theory (e.g. Happé, 1999), studies have produced mixed results, some of which have suggested autistic individuals do demonstrate holistic processing (e.g. Mottron, Burack, Stauder & Robaey, 1999).

1.1.6.3. Executive Dysfunction (Ozonoff, 1997)

The theory of executive dysfunction in autism aims to explain many of the social and behavioural features of the condition by drawing comparisons with the presentation of neuropsychological patients with frontal lobe damage. It has considerable empirical evidence (e.g. Ozonoff, Pennington & Rogers, 1991). It has also been suggested that social difficulties, frequently attributed to deficits in ToM, can be accounted for by executive dysfunction as some argue that executive functions allow a child’s ToM to develop (Russell, 1997).

However, executive functioning difficulties are not unique to autism and can also be observed in other conditions (e.g. ADHD; Hill, 2004). Similarly, not all individuals with ASC struggle with executive dysfunction, particularly not those with normal range IQ (Baron-Cohen, Wheelwright, Stone, & Rutherford, 1999). Thus, the executive dysfunction theory of autism fails to address all aspects of the condition across its spectrum.

1.1.6.4. Extreme Male Brain Theory (Baron-Cohen, 2002)

This theory of autism is based on the observation that, on average, women are better at empathising than men, and men are better at systemising than women. Baron-Cohen (2002) suggests that autism is an extreme form of the neurocognitive profile seen in men, that is people with ASC are good at systemising but struggle with empathising. Considerable empirical evidence provides support for some of Baron-Cohen's hypotheses (Teatero & Netley, 2013), such as the findings that females perform better on ToM tests than males, and that males perform better on such tasks than people with ASC (Happé, 1995). Furthermore, the gender differences in diagnosis, with a ratio of 4:1 (male to female) for autism as a whole and 13:1 for Asperger's, provides some support.

The Extreme Male Brain Theory is able to helpfully explain both difficulties in social and cognitive domains in ASC and heightened talents for some on the spectrum. However, as it includes assumptions about lack of ToM, research refuting that people with ASC do not have ToM also applies here.

1.1.6.5. Social Motivation Theory (Chevallier, Kohls, Troiani, Brodkin & Schultz, 2012)

An alternative to the cognitive theories of ASC, the Social Motivation Theory of Autism (Chevallier et al., 2012) postulates that autism can be viewed as a condition of extremely diminished social motivation. It describes psychological dispositions and biological mechanisms which in typically-functioning individuals mean they are oriented to seeking social contact and gaining reward from this. They suggest that the social and interpersonal difficulties reported in ASC can be explained by disruptions in those systems, for example impairments in social attention result in reduced social learning opportunities for people with ASC (Chevallier et al., 2012). The authors offer wide-ranging evidence from psychological, brain-imaging and population research which seems to support their theory. However, they admit that their theory only describes part of the autism phenomenon with a focus on social aspects which fail to offer an explanation for behavioural symptoms. Furthermore, although this theory allows some scope of accounting for environmental influences (e.g. lack of social learning opportunities), it nonetheless maintains an emphasis on individual deficits (e.g. diminished social interest) as the underlying cause for these environment interactions.

1.1.6.6. Critiques of common theories

The multitude of theories which have been put forward to explain autism show how little is understood about these conditions. Critics have noted that autism theories themselves lack ‘central coherence’ (Belmonte, Allen, Beckel-Mitchener, Boulanger, Carper et al., 2004) as there is no coherent explanation for the triad of impairments and thus accuse researchers and academics of the exact ‘deficits’ which they feel characterise autism. For instance, theories seem to focus on either cognitive and associated behavioural symptoms (e.g. weak central coherence theory or executive dysfunction theory) or social difficulties (e.g. Theory of Mind theory or Social Motivation Theory). Furthermore, the great heterogeneity of the spectrum means theories struggle to explain the full variation in behaviour and experience.

There is a growing movement of academics, people with autism and their carers and those working with people with ASC who are questioning the notion of autism as a viable diagnostic category and actual phenomenon. They critique theories of autism for working with the paradigm of ontology of there being one ‘truth’ of autism as a real and absolute concept. Nadesan (2005) highlights that standards of what is ‘normal’ are socially constructed and that these culturally influenced representations also affect how autism is viewed in society. She adds that definitions of what is normal change over time, for instance what may now be considered a symptom of autism might previously have been termed an ‘eccentricity’. People who ascribe to this view suggest that not merely should autism not be seen as a deficit but argue that the whole construct of ASC as definitive biologically-based and diagnosable conditions ought to be challenged (Davies, 2016).

Additionally, these theories notably fail to include the voice of those who experience ASC. Smukler (2005) suggested that researchers are thus demonstrating poor Theory of Mind in failing to understand autism from the perspective of those affected.

1.1.7. Legislation, policy and guidance

1.1.7.1. Autism Act

The Autism Act 2009 was the first disability-specific act of Parliament. It followed considerable campaign and activism from the National Autistic Society. This legislation set out a duty for government to produce an autism strategy and to publish guidance for local authorities for its implementation. Resulting from this legislation was the strategy ‘Fulfilling and rewarding lives’ (Department of Health, 2010), followed by an updated version in 2014, ‘Think Autism’.

1.1.7.2. Think Autism (2014)

The government strategy ‘Think Autism’ (DoH, 2014) sets out the responsibilities of government and local authorities in providing care and services for adults with autism.

These policy documents were published as a requirement of the Autism Act (2009). Think Autism notes “it is critical that local services and communities think autism in relation to older people too” (p. 15) although provides little concrete or practical guidance for services and local authorities.

1.1.7.3. NAS Report

In 2013, the National Autistic Society (NAS) published a comprehensive report covering the challenges faced by and future directions for older people with autism. Employing interviews, surveys and focus groups, this pioneering work aimed to ensure that policy makers adequately address the needs of this population and sought to ensure that the Autism Act is implemented as intended. It sets out recommendations for the Department of Health, for local authorities and commissioning groups in relation to diagnosis, research, access to healthcare, service transitions and future planning, specialist support services and adapting mainstream provision.

As an extension of that report, the NAS published a response to the Centre for Policy on Ageing’s call for evidence on the role of local government in preparing for an ageing society (NAS, 2014). It highlights the key issues of concern for older people with ASC including diagnosis and identification, health and care needs, social isolation, advocacy. It also offers practical guidance for local authorities, such as developing clear diagnostic pathways and setting up volunteer-led support services for isolated older people with autism.

1.1.7.4. Report for the Welsh Assembly Government

The Welsh Assembly Government commissioned a report to examine the circumstances and support needs of older individuals with autism (Stuart-Hamilton, Griffith, Totsika, Nash, Hastings et al., 2009). This project incorporated a survey, in-depth interviews of people with ASC in middle adulthood and analysis of a dataset of adults and older adults with intellectual disability and autism (or without) in Wales. One key finding was that few older adults were found to take part in the research, indicating the inaccessibility and under-diagnosis in this age group. They stated that high levels of unemployment, depression and anxiety were common across older people with ASC as they are with younger adults with the condition. Isolation was a further difficulty, which may increase as people age and family members such as parents are no longer around to provide support and companionship. The report further outlined a number of recommendations for policy makers and service providers, including a need for collaboration in research and practice to investigate and address the support needs of this population. Additionally, they recommend that people with ASC are involved in design, development and delivery of services.

1.1.7.5. NICE Guidelines

The National Institute for Health and Care Excellence (NICE) published guidelines for adults with autism in 2012 (NICE, 2012). They focus on the importance of diagnosis and make recommendations for assessments of adults. Whilst the guidance recognises that the majority of adults with ASC face social and economic exclusion, it offers few suggestions for support and only specifies employment provisions for those struggling vocationally.

The guideline highlights the need for working in partnership with people with autism and taking into account the person’s preferences but fails to offer more detail on this.

1.1.8. Autism across the lifespan

ASC are thought of as life-long conditions. Brugha et al (2011) found incidence rates to be relatively stable at around 1% across the age ranges with only a 0.1% drop in the over-75s. Whilst autism in childhood and adolescence is a much-researched area (Barber, 2015), considerably fewer publications exist which address adulthood or beyond (Mukateova-Ladinska, Perry, Baron & Povey, 2012; Piven & Rabins, 2011; Salvatori, Tremblay & Tryssenaar, 2003). Yet older individuals with ASC may face unique issues, both personally and contextually (Wright & Wadsworth, 2016).

A review of the literature on adults with autism concluded that outcomes in terms of employment, social relationships, physical and mental health as well as quality of life are poor, even for those with average or above average IQ (Howlin & Moss, 2012). The review also found that support is often lacking and that little is known about what kind of interventions could help adults on the spectrum. The authors further highlight the paucity of research and note a particular lack of studies looking at persons in middle or late adulthood.

A meta-analysis summarising 15 studies calculated that around half of children with autism have poor adult outcomes (Steinhausen, Mohr Jensen & Lauritsen, 2016). Although they speculate that specific subtypes or diagnosis may be a predictor for later outcome, the authors report that predictors are not well-understood.

A more recent review of adult outcomes for ASC (Howlin & Magiati, 2017) echoes this negative view yet highlights a range of methodological issues which make commenting on outcomes for such a diverse group of individuals difficult. The authors also emphasise a particular lack of studies looking at outcomes for older adults.

Regarding symptom severity, Seltzer, Krauss, Shattuck, Orsmond, Swe et al. (2003) found that symptoms improved from childhood to adolescence and adulthood.

Although they note that this observed change may be due to changes in diagnostic criteria and practices or other cohort effects, they also discuss lifespan developments as influencing symptoms of autism. Their results suggest an improvement in symptoms relating to restricted and repetitive behaviours. In some participants the improvements were such that they no longer met diagnostic criteria for ASC, a finding which has been replicated by other studies (Totsika, Felce, Kerr & Hastings, 2010).

1.1.9. Experience of adults with ASC

The overwhelming part of research into autism addresses children and adolescents (James, Mukaetova-Ladinska, Reichelt, Briel & Skully, 2006) and most focus on parents', siblings' or professionals' views with little focus on the accounts of people with lived experience (DePape & Lindsay, 2016; Salvatori et al., 2003). Yet studies looking at adulthood have been increasing in numbers and, to a small extent, qualitative papers exploring the lived experience of adults on the spectrum are among these.

Hurlbutt & Chalmers (2002) published an early account of three adults with ASC which identified several challenges faced by participants including employment difficulties and struggles in social interaction. They also noted participants' strong desire to be consulted on issues relating to autism and thus offer further incentive to include their voices directly in research.

Salvatori et al (2003) conducted interviews with adults with developmental disabilities, relatives and service providers. The adults themselves reported that interpersonal relationships were very important to them and identified a need for more social opportunities. They also spoke about negative life experiences as well as a need for autonomy.

Müller, Schuler & Yates (2008) gave further weight to the issue of social difficulties for adults with ASC. Their qualitative study focussing on social challenges reported themes of isolation, difficulties initiating social contact and a desire for intimacy. Participants also made recommendations for support including structured social groups, communication supports and self-help provisions.

A study investigating problem behaviours with individuals with intellectual disabilities and autism reported on themes of communication difficulties and a need for autonomy and privacy amongst others (Ruef & Turnbull, 2002).

A more explorative study interviewed adults with AS between the ages of 17 and 62 and revealed themes of feeling different, wanting to fit in and finding safe spaces away from social or sensory overload (Ryan & Räisänen, 2008). This study echoed findings from earlier research, which consistently raises the issue of difference and not fitting in (e.g. Portway & Johnson, 2005; Stuart-Hamilton et al., 2009).

A recent meta-synthesis of 33 studies on lived experience of adults with ASC identified four themes (DePape & Lindsay, 2016). Adults with autism raised issues around identity in light of ASC, social interactions, experiences at school and factors relating to employment as important aspects of their experience.

1.2. Part II. Understanding Ageing

1.2.1 Definitions of ageing

Ageing can be varyingly defined but with respect to humans it may be considered as the process of becoming older (Akman, 2009). This encompasses both biological ageing of bodily cells as well as psychological and social ageing. A multitude of research has focussed on biological markers of ageing or investigations of cognitive changes and decline with age. For the purpose of this study, the focus will be on psychological and social ageing, including changes to the emotional landscape, perceptions of the world, interpersonal and social changes, and the subjective experience of growing older.

1.2.2. Theories of ageing

Numerous theories exist aiming to describe and explain the process of ageing. The focus here remains on psychosocial, rather than biological theories of ageing. The former situates individual ageing within social, cultural and historical contexts (Bengtson & Settersten, 2016). It is noteworthy that most of the theories have been developed in and apply to Western cultures and that the experience and perception of growing older may differ in other cultures or subcultures.

1.2.2.1. Erikson’s Stages of Psychosocial Development

Erikson’s theory of development is a model of psychosocial development across the lifespan. It includes eight distinct phases which describe psychological tasks that need to be mastered by an individual. The stages relating to middle and later adulthood are ‘generativity versus stagnation’ (ages 40-65) and ‘ego integrity versus despair’ (ages 65 and above) respectively. Later, Erikson’s wife Joan added a final, ninth stage where the tasks of the earlier stages are revisited (Erikson, 1998). The theory postulates that completion of each task results in acquisition of a basic virtue which adds to a person’s maturity and aids in the mastery of the subsequent stage. There is considerable research evidence for Erikson’s model, including for the latter stages (e.g. Hearn, Saulnier, Strayer, Glenham, Koopman et al., 2012).

1.2.2.2. Disengagement Theory

One of the first theories to attempt to explain social ageing, Disengagement Theory (Cummings & Henry, 1961) proposed that as people get older, they disengage from society and their links with the community are severed or weakened. This process can be initiated by the individual themselves, or by the wider society. However, this theory does not account for older people who remain actively engaged in their community, social life or even employment. Furthermore, evidence for this theory is describes as ‘inconclusive’ (Hochschild, 1975).

1.2.2.3. Activity Theory

Just as the Disengagement Theory suggests reduced activity and involvement in society accounts for some of the psychosocial phenomena observed in later adulthood so the Activity Theory of ageing (Maddox, 1963) proposes that to age successfully individuals must retain a level of meaningful activity beyond retirement. It suggests that a person’s self-worth is linked to the roles they fulfil and that new roles should be found to replace ones lost with age (e.g. through retirement, children leaving the home, etc.). Although evidence supports the notion that meaningful engagement increases quality of life (e.g. Low & Molzahn, 2007), the theory’s narrow focus on activity level perhaps misses aspects of ageing such as health and social belonging.

1.2.2.4. Selection, Optimisation and Compensation

A model which may be able to account for aspects of both the Disengagement and Activity Theories is the theory of selection, optimisation and compensation (Baltes, 1997). This lifespan development theory suggests that when faced with declining personal resources, older individuals will engage in re-evaluating and selecting appropriate goals and optimising processes to achieve these. This may involve reducing engagement in other, less vital activities, or practicing the skills needed for a particular task to optimise performance. Compensation refers to the use of alternative or compensatory strategies when original processes or skills are impaired. Considerable empirical evidence supports this theory as an explanation of processes in old age (e.g. Carpentieri, Elliott, Brett & Deary, 2017).

1.2.2.5. Dynamic Integration Theory

Labouvie-Vief (2009) proposed a model of ageing that addresses emotional regulation in later adulthood. It aims to integrate the opposing views and contradictory empirical findings which on the one hand suggest improved emotional wellbeing in older adults due to better emotional regulation (e.g. Carstensen, Isaacowitz & Charles, 1999) and on the other hand indicate that older individuals' emotional processing capacity is compromised with increasing age (Labouvie-Vief & Marquez, 2004). It thus includes and aims to integrate other models, including the social-emotional selectivity theory (Carstensen et al., 1999). The model suggests that older people develop compensatory mechanisms to manage challenges of this life stage or even develop highly adaptive strategies that result in emotional equilibrium which is the task of Erikson's (1985) eighth stage in life.

1.2.2.6. Convoys Model of Social Relations

Taking a more relational viewpoint is the Convoys Model of Social Relations. First described by Kahn & Antonucci (1980), it explains how cohorts of people growing up together provide feedback to each other in order to successfully master developmental tasks. The 'convoy' refers to close social relationships which surround the individual and provide a secure base for personal development. Although the model suggests that everyone needs convoys, or social relationships, it allows for individual differences by acknowledging that the amount and type of support needed by each person will vary according to characteristics and circumstances (Antonucci, Birditt & Akiyama, 2009). This interdisciplinary model acknowledges whilst social support systems can be described and categorised, the subjective experience of these may not always match the 'on paper' description. Empirical evidence supports the model's suggestion that social relations are important for health and wellbeing, including both mental (Antonucci, Fuhrer & Dartigues, 1997) and physical health (Vaillant, Meyer, Mukamal & Soldz, 1998).

In a later modification of the model, the role of social relationships as a buffer for stress was included which highlights how the negative impact of stress is smaller for people with stronger social networks. This is important when considering older people, who often have smaller social networks (Ajrouch, Antonucci & Janevic, 2001).

1.2.3. The experience of ageing

A full review of research relating to the experience of ageing is not within the scope of this thesis, thus, a brief overview is offered.

Wright-St Clair, Grant and Smythe (2014) noted that studies into the experience of ageing more generally, including those of neuro-typical individuals, are an important yet neglected area of research. A qualitative synthesis of studies available in the field reported the importance of social connectedness and independence in older people and highlighted that the elderly need to develop new strategies to balance the demands of dependence versus autonomy (Abad-Corpa, Gonzalez-Gil, Martınez-Hernandez, Barderas-Manchado, De la Cuesta-Benjumea et al., 2012).

In an interview study of UK elders, Woolhead, Calnan, Dieppe and Tadd (2004) reported three major themes including dignity of self, human rights and autonomy. The latter theme highlighted the importance older people place on independence and having control over their own lives.

Although little research exists exploring ageing with autism, some studies have investigated getting older with other neurodevelopmental conditions, such as ADHD. A recent Dutch study (Michielsen, de Kruif, Comijs, van Mierlo, Semeijn, et al., 2018) interviewed 17 people over the age of 65 with a diagnosis of ADHD. They noted themes relating to ADHD symptoms as well as ‘low self-esteem’, ‘overstepping boundaries’ and ‘feeling misunderstood’. Symptoms of ADHD were also reported to decline with age.

Similarly, Brod, Schmitt, Goodwin, Hodgkins and Niebler (2012) found that older people with ADHD were financially less well-off, had lower educational achievement and job performance, as well as increased social isolation due to their ADHD.

1.3. Part III: Participatory Research

1.3.1. Definitions

Participatory research (PR), sometimes referred to as participatory action research, community-based participatory research or co-production, is a ‘collaborative process of research, education and action’ (Hall, 1981) which challenges the traditional hierarchy of researchers and the ‘researched’ (Wadsworth, 1998).

PR has further been described as

> “a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview … [and bringing] together action and reflection, theory and practice, in participation with others in the pursuit of practical issues of concern to people, and more generally flourishing of individual persons and communities.” (Reason & Bradbury, 2006; p. 1)

As such, PR as a research paradigm places great emphasis on the value that those not traditionally included in the research process can bring to the design and completion of a study. It recognises that lay people and in particular experts by experience have valuable contributions to make to research. In fact, not including this knowledge and expertise in research risks omitting a central part of the studied phenomenon (Kindon, Pain & Kesby, 2007).

The aim is to empower ordinary individuals to become involved in the design, conduct, analysis and dissemination of research. Lay researchers, or 'experts by experience' are thought to bring fresh ideas, new perspectives and novel questions to the conceptualisation of research. Crucially, they are also thought to add social validation and authenticity to a study.

It is a more far-reaching and meaningful extension of service user involvement in research which facilitates a significant exchange between researcher and lay people. The outside researcher becomes integrated in the community which is being studied with the aim of creating a platform for equal and democratic decision-making, shared learning and collaborative analysis. The researcher is required to relinquish some control to become a facilitator of a shared process of knowledge acquisition.

Participatory research strives to "break the monopoly on who holds knowledge and for whom social research should be undertaken" (Kindon et al., 2007, p.11). It makes explicit efforts to work with marginalised or vulnerable groups.

1.3.2. Participatory research and autism

PR has been applied to numerous fields of study, including public health (e.g. Israel, Parker, Rowe, Salvatore, Minkler et al., 2005), domestic violence (e.g. Burke, Hess, Hoffmann, Guizzetti, Loy, Gielen, et al., 2012), supporting parents of children with learning disabilities (Walmsley & Mannan, 2009) amongst others. Few have used this approach to research with autism, although publications in this area have been increasing (Wright, Wright, Diener & Eaton, 2014). Published papers often report on using PR in educational or classroom-based autism interventions (e.g. Dymond, 2001; Asberg Zander, Zander, Dahlgren & Sandberg, 2012), or with assistive technologies (e.g. Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012) and tend to involve children or young people. Jones, Huws & Beck (2013)'s paper reports on data from a previous study which they re-analysed with a person with autism. To the author's knowledge, this is the only study that includes adults with autism as co-researchers. They also did not employ a full participatory framework, only including the person with autism in the analysis but note that this was useful.

PR research is a relatively new concept only slowly emerging in the published literature. It seems particularly sparse in autism research with little evidence of meaningful service user involvement or truly co-produced projects, despite the repeated calls for the voices of people with ASC to be included in the research process (Barber, 2015) and to recognise people with autism as experts with a key role in knowledge production (Milton, 2014).

1.4. Part IV. Systematic Review

1.4.1. Article Identification

Initially a search was conducted (appendix A) to review the qualitative literature on experiences of ageing with autism to offer a background to the present study. However, this search yielded only two empirical papers using qualitative methodology and addressing the subjective experience of growing older in the context of ASC (one found through systematic search, the other through snowballing). Hence, the search was widened to explore the experience of adults, whether younger or in middle adulthood, with autism. Papers which included adolescents as well as adults were also included if they met the other search criteria. The two papers on ageing with autism are reviewed separately from the main review.

A search was conducted across several databases including PsycINFO, PsycARTICLES, MEDLINE and CINAHL Complete, followed by a manual search of references using a ‘snowballing’ technique. To facilitate a focus on experiential narratives, results were narrowed to include only papers using a phenomenological approach, as used in the present project. This resulted in 86 papers, which was reduced to 44 papers published in peer-reviewed journals. Snowballing yielded no papers which had not been generated in the main search. These were abstract-screened, and papers excluded according to the exclusion criteria: data not from the perspective of the individual with ASC (carers, professionals), research topic specific to one area or intervention, participants not adults, participants not having primary ASD. This yielded a total of eight papers reporting on seven original studies which were included in the formal review. For full details of search terms used and results generated see appendix A.

Table 1. Summary of studies identified for systematic review.

No.	Study	Sample Size and country	Participants	Methodology	Data Analysis	Themes
1	Williams (2004)	10 Several	Males and females, high-functioning autism or Asperger's, ages not specified	Analysis of published auto-biographical accounts	IPA	1. Distance between self and other people 2. Inaccessibility of social and emotional cues for interaction 3. Coping strategies 4. Limited success of coping strategies
2	Huws & Jones (2008)	9 UK	Males and females, ASC, age range 16 – 21	Semi-structured interviews	IPA	1. Disclosure delay 2. Providing explanations 3. Disruptions and opportunities 4. Acceptance and avoidance
3	Punshon, Skirrow & Murphy (2009)	10 UK	Men and women, Asperger's Syndrome, age range 21 – 45	Semi-structured interviews	IPA	1. Negative life experiences 2. Experience of services (pre-diagnosis) 3. Beliefs about symptoms of Asperger syndrome 4. Identity formation 5. Effects of diagnosis on beliefs 6. Effects of societal views of Asperger syndrome
4	Griffith, Totsika, Nash & Hastings (2012)	11 UK	Males and females, Asperger's Syndrome, age range 37 – 57	Semi-structured interviews	IPA	1. Living with Asperger syndrome 2. Employment issues 3. Experiences with mainstream support 4. Future steps towards supporting adults with Asperger syndrome
5	Krieger, Kinebanian, Prodinger & Heigl (2012)	6 Switzerland, Austria, Netherlands	Males and females, Asperger syndrome, age range 32 – 45	Semi-structured interviews	Develop-mental and hermeneutic narrative approach	1. Social context 2. Cultural context 3. Physical context 4. Temporal context
6	Haertl, Callahan, Markovics & Strouf Sheppard (2013)	24 USA	Males and females, ASC, age range 27 – 55	Semi-structured interviews and focus groups	Phenomeno-logical (inductive and deductive analysis)	1. Receiving the diagnosis 2. Diagnostic effects on identity 3. Socialisation versus isolation 4. Education 5. Play/Leisure 6. Work 7. Social Participation

						8. Occupational Patterns 9. Need for services
7	Huws & Jones (2015)	9 UK	Males and females, ASC, age range 16 – 21	Semi-structured interviews	IPA	1. Changes over time: 'I'm really glad this is developmental' 2. Degrees of autism: 'They've got it really bad' 3. Degrees of ability: 'I'm not really disabled-disabled'
8	Lewis (2016)	77 USA	Men and women, ASC, age range 18 – 65	Open-ended online survey	Phenomeno-logical (Colaizzi's 1978 method)	1. I always knew I was different 2. Riding the emotional rollercoaster 3. Striving for self-acceptance 4. Strategizing towards a better life 5. Maintaining normalcy 6. Wandering into the future

1.4.2. Review Procedure

Thematic synthesis was used as described by Thomas and Harden (2008) and outlined by NHS Quality Improvement Scotland (2011). This method was selected as it allows flexible yet clear identification of themes (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005).

Primary studies were read and re-read and a list of themes produced. The list of themes was analysed and assessed for convergence and divergence. Related or overlapping themes were grouped together into superordinate themes using principles of content analysis. Minor themes were included if evident in at least two of the studies reviewed.

1.4.3. Critical Appraisal

The selected studies were assessed on quality using the Greenhalgh & Taylor (1997) and Critical Appraisal Skills Programme (CASP, 2002) tools for appraising qualitative literature. A summary of the critical appraisal can be found in appendix B. Some limitations were noted, such as few studies using triangulation. Similarly, only two studies reported using members checks for social validation and none included those with lived experience in a more substantial way, such as co-producing the research. Nonetheless, the overall quality of the studies was judged to be satisfactory for inclusion in the below review.

1.4.4. Findings from Systematic Review

It is noteworthy that there was considerable heterogeneity of papers despite a focus on studies of adults and on phenomenological approaches (see table 1). Study focus and research questions varied across the selected papers with some concentrating on experience more generally whilst others focussed on topics such as diagnosis (e.g. Punshon et al., 2009; Lewis, 2016), employment (Krieger et al., 2012) or support experiences (Griffith et al., 2012). Participant age ranged from some studies recruiting younger adults (e.g. Huws & Jones, 2008) and others including middle adulthood (e.g. Punshon et al., 2009). Methods of data collection varied including the use of semi-structured interviews (e.g. Griffith et al., 2012), online surveys (Lewis, 2016), focus groups (Haertl et al., 2013) and analysis of published autobiographical writings (Williams, 2004).

Despite this heterogeneity, attempts were made to synthesise the research outcomes. Through this process, five main themes emerged which included diagnosis, being different and self-identity, social difficulties, mental health difficulties, and coping and support.

The review synthesises the authors' interpretations of their own data. To illustrate certain themes however, direct quotes from participants have been included.

1.4.4.1. Theme 1: Diagnosis

All but one study addressed the topic of autism diagnosis in some way. Only Williams (2004) did not generate diagnosis as a specific theme which may be due to the different nature of the data used in her study. Nonetheless, this was a prominent theme, divided into five sub-themes; emotional reactions, providing explanations, mixed reactions from friends and family, misdiagnosis and self-acceptance.

Emotional reactions to diagnosis addressed the "emotional rollercoaster" (Lewis, 2016) which participants described on learning of their diagnosis in adulthood. This encompassed both negative and positive emotions. Huws & Jones (2008) spoke of both acceptance and avoidance whilst Lewis (2016) described denial as well as relief amongst her participants. Relief was echoed in Punshon et al.'s (2009) study, however they also told of anger and a sense of loss amongst their interviewees. Similarly, Haertl et al. (2013) reported both relief and an exacerbation of feeling different to others. The conflicting emotions related to receiving a diagnosis were highlighted by one of Lewis's (2016) participants:

> *"I had to go through a mourning period, as I thought I was a unique individual because I was different, but it all seems to be autism that made me think/behave this way'."*

Participants in most studies (Huws & Jones, 2008; Punshon et al., 2009; Krieger et al., 2012; Haertl et al., 2013; Lewis, 2016), reported that receiving a diagnosis provided an explanation for difficulties they had previously struggled to make sense of.

> *"Irrespective of when the diagnosis was disclosed [ ], knowing that they had autism enabled participants retrospectively to develop an understanding of previous life events."* (Author, Huws & Jones, 2008)

This sense of there being an explanation for their difficulties was also experienced as a removal of blame.

> "*I got the letter saying that I had Asperger syndrome, it was a bit like standing up in court and hearing the jury say 'not guilty'."* (Participant; Punshon et al., 2009)

Misdiagnosis prior to receiving an autism label was common (Punshon et al., 2009; Krieger et al., 2012; Haertl et al., 2013; Lewis, 2016) and related unsuccessful treatments reinforced negative beliefs about the self.

Two studies described a process of re-evaluating own sense of self leading to self-acceptance following diagnosis (Krieger et al., 2012; Lewis, 2016), a theme which linked to the second higher-order category.

1.4.4.2. Theme 2: Being Different / Self-identity

Difference was discussed in one form or another by participants of all studies. However, the way difference was described varied somewhat across studies. Haertl et al. (2013) described a psychological paradox of participants feeling different yet wanting to fit in. This sense of feeling different to other, non-autistic people was further illustrated by Williams (2004) who described a "gap between themselves which is unbridgeable" (p. 709). A desire to be 'normal' was reported by some (Punshon et al., 2009). Punshon et al.'s study also described a process of social comparison where participants would compare themselves to other people with autism, people with other conditions or with disabilities, or to neurotypicals. This seemed to serve a purpose of participants positioning themselves in relation to others and of defining their own identity.

Areas where description of difference did overlap were grouped into minor themes including positive and negative views of difference and ability versus disability.

For most participants, a sense of being different had always been in their life.

> *"Since I was a little kid, I always wondered why am I different and why are people looking at me as being different [ ]"* (Participant; Haertl et al., 2013)

Difference was conceptualised as positive by some participants and some highlighted their own abilities in comparison to others.

> *"I knew I didn't think like others, but knew I was, in many ways, superior to them"* (Participant; Lewis, 2016)

Despite some positive views, negative voices regarding being different were also noted by some who experienced their autism as limiting.

> *'I wished that I'd never had autism because it stopped me doing that [engineering] and what everyone else was doing'*
> (Participant; Huws & Jones, 2015)

A number of participants viewed ASC as a disability whilst others felt it was not a disability and highlighted their own strengths and abilities.

> *"They did not necessarily see this as a disability, but instead saw the challenges and advantages of having a different personality."* (Author; Krieger, et al., 2016)

Others however, spoke about it as a *"mental disability"* (Huws & Jones, 2015), albeit not as severe a one as other, physical disabilities.

This discrepancy between ability and disability, or degrees of disability, was illustrated by one paper

> "*Although autism was described by all participants as a type of disability, it was also perceived as being different and not as severe as the disabilities that some other people had. Having autism meant that only a degree of disability was held."* (Author; Huws & Jones, 2015).

A number of accounts related to making social comparisons both within the autism community and with neurotypical people. This was particularly evident in participant reports from Huws & Jones's (2015) study.

> *"He's worse than what we've got. (Jemma)*
> *I understand more than them. (Joshua)*
> *I'm not as bad as the others here. (Clare)*
> *I've improved more than everyone. (Darren)"*
> (Participants; Huws & Jones, 2015)

1.4.4.3. Theme 3: Social Difficulties

All but two studies (Huws & Jones, 2008; Huws & Jones, 2015) explicitly discussed difficulties in social interactions and relationships. The varying accounts were synthesised into five sub-themes of the enigma of social interactions, withdrawal and avoidance, bullying and experiencing distance.

The enigma of social interactions, or finding interpersonal relationships puzzling, was expressed by participants of three studies (Williams, 2004; Griffith et al., 2012; Lewis, 2016). They described finding conversations, social occasions and human interactions mysterious or somewhat out of reach. This was exacerbated by difficulties of picking up social cues.

> *"Humanity is basically nothing but an enigma to me"*
> (Participant; Williams, 2004)

Withdrawal and avoidance from social situations were consequences of social difficulties for many participants, or were used as a mechanism for managing social demands.

Bullying by both friends and family was experienced by the majority of participants and some described internalising the negative comments received, thus negatively impacting on their self-worth.

> *"Many described painful experiences of being bullied or teased as children and found it a challenge to form friendships and romantic relationships."*
> (Author, Haertl et al., 2013)

These negative experiences led to a general feeling of distance from others, highlighting a sense of being removed from others, or on the periphery of a group.

