Surviving or Thriving: A Constructivist Grounded Theory Study Exploring the Wellbeing of Older Autistic Adults

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Abstract

The British Medical Association (BMA) estimates around 1% of the UK population to be autistic (BMA, 2021). Despite autism being a lifelong condition (UK Gov, 2021) much of current autism research is focused on children. There is a paucity of research with older autistic adults (Mason *et al*. 2022. Mukaetova-Ladinska *et al.* 2012). There is a growing awareness of the richer perspective qualitative studies can provide into the lived experience of autistic individuals particularly in reference to unknown and underexplored areas (Schalkwyk & Dewinter, 2020). However, there is a lack of qualitative research exploring the views and experiences of autistic participants (Bolte, 2014, Pellicano *et al*. 2014).

Unfortunately, life expectancy and quality of life are significantly lower for autistic people than their neurotypical counterparts (Hirovikoski *et al.* 2016), and suicide is a much bigger risk within the autistic community (Cassidy *et al.* 2014, Cassidy *et al*. 2022, Mason *et al*. 2018). The purpose of this research is to explore the most important factors that assist autistic older adults in maintaining their own personal physical and mental wellbeing. This research answers international calls for research on issues affecting older autistic adults (Mason *et al*. 2022. Mukaetova-Ladinska *et al.* 2012. Piven & Rabins, 2011).

This thesis presents a constructivist grounded theory (Charmaz, 2006) project exploring factors that enable and inhibit the wellbeing of older autistic adults (aged 50+). In-depth semi-structured interviews which incorporated a person-centred design were conducted (17) with 14 older autistic adults (without an intellectual disability). Wellbeing experiences were analysed and highlighted a distinction: participants either ‘thrived’ or ‘survived’ post-diagnosis. The grounded theory presented in this thesis, ‘the thriving cycle’ proposes that for autistic older people to live well following a diagnosis, they need to thrive. The theory indicates what facilitating factors enable autistic older adults to thrive. This would lead to increased confidence and self-efficacy with increased feelings of empowerment which contribute to enhanced wellbeing.

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I dedicate this thesis to all the wonderful autistic people that I know and have met along this journey.

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1.1 Introduction

The purpose of this chapter is to contextualise the thesis. It starts with a brief discussion of the conceptualisation of autism including details of key terms and language used within the thesis. Following this is a rationale of why this study is needed. Then a reflective statement regarding my prior experiences, influences and motivations for the study. I then outline the aims and research question. The chapter concludes with a brief synopsis of each of the subsequent chapters of the thesis.

1.2 What is Autism?

> *If you have met one autistic person, you have met one autistic person.* (Dr Stephen Shore, 2001)

This oft cited quote about autism (McCall, 2017) emphasises the great diversity of the autism. Autistic people may share some commonalities, such as differences in communication, social interaction, sensory receptivity and highly focused interests, however it is very important to recognise that the constellation of these characteristics blend together differently for each autistic person (Fletcher-Watson & Happé, 2019).

Autism is a complex human phenomenon. There are behavioural explanations, biological explanations, cognitive explanations and societal explanations. Indeed, there is much discourse about the way in which autism should be conceptualised. The way in which understanding and perception of autism is perceived and understood is constantly evolving, and this study serves to add to our growing knowledge base and further enhance understanding of the autistic experience.

In 2013 when I was first examining the literature and was planning this research, autism was described and viewed in a distinctly different way than it is in 2022. The way autistic people experience the world has not changed, but during the intervening period, great change has occurred in the way that autism is conceptualised. As such definitions used to describe autism have altered. This is reflective of the significant strides made in socio-political theorising about autism as well as public awareness and acceptance.

> *Led by autistic advocates, community leaders and scholars, we now find ourselves at a turning point in the conceptualization of autism. Autistic people have become pioneers of the disability rights agenda, emphasizing a social model of disability and demanding a role in shaping the policies and services that affect their lives.* (Fletcher-Watson & Happé, 2019:22).

In 2013, at the start of this study, definitions of autism tended to be deficit focused and mainly presented through the lens of medical model of disability. They were formulated with little (if any) consultation with autistic people. They used what may be considered today as inappropriate language such as terms like ‘high and ‘low’ functioning (Williams, 2019) and person first language which is now also unpopular (Hearst, 2015; Kenny, 2016; Sinclair, 2013). This was because autism research had mainly been viewed from the neurotypical observer, and the research world has neglected to speak to autistic people about their experiences. Donna Williams, a famous autistic advocate and prolific author eloquently outlined this unsatisfactory situation:

> *Right from the start, from the time that someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the insider according to how it is experienced.* (Williams, 1996:14).

There has been much progress since this time. Autistic advocates, community leaders and scholars (both autistic and neurodivergent) are contributing to a new conceptualisation of autism. Therefore, autism definitions at the time of writing (2021) are distinctly different. They reflect the varied way in which autistic people experience the world and the language used has been selected based on consultation with the autistic community (Kenny *et al*. 2016).

However, this is not a universal change and there are some disciplines, research areas and countries that are still to catch up with the fast-paced changes that are occurring. However, notable UK organisations, such as the Department of Health have started to alter the way in which they describe autism. To illustrate this, I include the definition of autism used in 2010 in the first autism strategy (see box 1) and the broader more nuanced definition used in the 2021 autism strategy reflecting the variation of experience of autistic people (see box 2).

Box 1: Description of Autism given in Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010) Department of Health

For the purposes of this strategy, autism is defined as a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which *all people with autism* share, are known as the ‘triad of impairments. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- social interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own)
- social imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine).

Many *people with autism* may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People *with autism* often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many *people with autism* may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia. Autism is known as a spectrum condition, both because of the range of difficulties that affect *adults with autism*, and the way that these present in different people. For example, Asperger syndrome is a form of autism. *People with Asperger syndrome* typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.

Box 2: Definition of Autism from the National Autism Strategy for Autistic Children, Young People and Adults 2021 to 2026. (2021)

Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all *autistic people* see themselves as disabled. With an estimated 700,000 autistic adults and children in the UK – approximately 1% of the population – most people probably know someone who is autistic. In addition, there are an estimated three million family members and carers of *autistic people* in the UK (National Autistic Society).

Autistic people see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives. While autism is not a learning disability, around 4 in 10 *autistic people* have a learning disability (Autistica).

Some autistic people will need very little or no support in their everyday lives while others may need high levels of care, such as 24-hour support in residential care. People may need help with a range of things, from forming friendships, coping at school, managing at work, or being able to get out and about in the community. In this strategy, we also talk about neurodiversity, which refers to the different ways the brain can work and interpret information. It is estimated that around 1 in 10 people across the UK are neurodivergent, meaning that the brain functions, learns and processes information differently (Embracing Complexity Coalition, 2019).

1.2.1 A Note on Language

The language used to describe autism has been under intense debate (Gernsbacher, 2017; Kenny *et al*. 2016,) and there is divided opinion amongst the UK autism community members: autistic people, parents and their broader support network. As such I consulted with the participants in this study regarding their preferences. A number of participants had no preference on language use, but those that expressed a preference felt that identity first language e.g. autistic person (Brown, 2011) should be used along with the terms neurodiverse and neurotypical to refer to the autistic and non-autistic population respectively. A preference against the use of functioning labels (e.g. high and low functioning) was also expressed. As such I have respected the wishes of my participants and used terminology in line with their preferences throughout this thesis.

1.3 Autism Prevalence

The National Autistic Society (in 2012) estimated that approximately 1% of children and adults in the UK population were autistic (600,000) (Happé, 2012). The British Medical Association (BMA) also estimate it to be around 1% in 2021 (BMA, 2021). There is currently no accurate data on the size of the diagnosed autistic adult population. However, autism is now known to be lifelong with comparable prevalence rates throughout the lifespan (Brugha *et al*. 2012). Therefore, it means that approximately 1% of the older adult population will also be autistic. There are nearly 12 million (11,989,322) people aged 65 and above in the UK (Age UK, 2019) hence approximately 120,000 over 65s will be autistic (diagnosed and undiagnosed).

1.3.1 Why Is a Greater Understanding of the Wellbeing of Autistic People Necessary?

In 2010 the Department of Health (DoH) published *'Fulfilling and Rewarding Lives: The strategy for adults with autism in England* in recognition of the difficulties faced by autistic adults:

> *…we know that adults with autism remain socially and economically excluded. They, and the people who care for them, have often been badly let down by public services which have failed to recognise or respond to their needs.* (Department of Health, 2010:6)

In the same document the DoH set out their vision to remedy this:

> *All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.* (DoH, 2010:6)

Much change is still required. Though autism was first described almost 80 years ago, and the first autism UK strategy was laid out twelve years ago, there remains a distinct lack of knowledge regarding autism amongst professionals, services and the general public. In 2019 a public call for evidence was launched with autistic people, their families and carers, professionals, and voluntary organisations. The results of this report indicated that although there had been some change since the 2009 Autism Act that there was still overwhelming unmet need caused in part by a widespread lack of understanding of autism:

> *.. the overwhelming picture that emerged is one of deeply concerning unmet need. Many thousands of autistic people who need support in the classroom, at home, at work and in every aspect of everyday life, simply are not getting it. These unmet needs stem from poor autism understanding by professionals and low awareness of the duties that are included in the Autism Act. But… these factors are having a profoundly negative impact on the lives of the 600,000 autistic people in England and their families. Too many are facing unacceptable health inequalities and are at risk of falling into mental health crisis or social isolation and of dying early. The APPGA Autism Act Inquiry Report* (National Autistic Society, 2019:4)

In 2021 the new autism strategy set its focus as improving the lives of autistic people through six main themes. The first being *'improving **understanding** and **acceptance** of autism within society'.*

> *By 2026, we want to demonstrate that we have significantly improved public understanding and acceptance of autism, and that autistic people feel more included in their communities and less lonely and/or isolated. We want the public to have a better understanding of autism and to have changed their behaviour towards autistic people and their families.* (DoH & Social Care and Department of Education. 2021:12)

This serves as confirmation that there still needs to be a greater understanding and acceptance of autistic people in society. Insights into lived experience of autistic people are undoubtedly required if professionals and the general public are to try '*accept and understand'* autistic people.

1.4 Reflective Account Outlining the Motivation for the Study

This following reflexive statement details my professional experience, my personal motivations and my influences in this research area. I outline these here and acknowledge that they all played a part in influencing this study.

Autism has always been an intriguing phenomenon for me, I am a psychology graduate and neurological difference had always fascinated me. However, it was only when autism touched my personal life that my desire for an in-depth understanding grew. I am also a qualified teacher who had worked in both primary and secondary settings with a particular interest in special educational needs. During my social research MSc. I focused my dissertation on a learning support unit within a high school (Schroeder, 2015). Latterly I moved from education into a career in health care research and at around the same time we received an autism diagnosis in the family. Prior to this, autism for me was one of those things that I knew about (or I thought I did). I had spoken about it with teacher colleagues, had supported autistic children and I believed I was sensitive to the needs of autistic people. I found autism fascinating and had watched many stereotypical portrayals of autism in the media. However, the impact of a family diagnosis caused me to reflect on how little I understood about autism and started my journey to seek knowledge and gain a better understanding.

1.4.1 Family Experience

I began to realise and be frustrated by the fact that there was little understanding of autism amongst my colleagues (educational and health professionals) or the general public (myself included). I observed how neurotypical people seemed to fixate onto stereotypical portrayals of autism from the media such as savant autistics or aggressive and dangerous people (Draaisma, 2009; Huws & Jones, 2011; Jones & Harwood, 2009). This clearly has a damaging social effect for autistic people and causes barriers to a broader understanding and acceptance of autism (Berryessa, 2014; Draaisma, 2009). The nuanced difficulties in life that our family member experienced were incredibly problematic to explain to people. The fact that our family member is intelligent, in employment, has friends, does not have any savant skills and is able to live independently and is not 'obviously' autistic made it hard to convey how autism had an impact on his/her life. The subtle difference of his/her communication and the fact that our family member looked and acted in a neurotypical way made it incredibly hard for people to understand or accept his/her neurodiversity.

1.4.2 Autistic Voices

Through trying to increase my own knowledge about autism I became familiar with reading and hearing proxy descriptions of autism from medical professionals, parents and teachers. It was only when I attended my first autism conference that I started to hear some very eloquent and insightful personal accounts of being autistic. This highlighted to me how personal lived experiences of autistic people were distinctly different from the proxy descriptions I had read in the literature. Individual accounts clarified how autism personally affected the individuals and how they experienced life.

This emphasised to me the fundamental importance of listening and learning from the lived experience of autistic people. A revelation that I am now a little embarrassed about, as of course it should have been so obvious! I began searching for research which included autistic voices and was frustrated to find very few studies. Indeed, the dearth of this type of research is highlighted by several researchers who have called for more research from the perspective of autistic people (Bolte, 2014; Carrington & Graham, 2001; Happé, 2012; Huws & Jones, 2008; Griffith *et al.* 2012; Pellicano *et al*. 2014; Piven & Rabins, 2011). Historically autism research has side-lined potential valuable insights from qualitative and/or participatory studies (Bolte, 2014; Milton, 2012). This is despite protest from the autistic community under the political slogan of '*nothing about us without us' (ASAN, 2021).*

I found many extremely interesting published 'autobiographies' available (Grandin, 1995; Jackson, 2002; Lawson, 2000; Shore, 2001; Williams, 1992, 1994). These provided me with insights into daily life and experience of the autistic authors. They were much more positive than the outcomes reported in the quantitative research literature. The autobiographical accounts highlighted aspects of autism that they felt enhanced their skills and contributed to their wellbeing. This was another revelation to me as previously I had only ever read about negative/deficit aspects of autism. It occurred to me that autistic people had acquired a vast wealth of knowledge and experience of autism and that they should be considered experts in autism (Ashby & Causton-Theoharis, 2009).

1.4.3 Focus on Wellbeing

One of the things that I found so valuable from the personal accounts from autistic people was the optimistic and proactive approach taken. Many of the authors seemed to be incredibly well acquainted with their own personal needs and they incorporated specific factors within their lives to ensure they maintained their own wellbeing. These proactive and personalised strategies and ways of living seemed much more positive than the 'treatment' focused quantitative research literature. I found the accounts I read and heard fascinating, and it motivated me to want to explore more factors associated with wellbeing.

1.4.4 Focus on Older Autistic People

The specific focus for the study on older autistic adults came from attendance at a National Autistic Society conference in 2012. *'Who cares? Supporting older people with autism effectively'.* The keynote speaker Professor Francesca Happé highlighted that we knew very little about autism in older adults. She believed that this was for a variety of reasons. Autism was first recognised by Kanner in 1943 and therefore the first cohorts of children diagnosed in the 1950s are just now going into later life. Autism was initially known as 'early infantile autism', and it is only relatively recently that people have started to recognise autism in adults. Recognition of the fact there is a gap in knowledge about adult autism really started to grow as the children diagnosed with autism in the late 1990s and early 2000s entered adulthood. Also, there is the fact that traditionally autism research has been driven by parents and therefore adults and older adults have become somewhat neglected (Happé, 2012). Anecdotally, it had been reported that researchers have great difficulty securing funding for later life autism research (Happé, 2012) suggesting that was not a research priority at that time. However, there was increased interested in this age group and there had been several international calls for more research on issues affecting autistic adults (Happé, 2012; Piven & Rabins, 2011).

I started to investigate research into autism and older people and was concerned to note just how neglected this population was in research terms. A 2012 review in the *International Journal of Geriatric Psychiatry* counted the number of publications in PubMed that focused on autism and split them by age range of participants between 1946-2011.The results highlighted the gap in research into older adults. Of the 18,000 publications identified in the search, only seven were focused on older adults (Mukeatova-Ladinska *et al*. 2012). Although there is now growing interest in the research area of older autistic adults, the population remains under researched[1].

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[1] The review conducted in 2012 has been replicated a decade later (Mason et al, 2022). It shows that there is still a huge disparity in the amount of research conducted focusing on the older autistic population. In 2011-2021 just 212 papers were published focusing on older autistic adults, whereas there were over 35,000 in the same time focused on children. This disparity has also recently been confirmed in a review of the autism research funding landscape conducted by Autistica, where just 3% of funding went towards projects recruiting older adults (Warner *et al*, 2019).

Whilst I understood the reasons why this imbalance in research had occurred, it seemed that the research world was missing a huge opportunity for valuable and useful information. It was clear to me that if I wanted to gain insight and understanding of the wellbeing of autistic people, I should be consulting those with the most experience, older people who have 50+ years experiences of being autistic.

1.5 Aims

This research implements constructivist grounded theory to explore the wellbeing of older autistic adults. The aim of the project is to extend the current knowledge base on the lived experience of older autistic adults and contribute to a better understanding and acceptance of autism.

1.6 Research Question

What do older autistic adults feel are the most important factors that assist them in maintaining their own personal physical and mental wellbeing?

1.7 Overview of Thesis

In this chapter I have presented the reasons why this research is important and described how I came to have a personal interest in this area. In chapter two I outline the background of autism, the policy in England, the diagnostic criteria changes that have happened over the years and the importance of a focus on wellbeing issues. Following this, chapter three discusses the results of the literature review of qualitative research conducted with autistic adults (up to 2015) that highlighted sensitising concepts for this study. Chapter four provides descriptions of the theoretical perspectives underpinning the study and continues with a step-by-step guide of the methods employed to generate data. Chapter five introduces the 14 older autistic adults that took part in the study using pen portraits. Chapters six to eight provide an in-depth presentation of the findings of the study. Following this I conclude the thesis with a discussion of the findings and resultant theory and how it fits with the current literature/ research field and finishes with concluding remarks and how this study has implications for current practice.

2 Chapter Two: Background

In the previous chapter I outlined why this research is important and highlighted how this study could help to fill the gaps in the current knowledge base. In this chapter I outline the history of autism policy in England; this discussion serves to highlight how an increased general awareness and understanding of autism is still required and reinforces the need for this study. Then I provide a brief overview of changes in diagnostic criteria, the impact this has had on the diagnosis of adults and a brief discussion on the social construction of autism. I conclude the chapter with a rationale for focusing on wellbeing issues for this study.

2.1 Autism Policy in England

After much campaigning by autism charities, autistic people and their families, on 12th November 2009 the UK government passed the Autism Act. (2009). This was the first ever condition specific legislation of its type passed in England. The Act committed the government to publishing an autism strategy which was to be revised periodically. Box three displays a brief synopsis of autism policy in England

The first ever autism strategy was published on 3rd March 2010, *Fulfilling and rewarding lives: the strategy for autistic adults in England* (DoH, 2010*).* It outlined the plan to meet the needs of autistic adults in England and recommended improvement of the provision of relevant services provided by local authorities and the NHS for autistic adults. The first of five focused goals outlined in the strategy was:

> *Increasing awareness and understanding of autism among frontline professionals.* (DoH, 2010).

In 2014 The Autism Strategy: *Think Autism,* provided an updated strategy which built of the preceding strategy and had several focused areas for change the first of which was:

> *Building communities that are more aware of and accessible to the needs of people with autism.* (Department of Health, 2014)

In 2019 there was a report from the All-Party Parliamentary Group on Autism (APPG, 2019) to explore the progress from the Autism Act (2009) – ten years on. This report had several key recommendations the first of which was to:

> *Create and fund a long-term, properly funded national autism understanding campaign, aiming to shift the attitudes and behaviour of millions of people*. (2019)

In 2021 (DoH) the most recent autism strategy was launched. The first of six key focused areas of need is:

> *Improving understanding and acceptance of autism within society.* (2021)

Although there has been some improvement in the awareness and understanding of autism in the last decade, each of these key strategies (2010 - 2021) identifies there is still a lack of adequate autism awareness and understanding. Thus, reinforcing the need for the present study.

Box 3: Brief History of Autism Policy in England

2009- The Autism Act - The first ever condition specific legislation of its type passed in England.

2010 (Mar) -The Autism Strategy: ***Fulfilling and rewarding lives: the strategy for autistic adults in England"***

The first autism strategy. The strategy focused on five core areas of activity:

1. **increasing awareness and understanding** of autism among frontline professionals
2. developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a **personalised needs** assessment
3. improving access for adults with autism to the services and support they need to live independently within the community
4. helping adults with autism into work
5. enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs.

2014 -The Autism Strategy: ***Think Autism: Fulfilling and rewarding lives, the strategy for adults with autism in England: an update*.**

The updated autism strategy. It built-on, rather than replaced, the 2010 strategy. The strategy focused on the following areas:

- building communities that are more **aware of** and accessible to the needs of people with autism, which have autism champions for change
- promoting innovative local ideas, services or projects which can help people in their communities through new models of care
- focusing on how advice and information on services can be joined up better for people.

2021 - The national strategy for autistic children, young people and adults: 2021 to 2026

- improving **understanding and acceptance** of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

2.2 Diagnostic Criteria

There is growing evidence that autism has a genetic foundation, and that autistic people have neurobiological differences (Fletcher-Watson & Happé, 2019). However, no biological markers have yet been found that can identify autism. Therefore, autism diagnosis is still based on a set of behaviours (Muhle *et al.* 2018). The fact that autism is diagnosed in this way leads to challenges for professionals as there has been great variation in how behavioural diagnostic features have been described over time and of course the potential different ways in which they are applied. King & Bearman (2009) describe how changes in diagnosing autism have had a substantial effect on prevalence rates. Diagnosing on behavioural traits is also problematic as autistic people may have comorbidities (Mazzone *et al*. 2012) and over the years adults have likely learnt to camouflage or mask their difference (Cage & Troxell-Whitman, 2019). This means that interpreting changing prevalence rates (Brugha *et al*. 2012) is difficult given the variability in diagnostic criteria that have been used over time and, of course, the ways in which they are potentially interpreted and applied in different settings.

Table one shows the changes in diagnostic criteria used for autism over time in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, DSM) which is used as the basis for autism diagnostic guidance. When the diagnostic criteria for autism first appeared in the third edition of the manual (DSM-III) in 1980 it was categorised as the very narrow category of infantile autism (Volkmar *et al*. 1988). The DSM-IV (1994) first categorised autism as a spectrum condition, which recognised the variability in the experience of autistic people. It included five Pervasive Developmental Disorders. In the fifth edition of the DSM (DSM-V, 2013) these subcategories were collapsed into one diagnostic category, 'Autism Spectrum Disorder' (ASD). The DSM-V states that '*symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning'* (DSM-V). These changes in diagnostic criteria mean autistic individuals who were born before DSM-III (1980) when very narrow criteria were introduced, may have gone undiagnosed or misdiagnosed (Brugha *et al*. 2012; Geurts, Stek & Comijs, 2016). Indeed between 1980- 1994 (DSM-V) the only diagnosis of autism will have been for those autistic people that adhered to the very narrow criteria laid out. As we know autism is lifelong so there will have been plenty of people with symptoms consistent with Asperger's Disorder, before this was added as a potential diagnosis in 1994 (DSM-IV). Furthermore, these autistic people may have received a diagnosis of something other than autism (Au-Yeung *et al*. 2019. Takara *et al*. 2015), as autism would have been considered too extreme a diagnosis for a person with Asperger's at the time.

Table 1: A Brief History of Autism Diagnostic Criteria

1952	DSM	The word autism appeared once, in connection with schizophrenia in young children.
1968	DSM-II	"Autistic, atypical, and withdrawn behaviour" was included and associated with schizophrenia in childhood.
1980	DSM-III	Autism first appeared in DSM as the narrow category separate from schizophrenia of: Infantile autism (Narrow category)
1987	Revision	Autism concept was broadened by adding a diagnosis of pervasive developmental disorder-not otherwise specified (PDD-NOS) removing early onset (before 30 months)
1994 & 2000	DSM-IV Revision	First mention of autism being a spectrum condition under five <u>Pervasive Developmental Disorders</u> (PDDs): Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Symptoms were divided into three areas: 1) social reciprocity, 2) communicative intent, 3) restricted and repetitive behaviours
2013	DSM-V	The diagnosis referred to as Autism Spectrum Disorder (ASD) no longer has sub-diagnoses. The new diagnostic criteria is rearranged into two areas: 1) social communication/interaction 2) restricted and repetitive behaviours.

Information taken from Hyman (2013) Zeldovich (2018) and The Autism History Project (Herman, E, 2019)

2.3 Diagnosis of Autism in Adults

As we have seen the diagnostic criteria for autism has widened significantly over the years, therefore some older autistic adults would not have been diagnosed as children under the very narrow criteria. Additionally, it was only in the Autism Act in 2009 that the provision of adult diagnosis services became the statutory duty of local authorities (Autism Act 2009). There is evidence showing that there has been a marked increase in adult diagnosis (Russell *et al*. 2021) as a result. Additionally, an increase in adult diagnosis was noted by Fombonne (2009) who highlighted that in several countries, referrals of adults for assessment for diagnostic assessment for autism had become more common. He found that referral often occurred for an adult whose child has recently been diagnosed with autism and who recognised similar developmental and symptom patterns in his or her own experience.

2.4 Research on Wellbeing of Autistic Adults

Studies of wellbeing of autistic adults are limited but have begun to appear in the last twenty years. They portray a bleak picture with generally poor outcomes. It is reported that most autistic adults were reliant on the support of their families/carers and remained dependent throughout their lives (Howlin, 2000). Employment rates are low (Howlin & Goode, 1998). Jobs, apart from for a few exceptional individuals, are low status and/or end prematurely, often because of social difficulties (Mawhood & Howlin, 1999). Under employment (failure to use their training and skills) was said to have the consequential effect of loss of self-esteem and for some, a cycle of anxiety and depression or other psychiatric disturbance (Howlin, 2005). Howlin *et al*. (2004) found that only a few autistic adults get married and, in their sample only 15 to 20 percent had friendships with shared enjoyment, despite autistic adults expressing a keen desire for social relationships. The combination of repeated social failures and intellect enough to realise their difficulties increased the risk of autistic people developing depression, anxiety, and other mental health concerns (Tantam, 2003). Social contacts were often derived from focused interests and skills rather than close friendships (Howlin, 2000). This lack of peer group may mean that autistic people have limited social support. Leading some to take sanctuary in routines and private preoccupations (Tantam, 2009), which leads to further isolation.

Autistic adults are also reported to be at high risk of psychological distress over their adult lifespan. In 2016 a study by Lever & Geurts they found that 79% of their sample met the criteria for a psychiatric disorder at least once in their lives (depression and anxiety were most common). High risk of sucicide is also identified in autistic adults (Came-Crosbie, 2018; Cassidy *et al*. 2014; Hirvikoski *et al*. 2016). The average age of death for autistic people with no intellectual disability is estimated to be 16 years earlier than the rest of the population and 30 years earlier for those with autism and an intellectual disability (Hirvikoski *et al*. 2016).

However, this gloomy picture contrasts to the story provided by many autistic authors (Grandin, 1995; Jackson 2002; Lawson, 2000; Shore 2001; Williams 1992, 1994). They are keen to point out the positive aspects of being autistic, such as careful attention to detail (Grandin, 1995); highly efficient visual memory (Lawson, 2000) and a different way of thinking (Shore, 2001). When reading autobiographies, listening to conference presentations, reading blogs or online chats by autistic people the picture is distinctly different from the research literature. Many autistic authors report treasuring their different way of thinking and say that they are proud of their 'neuro-diversity' (Grandin, 1995; Jackson, 2002; Lawson, 2000; Shore, 2001; Williams, 1992, 1994). Asperger himself thought that individuals who were diagnosed with "Asperger's syndrome" (Autism) had such specific skills that it allowed them to achieve things that neurotypical individuals may struggle with:

> *…only such people are capable of certain achievements. Their unswerving determination … their narrowness and single mindedness … can be immensely valuable and lead to outstanding achievements in their chosen areas.* (Translation by Frith, 1991, cited in Howlin 2000:65)

As we know the individual experience of being autistic can vary widely. Just like their neurotypical counterparts some autistic people have achieved high academic, professional or personal success. Well known examples include Temple Grandin who is Professor of Animal Science at Colorado State University, an author and a world-renowned speaker on both autism and cattle handling. Dr Wenn Lawson returned as an adult to education to gain her PhD in Psychology. She is also author of several books and is an international speaker. Indeed, many autistic adults have developed expertise in their own particular needs and way of thinking and have subsequently made adjustments in their lives to ensure their wellbeing (Grandin, 1995; Jackson, 2002; Lawson, 2000; Shore, 2001; Williams, 1992, 1994).

There are also now many autistic advocates who speak about their experiences and share their knowledge through various media avenues for the benefit of others. However, the research literature is yet to catch up on adequately representing the autistic voice. This is despite editorials from the journal *Autism* which is the most prestigious of the autism specialist publications reinforcing the importance and worth of qualitative research. (Bolte, 2014)

The juxtaposition between the autistic voice and the research literature shifted and sharpened my focus on this project. After reading several autobiographies written by autistic people and listening to autistic people giving insightful and rich accounts of their experiences in conference presentations, I felt the absence of the autistic voice in the research literature had to be remedied. I thought certain insights into wellbeing from autistic people would be enlightening. Impressions I gained from some autobiographical accounts from older adults suggested that many older autistic people find a niche for themselves as they grow older (Grandin, 1995; Lawson, 2000; Shore, 2001; Williams, 1992, 1994). They find personalised ways to maintain their own wellbeing, perhaps in professions where they have strengths and interests or with routines that suit their mental wellbeing or with likeminded people or through hobbies. If enabling factors could be identified that help autistic older adults maintain their own wellbeing it would provide a better understanding of how others can develop and maintain their wellbeing. If this was possible it could contribute to the current knowledge base and help with the crisis that have been highlighted such as premature death (Hirvikoski *et al*. 2016) or suicide (Cassidy *et al*. 2014).

2.5 The Social Construction of Autism

As we have discussed, the way in which autism is conceptualised is temporal and has recently altered significantly through diagnostic changes and through tireless campaigning from the autistic community which has undoubtedly shaped UK policy. Arguably therefore ‘autism’ can be seen as a socially constructed phenomenon. This is because it is shaped by the meanings that individuals and societies attach to it.

There is a certain assumption of what constitutes normalcy and anything that deviates from this undefined normal is thus labelled as deviant (Waltz, 2013).

Autism has until recently been solely defined through a lens of the medical model of disability (Oliver 1996). This defines disability to be totally within the person with the condition and they are perceived as medically dysfunctional. Where this lens is used, the person ‘affected’ is viewed as someone to be helped, altered or fixed. The medical model does not recognise ‘difference’ as having any positive attributes. However, an alternative way of viewing difference is through the social model of disability. This separates the effect of the physical and mental disability from the ‘oppression’ (Abberley, 1987) experienced by the person affected, by a society that holds false beliefs about normalcy and wellness. This model does not seek to deny that physical or mental pain, limitations and struggles exist. However, it views disability as a social issue, not an individual problem. It suggests external change to social and physical environments as the solution, rather than changes to the individual. This study is framed by the social model of disability (Oliver, 1983).

In this chapter I have outlined the policy changes that have occurred in England since the Autism Act in 2009, the changes to diagnostic criteria and the resultant temporal nature of the way autism has been conceptualised. In the next chapter I examine the qualitative research available before fieldwork commenced and discuss sensitising concepts and foreshadowed questions that arose from the literature and my background knowledge and experience.

3 Chapter Three: Literature Review.

3.1 Introduction and Structure of Chapter

Chapters one and two contained general contextual information concerning autism. This chapter outlines how the sensitising concepts for the study were developed. In this chapter I present the results of a systematic search and review of literature that was conducted prior to commencement of data collection (up to February 2016). The review of the literature was focused on qualitative research with autistic adults. This review was centred on the studies conducted prior to the start of the fieldwork. The search was repeated (2016 to 2021) to identify subsequent literature and these (see appendix one) were included in the discussion.

I begin the chapter with an outline of the place of a literature review in grounded theory research, followed by an explanation of the search strategy and process used. I then discuss the key themes which emerged from the literature. Lastly, the sensitising concepts and foreshadowed questions are presented.

3.2 The Literature in Grounded Theory

In this study the literature review was conducted prior to data collection. I recognise that the timing of the literature review in grounded theory studies has long been a subject of much debate. However, I endorse Kathy Charmaz's view who recommends that researchers start with a preliminary literature review, but she emphasises that such a review should be used in a way that it does not *'stifle your creativity or strangle your theory'* (Charmaz, 2014:308).

Classic grounded theorists Glaser and Strauss (1967) recommended that researchers should not delve into the previous literature until after analysis of data collected. They initially believed that research should not be influenced by previous research. They thought that this freed researchers from preconceived ideas about the topics under study. However, Strauss in a later work with Corbin later altered his stance and recommended consulting the literature in all phases of the study (Strauss & Corbin, 1998). They acknowledged that researchers may already have many preconceived ideas about a study area they are working in. One method to address the potential negative impact of early engagement with extant literature in grounded theory research is reflexivity. Reflexivity is described by Robson (2002) as the researcher being aware of how their background and social identity impacts the research process. Indeed, Charmaz (2017) describes reflexivity to be a staple ingredient of doing research within co-constructed social realities. She does not believe that researchers can be regarded as neutral or passive, but that their experience, positioning, beliefs and values play a big part in moulding the research process.

> *Situating grounded theories in their social, historical, local, and interactional contexts strengthens them and supports making nuanced comparisons between data and among different studies.* (Charmaz, 2014:322).

When embarking on this doctoral journey, I already had considerable experience and engagement with the autism research world, which is where my interest in the topic first arose. I had already explored the literature and attended conferences and read autobiographies for my own personal and family benefit. Therefore, it is important to recognise that I already held certain preconceived ideas regarding autistic experiences (which I outlined in my reflective statement in chapter one).

Reviewing the literature prior to data collection was also a requirement in order to establish a secure rationale for my study. It provided an opportunity to identify relevant knowledge gaps and confirmed that the study has not previously been completed. One of the strongest reasons for examining the literature prior to data collection was to ensure that I was able to be culturally/theoretically sensitive whilst conducting interviews. It was imperative that I was aware of the current changes in the contextualisation of autism and the issues and debates surrounding the research field. It was also vitally important that I was aware of factors to consider whilst planning my interviews (such a potential sensory sensitivity, possible processing delay issues, communication differences etc. (see chapter four for further discussion). It is important when conducting research with autistic participants that I was aware of the adjustments or considerations that could be required (Autistica, 2021). These factors made it essential for me to be well informed in the topic area so as not to inadvertently cause offence or be inconsiderate of my participants' requirements. At the time of commencing this study there was no best practice guidance available on how to conduct interviews with autistic people. It was therefore essential that I looked at the literature to ensure that I conducted my research sensitively.

3.3 Creation of Sensitising Concepts from the Literature Review

Sensitising concepts are “background assumptions and disciplinary perspectives” (Charmaz, 2006:16) that I started data collection with. They were developed from various sources including my professional background, my interaction with the autistic community and through examination of current research literature and the literature review presented in this chapter.

Sensitising concepts is a term at that derived from the work of American Sociologist Blumer (1954). He believed that sensitising concepts provide a *suggested* direction of research in contrast to definitive concepts that he described as being more *exact* and which identified a prescription of precisely what research was to examine. A sensitising concept lacks such specificity and therefore it does not provide an exact direction for a researcher. Instead, it provides the researcher a general guidance for approaching their study. Charmaz (2006:17) has referred to sensitising concepts as a departure point for research:

> *a place to start and not end. Grounded theorists using sensitising concepts as tentative tools for developing their ideas about processes that they define in their data. If particular sensitising concepts prove to be irrelevant, then we dispense with them.*

3.4 Use of the Literature

Literature in this grounded theory study is used in several ways. The first review of the literature was conducted prior to data collection (all available literature up to end of 2015) this allowed me to develop theoretically sensitivity and see important concepts in the data (Holloway and Todres, 2006). My doctoral studies were paused a number of times (see appendix two for a study timeline) resulting in a gap of five years between my initial literature review and completing data collection. A second systematised literature search was conducted after completion of data collection and analysis. At this point I repeated the process used in the initial search The results of this can be found in appendix two. This enabled more recent literature to be integrated into the discussion.

3.5 Literature Review

This part of the chapter comprises seven sections: search rationale, search method, search results, including data extraction table, critical appraisal of included studies and thematic analysis of included studies. The chapter concludes with a discussion of the implications of the literature review in relation to the sensitising concepts and foreshadowed questions of this study.

3.6 Search Rationale

The broad aim of this study was to explore the experiences of older autistic adults in relation to their own wellbeing. As discussed in chapter one, at the time of commencing this project there was a paucity of research with older autistic adults (Mukeatova-Ladinska *et al*. 2012). While parents or carers frequently participate in studies as proxies for their autistic children, proxy reporting for adults causes serious ethical and scientific validity concerns (McDonald & Raymaker, 2013). Therefore, the focus of this review of the literature is to explore the available evidence provided by qualitative research with autistic adults (not proxy accounts) and how their experiences broadly relate to wellbeing. To this end, studies that focused on parents, carers or professionals were excluded. It was necessary to broaden inclusion criteria for the review to include autistic adults of all ages, due to the gap in the research with older autistic adults (Mukeatova-Ladinska *et al*. 2012).

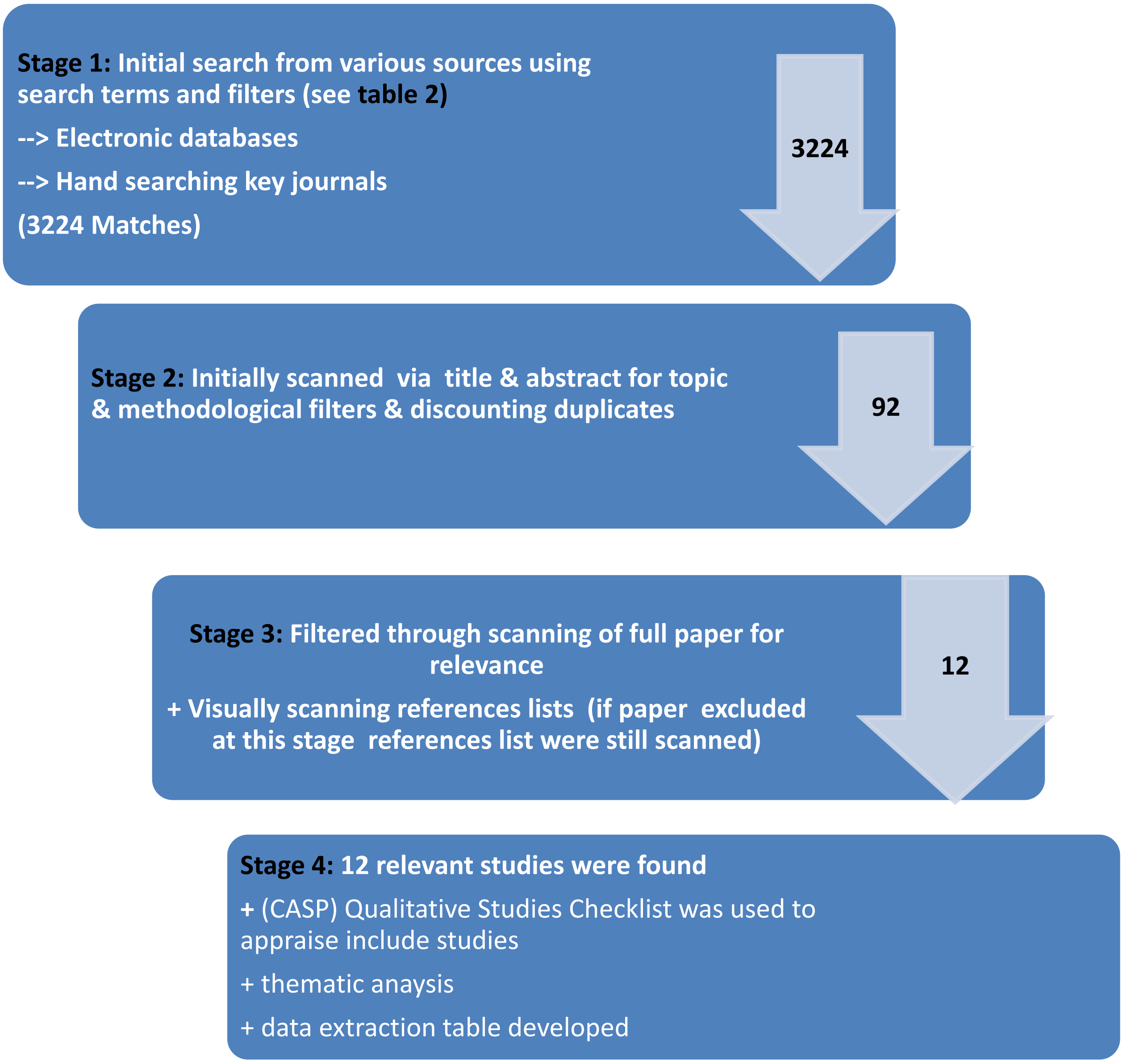
3.7 Search Method

A systematised search and review were conducted that consisted of four stages (presented diagrammatically in figure 1).

Stage 1

A database search was undertaken using a number of databases: CINAHL (Cumulative Index for Nursing and Allied Health Literature), The Cochrane Database and PsychInfo and PubMed. Search terms included '*Autis* OR ASC OR ASD OR Asperger** 'to denote the focus of interest and '*Qualitative OR Interviews OR Lived experience* OR narrative OR autobiographical OR biographical OR Life**' to capture studies of a qualitative methodology (see table two). No further search terms were used to narrow the search as wellbeing issues can be covered in many different topic areas. The search was therefore purposely kept wide. Further selection for inclusion was based on manual filtering for relevance based on the methodological filters and topic filters.

Figure one: Four Stage Literature Review Process



Filters were applied to include all studies with adult participants (aged 16+). As the search was undertaken in January 2016 this was the upper date search limit for the initial review. Key papers from the search were selected for thematic analysis using methodological and topic-based filters displayed in table two.

Citation tracking was undertaken in order to garner underpinning information and other potentially useful papers. The hand searching of identified key journals was conducted: *Autism*, *Research in Autism Spectrum Disorders, Good Autism Practice and Disability & Society.* These journals were selected as they were considered to be most relevant for the topic area. (See table two for a tabulation of the search terms and filters).

3.7.1 Inclusion Criteria

Papers were included for review through methodological filters if they used primary qualitative research methods and topic filters experienced based research with autistic adults.

3.7.2 Exclusion Criteria

Papers were excluded if they were not primary qualitative research, or where focus was aimed at children or proxy accounts.

3.7.3 Literature Search Terms

Table 2: Literature Review Search Terms

Search Terms #S1 (In Title or Abstract)	Autis* OR ASC OR ASD OR Asperger* AND Qualitative OR Interviews OR Lived experience* OR narrative OR autobiographical OR biographical OR Life	
Date range:	up to 2015	
Language:	English – This was selected due to resource issues	
Age range:	Adult 16+ This was selected as I am interested in research done on older adults. I included all adults over 16, due to the lack of research with older autistic adults.	
Source	Peer Reviewed Journals only – As a preliminary search I am interested specifically in research done in this area and therefore I have limited my search to academic journals only.	
Inclusion criteria:	Methodological filters • Qualitative research • Primary data	Topic based filters • 'Wellbeing' issues • Experienced based • Adults

Stage 2

3224 papers were found in the initial search results. These results were scanned via title and abstract for topic and methodological filters. After reviewing the title and abstract, all studies that could potentially contain some primary qualitative research with autistic adults were included. As a consequence, 92 papers were selected (duplicates were discounted).

Stage 3

These 92 papers were scrutinised for relevance on topic and methodological filters and either included or excluded after scanning the full paper. Reference lists of all 92 papers were examined for other potentially relevant studies.

Stage 4

A total of twelve studies met the inclusion criteria. The Critical Appraisal Skill Programme (CASP) Qualitative Studies Checklist (see appendix three) was used to assist in the appraisal of the quality of the studies. Additionally, a data extraction table (appendix four) containing pertinent information from each of the twelve papers was created.

3.8 Search Results

Table 3: Results of Literature Search 1

Database/source	Search Terms	Stage 1 (Matches)	Stage 2 (Matches)	Stage 3 (Matches)
PubMed	See table one	1021	21	
CINHAL	See table one	237	14	
Cochrane Review	"Autism"	0	0	
PSychInfo	See table one	516	23	
Autism (Journal)	"Qualitative"	236	12	
Research in Autism Spectrum Disorders	"Qualitative"	165	0	
Journal of Autism & Developmental Disorders	"Qualitative"	631	0	
Disability & Society	"Qualitative"	23	1	
References list searching	n/a	n/a	20	
		3224	92	**12**

A data extraction table from the twelve included studies can be seen in appendix four. This displays specific details of the papers including, aim, methods, participant details and location and recruitment strategy of the studies.

3.9 Critical Appraisal of the Included Studies

The literature search found just twelve qualitative papers published up to end of 2015 with autistic adults as participants. The specific focus of these papers covered various areas of the experiences of autistic adults; life experiences (Hurlbutt & Chalmers, 2002), employment (Hurlbutt & Chalmers, 2004; Krieger *et al*. 2012), the risk of non-obvious disability (Portway & Johnson, 2005), diagnosis (Huws & Jones, 2008 and Punshon *et al*. 2009), social challenges (Muller *et al*. 2008), support experiences (Griffiths *et al.* 2012), unusual sensory experiences (Smith & Sharp, 2013; Robertson & Simmons, 2015), social comparisons (Huws & Jones, 2015) and healthcare experiences (Nicolaidis *et al*. 2015). The studies were conducted in various locations, however the majority were conducted within the United Kingdom (7): three English studies (Portway & Johnson, 2005; Punshon *et al*. 2009; Smith & Sharp, 2013), two studies from Wales (Huws & Jones, 2008, 2015; Griffiths *et al.* 2012) resulting in three papers and a Scottish study (Robertson & Simmons, 2015). There were four studies from the United States of America, (Hurlbutt & Chalmers, 2002, 2004; Muller *et al.* 2008; Nicolaidis *et al.* 2015) and one study conducted in Switzerland (Krieger *et al*, 2012).

3.9.1 Recruitment

Recruitment for the studies was predominantly from the autistic adult population who were connected with services/support, such as a college for autistic young people (Huws & Jones, 2008, 2015), local service for autistic adults (Punshon *et al*. 2009), autistic support groups (Muller *et al*, 2008), autism support service (Portway & Johnson, 2005; Smith & Sharp, 2013), healthcare professionals (Krieger *et al*. 2012) employed by a single employer who recruited autistic people (Robertson & Simmons, 2015), autism related organisations (Griffiths *et al*, 2012; Nicolaidis *et al.* 2015) or through attendance at autism conferences (Hurlbutt & Chalmers (2002, 2004). This could mean that participants were particularly well informed as they already had contact with professionals and the autism community for support and advice. In the case of two papers from the same authors (Hurlbutt & Chalmers, 2002, 2004) the same participants were used in both studies. These participants had extensive knowledge about autism. They read extensively on the subject, they were regular autism conference delegates and had communicated with experts in the field of autism. This suggests that they were highly motivated to share their experiences and felt well informed about autism. This may explain the consensus that was evident in the study findings. The experiences of these three participants are certainly not typical and distinctly different from the other studies included in the review (Huws & Jones, 2008, 2015; Griffith *et al*. 2012; Muller, 2008; Portway & Johnson, 2005; Punshon, 2009) and results although interesting should be interpreted with that in mind. Similarly, in Robertson & Simmons' (2015) Scottish study, participants were recruited from an '*autism friendly'* employer and were all known to one another. This could have affected the results as their opinions may be similar due to cultural factors within the organisations influencing their thoughts. In their two papers Huws & Jones (2008, 2015), used the same data for both publications. Nine autistic young people were recruited purposively from a '*college for young people with ASC'*. All the participants therefore may have similar views as they all were exposed to similar constructions of autism from the college. Likewise, Punshon *et al.* (2009) recruited their participants from a group of autistic adults that were in contact with a specific autism support service. They might have had access to similar support and information, and this should be considered when interpreting findings from these studies.