> *"One of the best ways of understanding what autism is like is to imagine yourself as a perpetual onlooker."* (Participant; Williams, 2004)

1.4.4.4. Theme 4: Mental Health Difficulties

A less prominent theme, but raised by three studies (Punshon et al., 2009; Griffith et al., 2012; Lewis, 2016), was that of mental health difficulties related to experiences of autism. This was divided into two sub-themes of mood difficulties and internalised criticism.

Experiencing mood swings, depression and anxiety was described by some participants who felt these difficulties were related to their autism.

> *"I become very easily depressed and that is because I have Aspergers – because I haven't got the protection"* (Participant; Griffith et al., 2012)

These were severe at times, even leading to suicidal ideation.

> *"Self-reported depression and anxiety were very common in this sample, and two participants mentioned that they had considered or attempted suicide."* (Author; Lewis, 2016)

Bullying and negative attitudes in society towards autism affected some participants' self-worth as they internalised criticism and insults, which exacerbated mental health difficulties.

> *"I had nearly believed it myself [that I was stupid]"* (Participant; Krieger et al., 2012)

1.4.4.5. Theme 5: Support and Coping

The final theme which emerged during synthesis addresses the topic of coping with autism-related difficulties and support around these. Four sub-themes were identified, including formal support, difficulties accessing services, work and coping strategies.

Some of the studies highlighted participants' desire for formal support around their autism. This was in the shape of practical support or emotional support, often to process the impact of diagnosis.

Accessing the right support was described as challenging and mainstream services were not felt to be catering for difficulties specific to autism.

> *"I just fall through the gaps between departments [ ] I just don't fit in anywhere"* (Participant; Griffith et al., 2012)

The sub-theme of work encompassed participants' desire for meaningful employment. However, current or past employment had been challenging for some, including difficulties with supervisors and finding social aspects of work life hard. Some voiced that adaptations at work would help but felt unable to ask for modifications to be made by employers (Haertl et al., 2013).

The final sub-theme addressed coping strategies to manage difficulties around autism.

> *"Most of the writers comment on the fact that they had consciously set about devising explicit strategies designed to help them negotiate social situations in the absence of social intuition."* (Author; Williams, 2004)

Participants described finding skills training useful and reported developing tools and strategies which helped to navigate social situations.

However, these new skills did not always work, and participants described the limits to their coping strategies, including failure of strategies in new situations and a difficulty generalising.

> *"Despite their efforts to mask their difficulties, most soon realised that this was unsuccessful"* (Author; Punshon et al., 2009)

1.4.5. Phenomenological considerations

This review focussed on studies using a phenomenological approach to data collection and analysis, to the exclusion of other methodologies. This remit was applied to highlight experiential narratives of people with autism. Additionally, the double hermeneutic principle which is central to phenomenological approaches, offers a deep level of analysis which was felt to be a relevant way of accessing reflections on lived experience. Although not formally reviewed, studies using other qualitative approaches such as thematic analysis or grounded theory have been considered to comment on comparisons between results of the different epistemological stances.

There seemed to be no overarching differences in themes generated from studies using varying approaches. For instance, a study using constant comparative method of analysis (Ryan & Räisänen, 2008) generated themes which suggested that participants were engaged in a process of reflecting on and interpreting their own experiences. Similarly, Hurlbutt & Chalmers (2002) reported on experiential aspects of the lives of three adults with autism without using a specified phenomenological approach.

In some studies which did not use a phenomenological approach, this differing epistemological stance and related chosen method of analysis was felt to impact on results however. These papers (e.g. Ruef & Turnbull, 2002) generated themes relating to specific practical approaches including environmental dislikes, or thoughts on particular interventions. Whilst valuable, these studies gave less of an insight into what life is like for the individual and thus highlight the usefulness of phenomenological approaches in addressing those aspects.

1.4.6. Summary

The systematic review identified eight papers addressing the experience of ASC in adulthood using a phenomenological framework. Heterogeneity of study focus and data collection resulted in some challenges in synthesising study findings. Nonetheless, five superordinate themes relating to the experience of autism in adulthood were identified. Diagnosis was a pertinent issue, perhaps in part as most participants only received a diagnosis in adulthood, with associated impacts on their view of self and identity. Social difficulties and challenges in interpersonal relationships were also common. These experiences resulted in mental health difficulties for some. However, more positive themes of coping were also noted, despite a lack of suitable support services.

1.5. Part V. Ageing with Autism – the research picture to date

1.5.1. Ageing in Autism Research

In their review Wright, Brooks, D’Astous & Grandin (2013) note an increase in published papers on ASC in adulthood and ageing in the preceding five years, however, they also highlight that this represents a small proportion of the overall research interest in the autism domain. Of those papers published addressing autism in adulthood, fewer still address later adulthood. In their review of funding priorities in autism research, Pellicano, Dinsmore & Charman (2014) note that lifespan issues were the least well-funded areas of research with studies in domains such as biology and cognition receiving the most money.

In line with this, the first papers published on the topic of autism in late adulthood addressed the biological and cognitive aspects of the ageing process rather than subjective experiences (Pellicano et al., 2014). Early papers presented case studies (James et al., 2006) and focussed on diagnosis in old age (e.g. Naidu, James, Mukaetova-Ladinska & Briel, 2006), perhaps prompted by older people presenting in diagnostic clinics who had not received a diagnosis earlier in life. They may have evaded diagnosis due to ASC not being a diagnostic category, or not being widely understood, when they were children. Other studies are largely quantitative, employing methodologies such as surveys and analysis of demographic data, and focussed on areas ranging from prevalence of behaviour problems and comorbidity (Totsika et al., 2010) to quality of life (Stuart-Hamilton & Morgan, 2011). Some cross-sectional or longitudinal studies have followed individuals from childhood through to adulthood (although often not into later adulthood).

Results of studies on outcomes, quality of life and cognitive profiles of older people with ASC vary widely and it may be too early to draw definite conclusions. Some research suggests that outcomes are poor for adults with ASC when compared to non-autistic individuals in regards to impaired physical and psychological functioning as well as reduced quality of life and social outcomes (Happé & Charlton, 2012). Howlin, Moss, Savage & Rutter (Howlin et al., 2013) looked at elderly individuals specifically and found that the majority showed ongoing difficulties with romantic relationships and employment. A significant minority also showed declining IQ, language skills and psychological functioning (Howlin et al., 2013). However, Magiati, Tay & Howlin's (2014) review states that outcomes in ASC in adulthood are variable across studies and conclude that social functioning, cognitive and language skills are relatively stable over time. They further describe that adaptive functioning and behavioural symptoms of autism appear to improve with age and note that childhood IQ and language ability predict outcomes in adulthood. Some suggest that brain maturation and increased adaption, such as the acquirement of social skills, could result in reduced symptomatology and associated difficulties (Povey, Mills & Gomez de la Cuesta, 2011).

Van Heijst and Geurts (2015) conducted a meta-analysis and empirical study on quality of life in autism across the lifespan. They concluded that quality of life is considerably lower in people with ASC compared to those without ASC and this is so throughout the age groups. However, this finding was independent of age. They also note, that the focus of quality of life research is on younger adults with autism and that research attention should focus on the elderly.

Perkins and Berkman (2014) in their review of the literature on ageing with ASC concluded that growing older with autism presents considerable challenges, but that positive outcomes are possible.

Little research exists in relation to cognitive changes of ageing in people with ASC (Mukaetova-Ladinska, Perry, Baron & Povey, 2012). Some hypothesise that as cognitive profiles of autism are similar to those of normal ageing (e.g. executive functioning difficulties, episodic memory impairment; James et al., 2006), the impact of ageing may be less strongly felt in those with ASC (Mukaetova-Ladinska et al., 2012). Others propose that this could result in a ‘double jeopardy’ for those with autism (Geurts & Vissers, 2012; Piven & Rabins, 2011). A recent study found that executive functioning may be preserved in older adults with ASC in contrast to neurotypical individuals and thus suggests that ASC acts as a protection to later cognitive decline (Roestorf & Bowler, 2016) although it may be too early to draw definitive conclusions. Similarly, changes in social cognition can thus far only be speculated upon. Happé and Charlton (2012) suggest that there may be age-related decline in social cognition which could worsen interpersonal difficulties seen in ASC when those affected reach old age. However, others suggest that older people with autism may be demonstrating increased understanding of social situations thus leading to better functioning (Wright et al., 2013).

Some have argued that symptoms commonly experienced in later life may have especially significant effects on people with ASC (Piven & Rabins, 2011). For example, age-related sensory impairments may particularly affect people with ASC who have existing sensory perception difficulties. Similarly, motor difficulties experienced as part of ASC could be compounded with frailty and movement-related changes in old age. Thus, qualitative research on symptomatology seems largely inconclusive with varying hypotheses still unanswered. The research picture to date therefore illustrates a need for further research to truly build a picture of ageing with autism.

1.5.2. Qualitative Studies of Ageing in Autism

To the author’s knowledge only two papers have been published offering a qualitative analysis of the subjective experience of ageing with autism. Elichaoff (2015) presented a scoping study using thematic analysis on how ageing affects the individual’s experience of their autism. She interviewed four participants aged 58 to 63 with a diagnosis of ASC. The analysis generated six themes including the effects of diagnosis, depression, experiences with mental health professionals, the inverted relationship between educational level and lack of career, the participant as autism expert, and communication/social interactions. Positive effects of getting a diagnosis were highlighted, despite some regret of not receiving this earlier in life. Depression appeared to be common and some participants related this to the difficulties associated with their autism. Relatedly, contact with mental health services and professionals was oftentimes frustrating and resulted in feeling misunderstood. Consequently, participants wanted to be seen as experts and be included in the training of professionals. Difficulties in employment were recounted with a clear mismatch between individuals' educational level and career standing. It is widely-reported that adults with ASC struggle to find significant employment which is well-matched in terms of vocational ability (e.g. Taylor & Seltzer, 2011). Work, as well as friendships and other relationships, were negatively impacted by social and communication difficulties. The themes generated with this age group are similar and comparable to those with younger adults and adolescents, and perhaps surprisingly no age-specific themes emerged. This might suggest that age is not a significant factor which impacts on an individual's conceptualisation of their ASC.

These findings were echoed by a more recent study (Hickey, Crabtree & Stott, 2018) where 13 older individuals (ages 51 to 71) with autism were interviewed. Their study too used thematic analysis and identified three overarching themes; difference, life review and longing for connectedness. Diagnosis, which occurred in adolescence or adulthood for these participants, appeared to offer a lens through which to review and make sense of past experiences. The theme of life review, which included 'understanding the past', 'externalising autism' and 'self-acceptance' as sub-themes, appears to have a greater focus on the process of growing older than Elichaoff's paper. Nonetheless, Hickey et al.'s themes also echoed findings from qualitative research with younger adults with autism, thus suggesting that many experiences may be similar, and difficulties may be maintained across age groups.

1.6. Part VI. Focus of the present study

1.6.1. Gaps in the current literature

As the above summary of research and policy illustrates, ageing with autism is a relatively new field of research with papers only emerging in the past decade. Despite ASC considered to be lifelong and pervasive conditions, most research has focussed on children and adolescents (James et al., 2006) and individuals in middle adulthood (e.g. Griffith et al., 2012). However, Wright et al. (2013) stress that "autism does not have an age limit" (p. 25). Simply translating findings from research on younger people with autism to those in older age brackets is problematic (Geurts & Vissers, 2012) as symptoms, life experiences, social systems and cognitive profiles may differ. Portraying ASC as purely a childhood disorder denies these conditions to be considered across the lifespan and is "detrimental to current and future autistic adults" (Tan, 2018, p. 162). Numerous authors have identified that little research exists which addresses how ASC affect individuals as they reach adulthood and beyond (Mukaetova-Ladinska & Stuart-Hamilton, 2016; Barber, 2015; Kats, Payne, Parlier & Piven, 2013). It has been described as a "barely researched topic" (Happé & Charlton, 2012; p. 70) and is said to be "under-investigated and poorly understood" (Mukaetova-Ladinska et al., 2012; p. 116). Barber (2015) added that the topic of transitions specifically, such as retirement, social care and end-of-life issues, is largely ignored in the research arena. Fombonne (2012) summarised "We know next to nothing about people aging with ASD".

In a survey of individuals with ASC, their relatives and health professionals to establish research priorities in the field of autism in the UK Pellicano et al. (2014) highlighted lifespan studies as one of the key research priorities in the area. They further reported disappointment of adults with autism that investigations have tended to focus on biomedical aspects of autism which they felt represented “neurotypical priorities regarding us – not autistic people’s priorities” (p. 760). This illustrates the discord between researchers and ‘the researched’ and provides a rationale for including those who the research is about in the design and process of studies.

Furthermore, Povey et al. (2011) noted that social implications of ageing with autism ought to be considered by research in the area. Since those papers were published, research has slowly been emerging on ASC in older adulthood. Yet, heterogeneity of these conditions, as well as small samples and changes in diagnostic criteria mean that it is still difficult to summarise what adulthood is like for the individual (Cottle, McMahon & Farley, 2016). More specifically studies which give voice to perspectives of people with ASC and which address ageing from a subjective experiential perspective are needed (Barber, 2015; Wright et al., 2013). In their paper on research priorities for older adults with autism, Piven and Rabins (2011) specifically call for descriptive phenomenological studies, amongst other research areas. Krieger et al. (2012) note that research which primarily uses the accounts of people with Asperger Syndrome is rare as individuals have been seen as unreliable and not able to use self-reflection to consider their difference in relation to others. Tan (2018) highlighted that perspectives from individuals with autism are critical to research around the lived experience of ASC. She notes that autism research frequently focusses on the views of the carer when the individual affected is unable to provide their perceptions, or is discredited. Nonetheless, there has been a small but growing body of literature which addresses the lived experience from the view of the individual (Jones, Huws & Beck, 2013) and these have contributed significantly to our understanding of autism.

With research giving voice to individuals with autism being scarce it is perhaps not surprising that even fewer studies are available which meaningfully involve those with lived experience in the research process. Some researchers have made use of member checks or involved individuals with autism in the development of interview questions (e.g. Punshon et al., 2009; Hickey et al., 2018). However, more formal and extensive involvement and co-production in research is only slowly gaining popularity. Huws and Jones re-analysed data from a previous study (Huws & Jones, 2008) with a secondary analyst on the autism spectrum (Jones, Huws & Beck, 2013) and reported that the inclusion of an expert researcher aided the interpretation of participant accounts. In a study of academic experiences, MacLeod, Lewis & Robertson (2014) employed a participatory action research framework which aimed to promote agency in research production. In testing this methodology with an autism population they concluded that despite some barriers to participation, co-researchers were committed to the research process and expressed a wish for active engagement. They highlight some of the challenges involved in using participatory methodologies with marginalised groups yet call for a wider yet considered application of such frameworks.

In summary, considerable gaps exist in research which offers insights into the subjective experiences of growing older with an ASC. In particular, research which facilitates service user involvement and participatory approaches have been largely lacking in the field, in particular with older people. Calls from academics in the area as well as from the autism community are clear in identifying person-centred research into ageing with autism as a research priority.

1.6.2. Aims and research question

The aim of this study is to explore the experience of older individuals with an autism spectrum condition, with a specific focus on interpersonal relationships. The study hopes to add to the emerging literature in the field which explores the person with ASC's own view of later adulthood and to do so with the active and meaningful involvement of those with lived experience of autism.

The research questions are:

1. How do individuals with ASC experience growing older in the context of their autism?
2. How do individuals with ASC experience and make sense of social relationships, interpersonal difficulties and connectedness in later adulthood?

Chapter II: Method

2.1. Chapter Overview

This chapter provides an outline of the rationale for choice of methodology used in this study by offering a discussion of epistemological and ontological considerations in light of the study aims. Theoretical aspects of the choice of methodology are discussed, followed by a reflexive statement of the researcher background and positioning.

The chapter further offers a detailed description of design and procedure of the study as well as ethical considerations. It concludes with plans for dissemination of research findings.

2.2. Research Paradigm

2.2.1. Epistemology and ontology

Epistemology is the theory of knowledge and is concerned with its scope, nature and structure (Goldman, 2004). Ontology refers to the question of what can be known about the world and there are several assumptions that can be applied such as relativist or realist. Based on the chosen ontological assumptions, epistemological positions can be taken which include positivism, post-positivism, critical theory, constructivism and realism (Guba & Lincoln, 1994). They are not discrete categories but can be conceptualised as a continuum (Lyons, 2007). These assumptions and positions thus place any enquiry within a philosophical stance of what can be known and how this knowledge can be achieved.

Phenomenological approaches tend to fall between the ‘realist’ and ‘relativist’ ends of the continuum, in that although experience is conceptualised as always the product of interpretation, and is therefore constructed, it is nevertheless “real” to the person who is having the experience. The philosopher Husserl’s emphasis on going back to ‘the thing itself’ where ‘the thing’ is human experience points the researcher to focussing on the lived experience, rather than the philosophy of this (Smith et al., 2009). The “truth” can therefore only be seen as an intersubjective perspective which is influenced by the social world around us (Finlay, 2003).

The philosophical stance of the present study adopts a realist ontology and a constructivist epistemology. It thus occupies a space within the critical realism domain which suggests that there is a real world, yet this can only be known through socially constructed processes.

The research paradigm of this study also draws on aspects of social constructionism in that it acknowledges that meaning can be jointly constructed through societal exchanges and shared assumptions of a social or cultural group (Gergen, 2001). Although the focus of the research is on individual meaning-making social processes, societal 'truths' for example about difference or normality and jointly constructed realities are believed to be influencing individuals' own meaning-making. Constructionist approaches thus emphasise the discovery of patterns and meanings over any possible universal truths (Madill, Jordan & Shirley, 2000). These meanings are co-constructed through interactions in the world, and are influenced by personal, historical and socio-cultural contexts (Gergen, 2001).

Like most qualitative research, this study thus does not seek to, or believe it possible to, find or measure a 'truth'. Instead it aims to explore, describe and make meaning of individuals' experiences and their meaning-making.

2.3. Qualitative Framework

2.3.1. Choice of method

Several qualitative methods of analysis were considered for this study, primarily thematic analysis, narrative analysis and Interpretative Phenomenological Analysis (IPA).

Thematic analysis (Braun & Clarke, 2006) is a widely-used method in qualitative research which focusses on identifying patterns or themes in the data. Critics argue that its focus on frequency of content can be to the expense of deeper, more interpretative analysis (Biggerstaff, 2012). With the current research study aiming to capture participants' lived experience and their meaning-making of this, thematic analysis was not selected as a suitable method.

Narrative analysis involves listening to people’s stories (Sarbin, 1986). It has a phenomenological aspect in that it looks for meaning in these stories whilst also placing emphasis on language and discourse and the use of such stories (Biggerstaff, 2012). Whilst this methodology could have been a useful approach for the current study, a more specific focus on phenomenology was desirable.

IPA (Smith, Harré & Van Langenhove, 1995) was developed as a method to explore idiosyncratic experiences in depth. IPA emphasises the process of meaning-making undertaken by persons in context and also embodied. It is interested in a person’s reflections of their life experiences and aims to capture these through an interpretative endeavour with the researcher (Smith, Flowers & Larkin, 2009). IPA has a specific focus on individual experience and does not aim to generalise from the specific in order not to take away from the idiosyncrasies of personal lives. It therefore sees value in studies with small samples, or even single-participant case studies. IPA has been described as a ‘bottom-up’ approach in that it creates themes from the data rather than using pre-existing themes.

Transcripts are coded in considerable detail, with the focus shifting back and forth from the key claims of the participant, to the researcher's interpretation of the meaning of those claims (Smith et al., 2009). Staying close to the raw data is crucial so that the participants’ meanings and experiences are not lost in a process of amalgamation for analysis. There is also an acknowledgement that the researcher’s own personal and professional background, their theoretical stance and world view influences the analysis. In order to make use of this personal aspect without losing transparency and rigor, IPA identifies reflexivity as a key aspect of the approach.

IPA is frequently used for research questions that aim to understand what a given experience is like (phenomenology) and how someone made sense of this (interpretation). The aim of the current research was to explore what growing older with ASC is like for the interviewees and how they interpret and make sense of their experiences. As such, IPA was deemed a suitable methodology to achieve those research aims.

2.3.2. Theoretical underpinnings of IPA

2.3.2.1. Phenomenology

Phenomenology refers to the study of experience. It is interested in what a given person's experience is like. Introduced by the philosopher Husserl and further developed by Heidegger, it emphasises the essence of experience which should be examined on its own terms without the influence of previous theory or preconceptions (Smith et al., 2009). Husserl stressed the importance of first-order personal experience and paved the way for the structured examination of participants' lives as done in IPA. Heidegger built upon his teacher Husserl's work and introduced the concept of interpretation of people's meaning-making which is now central to IPA (Smith et al., 2009).

2.3.2.2. Hermeneutics

Hermeneutics refers to the philosophical theory of interpretation. IPA's hermeneutic stance is one of inquiry and meaning-making. It has in fact been described as 'double hermeneutic' (Smith & Osborn, 2003). This refers to a double interpretation where the participant interprets their experience and the researcher interprets this interpretation. In philosophical texts this is described as a 'hermeneutic cycle' which emphasises the dynamic relationship between the minute and the whole and suggests that in order to understand the wider picture and context, one must understand the smallest parts (Smith, 2007). There is an acknowledgement within this approach that the researcher can only access the participant's experience through what the participant themselves reveal, which is their own interpretation. This is a unique aspect of IPA and a way of differentiating it from other qualitative approaches, some of which may be more descriptive.

2.3.2.3. Idiography

Similarly to Heidegger's emphasis on understanding the part to understand the whole, idiography places its focus on the particular (Smith et al., 1995). This has been adapted by IPA in regards to studying a particular individual's experience in a particular context, as well as promoting a depth of experience at the individual and particular level.

2.3.2.4. Epistemology and ontology of IPA

Shinebourne (2011) described IPA as lying on the 'light end of the social constructionist continuum' as it has an experiential focus but also includes aspects of discourse analysis which pays attention to the linguistic and cultural construction of meaning (Eatough & Smith, 2008).

IPA is counter to positivist thinking in that it assumes that there is not 'one truth' but rather that what we know as 'truth' is only ever an interpretation of the observer. Thus, what interview participants say needs to be interpreted for meaning-making but can be regarded as 'their truth' (Smith & Osborn, 2004) hence making it very subjective. The 'truth' therefore depends on who interprets it.

IPA explores in depth the personal experiences of an individual and the idiosyncratic meaning-making of these experiences (Smith, 2007). IPA understands meaning-making as a process of interpretation which is shaped by an individual's social, cultural and historic context (Shinebourne, 2011) thus incorporating aspects of social constructionism and systemic theory. Although IPA aims to see experiences from the participants' perspectives, it also acknowledges the researcher's interpretation of the data. It makes this interpretation an integral part of the analysis process and celebrates it in terms of the benefits it brings (Shinebourne, 2011). IPA thus does not aim to find a generic 'truth' but rather strives to use the participant's and the researcher's interpretations of an experience to explore this.

Furthermore, IPA applies 'symbolic interactionism' (Eatough & Smith, 2008) which states that individuals act in relation to the meaning they make of things and events around them and that such meaning also emerges through social interactions (Blumer, 1969). This concept suggests that meaning is constructed; idiosyncratic whilst influenced by social interactions. It thus endorses social constructivism ideas that social, cultural and historic context shape how individuals interpret their life and the world around them (Eatough & Smith, 2008). Consequently, it sits halfway between experiential and discursive approaches.

2.3.3. IPA in this study

Although traditionally used to explore topics of health and illness, IPA has also been applied to questions around life transitions and identity (Shinebourne, 2011). Ageing and retirement fall within the 'life transition' domain and identity formation and re-formation is widely documented in regards to living with autism (Davidson & Henderson, 2010; Bagatell, 2007).

IPA's focus on idiosyncratic experiences maps well on to the current study's aims of exploring the lived experience with older people with autism. The phenomenological focus of this approach will allow a detailed examination of participants' lives. Its emphasis on hermeneutics and the hermeneutic cycle will enable the researcher to investigate the meaning-making of participants in terms of their autism, identity, life stage and transitions. The acknowledgement within hermeneutics that bracketing off preconceptions, professional stance and theories is difficult, and IPA's specific encouragement of interpretation, fit with the researcher's own theoretical stance. Lastly, idiography inherent in IPA allows the detailed study of the particular and enables studies to make meaningful contributions even where studied populations are small and difficult to recruit from (Smith, 2007).

As such, the current study's aims, as well as the researcher's own ontological leanings provided a good fit with IPA, which was thus selected as the most suitable method for the present study. The participatory framework employed in this study also complemented this philosophy.

2.4. Participatory Research

Participatory research (PR) is a research framework which has been adapted as a key paradigm for the current study. PR aims to meaningfully and equitably involve the communities studied in all aspects of the research process and making 'the researched' into 'co-researchers'. Central to PR is the premise of democratic working between parties involved (Wadsworth, 1998).

In regards to epistemology, PR aims to contest the traditional idea that an objective truth can be measured by professionals in academic institutions which are purposefully removed from the general population on lay people (Wadsworth, 1998). PR recognises and promotes the plurality of knowledge and argues that this can be found in a variety of settings which are not solely academic.

PR positions itself away from positivist traditions and within a social constructivism paradigm which allows multiple interpretations of the same phenomenon made by both researchers and participants (Greenwood & Levin, 1998).

Furthermore, PR is distinguished through a commitment to democratic and non-coercive research (Pratt, 2000). It thus does not prescribe to a specific research method or means of data collection; instead it allows for democratic discussions and decisions to agree a research methodology that is meaningful to the research question as well as the members of the PR group. It sees participants as competent and reflexive agents who are capable of contributing to all parts of the research process. Diverse experiences and opinions within a community are regarded as an opportunity for exchange, learning and to enrich the research process (Kindon, Pain & Kesby, 2007).

A key aspect to PR is reflexivity where both researcher and participants reflect on the skills they bring as well as their prejudices and limitations. This reflexivity complements that of qualitative methodology generally and IPA more specifically in that meaning-making is conceptualised as a subjective yet transparent process.

2.5. Reflexivity

As with most qualitative research methodologies, IPA views reflexivity as an integral part to the research process (Smith et al., 2009). With a particular focus on hermeneutics, and an encouragement of bringing the self into the meaning-making cycle, IPA places specific emphasis on this. One of the key aspects to judging the quality of qualitative research, including IPA, is to consider the level of reflexivity in the study (Greenhalgh & Taylor, 1997). The analysis in particular requires a high level of self-reflection, honesty and ability to consider one's own impact on the study design, completion and analysis. Relevant characteristics and personal details of the researcher need to be considered in regards to the material and the ontological stance of the research (Finlay, 2003).

In order to facilitate continued self-reflection, the researcher kept a reflective log from the conceptualisation of the study to the end (appendix C). This allowed all stages of the research to be thought about in light of the researcher's own background and assumptions. It also provided a record of personal and professional development over the course of the research.

2.5.1. Researcher background

Simply by being a person with my own lived experience, I am not an objective observer but rather an involved clinician/researcher with my own history, prejudices and assumptions.

I am a white female 32-year-old trainee clinical psychologist and completed this research as part of my doctoral training. I was raised in Germany with a German mother and British father. I do not have a diagnosis of ASC and do not self-identify as having ASC; however, I believe in the spectrum nature of autism and thus feel we all lie somewhere on the spectrum of autism characteristics. Similarly, I am not an older person and there was a considerable age difference between myself and the participant group. Nonetheless, I have ageing parents and have experience of older people both personally and in my professional work. It could also be argued that we are all ageing and thus I have experience of progressing through life's stages and maturing with advancing age, albeit not yet having reached older adulthood.

I had no experience of ASC personally or professionally prior to embarking on this project. My main experience prior to training was with older people and the focus on experiences of ageing was what attracted me to the project. I had close relationships with my grandparents whilst they were alive, and have also always enjoyed working clinically with this age group. In my experience this group comes with a range of stories, with resilience and a wealth of understandings which I have always found fascinating. I also have a general interest in the lived experience of people, their narratives and how they make sense of their world, which is what attracted me to training to become a psychologist.

As well as having little experience of direct working with people with ASC, I feel I understood little about their autism-related difficulties and what their lives may be like. On reflection I feel I probably held some of the many preconceptions about autism which are rife in the general public. For instance, I was unsure how I could build rapport with someone who supposedly struggled with interpersonal communication and social skills such as eye contact. I did not know how much people who apparently have difficulties with social imagination and Theory of Mind would be able to reflect on their lives. Even before my interviews, when working with my group of participatory researchers, some of these preconceptions were challenged. I found the group members incredibly engaging socially and certainly to be thoughtful and reflective when thinking about our research project. Similarly, I was surprised during interviews how much self-awareness and reflection participants showed and how rich the resulting data was.

The interview experience was nonetheless an unusual one, perhaps for me as well as my participants. For me, the experience of me asking questions and them offering detailed accounts of their personal, private lives is perhaps comparable to a therapy setting where I often find myself in as part of training to be a psychologist. However, the felt sense was profoundly different. I knew participants were there for a different reason. I needed something from them, and although they had offered their services so to speak by volunteering to take part, I nonetheless felt like I might be taking advantage, of harvesting their knowledge, insights and narratives for my own personal gain (a doctoral thesis). Unlike in a therapy setting, where I hope to be able to offer some help, relief or at least a non-judgemental space, I felt I was offering participants little for their time. The £15 voucher they were offered as a means of reimbursement seemed somewhat tokenistic. As a result of this 'researcher guilt' I perhaps felt even more motivated to do my utmost best in trying to tell a meaningful story from their experiences, and one which will hopefully be useful in some way. I feel this is the least I can do to repay my debts.

I wonder how participants reflected on the experience of the interviews. Whilst some had previously partaken in qualitative research, such a setting was likely still alien to them. Although the structure may have helped, some anxieties about social settings might have been raised nonetheless. It is important too to reflect on the interpersonal difference, which may or may not have played on participants' minds. I am young, female and in a professional career, characteristics which visibly set me apart from the participants. At the time of conducting the interviews I was also pregnant. Although perhaps not obvious to all, I wonder if some participants did notice. Interestingly, nobody commented on it. If people did notice, I wonder how this might have possibly increased the difference between us, especially as most did not have children of their own, and perhaps had never had the option of starting a family due to difficulties in building intimate relationships. It is possible that this difference mirrored, brought to mind or even exacerbated participants' feelings of otherness, a theme that came up in all interviews. I do not believe that the theme would not have come up if I had had fewer outward similarities to the participants, but it is useful to reflect on how it may have primed participants' minds, or provided perceived space, or denial of space, for particular topics.

2.5.2. Researcher position

Prior to embarking on this project, I regarded myself as a clinician rather than researcher. This will have influenced my choice of methodology in selecting a qualitative design which allows for greater exploration of subjective meaning-making with some similarities to a therapeutic encounter. Particularly my choice of employing a participatory framework I feel is a reflection of this self-identity as not a researcher. It placed me in the role of non-expert which fitted with the participatory ideology of mutual exchange and learning. It allowed me, within the constraints of a doctoral research project, to be open to the participatory researchers' input rather than being wedded to particular research processes and procedures.

Ontologically I feel that I lean towards a relativist position in that I have not aimed to find an absolute truth with this study, but rather wish to show each participant's individual truth, or their perception of their truth at that particular moment in time. I believe their individual truth to be idiosyncratic and influenced by their personal beliefs, culture and experiences. This fits with the way I work clinically where I acknowledge and work with many rather than a single truth, using different therapy models and continuously reviewing formulations to see if ‘the truth’ still fits.

Before commencing this study and hearing my participants’ voices as well as reading more critically around the topic of ASC, I never questioned it as a concept and diagnosis. However, whilst not entirely rejecting the idea and its associated label, I have begun to view ASC much more critically, taking influence from the neurodiversity movement for instance. This view is likely to have flavoured my analysis and write-up of the study.

2.6. Participants

2.6.1. Inclusion criteria

Individuals over the age of 55 and with a diagnosis of ASC, or who self-identify as being on the autism spectrum, were eligible to take part. This age was selected as other studies in the field have used this cut-off (e.g. Elichaoff, 2015) and as in the autism literature individuals of 50 years and above are often considered older adults. Choosing this age was thought to allow effects of growing older to be captured whilst ensuring sufficient participants could be recruited.

Due to the nature of conducting an interview study inclusion criteria also encompassed the ability to speak English, sufficient verbal communication skills to take part in an interview and ability to tolerate an interview setting.

2.6.2. Exclusion criteria

Individuals with severe autism who are non-verbal or struggle to communicate, ASC with an intellectual disability and/or who are considered to lack capacity to consent were excluded. As a result, participants had high functioning autism or Asperger's Syndrome, rather than more pervasive conditions. These individuals, particularly if not diagnosed until later in life, are often missed by services and research.

2.6.3. Sampling

Purposive sampling was employed in keeping with suggestions when conducting IPA research (Smith et al., 2009). The aim was to recruit participants through a specialist NHS ASC service with clinicians approaching eligible patients or contacting them by post. The study was also advertised on the Trust's research website with information on how to contact the researcher to volunteer to participate.

Four third Sector organisations in London and East Anglia were also approached to identify potential participants and distribute the Participant Information Sheet (see appendix H) to their members. Three did not respond to the request but the third passed information on to its members. Eligible members were able to contact the researcher directly by returning the slip to participate.

The researcher also attended several meetings of one particular third sector ASC support group where she talked about the study and interested individuals were able to come forward and speak to her about the study. Of those who approached the researcher for further information, seven agreed to take part and two declined.

The aim was to recruit 15 participants, with a minimum of ten individuals agreeing to participate and complete the study. Smith et al (2009) highlight the advantages of using a small sample when conducting IPA research. They argue that it allows depth rather than breadth in data. IPA's idiographic focus does not aim to generalise but capture the specific experience of the particular, thus smaller participant numbers are regarded to be sufficient providing rich and in-depth interview data can be obtained.

See results section for recruitment outcomes.

2.7. Design

The study used a qualitative design as previously outlined and also employed a participatory research framework.

2.7.1. Participatory research framework

The study used a participatory research design to offer a framework for meaningful expert-by-experience inclusion and co-production in an effort to challenge traditional research methods and create an equal and non-hierarchical research partnership (Coupland, Maher, Enriquez, Le, Pacheco et al., 2005). The researcher approached several third-sector autism organisations in London and East Anglia to search for volunteer researcher. To the researcher's knowledge two of the organisations disseminated the call for volunteers amongst their members. The researcher also attended a support group meeting for people with ASC in London. Three individuals came forward at this meeting to volunteer to become participatory researchers and form a research advisory group for the study. A further person contacted the researcher after hearing about the study through a local organisation, and offered her support as a participatory researcher. Thus, in total four individuals, three male and one female, all with lived experience of ASC joined the study in the context of the participatory aspect of the research. They were involved in all aspects of the research process as far as the constraints of a doctoral research project allowed. Specifically, they supported the

production of study materials such as participant information and consent sheets. They played an integral role in developing the interview topic guide with the aim of producing questions that were sensitive yet clear and would be meaningful for someone on the autism spectrum. One participatory researcher also volunteered to be involved in the data analysis and was able to code and analyse one of the interview transcripts. Another member of the group, who as well as being on the autism spectrum is also an older person himself, checked emergent themes and gave his thoughts as part of a process of social validation. For reasons relating to ethical approval conditions regarding confidentiality, participatory researchers were not able to be involved in interviewing or in transcribing. Similarly, because of this being a doctoral research project, participatory researchers were not able to partake in the study write-up.
All participatory researchers offered as little or as much input as they wished, and as their time and skills allowed them. Guidance and training, for example in IPA, was offered by the main researcher where needed and the main researcher in turn learnt from the lived experience and expertise on autism that the participatory researchers brought.

The aim was for those members of the group who wished to, to also be involved in dissemination of the project and possible co-authorship of any publications.

2.7.2. Method of data collection

Semi-structured interviews were selected as an appropriate method for data collection for this study as they allow the individual exploration of experience and are suitable for IPA (Smith et al., 2009). Whilst one-to-one social situations can be difficult for some people with ASC, it was felt that this method would nonetheless be easier to manage for most than perhaps a focus group. The semi-structured nature of the interview was thought to give structure yet enable flexibility (Marks & Yardley, 2003) which would allow the interview to follow the guidance of the person with ASC whilst also keeping the research aims in mind. Participants were offered a choice of location for the interview to include their home, a clinic space at the Tavistock Centre or a public space such as library or café. One participant chose to be interviewed at home; all others were interviewed at the Tavistock Centre. Verbal consent was given at the time of recruitment and written consent obtained at the time of the interview (see appendix I). Similarly, demographic information was collected at this time. Interviews ranged in duration from 60 to 110 minutes.

2.7.3. Development of interview topic guide

Members of the participatory research group were familiarised with the study aims and research questions to allow them to consider suitable inclusions for an interview topic guide. They were asked how to frame and articulate questions bearing in mind the idiosyncratic understanding and styles of information processing of some people on the autism spectrum. Specifically, they were asked to consider how they might understand a particular question, or how relatable they found certain concepts based on their own experience of autism.

As suggested by Smith et al (2009), an interview topic guide rather than schedule was developed which allows sufficient flexibility for participants to offer narratives which are important to them whilst also considering the research questions. The guidance was followed to offer initial general questions followed by mores specific enquiries. Some members of the participatory research group felt that beginning with an open and general question might be difficult for people on the autism spectrum, however, after some deliberation it was felt appropriate to include this as a guide with sufficient follow-up prompts prepared if participants needed these for additional structure. Other feedback from the group was incorporated into the question in terms of length, tone, sequence of questions and terminology used, for example using ‘condition’ rather than ‘disorder’ in ASC.

See appendix D for the full interview topic guide.

2.8. Analysis and Methodological Rigour

Analysis of the interview transcripts followed the guidelines from Smith et al (2009) and the main researcher also attended IPA training. Initially each transcript was read and re-read and thoughts were noted manually on the right transcript margins (see appendix K). This included comments of all kinds such as thoughts on content, process and language. A re-reading then enabled very early, emergent themes to be noted on the left-hand margin. Smith et al (2009) suggest keeping an open mind at this stage to allow any aspects of the material, and associations they bring, to be noted. A list of all initial comments was created. These were then reviewed and at this stage the researcher was able to draw on the early themes on the left margins as well as on her knowledge of psychological theory and concepts to create a second list, this one of emergent themes. This involved synthesising some notes and codes into emergent ideas and dropping others. This process was then repeated with each transcript. Once a list of emergent themes had been created, this was presented to and discussed with another participatory researcher as a means of social validation.

The next stage involved all emergent themes being written into a table, printed and cut out as suggested by Smith et al (2009). This facilitated a presentation of emergent themes which could then be visually grouped together where similar or divergent themes of related topics were grouped in one column and provisional superordinate themes created. Themes were moved around repeatedly, and grouped under different headings, until a final picture emerged which seemed to represent the experiences of participants. See Appendix E for example of this visual representation.

One of the interview transcripts was coded and analysed by one of the participatory researchers (appendix K). Her codes and emergent themes were checked by the main researcher and incorporated into the next stage of the analysis when comparing similar and divergent concepts and creating superordinate themes.

Throughout the process of analysis, as well as design of the study, methodological rigour was of key importance. To uphold standards of quality qualitative research, both Greenhalgh & Taylor’s (1997) and Yardley’s (2000) principles were considered. The latter, which highlights sensitivity to context, rigour, transparency and coherence amongst its principles, was particularly influential during the analysis process.

2.9. Ethical Considerations

2.9.1. Obtaining permission to complete the research

The study was reviewed by a Research Ethics Committee in line with legislation governing research carried out in NHS services using human subjects. The committee granted a favourable opinion. Ethical approval to complete research was also obtained from Health Research Authority (Appendix F). Further permissions were sought and obtained from the University of Essex Ethics Committee (Appendix G).

2.9.2. Informed consent

In order to facilitate informed consent and allow participants to fully consider the costs and benefits of participation, individuals were provided with a Participant Information Sheet (appendix H) which included relevant information to make an informed decision about participation. It was written in accessible language and reviewed by the participatory research group to ensure that information was relevant and easy to understand. Information provided outlined possible risks and benefits of participation in the project. Opportunities to ask questions were also given prior to signing the consent form (appendix I).

Some individuals with severe autism or autism with learning difficulties may lack capacity and thus not be able to provide informed consent. The study aimed to recruit individuals with high functioning autism and Asperger’s Syndrome who have the ability to consider participation and verbalise this, thus resulting in a participant group where capacity to consent could be assumed.

Some individuals with ASD may be considered vulnerable to persuasion or coercion. To minimise the possibility of this, participants were not offered any benefits for participation, such as better access to treatment or large payment, which could be conceived as coercion. Participants’ travel costs were reimbursed and they were offered a £15 gift voucher as a recognition for their time and support for the study, rather than as payment.

2.9.3. Reducing distress

It is possible that the content of the interviews, during which participants were asked personal questions about how they cope with their condition, could potentially have been distressing. These possible risks were outlined in the information sheet and also discussed with potential participants prior to them being asked for consent. This was to ensure that participants were aware of possible risks and burdens before agreeing to take part.

As difficulties in social interactions can be a feature of ASC, participants could potentially feel uncomfortable with the interview process of being in a room with an unfamiliar individual conversing at length. Participants were thus offered a choice of location for the interview with the aim of conducting it in a setting which was comfortable for them. Participants were also given time to speak with the researcher prior to the interview commencing to build rapport. A number of measures were taken to minimise possible discomfort including the interviewer asking participants how they wanted to be addressed, how they felt about the room set-up and whether they had any preferences regarding interpersonal interaction. Breaks were also offered with the hope of making participants as comfortable as possible and provide them with a sense of control of the interview. In addition, prior to the start of the interview, participants were offered the opportunity to ask questions and were also reminded of their right to withdraw at any stage of the interview process.

Lastly, participants were asked how they would like any possible discomfort to be dealt with and whether they would like to nominate a friend, family member or professional to be contacted should they feel distressed. The interviewer and participant thus agreed on a plan together of how any possible distress may be dealt with.

Following the interview, an opportunity to debrief was given to participants to speak about any concerns they had or to ask any questions about the interview process or next steps in the research. All participants were also provided with a sheet for helpline numbers and sources of support should they need this following the interview.

2.9.4. Confidentiality and anonymity

All participant identifiable data was kept confidential and only the main researcher and the supervisors had access to this data. As stipulated by the Research Ethics Committee conditions, participatory researchers did not have access to any data until it had been anonymised. They also did not have any contact with the study participants. Participants were made aware of their right to confidentiality prior to the interview as well as the limitations to this, including confidentiality being broken if risk to self or others was disclosed during the interviews. Participants were informed prior to the interview starting as well as on the participant information sheet that should they disclose such information, the referring clinician would be contacted to manage any risk.

Any identifiable information was anonymised. Although all efforts to anonymise quotes were made, full anonymity could not be guaranteed, and participants were made aware of this. Verbatim quotes and the personal nature of the interviews left a small chance of participants being identified in the study report although personal details were omitted or changed in the transcripts.

2.10. Dissemination

Following completion of the Doctorate in Clinical Psychology, the study will be available through the University research repository and available online.

A summary of the results will be sent to study participants, as requested by them. The researcher will also attend the ASC support group from where participants were recruited to deliver a short presentation of the research findings.

In June 2019 the research will be presented at an autism conference together with one of the participatory researchers for further dissemination.

The aim is to publish this study in autism or participatory research-related journals, such as Autism or Disability & Society.

2.11. Chapter Summary

This chapter has outlined the methodological considerations which formed part of the conceptualisation of this study. It has discussed the philosophical underpinnings of the research methodology and offered a reflexive statement outlining the researcher position and background with the hope of providing transparency. The research process of the study was outlined in detail with the aim of allowing others to understand the procedure used. Ethical considerations were also noted, and suggestions for dissemination made.

Chapter III: Results

3.1. Overview of results

In this section the results arising from the analysis are presented. Demographic data is referred to followed by a detailed description of the five superordinate themes and their subordinate themes developed from the transcripts.

3.2. Recruitment

During the planning stages of this study, the aim for recruitment was for 10 to 15 participants to take part. In practice, seven participants were recruited for which there were a number of reasons. Firstly, service issues within the recruiting NHS Trust meant that no participants were put forward for the study. This was because between the conceptualisation of the project and the actual recruitment stage, the criteria changed from being a lifespan service to only working with younger people up to age 25. Consequently, no older people were joining the service who would have been possible candidates for participation. Secondly, the inclusion of the participatory framework added additional aspects to the study. For example, consulting with participatory researchers around a number of issues in the research process and training one member in the use of IPA meant that the scope of the project would have become too large for a professional doctorate project if more participants had taken part. Lastly and most importantly, the interviews which were conducted lasted longer and were more detailed than had been anticipated. As such, the data gathered with the fewer interviews was considered to be rich enough to allow a detailed narrative of ageing with autism to emerge. Considering IPA’s focus on the particular, and its specific acknowledgement that small samples are acceptable if these provide ample data (Smith et al., 2009), a decision was made to end data collection after seven interviews.

3.3. Demographics

All seven participants were recruited from a third-sector ASC support group in London. They were all male and white. Walter was the only non-British participant. Their ages ranged from 55 to 70 years of age (mean = 61.6, SD = 6.13). Four of the seven had a formal diagnosis of an ASC whilst the other three self-identified as being on the autism spectrum. See table 2 for a summary of demographic information.

Table 2. Summary of participants' demographic information.

Allocated Pseudonym	Gender	Age	Ethnicity	Marital status	Employment status	Diagnosis
Chris	M	55	White British	Divorced	Full-time employed	Self
Peter	M	67	White British	Married	Part-time employed	Asperger's
Quentin	M	70	White British	Single	Retired	Asperger's
Walter	M	56	White European	Single	Part-time employed	Asperger's
Matthew	M	61	White British	Single	Unemployed	Self
Greg	M	56	White British	Single	Retired	Self
George	M	66	White British	Single	Unemployed	High functioning autism

3.4. Themes

Five superordinate themes emerged from detailed analysis which were named 'growing older', 'contemplating difference', 'relationships', 'life so far has been a challenge' and 'resources & resilience: managing difficulties'. Each has corresponding subordinate themes which further illustrate the complex narratives within and between participants. The structure of the themes is illustrated in table 3.

Additional themes were generated which are not addressed in this paper due to space and focus of the present study. For details on these, and reasons for exclusion, see appendix J.

Two topics were particularly evident throughout most of the themes and consequently some repetition is possible, with individual quotes illustrating several themes or crossing the boundaries between different subordinate themes. Specifically, the issue of difference as well as that of relational estrangement and societal marginalisation provide a thread through the individual themes. Participants' experiences can be made sense of through these lenses which provided a framework in analysing their accounts.

Table 3. Structure of superordinate and subordinate themes

	Superordinate Themes		Subordinate Themes
1.	Growing Older	1.1.	'Not bad little future': Thinking about the future
		1.2.	'It's better not to think about it': Concerns for the future
		1.3.	'That's my ambition': Hopes and plans and uncertainty about the future
		1.4.	'I've completely changed' versus 'self as stable': Changes over time
		1.5.	'Therapy or just practical support or maybe both': Suggestions for support
2.	Contemplating Difference	2.1.	'My brain is wired up slightly differently to everyone else's': Feeling different
		2.2.	'I feel quite normal': What is normality?
		2.3.	'Autistic people even become brilliant in that': View of autism
		2.4.	'There must be people with worse problems than me': Social comparison

	2.5. ‘A wonderful release … now trapped’: Diagnosis, self-identification and disclosure
3. Relationships	3.1. ‘I felt friendships were these random things’: Relationship difficulties
	3.2. ‘I can bounce stuff off him’: Positive experiences of relationships
	3.3. ‘One can’t get too close’: Need for distance
4. Life so far has been a challenge	4.1. ‘I was bullied by all the bullies’: Negative experiences
	4.2. ‘I just get walked over’: Poor treatment and being taken advantage of
	4.3. ‘I am talking from a different plane’: Not being understood
	4.4. ‘How do you deal with a really low place?’: Difficult feelings
5. Resources & resilience: managing difficulties	5.1. ‘I pursue things I’m better able to do’: Self-help and meeting needs another way
	5.2. ‘I’m sort of bluffing my way through’: Having a veneer
	5.3. ‘It’s one of my Asperger interests’: Special interests & advocacy

3.4.1. Growing Older

The first superordinate theme was one of two which were the most prominent themes and is referred to as ‘growing older’.

The theme encompasses considerations of ageing generally as well as with autism specifically. It highlights some of the participants’ fears, concerns, hopes and plans when considering the years ahead. Furthermore, it details deliberations of how their autism has, or has not, changed over the years. This theme is divided into five subordinate themes including thinking about the future and ageing, concerns, hopes and uncertainty regarding the future, changes over time and suggestions for support.

3.4.1.1. 'Not bad little future': Thinking about the future

This theme addressed participants' musings about their futures generally, when these were not specifically concerns or hopes. It evolved from an observation that participants, perhaps because of their age, or being at a crossroads in their lifespan development, were engaged in a subtle process of considering their life thus far and the next stages ahead. It included participants who had a sense of their future being positive, such as things they were looking forward to.

> *"I'm aware that my bones aren't what they used to be so you know I'm getting older but my mind says I'm gonna live to 125 so I've got 70 years to live so, that's my mentality."* (Chris, p. 37, line 2)

Some participants engaged in looking back on their life, considering their own contributions to the world and deliberating the choices they had made in life. In theoretical literature, life review has been identified as one of the key tasks of older adulthood (Erikson, 1959). Similarly, narrative theory postulates that narrative is a fundamental human strategy which facilitates the coming to terms with experiences (Herman, Manfred & Marie-Laure, 2010). As such, some of the participants in the present study can be understood to be telling their own stories as a way of meaning-making including of their experiences with ASC. In particular, three participants have written, or are currently writing a book, something which seemed to involve a process of life review. Matthew demonstrated this most powerfully by explaining:

> *"[ ] I've tried, I've constructed things, this [literature] project I'm involved in has enriched the world, I hope"* (Matthew, p. 27, line 15)

Thus, Matthew spoke about not literal, physical construction but seemed to refer to a legacy he has built which he hopes will survive him.

Similar to the present findings, Hickey et al (2018) also reported on a theme of life review in their study of older people with ASC.

Quentin expressed some regrets arising from his process of life review whilst considering his past employment:

> *"Well I suppose I would have liked to have done something more creative than doing these clerical jobs"* (Quentin, p. 24, line 6)

This also addressed the frequently-reported underemployment common in people with ASC (Howlin & Moss, 2012; Krieger et al., 2013; Hurlbutt & Chalmers, 2002). Represented in a later theme of 'life has been a challenge', a number of participants in this study felt they had not reached their vocational potential or had been overqualified for the jobs they had done.

Only a couple of participants named the process of ageing specifically. Chris has noticed signs of physical ageing whilst pursuing his hobby, dancing.

> *"As you get older your body isn't the same as it was 30 years ago. [ ] I know, my bones aren't the same, I got a groin strain recently, I got tendinitis in my feet"* (Chris, p. 36, line 21)

On the one hand he expressed acknowledgement and perhaps mourning of his younger, more able body. However, as evident throughout his interview, this acknowledgement has not stopped him from engaging in what he loves. Despite comparing his current body to his former physique, he seemed able to push through the additional physical challenges.

Matthew talked about ageing both in terms of physical changes as well as changes in his perceptions.

> *"but you know, you grow old, your arteries harden, the truth changes"* (Matthew, p. 28, line 9)

Suggesting that the truth changes might be understood as his world view, or his priorities changing with advancing age. Perhaps his physically older body enabled him to have a different perspective on what he considers important.

Greg described how he has lost several friends who were of a similar age to him. He expressed that such unexpected losses brought to his attention his own mortality.

> *"That's the first thing that, at 55 you get a sense of your own fragility for the first time."* (Greg, p. 55, line 28)

Greg, who described an active lifestyle of living in London, enjoying the nightlife and exercising, illustrated that what he viewed as old has changed over the years. He seemed to have reached an age now which he previously considered to be old, yet the goalposts of what old age means to him appear to move ahead as he is reaching said years.

> *"I thought by the time I was, I thought by 50 I'd be old enough to sort of just retire to somewhere quiet and just be in a rocking chair by the seaside"* (Greg, p. 73, line 2)

He thus showed that he feels young inside, despite what his chronological age might suggest. This might be true also for some of the other participants who all lead very active lifestyles.

Three participants also spoke about practical aspects of their future, specifically that of financial security. They demonstrated that they had thought ahead, saved in a pension scheme or invested in property to have an economically comfortable future. Only Chris voiced some financial concerns explaining that he was alright for now, but "for the future, I don't have a proper pension." (Chris, p. 35, line 16)

Interestingly, whilst most participants primarily reflected on their personal experience of growing older, some compared this to the experience of others, particularly thinking about whether their concerns are specific to people with autism or not. Discussing the idea of feeling more comfortable in his own skin as he's growing older, Quentin added:

> *"I suppose [health issues] could concern anybody really, whether they were autistic or not."* (Quentin, p. 10, line 34)

Here he also engaged in social comparisons, a topic addressed in the following superordinate theme.

Conversely, some participants suggested that they do not think about their future too much. Chris reflected on his sister's recent death as a reason for not worrying too much about what will happen. He seemed to be making a conscious effort to live more in the present moment drawing on strategies learnt from cognitive behavioural therapy.

> *"I'm aware of [growing old], but it doesn't even enter my head when I'm living my life now"* (Chris, p. 36, line 22)

3.4.1.2. 'It's better not to think about it': Concerns for the future

All participants expressed some concerns about the future. They tended to centre around fears regarding ill health whilst some described worries about losing independence or becoming a burden on others. However, the overall sense was not one of anxiety and gloom and participants did not spend a lot of time dwelling on their futures. Although this could illustrate a certain amount of avoidance and denial, for some interviewees old age genuinely seemed some while off, especially the younger ones amongst the group of participants. Furthermore, all participants were relatively active and engaged in groups and societies. Only George was experiencing specific health concerns which might be associated with old age.

Quentin highlighted concerns for both physical and mental health in later life.

> *"As you get older, I mean, health issues become, become more prominent."* (Quentin, p. 11, line 2)

In considering mental health in old age, Quentin drew comparisons to neurotypical older people, a process which other studies have echoed (Hickey et al., 2018; Krieger et al., 2013; Punshon et al., 2009). Quentin suggested that people with autism might suffer more from mental health difficulties, due to issues such as loneliness and isolation, something which is supported by research (Hassiotis & Turk, 2012).

> *"I suppose it's just possible that older autistic people could have, could be more prone to things like depression and things like that."* (Quentin, p. 12, line 5)

Some worried about ending up alone in the future without a romantic partner. Chris added however:

> *"But I also know that every day I'm getting more and more happy in my own skin and I know that it won't be that big a concern."* (Chris, p. 26, line 29)

Chris seemed to be demonstrating increasing acceptance of himself and perhaps his autism, becoming more comfortable in himself and recognising his idiosyncratic needs which again reflects previous findings with older people with ASC (Hickey et al., 2018).

Having retired early from a successful career, Greg spoke about retirement and the need for adjustments this brought, especially for people with ASC. Although adjustment to retiring can be a challenge for many, including those without an autism diagnosis (Van Solinge, 2013), Greg alluded to a difference in people with ASC in experiencing change as more difficult than others.

> *"Retirement is a big challenge. [ ] all through your life ... at school [ ] then employment ... is, life is managed for you. Though we like to have, we're kind of disorganised if you're on the spectrum. And work gives you structure. And that's good for everyone, if you have a structure. And it's particularly good if you're on the spectrum."* (Greg, p. 75, line 19, 27)

Being cared for by others and the associated loss of independence and agency was a concern for two participants, although it did not universally arise. It seemed a particularly difficult idea for participants due to their autism, which, for some, had meant seeking aloneness over close contact with others. Matthew illustrated this powerfully:

> *"Loss of independence is a problem for everybody, must be a problem for people who are very social but it would be a problem for me in that ehm being cared for is … dependent on another human being which is something I've assiduously avoided most of my life."* (Matthew, p. 23, line 20)

Only Peter and Matthew spoke about dying explicitly and this absence of addressing the end of life is evident elsewhere (Hickey et al., 2018; Elichaoff, 2015). Peter voiced concerns about his own death, as well as that of his wife and how he would cope if she passed away. The use of the word 'toy' seems to indicate that, despite its challenges, he has enjoyed life thus far. The idea that 'they take it away' suggests a certain degree of powerlessness.

> *"I don't particularly like the idea of death. They give you this wonderful toy called life and then they take it away from you (laughs). Ehm … well … you've got to think about it, what would happen if Linda died? Because I'm fairly dependent on her"* (Peter, p. 18, line 7)

Peter's concerns are arguably universal and are described well in Yalom's work on death anxiety (Yalom, 1980). However, Peter's reliance on his wife adds an additional anxiety about his spouse passing and him being left to manage on his own.

Conversely, although acknowledging some concerns, Walter suggested that he is not overly worried. This seemed to be an indication of some active avoidance of a topic which is potentially painful to think about.

> *"I'm not too uhm to think about my own passing [ ] it is better not to think about it".* (Walter, p. 21, line 43)

3.4.1.3. ‘That’s my ambition’: Hopes and plans for the future

All but two participants spoke about hopes for the years ahead. However, hopes and plans tended to be vague, giving the impression that participants had not spent a lot of their time thinking about what they wished for their later life. Themes of hopes were similar across participants and included wishing for a long and healthy life, remaining active and independent and able to engage in hobbies and special interests.

> *“That’s my ambition, I think, to stay long and healthy. To have a long and healthy life.”* (Greg, p. 89, line 7)

> *“So I will get on with my life and enjoy my dancing and enjoy the next 70 years of my life!”* (Chris, p. 39, line 13)

Some also mentioned a wish to find a romantic partner, such as George.

> *“Maybe find a nice lady, settle down”* (George, p. 25, line 24)

Interestingly, although there was a sense that some participants yearned for interpersonal closeness, few expressed an explicit wish to be in a romantic relationship. This seemed to be the result of a mixture of valuing being alone, and a resignation or in some cases acceptance that being intimately involved with someone was very difficult for them. It is feasible that this is a reflection of relational estrangement where participants no longer consider a relationship possible due to years of rejection and failed attempts to connect.

Most participants discussed hopes regarding their personal future. George and Walter also spoke about hopes for society more generally, in regards to autism, but indicated that this was also linked to his personal future.

> *"But on the positive side of it, how I see my life, well, maybe autism will be more understood."* (George, p. 22, line 18)

Walter echoed this suggesting that he is less concerned about his personal future and thinking more about wider society.

> *"I must say uhm I'm more concerned about how the world is going than, than my own future."* (Walter, p. 22, line 15)

This illustrated consideration of wider issues at societal level which was evident across most participants' accounts. All being members of an ASC support and advocacy group, many had thought about how autism is viewed in their community and seemed to bring forward ideas as to how society could be more inclusive.

A potential reason why participants' plans for the future were somewhat vague may have been their perceived uncertainty of what the years ahead would bring, which was expressed by four participants.

> *"Well you don't know what the future's going to hold anyway"* (Quentin, p. 10, line 24)
>
> *"Who knows who I could have turned into [ ] by the time I'm 60?"* (Greg, p. 85, line 8)

In saying this Greg also implied that his sense of self is flexible and that future life experiences may yet change him which allows speculation about a non-fixed self-identity.

Perhaps surprisingly, this uncertainty however did not seem to raise anxieties, rather, it seemed to be a comfortable acknowledgement that some of what the future holds is not predictable. It indicates an admirable submission to fate with the realisation that one cannot change the future providing a relaxed stance to the years ahead.

3.4.1.4. 'I've completely changed' versus 'self as stable': Change over time

Participants were asked how their life with autism had changed over the years, and whether they expected any changes going forward. Views on this varied across participants with some suggesting there had been little change and that they saw their own self as stable. Others did note some changes, both positive and negative.

Huws & Jones (2015) found that participants in their study reported changes over time, albeit this was with a younger adult population, and specifically related to improved social skills.

Matthew indicated that certain urges and needs lessen with age, specifically sexual desires. He added that other needs associated with autism remain, but he has learnt to manage them. For example, he felt that he has managed to find ways of addressing his paradoxical needs for personal connection and distance, which is addressed in the theme around relationships.

> *"Some of the challenges just diminish ehm some of them you find coping mechanisms"* (Matthew, p. 30, line 2)

He thus expressed both a natural reduction in some autism-related difficulties as well as improved ways of having his own needs met. This might reflect a process of maturity in getting to know one's own needs and finding strategies to address these within a neuro-typical world.

This positive change of things being easier was also articulated by Quentin who noted that since retiring and not being in school or employment, there were fewer pressures to fit in. He spoke about how being single and not being in full-time employment felt more acceptable in old age and as a result he experienced less need to comply with social conventions.

> *"Well it's a bit easier actually as you get older, because you've got choices. [ ] well somehow there's more pressure when you're young."* (Quentin, p. 3, line 26)

The use of the word 'choice' also suggests a certain freedom which Quentin had perhaps not felt before.

Whilst most believed that life with autism had become easier with advancing years, two participants felt there were increasing challenges. Greg spoke about how his sensory perception has changed with advancing years and that it is more difficult for him now to deal with noise. This is contrary to previous research which suggested that sensory issues in ASC can improve with age (Kern, Trivedi, Garver, Grannemann, Andrews et al., 2006).

Peter talked about difficulties accumulating over the years which was impacting on him emotionally.

> *"I'm worried I'm getting worse (nervous laugh). Ehm... you know I've got accumulative pile of stuff that's gone wrong in my life. Feelings then get bigger and bigger and I think I'm perhaps a bit more prone to meltdowns than I was..."* (Peter, p. 7, line 7)

His account highlights how struggling to make sense of experiences and coping with emotional difficulties with perhaps limited resources can cumulate into a greater issue which is harder to address. This seems a difficulty particular to the older person with autism who, unlike a younger individual, has had years of ‘stockpiling’ negative experiences and emotions. Peter provided a sense of just how overwhelmed he feels and the anxiety he experiences.

Whilst most participants had some lifelong and constant interpersonal relationships, two participants also discussed how relationships have changed for them over the years. Although they did not primarily attribute this to their autism, it could be an indication of interpersonal conflict (addressed in later theme).

> *“My friendships have changed, friends come and go.”* (George, p. 9, line 4)

The change that was discussed was not always related to advancing years. Some participants noted a change from before diagnosis to after. This suggested that their new understanding of themselves and their difficulties in light of a diagnosis (or self-diagnosis) altered how they viewed some of their experiences, and perhaps even how they related to themselves and the world around them. Previous studies have identified this shift amongst other older people with autism (Hickey et al., 2018).

> *“Oh yeah, I’ve completely changed my ehm understanding of me as a result of the suggestion that I might have autism.”* (Chris, p. 7, line 21)

Membership of a new group, the autism community, thus resulted in Chris changing his view of self, which has likely impacted on his sense of his place in the world. Social identity theory (Tajfel, Turner, Austin & Worchel, 1979) is a useful framework of understanding this process which describes that people's sense of who they are is based on which social groups they feel they belong to.

3.4.1.5. 'Therapy or just practical support or maybe both': Suggestions for support

The final sub-theme under the heading of 'ageing' addressed suggestions for support in the future. Participants were asked what support they envisaged needing, and what services should offer to older people on the spectrum. The suggestions ranged from practical to emotional support.

> *".... I'm not sure if it's counselling or therapy or just practical support or maybe both."* (Peter, p. 22, line 37)

> *"More clubs. A few clubs. [ ] Set up organisations like [Asperger's support and advocacy group] in all the boroughs."* (George, p. 26, line 29)

Social groups have been called for in previous qualitative reports (Elichaoff, 2015; Krieger et al., 2012). Greg echoed the need for groups and services to keep older people with autism active and engaged in life. He suggested that elderly individuals on the spectrum may otherwise withdraw and 'seize up' especially when faced with changes in technologies. He used the metaphor of a conveyor belt, suggesting a very passive role for the person with autism, who needs rescuing before being sucked into a machine.

> *"There's a really big role for services to play in keeping them on… on life's conveyor belt. They're only too happy to roll off. And they need to be kept on that conveyor belt."* (Greg, p. 94, line 2)

This focus on activities indicates a link to Activity Theory which postulates that to maintain wellbeing, older people need to remain active and engaged in their community. Participants seemed to suggest that people with ASC may need additional support to maintain activities, compared to non-autistic individuals. This may be as a result of the social exclusion and estrangement which people on the spectrum have often encountered throughout their lives thus making it potentially more difficult to be actively engaged in society.

Walter described difficulties he experienced when trying to access mental health support. He found himself at the edge of eligibility for care, with his problems deemed not severe enough to access specialist therapy services yet severe enough to cause him considerable distress. Again, this highlights the exclusion that people with high-functioning autism often experience where estrangement may have resulted in some mental health need, yet they fail to meet thresholds for services thus being excluded from care. Walter hence suggested having someone to talk to, even if not very specialist, would be helpful for him going forward.

> *"I think seeing a social worker for, for instance regularly that might be ehm a good thing, as long as ehm, they are not too, too intrusive."* (Walter, p. 25, line 18)

He consequently highlighted the fine balance for services between offering support and being experienced as overwhelming, something which was echoed by Quentin when discussing care workers coming into the house of someone with autism.

Despite indicating that services do not necessarily have to be specialist, Walter has found a lack of training in professionals to be one of the barriers to finding the right help and expressed a renewed feeling of rejection and exclusion.

> *"I think that's one of the things the NHS does, it's not referring autistic people to, to, to err the clinical psychologist because they often don't have the expertise to help autistic people."* (Walter, p. 24, line, 28)

Peter had experienced a similar lack of understanding of his autism-specific difficulties when he had received counselling in the past and therefore, unlike Walter, felt that

> *"I think counselling and psychotherapy needs to be Asperger-orientated"* (Peter, p. 24, line 1)

Although their suggestions for support were perhaps somewhat vague, participants suggested that an awareness and understanding of ASC amongst professionals is important, whether these be specialist or mainstream services, something which is echoed in the existing literature (Elichaoff, 2015; Griffith et al., 2012). This may be a reflection of participants' frequent experience of feeling misunderstood in the past, discussed in a later theme.