The study by Portway & Johnson (2005) was included in the review despite including proxy accounts in their data collection as their results are noteworthy and provided an interesting influence on the construction of sensitising concepts for the present study. However, their rationale for the data collection methodology was not clear, 'families' were interviewed with some young autistic adults being interviewed alone, some were interviewed with parents and some parents were interviewed instead of autistic adults. (I have focused my review on the section of the findings that derive directly from the interviews with autistic people and not proxy accounts). However, results from this study should be interpreted with this in mind.

3.9.2 Sample Sizes

The sample sizes were typically small ranging from 3 to39. This would be expected with in-depth qualitative research. The larger samples came from two American studies (Muller *et al.* (2008). n=18, Nicolaidis *et al.* (2015, n=39) and a UK study (Portway & Johnson, 2005, n=18). As shown in the data extraction table (table four), the samples tended to be heavily biased towards male participants and participants' ages were young to middle adulthood with only approximately ten participants across all the studies being over the age of 50 (excluding Nicolaidis *et al.* 2015).

3.9.3 Engagement with the Autistic Community

In all but three studies (Muller *et al*. 2008; Punshon *et al.* 2009; and Nicolaidis *et al.* 2015) there was a distinct lack of engagement with the autistic community when designing and conducting the included studies. This could negatively impact the results of the studies as the research methods and the implementation of the study may not have been appropriate to encourage full participation in the process. Likewise, the researcher’s interpretation of the data might not have been the intended meaning of the participants. Autistic thought and neurotypical thought can be quite distinct (Crompton *et al*. 2020, 2021; Milton, 2012; Sinclair, 1993) causing misinterpretation of the data. This lack of engagement with the autistic community from the studies does cast some doubt over their results, as data collection tools, the ways the interviews were conducted, and the interpretation of the results may all have been negatively affected (Milton, 2012). This potential effect is discussed further in chapter four.

3.9.4 Data Collection Modes

Except for Smith & Sharp (2013), who employed instant messenger to elicit responses from participants and Nicolaidis *et al.* (2015), who offered different modes for data collection, the collection of data was done predominantly via face-to-face methods; interviews and focus groups. This approach will only recruit participants who feel comfortable with face-to-face meetings and are confident to meet with researchers not known to them, potentially in a location unknown to them. Such methods could cause a lot of anxiety for many autistic adults (Grandin, 1995; Jackson, 2002; Lawson, 2000). and therefore may prevent them from volunteering to take part. This would mean participation would only be from those autistic adults who felt comfortable with this type of data collection. There was also an absence of the description of any reasonable adjustments or considerations made in research design to enable full participation by participants. As highlighted by the papers themselves (Griffith *et al*. 2012; Hurlbutt & Chalmers, 2002, 2004; Krieger *et al*. 2012; Muller *et al.* 2008; Nicolaidis *et al*. 2015; Portway & Johnson, 2005; Robertson & Simons, 2015; Smith & Sharp, 2013) there are many environmental factors that may be problematic for autistic people and therefore they should be considered when designing data collection methods. This is discussed in detail in chapter four. The fact that in all but one of the studies (Nicolaidis *et al.* 2015) there was no mention of how these factors were considered may have meant that the data collected could have been negatively affected by their absence.

In the two papers by Huws & Jones (2008, 2015) data was collected from one data set. Participants were recruited from a college for young people with ASC. Interviews were conducted in a college office. There was not enough information provided to say if the researcher had sufficiently clarified their role. These young people may have been familiar with seeing many professionals in college offices regarding their education, or personal wellbeing. This could potentially mean that the role of the researcher /participant may have been misconstrued if not clearly explained. It may have affected the results with participants potentially not being as candid as they may have been to someone outside these settings. This should be considered when interpreting the findings of their two papers. Equally, Robertson & Simmons's (2015) study, recruited participants through an employer that specifically employed autistic people. Recruitment was done through a gatekeeper 'training manager'. It was not clear how the researchers ensured that separation between their employment and the research. Participants may have been more reserved with their accounts as they may have perceived it could negatively affect their employment.

3.9.5 Translated Data

In one Swiss paper (Krieger *et al*. 2012) the study was translated twice from spoken Swiss dialect into the written German language, and subsequently into written English by native English speakers. Some richness of the narrative accounts may have been lost in this process.

3.9.6 Ethical Considerations

The studies did not outline the specific ethical considerations that might be important to consider when talking with autistic participants. This important dimension was not discussed in any of the papers, (perhaps due to the constrains of publishing word limits). They may well have been considered but it cannot be certain from the published papers. Roles such as the researcher / participant relationship could be fundamentally important especially when recruiting from colleges or workplaces. These roles need to be well defined and described so that their interpretation is not misconstrued. Autistic adults may be considered a vulnerable group which makes examination of this dimension vital.

However, all the included studies positively contribute to the knowledge base of the lived experience of autistic people. They start to fill the gap in research (Bolte, 2014). by being the first studies to include experiential accounts from autistic people directly and not through proxy accounts. They contribute to the wider literature by presenting personal experiences of autistic people and the value of their individual insight and all studies highlight the importance of listening to autistic people themselves.

3.10 Thematic Analysis of the Literature

A thematic analysis approach was taken to synthesise the current qualitative research evidence with autistic adults on issues surrounding wellbeing. This was performed to assist in the generation of sensitising concepts that were used as a tentative tool that informed the foreshadowed questions and the direction of inquiry at the start of my data collection.

Thematic analysis of the data provided by the included studies highlighted four main themes; struggles of daily living, inadequate support services, diagnosis and lack of understanding.

All the studies (except Nicolaidis *et al*. 2015) use the term Asperger's syndrome which in light of the change to diagnostic criteria (discussed in chapter two) I have altered to the term 'autism' to avoid future confusion.

3.10.1 Struggles of Daily Living

All studies highlighted aspects of daily living that were problematic for participants and negatively impacted on participants' wellbeing. There was a suggestion that comparison with the neurotypical population made participants feel that life was more of a struggle for them than their neurotypical counterparts (Griffiths *et al. 2012*) and that autism made them stand out from the neurotypical population (Punshon *et al,* 2009). Participants described feelings of exhaustion at the amount of effort required for day-to-day living, and that life was a constant struggle (Portway & Johnson, 2005; Griffiths *et al. 2012*). Indeed, these struggles covered many aspects of daily living including social issues, sensory factors, employment experiences and 'fitting in'.

3.10.2 Social Issues/ Lack of social connectedness

Participants noted that their social skills and communication were not like others and as a result they often felt excluded or marginalised by others. There was a consensus that their experiences were 'different' from the experiences of the neurotypical population. Some felt that this 'difference' led to their experiences of bullying or criticism from other people (Portway & Johnson, 2005; Punshon *et al.* 2009). This caused problems in healthcare settings (Griffiths *et al*, 2012; Nicolaidis *et al.* 2015; Portway & Johnson, 2005; Punshon *et al*, 2009) and employment (Hurlbutt & Chalmers, 2002, 2004; Griffiths *et al. 2012;* Krieger *et al*. 2012) and with forming friendships (Muller *et al*. 2008). The loneliness and isolation experienced by participants was a major theme discussed by Muller *et al.* (2008) who described individuals experiencing intense loneliness which caused them great stress and anxiety. Individuals reported being isolated in both childhood and adulthood, but the distress caused by this isolation increased as they grew older and became more aware of their 'difference'. Several participants in this study reported having no genuine friendships.

3.10.3 Sensory Factors

Feelings of isolation were reportedly exacerbated by participants' sensory experiences. 'Heightened senses' were described in the paper by Smith & Sharp (2013), the sensory stimulus appeared to be experienced more intensely beyond 'normal' experience. The stimuli that caused anxiety and those that were enjoyable were different to each participant: what one participant found to be pleasant, another found unbearable. These heightened senses led to strong feelings including: anger, fear and even pain. Participants were often forced to escape from the sensory situation or avoid the situation occurring in the first place. This was reported to lead participants avoiding going to social spaces and rejection from other people, adding to feelings of isolation. Indeed, these findings are echoed by Roberts & Simmons' (2015) insights into the intense effect sensory experiences have on the participants in their study. They found that sensory experiences could be so intense that they produce negative emotional states and could even affect the participant's perception of pain. This is supported by the findings of Nicolaidis *et al.* (2015) where they illustrate the impact of sensory experiences during healthcare visits the bright lights, the crowded waiting rooms exacerbate challenges with body awareness and ability to accurately describe pain. Robertson & Simmons (2015) also highlight the fact that sensory issues, positive and negative, are different for each individual. A major finding of the study was that a feeling of control was an important mitigating factor on the impact of sensory experiences which again supports the earlier work of Smith & Sharp (2013).

Additionally, participants described that once they became focused on a strong stimulus, it dulled other sensory domains. This led to an inability to consciously process information from them (Smith & Sharp, 2013). Indeed, the notion that both negative and positive responses to sensory stimuli are heightened in autistic people seemed to be a consensus between the studies. There was also agreement that there was a difference in the experience of sensory stimuli between autistic people and neurotypical people (Griffith *et al*. 2012; Hurlbutt & Chalmers, 2002, 2004; Krieger *et al*. 2012; Nicolaidis *et al*. 2015; Robertson & Simmons, 2015; Smith & Sharp, 2013). The impact of sensory overload was also reported by Krieger *et al.* (2012) who noted how sensory experiences affected participants' behaviour and learning patterns. In Griffith *et al.* (2012) they found that noise, strong lights, and smells were reported as having the capacity to become so overwhelming it became difficult to focus on anything else and Hurlbutt & Chalmers (2002, 2004) highlighted the negative impact these factors had on participants' employment.

3.10.4 Employment Experiences

Difficulties in gaining and keeping employment was a recurring theme amongst the papers (Krieger et al, 2010; Hurlbutt & Chalmers, 2002, 2004; Griffith *et al.* 2012). All three participants in Hurlbutt & Chalmers' study (2002) spoke of the difficulty they had in finding and keeping employment, their negative experiences in the world of work and the impact it had on their wellbeing. They reported trouble in finding work that was at an appropriate level for their skills and abilities and had difficulty keeping jobs. Mostly, they were unable to acquire employment in the field in which they were trained, and each had suffered many instances of employment loss in the past. They experienced repeated difficulties which interfered with employment success such as sensory issues and communication issues. Participants spoke about the exhaustion they felt through the social aspects of their employment. The fact that they were constantly 'mimicking' neurotypical people was exhausting. Participants also reported a continued sense of confusion and sadness over past events where there were misunderstandings at the workplace that sometimes led to termination of employment (Hurlbutt & Chalmers, 2004).

In Griffiths *et al.* study (2012) difficulties with social interaction and unpredictable mood swings were reported to make obtaining and/or retaining a job difficult for many participants. This, combined with a lack of autism knowledge among employers and colleagues, caused working life to be difficult. Participants described having numerous, often short-term jobs over the years due to problems in the workplace. Over half the participants were unemployed (n=6). Two hoped to re-join the workforce but four had given up and due to their previous bad experiences thought that they were destined to have indefinite unemployment; this was extremely detrimental to their wellbeing (Griffith *et al*. 2012).

Krieger *et al.* (2012) approached employment issues from a different perspective. They recruited autistic adults who had successfully been in employment for at least 18 months and wanted to explore factors which contributed to successful labour market participation. The authors noted how all participants developed skills during a process of constructing an identity, which included the personal confidence that they had the ability to adapt to the social demands of the workplace. Participants in this study acknowledged that the working world was not a world they were naturally comfortable with. However, they knew the 'rules of the game' so they could 'make it' using masking strategies to their advantage.

3.10.5 'Fitting In'

The notion of 'fitting in' was discussed across the studies as desirable and the implication being that it could enhance the wellbeing of participants. A number of studies discuss participants making conscious efforts to learn how to act in a neurotypical way. This was not a natural process, rather a planned strategy that was implemented to blend in (Huws & Jones, 2008; Muller *et al*. 2008; Portway & Johnson, 2005; Punshon *et al*. 2009). It was an attempt to combat some of the difficulties with communication they encountered. Some participants discussed trying to mask/hide their autistic traits as a strategy, while some mimicked the behaviour of others. This was a conscious planned process that was used in an attempt to 'fit in' socially in different situations in their lives. They believed that if they acted like neurotypical people then they would blend in more easily. They felt this had the potential to solve some of the communication issues they encountered. This was done through various methods including; academic study (Muller *et al.* 2008), attendance at social skills groups (Muller *et al*, 2008; Griffith *et al,* 2012) and using social mimicry (Krieger *et al.* 2012; Punshon *et al*. 2009). Despite this effort to learn to interact in a neurotypical way, social interaction remained problematic for participants. Factors such as using eye contact, knowing when and how to join and/or conclude a conversation and also understanding social nuances caused great difficulty (Griffith *et al.* 2012; Huws & Jones, 2008; Muller *et al*. 2008; Portway & Johnson, 2005; Punshon *et al*. 2009)

In the American study by Muller *et al.* (2008) participants reported actively developing social awareness through reading books and attending social skills groups. These activities reportedly helped areas where they perceived they had 'weakness' such as reading nonverbal communication or body language and using pitch and intonation in their voice. Participants also reported using physical activities to relive the stress derived from social situations. This approach also provided an opportunity to engage with others without the need for much communication.

The participants in the Griffith *et al.* (2012) study were worried about being viewed as '*odd'* by others, and this worry could exacerbate feelings of anxiety and depression. Participants described how they made a conscious, almost academic, effort to learn the unwritten *'rules'* of social interaction. However, this strategy of presenting a *'false self'* to others was reported to be very difficult. Despite this, participants thought that the effort required to do this was ultimately easier than 'being themselves' (Griffith *et al.* 2012).

Throughout all the studies there was discussion of the perceived pressure or desire to 'fit in'. There was a perception that people thought that they were odd or weird and that this caused a great deal of stress, anxiety and often contributed to depressive thoughts (Griffith *et al.* 2012; Punshon *et al*. 2009). There was a consensus that it was somehow important that the factors that led people to see them as different should be hidden (Griffith *et al*. 2012; Hurlbutt & Chalmers, 2002, 2004; Huws & Jones, 2008, 2013; Krieger *et al*. 2012; Muller *et al.* 2008; Nicolaidis *et al*. 2015; Portway & Johnson, 2005; Punshon *et al*. 2009; Robertson & Simons, 2015; Smith & Sharp, 2013). It was noted, however, that hiding or masking autistic traits was difficult and ultimately led to stressful situations for participants.

3.10.6 Inadequate Support Services

The focus of the paper by Griffith *et al.* (2012) was the support experiences and needs of autistic adults. They reported involvements with support services that were not good, as service provision was targeted for people with mental health problems, intellectual disabilities or physical disabilities, which has obvious negative effects on participants' wellbeing. Interactions with General Practitioners (GPs) were reported as being poor. GPs often misunderstood autism, lacked knowledge and were unhelpful (Griffith *et al*. 2012). These UK findings are similar findings to those of Nicolaidis *et al.* (2015) in the US. Indeed, the problems were so bad that some participants did not use healthcare services at all unless they experienced an emergency and instead opted for alternative therapies. There was evidence (Griffith *et al,* 2012; Nicolaidis *et al.* 2015; Punshon *et al.* 2009) that support services should be provided by people who specifically knew about autism, otherwise services could inadvertently cause more harm than good. In the study by Griffith *et al.* (2012) the findings emphasised the anxiety, depression, and communication difficulties that autistic people can experience. They found that available support was perceived by individuals as unsuitable for the needs of autistic people. Portway & Johnson (2005) found that their participants felt 'different', but that their difference was not substantial enough to be entitled to any support or interventions. All of their participants were mentally struggling with anxiety or depression and some also held suicidal ideations. This study highlighted the risks of having a non-obvious disability. Their unusual needs were not supported by the current support systems available. Nicolaidis *et al.* (2015) highlighted how healthcare professionals required additional autism specific training to adequately support autistic adults. They suggested that such training must focus not only on knowledge about autism but also on the attitudes, skills, and behaviours necessary to provide respectful, effective healthcare.

3.10.7 Diagnosis

Several of the included papers discussed diagnosis, participants' reaction to diagnosis and the impact it had upon their lives and wellbeing. The two papers by Huws & Jones (2008, 2015) identified that diagnosis had caused 'disruption' to the young participants in terms of their perceived opportunities. They thought autism created a barrier to what they had wanted to achieve. The young people talked about a range of reactions to diagnosis including shock, disappointment, and disbelief. All participants had, to some extent, revised their sense of personal identity after diagnosis. The new information diagnosis gave them about themselves caused them to reflect on their lives and experiences and view themselves differently. There were clear differences in the way that diagnosis was viewed, for some diagnosis was positive and for others it was negative. Being informed that they were autistic, for some gave feelings of relief as it gave them a reason for why they had been treated as ‘‘different’’ in the past. Others talked about not wanting their diagnosis and actively avoiding any information associated with it. The authors discussed the fact that autism had been an ‘absent presence’ in all the participants’ lives pre-diagnosis and that diagnosis for some retrospectively provided an understanding of their previous life events. The authors highlighted the difference between the young people in their approach to autism knowledge acquisition. The participants who were not happy about knowing about their autism avoided exploring further information regarding autism. Whereas some actively sought further information. There was no further discussion on the effect of participants’ wellbeing of seeking information or avoiding information.

Unlike Huws & Jones (2008, 2015) Krieger *et al.* (2012) found that there was an agreement amongst their participants that the diagnosis reportedly brought a sense of relief, enhancing the wellbeing of participants. The diagnosis was helpful as it legitimised their personal needs and allowed people around them to help understand their ‘quirkiness’ better. In another study which focused on diagnosis, Punshon *et al*. (2009) also found that receiving a diagnosis in adulthood gave participants a framework by which to explain their lives to themselves. Other participants reported a feeling of exoneration from being blamed for their previous difficulties. Indeed, three of the participants reported that family members felt a sense of relief regarding their diagnosis as they felt it cleared them of any responsibility for their relative’s difficulties. Punshon *et al.* (2009) made recommendations that autistic people along with their families should be supported in mentally processing their diagnosis and what it means to them, preferably with help from suitable professionals. They also noted that social comparisons were important in helping autistic people develop a sense of acceptance and, potentially, pride through developing links with other autistic people which ultimately would have a positive impact on their wellbeing.

3.10.8 Lack of Understanding of Autism

All the included studies highlighted a lack of understanding of autism by the general public (including family and friends) and professionals (Griffith *et al*, 2012; Hurlbutt & Chalmers, 2002, 2004; Huws & Jones, 2008, 2013; Krieger *et al*, 2012; Muller *et al,* 2008; Nicolaidis *et al*. 2015; Portway & Johnson, 2005; Punshon *et al*, 2009; Robertson & Simmons, 2015; Smith & Sharp, 2013). They emphasised the importance of an increased wider understanding of autism which could have a resultant positive impact on wellbeing. A study by Portway & Johnson (2005:82) eloquently concluded that:

> *The associated risks with having a non-obvious disability could not be completely ameliorated by greater understanding by others but could be greatly exacerbated by its absence.*

Punshon *et al*. (2009) highlighted that as a result of this lack of understanding participants felt that society placed too many demands on them as it did not truly understand autism, and inaccurate portrayals of autism in the media exacerbated this fact and had a negative impact on wellbeing. It was felt by Griffiths *et al.* (2012) that in raising public awareness there would be a general sense of more understanding amongst society. The general population would then be more accommodating of the needs of autistic people. This would assist in reducing participants’ feelings of social anxiety and isolation and therefore enhance wellbeing. Similarly, Nicolaidis *et al.* (2015) also highlights that greater understanding of autism is essential so that the stigma associated with autism and associated discrimination can be reduced. Several authors believed that the best way to help facilitate the enhanced understanding of the wider population was by listening to experiential accounts from autistic people through further qualitative research (Hurlbutt & Chalmers 2002, 2004; Huws & Jones 2008, 2013; Muller *et al.* 2008). It was felt that the rich experiential knowledge provided through qualitative research with autistic people would be an important influence on the current research and wider understanding of autism that has historically been too reliant on proxy accounts.

3.11 Summary

The literature review supports the need for this study by highlighting the importance of increasing wider understanding of autism through further qualitative research with autistic people. The review also confirmed that at the time there was a dearth of qualitative studies with older autistic adults showing them to be an under-researched group. Unfortunately, many autistic people never progress to older adulthood as life expectancy is significantly lower for autistic people than their neurotypical counterparts (Hirovikoski *et al*. 2016) and suicide is a much bigger risk within the autistic community (Cassidy *et al.* 2014). Therefore, it is important that factors affecting personal wellbeing are explored from older autistic adults' experience, who have, against odds navigated themselves into older age.

The review also highlighted that the current qualitative studies tended to focus on problems and difficulties in specific aspects of life such as employment, sensory issues, support services but with no studies focusing more broadly on wellbeing. It is well documented that autistic people do experience many difficulties and challenges in life; however, it could be argued that the current qualitative research literature focuses too heavily on the negative aspects of the autistic experience. Within the literature there is a focus on 'fitting in' and hiding/masking or trying to modify the participants. In one small study included in the review (Hurlbutt & Chalmers, 2002) the three participants had very strong and unified opinions. The participants noted how they had previously wanted to "fit in," to "be normal." But at some point, in their lives they realised that they were not able to do this and be themselves at the same time. They were passionate that they wanted to help autistic people to be proud of their autism and to promote self-acceptance. These findings echo some experiential accounts I have witnessed from other sources. The accounts I have heard from conference presentations by autistic people, autobiographical writings and my own family and professional experience highlight the juxtaposition to the accounts presented in the current literature. Since we received a diagnosis of autism in our family, I have learnt a lot about the autistic experience. Living in a society that is not understanding or accommodating of autistic people's difference is undoubtedly challenging. However, I have also learnt that the picture is not always as bleak as is illustrated through the current research. Some autistic people have developed mental and practical strategies that allows them to successfully manage their wellbeing to they lead full, happy and healthy lives. The disagreement between the two sources of evidence serves to demonstrate that there is a gap in the current literature. There is a need to explore how autistic people manage their own wellbeing. Exploration of positive approaches to wellbeing management could provide opportunities to disseminate meaningful research that will assist other autistic people in practical strategies and help successful management of their own wellbeing.

3.12 Sensitising Concepts and Foreshadowed Questions

Relatively brief sensitising concepts that have been generated from the literature and that have been influenced by my wider knowledge of autism are:

Sensitising Concepts

- Wellbeing covers issues in all areas of life.
- A sense of wellbeing is individualised and different for everyone.
- Diagnosis is a process and not a single event.
- Reaction to diagnosis is different for everyone.
- Diagnosis may lead to a revision of personal identity
- Legacy of poor experiences
- The notion of ‘fitting in’ as a common experience
- Lack of understanding by professionals/wider society/family/friends/self. (Not different enough)
- Autistic people as autism experts

A number of foreshadowed questions were formulated from the sensitising concepts:

- What are the factors that impact the wellbeing of older autistic adults?
    - What inhibits wellbeing?
    - What promotes wellbeing?
- What does an autism diagnosis mean to older autistic adults?
- How do older autistic adults view themselves?
- What support would older autistic adults feel would be beneficial?
- What strategies and coping mechanisms have older autistic adults developed?
- What impact do social comparisons have on wellbeing?

This is the starting point for this research study. These sensitising concepts and foreshadowed questions helped to inform the interview questions and enabled theoretical sensitivity which informed the personalised approach to data generation. However, it is important to note that these sensitising concepts/foreshadowed questions did not guide or constrain the research process but are merely a point of departure for the commencement of data collection.

In this chapter I have provided a review of the qualitative research literature available with autistic participants prior to field work commencing. I have outlined the sensitising concepts and foreshadowed questions that were informed by the review and my previous experience. In the next chapter I will explain and justify the selection of methodology and research design adopted to explore these foreshadowed questions regarding the wellbeing of older autistic adults.

4 Chapter Four: Methodology, Research Design and Data Generation Strategy

4.1 Introduction

The following chapter provides an explanation and justification of the research design and methodology selected. It describes why this methodology and design was deemed appropriate to investigate the foreshadowed questions highlighted by the literature review and my background experience. It starts with a synopsis of the theoretical underpinning of the study and their suitability to research with autistic participants. It continues with the rationale for the study's position within the qualitative research paradigm and the justification of the adopted approach of constructivist grounded theory. It then addresses research design and the suitability of the selected methods. Following this are specific details of data generation methods used. The chapter concludes with a discussion of quality measurement, the ethical considerations for the study and a reflexive account of my role and it' influence on the data generation and analysis process.

4.2 Theoretical Perspective

This study is rooted in the constructivist paradigm which is described by Denzin & Lincoln (2011) as assuming:

> *A relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic (in the natural world) set of methodological procedures*. (Denzin & Lincoln, 2011:64)

In this section, I discuss the three interconnected theoretical positions of this study. The ontology, epistemology and methodology. Influencing each of these positions lies my personal biography and my own set of ideas and questions about the subject area which are outlined in chapter one (Denzin and Lincoln, 2011). I describe each theoretical position in turn. I provide justification of why the perspectives are adopted and discuss their suitability to explore the experiences of older autistic adults regarding their own wellbeing.

4.2.1 Ontology

Ontological considerations are the nature of reality (Bryman, 2004). In other words, what can be known about, how things really are and how things really work. My theoretical perspective aligns with a relativist ontology. My positionality was influenced by attendance at my first autism conference in 2010 where for the first time I heard personal accounts of autism through numerous presentations. The presentations provided individual descriptions of similar life events by autistic speakers and highlighted how different their experiences were from one another. When I delved further into autobiographical accounts, online videos and blogs this perspective became even clearer.

A relativist ontology acknowledges that knowledge is influenced by the individual values and identities of the participants. Reality is not distinguishable from the subjective experience of it. This does not mean that the two cannot be separate but instead that the two are the same: reality is human experience and human experience is reality (Guba & Lincoln, 2005). Indeed, Stajduhar *et al.* (2001) believe this to go beyond two people experiencing an external world differently; but rather, that their worlds are different. There are different interpretations of experience and therefore multiple realities. Meaning there are as many different realities as there are people. Charmaz (2014) states that all knowledge is constructed, and that reality is fluid and subject to changes based on a participant's construction of it. As discussed in chapter two autism arguably can be perceived as socially constructed and has been influenced significantly through diagnostic changes and via tireless campaigning from the autistic community which has catalysed UK policy change. During my previous professional experience and my interaction with the autistic community I noticed temporal fluidity in the experiential accounts of autistic people. Perception and experience changes from childhood to adulthood and post-diagnosis were often highlighted. This fluidity of constructions concurs with the sensitising concepts of diagnosis being a process and how it can cause a revision of personal identity. This means there is a temporal fluidity in constructions. Although I have no personal experience of a diagnosis of autism, I can draw on the experience of witnessing a family member receiving a diagnosis and how this influenced their understanding and experience of themselves. Additionally, I have experienced personal crossroads in my life and as a result have changed my perception, which supports the concept of the fluidity of construction as stated by Charmaz (2014).

4.2.2 The Ontology of Autism

The relativist perspective is aligned with the views of autistic scholars and activists such as Milton (2012) and Sinclair (1993) who have challenged the ontological status of autism. Autism is diagnosed through several neurological or behavioural (perceived) *deficits* which labels autism as a neurological *disorder*. It is commonly believed that it is a pathological deviance from expected functional *'normal'* development (Milton, 2012). This belief leads to the autistic person being perceived as *disabled* and in need of treatment or modification or 'fixing' so that they can 'fit in' with mainstream society and culture.

One of the prominent theories about how autism disables people is the Theory of Mind (Baron-Cohen, 1985). This theory has widely been used to understand mentalising in autism. Theory of mind details the inability of autistic people to be able to effectively 'read' the subtext of a social situation, leading to inferred meaning being missed. This is often deemed to be a major feature of those diagnosed as autistic. However, Milton (2012) challenges this assumption:

> *Social subtext is never fully given as a set of a priori circumstances but is actively constructed by social agents engaged in material and mental production. There is a tendency in the application of positivist methodologies in cognitive psychology and science to incorrectly assume that there is a set of definable social norms and rules that exist for people to follow. … however. The 'theory of mind' and 'empathy' so lauded in normative psychological models of human interaction refers to the ability a 'non-autistic spectrum' individual has to assume understandings of the mental states and motives of other people. When such 'empathy' is applied toward an 'autistic person', however, it is often wildly inaccurate in its measure.* (Milton, 2012:884)

Milton coined the name the '*double empathy problem'* for this theory. It refers to a break in the 'natural attitude' (Garfinkle, 1967) that happens between people with different outlooks (autistic and neurotypical in this case) when attempts are made to communicate meaning. The emphasis here is that it is a *double* problem because *both* people experience it. It is not a problem located with one person (as proposed by the theory of mind). Rather it is based on the social interaction between two differently disposed people. The 'double empathy problem' theory has much support with autism researchers, autistic scholars and within the autistic community (Fletcher-Watson &

Bird, 2019. Nicolaidis *et al*. 2019. Mitchell *et al*. 2021), who believe that the dominant psychological theories regarding autism are partial explanations at best. There has recently been further experimental support for the double empathy problem theory, (Heasman & Gillespie, 2017) and the theory of mind theory has started to be discredited (Gernsbacher & Yergeau, 2019). Indeed, the 'double empathy problem' theory puts forward that these misunderstandings are not due to autistic cognition alone, but a breakdown in reciprocity and mutual understanding between two people that experience the world in different ways (Crompton *et al.* 2021).

My professional experience, interactions with the autistic community, autistic autobiographical literature, first person accounts, conference presentation and my interaction with the online autistic community, all inform my theoretical position. I have come to understand that my reality may be a different reality to that of my participants and indeed the participants will have different realities from one another. We all come from different perceived 'worlds' (Stajduhar *et al*. 2001). Acknowledgement and awareness of this and the 'double empathy problem' as described by Milton (2012) facilitated the design and conducting of this project. Consequently, this research is focused upon multiple realities using a relativist ontological position (Guba and Lincoln, 1989).

4.2.3 Epistemology

Epistemology is the study of knowledge, and how knowledge claims can be justified (Creswell, 2013). In other words, the relationship between researcher and reality. My epistemological stance is subjectivism. This is a view in the same spirit as relativism, indeed the two are difficult to discuss in isolation from one another. A subjectivist epistemology proports that findings are literally the creation of the process of interaction between the inquirer and inquired (Denzin & Lincoln, 2011). It recognises that knowledge is influenced by the individual values and identities of the inquired. As discussed earlier, autistic interpretations of reality and neurotypical interpretations of the same reality cannot be assumed to be the same (Milton, 2012). As such, epistemologically it would be inappropriate to assume that a universal knowledge of an external reality is possible without being affected by individual interpretations of it. Milton (2012) suggests that this is a double-sided issue. I agree and think that it is imperative to recognise that research findings are influenced by the researcher as much as the researcher is influenced by the researched.

My previous experience and knowledge lead me to understand that wellbeing cannot be simply quantitatively measured for autistic older adults. Wellbeing is a subjective concept and as such my own ideas of wellbeing may be different to those taking part in the study. Epistemologically, it is important that I highlight and remain aware throughout the research of the interrelationship between myself as the researcher and the participants, and the co-construction of meaning. This is highlighted by Mills *et al.* (2006:26)

> *Researchers, in their "humanness," are part of the research endeavour rather than objective observers, and their values must be acknowledged by themselves and by their readers as an inevitable part of the outcome.*

Following a relativist ontology and a subjectivist epistemology, a constructivist approach provided the structure for this research (Denzin & Lincoln, 2011). As such it is important that as a researcher that I am reflective. To recognise how I am personally influenced by my history and cultural context which will inevitably shape this research.

I felt it was important for me to have sufficient knowledge about autism before going into the field so that I may be credible, respectful and theoretically sensitive. According to Strauss and Corbin (1990) theoretical sensitivity is a multi-dimensional concept that includes the researchers:

> *Level of insight into the research area, how attuned they are to the nuances and complexity of the participant's words and actions, their ability to reconstruct meaning from the data generated with the participant, and a capacity to "separate the pertinent from that which isn't.* (Strauss & Corbin, 1990:44 cited in Mills 2006).

I feel this is particularly important in research with autistic participants. I have learned through my interaction with the autistic community, that autistic people have nuanced differences in the ways that they may communicate that can easily be misinterpreted. An example to illustrate this point is that a traumatic experience may be described in quite a 'matter of fact' way, free from emotionally laden language or expression. This should not simply be interpreted as an event that lacked emotion or impact for the participant, based on unconventional expression of the event. Co-construction of meaning via member checking will help describe the emotions attached to that event rather than attributing meaning to the storytelling performance. It is important that ideas regarding wellbeing are explored and co-constructed carefully paying attention to clarifying the meaning attributed to stories.

This study is rooted in the constructivist paradigm and therefore assumes throughout that:

1. Multiple realities exist (it is important to not assume realities of the researcher and researched are the same).
2. A power balance is maintained (participants can tell their story in regard to their wellbeing and a reciprocal relationship is developed where meaning can be established).
3. I remain reflexive as a researcher. (I am aware of my assumptions and influences).

4.3 Methodology

4.3.1 Quantitative or Qualitative?

Conventionally much of the current research into autism has used mainly quantitative research methods (Bolte, 2014) which importantly measures the cause and effects of phenomena (Silverman, 2013). Quantitative research traditionally lies within the natural sciences and takes on a mainly positivist stance. Positivism purports that there is a simple relationship between the world and our perception and understanding of it (Willig, 2001). It believes that phenomena to be researched can be measured empirically and little attention is given to the subjectivity of individuals. The main premise of the positivist research is to test hypotheses regarding relationships between variables as knowledge cannot claim to exist without empirical evidence (Robson, 2011).

Conversely, the tradition of qualitative research is focused on meaning and is interested in how people make sense of the world and how they experience it (Robson, 2011). According to Silverman (2000:8);

> *The methods used by qualitative researchers exemplify a common belief that they can provide a 'deeper' understanding of social phenomena than would be obtained from purely quantitative data.*

Rather than focusing on prediction and control of a phenomena it seeks to provide rigorous description and understanding of people's everyday experience. Qualitative research embraces the idea of multiple realities; different researchers (and participants) embrace different realities. Researchers get as close as possible to participants being studied and therefore subjective evidence is assembled based on the individual's view (Creswell, 2013).

Historically there have been long standing debates regarding the merits of each opposing paradigm of research with either side believing their epistemological and ontological perspectives to be the superior (Smith, 1983). However, more recently both paradigms are accepted and co-exist. Researchers from both paradigms recognise the value of the differing approaches and their ability to generate different knowledge varieties (Creswell, 2013). Traditionally quantitative methodologies have dominated natural science and social sciences but now a period of incorporation and expansion is taking place and according to Creswell (2013) qualitative methodologies are redressing the historical imbalance.

Indeed, it is true that some research questions simply cannot be fully explored using only a quantitative approach. This study is one such example. It was therefore necessary to examine qualitative methodologies in detail to find an appropriate approach.

4.4 The Qualitative Paradigm

The study's focus is to explore the wellbeing of older autistic adults. As described in chapter three this is an under-researched area, older autistic adults have been largely neglected in research (Mukteova *et al*. 2012). Issues of wellbeing (more widely termed quality of life) for autistic people have thus far been sparsely researched. There has recently been some exploration of this area using empirical measures (Mason *et al*. 2019), but the measure used have been validated through use on the wider, predominantly neurotypical population (Mason *et al*. 2018). The validity of such measures has been questioned due to the different interpretation of questions that autistic people may make (McConachie *et al*. 2017).

Wellbeing is in its essence subjective, and different for all people. This is particularly true for autistic people who are a heterogeneous group (Fletcher-Watson & Happé, 2019). The appropriate choice of methodological position should enable participants to discuss the meanings and interpretations that are important to them personally. This point has been highlighted by Hendricks & Wehman (2009) who emphasised the importance of listening to the voices of autistic people before drawing conclusions to guard against a misinterpretation. A qualitative approach provides the flexibility needed to explore personal feelings regarding wellbeing and would certainly provide a deeper insight than a predefined hypothesis-based study. Quantitative research would not provide the rich level of data needed to try understanding this under researched area.

This study aligns with qualitative research methodology for the following reasons;

- This study aims to explore the subjective wellbeing of older autistic adults. Older autistic adults are a neglected voice in the research literature and a qualitative approach will enable exploration of participants' own experiences and provide a rich data.
- It cannot be assumed that neurotypical wellbeing and autistic wellbeing are the same, and therefore it would be inappropriate to make assumptions relating to the wellbeing of autistic adults with little previous research in the area. A qualitative approach provides the flexibility to listen to the personal stories of the participants without imposing pre-determined focus.
- A qualitative approach enables a power balance in the research and permits exploration behind the meaning of the stories conveyed.
- This approach addresses the gap in the research literature and more recent international calls for more qualitative research with autistic people (Bolte, 2014, Carrington & Graham, 2001, Pellicano *et al.* 2014).

4.4.1 Selection of Research Methodology

Prior to designing the current study, attention was paid to the methodological and philosophical assumptions of several qualitative approaches: phenomenology, ethnography, case study research, narrative research, and grounded theory. In this section I will discuss each one in turn.

I am principally interested in exploring important factors contributing to the wellbeing of autistic older adults and attempting to generate a theory associated with maintaining wellbeing. I considered a phenomenological approach but according to Creswell (2013:81):

> *The type of problem best suited to this type of research is one in which it is important to understand several individuals' common or shared experience of a phenomenon.*

I do not believe this this would be suitable for this study. Wellbeing is a broad issue and participants may not have a *shared understanding* of what constitutes wellbeing. Narrowing the project's focus with phenomenology would mean that the project was too researcher led. Therefore, phenomenology was not deemed appropriate for this study.

I am familiar with an ethnographic approach (Schroeder, 2005). having used it in my MSc dissertation. Ethnography has its roots in anthropology and belongs to a tradition of 'naturalism' which emphasises the importance of understanding the meanings and cultural practices of people from within their everyday contexts (Griffin and Bengry-Howell, 2013). Ethnography is concerned with *"understanding the social world or culture – the shared behaviours, beliefs and values – of particular groups, typically via immersion in their community"* (Ritchie, 2013:13). This would not be consistent with the aims of this project. As discussed, I understand wellbeing to be a subjective issue, and although participants may share some aspects of autistic culture, this project's focus was on their *individual* experiences of wellbeing. *"Immersion in their community"* (Ritchie, 2013:13) would not provide me with their subjective experience and may potentially cause problems with interpretation of experience due to the double empathy problem (Milton, 2012). For these reasons an ethnographic approach was not selected for the present study.

Case study research was considered but then rejected as a possibility as this is primarily concerned with identifying a case, usually a unique case that has unusual interest and needs to be described and detailed (Creswell, 2013). I feel that exploration of the subjective experiences of wellbeing of autistic older adults would not be a suitable topic for this approach. I am interested in learning from experiences and developing a theory that might resonate and help other autistic adults rather than purely describing a case.

Narrative research was also considered. This is a method that collects stories from individuals about lived experiences. It is an in-depth process where significant data is gathered on an individual or group of individuals (Creswell, 2013). Although this research methodology is interesting, the depth of data collected is not necessarily suited to my research objectives. While it is not my intention to have a predetermined narrow focus, it is my intention to target wellbeing issues and all the factors that may be involved in the subject area. Although a potential option, I felt that grounded theory would be better suited and allow me to explore issues pertaining to wellbeing.

4.5 Grounded Theory

Grounded theory was developed within the field of sociology in 1967 by Barney Glaser & Anselm Strauss. In the seminal text '*Discovery of Grounded Theory'* (1967) they emphasised the generation of theory as opposed to the testing of theory or verifying a theory as was standard within empirical research. Grounded theory aims to develop abstract theoretical explanations of social processes. (Strauss & Corbin,1998). The key idea is that a theory is not predetermined and then tested, but instead is *grounded* in the data collected from the participants who have experience of the process. Glazer and Strauss in 1967 discuss discovering theory emerging from the data and separate from the researcher. This conflicts with my theoretical positionality. I believe the researcher plays a role in the data collected and it is important to acknowledge the influence the researcher has on that data generation and analysis process.

There have been several different approaches to grounded theory developed since the seminal work including some conceptual divergence between the original authors (Glaser, 1992). However, more recently Charmaz (2006) has advocated the use of constructivist grounded theory which adds yet another interesting dimension to the methodology.

4.5.1 Constructivist Grounded Theory

Constructivist grounded theory (Charmaz, 2006) fitted with my epistemological and ontological perspectives. Charmaz emphasises the flexibility of guidelines rather than methodological rules and requirements as was described in the original grounded theory text (Glaser & Strauss, 1967). Unlike Glaser & Strauss, Charmaz (2006:10) assumes;

> *…that neither data nor theory is discovered, but they are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices.*

Charmaz believes that research participants' implicit meanings and experiential views and the researcher's finished grounded theory are constructions of reality and not exact pictures of it (Charmaz, 2006). What is most appropriate for this study is the importance placed on the mutuality between the researcher and participant. This is particularly true during the in-depth interview where mutuality can grow based on questioning. The reciprocity created between researcher and participant in constructivist grounded theory results in a theory that is *grounded* in their own and the participants' experiences (Hunter *et al.* 2011). Given that this research is to be conducted with autistic older adults and there may be differences in interpretation (Milton, 2012) I feel that this approach is the most appropriate form of grounded theory for this study.

Next, I will discuss some of the essential components of a constructivist grounded theory study and their suitability to this research.

Grounded theory research presents the opportunity to be systematic and yet flexible in research design, and sensitive to the needs, thoughts and beliefs of participants. This flexibility is essential in allowing me to learn as much as possible from participants' experience. Charmaz (2006:2) describes grounded theory methods as;

> *Systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories 'grounded' in the data themselves and heuristic devices rather than formulaic rules.*

My detailed background research has given me knowledge of the autistic experience. However, this is often through proxy accounts and the autistic voice is often neglected, which risks misinterpretation of experience. It was important to approach this topic area using my personal knowledge, skills and experience thus allowing theoretical sensitivity, but without a preconceived agenda. I aimed to explore the wellbeing of participants with an approach that freed me from a predetermined hypothesis (Glazer & Strauss, 1967). The methodology selected had to provide a flexibility in its approach to guard against the effects of any mutual misunderstanding between two people that experience the world in different ways (Crompton *et al*. 2021; Milton 2012). A grounded theory methodology was deemed the most suitable approach to meet the research aims.

4.5.2 Reflexivity

An element of constructivist grounded theory outlined by Charmaz (2014) is reflexivity. The object of reflexivity is to increase transparency and trustworthiness of the research. This is an important element to contemplate in this project. As I initially outlined in chapter one, I have several different backgrounds in relation to autism. I have immersed myself in available literature, conferences, online blogs, social media and autobiographical accounts in an attempt to build an initial knowledge base and be theoretically sensitive.

I am a neurotypical researcher and therefore I expect to experience the world differently to autistic people. Considering ‘the double empathy problem’ theory (Milton, 2012) it is critical in this study that reflexivity is an integral part of the data generation and analysis process. It would be naive to assume that I can set knowledge and experience aside and passively collect the data. I would argue it would be wrong to do so, as I feel my knowledge and experience will contribute positively to the data generation and theory production. However, this scrutiny of my position/beliefs and the influence on the research experience, decisions, interpretations will allow the reader of this thesis to know what extent my interests, positions and assumptions influenced the inquiry (Charmaz, 2014).

> *Reflexivity involves questioning one’s own taken for granted assumptions. Essentially, it involves drawing attention to the researcher as opposed to ‘brushing her or him under the carpet’ and pretending that she or he did not have an impact or influence. It requires openness and an acceptance that the researcher is part of the research* (Finlay 1998).

Although reflexivity is often talked about in research, actual guidance on its implementation is sparse. I intend to outline a five-point reflexive statement at the end of this chapter as outlined by Gentles *et al.* (2014) to clarify my positionality.

4.5.3 Theoretical Sampling

Theoretical sampling, *'involves starting with data, constructing tentative ideas about data, and then examining these ideas through further empirical inquiry'* (Charmaz, 2006:102). Specifically, it involves seeking relevant data that helps to elaborate and refine those nascent categories that may shape the theory. This sampling method involves the selection of initial participants and the analysis of early interviews to inform the selection of both prospective participants and the topics to be explored. This is perfectly suited to this study as it is an under researched area and although the initial interview schedule was informed by the sensitising concepts identified in chapter three (Charmaz, 2006) it was not restricted by them. I did not expect to be able to anticipate all the potential factors important to the participants regarding their wellbeing. This emergent aspect of the constructivist grounded theory approach ensured that theoretical sampling in subsequent interviews was informed by data generated in previous interviews.

4.5.4 Constant Comparison

Constant comparison is a process of systematic analysis, based on the simultaneous data generation and data analysis, to develop concepts and categories emerging from the data. Constant comparative methods are at the heart of coding in grounded theory (Bryant & Charmaz, 2020) and is defined by Charmaz (2006:187) as:

> *A method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category and category with concepts.*

Throughout the constant comparative method, the researcher continually sorts through the data generation, analyses and codes the information, and reinforces theory generation through the process of theoretical sampling. This systematic analysis will support understanding and relationship with the data in this study. This technique helped me develop a deeper understanding of the nuanced issues discussed by the participants.

Having discussed and justified the theoretical underpinnings of the study and the selection of methodology I will now present the aims, research question and research design and the specific considerations made for involving autistic participants in research.

4.5.5 Research Design

This is a qualitative study which employs semi-structured interviews using a purposive sampling method designed to explore the foreshadowed questions outlined at the end of chapter two.

Aims: The aim of the project is to extend the current knowledge base on the lived experience of older autistic adults and contribute to a better understanding and acceptance of autism.

Research Question: What do older autistic adults feel are the most important factors that assist them in maintaining their own personal, physical and mental wellbeing?

In the following section I will describe how I ensured autistic people were involved in and informed the research process. This will be followed by a detailed explanation of the research methods used. I include details on their particular suitability and how adaptions were considered to ensure the research methods were suitable for autistic participants.

4.6 Advisory Group

When I first started to think about this project, I knew I wanted to hear from autistic people themselves as I recognised that there was a gap in the current evidence. However, as I learned more about the nuanced differences in the way in which autistic people can experience the world it became apparent how essential it was that I gained advice from autistic people early in the research process. I felt it was imperative that I gained some autistic expertise to test the feasibility and suitability of the proposed research focus and on the appropriateness of the research design and tools. To this end I recruited an informal advisory group consisting of four autistic people that I already had contact with. This type of advisory group is now commonplace and is held as good practice in more recently published guidance by the National Institute for Health Research (Grotz *et al*. 2020) and Autistica (2021).