3.4.2. Contemplating Difference

The second super-ordinate theme addressed considerations of difference. Although not an explicit question on the interview topic guide, all participants spoke about various aspects of how they feel different to others, both neurotypicals and other people on the spectrum. The theme also includes views of autism and encapsulates both positive and negative aspects of living with ASC. At points, discussions around this led participants to consider wider philosophical questions around identity, whether there is such a thing as 'normal' and the benefits of attaching a label to a person.

3.4.2.1. 'My brain is wired up slightly differently to everyone else's': Feeling different

Most participants described feelings of otherness, or narrated examples of how they function differently which is widely echoed in the qualitative autism literature including with older people (Hickey et al., 2018; Lewis, 2016; Müller et al., 2008; Ryan & Räisänen, 2008). Some voiced that they are not so different from others yet even for those participants, difference was evident in other parts of the interview.

> *"I've always thought that it was just there was something wrong with me. I've always thought ehm well 'Why has everybody got it together and I haven't?'"* (Chris, p. 7, line 25)

Peter suggested that differences are pervasive and far-reaching, affecting several parts of his being.

> *"The introductory term I use is 'my brain is wired up slightly differently to everyone else's', which I think describes it quite well. But… sort of beyond that there are quite a lot of differences."* (Peter, p. 2, line 5)

He thus employed a well-known description of ASC which suggests that he has both engaged with the prominent discourse on autism and integrated this into his self-identity (Tajfel et al., 1979).

Chris also used a helpful metaphor in describing his difference and his attempts of fitting in, particularly at work. It provides a powerful image of just how removed he feels from others, operating in an entirely different sphere.

> *"I, I work in a completely different box."* (Chris, p. 10, line 2)

Some participants felt more than just different; they used terms such as 'abnormal', 'limited' or 'disabled'.

One participant used the word 'retarded' demonstrating how derogatory language and stereotypes can be internalised. It is also a reminder of the era in which participants grew up and the common discourse of difference at the time.

Conversely, some described autism as not being a disability and in fact associated it with having special abilities. Chris in particular felt very passionate about this.

> *"So that's the message, we're not disabled – we're super-abled."* (Chris, p. 40, line 35)

But he added that societal views, or the treatment of others, may make people with autism feel less able:

> *"But we don't see it that way cause other people don't see it that way, and other people tell us that we're disabled."* (Chris, p. 40, line 36)

The rejection of ASC as a disability has been reported elsewhere (Lewis, 2016; Huws & Jones, 2015). Chris's description of why people with autism may see themselves as disabled aligns with what Oliver (1983) described in the social model of disability, that disabling environments are the cause for disabilities, rather than the condition itself. It powerfully narrates the experience of exclusion, and otherness being pushed to the margins by defining it as an undesirable category. Being given a label which prevents meaningful inclusion in society thus links to this data's overarching theme of relational estrangement.

Matthew illustrated how he functions differently, and how his needs, particularly in relationships, are unlike those of other people. He, as well as the other participants, demonstrated a considerable amount of insight and self-reflection when musing on this.

> *"Take the frequency of human contact. Many people like constant contact. [ ] Ehm some of my friends I, I only see every few years and that's sufficient – for me."* (Matthew, p. 8, line 11)

He thus accepted some aspects of his own difference in that his needs are legitimately different from the main.

Despite conceptualised as overwhelmingly negative, some also described their difference in positive terms or explained that others sometimes appreciate difference. There are similar accounts of appreciation of own difference in the literature (e.g. Lewis, 2016; Williams, 2004). Greg expressed some pride in his own difference (Hickey et al., 2018) and added that, particularly once out of adolescence, others may view his difference in a positive light.

> *"You're never run with the pack. But that becomes quite admirable later on. You get a lot of people saying 'Oh you're your own, you're your own man' you know."* (Greg, p. 49, line 25)

3.4.2.2. ‘I feel quite normal’: What is normality?

Related to the theme of feeling different, four participants spoke about the concepts of normal versus abnormal which included considering whether others are normal, or what normality really is. There was some divergence between as well as within interviews regarding whether participants considered themselves to be ‘normal’ or not.

Chris described painfully how he used to look at how others function and notice his difference in relation to them

> *“I’m looking at myself and saying ‘This is normal in inverted commas and everybody seems to be normal getting on with their lives and being happy and I’m here sad…”* (Chris, p. 12, line 12)

Later in the interview he continued this idea of people with autism being not ‘normal’ yet drew an important distinction between normality and disability suggesting that the absence of normality does not equate to impairment or limitation.

> *“They [people with autism] are not normal in inverted commas, they do things differently, but normal people are more disabled.”* (Chris, p. 39, line 25)

Interestingly, Greg described how his feelings regarding normality changed depending on whether he is around other people or not.

> *“The thing about Asperger’s, if you’re on your own you haven’t got it any more. If you’ve got that condition you’re on your own, when no one is bothering you and it’s quiet then you can be … normal again you know. [ ] I feel quite normal. Very normal actually.”* (Greg, p. 11, line 10)

He seemed to suggest that his difficulties with ASC only exist in the context of other people. Without this he is just himself, all he has ever known, and therefore ‘normal’. This echoed Chris’s thoughts outlined in the previous theme where his view of difference, disability and normality is affected by how others see him and the barriers this view enforces (Oliver, 1983).

A couple of participants also normalised ASC, highlighting the spectrum nature of the condition and thus conceptualising their self as normal in the context of human heterogeneity. Greg stated:

> *"I do think we, we ... I don't know, there's a little bit of it in everybody."* (Greg, p. 39, line 15)

He also describes autism as a "necessary part of the human condition" (Greg, p. 37, line 35) suggesting that rather than it being abnormal, autism is just a part of life. This can be conceptualised as a distancing, or externalising autism, as reported elsewhere (Hickey et al., 2018) but also aligns with the more critical literature of ASC (e.g. Runswick-Cole, 2014).

Walter seemed to mirror Greg's sentiments and illustrated the blurred lines between what is normal and what is not, a common debate especially when considering a spectrum disorder.

> *"[ ] I also sometimes wonder many of the things that autistic people experience, they are also experienced by people err who are not autistic"* (Walter, p. 2, ln 5)

3.4.2.3. 'Autistic people even become brilliant in that': View of autism

This theme includes participants' internalised as well as society's views on autism. There is some overlap between this and the two previous subordinate themes as ideas on difference and normality naturally shaped individuals' views on the condition. A specific focus on positive aspects and negative aspects of living with ASC indicated the creation of a separate theme.

Negative views described by participants included experiencing ASC as "limiting" (Matthew, p. 14, line 29) and considering it as "nothing to be proud of" (George, p. 12, line 15). Both Peter and Greg described a battle with autism where he would either "give in" (Greg, p. 32, line 7) or there sometimes being "quick little wins" (Greg, p. 33, line 27). He thus illustrated the internal conflict in managing ASC-related symptoms in the face of societal expectations. There was also some evidence of internalised negative stereotypes highlighted by derogatory language which some participants used to describe themselves or others with autism.

> *"You're emotionally slightly more retarded"* (Greg, p. 46, line 29)

Positive views were also expressed however, with four participants explicitly talking about strengths of ASC. Much of the research literature on ASC considers special skills and a recent study reported that their prevalence increases with intelligence and age (Meilleur, Jelenic & Mottron, 2015). Qualitative studies have also often presented participants' accounts and appreciation of their special interests and skills (e.g. Haertl et al., 2013; Müller et al., 2008; Williams, 2004).

Walter identified cognitive abilities which he attributed to autism and which allow development of such special skills.

> *"Autistic people are on the whole eh yeah are pretty good ehm in concentrating on one thing and they become even brilliant in that."* (Walter, p. 6, line 48)

He also commented on the benefits of being slightly removed from others which allows him clarity for observation.

> *"The positive thing is that err I can look at society i-i-in a rather independent way and, and err I see certain things in society happening which other people don't see [ ]"* (Walter, p. 10, line 48)

He thus considered ASC to allow him a special vantage point, placing him at an advantage compared to people not on the spectrum. This illustrates a positive rejection of the deficit model of ASC by positioning positively.

Matthew gave a poetic description of an autistic person's need for routine yet not being constrained by things such as social rules. He seemed to be alluding to a sense of freedom which his ASC provides where his difference, rather than being limiting, enables him to not have to conform.

> *"It's that balance between ehm having something to hold on to and being wonderfully unbound."* (Matthew, p. 32, line 1)

Greg and Quentin both highlighted that autistic people are not one homogenous group and that their needs and experiences will vary. They thus remind the reader that the experiences described in this study are unique to the individual participant and that conceptualisations of the condition are idiosyncratic.

> *"You see, everyone on the spectrum is affected very differently."* (Greg, p. 90, line 11)

3.4.2.4. ‘There must be people with worse problems than me’: Social comparison

The theme of social comparison was evident across all seven interviews as well as across earlier and subsequent themes. Participants compared themselves to other people with autism, to people with mental health problems or disabilities, or to neurotypicals more generally. This process has been described in the theoretical literature, particularly social comparison theory(Festinger, 1954), and is echoed in subjective accounts of ASC (e.g. Hickey et al., 2018; Huws & Jones, 2015; Punshon et al., 2009). There was a sense of in-groups and out-groups. Membership of groups, such as whether or not they identified with the autistic community, seemed to vary both within and across interviews. This fluidity was influenced by context, how long the person had knowingly lived with ASC, and what others around them felt. Some participants, particularly those who had found out about their autism most recently, and who were very high functioning, made efforts to set themselves apart from other, more “severely autistic” individuals as has been reported elsewhere (Huws & Jones, 2015). Comparing their difficulties to those of people with mental health problems was also common with a general consensus that autism was not ‘as bad’ as other issues. This downward comparison seemed to be a mechanism through which they could feel less different, less impaired and therefore less ‘abnormal’ (Festinger, 1954). Some also minimised their difficult experiences, such as bullying at school, by suggesting that other children were treated worse.

Walter, who alluded to having experienced mental health problems himself, drew several comparisons with such difficulties.

> *"Although you have worse conditions. If your child is paranoid schizophrenic or bipolar err then that's much worse than autism."* (Walter, p. 16, line 2)

Greg used social comparison to highlight how, compared to others with ASC, he is coping well with his autism.

> *"Some are angry that they've got it, but… [ ]. There's a lot of people on the autistic spectrum who feel terribly sorry for themselves."* (Greg, p. 104, line 34)

Similarly, Peter noted that "I've got fairly mild Asperger's though" (Peter, p. 14, line 11) when talking about the 'neurotypical milestones' such as marriage and full-time employment he has achieved and which a lot of individuals on the spectrum struggle with.

Unlike most others, Quentin did not set himself apart from others with ASC. He seemed to identify most with the autistic community, perhaps because he was diagnosed some 20 years ago and thus has had longer to incorporate the label into his identity. He drew more out-group comparisons with non-autistic people, for example he highlighted his difference to neurotypical colleagues at work.

> *"A lot of people seem to be able to do that, they can get on with their work and discuss their holidays and all that, which I couldn't"* (Quentin, p. 15, line 2)

3.4.2.5. 'A wonderful release … now trapped': Diagnosis, self-identification and disclosure

This theme, raised by five participants, encompassed considering the advantages and disadvantages of diagnosis, reflections on the diagnostic process and deliberations of whether disclosure was helpful or hindering. It was included in the superordinate theme of contemplating difference as it addresses some of the considerations of normality, difference and disability represented earlier in this theme.

Reactions to diagnosis of ASC in adulthood have been widely reported and include a range of emotional experiences including relief (Jones, Goddard, Hill, Henry & Crane, 2014), hopelessness (Punshon et al., 2009), anxiety and anger (Jones et al., 2014). Interestingly, when asked some of the questions around whether participants' perception of autism had changed with age, several participants spoke about their experience changing post-diagnosis. As such, there seemed to be a shift, not so much between their young self to their older self, but rather from their pre-diagnosis to their post-diagnosis self (Hickey et al., 2018). Hence, diagnosis (or self-diagnosis) provided a framework of understanding themselves for some and the effects of this were noted across numerous domains, including relationships (Hickey et al., 2018; Tan, 2018; Punshon et al., 2009).

Peter most powerfully described the internal conflict relating to the advantages and disadvantages of diagnosis. He recalled relief at receiving an explanation for his difficulties but noted that this feeling shifted to one of being stuck with a label.

> *"Eh, initially a wonderful release… but… now, I realise I'm sort of trapped with this. And whilst I realise there are pros, there are also cons."* (Peter, p. 5, line 19)

Walter described how having a diagnosis may provide some protection, for example in the workplace.

> *"I think um, the one, the one hand it is good, and ehm you will not get into situations, or are forced into situations you are not capable to do and that's the main advantage."* (Walter, p. 6, line 44)

Matthew, who does not have a diagnosis and had only recently started identifying as being on the autism spectrum, seemed to struggle most with the idea that diagnosis could be helpful. He expressed that receiving a diagnosis was somehow giving up or taking the easy route out.

> *"I've always thought that it was surrendering to allow yourself to be described by a diagnosis. [ ] to accept a diagnosis is submitting to the hegemony of our society, our culture. [ ] I just think one is more than that."* (Matthew, p. 4, line 16)

He emphasised this idea of being more than a label and addressed the unspoken implications of a diagnosis which he felt to reflect an indication of deficit.

> *"[ ] it's belittling the human imagination that one can be anything, and to say that ... I'm this clinical diagnosis ... says somehow you're an imperfect human being, you're limited, your potential is lowered, people have different expectations of you."* (Matthew, p. 6, line 12)

He again raised the importance of societal views and expectations of others, previously noted by Chris and described by social-constructionist accounts of ASC (Runswick-Cole, 2016).

He acknowledged however that some people can find it "immensely liberating" (Matthew, p.5, line 7) and that this was why he had started "experimenting" with the idea himself which might be why he had decided to take part in a study on ASC.

Greg contemplated in detail the pros and cons of disclosure. Although not formally diagnosed himself, he does identify as having Asperger's but has decided not to tell his friends. He suggested that it would be unfair to burden them with this information but there was a sense of him perhaps being worried about their reactions. He indicated that he had ‘played with’ the idea, echoing Matthew’s metaphor of autism and disclosure being things to be tried out. It is almost like a new coat which Matthew and Greg were trying on, to see if it fits them, and to see how others view them when wearing it. For Greg, it seemed that disclosure is high risk and he could lose friends as a result – “You’ve got to be a little bit careful about it.” (Greg, p. 36, line 19). Yet he described the value of diagnosis by suggesting that the greater understanding of autism brought by a diagnosis reduces anguish, and perhaps this has been the case for him.

> *“So think about all those people before then, who somehow had to suffer from cradle to grave with [ ] this condition and never understanding why, thinking it was a unique thing and therefore you must be a bad person.”* (Greg, p. 104, line 19)

3.4.3. Relationships

The third theme encompassed participants’ experiences of interpersonal relationships. The topic of relationships was one of the foci of this study with a particular interest in how relationships may have changed with age. It includes relationships with family, friends and colleagues, as well as professionals. This theme has tried to capture these experiences under three subordinate themes; relationship difficulties, positive experiences of relationships and need for distance.

Whilst represented in its own theme, the issues of relationships, estrangement, exclusion and marginalisation are intertwined with most of the other themes.

3.4.3.1. 'I felt friendships were these random things': Relationship difficulties

An important theme, with all participants describing it, was that of difficulties in relating to others or interpersonal conflict. Similar issues have been reported by other qualitative studies (e.g. Hickey et al., 2018; Haertl et al., 2013; Müller et al., 2008; Williams, 2004). Underlying these difficulties were feelings of not fitting in and being excluded from relationships or groups of people. Several participants gave detailed descriptions of challenges with social communication which they felt in many cases contributed to interpersonal problems (Travis & Sigman, 1998). Whilst several participants recognised that their own needs for closeness were different to those of most neurotypicals, there was nonetheless a desire to connect and belong, on their own terms.

Quentin described difficulties with relationships at work, and in his personal life. He noted that although he has some friends, intimate or romantic relationships have been more challenging, and he puts this down to some innate inability to connect. Quentin framed this as though he has a concrete, perhaps biological absence of something and this seems both lasting and unchangeable.

> *"Well I suppose I've got friends, but I suppose any kind of intimacy (chuckles) I find it a bit, I always find it a bit difficult any kind of real intimacy. [ ] I don't know really. It's just lack of instinct in knowing how to sort of relate to people."* (Quentin, p. 7, line 12)

A number of participants had experienced a breakdown in relationships. Greg explained that he did not find it that difficult to start a relationship, but felt maintaining them was a challenge.

> *"I'm very weary that a lot of friendships have fallen apart. A lot have ended, have ended angrily, you know so ehm … ehm it's very hard to be with people as well [ ]"* (Greg, p. 67, line 19)

Saying that it is 'hard to be with people' expressed the effort it takes for him to try to connect with others. He seemed somewhat puzzled by this and added that "people are very difficult to work out" (Greg, p. 70, line 7) giving an account similar to other studies (e.g. Williams, 2004). This sense that relationships can be confusing was echoed by Peter and George.

Relationship difficulties were experienced from early on. Chris described both past and current interpersonal conflict, particularly within his family. He noted that his difficulties started at school and demonstrated a sense of social exclusion in being placed in a group of 'otherness' thus exacerbating his feelings of difference and relational distance.

> *"I was just the loner, the nerd you know. I had one or two people I spoke to, the sort of nerds, but not necessarily wanting to be friends with them, wanting to be more friends with the popular people but not able to."* (Chris, p. 8, line 21)

Peter explained how his perceptions of relationships have changed over time, in particular since receiving his diagnosis. This allowed him to make sense of some of the difficulties he had experienced in initiating friendships (Lewis, 2016; Punshon et al., 2009), and he found this increased awareness helpful. The diagnosis thus provided a lens through which he could make sense of past relationship difficulties (Hickey et al., 2018).

> *"[ ] before I was diagnosed I felt friendships .... ehm ... seemed these random things that happened. Now... I understand why that, you know that's one of the things that's become apparent through my you know ...diagnosis."* (Peter, p. 9, line 28)

Some participants painfully described a desire to form relationships, yet not being able to do so. Chris expressed some dissonance between his internal desires and his ability to relate in a neurotypical world which left him feeling rather hopeless.

> *"I am aware that I like that person and I wanna sit down and talk to them but I can't think of what to say to them so it's not happening."* (Chris, p. 24, line 16)

Matthew used a metaphor throughout his interview of people being like doors and if only he could find a way into them, he would find "heaven" on the other side. He gave a sense of this promised paradise of a relationship that was inaccessible to him, but open to everyone else.

> *"Ever since I was a child I thought that people were ehm doors into heaven but I just could not find a way of opening these doors."* (Matthew, p. 2, line 12)

Both Chris and Matthew offered insights in their interviews into how hurtful this has been, yet also provide a sense of some acceptance.

3.4.3.2. 'I can bounce stuff off him': Positive experiences of relationships

Despite the numerous examples of interpersonal challenges, six participants also gave narratives of positive relationships and spoke of people who were important in their life. This ranged from wife, to son, to brother and to professional but mostly participants felt close to a good friend. With a general focus on relationship problems, some studies have also reported on positive relationships in ASC (e.g. Tan, 2018; Haertl et al., 2013).

Chris demonstrated closeness to a number of people, but particularly to his son.

> *"He's the most important person on the planet to me, my son. [ ] And we have a great relationship."* (Chris, p. 18, line 22)

Most participants had met friends through their special interests. Special interest groups they attended in person or online, or in some cases had founded and were chairing, provided a welcome forum of meeting like-minded people and making social connections. There was a sense of this being a safer space than general public life to try to build friendships. The structure of groups also helped to have a script of how to behave in a social setting. The autism support group, from which all participants were recruited, also offered this for some, although not all participants. Other studies similarly have reported that friendships are often gained from groups of people perceived as alike in some way (Tan, 2018; Hickey et al., 2018; Huws & Jones, 2008).

> *"I help organise beer festivals. [ ] That's another great way of meeting people, as well. Like-minded."* (Greg, p. 63, line 10)

Two participants, Matthew and Greg, explained that they get on better with foreigners or people from a different culture to their own. Walter is from a different culture himself and did not grow up in the UK. He commented that it might be easier for him to relate to British people, who are different from him. It is possible that the obvious difference between two people from different countries made the difference due to autism less obvious to them. Communication difficulties or misunderstandings might be more readily expected when relating to someone with a different cultural background, thus making it easier for participants to navigate those relationships without feeling too much out of the ordinary. Although autism is described in some of the theoretical literature as ‘a culture’ (Straus, 2013), this has not previously been reported in subjective ASC accounts.

Matthew explained how relating to someone from another culture allowed him to regulate distance in relationships.

> *“All the women I’ve been close to have all been from a different culture or a different language. That distance – is really helpful for me. One can’t get too close. Cause there’s always that ehm – unbridgeable cultural or linguistic gap.”* (Matthew, p. 8, line 30)

The majority of participants talked about how a lot of their friends also have difficulties, including ASC or mental health difficulties. Whilst this seemed to provide a sense of shared understanding for some, Walter felt he did not want to be burdened with the problems of others. He and Greg said they also made a conscious effort to relate to people who did not have autism which might be an indication of social comparisons being at work in terms of them negotiating their place in in- or out-groups. It is possible that this allowed both Greg and Walter to strive for a greater sense of normality, and to feel not solely defined by their autism.

3.4.3.3. ‘One can’t get too close’: Need for distance

Three participants, Greg, Matthew and Peter, expressed a need for distance in relationships. For them, interpersonal contact could, at times, be experienced as threatening or intrusive. Consequently, seeking distance was a tool for emotional regulation and they sought relationships which allowed them such space, or engaged in activities which met this need. The abovementioned seeking of friendships within another culture was one such example. Matthew for instance had a romantic relationship with a woman who lived in America. He argued that this suited him as it meant they could only see each other every couple of years. Similarly, Peter reported only seeing his best friend at long intervals and being content with this. He also described a distance in communication with his adult daughters, using his wife as a proxy to hear their news to avoid needing to speak to them directly. However, both Matthew and Peter were aware that this need for distance was particular to them. Matthew described it as "unsatisfactory for the other person" and recognised that this can make it difficult to sustain such a relationship. This reflection provides a sense of perhaps painful experiences where relationships have broken down due to unmatched expectations and needs.

Speaking about becoming overwhelmed in friendships, Greg illustrated that he knows his own needs for instance when he becomes overstimulated with interpersonal contact.

> *"[ ] you learn to keep people, when to, there's times when you need to keep your distance from them as well."* (Greg, p. 33, line 32)

As such, participants had found ways to regulate distance and closeness which allowed them to build relationships without feeling threatened or overwhelmed.

Divergent accounts to this need for distance included a want to belong and desire for closeness, raised by Matthew and Peter. Although most participants described wanting to fit in, especially at school, this desire to belong however was more current and expressed a deeper wish for meaningful connection with another person. For both of them this was a distressing experience of wanting a closeness which felt out of reach to them.

3.4.4. Life so far has been a challenge

This fourth superordinate theme encompasses participant narratives of difficult life experiences. Most participants had encountered challenges in early and later life that they attributed to their experience of autism. They recounted, at times painfully, how trying to fit into a neurotypical world had been full of challenges. For some, these experiences were formative and for all they appeared to leave an emotional mark.

The theme is comprised of four subordinate themes including negative experiences, being taken advantage of, not being understood and resulting negative emotions.

3.4.4.1. 'I was bullied by all the bullies': Negative experiences

Four participants referred to specific negative experiences throughout life. Some of these were of an interpersonal nature and add to the narrative of relational exclusion and societal marginalisation that was evident throughout the interviews. Participants' difficulties were largely not the result of personal symptoms operating in isolation, instead they presented in social context and in interaction with others.

Experiences of bullying in childhood were common (Van Roekel, Scholte & Didden, 2010) which resulted in withdrawal and low self-esteem whilst growing up (Haertl et al., 2013; Krieger et al., 2012). Most recounted finding school difficult, a typical experience for children on the spectrum (Ashburner, Ziviani, & Rodger, 2010), which participants attributed to the fact that their autism was not recognised at the time. All but one participant attended mainstream education with no additional learning support offered or available. They felt that an earlier identification could have helped teachers and parents make sense of their unusual behaviours, different learning styles or social needs at school and offered educational adjustments.

Greg, Chris and George discussed bullying at school and being excluded from peer groups.

"I was bullied by all the bullies and that was me" (Chris, p. 8, line 19)

He thus showed how being 'the bullied one' was such a formative experience that this became part of his identity hence illustrating the deep-reaching impact such experiences can have. The lasting effects of bullying during formative years have been widely documented, with mental health problems being a common consequence (Arseneault, Bowes & Shakoor, 2010).

The three of them also addressed academic difficulties and noted that this was not due to lack of intelligence, but that their learning style meant they could not pass exams. This presented an example of how adjustments need to be made for the idiosyncrasies of people with autism.
Greg indicated how these difficulties at school affected his sense of self-worth (Arseneault et al., 2010). He added that for him "the family home is not a refuge, ever" (Greg, p. 10, line 7) suggesting that difficulties extended beyond school to home. This was echoed by Chris whose narrative exposed his feelings of being victimised within his immediate family.

Negative experiences prevailed past childhood. Difficulties in gaining and maintaining appropriate employment are widely recognised for people with ASC (e.g. Taylor &

Seltzer, 2011). Chris spoke in detail about feeling unfairly treated and undervalued at work, a sentiment that was evident across a number of interviews, for example with Peter saying:

> *"I haven't progressed as far in my career as I ought to have done"* (Peter, p. 2, line 23)

There was a sense of disappointment with participants recognising their capabilities of making meaningful contributions, yet the neurotypical environments they operated in being discriminatory in not enabling participants to have their full impact. When asked what autism meant for him, Quentin said:

> *"It means being rejected from jobs and from relationships basically"* (Quentin, p. 1, line 15)

The casual way in which he offered this answer disguised the possible negative emotional effects of these experiences yet mirrored the description of difficulties from other participants. Whilst it may be argued that this is a presentation of their autism, it seems more an indication of how accustomed they have become to experiences of exclusion.

Bullying also extended beyond the school playground as illustrated by Walter. He expressed a sense of danger which can occur in any life situation and which gives a sense of his vulnerability in society.

> *"There's a certain risk of abuse from the public"* (Walter, p. 9, line 13)

3.4.4.2. 'I just get walked over': Poor treatment and being taken advantage of

A common thread in some of the negative experiences described in the previous theme was a sense of being taken advantage of or being treated unfairly, which replicates previous research findings (Luckett & Powell, 2003). This was such a prominent feeling, noted across four interviews, that it was included as a theme in its own right. It illustrates participants' sense of being exploited or used for the gain of others leaving them feeling side-lined and with lesser worth than others. The accounts also alluded to a certain feeling of vulnerability in participants.

Speaking about being underpaid and overworked in his role as an accountant, Chris demonstrated a sense of his talents and contributions not being recognised, especially when compared to his colleagues. He also expressed that he finds it difficult to be assertive, or to make his needs known in a constructive manner, which could be a result of communication difficulties or a consequence of repeatedly being overlooked.

> *"I get walked over and [ ], I just take it"* (Chris, p. 3, line 43)

A perception that everyone else was more important, and only looked after themselves was illustrated by George when speaking about social experiences in adolescence. He highlighted how his self-esteem was shattered by this type of treatment by others thus again demonstrating the significant emotional effects such treatment can have (Arseneault et al., 2010).

> *"As long as everyone else was alright, I was nothing, I was just a number"* (George, p. 4, line 23)

3.4.4.3. ‘I am talking from a different plane’: Not being understood

The experience of not being understood, or being misunderstood, was also commonplace across participants. Such accounts seem not unique to older people with ASC as studies of younger people on the spectrum have also reported feeling misunderstood (Lewis, 2016; Portway & Johnson, 2005). These feelings seemed to largely be related to social interaction difficulties and different communication styles that resulted in ‘crossed wires’ specifically between the participants and neurotypicals.

Illustrating both the experience of social communication difficulties and feeling not understood, Walter noted:

> *“I feel that I am talking from a different, a different plane [ ] there’s certainly a problem that non-autistic people have difficulties to understand autistic people [ ]”* (Walter, p. 12, line 38)

He interestingly positions the problem as located within non-autistic people who have a difficulty understanding him, rather that the other way around as the deficit model of ASC would suggest. Although it could be argued that he is externalising his difficulties (Hickey et al., 2018), Walter’s wider narrative, political involvement and liberal stance suggest that he has in fact adopted a critical view of neurodiversity.

Chris used the metaphor of a box again to highlight different spheres of communication in which he operates. He also expressed a feeling of exasperation at this lack, from both sides, of finding a joint understanding.

> *“I think outside that box, I think in a different box – nobody understands that box. [ ] You know, it doesn’t make sense to me.”* (Chris, p. 2, line 28)

3.4.4.4. ‘How do you deal with a really low place?’: Difficult feelings

Perhaps not surprisingly negative experiences and exploitation led to difficult emotions in participants. Their self-worth was adversely affected by these early and at times persistent attacks on the self. Nearly all participants talked about such challenges, with six of the seven interviewees describing an emotional landscape that was quite bleak at points in their life. Common feelings, also found in the existing literature, included sadness (Elichaoff, 2015), hopelessness (Portway & Johnson, 2005), loneliness (Hickey et al., 2018), frustration (Tantam, 2000) and anxiety (Lewis, 2016), often in relation to interpersonal difficulties. Some participants also spoke of more formal mental health problems, such as depression. A couple had had experiences of psychological therapy to address these difficulties.

George illustrated that some of the hurt experienced in the past was difficult to let go of and was affecting his self-worth to this day. He demonstrated just how long-lasting incidents such as bullying can be (Arseneault et al., 2010).

> *“I felt I wasn’t good enough. It still hurts me, 51 years [later]”* (George, p. 2, line 16)

Some participants described that these emotions can be difficult to deal with at times, particularly when formal offers of help, such as talking therapies, have been experienced as unhelpful or inaccessible.

> *“And another challenge I suppose is ehm … what do you do, you know, your emotions, all of us are states of, of going up and down, up and down, how do you deal with when you’re at a really low place?”* (Matthew, p. 13, line 7)

Matthew thus highlighted the complexities of his emotional landscape. Although he seemed to express some universality in his experience by suggesting ‘all of us’ his later explanation appeared to point to a particular struggle to manage his internal world. He alluded to both internal factors, such as not having tools to cope with distress, and external factors including mainstream supports not being helpful to him.

Similarly, Peter spoke about a battle with difficult emotions which he was trying to manage, although not always succeeding. This metaphor of a battle had been used by other participants in describing living with autism generally and provides a powerful image of how difficult it has been, but also that they are still engaged in battle, not having given up.

> *"I'm constantly fighting stress, not always winning"* (Peter, p. 1, line 16)

This feeling of stress may be linked to being overwhelmed and overstimulated by life, a sentiment which was raised by three participants.

Sadness, hopelessness and depression were expressed in a number of transcripts; Chris and George also spoke of past suicidal thoughts. Both experiences of victimisation in childhood (Klomek, Sourander, Niemelä, Kumpulainen, Piha et al., 2009) and having a diagnosis of ASC (Cassidy, Bradley, Robinson, Allison, McHugh et al., 2014) are associated with increased suicidal behaviour, particularly in men. George in particular showed just how much interpersonal difficulties had affected him by saying that he had felt close to taking his own life on two or three occasions. Again, this theme links to the overarching idea of relational estrangement which has, at times, left participants in a place of isolation and despair and with no one to turn to.

As mentioned in a previous theme, standard talking therapies for mental health difficulties were by some experienced as difficult to access as well as unhelpful.

> *"You know there's talking therapies but as an autistic person talking therapies is, just doesn't, is not relevant, it doesn't help!"* (Matthew, p. 13, line 13)

Peter, however, had found counselling helpful in the past, although had noted a lack of understanding of autism in mainstream mental health care. At the time of interview, he was on the waiting list for an Asperger-specialist talking therapy service but had had to wait two years for an initial assessment.

3.4.5. Resources and Resilience: Managing Difficulties

The final superordinate theme which arose from analysis was that of coping. This includes somewhat divergent accounts to the narratives of difficulties in previous themes and it is important to note that these topics did arise also. In fact, despite the many difficulties, the interviews were not experienced as overly negative or full of despair and the transcript data provides evidence of this.

In this last theme, participants demonstrated resourcefulness, resilience and personal growth in trying to overcome their difficulties, especially when others had been unable to help. These are represented in three subordinate themes around 'self-help', 'veneer' and 'special interests'.

3.4.5.1. ‘I pursue things I’m better able to do’: Self-help and meeting needs another way

Four participants spoke about specific ways of overcoming difficulties. Other studies too have noted the coping abilities of adults with ASC, for example making efforts to develop ways to manage social situations (Williams, 2004) or using tools to fit in (Ryan & Räisänen, 2008).

For some, coping involved avoidance of certain situations which were experienced as difficult or finding alternative things to do.

In speaking about closeness to others, particularly in social situations, Matthew described:

> *“I have organised my life around not having to deal with those difficulties. Or pursuing things I was better able to do.”* (Matthew, p. 1, line 32)

This points to an awareness and acceptance of his own strengths and structuring his life accordingly. There seems to be no judgement in this and in fact ingenuity is evident in how he and other participants have capitalised on the things they were better able to do. Matthew gave an example of seeking solitude in order to avoid feeling overwhelmed with human contact.

> *“There’s not a communication issue with flowers and gardens … [ ] I love sitting in coffee shops on my own.”* (Matthew, p. 7, line 4)

A number of participants spoke of a similar way of managing a certain need for human contact whilst not wanting to be too close which mirrored the need for distance previously discussed. They showed resourcefulness in finding means of meeting their needs that worked for them and these can be conceptualised as a method of self-help.

Both Quentin and Matthew used membership on committees and in groups to spend time with people in a structured manner whilst also not having to have one-to-one contact or engage in unstructured conversation. Chris attended dance classes to experience closeness with others without the need to talk. Walter had chosen a career in which he could work independently for many hours of the day and only meet with his team once a week.

Chris spoke at length about using self-help books and CBT manuals to manage his negative thoughts and associated low self-worth.

> *"Every time a negative thought comes close to me, I – banish it in my mind. [ ] I'm aware of what's happening and that it's not reality, these negative thoughts."* (Chris, p. 29, line 13)

He also used a narrative of overcoming difficulties with some of the moves in his dance classes that seemed to be a metaphor for wider difficulties in life. He expressed that persistence and practice pays off.

> *"But eventually I get it, in the class when the music comes on, about halfway through and something clicks. [ ] And it's coming to me one thing at a time. And it's not till near the end of the class that it all fits together."* (Chris, p. 30, line 17)

As a number of participants, including Chris, referred to things becoming easier with age, he may also be referring to a broader sense of 'things coming together' nearer the end of his life. Although this may in part be due to reduced pressures, it also seems to be because coping mechanisms have become more refined through years of practice and trial and error (Hickey et al., 2018). The dance class could thus be a metaphor for life with autism and the development Chris and the other participants have gone through.

Notably, most of the coping and overcoming difficulties was done independently and originated from within the participants themselves. Few relied on others for help which might be due to not having a significant person to help, or it not feeling comfortable to ask for or take up offers of support. Only Peter and Quentin demonstrated seeking help from others. Peter was the only participant in a romantic relationship and thus it is perhaps not surprising that he sought help from his wife, whom he described as his best friend and said he relied on a lot.

3.4.5.2. 'I'm sort of bluffing my way through': Having a veneer

This theme was only referred to by two participants, however some aspects of it were also evident in other transcripts. It addresses bluffing or putting up a front in social situations to manage or hide difficulties. Few studies have reported on this although Griffith et al (2012) wrote about their participants' 'false self' akin to the veneer which they presented socially. Matthew and Greg spoke about a veneer which goes up when they feel out of their depth, or as a means of connecting with people. It seemed that at times they felt they need to play a character in order to get by.

> *"I'm always aware that I'm sort of bluffing my way through it."* (Matthew, p. 2, line 1)

Similarly, he spoke about mimicking social behaviour in settings which are tolerable to him.

> *"If I'm chairing a committee, it appears social [ ]. But we have an agenda, we have minutes, [ ] we have a goal. It's ehm perfectly manageable."* (Matthew, p. 9, line 2)

As in previous examples, Matthew showed how he has found ways of engaging socially but that also do not overwhelm him. He is thus regulating his emotions and interpersonal closeness so that he can function in the world, but also engage in activities which he enjoys.

Although using a veneer was generally perceived by participants as a suitable way of managing situations, Greg also expressed a fear of being exposed.

> *"[ ] I'd think 'they're going to start finding out what I'm really like soon', you know?"* (Greg, p. 68, line 23)

This fear, but perhaps the use of a veneer more generally, seems to relate to the feeling of otherness previously discussed. The societal pressures to conform to a particular way of social relating made participants feel that they had to try and hide their true self.

Greg also recognised that sometimes, especially if wanting to build a genuine relationship, having a veneer may not work.

> *"You know, you can't manipulate a friendship. All you can be is who you are."* (Greg, p. 71, line 8)

Similarly, whilst acknowledging the need for an occasional front, Walter felt it was important to be yourself.

> *"I think eighty, ninety percent of the cases that is probably the best approach, being completely, being completely natural [ ]"* (Walter, p. 31, line 39)

3.4.5.3. 'It's one of my Asperger interests': Special interests & advocacy

The final subordinate theme of 'special interests' was included under the broader theme of managing difficulties as engaging with hobbies and groups was felt to be an integral part of participants' coping strategies. Hobbies and special interests enabled an escape and allowed participants to feel comfortable in themselves. Engagement in leisure activities has been found to decrease stress and improve quality of life in adults with ASC (Garcia-Villamisar & Dattilo, 2011) and was replicated with older adults here. Qualitative studies frequently support these findings suggesting that such activities aid wellbeing and offer social contact (Haertl et al., 2013; Müller et al., 2008; Williams, 2004).

The interests ranged from photography and poetry through gardening, pop music and sports to politics and vehicle registrations. All participants were members of at least one group (in addition to the autism support group they were recruited from) thus these interests also enabled group membership, and structure to their day, something which had previously been identified as being particularly important for older individuals with ASC when in retirement.

During the interview Peter showed when something captured his interest by becoming more animated, for example when discussing his passion for town planning. He had been able to turn this interest into a job.

> *"...planning law I sort of enjoy and is one of my Asperger interests"* (Peter, p. 14, line 20)

As can be common for people on the spectrum, interviewees showed real dedication and commitment to their particular hobby.

> *"I spend all my spare time dancing, six days a week"* (Chris, p. 26, line 11)

Aside from leisure activities, special interests also included a wider concern with issues relating to autism or political issues. It was felt this also formed part of managing difficulties as participants worked to change the status quo for people with autism on a societal or community level. Other studies have reported a similar involvement in advocacy, awareness raising and improving the situation for people with ASC (Lewis, 2016; Elichaoff, 2015).

All participants, apart from Matthew, were members and regular attenders of a London autism support and advocacy group which demonstrates further interest in and engagement with autism-specific issues.

> *"I run some internet groups and they all are about pretty important sub, subjects. One is about understanding oneself [ ] also I quite worry about the liberal society at the moment, I also have a group about that."* (Walter, p. 20, line 5)

There was a general interest in autism research and all participants requested a summary of the results of this study when offered. Peter in particular had been involved in several research projects and quoted published studies in his interview. Chris also expressed an interest in psychology.

Chapter VI: Discussion

This chapter begins by summarising the findings and considering these in relation to existing theory, research and policy. Strengths and limitations of the study are also discussed, and clinical implications and future directions considered. The chapter concludes with a reflective account of the researcher and one of the participatory researchers.

4.1. Overview of findings

The analysis yielded five superordinate themes which reflect participants' experiences with growing older in light of their autism. These will be summarised in turn, and links made to the existing literature and theory.

Common across all themes is the notion of relational estrangement, marginalisation and exclusion. Whilst relationships are addressed in an individual theme, most of the experiences relayed by participants seem to have been impacted by the way in which society has conceptualised their difference and hence treated them. It thus highlights that people with autism, as those without, do not age in an individual context, but in a social sphere whilst relating to the world around them. Focussing purely on individual psychological explanations, or cognitive-behavioural discourses, denies the acknowledgement of "the universal issue of relationality and interaction in the formation of a [ ] reconstructed social relation" (Milton, 2012, p. 884). As such, when evaluating findings from the present study, a framework of relational interactions may be usefully applied.

4.1.1. Growing older

The first of the superordinate themes, ‘growing older’, highlights participants’ considerations of their process of maturing as well as their hopes, fears and plans for the future. For some, it involved a process of life review as illustrated by looking back over some of their experiences thus far, evident in this as well as subsequent themes. This tendency to look back on life, and consider choices and contributions made, can be understood in light of the developmental tasks highlighted by Erikson (1959). Participants in this study are, according to Erikson, in stage 7 or 8 of the life cycle. These stages address existential questions including ‘Is it okay to have been me?’ which Erikson described as an acceptance of one’s own life cycle (Erikson, 1950). Coming to terms with, and finding acceptance in their own identity of associating ASC to be part of them, was evident throughout the data. For many participants this was a relatively recent process with all of them having been diagnosed (or self-diagnosed) in adulthood.

However, a number of the developmental tasks outlined in Erikson’s stage 7 relate to raising children into independent adults, making a comfortable home, and managing relationships with a spouse. Only two of this study’s participants had children and only one was currently married, or in a romantic relationship. As few adults with ASC are in long-term romantic relationships or have children (Howlin & Moss, 2012), these tasks may be not as relevant to this population. This might suggest that models of ageing developed for neurotypicals may not always map on to the lives of people that veer from the norm, for reasons of lifestyle choice, disability or differing ability. It thus questions the use of such general models to make sense of individual lives.

Participants tended to express a positive outlook on their future and despite raising some concerns, the overall sense was that they did not dwell on worries regarding the years to come. Only two participants directly addressed the process of physical ageing and only two spoke about the prospect of themselves dying. This notable absence could be because this sample was relatively young (mean age 61.5) and particularly active in their hobbies and special interests. It is also possible that it represents a level of denial of the perhaps unpleasant prospect of entering the latter stages of life. Death denial is a widely-recognised phenomenon referred to by sociologists as the 'denial-of-death-thesis' (Kellehear, 1984). This finding is mirrored in the only two other qualitative empirical papers on older people with autism; both Elichaoff (2015) and Hickey et al. (2018) do not report themes around physical ageing or death from their samples. Thus, it appears as though not addressing physical ageing, or death specifically, is common in both neurotypical populations and in those with ASC.

Although possibly representing some avoidance, a positive outlook has also been described as a key psychological resource for successful ageing (Bowling & Dieppe, 2005) and may therefore indicate adaptive functioning on the part of the participants.

The theme of 'growing older' also encompassed considerations regarding whether life with ASC had changed over the years. Previous papers have pointed to autism symptoms and behavioural and emotional problems associated with the condition reducing with increasing age (Mukaetova-Ladinska & Stuart-Hamilton, 2016) suggesting that older people diagnosed earlier in life may no longer meet diagnostic criteria. This has reportedly even been the case for children with significant symptoms of autism whose symptoms are classed as subclinical once they reach maturity (Russell et al., 2012). Others however raised the possibility that additional challenges of old age could lead to a 'double jeopardy' of impairment for elderly individuals with ASC (Roestorf & Bowler, 2016; Geurts & Vissers, 2012). In the present study, although a number of participants did notice a change in their autism over time, this tended to be attributed to diagnosis rather than age. As reported widely in the literature (e.g. Hickey et al., 2018; Punshon et al., 2009; Huws & Jones, 2008), their understanding of self changed following diagnosis that for many offered a new lens through which to make sense of their experiences. Thus, most changes were ascribed to their understanding pre- and post-diagnosis, which was addressed in a separate theme. However, some of the participants did reflect on their experience with autism having changed with age and over time. There was a split over whether participants felt life with autism was easier now, or more difficult with advancing age. Some felt that the stage in later life they were currently occupying meant fewer societal pressures such as expectations to be in employment, or to have a relationship. They felt it was more acceptable to not be working, or to be and live alone, than when they were in younger adulthood. Participants also were freer to an extent of some of the experiences associated with adolescence and younger adulthood, such as a need to fit in and bullying at school. Similarly, Hickey et al. (2018) noted that older people in their study reported reduced societal pressures with advancing age. Although these decreased external pressures may equally affect neurotypical elders, according to Erikson each life stage brings new pressures and tasks that need to be resolved, thus suggesting that other pressures, or tasks, replace the ones which have been reduced. One participant mentioned that his sensory perception difficulties had intensified with advancing age. Interestingly, previous cross-sectional research comparing younger people with ASC to older ones suggests that sensory issues improve with age (Kern et al., 2006). This is an important finding as sensory difficulties can affect neurotypical elderly (Piven & Rabins, 2011) and considering how pre-existing differences in sensory perception affect people with autism may be important in planning for services and care.

The theme of ‘growing older’ further addressed perceived support needs of older people with autism. Most participants in this sample felt they currently needed little support and notably did not make specific suggestions for care in old age. This is in contrast to a survey by the National Autistic Society (NAS) which suggests that 70% of people with autism feel they are not getting the social care support they need (Bancroft, Batten, Lambert & Madders, 2012). However, respondents to the NAS’s survey likely included the whole spectrum of severity of autism rather than the select sample of high-functioning individuals who took part in the current study. Despite participants in the present study not offering specific suggestions, a general sense was that professionals, whether in long-term care, in health services or in other support provisions, should have some awareness of autism and how this can affect the individual receiving support. There is acknowledgement in the existing literature that traditional services for older people do not currently have a workforce trained in autism (Wright et al., 2013) and that care practitioners need to prepare for an ageing population with autism (Wick & Zanni, 2009). Again, it is likely that participants’ relatively young age within the older adult category, and the fact that they were largely functioning very independently, explains why personal care is not (yet) on their minds. Despite being ‘older’, participants in this sample might be classed as part of the ‘young old’ and could thus be understood as being in a transitionary period between adulthood and old age. Their perceptions and views could be different in 15 or 20 years’ time when perhaps the prospect of personal care and additional supports might be more relevant. A further possible explanation if one accepts the deficit model of autism is that the autism-specific cognitive profile and associated impairments with imagination may have made it difficult for participants to imagine their own futures. Lind (2010) suggests that difficulties with self-awareness could mean people with ASC struggle to pre-experience their futures. Although participants in this sample appeared to have self-awareness and the ability to reflect, it is possible that this difficulty affected the number and quality of themes relating to their future generally, and future support needs specifically.

Griffith et al. (2012) reported that participants in their study felt a need for social skills support. The current group did not express a need for specific skills training but felt that more social engagement opportunities such as clubs for people with autism would be of benefit. With high social engagement largely viewed as a part of successful ageing (Bowling & Dieepe, 2005), offering such provisions may help individuals’ quality of life in older age.

It is worth highlighting that participants in the current study not only did not request social skills training, but did not mention interventions for autism at all, explicitly or in the meaning of what they said. They may thus be expressing their acceptance of autism by suggesting that autism requires no intervention and no cure (Davies, 2016).

Participants did highlight a need for psychological therapies although this seemed to be to address the emotional consequences of living with difference and associated relationship problems rather than to address their autism per se. It also illustrates that mental health difficulties are common in people with ASC (Howlin & Moss, 2012) which are addressed in a later theme. There were divergent ideas on whether therapy services needed to be autism-specific or not, but a general consensus that autism awareness was needed for professionals, which has also been reported in previous research (Elichaoff, 2015; Griffith et al., 2012). It is noteworthy that this was a particularly high-functioning sub-group of older people with ASC and that support needs and wishes for services may differ considerably across the heterogeneity that is autism. A survey of carers of people with ASC, who could be speculated to be more severely affected by autism, provided more specific thoughts on care provisions highlighting the unmet needs of this ageing population and stressing importance of person-centred care (Mukaetova-Ladinska & Stuart-Hamilton, 2016).

4.1.2. Contemplating Difference

This theme powerfully highlighted how participants feel different from others. This feeling of otherness had often been with them throughout their lives thus it seems to be an experience with autism that crosses the lifespan. A feeling of difference has been widely reported in qualitative studies on adults with autism (Huws & Jones, 2015; Haertl et al., 2013; Punshon et al., 2009; Williams, 2004) as well as older adults (Hickey et al., 2018). As in the current study, most report an early realisation of difference, although Huws & Jones's (2008) sample became aware of difference only post-diagnosis.

Feelings of otherness led participants to reflect on the concept of normality, and to debate whether they considered themselves to be normal or not. Feeling normal, alongside an acknowledgement of difference, has been reported in other studies (Lewis, 2016; Huws & Jones, 2015). Griffith et al (2012) reported that some of their participants felt ASC was separate from their 'core' self. Similarly, two participants in the present study described feeling 'normal' when alone and that their feelings of difference were reduced when not amongst others. This suggests that their difference is socially constructed or exists only in relation to others. The social construction view of disability (Asch, 1984) can be applied to make sense of this. Without denying the physical, or experienced, limitations of disability, it pays attention to disabling social environments in which the person exists where characteristics are turned into handicaps. When alone, these participants were perhaps free from those disabling environments and societal pressures to conform to a norm. It also links to ideas presented by Disabled People's International (DIP, 1982; cited in Goodley, 2011) which distinguish between impairment caused by a mental or physical limitation, and disability which they argue is socially-created marginalisation. This marginalisation is expressed amongst others, by a focus on deficits, exclusion of people and inaccessibility of parts of society. DIP argue that this socially-created disability is often what creates the real difficulties in people's lives. Participants in this study revealed several issues. Interestingly, they did not speak about ASC symptoms, or aspects of their condition which personally bothered them. Instead, they spoke about interpersonal challenges, about bullying, being misunderstood and being unfairly treated. It thus seems that, as Asch (1984) and the DIP (1982) suggest, their difficulties arose in a societal context of discrimination and marginalisation and hence the analysis's focus on relational estrangement.

Relatedly, participants also deliberated the construct of disability and whether or not autism should be classed as such. While the overall sense was that participants did not view themselves as disabled, there was some divergence between participants' accounts. This is reflected in differing findings from other studies (Lewis, 2016; Huws & Jones, 2015; Krieger et al., 2013). Although all highly-functioning, it is possible that those participants in this study who experienced more challenges such as bullying or employment difficulties felt more disabled than others in the sample. One participant in particular highlighted how he felt society views people with autism as disabled, which consequently affects how people with ASC see themselves. Again, the social construction of disability (Asch, 1984) is helpful in making sense of these views as it highlights how social structures focus on distinctions between inferiority and superiority (Collins, 1991). Participants demonstrated some rebellion against this oppression though as, despite showing some internalised stereotypes and regarding

some aspects of their autism as negative, they also gave positive descriptions of autism-related characteristics and strengths. Other studies have reported on people with ASC valuing their strengths (Jones, Gallus, Viering & Oseland, 2015; Williams, 2004).
All participants drew comparisons between their own difficulties and experiences and the autism community, and neurotypicals. Those most recently diagnosed made comparisons to other, more ‘severely autistic’ people. As such, there was a sense of, whilst identifying with the autism label, they wished to put themselves apart from those belonging to a ‘more disabled’ group. Such downward comparisons were also evident in participants comparing autism favourably to mental health problems or other disabilities, which echoed findings reported in other studies (Hickey et al., 2018; Huws & Jones, 2015; Punshon et al., 2009). Hickey et al (2018) described participants experiencing an autism ‘hierarchy’ in which they were navigating their personal place. Social comparison theory (Festinger, 1954) suggests that individuals evaluate themselves by drawing comparisons to others as a means of improving self-esteem (Wood, 1989). Downward comparisons, as shown by participants in this and previous studies, is a strategy to improve self-regard and wellbeing (Wills, 1981) and can thus be understood as a helpful strategy for participants to conceptualise their own difference. Comparing themselves to others with autism may also be an indication of participants, particularly those more recently diagnosed or self-diagnosed, exploring their own identity and their place within the autism community. Jones et al (2015) described in their phenomenological study how comparing own behaviours to others developed adolescents’ identity in relation to their ASC diagnosis. They described how this process contributed to individuals’ meaning-making of their differences and uniqueness.

The theme of diagnosis and disclosure has been widely reported in previous research with adults with autism (e.g. Lewis, 2016, Huws & Jones, 2015; Haertl et al., 2013; Krieger et al., 2012; Punshon et al., 2009, Huws & Jones, 2008) and with older adults (Elichaoff, 2015). As in previous studies (Lewis, 2016; Elichaoff, 2015; Huws & Jones, 2008), participants in this study spoke about a shift in their understanding of themselves from before diagnosis (or self-identification) to afterwards. They also demonstrated the complexity of both receiving and disclosing a diagnosis, highlighting pros and cons of ‘coming out’ with an ASC diagnosis (Davidson & Henderson, 2010), which is echoed in the existing literature (e.g. Huws & Jones, 2008). Participants in this study tended to be in their fifties before autism was identified thus they had led the majority of their lives feeling different but not having a reference frame for this. Although conceivable that such a late diagnosis might be unsettling, the overall sense from their narratives was a feeling of relief and welcome recognition, thus supporting previous research (e.g. Elichaoff, 2015; Krieger et al., 2012). Nonetheless some divergence was evident between participants in terms of perceived benefits and disadvantages of having an autism label. This might be explained by length in time since diagnosis with Quentin for example seeming most at ease with autism as part of his identity, having been diagnosed some 20 years before. Matthew, who had only recently started “toying with this label” expressed more conflicted feelings. His views seemed to align with the more critical literature on ASC which sees diagnosis as reductionist labelling with significant limiting effects as part of a self-fulfilling prophecy (Runswick-Cole, 2014). Davidson & Henderson (2010) describe how people with ASC may employ several strategies in regards to the question of disclosure which they argue forms part of identity formation in ASC. It is also worth noting however that experiences are likely to vary in regards to diagnosis as well as autism generally, particularly given the heterogeneity of this group of people. Interestingly, Matthew who viewed accepting a diagnosis as “surrender”, asked the researcher at the end of the interview whether she could give him a diagnosis based on the conversation they had had and was disappointed when this was sensitively declined.

4.1.3. Relationships

As mentioned above, the theme of relationships, or interpersonal contexts, is evident throughout all themes as the experiences described by participants all occur within a relational framework within a social sphere. However, specific narratives about relationships also granted the creation of a separate theme.

Difficulties in social relationships are widely accepted to be part of ASC, both in terms of diagnostic criteria (DSM-V; APA, 2013) and in subjective accounts (Hickey et al., 2018; Haertl et al., 2013; Williams, 2004). A survey inquiring about the issues facing ASC elders identified social problems as the most important difficulty for this age group (Mukaetova-Ladinska & Stuart-Hamilton, 2016) which had been raised by an early interview study of adults with developmental disabilities (Salvatori et al., 2003). Supporting previous research findings, participants in this study described how interpersonal relationships are puzzling and at times fraught with conflict. Some indicated that friendships and particularly romantic relationships seemed out of reach, which was more painful for some than for others. Although participants acknowledged their personal difficulties in for example initiating conversation, they also attributed aspects of this to others, for example when describing being excluded from groups or social situations. This suggests an understanding of their relationship problems as part of a wider marginalisation often experienced by individuals with disabilities generally and autism specifically (Runswick-Cole, 2016). It further suggests that individualist psychological or cognitive theories for explaining difficulties in autism may be inappropriate in explaining the complex social experiences of people with ASC. Rather, a relational framework and aspects of systemic therapy theory may helpfully account for the multi-directional estrangement and exclusion experienced by older people with ASC in this sample.

Other studies have frequently reported profound loneliness in people with ASC (Hickey et al., 2018; Müller et al., 2008) with Hickey (2015) describing loneliness and isolation as “an almost inescapable element of growing up and growing older with autism” (p. 92). The Convoys Model of Social Relations (Kahn & Antonucci, 1980) also raised the possibility of older people struggling with smaller ‘convoys’ or social cohorts leading to increased vulnerability to stress (Ajrouch et al., 2001). However, although participants in this study described a desire to connect and belong interpersonally, this was not felt to be an expression of loneliness. There was a sense of people having meaningful relationships, whilst also valuing time alone. In fact, only one participant in this study talked about loneliness. All participants spoke about some significant relationships in their life, and two had been married with children thus presenting a possibly more socially connected narrative than other studies. It nonetheless highlights that people with autism vary considerably in their experiences, and it is not a homogenous population.

The interesting finding that participants felt they could better relate to people from another culture seems to suggest that difficulties in social interaction may be concealed by the difference in culture. The cultural or linguistic gap is perhaps a more acceptable kind of difference than an interpersonal one and it allows participants to navigate relationships more easily, perhaps without feeling so different themselves. It is also conceivable that they use the ‘culture gap’ as a means of concealing their difference, or ‘explaining it away’. Considering this more broadly, it may further suggest that ASC can be conceptualised as a cultural rather than neurocognitive difference where variation is due to cultural variability rather than deficits. It thus clearly positions difficulties experienced as part ASC in a cultural and social context and gives weight to the theory around the social construction of difference. This also fits in with the more critical literature which aims to challenge the disability model of ASC (e.g. Runswick-Cole, Mallett & Timimi, 2016).

As well as describing friendships and other relationships, participants expressed a need for interpersonal distance. Again, this finding supported previous research (Williams, 2004). Creating distance in relationships was a way of regulating not just the quantity of interpersonal contact when this could become overwhelming or intrusive, but also a means of emotional regulation. Participants had found ingenious ways of building relationships which, to a large extent, allowed for such distance, for example making friends with people who lived far away. Some noted however, that such relationships did not last due to them perhaps being unsatisfactory for the other person involved. As has been reported in previous studies (Hickey et al., 2018; Müller et al., 2008), building relationships with other people on the spectrum was also common, where less frequent or less intensive contact was perhaps desired from both parties. Some had also chosen special interests or career paths which allowed time alone, something which participants seemed to value.

Participants are currently still autonomous, living independently and able to make decisions around how to or with whom to spend their time thus allowing them the freedom to regulate interpersonal distance as needed. With advancing age and possible greater dependency however, this may become more difficult. Based on participants' strong views on maintaining distance, being cared for by others, or living in a communal setting with limited privacy such as a care home, might pose significant challenges for this group.

Whilst some participants expressed a need for distance, others spoke about a desire to fit in, particularly at school, and a wish to belong. These themes have been widely reported in the literature, in adolescents, adults and older adults with autism (Hickey et al., 2018; Huws & Jones, 2015; Müller et al., 2008; Hurlbutt & Chalmers, 2002). Ryan & Räisänen (2008) describe the internal conflict of their participants in wanting to fit in and access social spaces yet needing to protect themselves from overwhelming situations by withdrawing and creating distance.

4.1.4. Life so far has been a challenge

Negative life experiences are perhaps universal, but the existing literature suggests that specific difficult experiences, such as victimisation and bullying, are particularly common in people with autism (Van Roekel et al., 2010). Bullying, especially at school, was described by participants, the painful effects of which have also been noted elsewhere (DePape & Lindsay, 2016; Haertl et al., 2013; Krieger et al., 2012; Huws & Jones, 2008; Portway & Johnson, 2005). Participants told of life at school being difficult generally, which they attributed to their autism not being recognised and hence learning support not being offered. Although bullying eased after leaving school, difficulties with mainstream systems continued. Unemployment or underemployment in relation to educational attainment is widely reported (Griffith et al., 2012; Taylor & Seltzer, 2011; Hurlbutt & Chalmers, 2002; Howlin, 2000) and the current study supports this with some participants not being in formal employment, and others working part-time or feeling that they worked in roles below their capabilities. Challenges at work and in particular with colleagues were also not unique to the present sample (Haertl et al., 2013; Krieger et al., 2012; Griffith et al., 2012; Müller et al., 2003; Howlin, 2000).

These difficulties may be understood in the context of systems theory (Bronfenbrenner, 1992) where an individual characteristic such as a desire for aloneness or preference for routine, as widely accepted to be part of ASC (e.g. Attwood, 2007), interacts with relational adversity such as social exclusion or discrimination in a circular manner. In the language of systemic theory, this creates feedback loops, in this case negative feedback loops, which maintain the homeostasis of an outsider identity of ASC. This has been similarly described in the critical literature of ASC (Runswick-Cole, 2014). It is clear in this, as in other themes, that participants' tendencies or temperaments alone do not account for their difficulties. Instead, the way in which these characteristics interact with society's treatment, an emphasis on otherness and out-group processes (Tajfel et al., 1979), seems to be crucially important in accounting for these challenges.

Participants provided narratives of being mistreated and experienced being taken advantage of which was represented in another subordinate theme. Their felt sense of vulnerability due to difference seems to have been exploited by others which demonstrates how people with autism can be marginalised. Although some research on people with disabilities reports on exploitation being wide-spread (Sobsey, Wells, Lucardie & Mansell, 1995), the studies on autism reviewed here have not noted being taken advantage of as a specific aspect of their participants' experiences. Studies have however reported bullying or poor treatment generally (e.g. Krieger et al., 2013; Hurlbutt & Chalmers, 2002).

Relatedly, participants spoke about being misunderstood, which has been widely reported in qualitative studies (Lewis, 2016; Griffith et al., 2012; Portway & Johnson, 2005) and personal accounts of autism (Grandin, 1995). In the survey conducted by Mukaetova-Ladinska & Stuart-Hamilton (2016) respondents identified not being understood as one of the key issues facing older people with ASC. However, experiences such as these are not unique to older people with ASC as studies of younger people on the spectrum have shown (Lewis, 2016; Griffith et al., 2012; Portway & Johnson, 2005). This suggests that such feelings may be maintained across the lifespan of ASC which is interesting considering participants' coping, and in some cases communication style, having improved for some. It might thus be speculated that, whilst likely an interaction between both individual and systemic factors, society's role in creating such misunderstanding remains.

With social communication difficulties being a diagnostic part of ASC (DSM-V; APA, 2013), miscommunications may be argued to be an expected experience amongst people with autism. However, although related to social interactions, their sense of being misunderstood seemed to refer to more than simple miscommunications. There was a deep feeling of others not understanding their world, of having a framework of making sense of the world that was different from the majority. Proponents of the neurodiversity movement might argue that neurotypicals are thus lacking theory of mind in being able to appreciate the world from an autistic view point which was alluded to by accounts such as Walter's. There was a link between being misunderstood and the previous theme of the feelings of difference and otherness. Furthermore, being misunderstood left some participants feeling angry, sad or isolated, which gave rise to the subsequent theme of emotional difficulties.

This final subordinate theme painted a picture of a bleak emotional landscape which reflected feelings also represented in other studies including hopelessness and depression (Elichaoff, 2015; Portway & Johnson, 2005), anxiety (Portway & Johnson, 2005) and frustration (Tantam, 2000). Hassiotis & Turk (2012) have suggested that rates of mental health problems are high and often undetected in adults with ASC, even when symptomatology improves. A survey of views on ageing with autism found that carers and people with ASC felt mental and behavioural problems to be a greater issue in old age than in younger years (Mukaetova-Ladinska & Stuart-Hamilton, 2016). The Convoys Model of Social Relations (Kahn & Antonucci, 1980) and its later extension may help explain increased mental distress in older people with ASC. It suggests that those with stronger social networks have a buffer against stress. The interpersonal difficulties and relational estrangement evident in this sample may thus provide less of such buffer, leaving participants more vulnerable.

Two participants indicated the magnitude of their emotional distress by speaking about past suicidal feelings which sadly, is not uncommon. A large-scale study found that 66% of people with Asperger's had experienced suicidal thoughts, compared to 17% of the general population, and 59% of people with psychosis (Cassidy et al., 2014). It is the leading cause of premature death for people with ASC (Hirvikoski, Mittendorfer-Rutz, Boman, Larsson, Lichtenstein et al., 2016) and provides further rationale for services to be providing adequate support which is accessible and acceptable for older people on the spectrum.

Participants in the present study particularly highlighted that they struggled to manage, or to regain a sense of balance when in emotional turmoil. Studies have shown that individuals with high-functioning autism or Asperger's can have difficulties with emotional regulation (Samson, Huber & Gross, 2012) and the current findings seem to support this. Although this struggle with emotions is perhaps common across human experience, participants also seemed to express additional barriers that may be more specific to autism such as limited coping mechanisms, sensory overload and difficulties accessing support services. Some participants felt mainstream mental health services designed for neurotypicals were not helpful, whilst others had made use of provisions such as counselling. This split sense of experience represented that found in the existing literature, with the overall evidence for effectiveness of talking therapies for adults with autism reportedly mixed (Binnie & Blainey, 2013). Some participants also expressed that there was a lack of understanding of autism amongst mental health care staff which again reflected some previous studies (Elichaoff, 2015), and noted the specialist nature and associated long waiting times for ASC-specific therapy provision.

4.1.5. Resources and resilience: Managing difficulties

The challenges faced by participants in their journey to becoming older adults were difficult and left marks on individuals' identity, self-worth and psychological wellbeing. As part of this journey however, participants also learnt to cope and manage adverse situations as best as they could. This final theme illustrated participants' resilience in overcoming difficulties. There was a sense of participants having developed mechanisms specific to their needs and that through a process of trial and error, of getting to know and accepting their own needs, they have learnt to cope in a world that had not always been easy to navigate. Several studies have described an ability to adapt and cope amongst adults with ASC (Griffith et al., 2012; Ryan & Räisänen, 2008). This included avoiding situations they have found challenging and finding alternatives. Despite this improved coping for some, this was not a 'problem solved' but rather an ongoing, and at times effortful, process of self-help. Ryan &

Räisänen (2008) suggested that although challenges may be overcome through the development of strategies, this is not internalised in the person with ASC but remains superficial. Further support to this is offered by accounts of people on the high-functioning end of the spectrum which illustrate that whilst being able to use social skills for instance, this remains at a conscious and effortful level (Williams, 2004; Grandin, 1995).