The advisory group provided guidance and advice on several key dimensions of the project:

- Clarity of the research question and affirmation of its importance.
- Ensuring the methods selected were appropriate for autistic people
- Reviewing study documentation
- Providing advice on the recruitment strategy.
- Providing advice on individual design factors that need to be taken into consideration during fieldwork.

The role of the advisory group organically developed throughout the project. They provided a fundamentally important function of acting as my interpreters to provide me with insight into nuanced autistic experiences. They provided an informal mechanism to discuss clarification of meaning and ultimately to test the resonance and usefulness of the grounded theory. The advisory group were fundamental to ensuring I could be sensitive to the needs of my participants and that the design was fit for purpose (Entwistle, 1998). Meetings and communications with the advisory group were held informally and individually as this was better suited to their individual needs and schedules. They provided advice and support throughout the project, and I made contact with them when appropriate but this worked out at about every six months, but there were more frequent contacts during data collection and analysis period.

4.6.1 Research with Autistic Participants

At the point this study started, there was a lack of guidance in the literature of how to conduct research with autistic participants. Specific to this research is the process of interviewing which, while extensively covered in the literature, lacks any autism specificity in relation to guidance. As discussed, when I entered the fieldwork phase of my project there was very little qualitative research with autistic people as participants. There was even less guidance for carrying out such research. I searched the literature and was able to find just one, short, two-page article (Brown, 2012). This concentrated on the physical aspects of conducting research with autistic people such as considering sensory issues and factors in the physical environment to consider. It also provided ideas on the construction of study documentation. However, I felt uneasy commencing the data generation process without further guidance. As the autistic experience is heterogenous (Wing, 1996) it is difficult to find a universally acceptable method or guide on how to sensitively conduct interviews with autistic participants. Nevertheless, I felt it important that I explored this dimension further. I spent a significant amount of time gathering evidence from autobiographical accounts, online blogs, social media and conference presentations so that I could formulate my own set of considerations in order to facilitate a person-centred approach to the research design. I consulted the advisory group and gained guidance on my design which gave me confidence to start the data generation process in a theoretically sensitive way. Given the dearth of guidance on this I shared the insights I had gained at the Scottish Autism Conference in 2018 (Kirton, 2018) (see appendix five)

My person-centred design gave careful attention to five key areas:

1. Planning the interview
2. The researcher-participant relationship
3. Considerations and information provision
4. During the interview: the personalisation of communication
5. After the interview.

I will give details of each area of consideration in turn as I progress through the explanation of each stage of the data generation methods[2]

4.7 Methods

4.7.1 Sampling and Recruitment

It was important that an inclusion criterion would be that participants have an official autism diagnosis rather than being self-diagnosed. This meant that recruitment was from a small potential population. As I outlined in chapter two the autism diagnostic criteria widened in 1994 to include autistic people without intellectual disabilities when Asperger's syndrome was added to the fourth edition of the Diagnostic and Statistical

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[2] Since I have conducted the research there has been some guidance and support for the strategies that I incorporated into the design. Where available I include references to them. However, this guidance was not available at the time fieldwork commenced.

Manual of Mental Health Disorders (DSM-IV). However older adults of 50+ at the time of data generation, would have been over 30 years old at this time when the diagnostic criteria widened (Brugha *et al.* 2011; Geurts *et al*. 2015). As part of the inclusion criteria for the study was that they must be willing and able to take part in an interview, this meant that participants would most likely be recruited from those that would not have been deemed within the narrower pre-1994 diagnostic criteria for autism. This means that my potential participants would most likely have received a diagnosis of autism in adulthood. This population would be small as adult diagnostic services did not become mandatory in the UK until 2009 and waiting lists for such services are still unsatisfactorily long (Russell, 2021).

In grounded theory studies there is some contention regarding how many interviews enable a researcher to reach data saturation and fully develop the model. Creswell (2013) believes it to be between 20-60 interviews. Charmaz (2014) states that 25 should be enough unless there is great contention in the model, however there are numerous studies with less. Indeed, Thomason (2011) conducted a study to examine sample sizes of interview based grounded theory studies. In his study he looked at 100 grounded theory studies published between 2002-8. There were 12% of studies that had under 10 participants and 32% had between 10 and 19 participants. The key to grounded theory research is to generate enough data so that details of the given phenomena can emerge (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Widespread advertisement of the study and remote participation modes enabled me to recruit fourteen older autistic adults to take part in the study. I did not attempt to recruit further as I felt I had a range of different autistic older adults with varied life experiences in the sample and the data generated in the project was rich (Dibley, 2011) and plentiful. By the last interview I found no new data emerging in regard to the research question, therefore there were no more categories developed and I felt I had reached data saturation (Morse *et al.* 2014).

4.7.2 Sampling

Purposeful sampling was employed in this study. This is a technique commonly used in qualitative research (Patton, 2002). This involves identifying and selecting individuals or groups of individuals that have experience of the phenomenon of interest (Creswell & Plano Clark, 2011).

4.7.3 Inclusion criteria

People were invited to participate in the study if they met the following inclusion criteria:

- Aged 50+
- Individuals must have an official autism diagnosis.
- Participants must be willing/able to take part in an interview.

4.8 Research Design

4.8.1 Study Documentation

All study documentation and advertisement information were checked by the advisory group for clarity and to check for missing information before it was sent out. The following details specific elements incorporated to the design of the study documentation to ensure they were appropriate for autistic participants.

- I used black Arial font and buff/pale yellow paper in all my paper-based advertisements and study documentation. (Brown, 2012)
- I used plain English and avoided unnecessary acronyms or research terms. This is thought to be generally more accessible for people with communication needs and therefore helps support the National Accessible Information Standard www.england.nhs.uk/accessibleinfo
- The study information sheet was set out as Frequently Asked Questions (FAQs) for ease of reading and locating information (see appendix six).
- I included a photograph of myself on the study advertisements and information sheet. I also included a recognisable logo (I chose the batman sign). I wore a badge of the batman logo when meeting participants for the first time, so they could recognise me, to assist participants who struggle to recognise faces (Winn, 2015).
- I used person first language in all documentation in line with the wishes of the autistic community as found in a recent study (Kenny *et al.* 2016).

These have more recently been outlined as a favourable way to design documentation for use with autistic participants (Gowan *et al*. 2019).

4.8.2 Advertisement and Recruitment

Several different methods were used to advertise the project (see box four), with new methods being added to the strategy when the subsequent method was exhausted.

Box 4: Methods used to advertise and recruit to the research

Autism conference delegate pack: A study information sheet and participation request was included in the delegate pack (see appendix six)

Advertised through National Autistic Society (NAS): I advertised the study on the NAS webpage of research projects seeking participants.

Adult social groups (n=6): Gatekeepers of support groups were asked to highlight the project within their meetings.

University wide email sent: 2,000 recipients

Snowballing from participant contacts

Facebook: I advertised the project on my personal Facebook (shared 21 times by my direct contacts). I also gained permission from the administrators of three Facebook pages that focused on autism to post details of the project on their 'home' pages.

Twitter: I advertised my project several times on Twitter and added associated hashtags.

4.8.3 Initial Contact with Participants

Upon receiving expressions of interest from participants, I provided more information about the project via email and phone. I supplied potential participants with a project information sheet (see appendix six) and confirmed that they met the inclusion criteria. I had discussions via email/phone answering any questions potential participants had about the project. Information was given so participants were aware of exactly what they could expect by taking part in the study, timeframes and locations were included.

Once participants were happy with the information provided and they had agreed to take part in the study we agreed on the best mode to conduct the interview and a time and a date of interview (that was at least three days ahead to provide a 'cooling off period'). If a face-to-face interview was selected at the University, I offered individually tailored direction instructions that could incorporate pictures to get to the specific room.

I also asked participants if they would like to see the questions/ topic areas to be discussed prior to the interview (Winn, 2015).

4.9 Data Generation

In the following section I will describe the data generation process using semi-structured interviews. I use the term *generation of data* which I felt was more helpful than *collecting data* as it does not invoke the idea that researchers are passive/neutral collectors (Mason, 2018). 'Generation of data' aligns with my epistemological stance: as a researcher I am engaged in constructing knowledge. The methods I discuss here are not merely procedures for gaining data. It was a process of different activities that are intellectual, analytical and interpretive that generated the resultant data (Mason, 2018).

4.9.1 The Semi Structured Interview

After much consideration of the individual needs of my potential participants and in consultation with the advisory group, semi-structured interviews were selected for generating data for this study. It was the flexibility of the interview implementation that was the key feature in their selection for this study, which is eloquently emphasised by Mason:

> *You will need to be flexible and sensitive to the dynamics of each interaction, so that you and your interviewee(s) are effectively tailor making each one on the spot. You will want to take cues from the ongoing dialogue with your interviewee(s) about what to ask them next, rather than go to the interaction entirely pre-scripted. this will enable you to follow up their specific responses along lines which are peculiarly relevant to them in their context and which you could not have anticipated in advance in a highly organic way.* (Mason 2018:113)

The ability to individualise the process, to guard against misinterpretation, to provide a safe space for participants to share their experience and to provide a practical method in terms of resources all meant that interviews were the perfect choice. In the following section I will discuss why I considered these factors particularly important when conducting research with autistic participants.

4.9.2 Individualised

Interviews not only provide rich data, but they also offered the opportunity to personalise the data generation process. One way to individualise the interview process was by offering different methods of conducting the interviews. The available literature suggested that the face-to-face interviews were the superior form of data generation tool, since a relationship can be built with interviewees and rapport can be formed (Opdenakker, 2006). However, to make a blanket application of this notion to interviews with autistic participants would be misguided and somewhat naïve. My own experience, research, reflection and consultation with the advisory group, guided me to carefully consider the mode of interview offered.

There are many reasons why different forms of interview other than face-to-face might be more appropriate for some participants. As highlighted in the autobiographical accounts, autistic people may have sensory sensitivities that can involve one or more of the senses (Grandin, 2006; Jackson 2002; Lawson, 2000; Shore 2001; Williams 1992, 1994). It may be difficult for a neurotypical person to detect these sensitivities and as revealed in the autobiographical accounts autistic people are used to camouflaging their effects. This makes it difficult to guard against their effect in the interview scenario. These sensory issues could cause anxiety and make potential participants reluctant to go to unfamiliar spaces thus preventing them from taking part in the research (Grandin, 2006; Jackson 2002; Lawson, 2000; Shore 2001; Williams 1992, 1994). Additionally, autistic people may have problems understanding or interpreting other people's thoughts, feelings or actions. The subtle messages that are put across by facial expression and body language can be missed (Grandin, 2006). By using non-face-to-face (NFtF) interviews these difficulties are removed from the situation and can provide a less confusing environment for the participant and interviewer. There are also more practical issues to consider, conducting NFtF interviews places less burden on the participants as they do not take as much time due to less travel time. An added bonus of this is that it reduces the risk of interviewees being stressed or anxious when starting the interview due to ‘incidents’ on the journey (Grandin, 2006; Williams 1992, 1994). The NFtF interview is also less intrusive on interviewees’ lives, allowing normal life to continue around them (Holt, 2010). It also gives participants the opportunity to take part in the interview in any way they feel most comfortable (stand up, walk around, pace) without having to worry about conforming to conventional communication styles. Additionally, incorporating NFtF interviewing techniques has the added benefit of permitting a wider geographical spread of potential participants in this small population (Brugha *et al*. 2012; Geurts & Jansen, 2011; Geurts *et al.* 2015). I felt it important to offer as many different ways to conduct the interview as possible as I was aware that participants would have different preferences. For these reasons recruited individuals selected a mode of participation which is best suited to their personal requirements.

The following choice of interview were included in the study;

- Face-to-face interviews
- Telephone interviews
- Synchronous internet communication - (private) e.g.MSM
- Asynchronous internet communication (private) – email
- Skype (video interview)

4.9.3 Misinterpretation and the 'Double Empathy Problem'

It was also important to ensure that member checking was a central part of the data generation process. Member checking is a technique for exploring the credibility of results. This allows researchers to return to participants to check for accuracy and resonance with their experiences (Birt *et al*. 2016). This process is very important in this study to guard against any potential misinterpretation (Milton, 2012). Personal interviews provided the flexibility to ask the participants for verification of meaning throughout the data generation process (both inside and outside the interview scenario). The flexible nature of semi-structured interviews would also allow participants the freedom to discuss issues pertinent to them and the opportunity to probe beyond the answers to facilitate richer generation of data (Creswell, 2013). This provided the opportunity to follow up interesting avenues that may have not previously been highlighted by sensitising concepts or foreshadowed questions. Through theoretical sampling (Charmaz, 2014) I was able to explore these novel concepts with other participants.

4.9.4 Practical Considerations

Pragmatically the selection of interviews was also appropriate as they could be conducted at a time suitable for both the participant and me as the researcher. They would also allow for time in between interviews for initial analysis to take place enabling constant comparative analysis and subsequent theoretical sampling (Charmaz, 2006).

All the factors discussed made semi-structured interviews the most appropriate method to be selected for this study.

4.9.5 Safety and Privacy

Personal interviews give the time and space to allow participants to share information that they may not feel comfortable discussing in a group setting. Participants can take their time and feel comfortable by setting the pace of the interview. This assisted in accommodating any potential processing delays or specific communication requirements of participants (O'Conner, 2012).

4.10 Methods

4.10.1 Conducting the Interviews

The Personalisation of the Communication

The advisory group and my own background knowledge helped greatly in anticipating the interview scenario and some of the factors I needed to consider. However, I found the best strategy was to have a candid dialogue with participants prior to the start of the interview. I spent some time prior to the interview meeting or at the beginning of the interview (whichever felt most appropriate) gathering information on the individualised way in which they wanted the interview to proceed[3] (see appendix seven). I reassured participants in each interview that I wanted the experience to be as comfortable for them as possible and that they could interrupt me, stop the interview or change topic at any time. I highlighted how although I had a few areas that I wanted to talk about, I really wanted them to guide the direction of the interview. It was *their* wellbeing that was the focus of the project and I emphasised that it was important that issues significant to them were discussed and that could decide what they wanted to include, likewise they could also decide if they did not want to answer certain questions. I stressed that I was a novice autism researcher. I invited participants to

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[3] A summary of some of the personalisation requests from participants that arose from these conversations are included in appendix six.

provide me with advice or information if I inadvertently did or said anything during the interview which made them feel uncomfortable, so that I could learn and modify the process in subsequent interviews. Ultimately, I took it as my responsibility to be reactive and responsive to participants' needs and often it was necessary for me to make modifications to my own style of communication.

4.10.2 Modification and Awareness of Personal Communication Style

I purposefully modified my communication style for the interviews. I attempted to talk at a slower and calmer pace than was natural for me and allowed pauses and hesitations that were longer than I would usually be comfortable with. I also refrained from chit chat but was led by the participant on their preference for this. I also tried hard to regulate my movements during the interview and ensured that I did not tap pens or shuffle papers etc. There is anecdotal evidence that small low-level noises can be very distracting for autistic people. I ensured that I spoke with clear and direct language and avoided overly complicated or ambiguous terms. I attempted to mirror the language and terms that participants used. I also asked participants what terminology they preferred to use when referring to the autistic community. I ensured I used their preferred terms throughout our communications and was careful that terminology was positively focused (Winn, 2015).

4.10.3 Researcher-Participant Relationship

As highlighted earlier, one of the important considerations when involving autistic people in research is the clarity of the researcher-participant relationship. Autistic people may be perceived as a vulnerable group which makes examination of this dimension vital. Some 'vulnerable' groups can lack social networks, and these sometimes can be made up more of professionals than friends. Stalker (1998) argues that researchers going into people's homes to conduct research need to be particularly sensitive to the fact that their presence could be misconstrued as being the participants' friends.

4.10.4 Practical Considerations in Preparation for the Interview

There were other practical considerations taken into account when planning the interviews. Many of the factors detailed below related to face-to-face interviews conducted at the University campus.

- **Physical factors during the interview**. I asked the participants how they felt most comfortable conducting the interview. Details such as where they felt most comfortable sitting or standing and offering to move furniture to facilitate their comfort.
- **Appropriateness of room**. If the interview was taking place at the University, I would select a room that was;
    - Easy to find.
    - Did not have automatic windows
    - Was near toilets
    - Did not have low level noise like buzzing monitors/pcs etc.

I had a selection of rooms that I checked were appropriate and that I specifically requested to book one of these rooms (Winn, 2015). I always visited a room prior to the interview to check the conditions were suitable.

- **Lights**. I ensured the lighting was appropriate. This was problematic in some of the rooms at the University as the lighting was automatic and it could not be turned off. It also would suddenly turn off if people in the room were still and it did not detect movement which would be disruptive to the interview.
- **Personal preparations.** On the days of face-to-face interviews, I did not wear perfume as I had been told anecdotally that strong smells can be very distracting for some autistic people. I also avoided highly patterned clothing for the same reason.
- **Time.** I took a digital clock with me to interviews to help participants keep track of time. I also asked participants if they had a specific time they had to leave and assured them we would start and finish on time. Not keeping to time can cause great anxiety for some autistic people (Winn, 2015)
- **Fidgets** – I had a couple of fidget items that participants could use during the interview if they wished.

- **Breaks.** At the beginning of the interview, I suggested we took a break half way through. I said I would pause at this point and ask if they wanted a break. However, if they wanted to continue, we did.
- **Refreshments.** I provided a fresh bottle of water for the participants to drink if they wished.

4.10.5 Member Checking

In line with the constructivist methodology most of the member checking was conducted throughout the interview (Charmaz, 2014). I implemented questions, paraphrasing, and summarising to ensure I understood the participant's experiences. I offered to conduct a second interview with the first four respondents to member check. After the fourth participant I reviewed this process. Member checking using interviews was very resource heavy and took a significant amount of time. After the fourth interview, I was feeling more confident in my interviewing abilities and became adept and obtaining clarification of meaning throughout the interview. I realise that conducting member checking during the interview, and after the interview by email, would be more effective and efficient and place less burden on the participants. To this end, from the fifth participant member checking was done outside the initial interview remotely. This enabled a more focused approach in gaining clarification on certain points

4.10.6 After the Interview

Once the interview was finished, I indicated this verbally. This was done in a formal way as there is anecdotal evidence that autistic people often have difficulty knowing when interactions come to an end due to the tendency on reliance on nonverbal cues to indicate this. '*Thank you very much, that is the end of the interview'* was used. I outlined the procedure I was going to take with analysing the interview data. I asked permission to contact them to check my understanding of their interviews (if necessary) and I confirmed the best way to do this (email, phone, text etc.). I asked if they would like to see a copy of the results and any published work.

4.10.7 Post Interview Field Notes

After each interview I reflected and made field notes. These were sometimes handwritten, but more often they were dictated. I found that recording my thoughts in an audio file was a much more efficient and effective way to reflect. I found by using this verbal reflection technique that I examined my thoughts more carefully than I would if I had a written diary entry. These diary notes included environmental notes, pre- and post-recording discussions and my initial thoughts about meanings of discussions in the interview and how they related to categories/previous interviews. I also added notes regarding how I felt the interview went or anything I was unsure about that I wanted to check with the advisory group. The audio notes included details of future theoretical sampling. These audio notes were transcribed as bullet points. They served as an *aide memoir* during times where I was 'stuck' with analysis. I would often return to listening to my field notes as these were an efficient way to take me back to the interview and often promoted further thoughts and insight into the data (see appendix eight).

4.10.8 Transcription of Interviews

All recordings were transcribed verbatim by an external person. There were 35 hours of audio recordings, and I was fortunate to receive a small pot of funding to cover these transcription costs from my University (Details of the ethical considerations associated with this process are discussed later in the chapter).

4.11 Analysing the Data

The data analysis process involved a mixture of activities that were intellectual, analytical and interpretive. It was not a linear process as I moved back and forth between the analysis components. Constant comparison of data, diagramming, memo making and contemplation all contributed to the process (Mason, 2018).

Figure two: The Data Generation Process

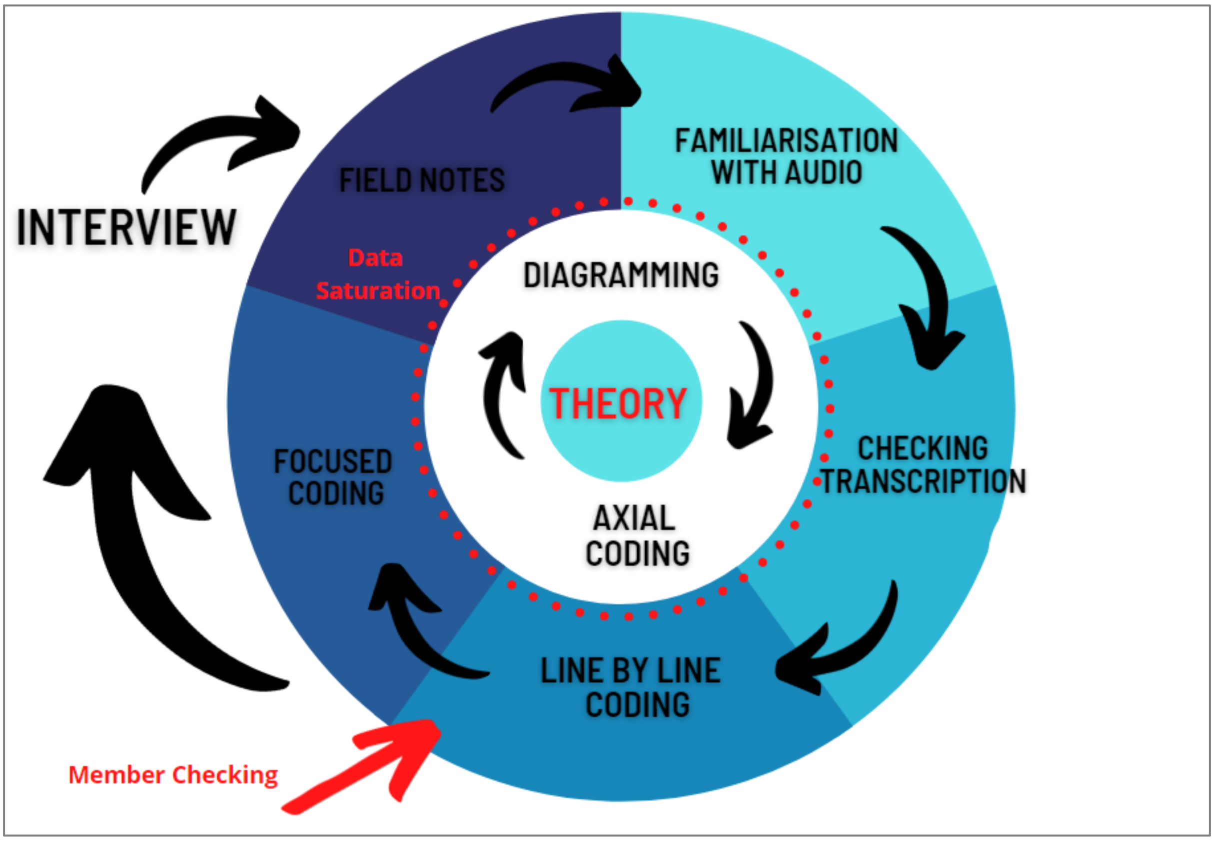


Figure two displays a visual representation of the data analysis process. Interviews were conducted, followed by field notes. Then a process of intense familiarisation with the audio. The audio was transcribed which was meticulously checked by listening to the audio once more. After that coding began with line-by-line coding for each transcript in turn, at this point any queries were member checked with participants. Focused coding was then completed. Once data saturation was reached and therefore all participants' data had been generated, a further analytical process was conducted. This involved two interlinked procedures: axial coding, and diagramming. After much revising and testing of the generated theory against participants' raw data the grounded theory was finalised.

I will now provide a detailed discussion of each of the elements of the data analysis process in turn.

4.11.1 Familiarisation with Audio Data

Whilst waiting for transcription to be completed I listened to each interview several times and made notes. On receipt of the completed transcript, I listened to the audio again and meticulously checked it was a correct record of the interaction. This was time consuming but extremely worthwhile as it gave me an intense familiarity with the participants' accounts. This also provided me with another opportunity to reflect on my interviewing technique. I used this process to make extensive notes and used diagrams to illustrate the contents of the interactions. This aided the analysis process and gave me the confidence that I had not unwittingly missed any information provided. This also formed the first part of analysis. This intense familiarity with the individual stories helped later in analysis when piecing the information back together again for theory development (Strauss & Corbin, 1998).

4.11.2 Data Management: Using NVivo

I undertook training in the use of NVivo qualitative data analysis software; (QSR International Pty Ltd. Version 11, 2015) a package originally designed specifically for qualitative data analysis with grounded theory in mind (Bringer *et al*. 2004;). This assisted greatly with data management. It provided a sophisticated way for me to organise the data. It provided a way to store, sort and re-sort data easily and it enabled me to have easy access to the data to locate quotes and relevant information quickly. With over 335,500 spoken words to analyse I found this invaluable. NVivo was used in the early stages of analysis and was mainly used for data management and as an archive for records of analytical work. NVivo is not capable of performing qualitative analysis or of interpreting judgments or the relationships between categories (Welsh, 2002) and all analysis was done by me with NVivo principally used as a data management assistant. NVivo proved to be an invaluable tool in the data management and early coding process.

4.11.3 Coding

There were three main stages of coding that were organically linked. Figure three illustrates an example of the relationship and evolution of the categories between the three coding types. In the following section I will outline the process I used in each of the three stages: line by line coding, then focused coding and finally axial coding.

4.11.4 Line by Line Coding

I began coding with line-by-line coding (Charmaz, 2006) this enabled me to break down what was being said by the participants and led away from any preconceived notions I may have had. As advocated by Charmaz (2006) I typically used *gerunds* (a verb that ends with *ing,* that acts as a noun, such as 'accepting'*)* This meant the codes represented processes or actions (see table five). This led to many codes being formulated. It helped build my analysis from the ground up (Charmaz, 2006). These were later broken down into categories and this process was easily managed with NVivo. I also used field notes and memo writing to assist with my thought processes and ideas. Before conducting a new interview, I would complete initial line by line coding and familiarised myself with the codes identified, compare them with my field notes and memos so that kept them in mind whilst conducting the next interview. In table five I show how an excerpt from Sheila's interview was coded line by line. It also shows how I also used *In vivo* codes (shown in italics) to keep a reminder of the participant's voice and terms that really captured their individual meaning and experience (Charmaz, 2006).

4.11.5 Focused Coding

Focused coding was the next step in my coding journey, this is where I started to group segments of data with conceptualisations. I applied focused coding by adding them as 'parent nodes' in NVivo so that I still had the initial codes below the parent node as a reference point. Before recoding I would make a copy of the NVivo workbook, so that I had a reference of my coding journey. Once I was happy with my focused coding, I then started to look at the categories of codes rather than the transcripts and started to look for theoretical links in the data. An example of focused coding on Sheila's transcript is shown in table five. I used Charmaz's questions (see box five below) to help guide me in the process and keep me on track:

Box 5: Charmaz guiding questions: (Charmaz, 2006:51)

- What process is at issue here?
- How can I define it?
- How does the participant act whilst involved in the process?
- What are the consequences of the process?

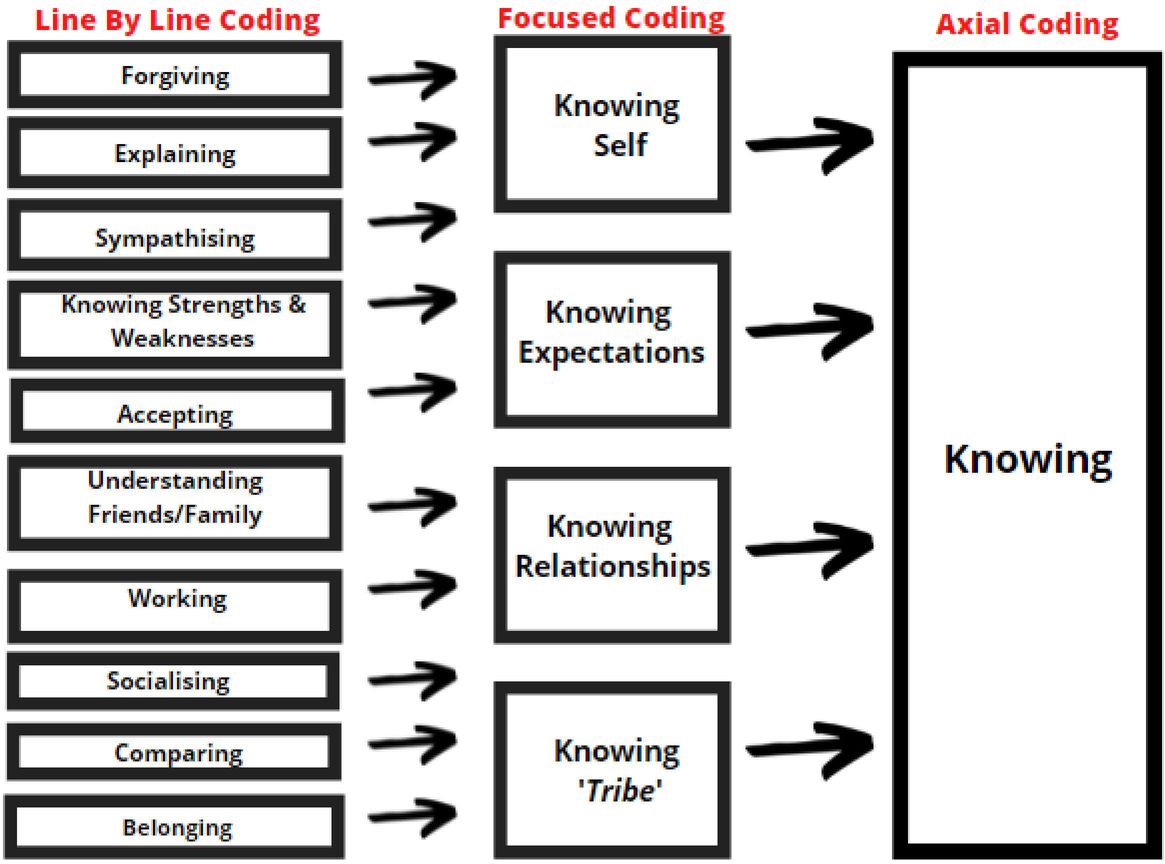
4.11.6 Axial Coding

Data analysis naturally moved to what Strauss and Corbin (1998) refer to as Axial coding. Axial coding is a process of linking categories to subcategories and determines a relationship between them. As suggested by Strauss and Corbin (1990) I used many diagrams to help make sense of what was happening.

Table 4: An excerpt from Sheila's interview displaying examples of coding

Excerpt Sheila Interview	**Line by Line coding**	**Focused Coding**
P: And when I got my—well… [sighs] I think there was a whole load of denial going on with the diagnosis, to be honest with you. But I think, you know, in this last couple of years or so, very much so reflecting, and thinking, ah yeah, that makes sense. In fact, it's been a huge light bulb moment.	Disappointing Denying, Resisting Dx Reflecting, Dx illuminating, *Light bulb moment*	Denial of diagnosis Delayed acceptance Diagnosis is a process Diagnosis is a process *Light bulb moment*
P: Yeah, yeah. And I know I need to do an awful lot of kind of healing, if you like, and, you know, coming to terms with things, and sort of like the way my family are and all the rest of it. But actually, I think knowing what you are is really helpful.	Recovering from injury, Rejecting Dx Reflecting, Learning to accept Gaining self-knowledge	Therapeutic healing Acceptance of Dx Self-awareness
P: And knowing that you can go forward with it, and it doesn't have to be awful, even though there are times when it is difficult, very much so.	Seeing positives Recognising, Struggling,	Moving on Diagnosis is a process

Figure three: Coding process from Initial Line by Line coding to Axial coding.



4.11.7 Theoretical Sampling and Constant Comparative Analysis

As the coding and analysis developed it became clear that the significant ‘phenomena’ impacting on wellbeing was receiving a late diagnosis of autism. The inclusion criteria specified that all participants had experience of this and therefore specifically theoretically sampling participants for topic issues was not necessary. Theoretical sampling took place in the form of inclusion within interviews with subsequent participants, based on the initial coding and reflection from earlier participants. Throughout the coding process the constant comparative method was used. This was an organic process and was aided due to my intimate knowledge of the data. I continually sorted through the data and made memos (see appendix nine) to help with the links I was making. This systematic analysis supported my understanding and enhanced my relationship with the data.

4.12 Memo Writing

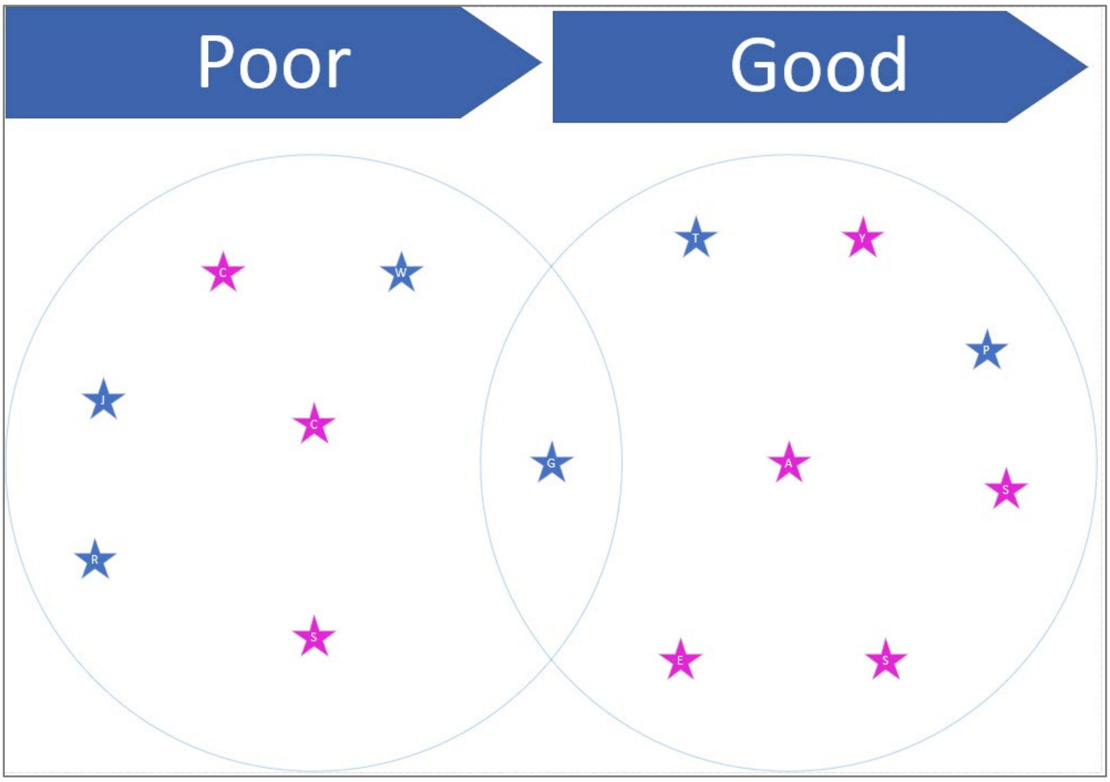
I found memo writing essential throughout the analysis process (see appendix nine). It helped the process of coding and trying to wrangle with the data analysis. I used it in three main ways:

- **Coding Tasks**: I assigned myself coding tasks through memos as a way of keeping myself organised and not losing the flow of analysis. E.g. '*check Ralph's interview as I am sure he mentioned this….*' etc.
- **Reflections**: Memo writing provided me with a 'project log' where I would note down my thinking processes. Often I would have many 'post it' notes that I would gather and type up so that the valuable thinking was not lost. This was very useful as the data generation and analysis spanned an extended period and memos helped me keep track. The memo function in NVivo was used to organise this process.
- **Theoretical Links**: I noted down some of the concepts that I was making links with and used the raw data to help with my memoing, a strategy advocated by Charmaz (2006). She believes that researchers should retain the participant's voice in memos using *In vivo* codes so as the memos and analysis become increasingly complex, the participant's voice remains clear and their meaning is present in the theoretical outcome. These notes combined with diagramming were essential in theory development.

4.12.1 Diagramming

Diagramming was an integral part of the analysis. Creating diagrams helped me notice the relationships between the data generated from different participants. The process of diagramming was particularly useful when I felt I was swimming in masses of rich but very messy data. At one point in my analysis I was having a crisis of confidence. My supervisors encouraged me to set my data aside and use diagramming to aid theory development. I developed a simple Venn diagram to plot how I perceived the wellbeing of my participants shown in in figure four. This simple diagram led me to first identify a divide in my participants and returning to the questions laid out by Charmaz (see box five) I was able to start to conceptualise my grounded theory model. Numerous diagrams were produced to aid analysis and my own conceptualisation of the process before I came to a suitable fully formed theory which I felt represented the process.

Figure four: Initial Simple Venn Diagram to Display Participants' Wellbeing Label Diagram



4.12.2 Testing the Theory

Once I had conceptualised the grounded theory, I returned to each participant's data to ensure the theory was reflective of their experience. Once I was confident of 'theory fit' with the data, I wrote the finding sections of the thesis which aided refinements to form the fully developed the theory and accompanying diagrams. Then I tentatively discussed the theory with my advisory group. I wanted to 'check' that the theory seems sensible and plausible and that the 'double empathy problem' (Milton, 2012) (described in chapter four) and my outsider perspective had not somehow completely misconstrued the data. The advisory group gave me positive feedback and confirmed that the theory resonated with their experiences. This gave me confidence to present an oral presentation at the Autistica[4] conference (Kirton, Ryan & Tod, 2021) and I received numerous positive comments regarding the presentation on social media. This has given me the conference to submit abstracts to the Autism Europe Congress and Autistica conference 2022.

4.12.3 Ethical Considerations

Ethical considerations are important not only to protect participants and researchers, minimise harm, assure trust and ensure research integrity, (Denzin & Giardina, 2007). They also help researchers to cope with new and challenging problems (Aluwihare-Samaranayake, 2012). The changing direction of interest during a qualitative study means that new and unexpected ethical dilemmas may present themselves throughout the course of the study. I was aware of this fact and prepared for this by ensuring that I was theoretically sensitive to the autistic experience and by consulting the advisory group on the data generation strategy.

Ethical approval for the study was granted by The University of Sheffield Ethics Committee (UREC) see appendix ten). The ethical considerations relevant to this study are discussed below. In order to consider and plan for any ethical issues in the study I used the four main health research ethical principles as a framework to guide me (Beachamp & Childress, 2009). These are: autonomy, nonmaleficence, beneficence and justice. In the following section, I examined each of these four principles and considered how my research design ensured that I was sensitive to them.

4.12.4 Autonomy

Autonomy requires the participants to be able to decide for themselves, without control from others and with enough understanding to provide for meaningful choice for participants (Beachamp & Childress, 2009, Mauthner & Birch, 2002). In order to address this principle, I have considered informed consent procedures.

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[4] Autistica is the U.K’s national autism research charity. Their conferences are well attended by autistic researchers and delegates.

4.12.5 Informed Process Consent

As is typical in qualitative research, it was not possible for me to predict the direction the in-depth interviews would take (Aluwihare-Samaranayake, 2012). Integral to the study design was the opportunity to contact participants after the interview to '*member check*' and validate my understandings of our interview interaction. Therefore, traditional one-off informed consent forms would not be suitable. I used *'informed process consent'* (Hellström *et al*. 2007) where consent was obtained at every contact. It provided participants with the opportunity to refuse further contact. The official nature of taking consent again, also delineated the research relationship further and prevented participants misconstruing further contact (Stalker, 1998). I obtained consent at each separate contact and re-iterated the right of the participant to withdraw from the study at any time.

Prior to gaining consent at the initial interview contact the following steps were taken;

- Participants were fully informed about the study and given a comprehensive information sheet (see appendix six).
- Participants had the opportunity to discuss the study with me and ask any questions they had.
- Participants were reassured that they had the right to withdraw from the study at any time without giving reasons.
- Participants who consented to take part had a planned 'cooling off period' of at least three days after receiving study information and before the interview was scheduled.

4.12.6 Nonmaleficence and Beneficence

Nonmaleficence and beneficence are interlinked and represent the risk-benefit analysis of taking part in the research. The principles emphasise that participants should not be harmed or placed at undue risk by taking part in the research and the benefits of taking part in the research should outweigh the risks.

4.12.7 Nonmaleficence

Nonmaleficence or the risk of potential harm posed to participants by taking part in this study was minimal. I ensured this through the careful consideration of the individual needs of participants. Care was taken to guard against potential source of distress. Consideration was given over the aspects of the study that could cause sensory or social distress (Brown, 2012; Winn, 2015). One such potential source was that of the researcher – participant relationship. Time was also taken to ensure that this was clarified and free from ambiguity (Stalker, 1998). Time was also devoted to thinking about the fact that participants could potentially become distressed talking about certain topic areas. The flexible, participant-led design of the interview reduced this risk. Participants were assured that they did not have to speak about topics that made them feel uncomfortable. I paid careful attention throughout the interviews to watch out for signs of upset or distress. If this occurred, I would ask participants if they wanted a break, to end the interview or to change the topic of conversation. Once the interviews were over, I checked that they felt comfortable with what we had discussed and welcomed their feedback on the process.

4.12.8 Beneficence

Beneficence (or the benefit to the participant of taking part in the research) can only be estimated. There was no financial benefit in taking part in the study but there is potentially a broader benefit. The study results were to inform a wider audience interested in learning about autism and therefore promote a wider understanding. However, these benefits are only *potential* benefits and cannot be guaranteed or measured. Participants may have the opportunity to experience a personal benefit from taking part in the research. Although the researcher is usually the one to gain most from any research study, qualitative research can be empowering as this study treats participants as ‘expert witnesses’ in the matter of their own lives (Birren & Deutchman, 1991).

4.12.9 Justice

Finally, I considered the ethical principal of ‘justice’, that research design and procedures should be fair and just. Significant time was devoted to ensuring data generation methods were flexible to allow participation. All participants were given equitable opportunity to take part and numerous measures were taken within the research design to ensure that individual needs could be taken into account and modifications made to enable participation. ‘Justice’ was also considered for this research to ensure that the research was appropriately disseminated, so that the time and effort that participants devoted to the research contributes to public knowledge as they had hoped it would. This process has been ongoing throughout the project and details of dissemination thus far and future planned dissemination can be found in appendix eleven. Additionally, I share the knowledge I have gained from this project daily within my professional and social contacts in an attempt to promote understanding and acceptance of autism.

There were other ethical factors that were pertinent to this research and therefore required careful consideration and I discuss them in the following section.

4.13 Confidentiality/Anonymity

Participants were assured of confidentiality in the research process and anonymity in research publications. Participants were informed that data would be used in presentations, the thesis and journal articles. They were assured that they would be allocated pseudonyms and any identifying data would be removed from the publications. Identifiable data refers to participants’ names, locations, organisations, professionals/services and employers. As snowballing was used as a recruitment strategy, participants could potentially know one another. It was pertinent that I outlined clearly that I was not able to discuss other participants or confirm or deny their participation in the study.

4.13.1 Disclosure of Potentially Harmful Information

It was difficult to attempt to predict if any harmful information would be shared during the interview process. However, I had planned for such occasions should they arise. I obtained details of support agencies to signpost participants to. These were Liverpool Asperger Team and the National Autistic Society. I contacted these organisations prior to field work commencing. I gained information on the support available and formed links in case I required any support and advice throughout my fieldwork.

4.13.2 Data Storage and Management

I was the sole interviewer. The digital voice recorder used for the interviews remained in my possession. It was kept in a locked storage drawer in my home office space. Immediately after the interview the audio files were transferred to my password protected computer and deleted from this device before it was used for subsequent interviews. Transcription was done through an internal bank of transcribers at my employing University. All transcribers signed a confidentiality agreement which sets out the required actions of all transcribers to ensure that the audio files and transcripts are managed according to the Data Protection Act (2018) and General Data Protection Regulation (GDPR) (2018). This includes encrypted transfer of files and permanent deletion of files from their computers once the transcription has been completed. The audio files were transferred to the transcriber through mailbigfile.com which is a secure and encrypted password protected system that is compliant with GDPR. I undertook data analysis alone and all transcripts were kept securely on a password protected computer. When discussing or sharing analysis with my supervisory team I was careful to remove any identifying factors from the material. The introduction of GDPR in May 2018 meant it was necessary for me to add a GDPR statement at the back of the information sheet for participants (4-14) (see appendix five).

4.13.3 Lone Researcher Safety

I work as a research associate and have previous experience conducting research in the homes of research participants. I work for a University research centre and we have developed a ‘researcher safety protocol’ that we implement in all our studies. I adhered to these guidelines to ensure I remained safe whilst conducting fieldwork. This protocol ensured that I always informed a colleague of a time and a place of an interview (by data secure methods) and gave a time where I would contact them to let them know the interview had finished and that I had safely left the location.

4.13.4 Quality

There are numerous competing ideas on how quality should be measured in qualitative research. Indeed, Seal (1999) noted that quality was somewhat of an elusive phenomenon in qualitative research. He noted that it can be difficult to measure and therefore guidelines are very useful in the process. Guba and Lincoln

(1989) outlined authenticity criteria for constructivist research which included five factors: Fairness, Ontological Authenticity, Educative Authenticity, Catalytic Authenticity and Tactical Authenticity. However, as highlighted by Nolan *et al.* (2003) the terminology used by Guba and Lincoln (1989) makes these guidelines inaccessible, regardless of the founding principles being something that I feel is useful and therefore they were not used. I would like lay readers of my thesis to be able to easily judge the quality of the study.

Arguably, due to the unique feature of grounded theory it should have its own set of evaluation criteria (Hutchinson *et al*. (2011). To this end I turned back to the guiding methodology for this research constructivist grounded theory and the clarity of the guidelines laid down by Charmaz (2014). The four tenets of which are: *credibility, originality, resonance and usefulness. Credibility* is concerned with having enough relevant data to be able to ask questions of it. This also involves an awareness of how the researcher's views and actions affect the research process. Charmaz says that *Originality* can come in many different forms, such as offering a new perspective or providing a fresh conceptualisation of a recognised problem. *Resonance* refers to how the concepts of the research should not only portray their research participants' experience, but also be relevant to others. *Usefulness* of the research refers to how it includes clarification for research participants' understanding of their everyday lives, forming a foundation for policy and practice applications and creating new lines of research. In table five I demonstrate how I have considered each of the four factors outlined by Charmaz and give details about the particular facets of the research design that help ensure quality for each of these four areas. The pragmatic approaches used for the four concepts will be further discussed and evaluated in chapter nine.