Participants demonstrated additional ways of coping, specifically in social situations, where they used a veneer, or a social front that helped them navigate interpersonal contact. There was a sense of participants feeling as though they were impostors or playing a part to fit in socially. It is possible that this was particularly so for this group of older people who had lived for most of their lives with a difference which had no name and thus no understanding and which consequently had to be disguised. Similarly, whilst acceptance of difference still has a long way to go, the time in which participants grew up in during the 1950s and 60s perhaps allowed even less room for being different from the norm. This may have promoted the development of such a veneer. Some participants also used this technique to make connections to people, although recognised that there was a risk of being ‘found out’. The perceived need to use a front suggests that participants retain a sense of being different or ‘wrong’ and that there are aspects of the self that need concealing, possibly for fear of rejection. Griffith et al. (2012) also reported on participants using a ‘false self’ in social situations, a conscious effort to not reveal the true self. This finding highlights how societal prejudices and rejection of difference can be so internalised that individuals feel compelled to alter themselves in front of others.

The final subordinate theme demonstrated participants’ varied special skills and interests. Special interests in ASC are widely described in the literature and form part of the common perceptions of autism conditions (Attwood, 2007). All participants spoke about hobbies and interests which seemed to provide them with opportunities for self-expression, as well as for social contact. They also offered a sense of agency, effectiveness and self-worth when they had experienced failure and rejection in other settings. In the literature, meeting others with a diagnosis has been reported as providing comfort (Jones et al., 2001; Punshon et al., 2009) which might also explain why participants in this sample were all members of an ASC support and advocacy group. Hickey et al (2018) referred to hobbies and special interests as both an escape and a way of managing anxiety. Similarly, Garcia-Villamisar & Dattilo (2011) found that recreational activities reduce stress and improve quality of life in ASC thus suggesting that hobbies are part of an individual's tools for emotional regulation. As such, engagement in these activities was an integral part of coping with life's challenges and a means of gaining positive emotional experiences, or possibly avoiding negative ones. Krieger et al (2013) note how special interest groups can be useful for individuals with Asperger's and provide a means of socialising and connecting with others in a tolerable way. More broadly still, being part of a group and the associated sense of belonging and one's contribution being valued may offer participants a means of countering the prevailing marginalisation and relational estrangement which has formed part of their ASC experience.

Engagement in meaningful activities is also suggested to be an important aspect in 'successful' ageing as proposed by the Activity Theory of ageing. Participants in this sample were particularly active and involved in numerous groups and activities. It is possible that this was part of why they are living relatively successfully and independently.

4.1.6. Summary of study aims and findings

Research questions of this study included how individuals with ASC experience growing older with autism, and how they experience and make sense of social relationships, interpersonal difficulties and connectedness.

Implicit in these questions is a query whether individuals with autism experience older age differently to people who do not identify as being on the spectrum, whether there is anything unique about their experience or whether their diagnostic or possibly neurocognitive difference is significant enough to alter their life experiences. Similarly, it may also be of interest to consider participants' experiences in relation to those of younger people with ASC. Whilst this is a qualitative study that does not aim to make comparisons to any control group, in interpreting the findings and linking it to existing literature comments may be made on how this sample was unique or the same as others. On the one hand what participants described was ordinary, part of the human experience and not necessarily unique to people with ASC. For example, the aforementioned tendency to avoid thinking about one's own mortality seems to be somewhat universal and not specific to this sample (Baum & Boxley, 1984). Similarly, participants in the present study appear to be engaged in a process of life review that is considered 'normal' and appropriate in the neurotypical literature of lifespan development (Erikson, 1959). This might be interpreted as there not being a significant difference due to ASC and that participants in this sample share many things in common with others who are not on the spectrum. Although participants did recount narratives which spoke of more challenging life experiences, there is also a reluctance to overstate difficulties as participants have shown such resilience in managing these.

Relatedly, some of the themes identified in this study correspond with issues raised by research with younger people on the spectrum. In particular, social challenges (Müller et al., 2008), difficulties fitting in (Ryan & Räisänen, 2008), diagnosis (Tan, 2018; Haertl et al., 2013; Huws & Jones, 2008; Portway & Johnson, 2005) and considerations of difference versus normality (Tan, 2018; Lewis, 2016; Huws & Jones, 2015) have been described by younger adults with ASC in a manner similar to that found in the present study.

On the other hand, some of the negative experiences described by individuals speak of relational estrangement, victimisation and societal marginalisation which are significant and not ordinary. These seem to be part of an experience specific to ASC, or certainly to disability and otherness. Additionally, their own sense of difference, whether socially constructed or not, was profound and deserves recognition and consideration. Thus, some accounts were divergent to the normative experience of ageing, and also differed to those of younger adults with ASC. As such, a paradox exists in commenting on difference or commonality that perhaps reflects participants' own contradictions when deliberating normality versus abnormality and ability versus disability.

Whilst acknowledging this paradox and the complexity of the issues raised in this research, conclusions may be drawn, albeit tentatively.

The findings suggest that some of the typical difficulties reported by younger adults with ASC, particularly social difficulties and emotional struggles, persist into older adulthood, which is echoed in the existing literature (Hickey et al., 2018; Stuart-Hamilton & Morgan, 2011). It thus supports the notion that ASC are pervasive conditions which extend across the lifespan. Alternatively, it could be argued to offer support to the notion that societal systems, which give rise to and maintain social difficulties, remain intact for older as well as younger people with autism. Although some experiences reverberated those of any older person, participants also felt that they had faced specific challenges, such as bullying, employment difficulties or issues with managing emotions which they attributed to their autism. Whilst it may be argued that such conclusions reinforce the labelling of otherness and even add to the oppression of these marginalised groups, it is this, the participants' self-identification with otherness and their belief that they have a story worth telling, which provides justification for this study, and for drawing conclusions, albeit with the caveat that these are tentative and idiosyncratic to this group of individuals.

4.2. Methodological Strengths

4.2.1. Novelty

The current study provides an insight into the experiences of older people with autism, an area of research which has largely been neglected (Mukaetova-Ladinska & Stuart-Hamilton, 2016; Happé & Charlton, 2012). To the author's knowledge, only two qualitative papers have been published to date that studied the subjective experiences of older people with ASC (Hickey et al., 2018; Elichaoff, 2015). Neither of those studies used a phenomenological approach, which was felt a useful tool for the present study to establish a sense of the lived experience and meaning-making of people with ASC in later adulthood.

4.2.2. Participatory framework and implications for analysis

The main novelty and strength of the current study lies in its participatory research design. To the author's knowledge no papers have been published using a participatory approach with older people with autism, and few have used this approach with the autism community at large (e.g. Asberg, et al., 2012). Several papers have called for the inclusion of the voices of people with autism not just in research studies but in research design (MacLeod et al., 2014; Wright et al., 2014; Huws et al., 2013). Participatory approaches in autism research have been described as sustainable and translatable science (Wright et al., 2014). The contributions of the participatory researchers were felt to offer invaluable and unique insights that favourably helped shape the research process. The main researcher being positioned as the ‘part-expert’ (having some knowledge of research processes and psychological approaches to studying phenomena) with the research advisory group members also being ‘part-experts’ (with knowledge of life with autism) created a dynamic of mutual exchange and learning. Although some practical constraints denied the full application of a truly co-produced piece of research (see limitations), it was felt that these multiple perspectives enriched the research process by all those involved learning to usefully question what they believed to be true. Furthermore, this approach aided in generating themes from the data which were felt to perhaps have more validity than had they been analysed only by the main researcher who had no personal experience of ASC. One participatory researcher was involved in the data analysis by coding and analysing one of the interview transcripts. The main researcher also coded the transcript analysed by the participatory researcher, to check that another researcher would come to similar conclusions (Shenton, 2004) and that the data could be used to construct a collective narrative. Interestingly, despite the codes generated overlapping in many areas, the participatory researcher offered a different style of analysis to the main researcher. At times she noticed aspects which varied from the focus of the main researcher, such as commenting on language used or questioning the meaning behind particular elements of the transcript, such as pauses in speech. Given IPA’s acknowledgement of individuality in analysis, this is perhaps expected between most researchers. However, there may also be additional differences between the main researcher and the participatory researcher which could have resulted in these diverse styles of analysis. It is possible that the participatory researcher's focus on this level of detail was part of her own autism presentation, as suggested by the Central Coherence Theory (Happé & Firth, 1996). As she herself suggests in her reflective account, "there are no half measures" in what she does, and she considers this to be part of her autism.

Overall, the different styles of analysis were felt to be complimentary rather than oppositional. Reading the annotated transcript of the participatory researcher for instance highlighted details to the main researcher that she may have otherwise missed when moving on to other transcripts. In line with the wider experience of using a participatory framework in this study, it made the researcher aware of aspects of the ASC experience that she may have otherwise been closed off to.

4.2.3. Quality assurances

Using a participatory approach also offered an opportunity for quality assurances such as social validation of themes through consulting one of the group's members following initial coding.

Other quality assurances employed included detailed transcription of all interviews, and initial reading of the transcripts being done whilst listening to the recording. Smith et al. (2009) suggest this as a means of keeping in mind the participant's voice and intonations whilst coding. Extracts of the initial codes were also checked by the two research supervisors.

4.2.4. Reflexivity

A reflective diary was kept throughout the interview and analysis process as suggested by Lincoln and Guba (1985) and Smith et al. (2009) (appendix C). This was used as a means of enhancing credibility and trustworthiness by encouraging reflexivity in the analysis process and reducing bias.

4.2.5. Sample

Despite it not having been an intended aim of the recruitment to solely recruit white male participants, having a homogenous sample can be helpful in an IPA study (Smith et al., 2009). The participant group shared further characteristics such as all being high-functioning, educated, articulate, living in London, living alone (apart from Peter) and having an interest in partaking in ASC community activities or support groups. According to Smith et al (2009) the use of a homogenous sample allows the analysis to remain contextualised to a particular setting. IPA does not aim to make generic claims or build theory, rather making tentative suggestions derived from localised samples.

4.3. Limitations

4.3.1. Sampling issues

Despite IPA recognising that studies with small samples or even case studies can offer a valuable contribution to a knowledge field (Smith et al., 2009), the present study did have a relatively low number of participants. In particular, the seven participants recruited for the study were fewer than had initially been intended. However, the long interviews and rich transcripts were felt to provide sufficient data to allow a detailed analysis resulting in a useful account of participants' experiences.

4.3.2. Participant demographics

Qualitative research does not aim to be representative and abovementioned benefits of having a homogenous sample apply. Nonetheless, the findings must be considered in light of the constraints of the sample demographics. The experiences reflected here apply to the white, male individuals living in London studied in this research who are all high-functioning. Experiences of other older people with autism are likely to be different particularly because of the wide range of the spectrum and heterogeneity of this group of people. The sample was perhaps unusually high-functioning, even within the Asperger's label, they were relatively well connected socially and even though older, they populated the 'younger' older adult category. The well-known saying of "If you have met one person with autism, you have met one person with autism" should be remembered when considering these results. This study thus did not aim to explain the experiences of all older people with ASC but rather add to the developing picture of what it is like to have autism in later adulthood.

Due to the relatively young age of the older adults interviewed for this study some of the themes associated with old age did not emerge from the analysis. It is possible that this is because they were not of importance for these individuals; however it is also possible that they were too young, perhaps still in a transitionary phase between adulthood and old age. Some of the participants were still in employment and thus had not yet experienced the transition into retirement. All were living independently and had not experienced major health difficulties which meant they needed increased support or care. All of these issues may be particularly interesting to explore with individuals with ASC. It is conceivable that relying on others for help, communication difficulties, changes to routine and sensory aspects involved in receiving personal care may present significant challenges for people on the spectrum. The current sample was not able to comment on these issues, as they were not part of their current lived experience. This however, points to an important area for future research.

The present study included individuals who did not have a formal ASC diagnosis but who identified as being on the autism spectrum. The two previous qualitative studies on ageing with autism (Hickey et al., 2018; Elichaoff, 2015) only included those with a formal diagnosis. The view of the researcher is that if individuals self-identify as having a certain condition, there is a reason for this in that they have experienced symptoms, or shared feelings of otherness with this group. This study was interested in subjectivity, meaning-making and identity and as such self-identification was deemed to perhaps be more significant to explore these matters than a formal diagnostic label. Additionally, Stuart-Hamilton & Morgan (2011) reported that in their study adults who self-identified with ASC and those who had a formal diagnosis did not qualitatively differ, apart from symptom severity.

4.3.3. Analysis

It must be noted that the analysis presented here is not the only way the data could be analysed. Researchers from other backgrounds or with differing ontological stances may arrive at a different narrative to the one reported in this paper. There were some noted differences for instance between the main researcher and the participatory researcher's analysis of the transcript of participant 2 which were a likely reflection between their different personal and professional backgrounds. However, the aim of this study was not to present a 'true' account of the participants' experiences. IPA allows for and encourages a personal encounter with the data and acknowledges that there is no one 'right' way of doing the analysis (Smith & Osborn, 2004).

4.4. Clinical Implications

The findings show the varied and at times difficult experiences older people with high-functioning autism or Asperger’s may encounter. They highlight that whilst having some concerns for the future, participants largely felt positive about the years ahead. They also however suggest a possible denial, or avoidance of thinking about problems they may encounter in the future. Additionally, participants felt that overall life with autism had gotten easier, with reduced societal pressures to conform to the dominant life model of employment and romantic relationships. Conversely, this illustrates the stresses that younger people with ASC face in regards to achieving milestones which may be irrelevant or not achievable for them.

Furthermore, the themes show that considerations of difference, diagnosis and identity remain important to people with ASC once they reach older adulthood. These issues, which have been widely reported in studies with younger people on the spectrum (e.g. Griffith et al., 2012; Müller et al., 2008; Punshon et al., 2005), seem to be pervasive across the lifespan. Although this may be specific to people who were diagnosed (or self-diagnosed) later in life, it suggests that professionals should be aware that questions around difference and acceptance of diagnosis may arise when working with this client group. This was supported by participants’ feeling that support for mental health may be important in old age, and that services should be autism-specific or as a minimum have staff who demonstrate awareness of ASC. Waiting times for specialist services are long and commissioners and those designing services should be aware of the needs for specialist provision for this growing population, particularly in light of significant mental health problems and suicidality. With some participants also reporting that traditional approaches such as talking therapies may not be helpful to them, alternative and creative provisions must also be considered. Although not addressed in detail by this study, this might include occupational therapies, for instance horticultural therapy if this is in line with the person's interest. It could also involve art, music or drama therapy or less traditional approaches such as peer support, the latter of which is often reported to be helpful by autistic people.

Additionally, some participants felt that practical support may be necessary for tasks that people with ASC can find overwhelming, such as dealing with services, making phone calls and other tasks of daily living which may include interpersonal interaction. This could take the shape of offering a personal assistant service for those autistic individuals who find this helpful, or someone who may navigate services with them. Looking at alternative ways of dealing with services such as the council, healthcare providers and similar providers may include helping the autistic person to sign up for online services which evades the need for telephone contact which is often experienced as difficult. Other individuals may benefit from someone to do their shopping if they find busy supermarkets overwhelming in terms of sensory input. Some retailers have started offering “autism-friendly” opening times with reduced sensory stimulation and this could be helpful for some if rolled out more widely. Service providers should take note of the need for individualised support, with participants reporting that offers of support need to be accessible yet not be intrusive (Griffith et al., 2012).

The themes generated in this study replicated some of the findings of studies with younger people with autism in regards to difficulties in social relationships, bullying and feeling misunderstood. Again, it is important for those working with and providing support for this client group to be aware of the pervasive nature of interpersonal difficulties that seem to cross the lifespan in ASC.

The final theme of the analysis highlighted individuals' strengths and resilience in coping with difficult experiences in life. Special interests seemed fundamental in allowing these older people with ASC to socialise in ways which were tolerable to them whilst fostering an expertise in a field of their choice. With structure and purpose perhaps reducing once older people retire, membership of special interest groups, autism community groups and other forums may become particularly important. Local commissioners, social care providers and voluntary organisations should work on increasing provision and accessibility of such groups, including for people on the more severe end of the spectrum. This also links with participants' explicit wish for more social groups and activities in their local areas.

The analysis showed that older people with autism have a range of experiences which influence their view of self, identity and emotional life. Despite some shared narratives, divergent accounts are likely when considering other groups of older people with ASC. As such, the overarching implication may be that services need to be needs-led rather than focussed on diagnosis. Professionals working with this group should ask questions that address the idiosyncratic experiences, values and goals of the individual rather than making assumptions based on a label or presumed neurocognitive profile.

4.5. Future Directions

As noted above, the current study provides an insight into the experiences of a small sub-group of older people with ASC. Future research is needed to address the experiences and needs of older old people on the spectrum as their stories may be different in light of other challenges faced in the latter years of older adulthood. This should include research with those with more severe ASC as well as those with autism and learning disabilities whose experiences of autonomy, care and relationships are likely to be different from the sample studied here.

From the analysis of the current study several themes emerged dealing with relationships and aspects of social and relational estrangement in the context of ASC.

As such, it would be helpful to consider research that includes significant others of people with autism, such as carers, partners or family members to build a picture of the complex relational dynamics. This should not be in lieu of giving voice to the individual with ASC but rather be an additional route of inquiry.

The participatory framework in the current study provided valuable additions to the research in regards to meaningful involvement of those with lived experience. Due to the constraints of this being a doctoral thesis, and associated academic and institutional requirements, full co-production was not possible. Cancian (1993) notes that to successfully undertake participatory research, academics must often bridge 'two conflicting social worlds' where expectations, goals and ways of achieving these can differ significantly, as was the case in this research. Future research should thus aim to offer a truly equitable process of research in all aspects of the study. This might include having participatory researchers conduct some of the interviews, as well as analysing more of the transcripts than was possible in this study. If full democratic co-production is the aim, participatory researchers will also need to be paid for their time.

4.6. Summary and Conclusions

The aims of this study were to explore the lived experience of older people with ASC with a particular focus on their interpersonal relationships, and using a participatory research framework. Participants gave rich narratives of their lives including experiences pre-diagnosis, how their life is now and how they see their future. Accounts included considerations of differentness and sameness, of normality and disability. Thoughts about their future were ordinary in many ways, and perhaps this group of older people with autism are not so different from other older people. However, narratives of how difficult life was growing up without a diagnosis, without an associated understanding of their differentness and with experiences of bullying and being misunderstood provided a framework for how their experiences may have differed from neurotypicals. Struggles in navigating personal space with a need for distance and closeness present in equal measures, indicated relationship difficulties which may be pervasive in ASC across the lifespan. Difficulties in managing emotions, many of which seemed to arise as a result of maltreatment and marginalisation, were evident in particular with few offers of appropriate support from mental health services. Nonetheless, participants demonstrated resilience and creativity in managing difficulties and had hopes for the years ahead.

Clinical implications of the study include suggestions for services in regards to autism awareness amongst professionals.

The study has provided an insight into what life is like for an older person with ASC. It is a snapshot and perhaps can contribute to the emerging literature in this under-researched area for this growing group of people. The study also offered an example of using a participatory design in a study of older adults with autism. Future research should take this approach further in conducting a truly co-produced piece of research. Studies should also investigate older older adults and enquire about life experiences with adults who perhaps are not as high functioning as the current participant group.

4.7. Reflective Account

4.7.1. Reflective account of main researcher

Conducting this research was a fascinating, emotional, difficult and enlightening journey. I started the project feeling that it was a somewhat necessary part of my path to becoming a psychologist, a hurdle to be jumped through. I did not expect, and thus was positively surprised, how invested I became in the topic matter and in particular in listening to, and hopefully giving voice to, participants' experiences. Knowing relatively little about autism when I started I found that in meeting my participants as well as the participatory researchers who worked with me, a lot of my own stereotypes about ASC were challenged. I was surprised and struck by the level of insight and ability to reflect of a group of people who are often said to not having theory of mind and thus said to not be able to reflect. I remember coming out of the first interview, which had taken nearly two hours, and feeling very grateful for being allowed to hear such a detailed and personal narrative of someone's life.

Throughout the interviews, the (often tedious) transcribing and the coding, I was moved by the accounts of my participants' lives, in particular the often painful realisation of difference and thoughtful ideas around the concept of normality and disability. Also, the wish for connection with others was powerful and was frequently denied, either by others, by societal expectations, or by participants' own needs for distance which did not always fit with the needs of others. Conversely, I was also pleased to learn of participants' resilience and strength in facing difficulties and going their own way.

There were numerous occasions where I felt overwhelmed, in particular when faced with the task of coding, summarising themes and writing up the results. With this group of people rarely studied to date, or with research focus on their bodies and brains rather than the voices of an ageing person, I felt pressure to give justice to the stories they had shared with me. Doing justice, and making sure each of the voices would be heard sufficiently, was difficult when themes needed to be combined, some subthemes dropped and words or quotes cut. To add to this was that one of the themes which emerged during analysis was that of being misunderstood. I think I worried that if not careful I could add to and confound this sense of not being heard properly and I feel this increased my perceived pressure of wanting to tell participants' stories well.

Time pressures also played a part; I remember telling my supervisor that I could happily spend another year going through the transcripts and coding to ensure that I captured all that felt important. I have had to realise, with help from both my supervisors, that many stories are present in the data but that not all can be told by me and at this time. Pragmatism sometimes has to win over idealism, especially with other demands in my professional and personal life.

A huge part of the project for me was the participatory aspect. Having come to this subject as a novice, it was invaluable to me to have the input, thoughts, feedback and contributions of this fascinating group of participatory researchers who volunteered their time to help me, and the study. I felt in awe of the amount of time and dedication they offered the project and oftentimes felt I should be doing more in light of how much they were putting in, particularly during the analysis. Using the participatory approach but without having a fully equitable and democratic design raised some ethical questions for me and I grappled with the notions of exploitation and further manipulation of a marginalised group. I hope that as well as doing justice to the participants' stories, I also did some justice to the work, thought and effort that my research advisory group put in. Future steps to recognise the work, such as co-authorship for the individual who contributed to the analysis in such detail are being considered, although I continue to feel indebted to them.

As well as enjoying the subject matter and the privilege of entering participants' lives, to my surprise I also enjoyed the research process itself. Having felt previously (as well as during some stages of the process, in particular the initial planning) that I would never engage in research again post qualification, I now feel much more positively and can see in particular the need for clinicians to engage in research too.

4.7.2. Reflective account of participatory researcher who analysed one transcript

I found the analysis of this transcript really interesting, and also quite emotional. So much of the way this person thought and spoke was familiar to me; the way he felt like he needed to justify himself, the tendency to underplay his difficulties because he was aware that others were ‘more autistic’ than he was, and his attention to detail and use of humour were all things I strongly related to. Whilst I had not met or spoken to this person, I felt that his sense of frustration at his own problems, and awareness of the impact of his autism on the people he loves, spilled out of the transcript pages and there were many points at which I felt very sad for him. I got the sense that this was a man who had actively tried, for many years, to make sense of his challenges, and to seek help for them, and when he finally had an answer about WHY he was different, he then read everything he could about it, joined support groups, spoke to his employers; he is someone who does everything 100%. This is so much like me! If I’m doing something, I’m doing it, there are no half measures. I also could really relate to the career issues he had experienced and reading about these triggered a lot of memories for me of being lost or bullied in the workplace, and struggling with (and eventually giving up on) a full time job. Reading about this participant’s fears for the future also made me think of my Dad, who is also on the spectrum, and who is also completely reliant on his wife in so many ways. More than anything, I noticed that the things the participant said about the diagnostic process were familiar, not just because I have experienced it but because I have heard accounts of this process from other late-diagnosed autistic people. The majority of a life feeling ‘less’, different or faulty in some way. The initial relief and understanding from the diagnosis, a strong sense of place and belonging in the autism community, and a push back against the ‘deficit’ model of autism with an acknowledgement of the strengths gained from it. Then, gradually, this awareness that,

> actually, KNOWING one has autism does not allow one to CHANGE aspects of one's behaviour that are difficult for others. That to function well, and to live a good life, one is reliant on the empathy and understanding of others. That is truly very difficult to accept for people that have a natural desire for certainty, predictability and control.

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Appendix A.

Table1. First literature review search strategy looking for studies with older people

No.	Data Base	Search words	Date searched	Years included	Results generated
1	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	autism or asd or autism spectrum disorder or asperger's or asperger's syndrome or autistic disorder or aspergers	20/11/2018	All	147,236
2	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	Ageing or ‘older adults’ OR elderly	20/11/2018	All	965,302
3	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	Experience OR views OR perceptions	20/11/2018	All	3,005,281
4	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	qualitative	20/11/2018	All	257,474
5	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	# 1 AND # 2 AND # 3 AND #4	20/11/2018	All	23
6	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	#5 limited to academic journals	20/11/2018	All	19 (17 excluding repetitions)

Of the found 17, only 1 was relevant to ageing with autism from person’s own perspective

Reasons for exclusion:
Carer view: 7
Not older adult: 2

Not primarily ASD: 5
Repetition: 2
Total excluded: 16 of 17

Table 2. Second literature review search strategy looking for studies with adults generally

No.	**Data Base**	**Search words**	**Date searched**	**Years included**	**Results generated**
1	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	autism or asd or autism spectrum disorder or asperger's or asperger's syndrome or autistic disorder or aspergers	14/12/2018	1950 - 2019	147,933
2	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	adults or adulthood or 'older adults'	14/12/2018	1950 - 2019	7,519,745
3	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	Experience OR views OR perceptions	14/12/2018	1950 – 2019	3,015,188
4	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	qualitative	14/12/2018	1950 - 2019	505,206
5	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	Phenomenological OR IPA	14/12/2018	1950 - 2019	68,552
6	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	# 1 AND # 2 AND # 3 AND #4 AND #5	14/12/2018		86

7	CINAHL Complete (with PsycINFO, PsycARTICLES and MEDLINE full text)	#6 limited to academic journals	14/12/2018	1950 - 2019	44

Reasons for exclusion:
Data not perspective of the individual with ASC (carers, professionals): 22
Research topic specific to one area or intervention: 3
Participants not adults: 2
Not primary ASD: 7
Repetition: 3
Total excluded: 37 of 44

Appendix B.

Table 1. Summary of CASP quality appraisal of reviewed articles.

Reviewed article	Clear aims?	Qualitative approach appropriate?	Appropriate research design?	Appropriate recruitment strategy?	Appropriate method of data collection?	Relationship between researcher and participants addressed?	Ethical considerations addressed appropriately?	Rigorous data analysis?	Clear statement of findings?	Valuable contribution?
Williams (2004)	2*	2	2	2	2	n/a	0	2	2	Novel research design adding unique insights. Findings related to theory (particularly Theory of Mind theory) but not practice. Clinical implications, limitations or further research not discussed.
Huws & Jones (2008)	2	2	2	2	2	1	2	2	2	Findings related to previous research, theory and practice. Clinical implications and limitations discussed. Further research identified.
Punshon, Skirrow & Murphy (2009)	2	2	2	2	2	1	2	2	2	Findings related to previous research and theory. Clinical implications and

										limitations discussed. No identification of further research.
Griffith, Totsika, Nash & Hastings (2012)	2	2	2	2	2	1	2	2	2	Findings related to previous research, theory and practice. Clinical implications and limitations discussed. Further research identified.
Krieger, Kinebanian, Prodinger & Heigl (2012)	2	2	2	2	2	1	2	2	2	Findings related to previous research, theory and practice. Clinical implications and limitations discussed. Further research identified.
Haertl, Callahan, Markovics & Strouf Sheppard (2013)	2	2	2	2	2	1	2	2	2	Findings related to previous research, theory and practice. Clinical implications and limitations discussed. Further research identified.
Huw & Jones (2015)	2	2	2	2	2	1	2	2	2	Findings related to previous research, theory and practice. Clinical implications and limitations

										discussed. Further research identified.
Lewis (2016)	2	2	2	2	2	1	2	2	2	Large sample. Data collection method allowed access to participants who may otherwise be excluded. Findings related to previous research, theory and practice. Clinical implications and limitations discussed. Further research identified.

* 0 = no; 1 = not able to tell; 2 = yes

Appendix C.

Reflective Log

<u>Extract of Reflective Notes from Interviews</u>

Interview 1

This being the first interview I was rather nervous beforehand. I felt I ought to have practiced my interview technique or at least discussed the style, etc with my supervisors. I read the Smith et al book's section on conducting the interview which was helpful though.

The interview was being held at the participant's home, which I am sure set the scene and created a certain dynamic which would have been quite different in a clinical setting. He seemed quite at ease, presumably because he was in his familiar surroundings. I wonder if I felt more nervous because I was in an unfamiliar setting, in someone's personal space. Also, the washing machine was rather loud and a little distracting.

A few thoughts I had during the interview:

I wanted to provide empathy statements, summarise and reassure as I do in therapy sessions and had to make a conscious effort to hold back. In this effort I think I said very little and perhaps did not probe enough. Having read Smith's emphasis on a slower pace and leaving lots of room for the participant to talk may have also made me less likely to interrupt or offer a new probe. In retrospect (although without having listened back to the interview) I feel I could have done more probing/prompting. He was very chatty but at times went off on a tangent away from the research question – although perhaps this kind of personal, reflective data is exactly what should come out and is the reason why a semi-structured topic guide is used in IPA rather than a structured interview schedule. Maybe during the analysis, I will find useful insights in these 'tangents'.

There were some avenues which I would have followed up in therapy, for example I might have asked why he has chosen to never seek a formal diagnosis, but I was unsure whether this was relevant to the research question and was weary of straying into 'therapy territory'. It highlighted my slight unease in switching from my usual therapist role to that of a researcher.

Overall I did feel it went well though as we seemed to be able to build a rapport, he was at ease and he did raise some really interesting points. I was particularly struck by the level of interpersonal difficulties he has faced, yet his overall positivity and his level of enthusiasm for the things he feels passionate about, like dancing and spending time with his son.

For future interviews I do want to discuss with Sarah about technique, applying prompts and carefully interrupting people.

Reflecting on the questions, I certainly feel it was good to have had a topic guide rather than a set interview schedule. Not all questions seemed relevant in the moment and I was able to adapt them based on what he had already said. I need to listen back to them though to see if I didn't leave out too many.

Interview 2

He was quite late and when he came in there was a bit of a stressed atmosphere. Interview did not seem as relaxed, and he required more prompting. Seemed a little hesitant in his answers. Looking back though he showed an incredible amount of insight and has clearly thought a lot about what autism has meant in his life, perhaps in part because he has had therapy and also has taken part in research interviews before.

I was struck by the pain he expressed in some of his narratives, such as when speaking about his daughters or his difficulties in communicating. He is clearly a very intelligent man and skilled at his job, which he seems to have really committed himself to. I wonder just how hard he has had to work to get to this level of functioning in a neurotypical world and with his problems not recognised for such a long time.

Interview 3

Much more laboured than the first two. Having to pull information, asking quite direct follow-up questions. Participant did not seem as at ease, or willing to tell me detail. I got the sense too that he was thinking quite concretely about questions/answers and not necessarily being able to self-reflect as much as the first two participants. There was much less flow and I left feeling a bit disheartened. Perhaps he gave as much as he could, but I had much less of a sense of him as a person and his life than I had hoped for…

Interview 5

This was such an incredibly interesting person to interview! He was full of reflections, articulate and poetic in his responses. I felt myself getting quite excited at the ‘great data’ I was collecting. Beyond that though I was also struck by this incredibly painful experience he kept returning to in his accounts of wanting to relate and be close to people yet not feeling able to do so. Beautiful metaphor of ‘doors to heaven’ the inaccessibility of which was really moving to be a witness to. Also moving was his telling me of how he looked after his elderly parents with such compassion that seemed to refute a lot of society’s (and maybe my own) preconceptions about autism. It made me think about the initial descriptions of autism by Kanner and Asperger who described these aloof children with no interest in others. Somehow he bears little resemblance to this and that’s quite interesting in itself. The image of this participant smoking a cigarette for his father because his father couldn’t and this creating an arch of connection between the two was beautiful. Maybe it shows a different kind of connection which people with autism have?

I was also quite in awe of his resilience and how he seems to embrace his difference, accepting that he is not like others and finding meaningful activities within his capabilities and tolerance for social spaces.

There were some really awkward moments, like when he talked about sex or how he has others inflict physical pain to him when he can’t manage his emotions. I didn’t really know what to say to that… Perhaps again something to ask Sarah about.

It was a bit sad, and also awkward, him asking me for a diagnosis at the end. He was really persistent in wanting to get an answer out of me. I wasn't sure how to handle this and felt perhaps I had mislead him – did he think that this was the purpose of the interview? I felt a bit panicked and thought I have to review the study information sheet. What is in it for the participants? I felt bad not being able to provide him with what he had clearly come for.