Table 5: Strategies Used to Ensure Quality Criteria

Quality Criteria	Strategies Used to Ensure Criteria Met
Credibility	Theoretically Sensitive Person Centered Design Recruitment strategy Advisory Group Consultation Member Checking Memoing Theoretical Sampling Constant Comparative Analysis Reflexivity
Originality	Addresses Gap in Literature (Mason *et al.* 2022) Qualitative Interview (personalised approach, participant led) Recruitment Strategy Advisory Group Consultation Member Checking
Resonance	Qualitative Interview (personalised approach, participant led) Advisory Group Consultation Member Checking Memoing Constant Comparative Analysis Initial dissemination and Knowledge Transfer (checking the theory)
Usefulness	Initial dissemination and Knowledge Transfer (checking the theory) Accessibility Thesis writing Dissemination strategy

4.13.5 Reflexivity

In chapter one I described my reflexive position, this included my background knowledge, professional experience, external influences and potential bias. I felt it was essential that I acknowledged these early in the study, so that I could maintain a reflexive approach throughout. I will now discuss reflexivity issues using the five-point structure laid out by Gentles *et al.* (2014):

1. Researcher influence on research design and decisions
2. Researcher-participant interactional influences during data generation
3. Researcher influence on the analysis
4. Researcher influence on the writing
5. Influence of the research on the researcher

1 Researcher Influence on Research Design and Decisions

The research design was specifically chosen because I noticed the disparity between the outcomes in adult life for autistic people reported by the research literature and the first-hand accounts I heard. I was new to the autism research field, and I felt very frustrated (and a little outraged) that there was a paucity of qualitative research with autistic people. The autistic voices I personally heard through conferences and published autobiographies were encouraging. With a recent diagnosis in our family, I was not willing to accept the gloomy picture put forward by the research world. I wanted to find out more from autistic people and gain an understanding of the issues that were pertinent to maintaining their wellbeing. I hoped that I would discover a different picture than was being reported at the time: early deaths, high suicidality (Cassidy *et al*. 2014), low employment rate (Howlin 2000), and poor quality of life (Balfe & Tantam, 2010). This potentially was a bias to the research as before fieldwork commenced, I had already felt that there must be a different picture of autistic experience to explore.

I also started the project from the perspective of the social model of disability (Oliver, 1983) and rejecting the medicalised deficit terms that have historically been used describing autism. I had been influenced by the neurodiversity movements and their compelling central premise outlined more recently as, "*variations in neurological development and functioning across humans are a natural and valuable part of human variation and therefore not necessarily pathological"* (Leadbitter *et al.* 2021:1). This undoubtedly affected my approach to the research. I do not view this as a negative bias but a positive attribute to the research which enabled me to be appropriately respectful to my participants and the autistic community.

2 Researcher-Participant Interactional Influences During Data Generation.

The interaction between myself and the participants was fundamental in my learning journey. I realised that I had a breadth of knowledge about autism mainly derived from professionals, families and anecdotal accounts from autistic people themselves. However, I appreciated early that I did not know anything about my participants' individual experiences. I could not make assumptions. My personal understanding of my novice status allowed me to open my mind to the individual experience of the participants. Indeed, the insight by Socrates felt quite fitting for how I felt when I started fieldwork: "*The only true wisdom is in knowing you know nothing" Socrates* (date unknown).

Interaction with the participants during the data collection caused me to realise that everything I had learned about interviewing in my career, and about the importance of building a rapport to make participants feel comfortable, needed to be revised. An example of this is the assumption I had before starting the project was that face-to-face interviews would be the superior data generation method which was led by some of the dominant literature (Opdenakker, 2006). I believed that this somehow weakened my study, naively believing that the face-to-face rapport building would be important to the quality of the data generated. However, the importance of offering different modes of interview was highlighted in my first telephone interview. The participant shared with me the fact that she would never do a face-to-face interview as she would not be comfortable, and she would end up 'masking'. Whereas on the telephone she felt much more anonymous and able to be more candid in her responses. This reinforced the importance of not making assumptions and that the data generation process should be individualised.

As it was my intention that data generation process would be participant led and I would be responsive and reactive to the participants' needs and communications style, I carefully modified my own communication style according to what was appropriate with each participant. It was clear that rapport building was not appropriate in many of the interviews by the way the participants were motivated to jump straight into the interview and from the information participants shared with me. Some participants shared that 'chit chat' is often confusing and meaningless to them whilst others were clearly happy to engage in 'chit chat' or rapport building.

I was nervous initially going into the field, as I felt ill equipped and lacking in knowledge and guidance in how to appropriately conduct interviews with autistic people. I was concerned about doing or saying the wrong thing. Reflecting on these feelings, I realise I was starting the fieldwork journey with a power imbalance ingrained in psyche. Even though I had outlined that I wanted to redress that imbalance I clearly felt that somehow, I needed to be the infallible professional that had all the answers. Once I recognised this fact and reassured myself that it was acceptable that I was a novice I resolved to be open with this information with participants. I realised that this was reassuring to the participants that I was there to hear about their insights and experiences and learn. The participants were very accepting of my honestly and my invitation for them to comment on my skills as an interviewer or give me tips on how to improve the process for subsequent interviews. I realised that the participants found the honesty of our reciprocal interview relationship refreshing. I shared with the interviewees about the gaps in my knowledge and the impetus behind the study, giving limited personal details. This led to the interview being participant led with few guiding questions and prompts. It also facilitated member checking questions along the way to ensure that my understanding was correct.

I had been nervous about discussing issues like outlining the research relationship as to me this felt awkward, but this straightforward approach was welcomed. This was another learning point for me, polite sugar coating of information makes things ambiguous. I realise that this was a common feature of my communication style. I often spoke with a polite veneer over uncomfortable topics or sensitive areas with an expectation of inferred meaning being understood. During the interviews I was carefully to alter my communication to being more direct whilst still being sensitive. Communication and perception difference were further highlighted through exchanges during interviews and were all used as learning points. During interviews I needed the participants to be free to discuss the matters that were pertinent to them. However, for pragmatic reasons (time and transcription) I needed to stay focused on wellbeing. One participant acknowledged that she was prone to long digressions, but that she did not like being interrupted. She explained that if she was interrupted when she was speaking it would be like a computer running and opening another page while the original page is still running in the background. The more that happened the more it would slow her down. She found these incidences very stressful. We discussed this and I asked her what the best way for me would be to alert her that I suspected she was digressing and that we needed to return to the topic. She identified the signal of ‘zip up your lip’ to the mouth would be fine. I explained to her that I found this uncomfortable as it felt rude. She found this odd as she was giving me permission to do it. As we both needed to be comfortable with the signal, we settled on a raised hand as a signal to review our conversation and perhaps get back on topic. This further highlighted the nuanced differences in our perceptions and understanding.

3 Researcher Influence on the Analysis

During the project I have been attending conferences, presenting at conferences, interacting with autistic and autism researchers, and keeping up-to-date with news and media articles. Although I have ensured that the categories and theory in this research have been grounded in my data, this process of external influences undoubtedly has influenced the project by sensitising me to new ideas. I am unable to quantify this, but as I absorbed more information from external sources, I am sure it enabled me to view data from different perspectives.

Throughout this research my passion to ensure that the autistic voice is heard has become stronger. I have allied myself with external influences that also realise the fundamental importance of autistic people being involved in research and have distanced myself from those that approach autism research in a more traditional experimental way. During this project I have become acutely aware of the differences between the autistic experience and that of the neuro-majority. This is often so nuanced that it is difficult to explain. However, I have come to realise that these nuanced experiences can have a profound impact on the autistic experience and have tremendous impact on wellbeing. Having this background knowledge undoubtedly led me to explore the data in further ways but all coloured by the fact that autistic experience and neurotypical experience was distinctly different. Although I was sensitised to the fact that autistic people have of often feeling different and finding the social world confusing, I had never personally experienced the feeling of ‘being different’ until the end of the data generation. I presented two posters from this study at The 50th Anniversary Scottish Autism Conference: *Innovation in Autism Practice: The Future is Calling* (Nov 2018). During that conference there was a parallel event organised by the Participatory Autism Research Collective (PARC). PARC is a research group that is made up of autistic researchers who focus on autism in their research interests. The parallel conference was conducted in an autistic friendly way. This was distinctly different to the main conference event. The lights were dimmed, there were no rigid social expectations, delegates were free to sit however they liked, stim, use fidget toys, get up and move around but overall there was just an acceptance that delegates could behave however they felt most comfortable. This was somewhat of a culture shock for me but a truly enlightening experience. For the first time in my life, I was in the neuro-minority which illuminated some of the challenges that autistic people face in a society not built for them. It was an awkward and strange experience for me, and I reflected on my participants who had all told me about 'being different'. I learned an enormous amount from that event, not only did it highlight the experience of 'being different' but it also highlighted the incongruence in autism practice. I felt incensed that the PARC event was a parallel event and not incorporated into the main conference. It further highlighted the lack of importance placed on the autistic voice. It felt like the people that were supposedly the focus of the conference were being marginalised and tucked away out of sight of the 'proper' conference.

4 Researcher Influence on the Writing

My background and experiences along with external factors and groups that I engage with influences my writing which uses positive terminology and focuses on different experiences and not problems (Kenny *et al*. 2016). In all my writing follows the principles laid out by the social model of disability (Oliver, 1983). The groups that I engage with have made me realise just how important and powerful language is, and how it can either empower or constrain individuals (Bottema-Beutel, 2021 Kenny *et al.* 2016).

5 Influence of the Research on the Researcher

This study demanded a great deal of time, energy and commitment from me. I look back at the way I thought and the way I wrote for my upgrade viva in 2013 and I see a different person. This research has been a long journey of discovery. Speaking with the participants and learning about their experience has encouraged me to examine my own feelings and actions. I always believed that I was a very accepting person who embraced difference. However, on reflection I do not think I was good enough. I do not think I understood what it felt like to *be different*. This study has shown me how 'being different', marginalised and not accepted can fundamentally affect people's lives. Acceptance is so simple. I now truly champion acceptance in every part of my life. Not just with autistic people but with everyone. This research has influenced who

I am as a wife, a mother, a sister, a daughter, an employee, a friend. It has influenced every aspect of my life, and I disseminate this knowledge and ethos daily in all my interactions. I am very thankful for the experience.

In this chapter I have presented the theoretical underpinnings of the study, explained the methodological approach and data generation strategy. I have outlined the thoughtful consideration given to the rational of the study and given insight into the reflections of the reality of data generation. The subsequent chapters present the research findings, beginning with a chapter presenting pen portraits of each of the participants.

5 Chapter Five: The Participants

5.1 Introduction

The previous chapter presented the theoretical perspective underpinning the research and the methods used to generate the data. The following chapters present the findings generated. In chapter five all the participants are introduced through pen portraits and demographic information. The pen portraits present a personal picture of the participants and serve to highlight their varied backgrounds and differing life experiences. The subsequent three chapters (six to eight) present findings related to three key categories. *Not Knowing* (chapter six) focuses on the life experiences of the participants' pre-diagnosis. Chapter seven is dedicated to the findings relating to the period of participants lives '*Gaining Knowledge and Knowing'*. In chapter eight the overarching conceptual grounded theory that was generated from the data is presented. The theory proposes that after a diagnosis older autistic people fall into one of two groups regarding their autistic identity. The theory indicates that older autistic people can go on a further journey of self-discovery post diagnosis; *the thriving cycle.* Through this journey they develop a *'thriving'* autistic identity.

5.2 Caveat

The findings show that all the participants have significantly varied life experiences to one another. Their experiences are therefore unique. However, they are similar in that they all received a very late[5] diagnosis of autism which meant that they shared similar experiences throughout life, living with unrecognised neurodiversity. The topics discussed within this findings section are done so with the acknowledgement that the fourteen participants are a heterogenous group (see pen portraits and demographic table). Some aspects of their experience are similar, but it is vitally important to bear in mind the uniqueness of their individual experiences when interpreting these findings. It is also pertinent to note that each of the participants self-identified as being 'different' from the neurotypical general population. This is not a distinction that the author has made, but one that was identified by the participants themselves.

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[5] A very late diagnosis: all participants received an autism diagnosis over the age of 47.

5.3 Participants

Fourteen older autistic people were interviewed between March 2016 and October 2018. The demographics of the participants are displayed in table six. Their ages ranged from 50 to 73 (mean 56.4 years old SD 6.26). All participants were diagnosed later in life (range 42-59, mean 50.6, SD.4.34). At the time of interview, they were between one- and 14-years post diagnosis (mean 5.8, SD3.26). There were nine women and six men interviewed. Six participants lived alone. Nine had children (two had stepchildren). Six were married (one same sex civil partnership), seven had been divorced (three of which remarried). Seven participants were employed, five were retired, two were unemployed (one was long term unemployed, and one was between professional contracts).

5.4 Pen Portraits

The following pen portraits are brief summaries of the participants and serve to introduce them as individuals to the reader. Verbatim quotations from the participants are used within the pen portraits and are denoted using quotation marks and italics.

Table 6: Demographics of Participants.

	Participant #	Age (in yrs.)	Gender	Age @ DX (in yrs.)	Time since DX (in yrs.)	Marital Status Y/N/Divorced	Living Status	No. of Children	Occupation
Theo	2	53	M	49	4	N	Live alone	0	Academic
Ralph	3	73	M	59	14	N	Live alone	0	Retired (Non-professional)
Christine	4	58	F	52	6	D	Lives with grown up children	2	Retired (Public sector)
Peter	5	55	M	48	7	D	Living with partner	2	Professional (Autistic Charity)
Yvette	6	52	F	51	1	D /Y	Living with partner	1	Professional (Autistic Charity)
Gary	7	53	M	47	7	D /Y	Living with spouse	2 (1 step child)	Professional NHS contractual worker (currently between contracts)
Amy	8	52	F	48	4	Y	Living with spouse & daughter	1	Professional
James	9	62	M	54	8	N	Lives alone	0	Retired Academic
Sheila	10	50	F	42	8	D/Y	Lives with spouse & stepson	1	Employed patient facing caring NHS role
Catrina	11	60	F	54	6	N	Lives alone	0	Retired (previously unemployed) had a string of unskilled jobs when younger
Sophia	12	53	F	52	1	D	Living with partner & stepson	1 (step child)	Professional Administrator
Sylvia	13	52	F	46	6	D	Lives alone	2	Unemployed previously full-time carer for autistic children until they went to FT residential care
Emma	14	54	F	50	4	Y	Lives with spouse	2	Employed (Public sector)
Walter	15	65	M	57	8	N	Lives alone	0	Retired Professional

Theo

Theo is 49 years old. He is single and lives alone in a very neat and well-ordered rented flat. He has a very considered manner and gives carefully thought out responses to questions. He is very intelligent and has numerous post graduate qualifications including two PhDs. He is very organised and plans his life meticulously. He moved to England ten years ago to gain employment in his subject of expertise. His two sisters and parents still reside in his birth country. He has never married and does not have children. He has a professional position in academia and an impressive employment history, working in many different roles within his specialist subject. He has been able to consolidate his interests and talents to form a career in his chosen specialism which he describes as, "*the perfect scenario*". He does not need any other outside interests or hobbies as his primary role gives him all he needs.

Theo has "*felt different*" all his life. In primary school he did not interact with other children. As he grew older, he adapted and got better at socialising, although it still does not come naturally. Theo does not socialise outside of work. Although he enjoys the company of others, he finds interacting with groups "*mentally depleting*". His one social outlet is attending an autism social group that meets every fortnight. He finds socialising with other autistic people much easier, and this has been an extremely positive post diagnosis addition to his life.

Theo has always suffered with anxiety and depression. He has periodic episodes of "*not seeing a perspective in life*", these periods can last for considerable time where he suffers mentally and physically. He works very hard at managing his focus and attention as he is aware that "*people like me are very focused and negative ruminations can take hold*". He was diagnosed three and a half years ago. This increased his self-awareness and helped him focus on improving his mental health and wellbeing. He has independently researched several therapeutic practices and now incorporates a custom-made 20 minute mental exercise into his daily routine. This "*helps my mental focus and helps to deflect negative thoughts and anxiety at the point where they arise*". If he misses this exercise for two days, he immediately feels more distressed, less focused, and at risk of anxiety or depression.

> *"The price of this permanent self-control is a lack of spontaneity and exhaustion through spending so much effort controlling behaviour."*

Ralph

Ralph is 73 years old. He lives alone in a rather cluttered flat in sheltered housing in an urban area. He has lived there all his life. Ralph speaks without giving eye contact and has a fantastic memory and enjoys quoting the bible which frequently appears in the conversation. His parents died when he was in his 20s. He feels bitter that he could not let them know *“what was wrong with me”.* Ralph has never married and did not mention having any romantic relationships He has a sister who lives geographically close who has “*kept an eye on*” him. Although he has lived independently all his adult life, he says he would not know what to do in a household emergency.

Ralph is retired, he worked in his main job for 20 years. This ended when it became a requirement that he could drive, which he was unable to do. He had a string of other non-professional jobs that he says all ended without him really understanding what he had done wrong. He went to university in his 50s and studied a language course, part of which meant that he lived abroad for a year. He received his autism diagnosis at the age of 59 after autism was highlighted to him by a lecturer. He was “r*elieved, I knew there was something wrong, I knew I was not like other people”.*

During his childhood he did not feel that he fitted in. He did not understand things that other people seemed to automatically realise. *“I just don’t seem to be properly connected up to the world somehow I feel as though I’m looking at it from afar”.* Ralph is an incredibly honest man and interprets things literally, he finds deviations from the truth upsetting and confusing.

He attends an autism social club which he greatly values. He also has a busy schedule of activities that he attends due to the nature of the topic of interest rather than to socialise. He leads a very solitary life. He has many focused interests that have changed over the years. He can speak six languages and regularly attends language groups. His interests are always absorbing, he can get “*carried away with them”*. He says he “*has to get wise to myself”* in order not get too obsessive about them.

Ralph has suffered with bouts of depression all his life. They tend to be triggered by health concerns. He manages to get out of a depressed state by *“catch your mind on something else”.* This could be a focused interest of the moment that helps lessen the ruminations. When asked if he considers himself to have a disability, he replied *“sort of in the twilight zone really, yes I am a bit disabled”*.

Christine

Christine is 58, she seems very relaxed and is very easy to talk to. She has two grown up children, a son and a daughter (who are both autistic). She owns her own home where she lives with her daughter and her daughter's boyfriend. Although they live together, they live separate lives, she lives downstairs, and they live upstairs. This upsets her as she would prefer, they eat and socialise together. Christine was divorced from her husband at 49 after being married over 20 years. She has recently been online dating but has had a few bad experiences. She is incredibly honest and expects others to be too. She cannot understand why other people would go online dating sites to abuse and steal.

In school Christine felt like an outsider, she described herself as a tomboy who hated going to parties and dressing up in girlie clothes. However, she did conform to what she felt was expected of her. This made her annoyed with herself as she preferred to be more truthful. This is a pattern that has recurred throughout her life.

Christine has struggled with her mental health throughout her life. She also struggles with sorting out bills and money issues. As a result, she has a great deal of debt. Clutter and hoarding are also a problem. The guilt of her not being able to deal with all these things contributes to worsening mental health. *"When I start getting the bad feeling it consumes me, it takes me over and makes me not want to be there and not cope, it's like here it comes again".*

Christine worked for over 20 years in the local authority, but her employment ended due to mental ill health aged 44 and she has not returned to work. Christine is a tenacious lady who will fight hard against any injustice. She is very self-deprecating and rarely thinks about herself first. Her whole life has been spent thinking of her children and others. Christine is a very talented artist. She combines this hobby with her other passion in life, animals. She goes to art groups. This is not to socialise, but to absorb herself in the artwork. She has recently volunteered as a guide dog puppy walker. Although there are many aspects of the role she does not like, she is dedicated to the training of the puppies. Christine received her autism diagnosis at 52. She was happy to get the diagnosis as she felt it helped her piece the strands of her life together: "*I am a person with Asperger's and I'm not a failure, it's not because I can't cope, it's because I am different. Its ok to be different".*

Peter

Peter is 55 and a very intelligent man with a vast amount of knowledge about autism and he is passionate about autism rights. He was diagnosed at the age of 48. He is divorced with two grown up children. He lives with his long-term partner and their nine dogs. He is a very intelligent and honest person and abhors lies and dishonest people. His home is his sanctuary where no one else is allowed, where he feels "*at peace*". He describes his dogs as *"real"* and "*easy to read and predictable",* unlike people. He describes meeting his current partner as a tipping point in his life. He says this was the first time in his life where he could truly be himself. The diagnosis and the fact that he has a loving and supportive partner has enabled him to be himself and reach a balance in life.

Peter is kind to himself and takes time and effort to look after his own wellbeing. He works for an autism charity. He says his job is perfectly suited to his skills set and he has a manager who understands his neurodiversity. *"I've found a niche. I found a niche that accepts me",* although he worries that his manager may one day leave.

Peter relies heavily on his partner. If she ever goes away from home with work, he takes holidays from his own work and stays at home. This is partly to take care of their dogs but mostly because with her away he does not feel safe. He does not carry money around as he will "*just spend it"* and he relies on his partner to deal with all financial matters. As a child he describes himself as being totally isolated. When he started school, he could read books well above his age range. Other children took exception to this. Combined with his complete honesty this cause him problems socially. He said he had no idea how to interact socially. Before meeting his partner, he experienced a tumultuous life, had severe mental health issues including suicidal ideation, and a lot of risky behaviour using drink and drugs. He had awful and degrading experiences with the mental health system (multiple incorrect diagnoses) which means he is opposed to ever obtaining support from them again.

Since diagnosis he feels he has been kinder to himself and has forgiven himself for his previous life experiences. He manages his interactions and life intensely and knows how to care for himself mentally. He is terrified of getting older and being left without his partner. He cannot conceive going into residential care and has planned for a time where he has no choice but to take the suicide pill he has purchased from the internet and hidden at home, to save him the trauma of residential care.

Yvette

Yvette is 52 and a very warm and funny lady who laughs a lot. She has an adult son whose father she has separated from. She is now in a same sex relationship with a colleague. They have recently married after being together for 13 years. Her partner has in-depth autism knowledge and accepts her for who she is and provides a great deal of emotional support to Yvette.

Yvette has two degrees and a teaching certificate in special educational needs. She obtained all her qualifications whilst working. She did not obtain good grades in school examinations. Her mother suddenly walked out on the family, at age 14, and as the eldest of four children, she was expected to take on the mothering role, which she did. She had a very strict upbringing with a fair bit of trauma due to her parent's tumultuous relationship. In school she was bullied and was "*quite isolated and a loner really with not many friends"*. She says she is the same in adulthood. Yvette found the unstructured times of the day the most difficult as she didn't understand the social rules, "*it's easier to spend time alone".*

She has worked for an autism charity for 25 years and has extensive knowledge of autism. She has been incredibly successful in her job and has climbed the ranks of the organisation over the years, but she remains very modest about her achievements. She describes her job role as being perfect for her. She likes attention to detail and experiences anxiety at work when people do not meet deadlines or follow the set guidelines.

Despite having extensive knowledge about autism Yvette did not recognise her own autism. She received a very late diagnosis aged 51. She paid privately for a diagnosis after experiencing additional stress at work. Work stress can have a physically debilitating effect on her that affects her breathing and causes her not to sleep.

Yvette suffers with anxiety and depression where she can feel incredibly bad about herself which usually manifests itself in crying. She generally struggles to identify where her strong emotions are derived from and can get very upset without being able to identify the exact cause.

Yvette says she has two focused interests, her job and shopping. The latter sometimes causes problems as she is unable to manage her finances and sometimes compulsively shops to "cheer herself up".

Gary

Gary is 53, he is a very relaxed man who likes to laugh and is very easy to talk to. He has a daughter from a previous relationship and two grandchildren. He lives with his wife who he describes as his main support. He says he "*would not have survived this long without [her]".* He says his wife describes him as "*living in a world of chaos"* and being *"oblivious to the chaos he creates around him".* His father passed away when he was 39. His mother has Alzheimer's now, but he suspects she is autistic. He is currently in the process of sorting out her estate as she is in residential care. His sister is estranged from him for reasons unknown to him. As a child he describes himself as feeling 'odd' or different' and thinks an earlier diagnosis may have meant that people understood him better.

Gary appears to be a confident person, who says he thinks his flippancy is a coping mechanism. He describes having regular *"slumps"* throughout life and these seem to be triggered by big changes. During long "*slumps"'* his partner has nursed him back to health and worked extra to pay all bills etc. He has never attempted suicide but feels that sometime life just feels too hard, and he would like a break from it.

Gary was diagnosed at age 47 whilst he was studying for his degree. He feels he has never truly accepted his diagnosis. Although he discloses it to everyone, he sees it as an ailment. Something "*in his brain that is not meant to be there*".

He has worked successfully in various professional consultancy roles in the NHS, however he often experiences relationship breakdowns with colleagues, and he is never sure why this has happened. He is currently between contracts of work. Gary has a good group of friends who he feels he can be himself with. He has many focused interests, music being a lifelong one. He goes to live gigs and gets a lot of pleasure from it. He loves following his football team and has a group of friends made through an online group. He says his focused interests can be both positive (such as planning a road trip to America) or destructive (such as obsessively buying things from 'bid up TV'). His partner will only intervene with a focused interest if it is destructive, as she knows it will be replaced when another comes along.

Amy

Amy is 52 and is married with two children. Her daughter (18) is autistic and is very challenging to care for. Her son (22) is undiagnosed, but she suspects he is autistic. She lives with her children and her husband, although she says she and her husband lead separate lives. Amy's life is very much involved with autism and he does not really accept or want to discuss it. Her main source of support is an autism charity group where she volunteers and runs a youth group. She has a group of good friends there that know her well and can identify and help if she is struggling. She is in contact with her mother who was involved in the diagnosis process, but she has previously deliberately cut her out of her life years ago.

Amy suffered abuse in her younger and adult life. She now looks back on this and realises this was in part due to her autism as she was misreading social situations. Amy graduated from university on a health course but was unable to complete the time in practice due to her childcare responsibilities. She was a stay-at-home mum for many years and just recently has gained employment as a support worker for an autistic adult. She is very good at this job. However, she does not enjoy it as she feels the other staff have taken a dislike to her straightforward no-nonsense approach.

Amy received her diagnosis four years ago after a ten-year battle with her GP to gain a referral to diagnostic services. Her focused interest is autism and fighting for rights. She is very knowledgeable about autism and is a tenacious lady who sees things very "*black and white".* This can cause her problems. She describes having "*no filter"* and often gets into trouble for being too honest. She has fantastic insight into her own needs and adopts many strategies to manage situations that she finds induce anxiety. However, she struggles with her mental health and has seen various therapists over the years. She does not sleep and often experiences periods of severe 'autistic burnout'. She believes this is due to the constant stress of masking. She spends most of her time and energy taking care of her daughter's needs and often neglects her own. She has low self-esteem and describes her life as chaotic and has issues with clutter and hoarding in her home which further affects her mental health.

James

James is 62. He lives alone in his family home where he had previously lived with his mother and father until they passed away. The house was very tidy, well cared for and full of books. He had several books about autism but despite being a voracious reader he had not felt like reading them. James has a sister whom he sees most days. He joins her when she is walking her dogs in the park opposite his house. He is extremely fond of her dogs and talks about them in a very affectionate way. James lived with a girlfriend several years ago, but it did not end well. He was not comfortable talking about the relationship. James did not talk about having any friends and it seemed that he lived quite a solitary life. He really enjoyed the experience of meeting up with the autism social group every fortnight and described finally having a 'peer group' after a life without one.

From an early age James had a sense of alienation and felt left out socially. He just felt "a bit different". James has completed two doctorate degrees and would like to do another. He has lived and worked abroad and his last job before early retirement was as a lecturer at a university for 19 years. He was forced to leave his position at the university as he was struggling with stress and anxiety and was experiencing mental health problems. He believes that his employers unfairly ended his career. This matter is unresolved in James's mind and he still ruminates about the situation. He also regularly ruminates about other jobs and negative experiences of bullying he experienced when working. He continues to have flashbacks and wakes in the night feeling anxious about such incidents that occurred up to 20 years ago.

James has Obsessive Compulsive Disorder (OCD) but he did not wish to talk about it. He has a history of suffering with depression and anxiety related problems. He has also attempted suicide in the past.

James received his diagnosis of autism aged 54. When the diagnosis was delivered, he mentally closed off from knowing any more about autism as he was informed that it was "an untreatable condition". He was unwilling to learn tricks to mask his autism and try to fit in socially. He likes honesty and learning such strategies does not feel right to him. The best thing about receiving a diagnosis, that he thought was life changing, is finally meeting like-minded people who accept him and who he feels comfortable with such as fellow autistic people.

Sheila

Sheila is 50. She is incredibly easy to talk to and very self-reflective and knowledgeable about autism. She has one grown up son who is away at university and has been married for 20 years to her second husband who is "*a wonderful man"* and her main support. She has been diagnosed for eight years, but she only started to accept her diagnosis and explore what being autistic meant, two years ago. She works in a hospital in a patient support role that requires caring, communication and empathy skills. She is very good at her job and pushes her own anxiety aside to prioritise the patients' needs. She attributes this to the fact that she is adept at masking. She identifies what each person needs and 'becomes' what they need by playing that role. With the help of autism specific (privately paid) counselling she has become very self-aware.

Sheila a sociable person who "bucks the trend" when it come to a lot of autism expected traits. Her focused interest is people though she confesses that she is no good at small talk and will get *"deep and meaningful in five seconds".* She has a good supportive set of friends. However, she feels extremely vulnerable, being a very honest person, she cannot see if other people are dishonest and relies on others to highlight this to her. She is part of the local church community and finds the community and spirituality an important aspect of her life.

Sheila's family were dysfunctional, and she describes her parents as *"unhappy and distant people who were emotionally unavailable*". She can see autistic traits in many of her family members, some of whom are diagnosed. In school she was a *"bullied swot, who felt far safer studying than socialising, but who masked everything with loudness, bubbliness and apparent confidence".* She thinks her desperation to be liked led her to be vulnerable and experience traumatic events of sexual assault in her younger adult life. These experiences combined with others caused her to have panic attacks, anxiety, depression, self-harm and suicidal thoughts. She has received lifelong medication for this. Since accepting her diagnosis she is becoming more aware of what she needs to do to maintain her wellbeing. She now *"experiences life-affirming love on a daily basis and has been able to learn how to create safe boundaries to protect myself from dangerous people and situations".* Although she is now much more self-aware, she still views herself as a *"work in progress".*

Catrina

Catrina is 60 and lives alone in a house that was previously her family home. Her parents died almost 20 years ago, and she still misses them terribly. She struggles financially and manages her small budget well. However, her Personal Independence Payment (PIP) payments have been stopped and so she struggles financially. She feels unable to appeal against the decision as she would not know where to go to get support. House maintenance is a constant worry for her, and the house is damp and cluttered and in need of repair. She is very intelligent, and she believes her intelligence leads people to have less sympathy and be disbelieving of her difficulties. She thinks she falls through the gaps with regards to service provision and support and is envious of a friend who has an “obvious disability”.

Catrina was bullied at school and at work where others made fun of her. She had several jobs when leaving school, but she could not cope and therefore has been unemployed for most of her life. She regularly ruminates about bullying events that happened over 40 years ago and this still causes her great anxiety.

She has several focused interests, Star Trek, science fiction, North Korean films and Finnish. She likes to watch North Korean films, and this helps her curb her anxiety. She saves box sets so that she has “something to look forward to”.

She suffers with her mental health and has passive suicidal ideation. Although she has no intention to commit suicide, she wishes she was no longer living. She has also suffered serious physical health problems with a brain aneurysm.

Catrina is vulnerable and has been taken advantage of several times by “friends” stealing from her. She also suffered abuse as a child from a distant family member. She had a boyfriend when she was younger and became pregnant with twins. The boyfriend was overseas and encouraged her to have an abortion and then never contacted her again. She regrets this daily and it causes her much sadness. She mourns this loss as well as the loss of her parents and wants to join them in heaven.

She attends language groups and an autism social group where she really appreciates the company. Her main anxiety is caused by her loneliness and the hopeless situation she feels she is in with her finances and house.

Sophia

Sophia is 53. She lives with her partner of ten years and their stepson. She has been married previously but that ended due to their lives going in different directions. She describes herself as a "*changeling*", who can "*detach herself from situations as easily as she can form attachments".* This has meant that she has lived a very interesting and varied life. She has moved from location to location, following focused interests of the time (which change with regularity). She has lived abroad, been an antiques dealer, call-centre manager, dog trainer, worked at ski resorts, worked with dysfunctional children and many other short-term roles. She is now a professional administrator in a dementia residential home (with a fabulous manger so she thinks "*this one may be maintainable*"). She is an incredibly honest person with a strong sense of justice. She has used these skills and has trained and been appointed to be a lay magistrate.

Her family was very wealthy, and she had two sisters. However, she described her childhood as "miserable", traumatic, affectionless and lonely. Her father was a domineering character (who she now believes is autistic). She was brought up to comply with the wishes of the men in the household and she feels this inherent compliance has made her vulnerable with relationships throughout life and has been sexually assaulted on several occasions.

She was a "monster" child that was educated in boarding school and expelled from a number of schools. She was told that she was 'stupid' by teachers and had no friends. Her first attempt at suicide was aged 10 and she has struggled with mental health all her life and has regular periods of what she now recognises to be autistic burnout.

In adult life she has learned that she is actually very intelligent and has completed two degrees. She has done a lot of therapy to reconcile the wrongs of her past and now has a much better understanding of her life. She has now been diagnosed for one year and is "*Delighted by finally knowing what the hell is going on in her world".*

Sylvia

Sylvia is 52. She is a very able lady who speaks with great passion and emphasis. Her daily coping is through planning. She plans everything meticulously. She lives alone in a dilapidated and freezing cold rented flat with her cats. She has two grown up children that are autistic who now live in residential care. She is divorced. She has never worked as she had her children at a young age and was their main carer until they went into residential care 12 years ago. She has not worked since. She volunteers in a learning disability group and at a church café. She struggles financially and often has to choose between heating and food. She uses food banks. Working in the café helps as she gets a warm meal, and she does not need to heat her flat while she is at the café. She has recently had been forced to shift from Disability Living Allowance to Personal Independence Payment (PIP). However, her PIP application was rejected as she says, *“it seems like I am making everything up*”. She has appealed this decision.

Sylvia had her diagnosis six years ago. *“It helps me to understand me better because I put things down to having autism now whereas before I just thought I was mad”.* She does not have a great understanding of autism and talks about it in deficit terms. She has not had much time to think about herself as her main priority has always been the children. She is now on a course to help her understand her autism better and she is finding this very useful.

Sylvia is very literal in her interpretation of things and has a very black and white view on the world. This causes her many miscommunications and she feels this is what stops her from getting a better paid job. “*A lot of the time when I’m working, I’m with people who really don’t get it [autism] at all which can make it very difficult”.* She needs very specific instructions and does not pick up on any nuanced or inferred meaning. She ruminates on miscommunications for weeks afterwards. Sylvia suffers with her mental health and gets “very low”. She does not call this depression as she has never talked to the doctor about it and therefore it has not been medicated or diagnosed. She describes life as a struggle and “*can’t think about what’s going to happen in years to come because ... there are too many problems going on in present life”*

Emma

Emma is 54 years old. Emma has two adult sons that no longer live at home. She received her autism diagnosis four years ago, after she started a new job where she wrote education and healthcare plans for autistic children and she recognised traits in herself. She lives with her second husband (married 19 years) who is very supportive. Since diagnosis they have a better understanding of one another. He takes care of the household chores so that Emma has some downtime at night after a stressful working day.

Emma was adopted as a child and had older parents. They died when she was much younger. She believes her parents had a "no nonsense" approach to child rearing which meant that she has learnt to mask and supress many of her autistic traits. She had lived most of her life believing that she was a bad or evil person as she behaved badly with other people and caused upset. Diagnosis helped her realise some of these things were beyond her control.

Emma struggled when her children were young. She had no friends or family to help her when her husband worked away. Reflecting on this period of her life still makes her feel bad.

Emma has been treated for depression and has taken anti-depressants all her adult life. The medication never worked, and she now believes that she was not depressed but anxious. She now takes beta blockers which help. She has been doing a lot of reflection on her own behaviours and "*quirks*". She is starting to recognise the therapeutic effect of allowing things like vocal tics and stims and the negative effects of masking and "people pleasing". She is also noticing things that make her feel calmer, like being on her bike, a swing or movement. She feels that she would like to get more holistic ways of managing her anxiety.

Emma reports not having any friends although that is not a problem for her as she is content on her own. She has started a group on Facebook to support autistic women that now has around 1500 members.

Her working life is an important factor in her wellbeing as she enjoys routine, but her current job is causing her a lot of stress. She has numerous meltdowns at work. However, she feels fortunate that she works in a *"bubble"* where people are knowledgeable about autism, so she experiences more understanding than most.

Walter

Walter is 65 and received his autism diagnosis at the age of 57. He lives alone in his own home. His twin sister lives locally and keeps an eye out for him and helps him with certain things. He struggles with getting repairs done in the house due to past bad experiences and this causes him much stress.

Walter had a very responsible professional science job for many years. He had a disagreement with the boss, and he refused to cut corners. A redundancy package was arranged in his mid-40s. In Walter's mind this was fundamentally wrong, he fought against this and won a financial settlement at a tribunal, but the process was very stressful, and he has not worked since.

As a young boy he realised he was different and moved differently to other people. He has consciously tried to hide his difference to 'blend in' but this has caused him much anxiety. He experienced intense bullying at school from both his peers and teachers. At 16 he became seriously ill and he believes this to be a result of the medication he was put on. He then became severely depressed for eight years and attempted suicide. However, he promised his mother that he would not do this again. It's important to him never to break a promise, so despite feeling like he wanted to end his life on a few subsequent occasions, this promise has prevented him attempting suicide again.

Walter has experienced mental health problems all his life and has received numerous incorrect diagnoses. Since his autism diagnosis he has tried to get support, however, he has been rejected as he's been told "*you look alright"* so is not entitled to support. Walter has had medical problems and finds communication with his doctor is difficult. His sister therefore now accompanies him to medical appointments.

Despite being a very mild-mannered person, Walter seems to receive unfavourable reactions from strangers. A psychologist once told him that it might be because he tends to stare. This causes him social anxiety and he limits places that he goes. If he has an incident in once place, he will not return to that place and this causes more anxiety as it sometimes prevents him from using local shops and amenities.

Attending an autism social group has made a big difference to Walter and it has given him a social group where he feels comfortable communicating. He also has a physically disabled friend and they assist each other and shop together. Walter helps with the physical demands of shopping whilst his friend helps with the social aspect of the experience.

5.5 Summary

In this chapter I presented the demographics and pen portraits of the fourteen participants to outline their varied life experiences. In the next chapter. I discuss their experiences together with the resultant impact on their wellbeing that occurred in the significant part of their lives prior to receiving an autism diagnosis entitled ‘not knowing’.

6 Chapter Six: ‘Not Knowing’

6.1 Introduction

The findings presented in this chapter focus on the period of participants’ lives before diagnosis, conceptualised as ‘not knowing’. All participants received a ‘very late diagnosis[6] of an autism spectrum condition (range 42-59, mean 50.6, SD.4.34). At the time of interview, they were between 1-14 years post diagnosis (mean 5.8, SD3.26). This meant that they had lived most of their lives ‘not knowing’ about their neurodiversity whilst being aware of their ‘difference’.

6.1.1 Being Different

The participants reported that they lived life pre-diagnosis with the feeling that their life experiences significantly differed from others. They shared a legacy of recurring and unexplained negative social interaction experiences. They all had feelings that they did not naturally belong in society and did not seem to ‘fit in’ as they felt others did.

They felt fundamentally different to everyone else they encountered. This unexplained feeling which featured throughout their life experiences had a profound and negative effect on their confidence and personal wellbeing.

> *I’ve always felt, and that’s quite common as well I believe, I’ve always felt different to other people.* (Emma/F/54/4)

> *I suppose it’s a bit of a cliché, but I always was different, I always felt that I was different to the other kids.* (Gary/M/53/7)

For all participants the feeling of ‘being different’ started at an early age. They believed that they did not seem to naturally ‘get on’ with their peers. Participants were not able to identify what they thought caused them to be ‘different’, but they reported the feeling of difference to be strong and ever present.

6.1.2 External Identification of Difference

It was when participants’ ‘difference’ was identified and confirmed by external sources as being negative, that participants became distressed by their difference. They reported incidences throughout their lives where they were singled out by others as

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[6] A very late diagnosis: all participants received an autism diagnosis over the age of 47.

‘different’ or ‘odd’. This occurred in all sections of their lives. For example, as a child Theo became renowned amongst his peer group in primary school because of his quirky behaviour. He was unusually eloquent for a child of his age. Theo used long words and often had in-depth debates with his teacher regarding very technical matters. He reported that his classmates were ‘*fascinated and amused’* (Theo/M/55/4) by him. However, this apparent fascination from his peer group was reframed to a negative difference by his teacher who did not understand how he could have this extensive knowledge. His difference was therefore discussed negatively by this teacher.

> *One of my primary teachers … said because of my strange behaviour I would not fit into the normal school system, I should go to a special needs school outside the normal school system, because they said yeah he’s talking all the things, but he doesn’t understand what he’s saying, it’s just parroting, she said, he can’t possibly understand what he’s talking about. She said some people in class perceived me as a little robot, … he’s very strange, and he doesn’t interact with the other children, so he needs to go to special school.* (Theo/M/53/4)

Indeed, all the participants had their internal feelings of difference highlighted externally by others who made negative comments or who treated them as though they were odd. This process caused them to assume that their difference meant that there was something fundamentally wrong with them and that it was somehow not acceptable or desirable.

The fact that participants did not naturally ‘fit in’ and behave like other people caused them social anxiety. Some participants felt it was easier to be alone than risk interaction with others:

> *…you don’t always know the social rules for things, you know: joining in, when it’s your turn to speak, and talking over people, or not knowing what to say: so it’s easier just to walk around the playground on your own.* (Yvette/F/52/1)

From an early age all the participants alluded to the fact that there was a pressure and expectation that they should ‘fit in’. Their differences or quirky behaviour was not celebrated and should therefore be supressed or hidden.

> *It’s impressed upon us so early that WE have to be the ones that make the difference, WE have to go and make the friends, WE’RE the ones who have to change to fit into THEIR society.* (Peter/M/49/4)

This encouragement and expectation to hide their natural instincts and act in a way that was felt artificial to participants further contributed to a negative view of themselves. It suggested to participants that they were somehow wrong, or not good enough and they should alter or hide themselves. This impacted negatively on participants' confidence and personal wellbeing. Christine reported being frustrated about being expected to behave in a way that felt artificial to her in order to avoid upsetting others. She is an extremely honest person, the fact that she did not feel permitted to act in a way that was true to herself was very unsettling for her:

> *I think you learn how to cope, I think you learn how to disguise things, how to be more polite and not upset feelings. I think it's something you wish you were more honest, … it's easier to conform. It makes you feel bad then and you think, why didn't I just tell them and be honest. It's a struggle.* (Christine/F/58/6)

The identification and confirmation of their internal feelings of difference often came from well-meaning family members or friends. They attempted social coaching and modifying participants' behaviour believing that they were assisting them to 'fit in'. This often had the unintended consequence of emphasising just how much they stood out, often having further negative effect on participants' wellbeing. Walter explained that he was always being corrected or modified:

> *When I was a child my grandmother used to say to me "walk properly, swing your arms". Well of course I'd start swinging my arms, but I'd be swinging it on the same side…, as a child it felt like I was being constantly criticised… I realised I must have been behaving differently. … I felt very aware of the way I was moving, very aware of the way I was saying things, very conscious of that and trying to blend in.* (Walter/M/65/8).

6.1.3 The Unwritten Rules

Participants described their perceived social separation as 'living without knowing what the rules were': that there were unwritten rules that everyone else apart from the participants, knew and understood. This was reported to be tremendously confusing. Peter described how people typically unconsciously just absorb social rules and therefore do not think to explain them to others:

> *You spend your life growing up having to play by an unwritten rule book that everybody seems to know and you don't.* (Peter/M/49/4*)*

In some cases, this led participants to isolate themselves as they did not seem to know how to act or behave in a way that was expected or accepted socially. Some participants felt that it was easier to keep away from others and not try to join in. Feelings of social isolation, alienation and social anxiety were common amongst the participants. Many participants used avoidance to separate themselves from 'typical' people or certain situations as they often felt scrutinised, judged and criticised by them. Peter described his feelings about some of his previous social encounters, and how he had decided that he is no longer going to take part in certain situations:

> *They don't want the weirdo involved, the weirdo just makes them uncomfortable because they don't know what's going on, well let's treat him like an outsider, he won't get involved and he'll go… I'm going to stop putting myself in that situation where I'm made to feel foolish … it's safer for me and it's calmer for me and it's just better for my health to avoid that situation.* (Peter/M/49/4)

6.1.4 Bullying

Instances of bullying were experienced by most of the participants interviewed in various and multiple areas of life: school, employment, friends and even within families. These events were traumatic for participants. The fact that this bullying often came from people that the participants knew, respected and trusted further added to feelings of social anxiety, confusion and mistrust. Participants often found it difficult to identify bullying behaviour at the time it happened. It was only retrospectively that they could identify it as bullying.

> *Certainly, at secondary school. I was sort of on the edge of a group and, you know, I was bullied and put down a lot. I mean, not physically bullied, but, you know, girls can be so nasty, but I didn't even see it as bullying at the time.* (Catrina/F/60/6)

Incidences of bullying were certainly not limited to participants' school days. Participants discussed incidences of both horizontal and vertical bullying. Indeed, several participants talked about being bullied in their place of work. The bullying was not just from colleagues but also from staff members in senior roles. Their communication differences and precise, literal and honest way of talking was perceived as unwelcome. Indeed, problems in the workplace were a common experience reported in all the interviews. These problems became anticipated by participants. They became an inevitable part of their working lives that participants felt powerless to change. For some participants the anticipation caused as much or more anxiety as the events themselves.

A third (five) of the participants described how they had finished their long-term successful professional careers due to unresolved disagreements that they felt could be described as bullying (all had been asked to sign a non-disclosure settlement agreement, so they did not wish for the details of the disputes to be recorded).

Retrospectively, they were able to see that part of the problem within the disputes was due to their undiagnosed autism and associated miscommunications. However, these incidences had a profound negative effect on participants and contributed to ongoing problems with their wellbeing. They became sources of the perpetual negative thoughts and ruminations[7]. Catrina describes here how she still ruminated about the incidences of bullying that she experienced in jobs forty years previously. They continued to cause her great upset:

> *I go over things people have said to me. Even from like forty years ago, I'll still go over them at times and get really upset.* (Catrina/F/60/6)

James explained how he was always worried and anxious about potentially being bullied because he had difficulty anticipating other people's reactions. He often found himself in social situations that he found difficult. The dread of finding himself in similar situations again caused great anxiety:

> *I was always on…on alert for potential situations, where I'd think this could…I could…get into a bullying situation here, so let's move away, steer, you know, steer away or whatever. I suppose I've always been a bit anxious. Except but when I find people that I'm comfortable with, that, you know, are really sort of…my anxiety levels fall, and it's just that I didn't find that many people.* (James/M/62/8)

6.1.5 Miscommunication

The participants all gave examples of how communication and social situations often developed in surprising and unexpected ways. They often were unable to identify what had gone wrong in many of these situations and this left them feeling helpless to remedy the situation. Participants reported how large amounts of their time and vast amounts of mental energy were spent ruminating about events to try to understand what had occurred. Without insight into their neurodiversity or external assistance (pre-diagnosis) it was often impossible for the participants to decipher what caused the communication or social problem. This caused participants to feel helpless and unable to resolve issues that arose from these situations. Consequently, they experienced feelings of vulnerability and anxiety that the issue may arise again.

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[7] Rumination is defined as a pattern of thinking responding to distress with perseverative thinking about the causes or consequences related to that distress, at the expense of using problem-solving techniques to improve one's mood (Nolen-Hoeksema and Morrow, 1991).

Participants often spent time trying to learn from these incidents. They attempted to pinpoint and make assumptions about exactly what went ‘wrong’. The fact that these incidences happened repeatedly throughout their lives negatively impacted upon their confidence. They also reported a related problem, the anticipation that they would be regularly unsuccessful in social situations. As a result, they experienced a degree of despair and a feeling of hopelessness. Participants largely felt unable to do anything to prevent these miscommunications from occurring. Pre-diagnosis they had no frame of reference to help them understand these experiences. Consequently, these unexplained miscommunications were highly detrimental to their confidence and personal wellbeing.

Some participants spent time studying psychology or human behaviour to understand why miscommunications occurred. Although this gave participants small feelings of empowerment it was largely unsuccessful. As they had not known they were autistic at the time, they had been unable to properly frame what was occurring.

Social situations often ended badly, and they had regular disagreements with people, resulting in participants feeling that they were disliked or untrustworthy. This caused participants to have a low opinion of themselves. Emma’s experience was similar to that of other participants. She described feeling that she was a bad, or even an evil person who somehow deliberately upset others. She felt powerless to stop these incidences from occurring:

> *I can spend a lot of my life, a lot of my adult life, I suppose from a teenager really, feeling like I was a bad person, or I was an evil person because I knew that I behaved badly around people, but I didn’t seem to be able to do anything about it.* (Emma/F/54/4)

These feelings were traumatic for the participants who all cared tremendously about the feelings of others and placed great importance in honesty and fairness. Participants described their propensity for self-blame which was reinforced by the regularity of these incidences as well as the feelings of difference and worry that there was something wrong about the way they behaved.

A significant feature of Walter’s life had been his experiences of miscommunication. He felt that other people were often rude or at times even aggressive towards him because of his unconscious non-verbal communication differences (such as staring for too long). This has been traumatic for Walter and had an impact on his confidence and wellbeing and had caused him to feel anxious and nervous communicating with people that he did not know. He lived on his own and owned his property and therefore was responsible for its maintenance. Here he explained the problems that his communication difficulties posed with workman for necessary household repairs:

> *…how do I speak to someone about this (household repairs)? If I was to try and do this (communicate) on my own, people will misunderstand me because they have misunderstood me in the past and it will go down a different route. I've got no influence or control where other people are concerned because I don't understand how they work.* (Walter/M/65/8)

As a result, Walter tried to avoid employing contractors to do any jobs due to a legacy of poor interactions and the anxiety such arrangements caused. An illustration of this was that Walter had a dripping tap in his kitchen for years, which he knew required repairing. In order to avoid interaction with contractors he did not use the tap and bought bottled water instead. This strategy of avoidance was effective in preventing miscommunications. However, it had a larger negative impact on his wellbeing. It reinforced the feeling of being powerless, increased his frustration with himself and negatively impacted upon his self-worth and wellbeing.

Participants found it very difficult to interpret non-verbal communication. All the participants had some level of awareness that they struggled in this area. This awareness combined with a legacy of poor social interactions led them to be socially anxious. They felt that miscommunications were inevitable. Despite this happening regularly it continued to be just as traumatic and a very frustrating feature of their lives.

Sylvia was the only person in the study who had never been employed. She was married and had children at a young age. Her children are autistic, so she became their main carer. At the time of interview, she was 52 years old, and her children were in full time residential care. It was her desire to get a job, however, she felt that she would never be able to gain employment due to her frequent miscommunications:

> *My problems with Asperger's can come across as rudeness and the problem is, I don't know I'm doing it and if somebody turns around and says I'm being rude I turn around and say 'so which bit of those words that I said were rude? I said nothing rude', 'oh yes you did, it was your attitude'. Well I speak how I speak, if people think I've got an attitude well that's their problem because most of the time I haven't, it's just sometimes my tone of voice can come across as having an attitude.* (Sylvia/F/52/6)

Sylvia’s manner of speaking was very enthusiastic and loud, and she spoke with great conviction in her tone of voice. This could easily be, and in the past has been, perceived by people unknown to her as aggressive or rude. Like other participants she tended to interpret communication very literally and often missed inferred meaning in conversation. Sylvia described one such situation in her voluntary job in a church café. Here she explained a typical example of miscommunication that she felt may preclude her from gaining future paid employment:

> *I take everything totally literally so for instance in the café, my friend who I work with said ‘Can you go in the kitchen and wash the dishes’. I goes in the kitchen and washes the dishes as she has her lunch, after she’s had her lunch she says ‘Well, you didn’t clear the tables’ and I’m thinking but you asked me to wash the dishes, you didn’t mention clearing the tables, well now I know the definition of can you wash the dishes means clear the tables as well but at that time I thought well you never actually mentioned clear the tables, you just said wash the dishes…’But it’s obvious’, ‘no it isn’t’, … if I was working for a paid employer, I’d be doing that all the time.* (Sylvia/F/52/6)

Missing information that is inferred or not explicitly provided was a common experience amongst participants. Such examples of miscommunication may seem trivial to a neurotypical person. However, the regularity of this type of miscommunication for participants, coupled with the inability to correctly identify the exact source of the communication problem caused real distress and confusion in their lives. It was also reported to cause others to feel that they were being deliberately awkward and had negative impact on their relationships and contributed to relationship breakdowns.

All the participants also explained how they struggled and became anxious when they felt they had made a mistake. Therefore, incidences where there had been miscommunication caused them a great deal of stress and anxiety. In turn this contributed to a feeling of low self-esteem. Indeed, Sylvia ruminated about the incident described above for a significant period afterwards. A similar process was reported by all participants. Ruminations about social faux pas or miscommunications could dominate their thoughts for significant periods after the event.

> *Never forget it. I have an incredible memory for things that have gone wrong, I mean mistakes I've made when I was seven and stuff and they are as clear as day.* (Peter/M/49/4)

The detrimental effect social communications had on participants was summarised very eloquently by Sheila:

> *We grow up as fish out of water: strange, awkward beings who often, at best, hover on the fringes of social interaction. We don't understand people around us, are often confused and hurt by a response to our behaviour and can never seem to get 'it', whatever 'it' is, quite right. We are often isolated, lonely and unable to reach out, yet desperate for love, acceptance and human interaction. We misunderstand and are misunderstood so much of the time that it makes us especially vulnerable.* (Sheila/F/50/8)

6.1.6 Relationship Breakdown

Many of the participants experienced numerous breakdowns of relationships in their lives prior to diagnosis. Commonly participants were uncertain about how and why relationships had broken down. Sophia talks about regularly moving from one job to the next due to communication problems with employers. She reported a catalogue of examples of how employers took a dislike to her, and she was seldom aware of the reason. Here she described a typical scenario that she came to expect in employment:

> *I found a job on the reception desk of [large department store] so I migrated into that until my boss took a spite against me, so I had to leave that one, and this is a common pattern just repeats itself throughout my life.* (Sophia/F/53/1)

Like Sophia, all the participants were generally unaware of what had caused the relationship to be in trouble. They described how they assumed blame for the relationship breakdown and felt powerless to attempt to rectify the situation. Sophia's strategy for dealing with these recurring situations was avoidance, by finding another job. However, the miscommunication, stress, ruminations and worry caused her to have periods of time in emotional turmoil and caused her debilitating stress and anxiety. Relationship breakdown for unknown reasons was a familiar experience for many of the participants.

> *It became obvious that the area manager's P.A. didn't like [me], I don't know what I'd done, she just didn't like [me] and the relationship between me and her deteriorated more and more.* (Gary/M/53/7)

Unexplained breakdown in relationships were commonly experienced by the participants in all areas of life, not just their professional lives. Over half (n=7) of the participants had been divorced. In fact, only three out of the ten participants that had married, remained within the same marriage.

Having estranged family members was also a common experience for the participants in my study. Typically, they did not have a reason for the relationship breakdown. Here

Gary described his relationship breakdown with his sister whom he has not spoken with for many years:

> *I'm the only son, my sister doesn't speak to me or my Mam anymore, hasn't done for a number of years, …There was this one Christmas when I went up, everything seemed fine when we were having our meal just in a pub and we went to say goodbye and I went to put my arms around her and she was just that little bit standoffish, I just left it, I thought I'd obviously said or done something but I didn't broach the subject and it has just sort of snowballed from there.* (Gary/M/53/7)

Miscommunication often made it difficult to maintain relationships, even within families where the other parties involved may be familiar with the participants idiosyncrasies.

6.1.7 Ruminations

All the participants alluded to the fact that they were susceptible to experiencing recurring negative patterns of thought, that they felt at times unable to prevent. According to the participants' accounts, rumination appeared to be the process of mentally trying to figure out what had happened during negative interactions. Participants reported that it was a way of analysing events by re-living the event again and again, trying to piece together what occurred and attempting to gain an understanding of the causes of the incident.

These ruminations could be focused on a variety of things but quite often were focused on miscommunications, perceived wrong doings or underachievement's in life.

> *I think it's an autistic trait really, struggling to get rid of, not get rid of it, move on from the past, it seems to be quite an autismy thing.* (Emma/F/54/4)

This is a consistent lifelong process of analysis that caused great stress and anxiety. Participants described it as like reliving the negative incidents repeatedly which for some was as stressful and upsetting as the initial experience itself. Participants could not identify why these negative ruminations occurred and they found it very difficult to elude the thoughts once they had started. Sylvia explained here how she knew that ruminating was not good, but she described being powerless to prevent the thoughts from occurring:

> *It just tends to be all these repeating things that people have said that are not good. I keep trying to tell myself that doing this is not doing you any good at all.* (Sylvia/F/52/6)

Participants reported finding it frustrating not to be able to control these thoughts. Peter described how this was exacerbated by well-meaning neurotypical people suggesting that he should simply not worry about things. However, he finds it impossible not to worry:

> *When you say to somebody with autism, … 'don't worry about it'. It's the most offensive thing you can say. Do you not realise? …, oh, I wish he had said that to me before because I hadn't thought of that myself, [you] spend your life beating yourself up because you can't put these things away.* (Peter/M/49/4)

Participants explained that negative ruminations quite often dominated their thoughts and were a big problem. Theo explained that he thought these ruminations were linked to high incidences of depression in autistic people:

> *We (autistic people) have this very strong tendency that we are very good in focusing on one thing, but it also has a danger if one focuses on the wrong thing it makes it much easier to get into a negative, and to ruminate in negative thoughts, and to get completely absorbed into it, and that I think what makes people with Asperger's (autism) more exposed into developing depression.* (Theo/M/53/4)

6.1.8 Camouflaging[8]/Masking/Hiding True Self

Ten out of the fourteen participants reported regularly camouflaging (two men and two women did not). As we have discussed, from an early age, all participants, felt pressure to 'fit in' and to hide their differences. Most of the participants relayed incidences of how, throughout life, they had consciously attempted to modify themselves, supressed or artificially adapted their natural behaviour to 'fit in'. They used their experiences of social miscommunication, combined with their observation of others perceived 'normal' or 'successful' behaviour, as the basis to mimic and alter the way that they behaved socially. Participants developed many different strategies to camouflage their differences. These included teaching themselves to use eye contact, rehearsal of social skills, mentally cataloguing appropriate ways to behave in certain scenarios, mirroring group behaviour or acting overly confident to hide their insecurities, and supressing stimming[9] behaviours.

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[8] The terms masking and camouflaging are often used interchangeably to describe the process of hiding their autistic traits. Here we will use camouflaging as an umbrella term. A definition of *"the employment of specific behavioural and cognitive strategies by autistic people to adapt to or cope within the predominately non-autistic social world"* (Cook et al, 2021:1)

[9] Stimming are movements also known as 'motor stereotypes' such as hand or finger flapping or whole-body movements that are a coping mechanism for some autistic people. (Kapp et al, 2019)

The different ways in which participants reported using camouflaging can be spilt into two types of camouflaging, ‘conventional’ camouflaging and ‘relational’ (Cage & Troxell-Whitman, 2019) camouflaging. ‘Conventional’ camouflaging was purposely used for occasional use usually in official scenarios in life such as in a work capacity or at appointments and assisted getting participant through particular situations. This tended to be for shorter bursts of time and was used by all participants who camouflaged. For example, Theo had a catalogue of scenarios reserved to memory that he would use to help him communicate in a way he felt would be perceived as more appropriate:

> *I have some experience, I can remember a lot of similar situations, so I can use, I can draw on this to predict on what might be the right behaviour in such and such a situation.* (Theo/M/53/4)

For Theo ‘conventional’ camouflaging involved temporarily camouflaging his natural behaviour to get through a social situation in employment and thus avoiding drawing negative attention to himself. Although Theo found this strategy effective, he reported the exhausting effect it had on him, as it required a significant amount of mental energy and he found it ‘*mentally depleting’.*

Other ‘conventional’ camouflaging adopted by participants to ‘fit in’ did not go as they intended. These adaptations to behaviour were described as so uncomfortable that they were painful. Walter was told by his boss in his first job that that he was to look directly at her when he spoke to her (as Walter often avoided eye contact at the time). Walter forced himself to do this and he reported it making him feel physically sick, but he persevered as he had been instructed to do this. After a while he got used to it. However, Walter had not understood the nuanced way in which people look at one another when talking and instead he would stare. Here he relays how his boss did not react favourably, which clearly confused and frustrated Walter:

> *So I started looking at her and it was physically painful. It used to really hurt, and I got over it and then I suddenly realised I can look at somebody when they’re speaking to me. Six weeks later: ‘I wish you’d stop looking at me when I’m speaking to you. I find it very intimidating’ and I’m thinking you can’t win one way or the other. But of course, I’d learnt then to look at people.* (Walter/M/65/8)

Although Walter had forced himself to be able to look at people, and successfully mastered this, it seemed to cause him great problems, as it would seem he now stared at people in an unnatural way that made others feel uneasy. He discussed the negative reactions he was receiving from people with a psychologist he had been seeing. He was told that his problems were probably due to the way he was staring at people. It seems the modification Walter had made as a young man to satisfy his boss had inadvertently had a larger negative impact on his life experiences:

> *I've been out in other places and people have come up and said things like, 'I wish you were dead'. People who have been with me have said 'what have you done to cause that?' I said 'I've done absolutely nothing'. …I was seeing a psychologist at the time … he explained to me about this intense stare or gaze. He said people pick up on something, they don't realise what it is, they don't realise it's a stare or a gaze or whatever or a movement that is slightly different, and people either don't like this, it makes them feel uncomfortable so they will respond either by ridiculing you or showing you hostility. He said a lot of people won't be bothered. I said, 'I won't notice the people who aren't responding to me, I'll notice the ones who are being hostile.' So I'll think it's happening all the time.* (Walter/M/65/8)

'Relational' camouflaging describes camouflaging that was used to get by in relationships with others (Cage & Troxell-Whitman, 2019). In this study this was almost an unconscious act, that had become a habitual strategy which was done mainly by the women in the study. This was a more inherent part of their daily lives, something that they automatically did without thinking. Sheila described this as a lifelong process that causes her great stress:

> *…because I've grown up [laughs] with no diagnosis, and I've had to get on with it…I've kind of developed coping strategies possibly, or, if you want to call it a mask, maybe it's the mask… instead of knowing things instinctively, socially, you kind of, like, you spend a lot of time observing and copying and, you know, it's very confusing, and it's very stressful.* (Sheila/F/50/8)

Both types of camouflaging had a larger detrimental impact as they were physically and emotionally draining. Participants reported them to be exhausting and that they required time afterward to recover from the effect of camouflaging. However, the 'instinctive' camouflaging seemed to evoke more detrimental associated effects as participants' felt dishonest by hiding themselves. This added to a sense of shame participants held about their natural behaviour. Sophia describes how she felt that she had been hiding her true self all her life and described the juxtaposition this presented with her intrinsic honesty:

> *I've always been hiding stuff my whole life. I've been overly honest about everything and covertly hiding myself, so I'm a very honest ethical person but … well I tried very hard not to let people see of course… I've spent years learning to tone myself down, quiet it down, hide it from people.* (Sophia/F/53/1)

The female participants reported using camouflaging to help them ‘fit in’ on a wider level socially. This was apparently an instinctive process that began in childhood but as it had been such a big part of their lives, they became confused about their own identity:

> *I think someone like me challenges what autism is, because actually, I am very autistic. But yet, … I honestly think it’s because of the…the chameleon-like personality that I’ve developed over the years. Because you don’t have a sense of self, not particularly, because you don’t really—it’s not that you’re not self-aware, but you don’t really know who you are because you spend your whole life copying and mimicking other people.* (Sheila/F/50/8)

Indeed, some of the female participants felt that they had been ‘masking’ for so long that it was difficult for them to separate out the ‘mask’ from their natural identity and Emma linked this confusion directly to the fact that she had not known she was autistic, so was less aware of her tendency to camouflage:

> *From my perspective anyway, young people on, the only thing I can go by is the people that I see online that are in their twenties and are talking about it [camouflaging] they perhaps have always been aware [of camouflaging] since their diagnosis that they are doing it that they can say, ‘I did this and I did that, now I can stop because I’m home’. To me that is me, do you know what I mean? That is me and I think that’s been one of the weird things about it, trying to understand what is actually me and what is what I’ve been trying to hide from the world, if you like, without realising that I was hiding it. It just all gets a bit weird and intense when, I try not to think about it too deeply because it just ends up stressing me out.* (Emma/F/54/4)

Some of the female participants talked about their propensity to mask, and even in times of crisis when they were asking for help, they would still not show the extent of their struggle. They felt compelled to portray themselves as someone who was coping. They reported that this had become commonplace to them after spending their whole lives covering up and trying to ‘fit in’. This was particularly true of the participants who were mothers. They reported being terrified that they would be deemed unfit to care for their children and therefore lose custody. Amy explains how mentally taxing camouflaging was for her and how she felt her wellbeing suffered as a result but felt powerless to stop:

> *That’s what they see, because that’s what I want them to see, because I’m a parent. I don’t want anybody to think I’m not coping. And then once everybody’s gone to bed on a night that’s when the mask drops and that’s when I’m a wreck. because it’s that coke bottle effect where you shake it and shake it, … and then that’s it. So, the forfeit of my sleep or my diet or whatever… then I get up the next day and go and do the same thing.* (Amy/F/52/4)

Some participants reported that camouflaging was effective in that it enabled them to ‘pass’ as ‘normal’. However, for some camouflaging did not work. Indeed, it almost accentuated their feeling of difference and caused them to further stand out. It made them seem unnatural or fake and so people became wary of them as a result. This is explained by Sophia:

> *I knew that I was socially ungracious to say the least and I’d spent years learning tricks for not letting that show, but what used to happen, wherever I went people would think there’s something bloody odd about this person, something dishonest about this person you know, they’d start to dislike me and start to back off from me then I’d get upset and try too hard and it just got worse and worse, and I got rejected all through my life all over the place, jobs, schools you name it because I mean I was trying too hard.* (Sophia/F/53/1)

The process of hiding their true selves or adopting ‘conventional’ camouflaging ways to ‘fit in’ was reported to be exhausting and stressful. However, those participants that also engaged in ‘relational’ camouflaging experienced a further internal struggle. All participants commented on the fact they have always had a strong preference for honesty and straightforwardness. The ‘conventional’ camouflaging did not seem to pose a problem with this as it is widely accepted that all people temporally act in different ways in different circumstances. However, the ‘relational’ camouflaging seemed to evoke feelings of being dishonest and that they were deceiving people which promoted feelings of guilt and caused further anxiety. However, it also reinforced their negative self-identity as they felt could not be honest about who they were and further supported the notion that there was something ‘different’ about them and that the difference was not positive and therefore not acceptable. Sheila described the impact camouflaging had on her:

> *We all have to put different faces on, different masks. Whatever you’re doing, you have to put different hats on, if you like. But I think the major difference between somebody who is autistic doing it, is that not only are you doing that, you are also covering up your autism in order to appear to be acceptable, because you do not feel accepted. I think that is the major, major difference. So, you’re operating on two very different levels, and so it’s an extra layer of stress.* (Sheila/F/50/8)

Often simply opting out of situations that would require camouflaging was a less exhausting option for some participants. However, pre-diagnosis this could have a negative impact on participants’ wellbeing and could trigger negative ruminations reinforcing feelings of low self-worth surrounding not being able to ‘fit in’.

6.1.9 Vulnerability

The fact that miscommunication led participants to feelings of self-doubt and low self-esteem also made some participants feel that their opinions or actions were of a lesser value than the opinions of others. This led to self-doubt and meant some participants became compliant and susceptible to being unquestioning of the opinion of others.

Participants reported occasions throughout their lives when they would unquestionably accept the word of people in perceived authority, such as doctors, solicitors, teachers, and parents. Even if they felt that what this person said was wrong, they would put the opinion before their own and assume that their own opinion was wrong. Sophia had always been told at school that she was stupid, and therefore she unquestioningly believed that this to be true. It was only when she had a technical assessment for a job many years later that she first started to suspect that this was not the case:

> *It was weird the first hint I had was that I was very clever, they did a technical assessment on me … apparently I'd scored higher on their pre-emptive test that they do then anybody has ever scored, I had no idea, I'd always been told I was stupid.* (Sophia/F/53/1)

As discussed previously participants were used to supressing their own natural behaviour and opinions to 'fit in' and felt that their behaviour or opinions were somehow deficient in comparison to others. Many participants therefore felt unable to self-advocate and challenge advice or opinion from professionals and often would agree to things even if they felt they were not appropriate. Christine described how she had not been happy in her marriage for five years. She was living her life in a 'sham marriage' just for show and this made her feel very uneasy as she does not like dishonestly. She visited the solicitor to start divorce proceedings, but the solicitor persuaded her not to proceed with it. As with other participants Christine would often act on the opinion of others and disregard her own feelings or thoughts. This meant that she remained married years longer than she wanted.

> *I would go to a solicitor and say, this isn't a marriage this and then he'd talk me out of it and say, 'It's because you're depressed.* (Christine/F/58/6)

The women in the study seemed particularly susceptible to following the wishes of other people and being compliant. Emma described how she identified that even post diagnosis she still felt compelled to be compliant:

> *I'm still that person I suppose who does whatever is asked of me a lot of the time, even if it made me feel uncomfortable, I'd just put up with it and deal with it myself afterwards if I was having problems.* (Emma/F/54/4)

Amongst the women in the study, it was reported that these feelings of consistently making mistakes in social situations, combined with their desperation to 'fit in' made them particularly vulnerable. This has had distressing consequences in their lives. Within this study six out of the eight women interviewed disclosed that they had suffered some form of sexual abuse (some they disclosed to me, but they did not wish to appear in the transcript). This abuse came from a variety of sources, family members, blind dates, boyfriends and parents. The constant misunderstandings in social situations contributed to making the participants feel that their comprehension of what was occurring within these encounters could quite possibly be incorrect and caused them not to predict the direction of these interactions. Sophia had been a victim of rape twice (she did not want to include the details of the encounters in the transcript) but she explained how misunderstanding social situations she believed made her very vulnerable:

> *It [not understanding social cues] makes you a lot more vulnerable yes, my first experiences of, even sort of consensual sex took me somewhat by surprise because I hadn't really realised that's what I was doing and so yes, you are an awful lot more vulnerable for that sort of thing …I didn't really see it coming and I didn't really know when to stop it.* (Sophia/F/53/1)

All the women that experienced abuse (pre-diagnosis) internalised the blame for the abuse taking place. They explained that they assumed that they were at fault, that perhaps they had mis-read the social subtext and given the wrong impression. (Pre-diagnosis they would have been unaware that a common autistic reaction to trauma is to mentally shut down (Williams, 2002)). They blamed themselves for not protesting of fighting back during the abuse. That they had not somehow reacted in a way they felt was appropriate. They were so well acquainted with the experience of socially making mistakes that they assumed that they had done so in these encounters also.

> *This is the problem, because what had happened previously [been a victim of rape] is I'd been in a situation where I had no idea, I had no idea of any of this kind of thing at the time [autistic traits], that I went very mute, and I couldn't - I didn't want to do this thing, but I couldn't articulate it…. And this person showed an interest in me, and I had absolutely no idea that it was just going to be like a very predatory kind of thing for them, and I wasn't able to articulate. I was in a situation where I just - I was just so sort of shocked, I was mute, and I couldn't, you know, do anything about it, really. But I didn't fight him. But because I was always used to having to be compliant, 'cause a lot of autistic women are compliant, very much so, I let him do what he wanted to*

> *do. Now, it didn't feel right at the time, but I couldn't actually name it as rape at the time. But I can now.* (Sheila/F/50/8)

Participants also reported being overly trusting of people which also contributed to their vulnerability. They reported not always judging situations correctly. This meant that they would not necessarily detect that friends could not be trusted, or boyfriends were acting in a manipulative way or if relationships became unhealthy. Years of doubting her own judgement meant that like others, Christine blamed herself for abusive sexual encounters she experienced:

> *It just made me feel that I had a bad choice in men or I was too trusting, trust issues and me being too depressed or too low, or not understanding the signals and understanding these men who should be trying to make love to you or trying to be nice to you are there to abuse you and be horrible to you.* (Christine/F/58/6)

Participants were often socially isolated which meant that they did not have peer support to help identify certain behaviours as wrong, leaving them even more vulnerable to unscrupulous or predatory people. Amy described how she had lots of experience of these types of encounters in her life, that post diagnosis she links with her neurodiversity:

> *I've had a lot of abuse and stuff when I was younger and obviously stuff's happened in my adult life and my younger life which now I've put down to misreading people and not recognising signals. And you know they could sort of directly link to my autism, people taking advantage and stuff.* (Amy/F/52/4)

6.1.10 Burnout, Mental Health and Suicide

All the participants had been in touch with healthcare professionals throughout their lives due to problems they were experiencing with their mental health. Eleven out of the fourteen participants were on prescribed medication for mental health conditions and eight disclosed suicidal thoughts (with five disclosing actual attempts at suicide).[10] Table seven provides a brief summary of participants reported mental health concerns.

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[10] This number could be more as participants were not directly asked about suicide.

Table 7: The mental health problems/ suicidal ideation reported by participants

	Age at Diagnosis	**Time Since Diagnosis**	**Medication for MH**	**Suicidal ideation***	**Brief summary of mental health experience.**
Theo	49	4	No	No	For the last 20 years he has experienced acute episodes (that he now recognises as autistic burnout) and suffers with anxiety and depression.
Ralph	59	14	No	No	He often gets depressed, but he does not seek medical advice/treatment, he just tries to '*catch his mind on something else'*.
Christine	52	6	Yes	Yes	She suffered with postnatal depression after both pregnancies and was hospitalised as a result. Since '*she has been in and out of the mental health system'*, and has passive suicidal ideation.
Peter	48	7	Yes	Yes	He suffered with anxiety and depression all his life and takes regular medication. He had '*an awful degrading experience with mental health services'* and suicidal thoughts.
Yvette	51	1	Yes	No	Anxiety and depression receives prescribed medication for it.
Gary	47	7	Yes	Yes	Has an '*ongoing diagnosis for depression'* and has regular '*slumps*'. He takes medication for anxiety and depression and has passive suicidal ideation.
Amy	48	4	Yes	Yes	She has regular episodes of anxiety and depression and has attempted suicide.
James	54	8	Yes	Yes	He has struggled continually through life with depression. He has been diagnosed with OCD and is on medication that currently manages his depression well. He attempted suicide earlier in his life.
Sheila	42	8	Yes	No	She has had mental health problems since her teens and is taking medication to help with anxiety and depression.
Catrina	54	6	Yes	Yes	She has been in touch with mental healthcare professionals and treated for depression all her life. She suffers with anxiety and depression and feels that there is no support for her. She is on antidepressants but has constant passive suicidal ideation.
Sophia	52	1	Yes	Yes	She has suffered with depression and anxiety for years and her first attempt at suicide was aged ten.
Sylvia	46	6	No	No	She describes suffering with depression but has never consulted the doctors about it so therefore does not call it depression, just '*feeling very low'.*
Emma	50	4	Yes	No	She has been treated and taken medication for years for depression that was not effective. Post diagnosis she now thinks that it was anxiety and takes medication for it that has started to help.
Walter	57	8	Yes	Yes	He has suffered with anxiety and depression since he was a child that started after a severe illness age 16. He has attempted suicide.

*Participants were not directly asked about suicidal ideation.

Participants often lived in the emotional peaks and troughs of life and struggled to keep emotional balance in their lives. They felt quite powerless to change their situation and tolerated life trying to cope with the emotional roller-coaster they experienced. A lack of knowledge about facets of their neurodiversity meant that they did not have insight into their experience and life was somewhat emotionally chaotic. Catrina lived alone and she suffered severely with her mental health, she described her feelings about her life:

> *I feel like I'm hanging on by my fingertips over the abyss, you know. From time to time, I fall into it. And then when I'm not in it, I'm always hoping I don't fall into it again. It's like a tightrope: I'm constantly on a tightrope. … I try not to think about it 'cause it is terrifying.* (Catrina/F/60/6)

Participants reported that daily living was a harder struggle than it seemed to be for their neurotypical counterparts. They struggled with anxiety, mental health issues, poor self-esteem, continued miscommunication issues, social isolation, employment problems and just did not seem to be 'sailing through life' (Gary/M/53/7) as they perceived others were. They felt that they were struggling through life:

> *I've never considered suicide or anything like that but sometimes I just feel like being alive is too tiring … it is hard work and I don't think anybody who hasn't got autism or Asperger's, I don't think it's easy for them to understand that ... Sometimes, life, I just feel like I've had enough of life. (Gary/M/53/7)*

The fact that participants often compared their experience with others exacerbated their feelings of hopelessness. They could not understand how other people seemed to cope well and get on and enjoy life whilst they experienced such struggles. Gary shared an analogy he had heard that he felt perfectly illustrated this feeling:

> *She said that Asperger's to her was like riding a bike on a path next to a lake and all the non-Asperger people were in the lake and they were sailing boats… She could appreciate what they were doing and she could see they were all having a lovely time, but she felt like if she stopped pedalling she would fall off her bike and she would hurt herself. So she was trapped in this thing of having to ride a bike. She could appreciate the fact that these people were having a lovely time, she just didn't feel like she could join in because if she fell off her bike. … I've never ever found a better way of putting it, ..…That made a lot of sense to me because I can see these other people and I can see they're having a lovely time and here I am on the side, pedalling away like mad because I don't want to fall over…It was a really good analogy.* (Gary/M/53/7)

Living with their unexplained differences and struggles, contending with their propensity for self-blame, alongside high expectations of themselves, often led to periods of breakdown. Participants retrospectively identified this as 'autistic burnout'[11] (Higgins *et al*. 2021). Many participants had experienced periods in their lives where they had episodes of being unable to cope with life. These episodes often punctuated their lives pre-diagnosis and usually coincided with times of change and transition in their lives such as changes in employment, new babies etc. Amy regularly experienced autistic burnout and at the time of interview she felt that she had reached a burnout state again. She described her experience of burnout and hints at the lack of support she receives from her General Practitioner (GP):

> *…Well I don't sleep. I'm like, I get by on three, four hours disturbed sleep at night. I lose my appetite and that's, I think that's the point where the GP actually started to take me seriously last time because I'd gone down to six stone.* (Amy/F/52/4)

It was only with hindsight post diagnosis that some participants recognised these episodes as autistic burnout. Being unaware of their neurodiversity participants would not necessarily recognise stress and anxiety triggers which could therefore mean that they were more at risk of regular autistic burnout periods. Indeed, many participants' accounts describe what could be considered autistic burnouts throughout their lives. Without understanding the cause or how to recover from these burnouts, the effects of these periods would be even worse.

> *I think now it was an autistic burnout …I do burnout occasionally, like that big one a couple of years ago.* (Sophia/F/53/1)

These experiences often coincided with times where participants reported having suicidal thoughts at some time in their lives. Indeed, several had a history of actually attempting suicide. Participants described long histories of contact with mental health services throughout their lives. They also had experienced misdiagnosis, having been ascribed several different incorrect labels for the mental anguish they experienced:

> *…first one was borderline personality disorder but then I had bipolar because of the depressive kind of stuff and then … manic depression … I was actually depressed because of the anxiety and stress that went along, you know, seeing no change and not thinking that there would be anything ahead … the mental health system is a horrible, horrible system it is incredibly degrading.* (Peter/M/49/4)

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[11] Autistic Burnout is *"a highly debilitating condition characterised by exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits – and distinct from depression and non-autistic burnout"* (Higgins et al, 2021:2356)

Mental health misdiagnosis meant that on occasion the participants had been provided with treatment they now felt was inappropriate:

> *Well, I've been treated for depression for years before my diagnosis but now I don't think it was depression, I think it was anxiety that I didn't recognise. I've been on anti-depressants on and off for years and none of them have ever worked, at the moment I take beta-blockers which sort of work, for the anxiety.* (Emma/F/54/4)

This experience was shared by many of the participants and some actually believed that their experiences of mental health care had actually been detrimental to their personal wellbeing:

> *I have had a really bad experience with the mental health service, so I really haven't got anything good to say about them because it's been a slog, it's been a fight all the time. I can't see any positives that way.* (Christine/F/58/6)

All participants talked about the negative impact stress had upon their wellbeing and the fact that their anxiety could be crippling leaving them unable to vocalise their problems. This made communication of their feelings or symptoms to healthcare professionals problematic. Without their autism diagnosis to frame and efficiently relay their experiences they struggled particularly in times of crisis:

> *If you're having a particularly bad period, and you're very anxious and you're very stressed, you'll come across in a completely different way to a calmer period.* (Catrina/F/60/6)

Indeed, they found visiting healthcare professionals extremely difficult. Without the insight diagnosis provided they were not aware of the reasons that they found it anxiety provoking. This meant they were powerless to manage this stress. Likewise, without an autism diagnosis healthcare professionals would be unable to provide them with effective and appropriate reasonable adjustments or treatments.

6.1.11 Believability

Participants all sought medical help pre-diagnosis to assist them with the stresses of daily living. Medical professionals acknowledged their personal feelings of 'difference' and apparent problems but were unable to adequately support them or indeed signpost them to the autism diagnostic service.

There were some cases where participants did not feel that healthcare professionals believed or empathised with their experiences. The camouflaging and apparent uneven or 'spiky profile[12]' of the participants caused problems when trying to access help. The participants were academically very competent, most were married, employed, homeowners, parents and lived independently. Yet in times of stress they may not be able to cope with basic tasks. The participants explained that people did not always believe what they were reporting to be experiencing because of the non-typical way in which they respond to stressful situations or pain.

The fact that participants' differences or difficulties were truly hidden caused them lots of additional problems. Participants reported that people tended to have no empathy for them as they thought that they were not being honest or were in some way '*trying it on'* (Ralph/M/73/14). In this way, having an unknown neurodiversity was reported to be very difficult. Catrina reported that she often was envious of a friend who had a physical disability as people appeared to be kinder to her as her difficulties were more obvious and therefore accepted and accommodated for.

> *That's the worst of it, you see. 'Cause I know, like, [friend]… she has learning difficulties. I mean, they're only mild, but they are quite obvious, so she gets a lot of understanding: and when she's really anxious, … 'she can't help it'. But with me, 'cause they know I'm really intelligent, it's like they think, well, how can I be so anxious? I mean, I even had a counsellor say to me, "For somebody so intelligent, you're being really stupid.* (Catrina/ F/60/6)

The problems associated with unidentified neurodiversity and believability were exacerbated for participants in healthcare scenarios because of a tendency to communicate distress or pain in a non-typical way. The manner in which a participant's reported pain could be quite matter of fact and lacking in the emotion that is usually displayed and expected from the neurotypical population. Medical professionals can be unfamiliar with this. Participants thought this may have led to professionals disbelieving what was being reported:

> *The main sort of prevalent attitude ... is disbelief, …and that is a humongous problem …because how can you stand there in a perfectly normal voice and say I think my bladder's about to burst out of my body, that's just me. Expressing emotions is not an autistic forte, you might be feeling absolutely appalling inside but on the outside people see someone who's perfectly fine.* (Sophia/F/53/1)

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[12] Spikey profile is when a person exhibits great skills in some areas and struggles in other areas in a non-typical way

The factors described here are particularly problematic in providing healthcare suitable for autistic people. The issues identified may go some way to explain why all the participants had problems (pre-diagnosis) in obtaining adequate healthcare support and why they have such negative feelings about mental health services.

6.1.12 Discovering Autism

Participants identified themselves as ‘different’ to the general population. They all highlighted problematic scenarios that they felt ‘being different’ had caused in their lives. They spent a significant amount of time and energy trying to understand what this difference was, either by independent research or through seeking help from professionals in healthcare services. Participants felt strongly that it was important to *know* why they felt different and why their life experiences differed to the experiences of others. Participants eventually discovered information about autism. The description of the autistic experience seemed to fit their own and therefore they started the process to seek a diagnosis. They thought confirmation through diagnosis would finally give them an answer that would adequately explain their ‘different’ life experiences. They also thought that a diagnosis would be beneficial for them as they would finally have access to appropriate help and support.

The majority of participants (13) approached diagnosis as a goal that they were striving for. They desired the diagnosis and felt certain that their experiences fit the autism diagnostic criteria. Diagnosis was not something that they were apprehensive about but something that they moved towards with positivity and hope.

6.2 Summary

Throughout the interviews all the participants recounted their feelings and thoughts of ‘difference’. They described how they struggled in life and were constantly attempting to fathom an explanation to adequately describe and give reason for their experiences. They describe feelings of mental anguish and confusion, of not being able to adequately label or describe their ‘difference’. ‘The negative impact of ‘not knowing on participants’ wellbeing is represented diagrammatically in figure five.

Figure five: Impact of ‘Not Knowing’ on Wellbeing

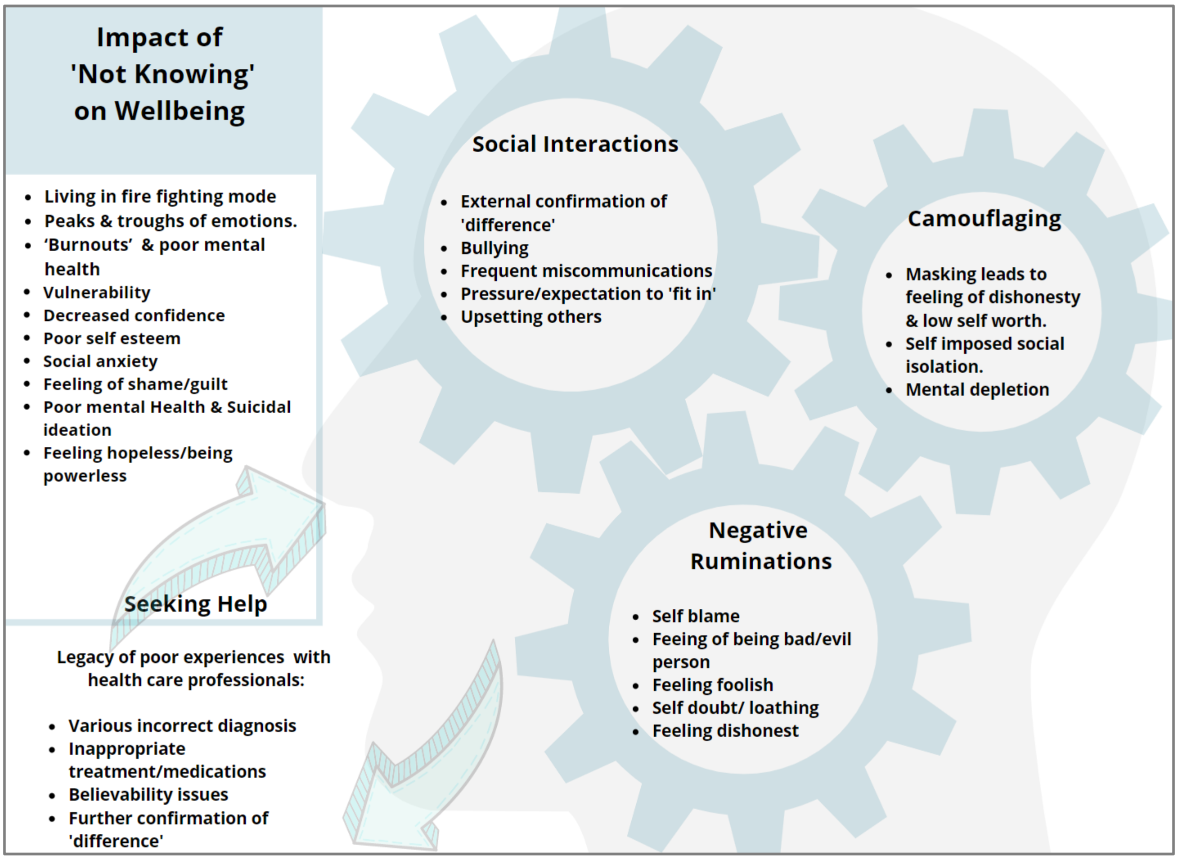


Figure five shows the negative impact on participants’ wellbeing of ‘not knowing’. It demonstrates diagrammatically the combined effect of how social interactions, camouflaging and negative ruminations all contribute to an internal negative view on themselves and how these feelings were confirmed externally through seeking help from professionals.

Participants universally reported a legacy of poor social interactions and a compounding feeling of not belonging despite desperately trying to ‘fit in’. These interactions provided external confirmation of their ‘difference’. They experienced traumatic events such as bullying and abuse which exacerbated the feelings of being broken. They felt overwhelmingly that they should be able to ‘fit in’. The fact that they could not led to feelings of failure or the feeling of being somehow broken or deficient and therefore in need of help or ‘fixing’. A natural strategy for most was camouflaging or hiding themselves, however this further exacerbated stress and anxiety as it added to feelings of low self-worth as participants felt they were being dishonest and the process of hiding their autistic traits was stressful and exhausting. This led some participants to socially isolate themselves. Participants often focused on their negative life experience and had perpetual negative ruminations which were seemingly impossible to control. This process further added to participants blaming themselves and feeling foolish, dishonest and in some cases bad/evil. Seeking help from healthcare professionals provided external confirmation of their ‘difference’ but led to misdiagnosis and inappropriate medications and treatments. It also fostered more self-doubt as professionals often did not believe or understand their feelings and experiences. Without ‘knowing’ about their autism participants felt unable to make positive changes to their lives and tended to feel that they were constantly battling or living in firefighting mode with significant peaks and troughs of emotion that they felt unable to control. Participants reported living with high anxiety, and many frequently suffered with depression and autistic burnouts and most participants had contemplated, and some attempted, suicide.

Participants felt that there was something fundamentally different or wrong with them but despite searching for reasons, solutions and asking for help they were unable to find an appropriate answer. Information about the autistic experience was discovered and felt that this could be a plausible explanation for their feelings. Many described striving towards a diagnosis which they felt could finally bring some clarity and meaning to their life experiences. Indeed, most participants anticipated a diagnosis and placed high expectations of the changes a diagnosis would bring to their lives.

In this chapter I have presented the findings in regard to the traumatic and confusing period of the participants lives; ‘not knowing’ and the negative impact on their self-identity and mental health. In the next chapter I will present the experience of ‘gaining knowledge and knowing’ that occurred during the process of gaining a referral to diagnostic services, the process of diagnosis and the participants’ reaction to diagnosis.

7 Chapter Seven: Gaining Knowledge and ‘Knowing’

In the previous chapter, I discussed the traumatic life experiences of participants prior to realising they may be autistic. This time is described in this study as ‘not knowing’. In this chapter I focus on the period of their lives described as ‘gaining knowledge and knowing’. This describes the process of initially discovering autism and identifying that they could be autistic, the road to seeking confirmation through diagnosis, the reaction to gaining the diagnosis and the impact of ‘knowing’ on the participants’ lives.

7.1 Gaining Knowledge

7.1.1 The Discovery of Autism

For all of the participants the lifelong quest for an appropriate explanation of the differences and difficulties they had experienced eventually led them to a diagnostic assessment for autism. The participants initially discovered autism via differing avenues. Only one ‘discovered’ autism through identification by a healthcare professional. This is despite the fact that most the participants had sought help and support from a variety of different healthcare professionals throughout their lives. Table eight shows the different routes to the discovery of autism for each of the participants.

Table 8: Route to 'Discovery' of Autism.

	Route to 'discovering' autism					
	Diagnosis of child in family	Told by another autistic person	Worked in roles where they were exposed to autism literature	Hearing information about autism by chance	Education professional	Informed by healthcare professional
Theo				X		
Ralph					X	
Christine	X					
Peter				X		
Yvette**			X			
Gary				X		
Amy			X			
James				X		
Sheila	X					
Catrina		X				
Sophia			X			
Sylvia*		X				
Emma			X			
Walter						X

*Sylvia's two children are autistic, and she knew a great deal about their experiences of autism. She did not 'discover' autism relating to her own experiences until an autistic stranger said that he thought she was autistic.

** Yvette had 25 years' experience working supporting autistic people but did not recognise her own autism until recently.

Before discovering autism, it had been an unknown condition to the participants. They had little or no knowledge of autism. The description of autistic experiences they finally discovered mirrored their own life experiences and this motivated them to gain verification of their suspicions through official diagnostic assessments.

7.1.2 Referral to Diagnostic Services

When participants came to request a referral to diagnostic services, most had gained autism knowledge and had decided that autism was a reasonable explanation for their ‘different’ experiences in life, indeed many felt sure they were autistic. However, it was extremely important to all participants that their suspicions of autism were confirmed officially. Therefore, they went on to request a referral to autism diagnostic services. A different journey to diagnostic services was described by each participant. However, for the majority it was a prolonged and frustrating process during which they experienced believability issues with professionals who did not believe that they were autistic and, in many cases, refused to refer them for diagnosis. In addition, they described a lack of empathy and little understanding of the personal importance and potential benefits an autism diagnosis could bring to the participants' lives. The time between first ‘discovering autism’ and being diagnosed was considerable for all (1.5-10 years, mean 4, SD 2.64). Table nine shows the different referral pathways to diagnosis and the approximate time from ‘discovering autism’ to diagnosis.

Table 9: Experience of referral pathway to diagnosis

Participant	Approx. time from discovering autism to diagnosis	Struggled to get referral for diagnosis						**Eventually Referred through**
		Diagnosis request processed by GP with no problems.	Paid for Private Dx	Informed by HCP giving yourself a label is *damaging*	Informed by GP NHS would not support Dx	Not believed by GP	Informed by GP/HCP Dx pointless	
Theo	4 years					X		Counsellor eventually referred him.
Ralph	2 years	X						GP
Christine	6 years					X		GP
Peter	4 years					X		GP
Yvette	5 years		X				X	Private
Gary	4 years					X	X	GP
Amy	10 years					X	X	Self-referral
James	2 years	X						GP
Sheila	1.5 years	X						GP
Catrina	1 year	X						GP
Sophia	2 years		X		X			Private
Sylvia	2 years	X						GP
Emma	1.5 years	X						GP
Walter	9 years			X			X	CBT Therapist

For most participants, the first port of call in obtaining referral for a diagnostic assessment was a General Practitioner (GP). For Ralph, James, Sheila, Catrina, Emma and Sylvia the process was relatively simple. Their GP validated their suspicions and ostensibly had some personal understanding of autism. They fully supported their requests for referral to diagnostic assessment.