Extracts of Reflective Notes from transcribing

P1

Why did I let him talk so much, without almost pausing for breath? I remember being very drawn into how he was speaking, not so much what he was explaining. It was hard to follow at times I seem to remember yet I felt engaged and intrigued. Listening to the tape though I do wonder why I interjected/added/asked so little

P7

This is getting so tedious now… This interview in particular seems long to transcribe. Perhaps because it is the final one but I am also losing interest in the narrative. This participant was not as reflective, his stories not as rich. I need to make sure I don't lose sight of what he does say though. I find myself having to remind myself that his account is also valid, and important, even if not as articulate and interesting as some of the others. I guess it shows the spectrum of people and experiences.

Extracts of Reflections from Analysis

21/12/18

Coding is tedious and long. Re-reading the transcripts feels like going over stuff you know as I've read it so many times so to maintain concentration to look for new ideas, or connections, is difficult. I just wanna be done so I can start actually telling a story. And writing this thing.

I feel worried that I will miss things. What if participants read it and feel their story is not there?

5/1/19

I find myself keeping going back to the IPA book to check whether I'm doing it 'right'. I know there is no one 'right' way of doing it. Maybe it shows my own anxiety. I haven't done this before and there's no one to tell me how to do it! It's a bit like a felt when I started doing therapy sessions when I would go back to the therapy manual again and again before a session. Only to find out that the session never works out that way! I remember a supervisor telling me to 'let go of the clipboard' so maybe I need to do the same here and follow my instinct with the data?

26/1/19

Started writing lists of themes so finally feel like I'm getting somewhere. Could probably have spent another year re-reading transcripts and coding but had to draw a line somewhere – encouraged by impending deadlines! Cutting themes out and moving them around makes it feel more concrete which is exciting and also daunting. What if I haven't captured the stories right?
Also struggling to think what to name themes. I don't wanna sound condescending in the labels I give…

13/2/19

Themes coming together now. But they are not that exciting! Many things people have said are really normal, or what you might expect from autism study. Does that mean I just found what I had in mind? Did I not follow the data but my own pre-existing ideas? Ahhhhh!

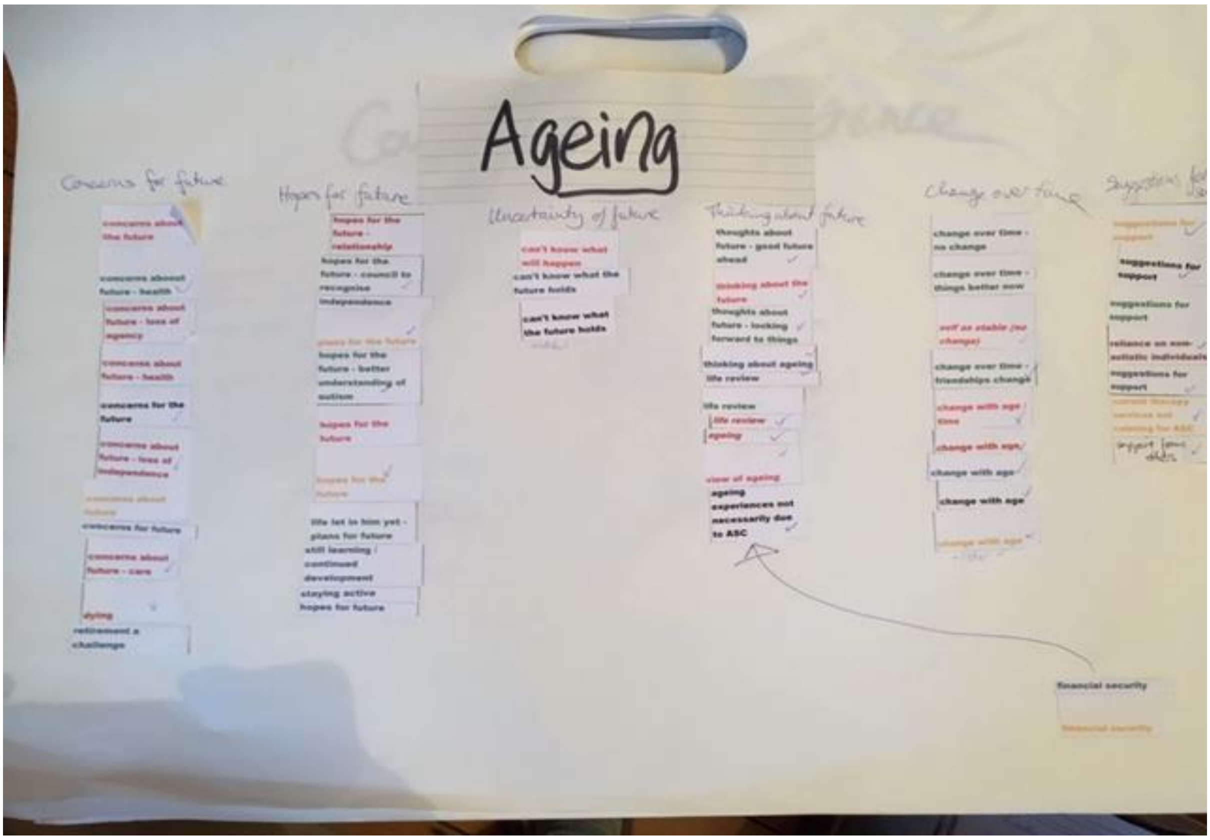
Appendix D.

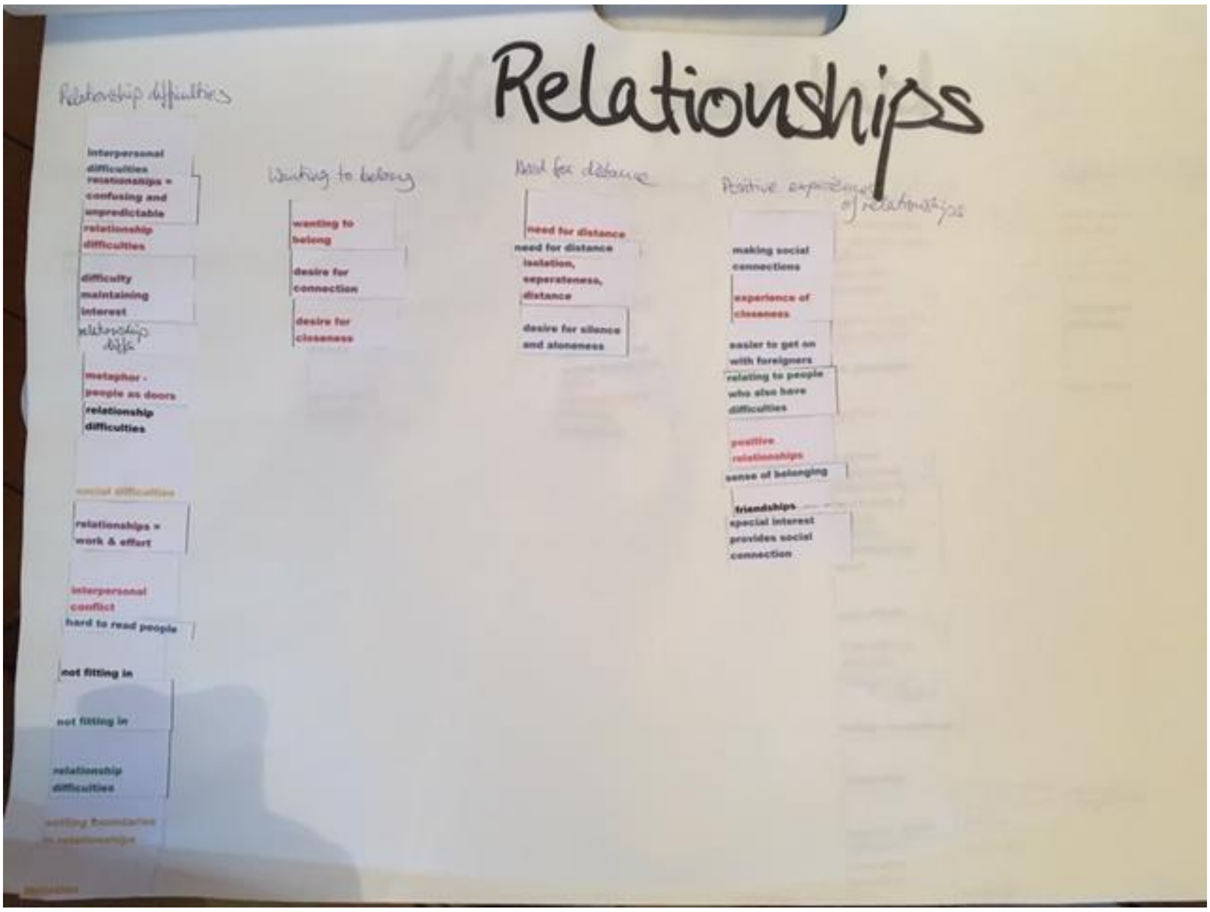
Interview Topic Guide

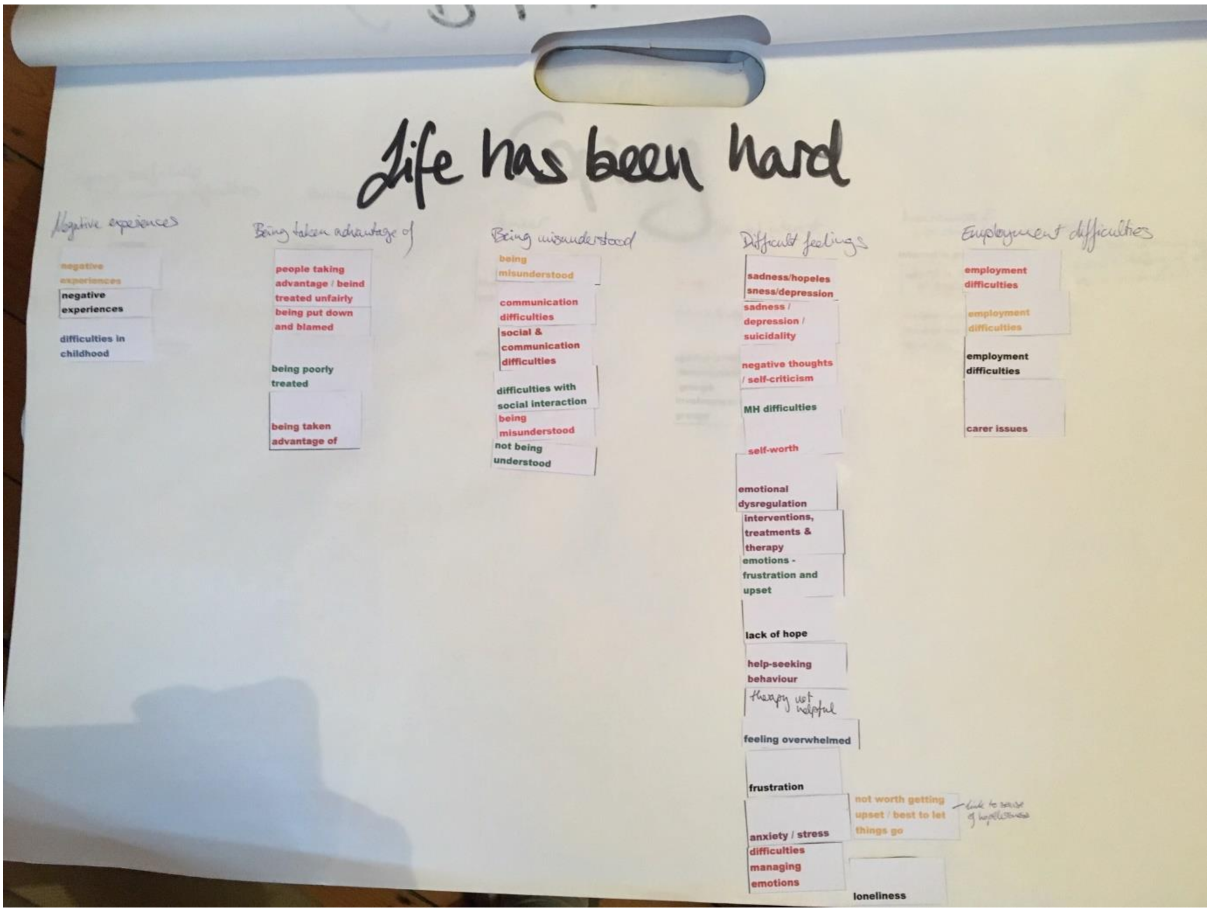
1) **Tell me about life with autism.**
   Prompt: What is it like living with autism?
2) **How has living with autism changed as you have grown older?**
   Prompt: What changes have you noticed?
   Have there been any changes in your relationships/friendships?
3) **Tell me about positive aspects you experience in living with autism.**
4) **Tell me about difficulties you experience in living with autism.**
5) **How do you feel you relate to people?**
   Prompt: Is there a person who is important in your life? Please tell me about them.
   Why are they important to you?
   Do they support you? How?
   Has your relationship with them changed over the years?
   Has the nature of your relationships generally, or the number of your friendships, changed over your life? How? And why?
   How do you see your relationships in the future?
   Do you feel your relationships are different from relationships neuro-typicals your age have? How does this make you feel?
6) **Have you ever struggled with relationships or friendships? How?**
   Prompt: Has this changed with age?
7) **How do you see your future?**
   Prompt: Do you have any fears or concerns?
   Do you have any hopes?
   Who is important to you as you grow older?
8) **How can services best meet the needs of older people like yourself with an ASC diagnosis?**
9) **What should services not do?**

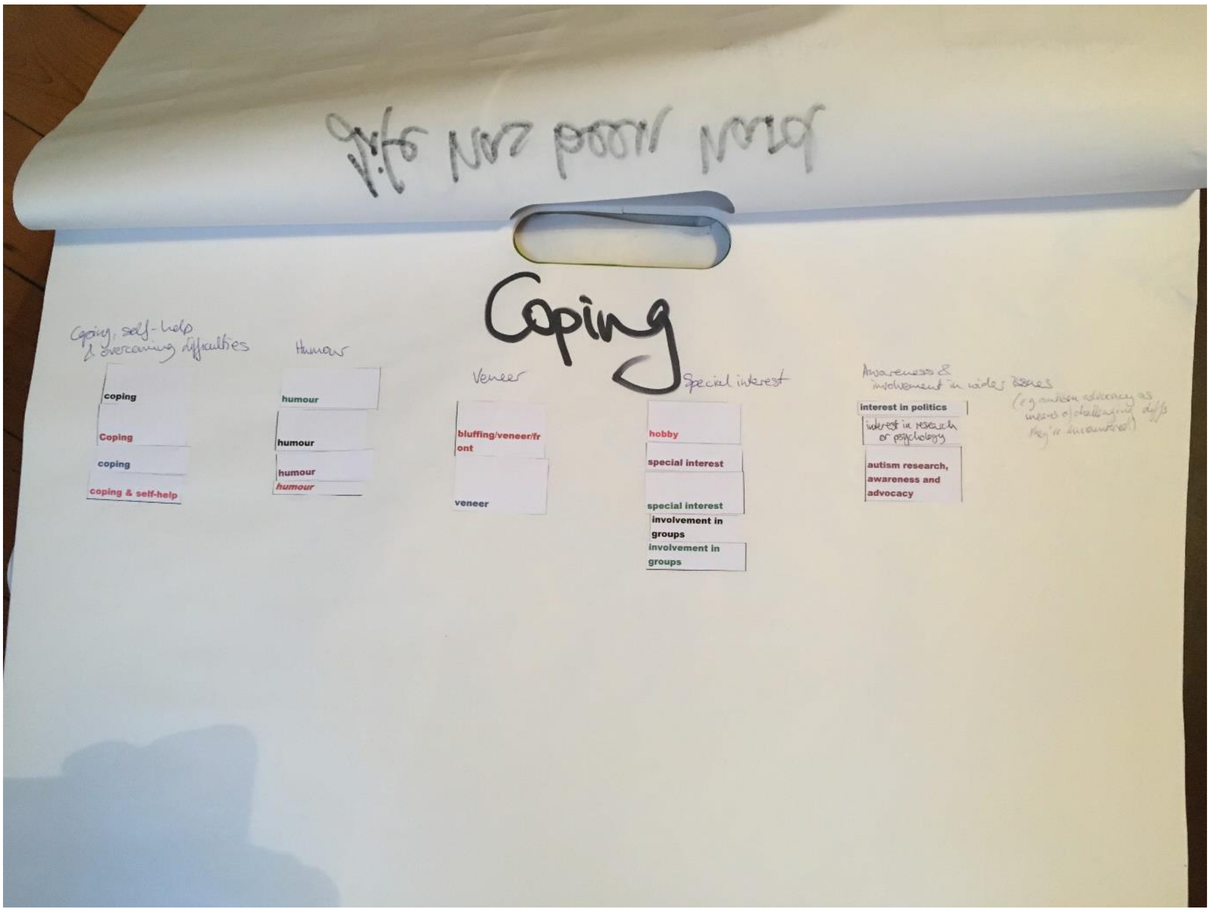
Appendix E.

Visual representation of emergent themes




Relationships
Relationship difficulties
interpersonal difficulties
relationships = confusing and unpredictable
relationship difficulties
difficulty maintaining interest
relationship diffs
metaphor - people as doors
relationship difficulties
social difficulties
relationships = work & effort
interpersonal conflict
hard to read people
not fitting in
not fitting in
relationship difficulties
setting boundaries in relationships
Wanting to belong
wanting to belong
desire for connection
desire for closeness
Need for distance
need for distance
need for distance isolation, seperateness, distance
desire for silence and aloneness
Positive experiences of relationships
making social connections
experience of closeness
easier to get on with foreigners
relating to people who also have difficulties
positive relationships
sense of belonging
friendships
special interest provides social connection


Life has been hard
Negative experiences
negative experiences
negative experiences
difficulties in childhood
Being taken advantage of
people taking advantage / beind treated unfairly
being put down and blamed
being poorly treated
being taken advantage of
Being misunderstood
being misunderstood
communication difficulties
social & communication difficulties
difficulties with social interaction
being misunderstood
not being understood
Difficult feelings
sadness/hopelessness/depression
sadness / depression / suicidality
negative thoughts / self-criticism
MH difficulties
self-worth
emotional dysregulation
interventions, treatments & therapy
emotions - frustration and upset
lack of hope
help-seeking behaviour
therapy not helpful
feeling overwhelmed
frustration
anxiety / stress
difficulties managing emotions
not worth getting upset / best to let things go
link to sense of hopelessness
loneliness
Employment difficulties
employment difficulties
employment difficulties
employment difficulties
carer issues


Coping
Coping, self-help & overcoming difficulties
coping
Coping
coping
coping & self-help
Humour
humour
humour
humour
humour
Veneer
bluffing/veneer/front
veneer
Special interest
hobby
special interest
special interest
involvement in groups
involvement in groups
Awareness & involvement in wider issues
interest in politics
interest in research or psychology
autism research, awareness and advocacy
(e.g. autism advocacy as means of challenging diffs they've encountered)

Appendix F.

Health Research Authority Approval Letter

NHS
Health Research Authority

East of England - Essex Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

<u>Please note</u>: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

18 April 2017

Mrs Alice Harwood
Trainee Clinical Psychologist
North Essex Partnership University NHS Foundation Trust
103 Stapleford Close
Stapleford House
Chelmsford, Essex
CM2 0QX

Dear Mrs Harwood

Study title:	**Ageing with Autism: Experiences of relationships of older individuals with autism spectrum disorder - A participatory research study**
REC reference:	**17/EE/0143**
Protocol number:	**N/A**
IRAS project ID:	**215649**

The Research Ethics Committee reviewed the above application at the meeting held on 06 April 2017. Thank you to you and Dr Danny Taggart for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Review the PIS and correct any typographical errors in the PIS
2. Add additional information to the PIS to make clear that whilst every effort will be made to anonymise quotes, anonymity cannot be guaranteed.
3. Reformat the poster to remove hyphenated words which may look odd to some individuals.
4. Add detail to the poster to clarify the reason for recruiting participants over the age of 55 years.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Summary of discussion at the meeting

- **<u>Social or scientific value; scientific design and conduct of the study</u>**

  The Committee asked who would be transcribing the interviews.

  The applicants said that this would be undertaken by the Chief Investigator.

- **<u>Recruitment arrangements and access to health information, and fair participant selection</u>**

  The Committee noted the recruitment target of 15 participants and asked why this number had been decided upon,

  The applicants said that the clinical contact at the [redacted] had advised that this was a suitable number.

  The Committee asked if recruiting 15 participants would be a high proportion of service users at the [redacted].

  The applicants advised that if it was not possible to achieve the target at the [redacted]*, other recruitment sites had been identified.*

- **Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity**

The Committee noted that interviews would take place in participants' homes and asked how any distress would be dealt with in this environment.

The applicants replied that this had been considered. If a participant chooses to be interviewed at home, Dr Sarah Helps, clinical contact at the [redacted] *has offered to be available on the telephone at the time of the appointment. The Chief Investigator said that her experience in clinical psychology would help her to deal with any situation which arose and distressed participants would be signposted to further support. The participant will be offered the opportunity to contact a family member or friend.*

The Committee asked if there was a possibility of the researcher being at risk and if there was any reason to suggest that stress experienced by a participant may present as aggression.

The applicants said there was no evidence to suggest that people with autism are any more likely to become aggressive than anyone else. The applicants said that a buddying system would be initiated with Dr Sarah Helps and the chief investigator would be checking in and out with her.

Members said the Chief Investigator should be aware of her personal safety.

The applicants said that the [redacted] *has a lone working policy which would be followed.*

☐ **Informed consent process and the adequacy and completeness of participant information**

The Committee noted a number of typographical errors in the PIS and requested that it be reviewed and corrected.

The applicants agreed.

Members noted that quotes might be used in the write up of the study and asked the applicants to add information to the PIS to say that anonymity cannot be guaranteed.

The applicants advised that this information was already noted in the PIS.

In private discussion

The Committee asked for further information to be added to the PS to make clear that whilst every effort will be made to anonymise quotes, anonymity cannot be guaranteed.

☐ **Suitability of supporting information**

Members noted that the poster was written for a high-functioning cohort and queried whether this was suitable for the target participant.

The applicants replied that the study was intended for participants with high functioning autism.

The Committee asked for the poster to be reformatted in order to remove hyphenated words which may look odd to some individuals.

The applicants agreed.

The Committee also noted that the poster invited participants over the age of 55 and asked for detail to be added to clarify the reason.

The applicants agreed.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment Poster]	1	13 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance Cover]	1	14 March 2017
Interview schedules or topic guides for participants [Interview Topic Guide]	1	13 March 2017
IRAS Application Form [IRAS_Form_17032017]		17 March 2017
IRAS Application Form XML file [IRAS_Form_17032017]		17 March 2017
IRAS Checklist XML [Checklist_17032017]		17 March 2017
Letter from sponsor [Confirmation Letter from Sponsor]	1	14 March 2017
Letters of invitation to participant [Participant Cover Letter]	1	13 March 2017
Non-validated questionnaire [Participant Demographics Form]	1	13 March 2017
Participant consent form [Participant Consent Form]	1	13 March 2017
Participant information sheet (PIS) [Participant Information Sheet]	1	13 March 2017
Referee's report or other scientific critique report [Initial Study Proposal Feedback]	1	13 March 2017
Referee's report or other scientific critique report [Initial Study Proposal]	1	13 March 2017
Research protocol or project proposal [Project Proposal]	1	13 March 2017
Summary CV for Chief Investigator (CI) [CV Chief Investigator Alice Harwood]	1	13 March 2017
Summary CV for student [CV Chief Investigator Alice Harwood]	1	13 March 2017
Summary CV for supervisor (student research) [CV Supervisor Danny Taggart]	1	13 March 2017
Summary CV for supervisor (student research) [CV Supervisor Peter Appleton]	1	13 March 2017

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-thehra/governance/quality-assurance/

HRA Training

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

17/EE/0143	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp

Dr Gerry Kamstra
Vice Chair

E-mail: NRESCommittee.EastofEngland-Essex@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Ms Sarah Manning-Press*
[redacted]

East of England - Essex Research Ethics Committee

Attendance at Committee meeting on 06 April 2017

Committee Members:

Name	*Profession*	*Present*	*Notes*
Ms Carol Alves	Research Quality Facilitator	Yes	
Dr Shahira Amr	Pharmacist	No	
Mr Tony Baker	Retired Consultant Head of Medical Physics	Yes	
Dr Niki Bannister	Retired Hospital Doctor	No	
Dr Gerry Kamstra	Retired Solicitor	Yes	Chairing
Ms Julie Lockhart	PPI Representative	Yes	
Ms Sarah Starr	Senior Nurse	Yes	
Dr Andy Stevens	Media Consultant & Retired Principal Lecturer	No	
Mrs Jill Troup	Senior Nurse	Yes	
Dr Nkiruka Umaru	Pharmacist	Yes	

Mrs Melanie Wakelin	Independent Statistical Consultant	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ellen Swainston	REC Manager

Written comments received from:

Name	*Position*
Dr Andy Stevens	Media Consultant & Retired Principal Lecturer

Appendix G.

University of Essex Letter of Ethical Approval

20/07/2017

MISS A. HARWOOD
[redacted]

Dear Alice,

Re: Ethical Approval Application (Ref 16083)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee
Ethics Administrator
School of Health and Human Sciences

cc. Research Governance and Planning Manager, REO
Supervisor

Appendix H.

University of Essex

PARTICIPANT INFORMATION SHEET

Ageing with Autism: Experiences of relationships of older individuals with autism spectrum disorder - A participatory research study

I would like to invite you to take part in a research study. Before you decide whether or not to take part it is important that you understand why the research is being done and what taking part would involve for you. Please take time to read the following information carefully. You can ask questions if anything you read is unclear or you would like more information.

What is the study about?

This study is a piece of research to explore the views of individuals with an Autism Spectrum Conditions as they grow older with a particular focus on interpersonal relationships. There are lots of studies about the experiences of children and young people with autism but few studies have looked at how people aged 55 and above view things. This study will carry out individual interviews to understand relationships older people with ASC have with others. It was designed by the researcher together with a group of individuals who also have an autism condition.

During the study, the researcher will ask you questions about your experiences of ASC, any challenges you may face as you get older and how your relationships with others may have changed as you have aged.

The study is part of the researcher’s doctorate programme in clinical psychology, so it is a requirement for completion of a professional university degree.

Why have I been invited?

This study is interested in older adults with ASC. Individuals over 55 are classified as ‘older’ and as such anyone in this age group is invited to take part. Any person with a diagnosis of high functioning autism or Asperger’s Syndrome over the age of 55 is able to take part. There is no upper age limit.

Do I have to take part?

No, taking part is entirely voluntary. You will be given information about the study and will have the opportunity to ask questions before you decide. I will give you time to think about whether you would like to take part. If you like, you can also discuss this with friends or family or a professional involved in your care.

If you decide to take part, you can tell Dr Sarah Helps or sign the consent slip below and send this to me in the enclosed envelope. You are free to withdraw from the study at any time and you don’t have to give a reason. If you withdraw, any data you have given will be destroyed and your name removed from study lists.

What will happen to me if I take part?

If you agree to take part and have sent the consent form:

- you will be contacted by the researcher to answer any questions
- we will arrange an appointment for the interview – this can be done on a date and time that suits you
- the interview will be held at a location agreed together and will last about 1-2 hours
- the interview will be audio recorded
- after the interview you can ask any questions you may have
- if you are interested in the results you can be sent a summary of these once the study is completed

Where will the interviews be held?

The interview can be held at a location which is convenient and comfortable for you. This could be at your home, at the [redacted] or another local service. The researcher will arrange the best location with you before the interview.

What will happen to the information from the interviews?

All information collected will be held in concordance with the Data Protection Act 1998. The interviews will be audio recorded and transcribed. All information will be strictly confidential and held securely on a password protected computer. Only members of the research team can access your personal data such as your name. However, other individuals will have access to the anonymised interview data but they will not be able to see data that personally identifies you.

In the interview transcripts any identifiable information from the interviews will be disguised so that your identity remains protected. Although every effort will be made to anonymise the data, anonymity cannot be guaranteed completely. Direct quotes from the interviews will be published and whilst we aim to make them unrecognisable, it is possible that such personal quotes could be identified, for example by someone who knows you.

Although the information provided during the interviews will be confidential, there are exceptions when confidentiality may have to be broken. For example, if you told me something that raised concerns about your own or someone else's safety or wellbeing, I would have to speak to someone, such as a mental health professional, about this. These situations are rare and only occur when there is a serious risk to someone's wellbeing or safety.

What will happen to the information once the study is completed?

The audio recordings will be held in a secure locked cabinet and will be destroyed once the study is completed. The interview transcripts will be kept securely for 10 years. The anonymised interview transcripts might potentially be shared with other researchers, or be used as part of future studies.

What about expenses?

Any reasonable travel expenses will be reimbursed. I will also be able to come to a location near to you, so that you won't have to travel too far.

As a thank you for participating you will also be offered a £15 gift voucher.

What are the possible disadvantages of taking part?

- The time it takes (1-2 hours for the interview, plus possible travel)

- Some people may find talking about their condition upsetting (support will be offered if this is the case)

What are the possible benefits of taking part?

- Being part of new research which can help broaden understanding of ASC
- Being able to tell your story and have your voice heard

What will happen to the results of the study?

The results of the study will be written up into a research report which will form part of the researcher's doctoral thesis. The aim is also to submit the results for publication in a professional journal. If you decide to take part, you will be offered a copy of the report, or a summary of this, once the study is complete.

Who is sponsoring the research?

The study is sponsored by the University of Essex.

What if there is a problem?

Support services and helpline numbers will be offered to you after the interview should you wish to speak to someone.
If you have any questions or concerns about the study, you can contact the researcher, Alice Harwood via email: ajmalz@essex.ac.uk
If you continue to have concerns, you can contact Danny Taggart (Clinical Tutor) who is one of the supervisors for this project (University of Essex, Wivenhoe Park, Colchester CO4 3SQ; dtaggart@essex.ac.uk). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Planning Manager, Research Office, University of Essex, Wivenhoe Park, Colchester CO4 3SQ, by emailing: sarahm@essex.ac.uk.

Next Steps

If you wish to participate in the study, please discuss this with Dr Sarah Helps.
Alternatively, you can cut off the slip below and post it in the enclosed Freepost envelope. Please ensure you post this by …………………..
You will then be contacted by the researcher.

✂ ……………………………………………………………………………………………

Ageing with Autism: Experiences of relationships of older individuals with autism spectrum disorder - A participatory research study

I am interested in taking part in the above study. Please contact me to discuss participation.

Name:

Best means of contact:

Post – Please provide postal address ☐

Email – Please provide email address ☐

Phone – Please provide phone number ☐

Appendix I.

University of Essex

PARTICIPANT CONSENT FORM

Ageing with Autism: Experiences of relationships of older individuals with autism spectrum disorder - A participatory research study

Participant ID ☐ Date ☐

Please read each statement carefully and if you agree place your initials after the statement.

1.	I confirm that I have read the information sheet dated.................. for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and I also understand that my withdrawal will not affect my medical care or legal rights.	
3.	I agree to being audio recorded during the interview. I understand that the interviews will be transcribed and that any identifiable information will be removed from the transcripts.	
4.	I agree that anonymous quotes may be used in the research report.	
5.	I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
6.	I understand that the data collected during the study may be looked at by individuals other than the research team, such as members of the university, regulatory bodies or NHS Trusts. I give permission for these individuals to have access to my anonymised data.	
7.	I agree to take part in the above study.	