> *I'd had a really, very good relationship with my GP, I said to her, 'can I go for a diagnosis?' And she said, 'Yeah. I've always thought you were a bit special'…. she put me through for a diagnosis.* (Sheila/F/50/8)

7.1.3 Negative Diagnosis Referral Experiences

Unfortunately, most of the participants had a negative experience whilst trying to obtain a referral for diagnosis. Their diagnostic journey echoed the problems that they had experienced throughout their lives 'not knowing' (chapter six). Their encounters with healthcare professionals were frustrating. Participants felt that their views and opinions were not valued, and they had frequent miscommunications throughout the process. Many professionals they encountered did not empathise with their need to 'know' and often did not foresee the potential personal value of gaining a diagnosis would have for participants.

7.1.4 Lack of Recognition of the Personal Value and Importance of Diagnosis

General Practitioners and Health Care Professionals (HCPs) approached by some of the participants did not seem to recognise or acknowledge the potential personal value that an autism diagnosis might have for the participants. Although Gary's GP agreed that he might be autistic, he did not believe having a diagnosis would be of any personal benefit to him. The GP believed that factors in Gary's life such as him being married, employed and having children led his GP to believe that a diagnosis would not be of benefit to Gary's life. This was despite the fact that Gary had a long history of depression and anxiety. At the time of requesting a diagnosis his deteriorating mental health was also having a negative impact on his physical health and employment.

As mentioned in the previous chapter, many of the participants doubted their own judgement as they were accustomed to frequent miscommunications and self-blame when interactions did not proceed in the way they anticipated. For participants with low self-esteem this could result in them tending to value the opinion of others over their own. They did not necessarily have the self-confidence to be able to challenge decisions/opinions they did not agree with or be resolute in their referral requests. This meant that participants could easily be susceptible to being ‘fobbed off’ by the GP. After Gary’s initial request for a diagnosis and being advised by the GP that a diagnosis would not be of any benefit to him:

> *He said, well if you have got it, you’re obviously very high functioning, you’re in a relationship, you work, you’ve had a child at some point so, I don’t think that an actual diagnosis wouldn’t do you any good.* (Gary/M/53/7)

Despite being certain that he was autistic and being unhappy about not receiving a referral he chose not to go against the doctor’s opinion. However, Gary returned to a different GP four years later with worsening mental health. In his eyes he experienced an unnecessary four-year delay in ‘knowing’ about his autism.

Participants reported the fact that medical professionals in other sectors had also been dismissive or negative in their attitude towards the request for a diagnostic test. In some cases, they had even actively attempted to discourage it. Walter had been informed by a psychiatrist nine years before his diagnosis that he had Asperger’s syndrome. However, he was not given any further information on how to pursue an official diagnosis or indeed what that term meant. Due to the fact he placed great trust in professionals, he hadn’t pursued further information. He trusted that the psychiatrist would have given him more information about Asperger’s syndrome if it was important. Some years later Walter mentioned Asperger’s syndrome to a psychologist who informed Walter that seeking out a diagnosis would be detrimental to him. She believed that giving himself a label could be very damaging.

> *I’ve been told by a psychologist you’re giving yourself a label and that can be very damaging. And I said ‘No, if you’ve got Asperger’s and you get the label of Asperger’s, you know what you’re dealing with. If you don’t get the label, it’s still there, it just doesn’t have a label.* (Walter/M/57/8)

Although Walter clearly did not agree with the psychologist’s opinion, he was not able to be firm in his request and he did not pursue a diagnosis any further at this point. Walter was eventually referred for diagnosis nine years after it was initially mentioned to him. A therapist from a Cognitive Behavioural Therapy course he was attending identified potentially autistic characteristics and referred him on for a diagnosis.

Indeed, several of the participants reported how they had been told by healthcare professionals that there was very little merit in obtaining a diagnosis and had discouraged them from seeking one. Sophia worked daily with information about the autistic experience and therefore felt certain that she was autistic. She asked the opinion of a psychotherapist (four years before her official diagnosis):

> *She [psychotherapist] looked into it for me and came back and said no the NHS (National Health Service) doesn't really test people at your sort of stage of life (48 at the time) because there is very little thought about there being a benefit to a diagnosis you've come this far as it were, so she even spoke to a colleague and the colleague said really not worth it so nothing happened.* (Sophia/F/52/1)

She subsequently started a new job and had a manager who had knowledge of autism. She shared her suspicions with the manager who validated them. She went to her GP who blocked her from obtaining a referral for diagnosis, the GP told her that the NHS would not support a diagnosis at her age. Sophia felt that it was important that she 'knew' so she went on pay for a private diagnosis. This was four years after she initially suspected that she might be autistic.

Yvette had worked supporting autistic people for over 25 years. After experiencing difficulties in work and doing some self-reflection she recognised traits in herself and mentioned it during counselling. Her counsellor discouraged her from seeking a formal diagnosis. Some years later there were some significant changes in Yvette's work, which caused her problems. At this point Yvette decided that a diagnosis would help her. She worked in an autism charity and so was well acquainted with the difficulties people experienced when trying to gain a diagnosis referral. This combined with the previous reaction she had from her counsellor led her to decide to borrow the money from a friend to pay for a diagnosis privately. This was five years after initially recognising autistic traits in herself and raising her concerns with the counsellor.

All these participants' requests for a diagnosis were dismissed by healthcare professionals. The healthcare professionals did not seem to have any insight into the fact that 'knowing' and learning about their neurodiversity would be incredibly beneficial for participants. Instead, they were left feeling frustrated, ignored and their opinions devalued.

7.1.5 Believability

In chapter six it was noted that participants did not naturally express distress or pain in a typical way. The matter of fact way in which some participants reported their experiences, led to believability issues with professionals when requesting a referral for diagnosis. Participants felt that healthcare professionals did not believe their accounts or value their personal judgement and assessment of their experiences. Amy's GP was against a diagnostic referral and did not believe Amy was autistic. Amy was very knowledgeable about autism as her daughter was autistic. As such she had undertaken significant in-depth research into autistic experiences. She also volunteered at an autism charity. Despite her extensive knowledge and experience the GP did not value her judgement. Amy reported having a ten-year battle with her GP. He believed that she was not autistic but depressed and that a diagnosis would not be of any benefit anyway. After Amy had been denied a diagnostic referral many times, she concluded that she would have to start '*ticking their* [GP] *boxes and playing their games'*(Amy/F/52/4) in order to get a diagnostic assessment. This process consisted of complying with various other recommendations that were made by the GP. One such recommendation was attending a stress management course. Amy reported that this course had been extremely inappropriate and had actually exacerbated her stress and anxiety. Amy was desperate for a diagnosis and so followed the GP's inappropriate advice for several years. It was only when Amy began to have suicidal thoughts that she was eventually supported by her GP to self-refer for diagnosis. This was ten years after her first request.

Participants had often done a significant amount of research regarding autism prior to approaching their GP, but this often was not valued. Theo had felt certain that he fitted the diagnostic profile for Asperger's syndrome after hearing a radio programme that described autistic experience. He did extensive research which he felt supported the fact he was autistic. He spoke with his GP, shared his thoughts, and requested a referral to diagnosis. However, the GP did not agree and instead he was referred to counselling for general anxiety disorder. Despite Theo's best efforts, the counselling sessions did not assist him. Eventually the counsellor referred him through to the local Asperger's team who agreed that he should be formally assessed. This was five years after first suspecting he could be autistic.

It was noted by the participants in my study, that when approaching professionals for help they did not feel 'believed'. Professionals questioned their autism knowledge and personal judgement. This left participants feeling frustrated, undermined and alone. These barriers to diagnosis meant there were significant periods of time between 'discovering autism' and diagnosis (1.5-10 years, mean 4. SD. 2.64). In this time participants reported worsening self-esteem and mental health. Participants experienced a lack of understanding or empathy amongst professionals they encountered and there seemed to be little knowledge of the potential personal value and benefits of obtaining a diagnosis. Indeed, participants felt there was a lack of awareness that a better personal understanding of themselves through diagnosis would benefit their wellbeing.

7.1.6 The Diagnostic Process

Once participants got to the stage of diagnostic testing, all except Walter and James felt certain that they were autistic. This was because of the extensive knowledge about autism they had gathered pre-diagnosis. There was great anticipation of the diagnostic test and there was a common feeling amongst participants that they may finally gain an explanation for their 'difference'.

Participants described the diagnostic process itself in different ways. Some found the process very helpful. They thought that because their family had been involved in the process the family members had gained a better understanding of them. For example, James found the fact that his mother and sister were involved to be beneficial, as it helped explain their previous relationship and the difficulties that they experienced.

> *Since my mum was part of the assessment process, I was grateful that we both realised that all the years of misunderstanding we had, wasn't anybody's fault: I hadn't deliberately tried to be annoying, the problem was about communication.* (James/M/62/8)

Walter also found the fact that his sister was involved in the process to be positive. He reported that she realised that he had not been deliberately awkward in past problematic family situations. It was that autism had a fundamental impact on the way he reacted in certain situations.

> *So she [sister] had memories of me at times being awkward and maybe she thought I'd been deliberately so and I can see why some of those things of being deliberately*

> *awkward and this, that and the other and then she realised from what she was told, oh no it was nothing like that. He could not help this. It was his way of managing stress or anxiety or whatever, so it gave her an insight into how difficult it had been for me and that really did upset her.* (Walter/M/57/8)

The diagnostic experience itself was not always positive. Amy had found the professionals involved incredibly patronising and the process had a negative impact on her confidence and wellbeing. Since Amy had become proficient at camouflaging her autistic traits and that masking was such an automatic way for her to present herself, the diagnostic process was difficult. It took four different appointments instead of the planned three. She explained how she had been asked to make up a social story using children's toys. She was very annoyed because she felt this was unsuitable and inappropriate for adults. Her strong feelings about this caused her to drop her guard and let her true feelings and true self show. She reported that this had the effect of assisting in the diagnostic process as the panel were able to now see her true experience.

> *I told them, you're just taking the piss now. I'm a 48-year-old woman and I'm having to sit and play with toys and tell you a story…, can't you think of better tools that aren't so patronising. And then they started ticking boxes then because obviously I'd dropped my guard then…*
>
> *I: So even though you knew you were going for diagnosis you were still being quite polite and almost masking?*
>
> *Yeah and then I realised that wasn't doing me any favours. So I thought no, let them see…Let them see the true me because it's like taking kids to a sweet shop and then saying there's all the sweets but you can't have any of them. You've come so far and you're still having to prove it even though all the people around me who know autism, could see it. And these, because I didn't fit neatly into one of their little boxes.* (Amy/F/52/4)

As illustrated by Amy, sometimes participants were so familiar with hiding their traits and supressing their natural instincts that this became almost unconscious behaviour. Even in the diagnostic test, she still had not permitted herself to act naturally. As a result, it was incredibly difficult for the professionals to gain an accurate picture of her experience.

7.1.7 Delivery of Diagnosis

The diagnostic test results had been communicated in differing ways. They were either communicated by letter or face-to-face. Regardless of the method of delivery there was no post-diagnosis support or information for the newly diagnosed participants, considering the tremendous impact this news would have on their lives.

James was informed that he was autistic, and that autism was a '*non-treatable condition'*. This caused him to block off from learning any more about autism because there was nothing useful, he felt he could do to help live with autism. Therefore, any potential beneficial effect of his diagnosis was limited. As a direct result of the language used, he did not develop any more self-knowledge or made any changes in his life regarding his autism. Eight years post-diagnosis, he still had very little knowledge or understanding about autism despite being a person who enjoys acquiring new knowledge.

> *Oh…when the comment, "non-treatable condition", was made. … it really, I think it was that. It was sort of, ooh, this explains things, and I know how I come across to others — I can see. But the thought of learning… sort of rules that I had to apply, that I didn't really understand, in different situations. Or…I don't like that, you know, the feeling in that…I prefer things to sort of come naturally sort of… if it doesn't seem natural, if I've got to think about a rule…almost that you're not being true.* (James/M/62/8)

Sylvia was informed via letter that she was autistic. As was typical for all the participants she was not offered any support or guidance. She described searching for a course for six years to learn more about herself and her autism. Eventually she had found a course. At the time of interview, she had been to two sessions and she felt that it was very helpful for her.

7.1.8 Post Diagnostic Formal Support and Information

None of the participants were offered any support following their autism diagnosis. They therefore thought that there was not any autism specific support available for them to access independently. Participants largely felt that they '*fell through the gaps'* (Catrina/F/60/6) as they were living independently and apparently coping, so there was no support for them unless they were at crisis point. Catrina explained she thought the only support available would be through mental health services which she felt were not necessarily appropriate for autistic people.

A psychologist suggested to Gary that there would be no point in offering support usually offered to children and younger people because, as an adult, he had developed his own way of coping. At the time of diagnosis Gary was struggling to cope and had a long history of anxiety and depression. He sought a diagnosis in an attempt to gain insight into himself, and to get help to cope with daily living.

> *When I had the diagnosis… she went through the history of Asperger's, went through all the analogies of what Asperger's is and stuff like that. One of the things she said was, if you were a child or you were a lot younger than you actually are, she said, we would coach you in coping skills but because you're the age you are, by now you've developed your own coping skills and whatever we give you, they will just interfere with that so there is no point in us giving you something if you've already developed your own coping skills.* (Gary/M/53/7)

All the people interviewed had sought (and in some cases fought) for a diagnosis as they were seeking an explanation for their feelings of difference. Many persevered through all the barriers to diagnosis as they were at crisis point. They were not coping with certain aspects of life and were seeking some sort of resolution to their struggles. However, none of the participants were offered any support post diagnosis. They were provided with very little/no guidance on how to manage this life changing information.

7.2 Knowing

7.2.1 Reaction to Diagnosis

Post-diagnostic slump

Most of the participants predicted that the diagnostic test would provide an 'official' confirmation of their personal suspicions. As previously discussed, no support or information was provided to guide participants on how to incorporate this information into their lives and many participants floundered post-diagnosis. They described a temporary feeling of elation from being given a suitable explanation for their feelings of 'being different'. The diagnosis meant they felt vindicated after a long battle to get there. However, this turned out to be an anti-climax and participants reported that the diagnosis was quickly followed by a huge *'slump'* (Gary/M/53/7). They struggled to cope adjusting to life with this new information about themselves. Their mental health and wellbeing therefore suffered.

Emma had been convinced that she was autistic but had still been surprised by the effect the diagnosis had actually had on her. Four years post diagnosis she was only just starting to mentally process what it meant:

> *Yeah, there was a lot of different emotions and things to process afterwards. Its only really now that I think that I'm starting to, because I can talk about it now without getting upset which I couldn't do for a long time.* (Emma/F/54/4)

Sheila had suspected that she was autistic ever since her nephew had been diagnosed a few years prior. Despite this, she found the actual diagnostic confirmation a real shock. It took her six years to mentally process the information. She reported a process of denial regarding her diagnosis.

> *I think there was a whole load of denial going on with the diagnosis, to be honest with you. But I think, you know, in this last couple of years or so, very much so reflecting, and thinking, ah yeah, that makes sense. In fact, it's been a huge light bulb moment.* (Sheila/F/50/8)

Grieving

Some participants reported having a feeling of grief after diagnosis. This was derived from wondering what their lives may have been like had they 'known' when they were younger. Ralph was diagnosed aged 59, fourteen years prior to our interview. He felt very sad that his parents did not know about his neurodiversity because this may have helped them understand him better.

> *Well the thing is they just didn't know what was wrong with me, and that's one of the things that I feel very bitter about, I was not able to tell them what I had that made me different.* (Ralph/M/73/14)

Ralph also felt that, if he had known about his neurodiversity earlier, his health would have been better. He would have been able to select employment that was more appropriate for him and he would not have been in and out of work. Instead, he lost the necessary confidence to return to work.

> *Well I probably wouldn't have diabetes and I would know when I lost a job, I'd have got a job where I was under some kind of supervision you know and if I couldn't do one I would've just lost confidence in myself.* (Ralph/M/73/14)

Pre-diagnosis participants had spent years searching for an appropriate solution, treatment or medication that would have provided some relief for what they felt was 'wrong' with them. They had hoped this would 'fix' their problems and make life easier. However, for some, rather than making life easier, receiving a diagnosis confirmed that life would continue to be difficult and that their experiences and struggles would not significantly change.

Emma found it very challenging to process the diagnosis. Although she was happy with her diagnosis at the time of her interview, for the first three years post-diagnosis she struggled:

> *My initial reaction, I suppose, was to think that there was something wrong with me and I was never going to be able to be normal or change things or improve things… I've heard people kick off when you describe it like this, but I would describe it as grieving. That I am in a grieving process for the person that I thought I was and the things I thought I was going to perhaps achieve. People don't seem to like that but that's the only way I can describe it really from my perspective as a grieving process really.* (Emma/F/54/4)

Gary was pleased that he had received confirmation that he was autistic. However, he had a year long period of 'turmoil' post-diagnosis where his mental health suffered. He became badly depressed whilst trying to come to terms with his diagnosis and his new identity.

> *It was a bit mixed; it was nice to have that affirmation that, yes, I did have Asperger's syndrome but then I'd say I was through crisis for about a year of coming to terms with it. I didn't really have, I didn't really feel like I had any support, apart from [spouse], obviously, but I didn't know where to turn for support, I didn't know what to do to get any support and, like I say, for about a year, mentally, I think I was in turmoil.* (Gary/M/53/7)

Positive Reactions

Yvette worked for an autism charity and had been very familiar with the diagnostic process. She described positive feelings following diagnosis and found the news empowering. Diagnosis made her realise that she had beaten adversity to come out as a survivor and it had a positive effect on the low self-esteem, she had been experiencing pre diagnosis:

> *I felt great, 'cause I thought, God, against the odds, look where I am and, you know, what I've done and what I've achieved, you know. So it did, it felt amazing, it felt really good.* (Yvette/F/52/1)

Sophia like other participants also shared Yvette's sense of being a survivor. Gaining insight and knowledge about her neurodiversity allowed her to be more sympathetic when reviewing their past life experiences:

> *I've forgiven myself and I'm a bit awed by what I've managed to achieve in my life, I mean I think now that I know I'm slightly flabbergasted by the fact I've come so far and I'm so well you know yes I mean without wanting to sound fully big headed I've done amazingly well under the circumstances.* (Sophia/F/53/1)

The official diagnosis confirmed and validated their prior experience and feelings and unlocked the door to a state of 'knowing'. Participants referred to positive life-changing consequences as a result of 'knowing'. These are presented here as four different ways of 'knowing': knowing self, knowing expectations, knowing relationships, and knowing their *'tribe'*.

7.2.2 Knowing Self (Forgiveness)

The mechanism of gaining a diagnosis provided participants with additional information about themselves and underlying reasons for their behaviours. Christine felt that diagnosis started to make her past life experience make sense. As a result, she felt that she was able to look on her previous actions a little more sympathetically.

> *Once I got it (diagnosis) I started to put the puzzle pieces together and think this is why I was like that, this is what happened, I can see why I felt that I didn't fit in, I can see why I hated going to parties, hated going to doing this, you've got the popular kids at school and I felt like an outsider, I felt awkward and stuff like that.* (Christine/F/58/6)

As a young man Peter behaved recklessly, drank heavily, and spent significant time later in life ruminating about this and feeling guilty. Peter reported that diagnosis provided him with the knowledge that facilitated a sense of forgiveness for his younger self, not only for behaving badly but his self-perceived under-achievements in life. He was able to reflect on his experiences and to apply a new level of understanding that he had never previously been able to do. This helped tremendously to reduce his negative ruminations and increased his personal wellbeing.

> *…there's a sense of forgiveness. If you continually do stuff that upsets people or then you kind of think, 'oh, I must just be a shit'… whilst being autistic isn't an excuse, it explains it in some ways. And I suppose I'm then in a position to kind of say, well actually, I can stop giving myself a hard time about that because it doesn't matter how hard I tried there, it was never going to be able to do that because it just wasn't. It's just beyond my ability to do.* (Peter/M/55/7)

Certainly, for some participants diagnosis provided solid reasons to explain why things might be more difficult for them than others without autism. This gave them the ability to be more sympathetic of themselves. Confirmation through diagnosis reportedly eased the stress and confusion in participants' lives. Now that they knew they were autistic they had a guide that helped to negotiate the world and understand what situations they may struggle in:

> *On the other hand that I've also after diagnosis I come to accept that it's just difficult for me, and that is ok.* (Theo/M/55/4)

> *It becomes a whole hell of a lot easier to negotiate the world and it becomes a whole hell of a lot easier to identify the bits of the world that are really problematic to negotiate.* (Peter/M/55/7)

7.2.3 Knowing Expectations (Social Comparisons)

Diagnosis gave the participants permission not to judge themselves so harshly and have more realistic expectations of themselves. The diagnosis assisted them in becoming more aware of their individual strengths and weaknesses. There was a realisation for some that it was not fair to compare their own experience with a neurotypical experience. As a result, they reported being kinder to themselves.

> *It's that old quote; judge a goldfish by its ability to climb a tree. So it's going to be shit. I can't do those things. They're not something that it's in me.* (Peter/M/55/7)

Diagnosis also helped participants deal with and accept the more difficult aspects of autistic life, such as constant anxiety. This reportedly made their experiences easier as participants could manage their expectations more appropriately. Sheila found this aspect of gaining a diagnosis reassuring. She now accepted her unique experience as 'her normal' and that made it much easier for her to cope.

> *If you're autistic, you are going to be anxious, and that is your benchmark for the day. And I've always suspected this, actually. But to actually discuss it with a trained counsellor … I found, really helpful, because it's kind of like, for an autistic person, this is normal, and your normal is very, very different from someone who is neurotypical. That in itself is actually, it's very validating.* (Sheila/F/50/8)

7.2.4 Knowing Relationships

Diagnosis provided family members with new information to use, that enabled them to understand participants and their relationship interactions. This was reported to be helpful in improving personal relationships. Sharing their diagnosis and information about autism with significant people in their lives had a positive effect on several participants' relationships. This resulted in the participants experiencing more understanding and tolerance from others about their behaviour.

Emma's experience illustrates this. She found her work life incredibly stressful and by the time she came home in the evening she was mentally and physically exhausted. Therefore, she felt unable to do chores around the house and needed time to relax.

This had previously caused tensions in the relationship with her husband. He was unhappy that he was left to do all the chores without help from Emma. Diagnosis taught Emma and her husband that contending with the demands of camouflaging and coping in a busy office environment was going to make her feel this way. This new knowledge of herself also had the added effect of validating Emma's feelings and reducing her guilt.

> *I don't think he really realised what the implications of it were to be honest, when I first broached the subject with him, he said well if you are then it's a very mild version of it but I think that now that I've got the diagnosis he's done research himself and he understands, we both understand each other a lot better since the diagnosis.* (Emma/F/54/4)

7.2.5 Knowing Tribe

The community network that a diagnosis provided was one of the most positive aspects to be derived from the participants' diagnosis. This was true for all but one of the participants. 'Knowing' that they were autistic enabled them to access a community, to start to communicate and socialise with other autistic people. This addition to participants' lives was a monumental benefit. They reported finally feeling able to communicate and make appropriate social comparisons with people who had similar experiences. As a result, they felt empowered.

James describes the fact that pre-diagnosis he preferred his own company. He found an immense improvement in his life after his diagnosis despite finding out very little information about autism. The improvements came from having a group of people who he enjoys spending time with and where he feels comfortable. He spent time with a local informal social group. His attendance was not about seeking out any more information about autism, but he found it comforting to have a peer group that accepted him and that were 'like him'. For the first time in his life he had found a social setting where he felt at ease and was accepted;

> *…now that I've met others (autistic people), I prefer, you know, their company… because I feel relaxed…cause we seem to understand each other. Everything from sense of humour through to, you know…we accept things, apparently, I never was aware of; things like a slow response and things like that. We're more accepting of things like that between ourselves.* (James/M/62/8)

Socialising with other autistic people post-diagnosis had, therefore, given some participants a social life that they had previously never experienced. This seemingly minimised feelings of isolation, increased participants self-esteem and promoted wellbeing.

> *I find that with other people with Asperger's I can socialise relatively easily, something that I otherwise don't do, so I now have a regular event once a week, I meet with people in the pub over a beer, or coffee, or tea, and that kind of social life I haven't had for the past 10 years.* (Theo/M/55/4)

A number of participants commented that they found it much easier to communicate with other autistic people than neurotypical people. Theo explains why he thought this was:

> *It's a difference when I meet with other people in my group with Asperger's I don't have this feeling of depletion afterwards, its less exhausting, but it's probably because we tend to communicate in a different style you know in such a group with one another. It's still a group, but it's much less of fast dialogue with people exchanging, but it's a smaller succession of monologues, and ok if you keep quiet for an hour without anybody being concerned, or about what is wrong with you, and that really makes a lot of difference.* (Theo/M/55/4)

The participants did not have a full understanding of why it felt much easier to have face-to-face communication with autistic people than neurotypical people. Emma thought that it might be because other autistic people were less judgemental and more understanding of their communication differences:

> *Obviously, there are different personalities within autistic people, same as there is within anybody but I think there is less judging going on because they all already know the difficulties that the other people are coping with. That's how I've interpreted it, I could be wrong. You come across another autistic person and they get you straight away, they understand, they don't judge you, then it's quite a positive experience really, you can just be yourselves.* (Emma/F/54/4)

The social contact did not necessarily have to be face to face to have beneficial effects and promote wellbeing. Access to the internet had been invaluable for many of the participants as they used the online community to talk to other autistic people. They found this to be life changing. They reported that it is comforting to know that other people behave in a similar way and share similar experiences. Those who wished, were able to explore this virtual autistic community and gain information from the safety of their own home, on their terms and relatively anonymously. The fact that the information that they gained was on their own terms was key; they could engage as much as they wanted. It provided them with the opportunity to gain genuine advice and support from people 'in the same boat'. In Emma's case she was able to start virtual groups of her own. She set up a social media group for autistic women after her diagnosis. She reported not really having many friends, which she was not unhappy about because she could receive personal support and validation from this virtual group.

> *"I've never had many friends. I had one friend when the boys were younger, that's it really. I was going to say I've never felt lonely, I do feel lonely occasionally but most of the time I'm quite happy, especially now after my diagnosis, I'm quite happy to not have close friends if you like. It's not a problem that I haven't got friends but sometimes it would be nice to just have somebody to go out and spend time with. …I've actually got a group on Facebook that I started for women with autism and it turned into this, it was meant to just be for UK women but it's kind of like everybody is joining, there's about 1500 people. It's kind of a support group, I suppose for people, if they've got a problem and they want to ask for help or suggestions, they just post in there and people help, try and give them information or answers.* (Emma/F/54/4)

Participants also stated that they benefitted from knowing that there were other people like them. People with whom they could share their experiences without fearing judgement. After a life spent feeling 'different', suddenly feeling 'sameness' was reported to be novel and comforting experience. Having a community of people that had similar life experiences provided support, advice, and information and this was highly valued by most of the participants. They reported turning to these groups to gain advice for aspects of life they struggled with. They no longer felt alone in their difference.

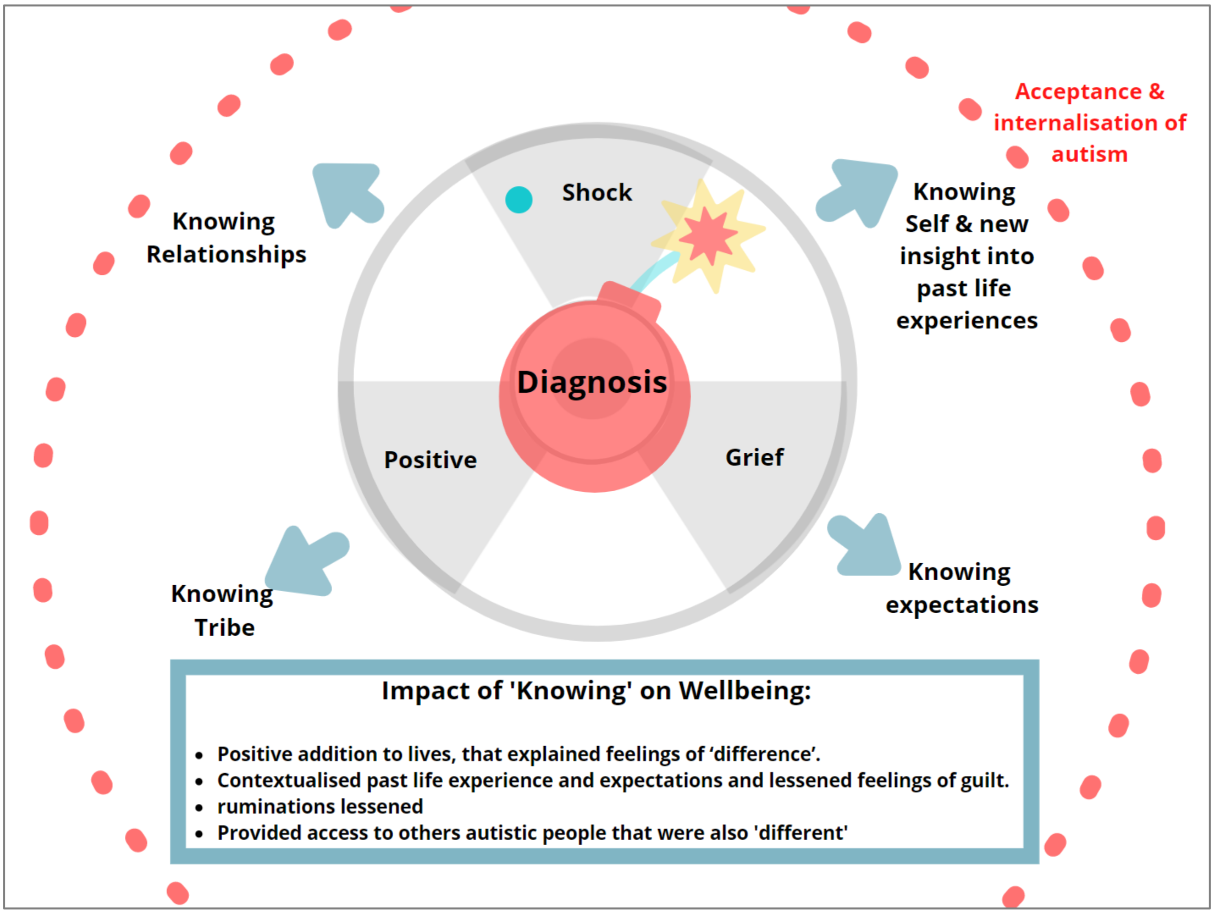
7.3 Summary

Although all the participants had varying mental health problems and were struggling to cope with life, the professionals they approached to gain access to a diagnostic test generally felt that there would be no benefit in them gaining a diagnosis at their later stage of life. Many participants experienced believability issues and a lack of insight by professionals to the personal value and benefit a diagnosis could bring. These factors resulted in long delays and further negatively impacted on their wellbeing.

The majority (13) of participants strongly suspected that they were autistic, and in many cases, they had fought to gain access to diagnostic services, however, gaining a diagnosis was still a bombshell. None of the participants were offered post diagnostic support. For many there was a period of adjustment and for some emotional turmoil before they could truly say that it was a positive addition to their self-knowledge. Some participants experienced prolonged periods of anxiety and depression as they struggled to come to terms with their new identity.

Figure six provides a diagrammatical representation of the effect of gaining an autism diagnosis. It displays the varied reactions to diagnosis by participants, of shock and grief while some participants instantly felt it was a positive addition to their lives. It shows how diagnosis led to participants knowing themselves better and provided insight to past life experiences and enabled them to be more sympathetic and forgiving in their reflections. Knowledge of relationships provided information on the interactions made in the close relationships in their lives. In some cases, this helped significant others to be more understanding of their behaviours and needs. Knowing expectations gave participants the knowledge that it was not fair to compare their own experiences with the experiences of neurotypical others as they now knew their experiences would be different, leading to less self-blame. Knowing their ‘tribe’ and therefore knowing that they could find sameness in their ‘difference’ was overwhelmingly positive as they found much comfort in knowing that there were other people that were ‘different’ like them.

Figure six: Impact of 'Knowing' on Wellbeing



Impact of 'Knowing' on Wellbeing:

- Positive addition to lives, that explained feelings of 'difference'.
- Contextualised past life experience and expectations and lessened feelings of guilt.
- ruminations lessened
- Provided access to others autistic people that were also 'different'

All participants felt that they finally had an answer that adequately explained their feelings of 'difference'. The increased self-knowledge and awareness that came with diagnosis (even though for most it took some time to accept) was ultimately useful for all the participants and their feelings are summarised by Sheila:

> *I think knowing what you are is really helpful… and knowing that you can go forward with it, and it doesn't have to be awful, even though there are times when it is difficult. (Sheila/F/50/8)*

Having considered the factors in the phase of 'knowing', in chapter eight, I will discuss and present the grounded theory 'the thriving cycle'. The theory explains how the data shows that some participants move forward from 'knowing' and embark on a further journey of self-discovery to develop what I have conceptualised as a 'thriving autistic identity'.

8 Chapter Eight: ‘Surviving’ to ‘Thriving’

> *I haven’t just survived; I now thrive and embrace the strengths that autism gives me.* (Sheila/F/50/8)

In the previous chapter, I discussed the similarity of life experiences that participants shared during the diagnostic process and how they came to be in a state of ‘knowing’. I discussed the reasons that ‘knowing’ about their neurodiversity had a beneficial impact for all the participants’ lives and increased their personal wellbeing. In this chapter, I present the theory: ‘the thriving cycle’. The theory draws on differences between participants after the period of ‘knowing’. This theory identifies that some participants are observed as thriving, whilst others merely ‘survive’.

8.1 Emergence of ‘Thriving’ Autistic Identity: The ‘Thriving’ Cycle

Participants approached diagnosis as a final destination, feeling that it would provide answers and resolutions to the lifelong issues they had experienced. Indeed, diagnosis was overwhelmingly positive for all participants. However, I propose that diagnosis alone is liminal. It is merely a waypoint in their journey towards self-discovery. The data indicates that the process beyond diagnosis provides new opportunities that can further promote participants’ wellbeing. Diagnosis did provide participants with answers to many of the lifelong questions they had about themselves. It undoubtedly assisted with meaning-making and enhanced their self-esteem and wellbeing. However, diagnosis on its own offered limited solutions to the difficulties participants experienced in life. For some, however, it provided access to a further journey of self-determined discovery of their autistic selves. The findings support the proposition that it is only if participants embark on this further journey that they can truly ‘thrive’.

The theory proposes that for autistic older people to live well following a diagnosis, the notion of ‘thriving’ is a pivotal experience. These data suggests that there are two causal conditions that are inextricably linked that must be present to ‘thrive’. These are the self-acceptance and internalisation of autism and the exposure to positive constructions of autism. The presence of these two factors activated a continuous ‘‘thriving cycle’’ (see figure seven). The ‘‘thriving cycle’’ is unceasing and consists of autism knowledge acquisition, self-reflection and development of effective personalised life management skills. This generates self-efficacy, increased confidence and feelings of empowerment all of which enhance wellbeing. This is a self-perpetuating cycle; success in the development of effective personalised life management skills in one area motivates participants to continue the cycle and seek improvements in other areas of their lives.

8.2 ‘Thriving’ or ‘Surviving’

Thriving

The theoretical proposal made here is that ‘thriving’ means participants reconceptualised their self-identity and removed the ‘spoiled identity’ and embraced a neurodivergent identity. They felt empowered and able to take control of their wellbeing following their diagnosis. Their personal experiences were validated, and participants had the confidence to manage their lives in a personalised way. As a result, over time, they were able to develop a deep insight into their own experience and better understand fundamental elements that were important to maintain their own personal wellbeing. Participants felt empowered with self-efficacy and the development of proactive life management skills which enhanced wellbeing.

Crucially the participants embarked on this journey towards a thriving autistic identity at differing times. It tended **not** to be directly after diagnosis. As discussed, in chapter seven many participants experienced a period of emotional turmoil post-diagnosis and it was not until they accepted and internalised their autism and were exposed to positive constructions of autism that they started the journey. This was often some years post-diagnosis.

Surviving

According to this theory, those participants who did not ‘thrive’ were observed merely to ‘survive’ following their autism diagnosis. For them ‘surviving’ meant they remained in a state of ‘knowing’ and enjoyed all the benefits that finally ‘knowing’ brought. However, the lives for these participants did not alter significantly after diagnosis and they still held the ‘spoiled identity’. However, ‘knowing’ was hugely beneficial for them and helped to understand past life experiences. It was also helpful when explaining their experiences to others. To finally have a ‘label’ helped outsiders understand participants’ experience which enabled provision of reasonable adjustments or facilitated others being more accommodating of their needs/difference. However, ‘surviving’ participants did not move towards thriving, and the deeper understanding of their autism that this engendered. The participants that ‘survived’ settled for life as it was and focused on the barriers that they perceived autism to create in their lives. Diagnosis was used as an explanation of their perceived failings and they saw autism as a deficit, an illness, or as something that was fundamentally ‘wrong’ with them that they were powerless to alter. Surviving participants felt incapable of creating significant change in their lives and tended to live in a firefighting mode with significant peaks and troughs of emotion. They lived solitary lives and mainly used strategies like avoidance to cope.

Those who were ‘surviving’ saw their autism as something that was external from themselves. Whilst they accepted their diagnosis as a reasonable explanation of their ‘difference’, they did not accept themselves. They still viewed themselves as broken and deficient. Although they were in contact with the autistic community, they had not opened their mindset to the possibility that autism need not be an insurmountable barrier to making positive changes in their lives. Contact with the autistic community was for companionship and not for knowledge acquisition.

8.3 Theoretical Propositions

For older autistic people to thrive and live well after an autism diagnosis, support needs to be provided to facilitate three things to occur.

In order to thrive and live well, autistic older people:

1. accept and internalise their autism. (this often occurred several years post diagnosis)
2. are exposed to positive constructions of autism.
3. engage in a ‘thriving cycle’: an unending cyclical strategy of in-depth autism knowledge acquisition and self-reflection, which promotes the development of effective personalised life management skills.

8.3.1 Acceptance and Internalisation of Autism

Theoretical proposition 1: In order to thrive and live well autistic older people accept and internalise their autism.

The thriving participants had a distinctly different view of their autism in comparison to the surviving participants. They had accepted and internalised their autism. These two factors are inextricably linked as acceptance promotes the internalisation of autism and vice versa. Thriving participants saw autism as a part of themselves and they viewed their neurology as different but not deficient.

> *It is just this idea that you know a person with autism. I'm a person with a bag. I put the bag down, and I'm no longer a person with a bag. I am not going to put my autism down… because it's who I am.* (Peter/M/55/7)
>
> *It becomes part of you* (Sheila/F/50/8)

Most thriving participants experienced acceptance in their lives from significant others such as husbands and partners. They did not feel perceived by these people as 'disabled' but as unique people who had a non-typical life experience. This acceptance of their uniqueness assisted participants in accepting themselves. It provided a solid foundation to explore their autistic identity.

> *He's [husband] a massive support…He is. I mean, all this has been a massive learning curve, because for the first, what, I don't know…fifteen, sixteen years of our marriage, I always had mental health problems. But, we didn't have any idea it was autism at the root of it…he wasn't surprised. But he's always seen me as a person, so… But, you know, he's very up to learning about it, and sort of like, you know, he's accommodating.* (Sheila/F/50/8)
>
> *I have somebody that accepts me for who I am. Freed me. It freed me as a person and allowed me to do things and experience things I never thought I could, so when it comes to my life [partner name] was a pivotal, was everything.* (Peter/M/49/4)

Thriving participants did not view their autism as an ailment/deficit, but as a difference. This distinction was fundamental to participants' self-acceptance. It enabled them to acknowledge that their neurodiversity was problematic in their lives, but not because they are disabled by it. Instead, they felt that their problems were derived from the fact that society was not accepting of difference, which caused difficulties and miscommunications within their encounters with others, something that they had learned to accept.

> *I cope with it very much by acceptance it's the only thing I can do. What can you do? I accept. … acceptance is the only way to deal with these things.* (Sophia/F/53/1)

Acceptance and better understanding of problematic situations in their lives and the anticipation of their occurrence, minimised self-blame regarding these situations and therefore increased self-esteem. There was a realisation that they did not necessarily speak the same social language as others and therefore it could be reasonably anticipated that there would be communication problems:

> *You know what, you might have difficulties with that, but do you know what that's not the end of the world, you're not a failure, you can do lots of things and you know just because that person there doesn't think [the same way as you do], well they're a dickhead!* (Peter/M/55/7)

Acceptance enabled participants to be more forgiving of themselves and the miscommunications they experienced. Sophia found that once she accepted that her behaviour was different and that at times, she would upset others, she resolved to stop worrying about it and this provided a great deal of comfort:

> *When I was beginning to accept myself … my biggest wish was I wish I knew how to stop doing this [upsetting people] but if I don't know it how I can stop doing it and I never will be able to, so I said to myself come on Sophia you've just got to accept yourself [laughs] just accept it, I'm a great believer in that. Have you come across the serenity prayer? It's the thing they use in America with AA the alcoholics and all of that sort of thing, they chant this chant at the end of their sessions which actually makes a hell of a lot of sense to me and has been really supportive to me on the way along. What they say is 'Grant me the Serenity to accept the things I cannot change; Courage to change the things I can; and the Wisdom to know the difference'. … it's been something I can put myself back onto when I was feeling particularly morbid, that hang on a minute what can I change, what can't I change so now you've done everything you can, get over it.* (Sophia/F/53/1)

Some thriving participants remained in a state of 'knowing' for a significant period of time post-diagnosis. The data indicates that the process beyond diagnosis provides new opportunities that might promote or inhibit wellbeing merely 'surviving' before they were able to move onto 'thriving'. Sheila for example was diagnosed for six years before she stopped denying her diagnosis and started to internalise it and accept herself:

> *It has taken me the last few years to come to terms with this diagnostic bombshell, gain understanding and start moving through a position of acceptance and now, celebration of my particular difference…I think I'm becoming much more aware of my autism. But I'm also learning to befriend it and accommodate it more, and actually it gives me more strength in some ways now.* (Sheila/F/50/8)

The thriving participants did not view their autism as a barrier to success or change in their lives. Self-acceptance and internalisation of autism encouraged thriving participants to be more aware of their autism. This combined with the exposure of positive constructions of autism enabled them to have a positive mindset and be open to opportunities for change and improvement in their lives.

8.3.2 Positive Constructions of Autism.

Theoretical proposition 2: In order to thrive and live well autistic older people are exposed to positive constructions of autism.

All thriving participants were exposed to positive constructions of autism. Positive constructions of autism highlight the positive aspects of their neurodiversity rather than focusing on the negative and deficit model. These positive constructions came from various avenues, through personal relationship support, social media, literature and internet interactions. Most of which were from the voices of the autistic community. Hearing the accounts of other autistic people validated their own experiences. It gave participants confidence and permission to be themselves:

> *It's hard but often it takes somebody from the same place [being autistic], coming with a similar level of understanding to say, do you know what, you don't have to listen to them. You don't have to listen to the educationalists, you don't have to listen to doctors, you don't have to listen to psychiatrists or psychologists. You just be you…We don't have to leave our homes but we have friends, we have people online who we talk to who we can get support from, they might be in Bangladesh, they might be in Sydney, Australia, they might be in Ottawa, Canada, they might be in Rio de Janeiro and 4, 5, 6 people can be having a conversation all over the globe about things that they experience themselves and the commonalities that we have. Well once you start meeting other people, you're less of a freak…. And you gain the confidence.* (Peter/M/55/7)

This validation quite often came from other people, perhaps unknown to the participants, via social media, the internet, or social groups. Hearing others had experiences that were similar to their own was reassuring and assisted in contextualising their own experience.

> *To be brought into contact with other people with a diagnosis, that is very valuable because comparing experiences helps me to put my own experience into context.* (Theo/M/53/4)

Social media played a large part in this process for many of the participants.

> *It's exciting isn't it I mean Twitter has been revelatory for me because it allows me to find out how other people are beginning to realise. I'm so far from alone with being a late diagnosed autistic you know there's so many of us out there. We all have different opinions and some of them I could definitely swat around the head [laughs] but then that's us that's the bunch that I'm a part of. They're very varied diagnosed people with very strong opinions.* (Sophia/F/53/1)

Engagement with other autistic people through social media gave some participants an unexpected community and a reciprocal process to give and provide support for others:

> *… I think that's the biggest positive I've got from being on the internet groups, is that knowledge that there are other people out there like me.* (Emma/F/54/4)

The constructions of autism that the thriving group chose to engage with were mainly derived from the autistic community: from first-hand knowledge of autism. This was distinctly different to when participants initially discovered autism, and whilst they were going through the diagnostic process. The constructions of autism that they were exposed to then focused on deficits, impairments and barriers which is typical of diagnostic language. Although they still referred to the knowledge from these sources, they had moved to being more reflective and influenced by positive and empowering personal stories and experiences from the autistic community themselves. This was reflected in the use of language of the participants. Those who were survivors described autism in terms of deficit led focus whereas the 'thrivers' talked with more positive language.

All participants found comfort in diagnosis as it gave them the knowledge that there were other people like them who were 'different'. However, the thriving group went on to actively use the experiences of others to examine and better understand their own.

> *A positive thing was interacting with other people having a form of recognition of what is different about me, and so that I can build upon this for my own research.* (Theo/M/53/4)

Having positive constructions of autism from people with lived experiences was beneficial. Hearing accounts from others that were similar to their own was helpful for the participants and validated their own personal feelings and experiences. It falsified the perceived barriers that participants had previously thought that being autistic created. It opened their mindset to feeling that improvements in life were possible and gave them a thirst for further autism knowledge acquisition.

8.3.3 The ‘Thriving Cycle’

Autism Knowledge Acquisition, Self-Reflection and Development of Effective Personalised Life Management Skills:

Theoretical Proposition 3: In order to thrive and live well autistic older people engage in a cyclical strategy of in-depth autism knowledge acquisition and self-reflection that promotes the development of personalised life management skills.

The ‘thriving cycle’ was initially naturally and unconsciously adopted by participants. Internalisation and self-acceptance coupled with exposure to positive constructions of autism sparked curiosity and a deep interest in autism. It led to in-depth research which in turn naturally led to self-reflection and an opportunity to adjust their lives based on this newly acquired knowledge. Participants experienced success and developed effective life management strategies which had a positive impact on their daily lives. This gave them feelings of self-efficacy and increased confidence and feelings of empowerment and thus they were motivated to continue the ‘‘thriving cycle’’. They continually actively used this to enhance their life experiences and wellbeing.

Figure seven: Surviving to Thriving

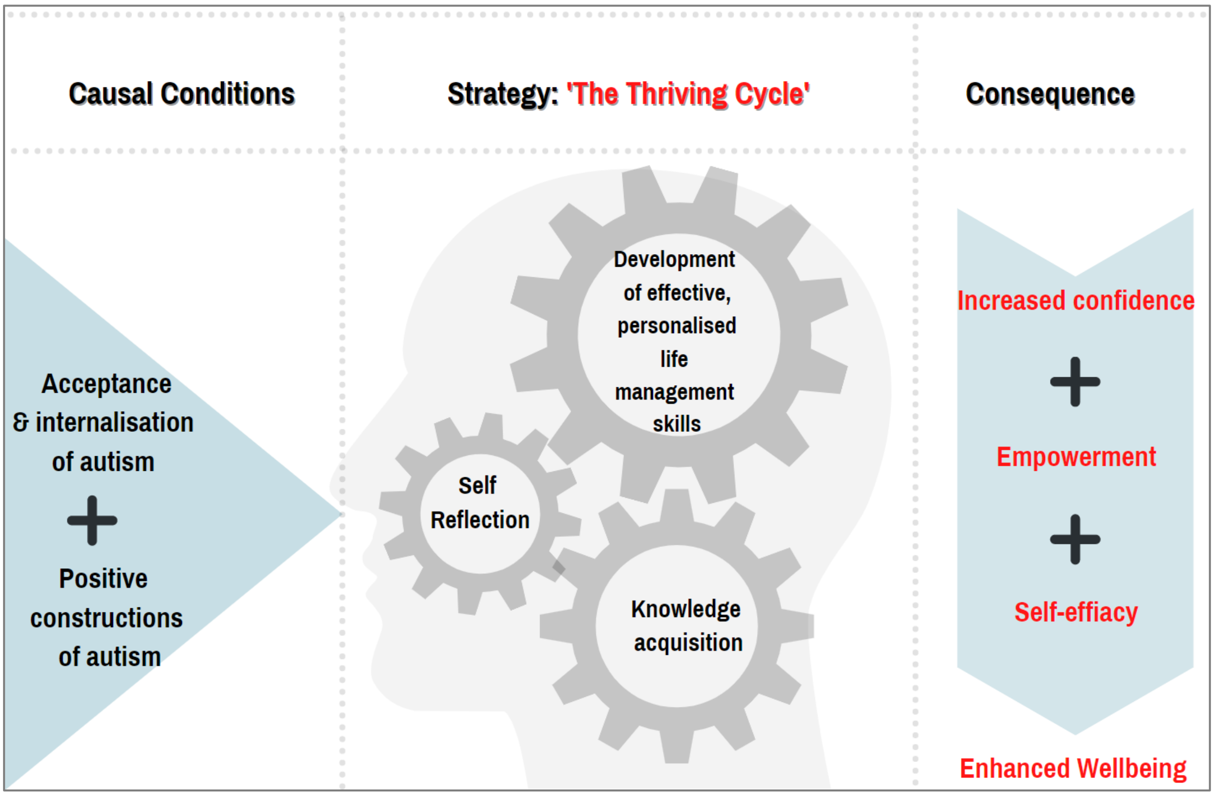


Figure seven displays a visual representation of how thriving participants engaged in the ‘thriving cycle’. The two causal conditions that permitted access to the cycle were the acceptance and internalisation of their autism combined with being exposed to positive constructions of autism. This led to the strategy of autism knowledge acquisition and engaging in self-reflection which assisted participants in understanding facets of their life experiences that they previously struggled to understand. They were therefore able to develop effective personalised life management skills that increased their confidence, gave them feelings of empowerment and self-efficacy which enhanced their wellbeing.

8.4 Life with a Thriving Autistic Identity

Through the ‘thriving cycle’ participants felt empowered. They were no longer merely passengers in life (surviving), they felt able to take control and drive their lives in the direction most suitable for their own personal needs and wellbeing and thrived as a result.

‘Thriving’ participants had a much-improved self-image than those participants that were ‘surviving’. They felt that their life experiences were validated by their own understanding. They had good self-knowledge and knew the importance of affording themselves time for self-care. They also did not directly compare themselves to the experiences and achievements of the neurotypical population. Their anticipation that their experience would be different created more balance and self-acceptance.

Thriving participants felt empowered by their knowledge. They had moved away from a life of just coping and surviving in a fire-fighting type process. They now lived by actively developing personal life management skills to cope based on their knowledge acquisition, experiences, and self-reflection. They still experienced difficulties and struggles in life, but their enhanced self-knowledge meant that they were better equipped to manage them. They were more able to identify triggers that may induce anxiety and were prepared with strategies and plans in place for times of crisis. The effective development of these strategies further contributed to the feeling of self-efficacy and empowerment. As a result, ‘thriving’ participants were more likely to be able to advocate for themselves and request reasonable adjustments from other people based on their neurodiversity and personal needs. They felt better equipped to manage their own physical and mental wellbeing.

8.5 Summary

This chapter presents the distinction between ‘surviving’ and ‘thriving’ participants. It outlines the beneficial impact on wellbeing that ‘thriving’ participants enjoy. ‘The thriving cycle’ describes the contributor factors that are required to start on the path towards thriving. The acceptance and internalisation of autism and exposure to positive constructions of autism are inextricably linked and fundamentally important to enable the journey towards thriving. The cyclical process that thriving participants undergo increases confidence and provides feelings of empowerment and self-efficacy which creates enhanced wellbeing.

The four findings chapters have presented the heterogeneous experiences of the participants through the individualised pen portraits chapter. The ‘not knowing’ chapter provided illustration of the confusing and negative experiences living without knowledge of their autism. The ‘gaining knowledge and knowing’ chapter provided evidence of the process of finally finding out about their autism and the impact it had on their lives. Finally, this chapter has illustrated a distinction in the wellbeing between participants, the contributory factors and process that assisted some participants to thrive. This highlighted the fundamental importance of thriving to participants wellbeing. In the next chapter I discuss the findings in relation to other research and highlight the unique contribution to knowledge made by this study.

9 Chapter Nine: Discussion

9.1 Introduction

This is the first study to fully explore experiential accounts of the wellbeing of older autistic adults in the UK. It provides an important platform for their voice which has thus far been neglected in the academic literature (Bolte, 2014; Mason *et al.* 2022; Milton, 2012; Pellicano *et al*. 2014). This study addresses two gaps in the present evidence base. The first is in relation to the dearth of academic studies focusing on autistic older adults (Mason *et al.* 2022; Mukaetova-Ladinska *et al.* 2012). The second relates to the lack of qualitative research with autistic adults (Bolte, 2014; Milton, 2012; Pellicano *et al*. 2014). This research addresses both these gaps together with reflecting the research priorities identified by the autistic community (Cusack, 2017; Pellicano *et al.* 2014; Wallace *et al.* 2013) and answering calls from leading professionals for research to explore and understand the experiences of older autistic people (Happe, 2020). The study's research question was:

What do older autistic adults feel are the most important factors that assist them in maintaining their own personal physical and mental wellbeing?

9.2 Evaluating the Quality of this Research

9.2.1 Contribution

This is the first study to explore the wellbeing of older autistic adults. This constructivist grounded theory study is a novel piece of research regarding the experience of the fourteen older autistic adults (aged 50+). It makes a significant contribution through the conceptualisation of 'the thriving cycle' and its components presented in chapter eight, along with the foundational evidence presented in chapter six 'not knowing' and chapter seven 'knowing'.

This study is the first to specifically highlight the detrimental impact of 'not knowing' on the wellbeing of older autistic adults. It also emphasises the increased wellbeing gained from 'knowing' with specific novel emphasis on the older population of autistic participants. These factors create new emphasis on the urgent need for improved diagnostic services to assist in identifying 'the lost generation' (Lai & Baron-Cohen, 2015). It is also the first study to highlight the potential crisis point post-diagnosis where participants experienced a period of turmoil and worsening mental health as they were trying to adjust to their diagnosis.

Additionally, to my knowledge, this is the first study to identify the fundamental importance of positive personal conceptualisations of autism. The enormous contribution this makes to wellbeing has implications for diagnosticians and post diagnostic support. Autism should be framed with the concepts and principles outlined in *‘the thriving cycle’* to help assist autistic adults to thrive from the time of diagnosis.

The findings presented are grounded in the data gathered and represent the participants’ experiences of wellbeing. Whilst I am confident that the evidence presented is a clear representation of participants’ experience and grounded in the data collected, it is important that there is evidence provided to enable the reader to assess the quality of the research independently. To this end, prior to discussing the study’s findings in relation to the existing literature, I present a framework that enables evaluation of the quality of the study utilising criteria outlined by Charmaz (2014: 337-338). I discuss the quality of this study by implementing the guiding principles that Charmaz proposes using four criteria for evaluation: credibility, originality, resonance and usefulness. Each component will be discussed in turn with the use of Charmaz’s guiding questions to provide clarity.

9.2.2 Credibility

Box 6: Quality Criteria for Grounded Theory Studies: Credibility. (Charmaz,2014: 337-338).

- Has your research achieved intimate familiarity with the settings or topic?
- Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.
- Have you made a systematic comparison between observations and between categories?
- Do the categories cover a wide range of empirical observations?
- Are there strong logical links between the gathered data and your argument and analysis?
- Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?

The impetus for this research came from my family, professional experience and observation of the autistic experience. It was inspired by a concern for the wellbeing of autistic adults and the lack of support available. Prior to the research commencing I had immersed myself in autistic literature, attended conferences and engaged with online material. This enabled me to be theoretically sensitive when designing the study, as I was able to attune more closely with the autistic experience. As discussed in chapter four, there was very little guidance on how to conduct interviews with autistic people when I started my fieldwork. It was therefore necessary for me to explore the autistic experience on a deeper level and think about the practical arrangements for data generation. This process provided me with awareness of the nuanced experiences of autistic people and undoubtedly enhanced my theoretical sensitivity. The advisory group was essential in this process. They enabled me to check on practical procedural elements of the study, but it also provided the opportunity to gain feedback on whether the study was appropriate and indeed necessary. Implementing the knowledge gleaned prior to data generation enabled me to focus on participant led data generation techniques. It was essential that the wellbeing issues discussed were volunteered by the participants ensuring they were topics that were important to them, rather than responses to specific questioning.

Fourteen older autistic adults were interviewed, eight women and six men. Thirty-five hours of interviews were conducted. Participants were very honest and motivated to share personal stories. The theoretical model is grounded in the thick data provided which was enabled by a considerate approach to the data analysis and use of the strategies outlined by Charmaz (2014) such as theoretical sampling (topic), memoing and constant comparison. It is recognised that the sample size and recruitment may be a limitation to the study, however, I argue the sample size enabled deep focus of individual experiences and prevented the personal experiences from being diluted. However, the resultant theory is sufficiently abstract to have resonance with a wider autistic population.

Constant comparison was aided by the use of memos (both written and audio) to make links between categories. This was done between participants and within and between categories. This process was supported by my intense familiarity with the data and the use of NVivo which meant that I could easily and readily access previous data when I identified new categories. These categories were validated through member checking with participants and informal discussions with the advisory group to ensure that I was not misinterpreting that data, conscious all the time of the double empathy problem (Milton, 2012). Combined with conversations with my supervisory team and colleagues I thoroughly ensured that I explored the data from multiple perspectives. Indeed, significant time was spent immersed in the data and drafting and redrafting the findings. This process continued until I felt content that they were representative of comparison between categories and that they captured participants' experiences covering several decades. Many verbatim quotations from the participants were included within the thesis, together with individual pen portraits. This shaped the finding chapters for the reader and aimed to provide a sense of the personal experiences of the participants.

9.2.3 Originality

Box 7: Quality Criteria for Grounded Theory Studies: Originality. (Charmaz,2014: 337-338).

- Are your categories fresh? Do they offer new insight?
- Does your analysis provide a new conceptual rendering of the data?
- What is the social and theoretical significance of this work?
- How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?

The present study offers new insight by virtue of the fact the topic area is unexplored with this age group. The experiences of these autistic older adults have only been qualitatively explored in three previous studies; Two UK studies focusing on diagnosis through interviews (Stagg & Belcher, 2018) and a survey-based study (Leedham *et al.* 2020) plus an Australian autobiographical study (Lilley *et al.* 2021) none of which focused on wellbeing and mainly concentrate on the impact of diagnosis.

The impetus for focusing this study on older autistic adults was a review that highlighted the dearth of research with this older population (Mukeatova-Ladinska *et al.* 2012). It highlighted that there had been only seven published studies focusing on older autistic adults up to 2011. It was fortuitous that the review by (Mukeatova-Ladinska *et al.* (2012) has been replicated and has been published just prior to my submission (Mason *et al.* 2022). In 2021 there are now 212 articles identified which focus on this population. The most researched areas being cognition, the brain, and genetics. Despite this increase, research focusing on older autistic adults is still limited to just 0.4% of published autism studies within the past decade. This research area continues to be neglected. The size of the general population of older adults in the UK is equivalent to that of children, that in turn means that the older autistic adult population will be equivalent of the autistic children's population, and yet by way of comparison research focused on autistic children accounted for over 35,000 publications in the same period (Mason *et al.* 2022).

This study extends the current knowledge through highlighting risk factors for autistic people both undiagnosed and diagnosed. It highlights the trauma that autistic people experienced living 'not knowing' and how the 'spoiled identity' derived from this period must be considered by support services. It highlights the crisis points and the significant barriers to diagnosis, and the post-diagnostic slump. It also clearly presents the causal conditions needed for autistic people to thrive through the grounded theory of *the thriving cycle*. This provides new conceptual insight into the experience post-diagnosis. The discussion section explores these concepts in depth. This study challenges the assumption that diagnosis alone provides access to enhanced wellbeing. It provides evidence that some people do not thrive post diagnosis and suggests that with support and guidance using the causal condition identified in the thriving cycle that they may be assisted to thrive.

9.2.4 Resonance

Box 8: Quality Criteria for Grounded Theory Studies: Resonance. (Charmaz, 2014: 337-338).

- Do the categories portray the fullness of the studied experience?
- Have you revealed both liminal and unstable taken-for-granted meanings?
- Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?
- Does your grounded theory make sense to your participants or people who share their circumstance?
- Does your analysis offer them deeper insights about their lives and worlds?

The categories were generated from a structured and lengthy process described in chapter four. Categories were defined and then redefined many times. Constant comparative analysis was used along with memoing and using *In vivo* codes within memoing was particularly useful to ensure that categories remained grounded in the data. The raw data was returned to on numerous occasions throughout the analysis, sometimes through rereading the transcripts but other times through listening to the audios. I had an intimate knowledge of the raw data from the initial stages of analysis, and I was able to reflect on previous data if a category emerged in subsequent data. These processes enabled full exploration of the wellbeing of older autistic adults within this project.

The study presents the personal experience of autistic older adults' wellbeing. This is a very broad topic that deliberately was not constrained for the reasons discussed in chapters one and two. It was important that wellbeing issues that were significant to participants were discussed and not what I, as the neurotypical researcher, deemed appropriate for their wellbeing.

The current evidence base largely reports on the illuminative function of diagnosis (which will be discussed later in this chapter). However, this research explores the taken for granted assumption and suggests the beneficial impact of diagnosis to be liminal. The identification of two different groups in terms of wellbeing post-diagnosis suggests that diagnosis alone is not sufficient to significantly enhance wellbeing and move away from the ‘spoiled identity’. A further journey needs to be travelled in order to enjoy further beneficial impact on wellbeing and for participants to thrive. All participants in the present study were grateful of diagnosis and saw it as a positive addition to their lives, but not all thrived post-diagnosis. Indeed, for those that did thrive, this quite often was not immediate and there was a significant delay of several years for many. Regarding the wellbeing derived from diagnosis, one could say that was liminal and it has started to become taken for granted in the literature. This study exposes that diagnosis alone without further action is limited in the positive impact it has on wellbeing.

Within the study the participants discussed many institutions and their connection with them throughout their lives, such as schools, workplaces, and healthcare provision. A constant feature throughout all the institutions was the fact that they were inadequate at recognising, accepting, validating or accommodating participants’ experience. Participants reported believability issues amongst all institutions and the wider community as many of the participants did not fit the stereotyped media portrayal of autism which serves to further emphasise that although awareness of autism amongst general public is better, there continues to be little understanding about the less stereotyped presentation of autism, and it remains very much a hidden difference. There is a great need for widespread education to engender understanding and facilitate wellbeing.

The findings and resultant theory have been tested and checked through numerous avenues with autistic audiences. Initially through member checking with participants, then discussions with my advisory group, and with other autistic people known to me. I then progressed to tentatively using social media to post about aspects of the analysis to gauge resonance. The thriving cycle theory was then presented at an international conference Autistica Research Festival (Kirton, Ryan & Tod, 2021) that has a high proportion of autistic delegates (both researchers and non-researchers). The theory received favourable responses and prompted interesting questions relating to how my theory fits in with other work currently being conducted. I have received confirmation through all these avenues that the grounded theory resonates with autistic people's experiences.

9.2.5 Usefulness

Box 9: Quality Criteria for Grounded Theory Studies: Usefulness. (Charmaz,2014: 337-338).

- Does your analysis offer interpretations that people can use in their everyday worlds?
- Do your analytic categories suggest any generic processes? If so, have you examined these generic processes for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge? How does it contribute to making a better world?

The analysis of the experiential accounts demonstrates how the period of 'not knowing' has made lasting scars on the lives of the participants. One of the most impactful issues within that time was the experience of interpersonal traumas. Participants had been poorly treated because of their hidden difference. They had felt forced to hide and modify themselves due to external pressures to conform. This emphasises the detrimental impact on wellbeing of not being accepted.

It may seem idealist and overly simplified, but it is within the power of every person who reads this to use the presented knowledge to make change in their everyday worlds, by simply accepting people for who they are. Certainly, this is not unique to the autistic population, but the research serves to further highlight the detrimental impact of not being accepted has and emphasises its fundamental importance.

This research and the analysis contained within highlight numerous areas that require further research which will be discussed in greater depth later in this chapter but includes areas of diagnosis (including healthcare professionals' knowledge and training) and post diagnosis support and experience.

The amount this work has contributed to my personal knowledge is difficult to capture within this thesis. I share this knowledge everyday with my contacts. I spread the message of acceptance and understanding of autism. I have already used this knowledge to influence the creation of *The Core Capabilities Framework for Supporting Autistic People* (Department for Health and Social Care, 2019). (see appendix eleven). This is the underpinning framework for the mandatory training of all healthcare professionals in the UK. I was a member of the steering group for the creation of this framework and helped ensure that it was created in line with the principles of positive conceptualisation of autism discovered through this study. I will also use this work as the basis of numerous planned knowledge transfer activities within my University employer to train staff and the health, social care and medical professionals we train (see appendix eleven).

9.2.6 Conclusions of the Evaluation of the Quality of the Research

Having considered the credibility, originality, resonance and usefulness of this study, I feel I have demonstrated how I have ensured the quality of this research through careful use of data generation techniques, sensitive analysis and thorough reporting of the research findings.

The following section will serve to situate the present study in the current research literature and afford the reader the opportunity to make connections, further enabling appraisal of the quality of this contribution to the research area.

9.3 Discussion of Research in Relation to the Current Academic Literature

9.3.1 Key findings

The major contribution of this research is the 'thriving cycle' theory presented in chapter eight. However, the key findings that support the theory development have been condensed below and form the basis for the following sections.

1. Living 'not knowing' has a negative impact on wellbeing
2. Diagnosis is a positive addition to self-knowledge and wellbeing
3. Thriving promotes understanding of self and enhances wellbeing

The following section provides a discussion of how the findings of this study are significant. They provide new understanding of the experience of older autistic adults and provide further depth of understanding to previously published research. I incorporate the qualitative studies included in the literature review in chapter three, along with the additional qualitative studies from the second search of the literature (2016 - February 2022) (see appendix one). Additionally, I also include academic research that has direct relevance to this study's key findings.

9.3.2 Living in a State of 'Not Knowing' has Negative Impact on Wellbeing

Autism is a lifelong condition that affects approximately 1% of the population (BMA, 2021). The diagnosis of autism in adulthood is becoming more common (Jensen *et al*. 2014; Lai & Baron-Cohen, 2015). This is due in part to the widening diagnostic criteria (Brugha *et al*. 2012; Geurts *et al*. 2016), raised public awareness (Lai & Baron-Cohen, 2015) and increased focus on autism in legislation (Autism Act, 2009; Russell *et al.* 2021). The diagnosis of autism in adulthood means living significant parts of their lives 'not knowing'. It is become apparent that there is a sizable 'lost generation' (Lai & Baron-Cohen, 2015) of autistic adults that are living without recognition of the neurodiversity and therefore it is essential that life experiences of the period 'not knowing' are examined.

There is evidence within the present study and much anecdotal evidence to suggest that many healthcare professionals do not understand the benefit of a later life diagnosis of autism (Lewis, 2017). Indeed, some may question why adults in later life require to be identified as autistic, given that they have lived their whole life 'not knowing' and have are now in the mid- to older-age group. The limited available studies on autism in later life tend to focus on the transformational meaning of diagnosis (Leedham *et al.* 2020; Lilley *et al*. 2021; Stagg & Belcher, 2019) rather than how the individual's wellbeing was affected by living for so long 'not knowing'. It is important that this period of participants' lives is not overlooked. It provides essential information to understand participants experiences. In this way emphasis is placed on the importance of adult diagnosis so that support services may be designed that are appropriate to help newly diagnosed autistic adults make sense of their experiences. The following section discusses how the experiential evidence in this research can be used along with the wider evidence base to promote understanding of the negative impact living in a state of 'not knowing' has on autistic people and therefore reinforcing the importance of identifying 'the lost generation' (Lai & Baron-Cohen, 2015).

9.3.3 'A Spoiled Identity'

Participants' interaction with society with their undefined 'difference' had formed a pre-diagnosis self-perception that perpetuated their internally held belief that they could not 'fit in'. That is, they were indeed 'different' and that their difference was not a positive attribute. This is reflective of the reports across the qualitative literature with other demographic populations of autistic people. In their study which focused on autistic women Bargiela *et al.* (2016) found evidence of 'pretending to be normal' (3287) and Milner *et al.* (2019) 'fitting in with the norm' (2393). In autistic adults aged 20-40 Punshon *et al.* (2009:271) found 'not feeling accepted' was a common theme for their participants. Similar themes came from an international survey with young adults 'feeling othered' (Lewis *et al.* 2016:576) and participants diagnosed in mid adulthood reported 'feeling like an alien' (Atherton *et al.* 2021:9) and 'something dark and deeply wrong with me' (Tan, 2017:164). Indeed, this feeling of 'difference' is well reported in online communities and contributed to the name of one of the biggest online communities named 'wrongplanet.net'.

In order to combat this feeling of difference, great efforts were made by some participants to 'fit in' and be 'normal' by artificially learning strategies, mimicking or camouflaging. These strategies have also been found in earlier studies from different aged groups of autistic participants (Bargiela *et al.* 2016; Griffith *et al.* 2012; Hull *et al.* 2017; Huws & Jones, 2008; Muller *et al*. 2008; Portway & Johnson, 2005; Punshon *et al*. 2009). However, what has not been discussed in the previous literature is the externality of this pressure to 'fit in'. This study highlights the external pressure felt by participants to modify themselves to 'fit in'. This is a lifelong experience of pressure starting in early childhood and came from all areas of life including family, school and workplace. Participants experienced well intentioned others, including professionals, socially coaching them, and trying to modify them in order to 'fit in'. Coupled with the myriad of miscommunication experiences and social rejection, which all created a feeling of great pressure to conform and artificially alter the way they acted socially.

These external influences undoubtedly contributed to the already held negative self-narrative of being 'broken' and in need of fixing and further contributed to the belief that their true selves were not acceptable and should be hidden from view.

Individual's social self-concept is in part developed through a reflection of how we are perceived by others (Bulmer, 1986). If a person feels rejected in many areas of life, over a prolonged period of time, then it is logical to assume that they will develop a negative social self-concept. In the present study the participants' accounts suggest that they took on what Goffman (1963) terms as a 'spoiled identity'. Participants' accounts suggest that the period of their lives spent 'not knowing' was fundamental and where key aspects of their identity were formed through their interactions with society and their subsequent self-evaluation. This left them feeling broken and therefore in need of fixing or hiding. Leedham *et al.* (2020) in their qualitative study who examined female experience of receiving a diagnosis in middle to late adulthood found participants reported feeling 'wrong, broken or bad' prior to diagnosis (2020:138). The impact of not fitting in was often social exclusions, some for self-preservation, as being alone was easier and less stressful (Portway & Johnson, 2005; Punshon *et al.* 2009). Many reported having a lack of friends (Muller *et al.* 2008). However, in this study it was noted that being alone was not a problem, it was the external influences such as the pressure to fit in, exclusion and marginalisation that was most problematic to participants self-concept.

9.3.4 Camouflaging[13]

Most of the participants discussed masking or camouflaging their autism to different degrees and throughout their lives, which is also reported elsewhere. Indeed, camouflaging has recently started to be recognised in the literature as a frequent tool used by autistic people to help them navigate the non-autistic world (Bargiela *et al.* 2016; Cage *et al.* 2019; Hull *et al.* 2017). There is evidence to suggest that autistic women engage in camouflaging much more than autistic men. (Bargiela *et al.* 2016;

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[13] The terms masking and camouflaging are often used interchangeably to describe the process of hiding their autistic traits. Here we will use camouflaging as an umbrella term. A definition of *"the employment of specific behavioural and cognitive strategies by autistic people to adapt to or cope within the predominately non-autistic social world"* (Cook *et al*, 2021:1)

Cage, 2019; Hull *et al.* 2017). In the present study there was a distinction between the men and women in terms of camouflaging and the associated feelings about it. Ten of the participants reported camouflaging (two men and two women did not). The men who camouflaged tended to camouflage much less and be more ‘conventional’ in their use of camouflaging. However, the women who camouflaged did so much more frequently and were engaged in ‘conventional’ and ‘relational’ camouflaging. Indeed, gender differences in camouflaging behaviours is supported in the wider literature with autistic women demonstrating higher camouflaging scores in quantitative studies than autistic men (Cassidy *et al*. 2018; Lai *et al*. 2017; Schuck *et al.* 2019). What is novel in the present study is that the women in the study post-diagnosis reflected over decades of their life and recognised how much of their lives they had spent camouflaging. They reported starting to camouflage instinctively and from a very early age. For some it became an almost unconscious lifelong process. As reported in chapter six some of the woman said that the cost of this was confusion in their self-identity. It also reportedly caused problems when seeking assistance from healthcare professionals. In one case the diagnostic interview itself was affected.

The pressure to ‘fit in’ made camouflaging a perceived necessity for some. This was particularly highlighted by the mothers in the present study, as they were terrified that if they did not camouflage that they might be identified as not coping, and they would lose custody of their children. Indeed, the women in the study certainly felt increased external pressure to camouflage and in a different way to the men.

There has been recent interest in camouflaging in the autistic population with a flurry of studies being published. Younger adults were surveyed about their camouflaging experiences in three separate studies (Cage & Troxell-Whitman, 2019; Hull *et al.* 2020; Livingston *et al.* 2020) and through interviews with participants in mid-adulthood by Schneid & Raz (2020) and Raymaker *et al.* (2020). A study focusing on the experience of women was conducted by Bargiela *et al*. 2016. Indeed, the findings of the present study extend this wider literature base. It provides evidence that the role of camouflaging is comparable in the older autistic population with younger populations. The role of camouflaging in autistic women would appear to be magnified in comparison to the male population (Bargiela *et al*. 2016). Indeed, this phenomenon has recently been partly credited for the under-diagnosis of autistic women (Cage & Troxell-Whitman, 2019; Hull *et al.* 2020; Livingston *et al.* 2020; Schneid & Raz (2020).

The findings show the personal consequences of camouflaging and participants highlight how they felt compelled in '*trying to hide from the world'* (Amy/F/48/4) and how this takes an exhausting amount of mental and physical energy (in both 'strategic' and 'intrinsic' camouflaging). All the participants in the present study who used camouflaging acknowledged that it had serious negative personal consequences, which were derived from two main sources. The first was the mental and physical exhaustion caused by camouflaging.

The concept of camouflaging has long been discussed in the wider literature. In his seminal work *Notes on the Management of Spoiled Identity*, Goffman (1963) discussed 'passing' (camouflaging) and outlines the enormous effort that the process requires. Although many of the stigmatised or 'discredited' identities that Goffman referred to are now thankfully more accepted in society. His writing does however resonate with the experiences shared in the present study and emphasise the exhausting amount of effort required by participants to camouflage: Goffman points out how people who camouflage will need to be 'alive to aspects of the social situation which others treat as uncalculated and unattended' (1963:74). Meaning that people who are camouflaging cannot relax in a situation, they need to be alert and ready to calculate their next camouflaged interaction, as new scenarios arise constantly in which they must decipher a correct camouflaged response. Goffman says the person who camouflages has to be a constant 'Scanner of Possibilities' (1963:74) which is exhausting. Goffman goes onto describe what he terms as the 'The Cinderella Syndrome'. This shows how people who camouflage maintain their outward veneer and alludes to the exhausting experience they endure and the essential existence of a 'repair station' (1963:74) where they can rest without having to wear their disguise. In the current study participants 'repair station' was their home which was their safe space, and, in some cases, outsiders were not permitted. It was a place they could be themselves away from the stresses of pretending. This was an essential sanctuary that allowed them to recover. Undiagnosed participants may not have correctly identified the need for 'repair stations' and so may push through without recovering which could lead to meltdown or burnouts. Goffman's description resonates with the experiences of the participants within the study. Camouflaging necessitated a recovery time afterwards where they needed space and time to be alone and recuperate.

A secondary consequence of camouflaging was highlighted in the present study. For some the act of camouflaging further contributed to participants' feeling of low self-esteem as they were not being their true selves. This finding has also been highlighted by Hull *et al*. (2017) in their qualitative study with younger autistic adults. The perceived requirement of 'hiding' their true selves produced negative emotions as it reinforced feelings of being broken and not good enough and produced feelings of dishonesty. Their scrupulous honesty caused them to view 'intrinsic' camouflaging as a false presentation of self (Bargiela *et al*. 2016; Chevallier *et al.* 2012). A novel finding was that there was a difference in the 'conventional' camouflaging in the fact that it was not reported to have the same emotional response. It was equally as physically and mentally exhausting but was not associated with the same negative emotional response.

Despite the double negative consequences of 'relational' camouflaging, female participants continued to engage in this activity as they felt it was a necessary strategy to survive. In some cases, the women in the study had such confused identity, thus making them unable to identify exhausting behaviours associated with this ongoing relational performance. The personal consequences related to camouflaging have also been observed in other studies (Bargiela *et al.* 2016; Hull *et al.* 2017) and has a wider impact as it contributed further to negative self-esteem. Camouflaging might also have a further problematic consequence, although not specifically focused on autism, Newheiser & Barretto (2014) conducted four studies the results of which suggested that there were wider detrimental effects of hiding stigmatised identities. They found that hiding actually reduces feelings of belonging by internally held feelings such as 'felt inauthenticity' which supports the evidence provided in the current study. However, they also highlighted that the process of hiding a stigmatised identity can actually be detected by external observers which promotes feeing of distrust, which also support this study's findings.

The external pressure felt by participants to 'fit in' due to not feeling accepted compels them to take part in harmful camouflaging behaviour. This has been linked to increased self-reported anxiety and stress when compared with non-camouflagers (Cage and Troxell-Whitman 2019; Hull *et al.* 2017) and with suicidal thoughts and behaviours in autistic people (Cassidy *et al.* 2018, 2020). Indeed, a recent study has found some concerning consequences with a connection with poor mental health (Cage *et al.* 2018).

It is hoped that if participants felt accepted, they would no longer feel ‘spoiled’ which would remove the perceived external pressure to hide or ‘fit in’. The need for camouflaging would be diminished and optional camouflaging could take place in the form of ‘conventional’ camouflaging (that does not have the associate negative emotional attachments). The present study supports the wider literature showing that camouflaging is frequently used by autistic people to ‘fit in’ with the neurotypical society (Bargiela *et al.* 2016; Hull *et al.* 2017; Lai *et al.* 2017; Livingston *et al.* 2019). Great time, effort and energy is devoted to this quest. What is crucially important and is highlighted in the present study, is the external pressure being the factor that compelled them to camouflage in order to hide themselves as they did not feel their natural selves would be accepted.

9.3.5 Experience of Interpersonal Trauma

During their interviews regular experiences reported by participants were incidences of interpersonal trauma. Interpersonal trauma include events such as assaults, maltreatment, sexual abuse and bullying and this has been linked to depression (Fowler, 2013). There is growing evidence to suggest that autistic people may be at higher risk of experiencing traumatic events (Reuben *et al.* 2021). The vast amount of interpersonal trauma experienced by participants was largely blamed on themselves. Pre-diagnosis they thought that they were to blame, therefore contributed to negative constructions of self. A catalogue of interpersonal traumas which came in various guises through physical, emotional, and sexual abuse and from differing sources were experienced. This is unfortunately reflective of the wider literature associated with autism and peer victimisation in the younger autistic adults (Shtayermman 2007; Maiano *et al.* 2016). Indeed, there is evidence to suggest that autistic people are at increased risk of experiencing traumatic events (Kerns *et al.* 2015). Incidences of bullying were reported by all participants throughout their lives in school days, their working lives and in other areas of life including from strangers. The negative impact of bullying is well known and the impact on self-identity is also broadly discussed in the general literature, (Takizawa *et al.* 2014). Despite emerging evidence that autistic people would appear to be more vulnerable to lifelong experiences of adverse life events (Humphrey & Hebron, 2015), and that they experience lifelong scars as a result (Costley *et al*. 2017; Rumball *et al*. 2020) there is little exploration of this connection with trauma and mental health in the literature.

A form of interpersonal trauma that was at an alarmingly high rate in the present study was that of sexual assault/abuse within the female participants' experiences. Six out of the eight women interviewed disclosed that they had been affected by this. Participants alluded to the fact they felt that because of the undiagnosed autism they were particularly vulnerable. They often were compliant to try to make themselves more 'likeable' and 'fit in'. This high incidence of sexual abuse unfortunately is mirrored in other qualitative studies: Bargiela *et al*. (2016) nine out of 14 participants and Kock *et al*. (2019). four out of eight participants. These findings are also reported elsewhere (Kanfiszer *et al*. 2017, Lilley *et al*. 2021). Indeed, other studies have published similarly concerning results. Roberts *et al*. (2015) found that women with the highest level of autistic traits reported 1.5 times the prevalence of sexual abuse when compared to the non-autistic participants. This has also been the focus of larger quantitative studies (n=4500) where female autistic participants were three times as likely to be exposed to coercive sexual victimisation, (Gotby *et al*. 2018). When exploring vulnerability in the autistic population Griffith *et al*. (2019) found that autistic adults in a relationship more likely to have been abused by a partner compared to non-autistic adults in relationships. High rates of sexual victimisation were also found by Brown-Lavoie *et al*. (2014) where 78% of autistic respondents reported at least one occurrence of sexual victimisation, in comparison to 47.4 % in the non-autistic population.

The reasons for this have thus far not been extensively explored in the academic literature, however the women in the present study were able to provide novel insight based on their post-diagnosis reflections of these traumatic incidences. They felt there might be several reasons that contributed to their victimisation. They felt that a lifetime of growing up with external pressure to ‘fit in’ and conform may have contributed to their experience. This compliance and trying to please others was also found by Bargiela *et al*. (2016:3287) “*please, appease and apologise - do what you’re told”.* This was coupled by the fact that participants were desperate for acceptance which made them more vulnerable (Bargiela *et al.* 2016). ‘I’m prey in a world of predators’ (Milner *et al*. 2019:2397). Participants also alluded to being quite naïve, and the fact that they were scrupulously honest meant that they did not expect others to have devious motivations. Another contributary factor might be their tendency for missing social cues. They may not have picked up on non-verbal communication that indicated the interaction was leading to a sexual encounter. A further suggestion in the literature is the role of social mimickery (Bargiela *et al*. 2016, Milner *et al*. 2019). This means unconscious mirroring of other people’s behaviour in order to ‘fit in’ could potentially mean that they had inadvertently mimicked flirtatious behaviour. They then felt unable to stop the encounter progressing to intercourse. Participants in the present study also discussed a lifetime of copying and mimicking others, often unconsciously. A typical reaction reported in these situations was to retreat within themselves, and ‘let it happen’ without protesting. Being undiagnosed they could not recognise this as a typical autistic reaction to trauma. Coupled with the reasons given above, this led participants to internalise this trauma and blame themselves. This self-blame is reported in the general literature of sexual victimisation (Breitenbecher, 2006). Thus far there has been little focus on sexual victimisation and vulnerability in the autistic population. One paper that suggests that the role of self-blame is more significant in the autistic population than the non-autistic population is a case study by (Carbajal & Praetorius, 2020) and they highlight the damaging effects this has on self-identity and mental health.

All these interpersonal traumas happened to participants and on numerous occasions and yet participants had no clear idea of why this might be happening to them. Their only reason pre-diagnosis was to blame themselves which further added to their negative self-perception.

9.4 Ruminations

The study presented here reveals the high incidence and uncontrollable nature of the participants' negative ruminations. These were described as debilitating mental thought patterns that could overtake participants and lead to instances of reduced mental capacity and health and is indicative of a phase in the process of 'not knowing'. The increased level of ruminations that focused on interpersonal traumas amongst other negative thoughts and the resulting impact has also been reported elsewhere, (Golan *et al*. 2021; Gotham *et al*. 2015). According to Golan *et al*. (2021) rumination is a dysfunctional emotion regulation strategy which is implemented by individuals in an inflexible manner. Ruminations are reported to have connections with depressive symptoms in a neurotypical population (Nolen-Hoeksema *et al*. 2008). However, little is known about them with specific attention given to the autistic population. In their study about Chinese earthquake survivors Wu *et al*. (2015) categorised ruminations into two different categories. The first is brooding rumination which is comparing one's current position to one's desired position and the second is reflection rumination which is the internal examination of one's own problems. They suggested there are negative implications of brooding rumination and positive effects of reflection rumination (Wu *et al*. 2015). The findings provide evidence to suggest that participants in the present study could not have experienced the beneficial impact of reflective rumination as they were living their life undiagnosed. Therefore, pre-diagnosis, they were unable to properly conduct reflection in ruminations as their thoughts were focused through the lens of self-blame and lacking in vital causal information. Indeed, all participants described their ruminations in negative terms and as something that they desperately wanted to be able to control. This is supported by the finding of Golan *et al*. (2021) who reported increased brooding rumination in their sample of autistic participants. Indeed, rumination was found to be more prevalent in a sample of autistic adults (n = 28) compared with typical controls (Crane, Goddard & Pring, 2013), and to be significantly associated with depression measures in the same sample. Rumination and low self-esteem are both seen to be a risk factor in autistic people having suicidal ideations (Arwert & Sizoo, 2020). The literature on autistic ruminations is sparse but one of the first papers to start to try to explore this used psychological network analysis (Williams *et al*. 2021). They found that the significant nodes in the rumination network all included some form of reference to self. The authors suggest this may mean that the self-focused nature of ruminations could be important in relation to depressive thoughts. The participants' accounts in the present study emphasise how they internalise blame within their ruminations and focus on perceived wrongdoings. This certainly suggests that the role of rumination and their negative impact on mental wellbeing is significant. They served to further reinforce the negative self-perception and self-blame by participants that is exacerbated by 'not knowing'.

9.4.1 Post-Traumatic Stress Disorder (PTSD)

The intensity of the ruminations reported within the present study is particularly noteworthy. Incidences of interpersonal trauma that occurred many years previously were re-lived through ruminations and participants reported it being like it happening again and the memory of the event being just as traumatic as the original event itself. It caused intense anxiety, physical symptoms and disturbed sleep for some. These severe reactions to ruminations are suggestive of a more intense traumatic reaction. Ruminations have been identified as potential predictors of PTSD in the non-autistic population (Kleim *et al.* 2007). The American Psychiatric Association define an event where the resultant impact can be PTSD as: a *natural disaster, a serious accident, a terrorist act, war/combat, or rape or those who have been threatened with death, sexual violence or serious injury. (*American Psychiatric Association). This would not fit with the rumination subjects reported by the participants. However, it has been demonstrated that autistic individuals interpret a wide range of life events as traumatic, beyond those that would meet the strict definitions of PTSD. Examples include social insults and sensory overloads (Haruvi-Lamdan *et al*. 2020; Rumball *et al*. 2021), In addition there is evidence to suggest a link between bullying in children and PTSD symptoms in non-autistic populations (Idsoe *et al*. 2012; Mynard *et al*. 2000) and participants being troubled by memories of bullying incidences long after they have left school (Rivers, 2006). This is certainly reflective of the experiences shared by participants in the present study. The connection between autism and PTSD has thus far had limited investigation. In the present study there is evidence that ruminations about interpersonal traumas evoke intense physical and emotional reactions for participants that could be recognised as a typical response to trauma and potentially PTSD.

9.4.2 Mental Health, Burnout and Suicide

All participants in the present study had spent a lifetime battling mental health issues, with most consulting professionals for help and support without their autism ever being identified. Indeed, there is evidence to suggest that this is reflective of the wider population and that many adults when they go on to eventually receive an autism diagnosis are already being treated for mental health problems (Bishop-Fitzpatrick, Dababnah & Magana, 2019; Geurts & Jansen, 2012) and that their autism had been missed for years. Some participants received numerous incorrect diagnoses and unsuitable medication and treatments (Au-Yeung *et al*. 2019), with two participants reporting having a very bad and degrading experience with the mental health service (which they would regard as traumatic), that would prevent them from ever seeking further support. These experiences can help us to further understand the damaging impact of ‘not knowing’.

All fourteen participants experienced lifelong difficulties with anxiety and depression and nine had suicidal ideations with seven having actual suicide attempts and several discussed experiencing autistic burnouts. Although this is a relatively small sample, the wider anecdotal evidence suggests that the participant’s experience is reflective of the autistic population. The wider academic literature provides evidence to indicate that depression in the autistic population is nearly four times that of the general population (Hollocks *et al.* 2019; Hudson *et al.* 2019). Another study found that 79% of autistic adults had diagnosable mental health conditions (Lever & Geurts, 2016). There have also been rates of increased suicidal ideation in autistic people with depression being a potential risk factor for suicidality Cassidy *et al.* (2014).

Throughout the participants’ accounts they have described struggles with their mental health. Their accounts have been punctuated by discussions of periods that could be (and some post-diagnosis recognised as) autistic burnouts. Autistic burnouts have been discussed within the autistic community for some time; *‘Autistic burnout is an integral part of the life of an autistic person that affects us pretty much from the moment we’re born to the day we die, yet nobody, apart from autistic people really seem to know about it… (Rose, 2018*). However, only recently has information regarding autistic burnout started to appear in the academic literature. (Raymaker *et al*. 2020).

In their Delphi study consulting autistic adults as experts by experience Higgins *et al*. (2021) defined autistic burnout as *“a highly debilitating condition characterised by exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits – and distinct from depression and non-autistic burnout”* (2021:2356). In the present study several participants referred to regular periods throughout their lives where they have had episodes that they either now identify as autistic burnout, or that it can be inferred was a period of autistic burnout. Participants described chronic exhaustion, loss of skills, and reduced tolerance to sensory stimulus. They describe not being aware of what caused the burnouts at the time (undiagnosed) but some can later look back and identify stress triggers that built up until they just could not cope anymore. Participants discussed a significant length of time that it took to recover from these periods with mental and physical exhaustion and worsening mental health. The participants provided evidence to contribute to the dearth in the academic literature on autistic burnout. Without a diagnosis or contact with the autistic community, participants went through these periods without understanding them or knowing how to help themselves. Anecdotally autistic burnout has been linked to suicidal ideation and is said to be caused by the stress of camouflaging and living in an unaccommodating neurotypical world (Raymaker *et al*. 2020).

9.4.3 Summary

Autism has always been an ‘*absent presence’* (Huws & Jones, 2008:104) in the lives of participants. They had been aware of their difference since childhood and were acutely aware of how unacceptable their difference was. Participants felt the pressure to ‘fit in’ and their perceived rejection by peers and society. They had multiple incidences of interpersonal traumas, endured perpetual negative ruminations, all of which were viewed through the lens of self-blame. Many made monumental efforts to try to fit in and camouflage themselves and endured the emotional inner turmoil that this engendered. As a result, they took on a ‘spoiled identity’ (Goffman, 1963). This study suggests that the group of autistic people who receive a very late diagnosis of autism will have worse prevalence of mental health issues than the population that are fortunate enough to have an earlier diagnosis. What is fundamentally important when considering the experience of the participants is the added layer of confusion and self-blame participants endured ‘not knowing’ for such a lengthy period of their lives. Living ‘not knowing’ means attempting without support or accommodations to succeed in life with the expectations of experiences of a non-autistic person, unaware of why they are finding these things difficult (Lai & Baron-Cohen, 2015) which has the multiple negative consequences discussed.

The following quote from autistic advocate Carly Jayne Jones (2018) eloquently summarises the traumatic life experiences the participants in this study experienced in the ‘not knowing’ part of their lives:

> *You can’t have self-esteem if you don’t have self-identity, if you don’t know your identity, where do you start? You can’t start…. I felt like I was one person made out of lots of other people but I had no idea who I was and that is terrifying, it’s terrifying to live like that everyday… not really knowing”* (Carly Jayne Jones, 2018)

9.5 Diagnosis is a Positive Addition to Self-Knowledge and Wellbeing

9.5.1 Overall knowing

This study provides evidence of the different ways that ‘knowing’ positively impacted wellbeing of older autistic adults. Evidence indicates that participants faced significant barriers to gaining diagnosis as there was a lack of understanding amongst diagnostic gatekeepers of the personal value of gaining a diagnosis. Novel evidence is provided that highlights that post-diagnosis for some meant there was a lengthy time of adjustment that was challenging with worsening mental health and a possible crisis point. No post-diagnostic support was offered to any of the participants. In the following section I discuss these areas of the findings in relations to the other available literature.

All the participants felt that ‘knowing’ was a positive addition to their lives. It provided them with a resolution to their lifelong quest to find a reason for their ‘difference’. This supports the qualitative literature available from younger adults who also highlight the beneficial impact of ‘knowing’. Punshon *et al.* (2009:265) entitled their paper ‘*the not guilty verdict’* which was reflective of the relief participants in their study felt regarding their diagnosis. In Milner *et al*. Australian study which focused on women, a representative quote was “*I’m not so crazy after all*” (2021:2396) and one of the three other studies that included adults with a very late diagnosis Leedham *et al.* (2020:139) focused on the experience of women who had a sense of ‘*relief and vindication’* after diagnosis. In quantitative studies there is also evidence of the positive addition to lives, 73% of adults attending a diagnostic clinic felt positive regarding diagnosis (Powell & Acker, 2016). However, it should be acknowledged that there were also negative feelings reported. Likewise, Jones *et al*. (2014) reported 71% of participants being relieved by gaining their diagnosis with some participants reporting being anxious, confused, upset and angry. Certainly, the effect of diagnosis is not reported to be positive for all, and there have recently been attempts to measure the effect of diagnosis in quantitative terms with the development of an 'impact of diagnosis scale' for autism (Arnold *et al*. 2020). The overwhelmingly positive reactions to diagnosis found in qualitative studies may be due to the volunteering nature of obtaining the research sample. Those who felt more unhappy about their diagnosis may be less willing to take part in research about autism. It may also be reflective of how long participants had been diagnosed, some of the participants in the present study took some years to come to terms with their diagnosis. If their interview had taken place earlier after diagnosis, they may not have reported the same positive impact.