____________________ _______________ __________________

Name of Participant Date Signature

____________________ _______________ __________________

Researcher Date Signature

1 copy for participant; 1 (original) for researcher

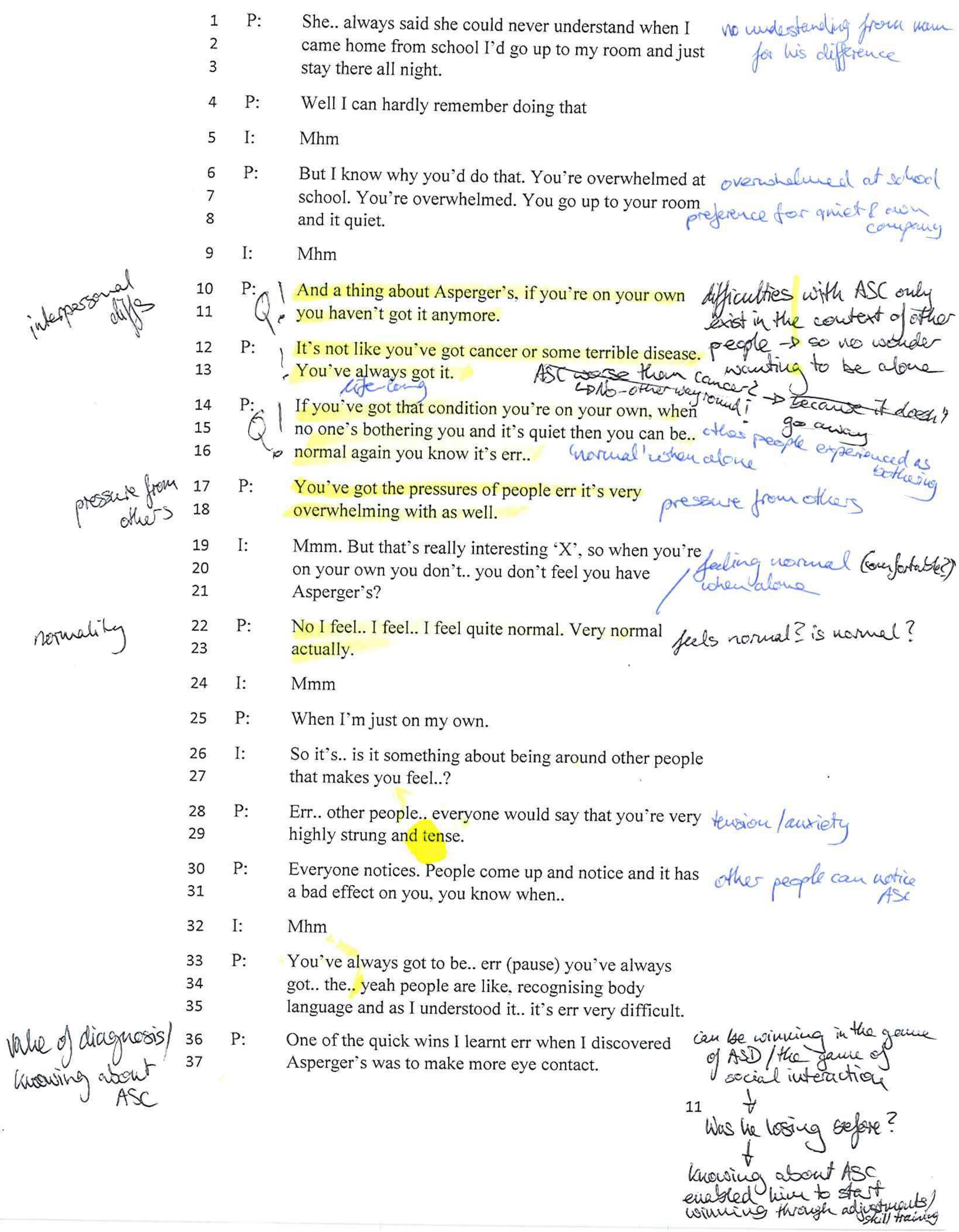
Appendix J.

Table of excluded themes

Theme	Description	Reasons for exclusion
ASC symptoms	Participants describing specific ASC-related symptoms such as literal thinking, difficulties reading social cues, issues with eye contact, specific communication difficulties including difficulties speaking on the telephone, etc.	Felt that, although part of their experience, a list of symptoms did not provide a phenomenological account; symptoms have been widely reported in existing literature
Need for sameness and routine	Descriptions of a need for sameness, rigidity and routine	Similarly to above, aspects widely associated with ASC and frequently reported on before
Use of humour	Subtle evidence of participants' use of humour as a means of connecting with the researcher during interviews	Only evident with few participants and although a felt sense in the interviews, there was little direct evidence of this in transcripts which would have allowed evidenced extracts from the analysis
Employment difficulties	Issues with work and interactional challenges with colleagues	Widely reported in studies which focus on vocational experiences of ASC; incorporated in broader theme of 'negative experiences'
Isolation, people with autism vary, memory issues, continued development, quest for understanding	Individual themes which only arose with a single participant	Individual themes which were classed as minor in that they only arose with a single participant and did not have relevance across interviews; some were included in wider description of other themes

Appendix K.

Extracts of transcripts with coding and emergent themes – Extract from Participant 6



P: She.. always said she could never understand when I came home from school I'd go up to my room and just stay there all night.

no understanding from mum for his difference

P: Well I can hardly remember doing that

I: Mhm

P: But I know why you'd do that. You're overwhelmed at school. You're overwhelmed. You go up to your room and it quiet.

overwhelmed at school
preference for quiet & own company

I: Mhm

interpersonal diffs

P: And a thing about Asperger's, if you're on your own you haven't got it anymore.

Q!

difficulties with ASC only exist in the context of other people → so no wonder wanting to be alone

P: It's not like you've got cancer or some terrible disease. You've always got it.

life-long

ASC ~~worse~~ than cancer? → No - other way round! → ~~because it doesn't~~ go away

P: If you've got that condition you're on your own, when no one's bothering you and it's quiet then you can be.. normal again you know it's err..

Q!

'normal' when alone
other people experienced as bothering

pressure from others

P: You've got the pressures of people err it's very overwhelming with as well.

pressure from others

I: Mmm. But that's really interesting 'X', so when you're on your own you don't.. you don't feel you have Asperger's?

feeling normal (comfortable?) when alone

normality

P: No I feel.. I feel.. I feel quite normal. Very normal actually.

feels normal? is normal?

I: Mmm

P: When I'm just on my own.

I: So it's.. is it something about being around other people that makes you feel..?

P: Err.. other people.. everyone would say that you're very highly strung and tense.

tension / anxiety

P: Everyone notices. People come up and notice and it has a bad effect on you, you know when..

other people can notice ASC

I: Mhm

P: You've always got to be.. err (pause) you've always got.. the.. yeah people are like, recognising body language and as I understood it.. it's err very difficult.

value of diagnosis / knowing about ASC

P: One of the quick wins I learnt err when I discovered Asperger's was to make more eye contact.

can be winning in the game of ASD / the game of social interaction
↓
Was he losing before?
↓
knowing about ASC enabled him to start winning through adjustments / skill training

11

I: Mhm

P: Because I never made eye contact. I'd be looking right down most of the time.

repetition – people turn bad
Has he been treated badly?

I: Mhm

P: Doing this. That has a bad effect on people because they think you're.. they're either boring you or you're not paying attention.

people misinterpret ASC symptoms

I: Mhm

P: But if you.. the difference if you can maintain some sort of eye contact there's a fundamental difference to suddenly

things change with conscious skill training / adjustment

I: Mmm

P: It's err. It's very subtle.

P: So, there was that so.. but I couldn't wait to leave home, basically.

wanting change & independence

I: Mhm

P: (Laughs) it was a new adventure. Because the other thing around 18.. I had no idea, I thought everybody else was wrong, it was me that was normal.

What is normality?

↳ if you're not normal, you're 'wrong'

externalising his difficulties
↳ coping mechanism?
'I'm normal, they're not'
maybe he's right – who is to say what's normal? Why should he have to change?

I: Mhm

P: It was just everybody else didn't get me you know.. yeah.. that's it (chuckles).

I: Mhm

P: But I was going to London I'd meet people, normal people, and then everything would be ok.

hopes when he was young

locating problem in others – if only I can be around different people, it'll be ok

I: So that's what you did, you went to London?

P: And. I went to London, yeah. And it's.. well.. it started very well but then all the problems that I had before then err.. then resurfaced.

running away from problems didn't work

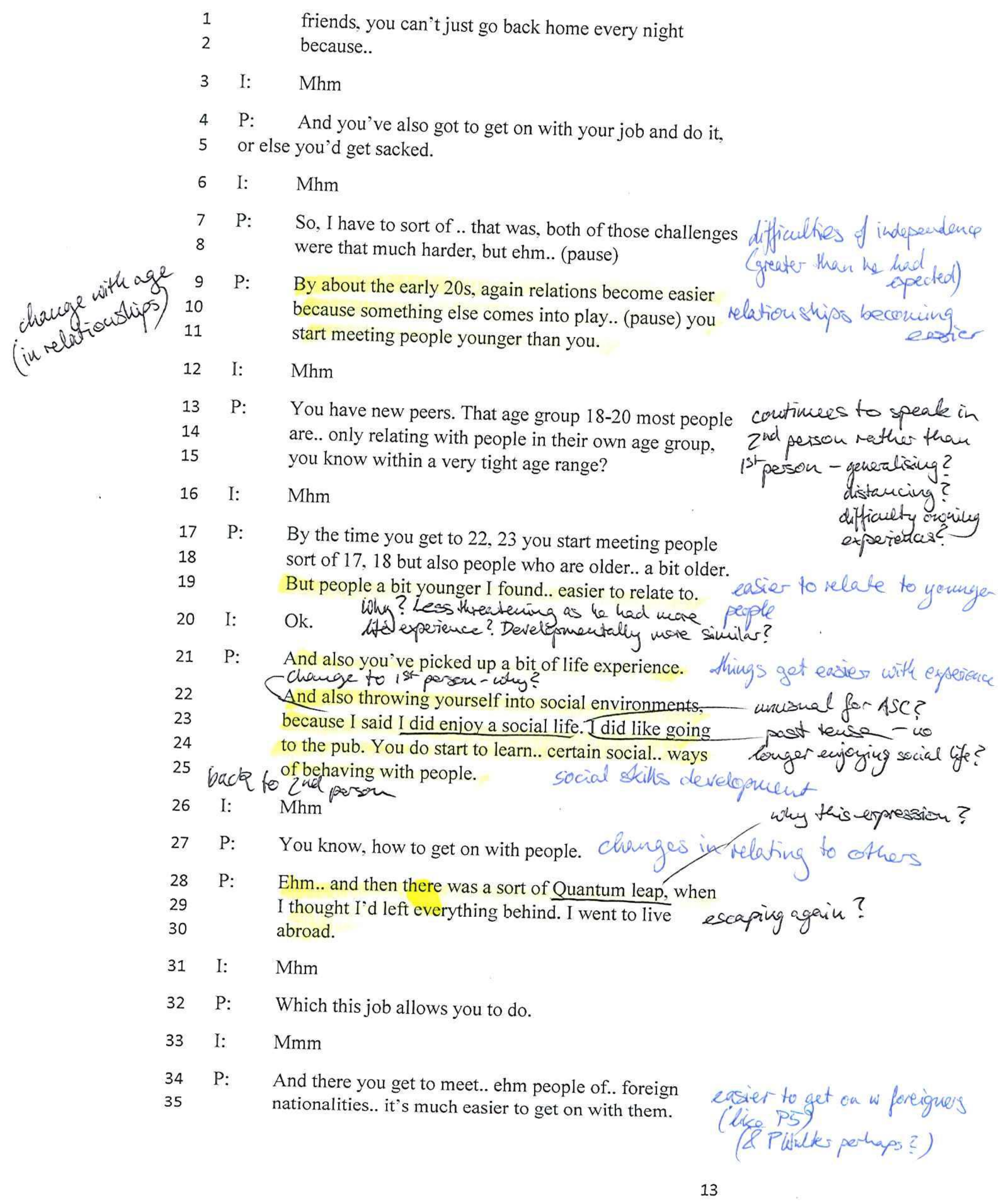
P: And it effected the work as well, I couldn't organise my workload which was another problem with disorganisation.

ASC difficulty

I: Mhm

P: I couldn't prioritise.

And unlike most people I had two challenges. (Pause) You go to a new place you've got to fit in and make



friends, you can't just go back home every night because..

I: Mhm

P: And you've also got to get on with your job and do it, or else you'd get sacked.

I: Mhm

P: So, I have to sort of .. that was, both of those challenges were that much harder, but ehm.. (pause)

difficulties of independence (greater than he had expected)

P: By about the early 20s, again relations become easier because something else comes into play.. (pause) you start meeting people younger than you.

change with age (in relationships)

relationships becoming easier

I: Mhm

P: You have new peers. That age group 18-20 most people are.. only relating with people in their own age group, you know within a very tight age range?

continues to speak in 2nd person rather than 1st person – generalising? distancing? difficulty owning experiences?

I: Mhm

P: By the time you get to 22, 23 you start meeting people sort of 17, 18 but also people who are older.. a bit older. But people a bit younger I found.. easier to relate to.

easier to relate to younger people

I: Ok.

Why? Less threatening as he had more life experience? Developmentally more similar?

P: And also you've picked up a bit of life experience. And also throwing yourself into social environments, because I said I did enjoy a social life. I did like going to the pub. You do start to learn.. certain social.. ways of behaving with people.

things get easier with experience

change to 1st person – why?

unusual for ASC?

past tense – no longer enjoying social life?

back to 2nd person

social skills development

I: Mhm

P: You know, how to get on with people.

changes in relating to others

P: Ehm.. and then there was a sort of Quantum leap, when I thought I'd left everything behind. I went to live abroad.

why this expression?

escaping again?

I: Mhm

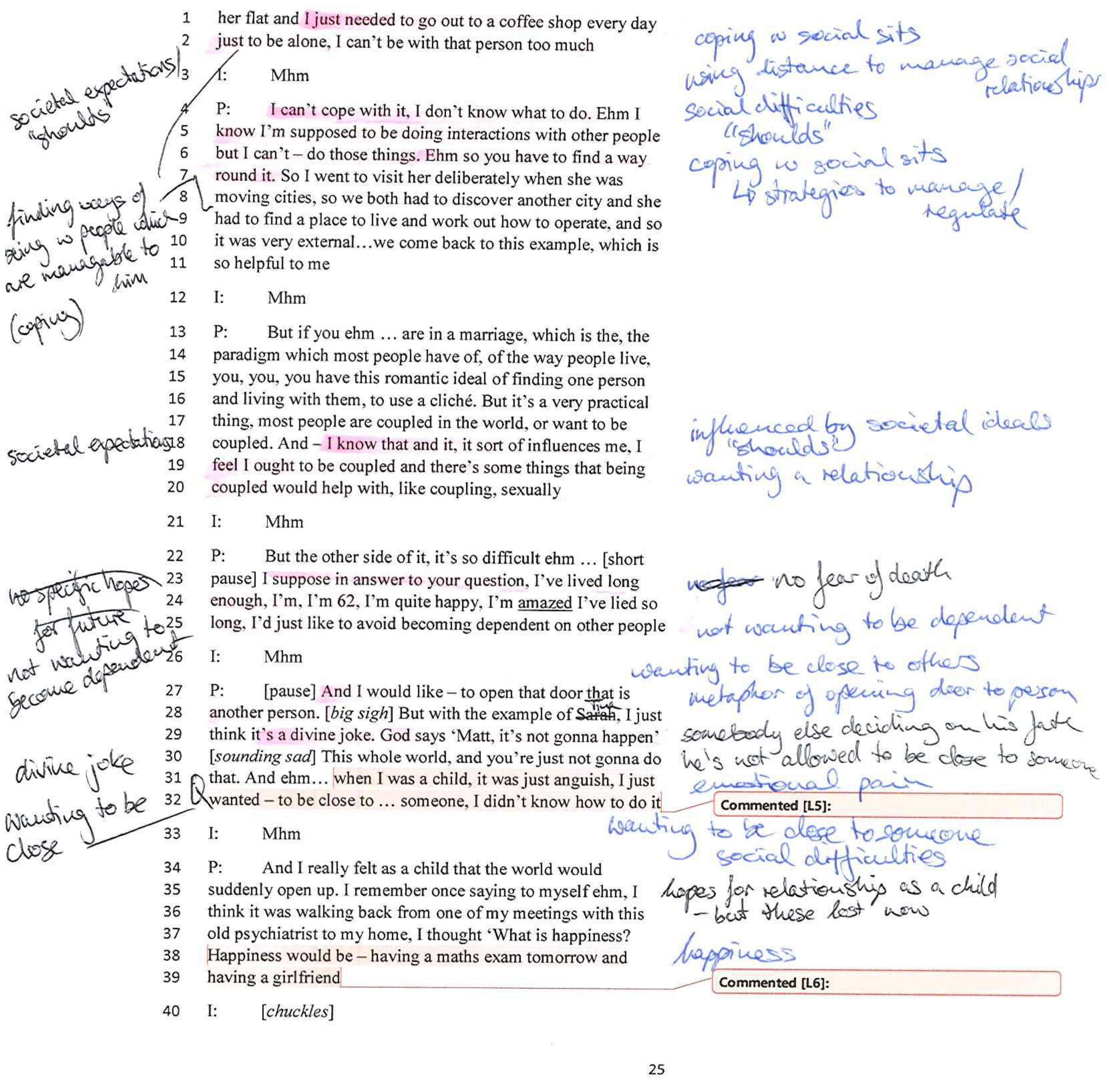
P: Which this job allows you to do.

I: Mmm

P: And there you get to meet.. ehm people of.. foreign nationalities.. it's much easier to get on with them.

easier to get on w foreigners (like P5) (& PWilks perhaps?)

Extract from Participant 5



her flat and I just needed to go out to a coffee shop every day just to be alone, I can't be with that person too much

coping w social sits
using distance to manage social relationships

I: Mhm

P: I can't cope with it, I don't know what to do. Ehm I know I'm supposed to be doing interactions with other people but I can't – do those things. Ehm so you have to find a way round it. So I went to visit her deliberately when she was moving cities, so we both had to discover another city and she had to find a place to live and work out how to operate, and so it was very external…we come back to this example, which is so helpful to me

societal expectations/
"shoulds"

finding ways of being w people which are managable to him
(coping)

social difficulties
"shoulds"
coping w social sits
↳ strategies to manage/regulate

I: Mhm

P: But if you ehm … are in a marriage, which is the, the paradigm which most people have of, of the way people live, you, you, you have this romantic ideal of finding one person and living with them, to use a cliché. But it's a very practical thing, most people are coupled in the world, or want to be coupled. And – I know that and it, it sort of influences me, I feel I ought to be coupled and there's some things that being coupled would help with, like coupling, sexually

societal expectations

influenced by societal ideals
"shoulds"
wanting a relationship

I: Mhm

P: But the other side of it, it's so difficult ehm … [short pause] I suppose in answer to your question, I've lived long enough, I'm, I'm 62, I'm quite happy, I'm amazed I've lied so long, I'd just like to avoid becoming dependent on other people

no specific hopes for future
not wanting to become dependent

~~no fear~~ no fear of death
not wanting to be dependent

I: Mhm

P: [pause] And I would like – to open that door that is another person. [*big sigh*] But with the example of ~~Sarah~~ Tina, I just think it's a divine joke. God says 'Matt, it's not gonna happen' [*sounding sad*] This whole world, and you're just not gonna do that. And ehm… when I was a child, it was just anguish, I just wanted – to be close to … someone, I didn't know how to do it

divine joke
wanting to be close

wanting to be close to others
metaphor of opening door to person
somebody else deciding on his fate
he's not allowed to be close to someone
emotional pain

Commented [L5]:

wanting to be close to someone
social difficulties

I: Mhm

P: And I really felt as a child that the world would suddenly open up. I remember once saying to myself ehm, I think it was walking back from one of my meetings with this old psychiatrist to my home, I thought 'What is happiness? Happiness would be – having a maths exam tomorrow and having a girlfriend

hopes for relationship as a child
– but these lost now

happiness

Commented [L6]:

I: [*chuckles*]

25

P: I had lots of maths exams [*chuckles*] but I never managed – to do that, to have a girlfriend.

never managed to have a relationship

I: [short pause] Would you still describe the feeling of 'anguish' – now?

Change w age – turning anguish into sth productive

P: [long pause] Yeah but I've turned it into something productive, as one should do. Ehm … one of the things I've spent the last 25 years doing ehm is … ehm … one of my companions, one of my friends is John Keats, long dead, but he is my constant companion. And he lived in several houses and two survive and so the last 25 years I've been trying to get them into trust cause he's a really important person, he asks great questions, and ehm … Two years ago I managed to get the cottage, the minor one into trust

turning neg. emotions into sth else
"should"

special interest

I: Mhm

P: So I've been dealing with that project. But the really difficult one is London. But I've had rooms in his London house and the rooms are there so that people come and I meet people, they pass through. It's an opportunity to meet people I find interesting because they are interested in John Keats too, they are radical people, they're poets, they're artists, that, they challenge the world!

keeping busy

finding ways of connecting to people

admiration for those people

I: Mhm

P: They don't take the nonsense that is imposed upon them. So it's been rather like a filter. I've used as an opportunity to try to meet people I might be close to! And over the years I've met some remarkable people, and some people I really wanted to solve that anguish with and … one or two people, the woman in America, she was a Keats scholar. So I court, I went out with this elaborate way of trying to get close to another human being and ehm … the door – opened and I can't keep it opened. ~~So it opened, and my world expands, I~~ visit America, another person shows you their enthusiasm, you share your enthusiasms with them – but keeping that door open – after a while people know there's something missing that I, emotions, I'm bluffing

using special interest groups for social contact

wanting to be close to people

being close to others = world expands

occasionally able to establish relationships but not able to maintain those

! ('not able to keep door open' → such anguish

veneer

Commented [L7]:

bluffing emotions

I: Mhm

P: They're not there – in a way that I can articulate. I'm not saying I don't have emotions but I

difficulties articulating emotions (not non-existent)

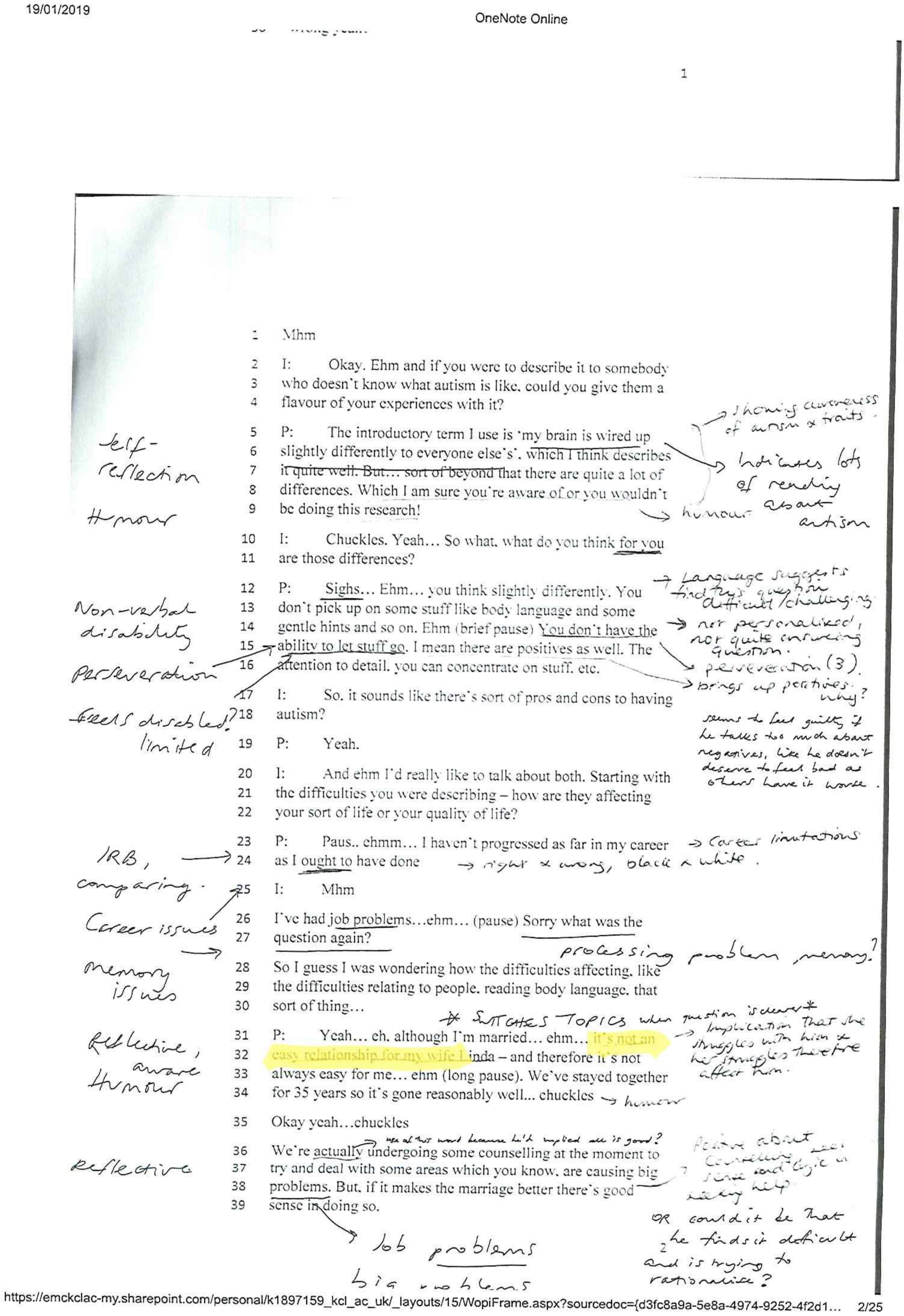
I: Mhm

P: I can't articulate them in a way that is satisfactory to another person. And ehm many of the things that other people

difficulty is articulating emotions

relationship diffs

Extracts from participatory researcher (Participant 2)



Mhm

I: Okay. Ehm and if you were to describe it to somebody who doesn't know what autism is like, could you give them a flavour of your experiences with it?

P: The introductory term I use is 'my brain is wired up slightly differently to everyone else's', which I think describes ~~it quite well. But… sort of beyond~~ that there are quite a lot of differences. Which I am sure you're aware of or you wouldn't be doing this research!

self-reflection

Humour

→ showing awareness of autism & traits.

→ indicates lots of reading about autism

→ humour

I: Chuckles. Yeah… So what, what do you think for you are those differences?

P: Sighs… Ehm… you think slightly differently. You don't pick up on some stuff like body language and some gentle hints and so on. Ehm (brief pause) You don't have the ability to let stuff go. I mean there are positives as well. The attention to detail, you can concentrate on stuff, etc.

Non-verbal disability

Perseveration

Feels disabled? limited

→ Language suggests finds this question difficult/challenging

→ not personalised, not quite answering question.

→ perseveration (3).

→ brings up positives. why?

seems to feel guilty if he talks too much about negatives, like he doesn't deserve to feel bad as others have it worse.

I: So, it sounds like there's sort of pros and cons to having autism?

P: Yeah.

I: And ehm I'd really like to talk about both. Starting with the difficulties you were describing – how are they affecting your sort of life or your quality of life?

P: Paus.. ehmm… I haven't progressed as far in my career as I ought to have done

→ Career limitations

→ right & wrong, black & white.

IRB, comparing.

Career issues

I: Mhm

I've had job problems…ehm… (pause) Sorry what was the question again?

processing problem, memory?

memory issues

So I guess I was wondering how the difficulties affecting, like the difficulties relating to people, reading body language, that sort of thing…

P: Yeah… eh, although I'm married… ehm… it's not an easy relationship for my wife Linda – and therefore it's not always easy for me… ehm (long pause). We've stayed together for 35 years so it's gone reasonably well... chuckles → humour

* SWITCHES TOPICS when question is clearer *

→ Implication that she struggles with him & her struggles therefore affect him.

Reflective, aware Humour

Okay yeah…chuckles

We're actually undergoing some counselling at the moment to try and deal with some areas which you know, are causing big problems. But, if it makes the marriage better there's good sense in doing so.

→ use of this word because he'd implied all is good?

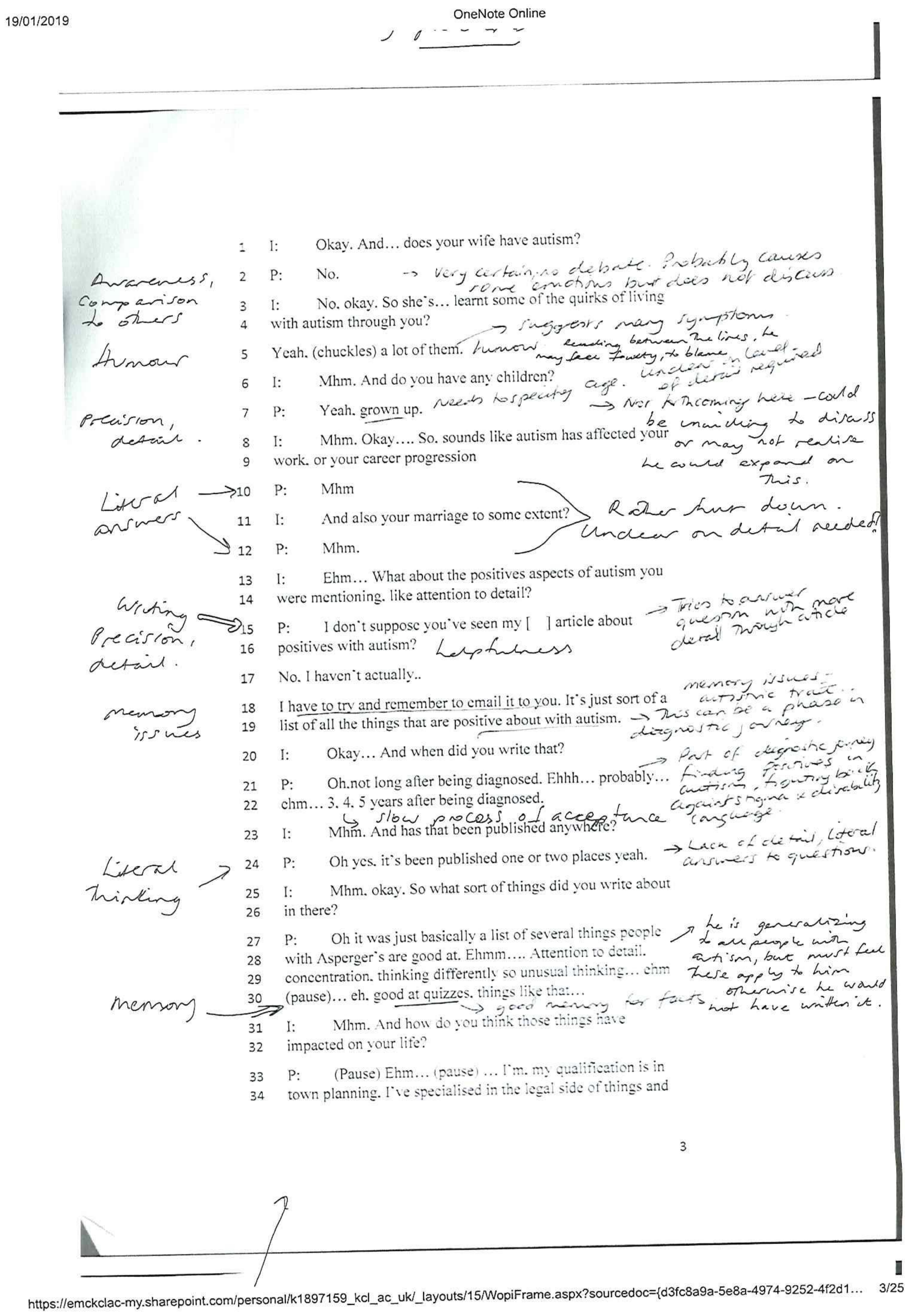
Reflective

Positive about counselling, sees sense and logic in seeking help

OR could it be that he finds it difficult and is trying to rationalise?

Job problems

big problems



19/01/2019 OneNote Online

I: Okay. And… does your wife have autism?

P: No. → Very certain, no debate. Probably causes some emotions but does not discuss.

Awareness, Comparison to others

I: No. okay. So she's… learnt some of the quirks of living with autism through you?

Yeah. (chuckles) a lot of them. humour → suggests many symptoms. reading between the lines, he may face anxiety, to blame

Humour

I: Mhm. And do you have any children? Unclear on level of detail required

P: Yeah. grown up. needs to specify age. → Not forthcoming here – could be unwilling to discuss or may not realise he could expand on this.

Precision, detail.

I: Mhm. Okay…. So. sounds like autism has affected your work. or your career progression

P: Mhm

I: And also your marriage to some extent?

P: Mhm.

Rather shut down. Unclear on detail needed!

Literal answers

I: Ehm… What about the positives aspects of autism you were mentioning. like attention to detail?

P: I don't suppose you've seen my [ ] article about positives with autism? helpfulness → Tries to answer question with more detail through article

Writing

Precision, detail.

No. I haven't actually..

I have to try and remember to email it to you. It's just sort of a list of all the things that are positive about with autism. memory issues – autistic trait. → This can be a phase in diagnostic journey.

memory issues

I: Okay… And when did you write that?

P: Oh.not long after being diagnosed. Ehhh… probably… ehm… 3. 4. 5 years after being diagnosed. → Part of diagnostic journey finding positives in autism, fighting back against stigma & disability language.

↳ slow process of acceptance

I: Mhm. And has that been published anywhere?

P: Oh yes. it's been published one or two places yeah. → Lack of detail, literal answers to questions.

Literal thinking

I: Mhm. okay. So what sort of things did you write about in there?

P: Oh it was just basically a list of several things people with Asperger's are good at. Ehmm…. Attention to detail. concentration. thinking differently so unusual thinking… ehm (pause)… eh. good at quizzes. things like that… → good memory for facts

↗ he is generalizing to all people with autism, but must feel these apply to him otherwise he would not have written it.

Memory

I: Mhm. And how do you think those things have impacted on your life?

P: (Pause) Ehm… (pause) … I'm. my qualification is in town planning. I've specialised in the legal side of things and

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