There were several factors that engendered the positive thoughts reported in the present study about diagnosis. Diagnosis provided participants with an explanation for their life experiences 'not knowing' and engendered self-forgiveness for their perceived 'spoiled identity'. The positive impact of diagnosis has been reported in a number of other studies with other populations; in adolescence (Huws & Jones, 2008), younger autistic adults (Punshon *et al*. 2009), in mid-adulthood (Portway & Johnson, 2005; Hurlbutt & Chalmers, 2002; Muller *et al*. 2008 and mid-adulthood women (Bargiela *et al*. 2016). It has also featured in the three other studies on older adults (Leedham *et al*. 2020; Lilley *et al*. 2021; Stagg & Belcher, 2019). Diagnosis provided self-knowledge and meant an end to the lifelong quest for an appropriate reason to explain their difference which has been identified as a major source of distress in their lives (Tan, 2018). It also provided legitimacy by providing a name for their experience and acknowledgement by healthcare professionals that their experiences were at last being recognised. This resolution to this puzzle provided an end to the lifelong emotional search for an explanation of their 'difference' which had meant significant interactions with the mental health service and multiple misdiagnosis and inappropriate treatments (Fusar-Poli *et al*. 2020). For some they had been labelled with conditions that they never felt fit (Au-Yeung *et al*. 2019) and receiving an autism diagnosis confirmed that they were indeed previously wrongly diagnosed with other conditions. This phenomenon was investigated by Au-Yeung *et al*. (2019) who found that autistic and possibly autistic adults were significantly less likely to agree with mental health diagnoses as they felt that their mental health condition that was diagnosed was confused with characteristics of autism and they felt that the mental health conditions to be caused by autism. They found that reasons for barriers to accurate diagnosis was a lack of autism knowledge by healthcare professionals and poor communication. The fact that participants in the present study now knew that they were autistic, and had always been autistic, and always would be autistic, meant that they were no longer chasing a ‘cure’ or medication to ‘fix’ them (Tan, 2018). This settled their life expectations and reduced the frustrations and for some enabled them to shake off harmful misdiagnosis labels.

A lifetime of miscommunications and misunderstanding had taken a toll on some relationships in participants’ lives and had an eroding effect on them. The provision of a new lens to understand interaction provided clarity for some and improved relationships. It provided signposting so loved ones could seek information to understand their communication. In some cases, this came from family members being part of the diagnostic process, as it helped family to understand that participants had not been deliberately difficult (Hurlbutt & Chalmers, 2002; Lilley *et al.* 2021). Knowing engendered enhanced understanding of one another. Likewise, it also helped acceptance of certain character traits, through better understanding.

One of biggest benefits that participants reported was that of ‘finding their tribe’, that it that they finally found ‘sameness in their difference’. In chronic illness it has been found that a shared diagnosis can help to create a group identity (Jutel, 2009). To know that there were other people who were different like them, was incredibly reassuring. Finding others that had similar experiences was extremely validating (Lai & Baron-Cohen, 2015; Tan, 2018). Some participants contacted other autistic people for companionship and meeting up socially. They reported that they felt it was easier to communicate with other autistic people in comparison with neurotypical people. These findings have had much anecdotal support and have recently been supported in an empirical study (Crompton *et al.* 2020). For others the autistic community was a great source of knowledge where they could find more information about themselves and promote understanding of their behaviours. Leedham *et al.* (2020) also found that connecting with other autistic people helped with meaning making of diagnosis. In the present study participants felt part of a community which was the first time they had felt like this in their lives and the experience was quite thrilling. This contact with other autistic people reduced a sense of social isolation and these findings were also reported in younger autistic adults by Punshon *et al.* (2009) and the beneficial impact of autistic community membership has been highlighted for its positive effects (Lai & Baron-Cohen, 2015).

9.5.2 Barriers to Diagnosis

There were significant barriers to diagnosis reported in the current study for two reasons. The first factor, and perhaps more concerning, is the fact that GPs did not see that there was any benefit to a diagnosis later in life. This study and numerous other pieces of research with younger autistic people refute this strongly (Hickey *et al.* 2018; Jones *et al.* 2014; Kock *et al.* 2019; Lewis *et al.* 2016; Powell & Ackers, 2016; Punshon *et al.* 2009) and UK policy also emphasises the importance of diagnosis (Autism Act 2009, Russell *et al.* 2021). However, gatekeepers did not seem to be aware of this beneficial effect. Perhaps one explanation could be that they were focused on the lack of post-diagnosis support available. This was highlighted by GPs who indicated that this was cause for concern in a survey in the UK in 2017 (Unigwe *et al.* 2017). Also, the fact that participants were past the age of education, and some were no longer in employment, therefore they would not receive services usually accessed when a diagnosis was received by the younger population. There was little recognition of the personal importance and value of a diagnosis and how that it would enhance self-knowledge. This is inextricably linked with the second reason for barriers to diagnosis in the fact that the gatekeeper did not recognise autism in participants. This was also highlighted in the survey of GPs in the UK which found that GPs lacked confidence in recognising autism in adults Unigwe *et al.* 2017). There are several reasons for this provided in the literature; it has been noted that healthcare professionals do have limited experience and training in adult autism (Au-Yeung *et al.* 2019; Doherty *et al.* 2022; Mason *et al.* 2019). It may be particularly difficult to recognise autistic people that are not behaving like the stereotypical media portrayals of autistic people to which we have become accustomed. Incorrect notions such as autistic people being unable to hold eye contact or be employed or have a family, have contributed to autistic people remaining undiagnosed (Fusar-Poli, 2020). There was also evidence of believability issues in the present study. This invalidated participants' experiences and made them feel that healthcare professionals were making judgements that the participants lacked knowledge about themselves. Indeed, fear of not being believed was the largest identified barrier to diagnosis by autistic people in a multinational survey study (Lewis *et al*. 2016). These problems have been reported elsewhere; professionals not recognising signs of autism has been attributed to delays before assessment takes place (Bargiela *et al.* 2016; Griffith *et al.* 2012; Jones *et al.* 2014), causing gaps of several years between first recognition of autistic traits, professional consultation, and diagnosis (Au-Yeung *et al.* 2019; Geurts & Jansen, 2012; Jones *et al.* 2014). Thus delaying the potential positive effects of diagnosis and as in the present study undiagnosed autistic people could have worsening mental health in this interim period which is potentially a huge risk factor given the high suicidal characteristics reported in the autistic population (Cassidy *et al.* 2014. Mandy, 2022). This must be addressed as it has been identified that delayed diagnosis has a significant impact on quality of life (Lehnhardt *et al.* 2016). In the present study the misdiagnoses and barriers to diagnosis that caused long delays certainly contributed significantly to reduced wellbeing. This further emphasises the serious consequences to these shortcomings in current service provision.

This study demonstrates the tenacity and persistence that some participants required to undertake in order to break through these diagnostic barriers. Their determination was remarkable considering they had struggled with lifelong mental health issues and had negative self-identity. This further invalidation of their experience by HCPs they had approached for help and diagnosis could be catastrophic. Given the high rates of depression and suicidality in the autistic population (Cassidy *et al.* 2014; Mandy, 2022) these barriers pose a great risk and make identification of the 'lost generation' (Lai & Baron-Cohen, 2015) even more difficult. Indeed, there has recently been suggestion of the catastrophic effects of missed and misdiagnosis. A recent study has identified an unusually high prevalence rate of likely undiagnosed autistic people who died by suicide (Cassidy *et al*. 2022).

9.5.3 Post Diagnosis

The findings show that all but two participants in the present study felt quite sure that they were autistic pre diagnosis. Indeed, they strived towards diagnosis as a goal they wanted to achieve as it would finally provide them with a reason for their lifelong ‘difference’. Despite this fact, four of these participants mentally struggled post-diagnosis and described a post-diagnostic ‘slump’ or a period of ‘turmoil’ where they were trying to come to terms with what their diagnosis meant. This lasted for a significant period (one-six years). This has not been previously highlighted in the literature. However, on close examination of the studies from younger autistic adults there are hints of a similar experience; *“there was this dip”* (Punshon *et al.* 2009:278) and in her multinational survey Lewis reported ‘*depressive episodes for months’* (2016:349) and Tan (2018:166) reported that a participant was suicidal ‘*which he attributed to early experiences and internalisation of alienating messages about disability’*. However, it has not yet been highlighted as a major concern in the literature. I feel the evidence from this study and suggestions from other qualitative studies make this is a real risk factor for newly diagnosed autistic adults. Given the high prevalence of suicide (Cassidy *et al.* 2014) and the paucity of post diagnostic support this certainly merits further investigation.

9.5.4 Language

Mentally processing a diagnosis could be made more problematic by the literal thinking that is common in autistic people (Lai & Baron-Cohen, 2015) and part of the diagnostic criteria (DSM-V). This might lead to the formation of negative feelings of hopelessness post-diagnosis as clinicians are prone to using deficit led terms which can reflect ableist ideologies and can have a negative effect on how autistic people view themselves (Bottema-Beutel *et al.* 2021). There is direct evidence of this effect in the present study. James was told that it was ‘an untreatable condition’ and therefore he has learnt very little else about autism which he attributes directly to the language used at diagnosis. This clearly limited the potential positive effect diagnosis has on his life. Indeed, the language that is used to describe autism has the power to shape people’s perceptions of autism (Kenny *et al.* 2016) and therefore the language choice of diagnostic clinicians or gatekeepers should be considered carefully (Bradshaw *et al.*

2021). The use of positive terminology at diagnosis could help to facilitate acceptance of a diagnosis (Bottema-Beutel *et al.* 2021).

9.5.5 Post Diagnosis Support

Another incredibly worrying facet to the experiences shared in this study was the complete lack of post diagnostic support. The NICE guidelines say that post-diagnostic support for adults should be implemented, for example, via written recommendations for medical issues and healthcare and how to manage risks and crisis (NICE 2012). Indeed, it is advised that *'negative effects of diagnosis such as concerns about stigma or a sense of hopelessness should be carefully handled through counselling'*. (Lai & Baron-Cohen, 2015:1024). However, despite this none of the fourteen participants were offered any sort of support post-diagnosis. This lack of support is evidenced in the wider literature, with GPs identifying it as a problem (Unigwe *et al.* 2017) which is also identified with autistic older adults (Stagg & Belcher, 2019) and in their survey Jones *et al.* (2014) found that less than half of their respondents were offered post-diagnostic support despite there being evidence that strong post-diagnostic support can enhance the quality of life of autistic adults (Renty & Roeyers, 2006). It seems ludicrous to provide a diagnosis to an older autistic adult without accompanying support provision. Especially given that there is evidence from a study that most adults have diagnosed mental health conditions prior to diagnosis (Au-Yeung *et al*. 2019) and that newly diagnosed autistic adults reported 66% lifetime experience of suicidal ideation and a 35% lifetime experience of planned or attempted suicide (Cassidy *et al.* 2014). These unfortunate figures provide emphasis on how important it is to provide *appropriate* support post-diagnosis to help newly diagnosed autistic people to come to terms with the 'diagnostic bombshell'. Currently, there are various post- diagnostic support available for parents (e.g. EarlyBird) but there is little available support for adults (Crane *et al.* 2020).

This study recruited people who had made it through the diagnostic barriers, received their diagnosis and progressed through to the post-diagnostic period where they were coming to terms with their new identity (without support) to finally come to a place of 'knowing'. All fourteen participants at the time of interview felt an autism diagnosis was a positive addition to their wellbeing. Knowing self, knowing expectations, knowing relationships and knowing tribe was undoubtedly positive in their lives. However, one must wonder how many do not make it?

9.5.6 Summary

This study supports and adds to the current knowledge base and provides evidence that receiving an autism diagnosis was beneficial to older autistic adult participants, it adds to the current literature in that it demonstrates that receiving a very late diagnosis for older adults is also as beneficial as it is for younger autistic people. It means that healthcare professionals should be made aware of the positive personal impact on wellbeing to older autistic adults to receive a diagnosis and receive training on how to identify and support the diagnosis process. A novel contribution is made through the highlighting of a post-diagnostic slump with worsening mental health. This is a real cause for concern and a real risk factor for newly diagnosed autistic adults. Clearly appropriate post-diagnostic support is urgently required to help autistic adults adjust to their new identity.

The following quote by Dr Ava Ruth Baker, who is an autistic diagnostician in New Zealand provides insightful thoughts on how receiving an autism diagnosis can be perceived:

> *Diagnoses are often thought of as labels, but they could also be considered as signposts. Signposts do something more than labels they help people find their way on a journey. Dr.* Ava Ruth Baker (2015) cited by Caroline Hearst

In the following section I will discuss the liminal nature of ‘knowing’ and how, although beneficial, that to enhance wellbeing a further journey of self-discovery is needed to help participants thrive.

9.6 Thriving Promotes Understanding of Self and Enhances Wellbeing

The previous sections outlined the period of participants’ lives conceptualised as ‘not knowing’ and ‘knowing’. In this section I will discuss the conceptual model called *‘the thriving cycle’* derived from the foundational data discussed in ‘not knowing’ and ‘knowing’. I will discuss the benefits of thriving, the supportive evidence in the current literature, the links this theory makes with the neurodiversity movement and the implications it has for much needed supportive therapies.

At the time of interview participants within this study could be viewed as two groups split by an invisible and profound divide in wellbeing. These two groups were conceptualised as either ‘thriving’ or ‘surviving’ post diagnosis. The thriving participants’ wellbeing was greatly enhanced in comparison to the ‘survivors. ‘Survivors’ had improved self-knowledge from ‘knowing’ but felt a sense of helplessness that their lives were limited by the barriers they perceived autism to create in their lives. The ‘thrivers’ had enhanced wellbeing, more autonomy and felt empowered. Further examination of the experiential accounts identified contributory factors to being a ‘survivor’ or a ‘thriver’. Evidence of causal conditions that were necessary to thrive were found which provided access to a cyclical process of knowledge acquisition, self-reflection and development of personalised life management strategies that were conceptualised *as ‘the thriving cycle’*. The consequence of which was increased confidence, empowerment, self-efficacy and enhanced overall wellbeing. In the following section I will discuss each element of this process and how it can be interpreted within the current academic literature. I will discuss how the way that participants viewed autism was critical to their wellbeing. The causal conditions of acceptance and internalisation of autism are inextricably linked to positive constructions of autism and occur in tandem. First, we will discuss the role of acceptance and internalisation of autism.

9.6.1 Causal Conditions: Acceptance and Internalisation of Autism

The ‘surviving’ participants perceived autism as a deficit and externalised it. They viewed it as something that was wrong with them and used language that likened it to an illness. One participant compared it to a tumour that often controlled his life. Another participant compared it to a brain aneurysm. This mirrors the finding of Hickey *et al.* (2018) who identified this externalisation of autism as a helpful process that encouraged participants to reattribute previous self-blame. This process focused on autism being the culprit of their negative life experiences. Similarities were found in Atherton *et al.* (2021) small study of mid-adulthood, although grateful that they finally were in a position of ‘knowing’, participants externalised their autism and spoke of it in deficit terms. This was also true of the mid-adulthood participants in Griffith *et al*. (2012) study who referred to autism externally. This helped to externalise blame for previous negative life experiences and assisted reflection on life events through a different lens that was less laden with self-blame. Indeed, this approach is common practice in narrative therapy, known as '*externalising the problem'* and has been derived from the work of Michael White (White & Epston, 1989). It assumes the problem and the person are separate, which is thought to help to externalise the problem and to internalise personal agency (White & Epston, 1989). However, I propose that this form of therapeutic perspective is only effective in reference to autism if 'the problem' is accurately ascribed. What is of critical importance is that the surviving participants, (like the participants in other studies; Atherton *et al.* 2021; Hickey *et al.* 2018; Griffith *et al.* 2012) who externalised autism, identified autism as 'the problem'. They viewed autism in terms of the medical model of disability (Shakespeare, 2002, Oliver, 2009). Although externalising autism does have some beneficial effects, it has negative long-term consequences of inhibiting participants' wellbeing. Indeed, externalisation of 'the problem' is usually advocated in therapy for subjects that can be changed or recovered from such as stress or depression. However, the crucial distinction is that autism is lifelong, and an inherent part of the individual's neurobiology. It will not be cured and will not be recovered from. I propose that externalising autism as 'a problem' cannot be a beneficial long-term strategy. Autism is an ever-present entity in participants' lives and if it is externalised it will become an insurmountable barrier to their lives and wellbeing. These findings contrast with Hickey *et al.* (2018) who report the beneficial effect of externalising a diagnosis of autism. The evidence from this study suggests that any benefit from externalising autism is short-lived and potentially harmful to wellbeing.

In line with the neurodiversity movement, thriving participants reframed their thinking, in that 'the problem' was not autism, but 'the problem' was the way their perceived 'difference' (created in part by their neurodiversity) had been accepted/unaccepted by others. Thereby internalising autism as part of themselves whilst still externalising the blame for past experiences. This different conceptualisation of autism seemed to be monumental in the way that it liberated participants. Instead of autism being an insurmountable ever-present problem in their lives, participants internalised it as part of themselves and aligned their self-concept with the ideals of the neurodiversity paradigm. That neurodiversity is an essential form of human diversity. Indeed, it rejects the pathologising of autism and the need to normalise autistic people and cure autism.

It supports the view that factors that are external to the individual cause the disabling factors in their lives (Sinclair, 2010; Kapp *et al*, 2013; Shakespeare, 2002)

This re-conceptualisation as neurodivergent was empowering for participants; it removed and perceived barriers and created possibilities to explore life with a new outlook. This was a distinct shift from the 'spoiled identity' of 'not knowing' and for the first time in their lives participants were not viewing themselves as broken or deficient. The positive effect of self-acceptance has also been reported elsewhere to be beneficial (Lai & Baron-Cohen, 2015; Punshon *et al.* 2009) and self-acceptance has been found to have a negative correlation with depression in the non-autistic population (Flett *et al*, 2003) and a protective effect against depression and anxiety (Cooper *et al.* 2017). Additionally, Cage *et al.* (2018) found that greater personal autism acceptance was linked with lower depressive symptoms and important for mental health and could be linked to reduced harmful camouflaging (Cage & Troxell-Whitman, 2020). Indeed, Lewis *et al.* (2016) found that self-acceptance was important in wellbeing. In an examination of the blog posts of autistic women focusing on identification and diagnosis experience, acceptance was found to be a central issue which promoted understanding (Harmens, Sedgewick & Hobson. 2021).

The role of acceptance by others was fundamental and underpinned the self-acceptance in the 'thriving' participants in the present study. This acceptance came from several sources: spouses, partners, colleagues or friends. This support was important in participants' lives and seemingly provided strength and reassurance for them to explore and build their new self-identity. These findings are in concordance with earlier studies, Hurlbutt and Chalmers (2002) stated that families had a major role in helping autistic people develop the skills to become successful adults in society. Tantam (2000) also highlighted that external acceptance of adolescence could protect them from developing depression. Lilley *et al.* (2021) highlighted how the reaction and support from others was important in adjusting after receiving a late diagnosis in adulthood which included *'being treated like an individual by the important people in their lives'* (2021:140). The surviving participants in this study did not have this support, indeed they were single and most were perhaps without the support and confidence of any close relationships in their lives. The present study does not provide the evidence to determine how much of a barrier to 'thriving' this was but it is worth further exploration. Single autistic people may require additional support to thrive. The acceptance and internalisation of autism was powerful, but it was the combination of these entwined inseparably with positive constructions of autism, from the autistic community that catalysed the thriving cycle.

9.6.2 Causal Condition: Positive Constructions of Autism

Constructions of autism that participants had previously been exposed to were from gatekeepers to diagnosis and healthcare professionals who follow the medical model of conceptualising autism. As discussed in chapter six healthcare professionals were respected authorities and participants valued their opinions and therefore were reluctant to question them (Bradshaw *et al.* 2021). The way autism was spoken about will have been deficit focused. There is evidence to suggest that feelings of having a 'spoiled identity' could be reinforced by the referral process and the diagnostic process itself (Bradshaw *et al.* 2021. Brown *et al.* 2021, Bottema-Beutel *et al.* 2021). Indeed, participants received a diagnosis confirming that they were 'disordered' (American Psychiatric Association, DSM-V, 2013). The language used throughout the process focused on deficits and impairments and there is evidence to suggest that use of such terminology is harmful to autistic people as it reinforces the stigma, emphasises barriers and prevents acceptance (Bradshaw *et al.* 2021). Using deficit-based language also reinforces the message that participants are broken, or in need of fixing (Bradshaw *et al.* 2021). It has recently been highlighted that the way in which diagnosticians explain autism affects the way diagnosis is accepted. If autism is framed in the correct way (through positive terminology) it can encourage autism acceptance (Crane *et al.* 2018) but using with deficit-based terms can create barriers to self-acceptance (Brown *et al.* 2021 & Bottema-Beutel *et al.* 2021).

Receiving a diagnosis gave participants access to the autistic community which provided opportunities for participants to experience sameness in their difference. There is growing evidence regarding the importance of such connections (Baker, 2008; Lai & Baron-Cohen, 2015; Milton & Sims, 2016; Leedham *et al.* 2020; Tan, 2018). The contact provides feelings of acceptance and validation of their experiences, (Baker, 2008; Bargiela *et al.* 2016; Hickey *et al.* 2018; Lewis *et al.* 2016; Punshon *et al.* 2009; Tan, 2018). For the first time in their lives, they could compare their experiences with others with similarities of experience.

Autistic online communities tend to conceptualise autism in terms of difference as opposed to disability in line with the neurodiversity movement (Sinclair, 2010; Kapp *et al.* 2013; Shakespere 2006). This provided participants with a new light to view autism by. This perception had increased validity as it came from experiential views. Indeed, the beneficial impact of information from first-hand accounts has been demonstrated in a small study of interviews with autistic adolescents. First hand experiences of autism were much more relevant and meaningful than the information received at diagnosis (Mcleod *et al*. 2013). Communication with autistic people legitimised and validated experiences and helped with the formation of an autistic self-identity.

Certainly ‘finding their tribe’ was positive for all participants. However, it was the way in which participants engaged with the autistic community that differed between ‘survivors’ and ‘thrivers’. ‘Survivors’ were in touch with the autistic community for companionship and to enjoy the novelty of communicating with people who accepted their style of communication (Crompton et al, 2020). However, those on the journey towards thriving, importantly used the community support to gain validation of their own experiences which has been highlighted in therapeutic circles as essential and empowering (Zener, 2019). Communication was mainly done online seeking information. Importantly participants could engage on their terms which enabled participants to be anonymous. The ease of access to this community was also found to be beneficial in other studies as the reliance of text-based communication provided equity of communication, time to process responses and removed the need to read non-verbal communication (Bargelia *et al.* 2016). The autistic community provided participants with a sense of belonging which was clearly beneficial (Milton & Sims, 2016) and it promoted a deeper understanding of themselves and combined with positive constructs of autism and self-acceptance catalysed the thriving cycle.

9.6.3 Strategy: The Thriving Cycle

All participants reflected on their lives once they gained their diagnosis and were able to view their life through a new lens and these findings have been widely reported by other studies (Hickey *et al.* 2018; Huws & Jones, 2008; Leedham *et al.* 2020; Lilley *et al.* 2021; Tan, 2018.). Crucially though there is a fundamental difference between the earlier studies and the present study as other studies seemed to focus on the reflections of past experiences, whereas the thriving participants also discussed the impact diagnosis had on their present and future selves. Powell & Ackers (2016:78) highlight '*reflection and reassessment of the past'* which focused on looking back and explaining why they had struggled socially and emotionally. Similar narratives are given by Punshon *et al.* (2009:265) in *'the not guilty verdict'* again moving blame externally. '*Reliving life through a new lens'* (Leedham *et al.* 2020;139) who focused the findings narrative on looking back and the sadness and intense emotions, and associated grief. Hickey *et al.* (2018:364) highlighted '*reviewing one's life through the lens of the autism diagnosis'* which also has a backward focus. In distinct contrast, what this study's findings show, are that although participants did have the beneficial impact of looking back and making sense of their lives, they moved forward in a more purposeful and different direction than has been reported elsewhere. After accepting and internalising autism and being exposed to positive constructions of autism the 'thrivers' started a further journey of self-reflection. This had some elements of backwards reflection but also of current experiences which was facilitated by in-depth and experiential autism knowledge. This enabled them to have a deeper understanding of themselves. They became proactive and able to develop helpful life management strategies that enhanced wellbeing.

9.6.4 Knowledge Acquisition

Crucially the knowledge acquisition was derived mostly from non-medical sources and mainly from highly valued experiential accounts which have been reported elsewhere to be influential (Baker, 2008; Lai & Baron-Cohen, 2015; Fletcher-Watson, & Happe 2019; Mcleod *et al.* 2013). For most of their lives participants had the understanding of themselves dictated to by others and often this was with a negative focus (Leedham *et al.* 2021). Indeed, participants had long had their experiences disbelieved or questioned (Lewis *et al.* 2016). These experiential sources provided validation of their experiences and encouragement to gain a deep understanding of the causal reasons for their personal experiences (Baker, 2008, Milton & Sims, 2016).

The different ways in which information about autism was acquired by autistic participants post-diagnosis was discussed by Huws & Jones (2008) in their study of adolescence diagnosis. They noticed a distinction in the amount of autism information participants wanted post-diagnosis which they linked to Pinder's work on chronic illness (1990). They identified the fact that information seeking about autism was linked to whether autism was a positive or negative addition to participants' lives. If diagnosis was not welcomed, their participants tended to avoid seeking further information about autism. However, if it was a positive addition to their lives, they became *seekers* of information. This would support the findings of the present study, as survivors who viewed autism as a deficit sought out much less information and tended to rely on the medicalised information given to them at diagnosis. The causal conditions of *the thriving cycle* mean that *thrivers* gain a positive conceptualisation of autism and become what would be in Pinder's work (1990) seen to be *seekers* of autism knowledge. Consequentially, autism knowledge acquisition for thriving participants became a focused interest and a lot of time was devoted to it. Autistic people tend to have a monotropic style of thinking (Murray *et al.* 2005) which provides hyper focus, part of the diagnostic criteria for autism (DSM-V). This skill helped participants to research autism itself (Hurlbutt & Chalmers, 2002) and much time was given to gathering extensive information to explain their experiences. This led many participants to becoming experts in autism (Hurlbutt & Chalmers, 2002; Baker, 2008; Jones *et al.* 2013, 2015; Huws & Jones, 2015). Their extensive and in-depth knowledge initially was derived from experiential accounts but was also supplemented by some with applied knowledge from academic literature. Indeed, participants' reflection on their experiences were unconstrainted by typical thought processes (Milton, 2017) which is advantageous as this leads to questioning commonly held assumptions about autism (Gillespie-Lynch *et al.* 2017) which in turn contributed to a deeper understanding of themselves.

9.6.5 Self-Reflection and Strategy Development

Being exposed to experiential accounts and gathering knowledge from community members enabled participants to reflect on their own experience and review and compare their experiences with others (Tan, 2018). They were able to view facets of their lives through a different conceptual framework. They searched deeper for meanings and gained new understandings of themselves. This re-gauging of experiences was also described by Tan (2018) to be beneficial. It facilitated higher expectations from their life than they had had previously experienced and provided an empowered feeling that they could take control and make changes to enhance their experiences.

The resultant impact of this expert self-knowledge development meant that instead of merely *surviving,* they started to explore ways in which they could improve their wellbeing (Leedham *et al.* 2020). For the first time in their lives they had autonomy in selfhood and started to ask ‘why’ they experienced things differently, rather than just accepting their difference as a barrier. Participants’ improved self-understanding has also been alluded to elsewhere (Tan, 2018). The deconstruction of their experiences enabled participants to develop useful individualised everyday personalised strategies which provided feelings of self-efficacy and encouraged the process to continue.

9.6.6 Consequence: Thriving Autistic Identity

Increased Confidence, Empowerment, Self-Efficacy and Enhanced Wellbeing

Knowledge acquisition and self-reflection altered participants’ expectations and promoted a different conceptualisation of themselves. Instead of trying to modify themselves to ‘fit in’ and have a better neurotypical experience, they focused on modifying their experience to have a better autistic life. They reconceptualised themselves, removing their ‘spoiled identity’ to a new accepted neurodivergent identity’. Thriving participants started to embrace their difference. These findings mirror those found by Tan (2018) who recruited participants (22-65) from autism activist groups to take part in her study. She entitled the resultant paper *‘I am a normal autistic person not an abnormal neurotypical’* (Tan, 2008:161). In this paper Tan outlines the transformational experience of normalising autism and reframing of experience. Indeed, there are striking similarities between the findings of Tan (2008) and the present study. There is concordance between the two studies regarding the beneficial impact the reconceptualisation of autism can have for autistic people; in this study from ‘spoiled identity’ to ‘thriving’ and in Tan’s ‘devaluation to redemption’ (Tan, 2008:164). Tan discusses *biographical illumination* which mirrors a ‘thriving autistic identity’. Indeed, they appear to be very similar concepts and could be considered as the same way of conceptualising autistic experience. However, in Tan’s study (2018) there is no suggestion of any catalyst or prerequisites to the process other than diagnosis. All her participants experience *biographical illumination.* This is potentially because she recruited through autism activist web communities. It is possible that her participants had gone through the causal conditions needed to thrive, but this is not explicitly explained. She also highlights that not much is known about those who do not have the opportunity to partake or chose not to align themselves with autistic advocacy organisations, which emphasises the novelty of this study as these would be the ‘surviving’ participants. Nonetheless *biographical illumination* and *thriving* appear to be tantamount to the same conceptualisation of autism with the same effect of enhancing wellbeing. Certainly, the evidence given by Tan further supports the resonance of the ‘thriving cycle’.

In her study Tan’s (2018) findings discuss the fact that gaining a diagnostic label typically increases medical interaction, but she argues that when diagnosis evokes *biographical illumination*, it can paradoxically reduce medicalisation, as individuals become more self-aware. This has positive implications for both wellbeing and economic reasons. With the similarity identified between *thriving* and *biographical illumination,* we could assume that similar findings might have been discovered in the present study had it been specifically explored. What is clear is that feelings of self-efficacy and enhanced wellbeing are associated with *thriving* and therefore one might assume that reduced medicalisation would follow. This would certainly give further emphasis and perhaps economical support for encouraging autistic adults to experience the causal conditions and thereby starting their journey on the thriving cycle.

9.6.7 Summary

Thriving can be viewed as a reconceptualisation of self. It goes beyond viewing life through a new lens as discussed in previous studies, but aligns with biographical illumination (Tan, 2018). Embracing an autistic identity through internalising and accepting autism, together with being exposed to positive constructions of autism sets the thriving wheels in motion. Not only does it foster the ability to reinterpret previous life events, but it provides new self-information which is empowering and allows participants to make significant changes in their current life and remove perceived barriers.

This study provides a novel contribution to knowledge through '*the thriving cycle'*. It acknowledges that an autism diagnosis can be beneficial to removing blame for a perceived 'spoiled identity' but that the beneficial effect of this alone is liminal. In order to thrive, participants must go on a further journey of self-discovery. It was only when participants were able to reconceptualise autism in a more positive light by internalising and accepting autism and being exposed to positive constructions of autism, did they feel impetus to become a *seeker* of autism knowledge (Huws & Jones, 2008). The knowledge acquisition, support, and validation they received from the autistic community gave them confidence to reflect on their own experiences and make modifications based on their new expectations of life. They no longer viewed autism as a barrier, but a part of themselves and they recognised their personal strengths and weaknesses. They felt empowered, had increased confidence and had overall enhanced wellbeing.

The discussion has brought together international literature from across the autism research field it has also included perspectives from different participants' groups including adolescence and mid- to late-adulthood and this study adds much needed older adult perspectives to the research landscape. It has also included empirical evidence from relevant sources and where necessary drawn wisdom from other research fields to foster understanding of the findings. This thesis highlights the plight of undiagnosed autistic people and emphasises the urgent need of better diagnostic pathways which includes appropriate post-diagnostic support that should be designed and framed using the conceptual understanding provided by *the thriving cycle.*

The premise of the thriving cycle can be summarise by the following quote by the humanist psychologist Carol Rogers:

"*The curious paradox is, that when I accept myself just as I am, then I change".* (1995)

9.7 Overall Reflection

In this section I will reflect on the decisions made throughout the research process and include details of the important lessons I have learnt that I will utilise in my future research career. In designing the study, I was highly motivated with very honourable intentions to explore the wellbeing of older autistic people. With my autistic family member in mind, I wanted to contribute to knowledge in specific ways, with practical solutions that could promote wellbeing for autistic people. Despite apparently embracing the social model of disability, I started the research with the completely misguided presumption, I am now ashamed to admit, that I could find a way that would help autistic people ‘fit in’ better and thereby enhance their wellbeing. Admission of this ill-advised presumption is the best way I can illustrate the growth and learning I have undergone throughout this study. My personal conceptualisation of autism is different, my philosophy of life is different, and my understanding is now completely different. I now realise that ‘fitting in’ is not a goal for autistic people, indeed it is a barrier, acceptance is key. This is an invaluable lesson that will prove essential in life and my future research career. Having shared the unpleasant truth of my misguided beginnings, I will now reflect on the different elements of the research process.

Reviewing the literature prior to data generation was essential for the reasons outlined in chapter three. I needed to be theoretically sensitive in my data generation, I did not want to go into the fieldwork phase of the study and inadvertently offend or upset one of the participants. The decision was made to only include qualitative research studies that had been conducted with autistic adults in the literature review. This decision was taken as I felt strongly that it was only the autistic voices themselves and not that of proxy accounts that I wanted to consider. On reflection I could have included autobiographical accounts that had been published, such as Temple Grandin’s *Thinking in Pictures* (2006); Donna Williams’ *Nobody Nowhere* (1992) or *Somebody Somewhere* (1994) or Daniel Tammet’s *Born on a Blue Day* (2007). This would have added a breadth to the literature review given the scant number of qualitative studies available. However, at the time I thought that it might have confused the results and overwhelmed the other autistic voices that were not quite so eloquent or edited. Prior to starting this research, I had read a number of autistic biographies, read blogs, attended conferences and watched online videos from autistic people. This information was used to ensure I was theoretically sensitive but was not included within the review in chapter three.

Thinking back to recruitment, it started with attendees at an autism conference. After which other avenues were subsequently used for recruitment, with social media use being the last element added. Recruitment was difficult, and this was anticipated as discussed in chapter two there were only a relatively small numbers of over 50s that were diagnosed. It was frustrating that I had not recruited more participants from the conference attendees. However, on reflection this was fortuitous. The fact that recruitment was difficult, led to participants being recruited through various means with a spread of experiences. The thriving cycle would never have been discovered if all 14 participants had been highly motivated information seekers recruited through the conference. Neither would it have evolved if I had turned straight to social media to recruit, which may have had similar effects.

The process of data generation and interviewing the autistic older adults that I met, was by far my favourite part of this project. Despite it being awkward at times, as I altered my natural style of communication in recognition of the participations needs, I will always remember these interviews. The fact that I deliberately altered my natural self in our interactions and felt how strange, and at times stressful that was, was an important experience for me. Once the findings of the study were starting to emerge I realised that in those moments my feelings resembled the feelings the participants were describing to me in their social interactions. I reflected on, how nervous I felt, how I was looking for every verbal and nonverbal cue possible, how I was unusually aware of the environment, the lights the sounds the smells because I wanted the participants to feel comfortable. In one of my post interview reflective audio memos, I remark *'I'm totally exhausted after that [the interview]'.* The feeling of exhaustion had post interview helped me empathise with the experience of the participants and highlighted to me just how tiring it was to modify and be aware of my social interaction style.

The advisory group were invaluable. Initially I felt their role would be very much in traditional Patient and Public Involvement (PPI) format, checking study documentation and interview questions etc. However, their role organically grew to something much more. Talking with them, both directly about the project and in general was enlightening. They enabled me to be better attuned to the nuanced autistic experiences that as a novice autism researcher I may have overlooked. They provided insight into communication and gave me the confidence to theoretically sample on difficult topic areas. A pertinent example to share is the uncomfortable and disturbing topic of sexual abuse/assault. This was stumbled upon in the interview with my first female participant. Sexual assault was casually mentioned within a different conversation topic. At the time I did not feel confident enough to probe this issue, as it had been casually mentioned and then moved away from quickly. I spoke with the advisory group about this. I shared my naïve presumption that the participant did not seem upset by it as it was not disclosed with any gravitas or emotion and in a matter-of-fact way. Again, this reflection feels embarrassing now, of course the advisory group explained to me that I should not be distracted by non-conventional delivery of information. The conversation with the advisory group gave me confidence to member check with the participant about this incident, which of course was an incredibly emotion laden event. Without the advisory group helping to attune me to the nuanced communication styles or giving me the confidence to member check on difficult subjects I feel I may have missed a lot of meaning within the data.

Another part of the project that has been nerve wracking whilst simultaneously being one of my favourites, is the dissemination of the results that I have done so far. Attending and presenting at the Scottish Autism Conference in 2018 was an enlightening experience which I reflect on in chapter four. I had just finished data collection and was immersed in the analysis of the project. I had learned so much from listening to autistic people and reflecting on their experiences. However, I attended this conference and was appalled. My new in-depth knowledge of the experience of autistic people meant that I knew that the venue, the lights, the configuration of the rooms, the information pack and the lunch were all completely inaccessible for autistic people. It was clear that autistic people had not be involved in any of the organisational aspects of the conference. The Participatory Autism Research Collective (PARC) parallel ‘conference’ was upstairs tucked away from the main conference, with very few of the delegates (except me) from the main conference attending sessions. This made me reflect that even the biggest autism organisations were not listening or considering autistic needs, and that the autistic voice was still not truly valued. This gave me renewed assurance that this project is vitally important and that the findings will influential.

Overall, the amount I have learnt and developed throughout this process is impossible to document here. These lessons will always stay with me and will inform future research projects and my wider life. I am passionate about continuing working in autism research and know I still have much more to learn.

9.7.1 Limitations

This study offers careful and considerate design which has provided a much-needed opportunity to gain insight from the experiences of older autistic adults. As such, this study can be seen to have many strengths. Not only has the project provided evidence to important factors that influence the wellbeing of older autistic adults, and arguably all autistic people, but it has demonstrated its high-quality person-centred methodology. Prior to sharing the implications of this study for research, policy and practice it is important to discuss the limitations of the project so that the reader is aided to correctly interpret the findings.

9.7.2 Limitations Related to Participant Sample

The study is comparatively small with fourteen older autistic adults' experiences included. It was not anticipated that the results would be widely transferable (Sikolia *et al.* 2013), particularly considering the heterogeneity of the autistic experience (Fletcher-Watson & Happe, 2019). Due to the inclusion criteria of an official autism diagnosis and the small number of diagnosed autistic adults aged over 50 recruitment was anticipated to be difficult. Despite this being a relatively small sample, participants were recruited through different avenues and the resultant sample included a broad range of life experiences that were substantially different to one another. This is demonstrated through the pen portraits of chapter five.

Despite the differing life experiences of participants there was a homogeneity of participants' group characteristics. All participants were of white ethnicity and all but one was British. No participants had a learning disability. This is not representative of the autism population. An ethnically diverse sample would be beneficial to explore the nuanced way in which autism is experienced in different ethnicities/cultures and countries.

An inclusion criterion was that participants had an official autism diagnosis. The findings have highlighted the problematic route to diagnosis and its many barriers. There is growing anecdotal evidence that many autistic adults are not seeking an official autism diagnosis due to these barriers and are living with a self-diagnosed autistic identity. Indeed, all but two of the participants had recognised themselves as autistic prior to diagnosis. Therefore, I feel the inclusion criteria of having an official diagnosis may have limited the recruitment to this study. It may be pertinent to include those who are self-diagnosed and use standardised measures such as the Autism Spectrum. Quotient (AQ) (Baron-Cohen *et al.* 2001) to measure autism characteristics of the sample.

9.7.3 Limitations Related to the Researcher

The fact that I am not autistic has posed a potential limitation within this research. This is something that I have been aware of and planned to mitigate the effects throughout the research. Immersing myself in autistic culture together with academic literature helped me to understand the nuanced experiences that I may otherwise have overlooked. I attempted to guard against any double empathy problem (Milton, 2012) by forming and consulting the advisory group. Despite these mitigation factors, I cannot be certain that my neurotypical interpretation did not impact the results. Using Arstein's (2019) model of citizen partnership, a *partnership model* or *delegated powers* model would be a more appropriate model to facilitate amelioration of this problem and will be the basis of all my future autism research projects.

9.7.4 Limitations Relation to Data Generation Methods

The data generation was conducted pre-pandemic and although many modes to participation were offered and a person-centred approach to design incorporated there were fewer remote data generation methods selected by participants. This could potentially have been due to the age group I was seeking to recruit. However, since Covid-19 pandemic, through necessity, video conferencing and remote methods have become more commonplace. Indeed, it is now a more accepted way of conducting research and could potentially now facilitate better engagement within the older autistic population (Bolan *et al.* 2021).

The data generation methods, and very nature of volunteering to take part in an interview study could be perceived as a bias to the results. I feel certain that this has occurred in this sample. All participants at time of interview felt autism was a positive additional to their lives. I feel that the interactional nature of an interview-based study may preclude those who do not feel positively about autism. Therefore, they would not be motivated to take part in research as they may avoid information or talking about autism (Huws & Jones, 2008). The wellbeing of those who do not view autism positively and those experiencing the post diagnostic slump are of major concern and methods to capture their experiences should be explored.

9.8 Implications, Recommendations and Conclusion

9.8.1 Implications for practice

The study has highlighted several key implications for policy and practice. I will summarise each below:

Autism Expertise: The findings have shown that autistic people are experts by experience and have a wealth of knowledge and insight about autism. Service design and provision and future research should always have autistic expertise integral in the process.

Autism Diagnosis: As highlighted by the findings, the life experience and confusion caused living by ‘not knowing’ is harmful to wellbeing. This reinforces the need for early recognition and diagnosis of autism. However, there are many adults in the ‘lost generation’ (Lai & Baron-Cohen, 2015) like the participants in this study might require referral for a very late diagnosis of autism in mid- to late-adulthood. Gatekeepers must receive further training on autism that covers three essential points. First, that an autism diagnosis is beneficial to personal wellbeing despite inadequate post-diagnostic service provision. Second, how to appropriately recognise a non-stereotypical presentation of autism in the older adult population and to value the person’s self-diagnosis and opinions. Third to appropriately frame autism, so conversations can start with terminology that will not be detrimental to acceptance (Bottema-Beutel *et al.* 2021).

The findings clearly show the powerful effect that positive constructions of autism have. Diagnostic services who are often one of the first to frame autism for individuals and their families should consider altering the language used throughout the process and should refrain from using deficit-based terms. This can help foster self-acceptance and internalisation of autism that will help to initiate the thriving cycle and therefore enhancing wellbeing.

Post Diagnostic Support: As highlighted in the findings, diagnosis for older autistic adults is a transformational experience. To assist newly diagnosed autistic older adults make sense of their diagnosis they should be offered a programme of post-diagnostic support in line with NICE guidelines (NICE,2012). The findings indicate that for autistic people to thrive this support should utilise the principles of *the thriving cycle*. Support designed in this way would assist with the internalisation and acceptance of autism and should be framed by positive constructions of autism. Such post-diagnostic support should be led by thriving autistic older adults who have experienced a very late diagnosis. A group peer support autistic led model could be best placed to provide support as suggested by Crane *et al.* (2020), or individual therapy using the clinical framework (INVEST) put forward by Zener (2019). However, autistic people should undoubtedly be involved in any development of any post-diagnostic support to ensure it is appropriate.

The participants' accounts show that self-acceptance and internalisation of autism was supported by significant relationship in the lives of thriving participants. Post-diagnostic education should be provided to support families and significant others in the lives of the newly diagnosed autistic people in their acceptance and understanding of autism. This should also be framed by the principles of the thriving cycle to help promote understanding and acceptance.

The findings identified a lack of post-diagnosis formal support. The importance of social relationships with other autistic people has also been highlighted. These relationships reportedly legitimise and validate newly diagnosed autistic people's experiences. They also provide the novel experience of social interaction with an accepting group with similar communication styles. Therefore, creating formal spaces and times for these groups to take place that can be signposted at diagnosis is of paramount importance. These groups should be offered in different formats both virtually and in person.

Autism Education and Training – As highlighted in the findings the most detrimental facet of the participants' lives was not being accepted. This is born out of a lack of knowledge and understanding of the general public. New importance should be placed on ensuring mandatory autism training is appropriate and completed by all. Thriving participants viewed autism as a positive part of their self-identities thus it is important for training to recognise and value autistic adults' strengths while providing ideas of how to support them in areas of difficulty.

9.8.2 Future Research Priorities and Recommendations

The findings have identified facets of the participants' experiences that warrant further research, as research in this area is still sparse (Mason *et al*. 2022). Further research is undoubtedly required to gain a fuller understanding of the experiences of older autistic adults. This research should be participatory or autistic-led for both epistemic and ethical reasons (Crane *et al.* 2018; Fletcher- Watson *et al.* 2019; Milton & Bracher, 2013). The recommendations for future research priorities are all presented with this ideology.

The thriving cycle needs to be tested for resonance and usefulness with various groups of participants. Further studies should include populations omitted from this research such as ethnically diverse participants, participants with learning disabilities, different nationalities, different age groups and with autistic people who do not view autism positively. It would be useful to undertake longitudinal studies starting at diagnosis to test the journey of the thriving cycle.

This research has also highlighted a potential crisis point post-diagnosis that has thus far not been highlighted in the literature. A post-diagnostic slump that lasted a significant time with worsening mental health was experienced by some participants. Due to the high prevalence of suicidal ideation and suicide attempts in autistic people, further research needs to explore the hypothesis that there may be a high incidence of suicide attempts/completions post-diagnosis.

There is a lack of support services for newly diagnosed autistic adults. An action research project that designs post-diagnostic support based on the principles of the thriving cycle together with the needs and experiences of previously diagnosed and thriving autistic adults should be designed, trialled, and evaluated.

The findings suggest that after gaining a position of ‘knowing’ that acceptance and internalisation of autism together with positive construct of autism are important causal conditions to start the thriving cycle and gaining a thriving autistic identity. Some autistic adults gain a position of ‘knowing’ without diagnosis and are self-diagnosed. Further investigation would be beneficial to explore if the causal conditions for the thriving cycle are more influential than actual diagnosis on reaching a thriving autistic identity.

The thriving participants with enhanced wellbeing used the autism community as peer support that was valuable as it provided validation, confidence and opportunity for appropriate social comparisons. In-depth research into functions of peer support, characteristics of online communities could inform collaborative development of formal peer support services by autistic adults, services and organisations.

9.9 Conclusion

This research aimed to explore the wellbeing of older autistic adults. The study’s findings contributed to the conceptual theory of ‘*the thriving cycle’*, which captures the self-determined process beyond autism diagnosis and the causal conditions which enhances the wellbeing of older autistic adults. The presentation of this theory challenges the current understanding of autism diagnosis in the literature. It suggests that the beneficial impact of diagnosis on wellbeing is liminal and proposes that diagnosis alone is insufficient to significantly enhance wellbeing.

Ultimately the theory conveys how thriving is a self-determined process that can only be accessed through internalisation of autism, self-acceptance and positive constructions of autism. The theory recognises the fluidity of the participant’s self-identity. From ‘spoilt identity’ of ‘not knowing’, to a forgiven but ‘spoilt identity’ via ‘knowing’ that is reconceptualised as an ‘accepted neurodivergent identity’ through the ‘thriving cycle’.

The ‘thriving cycle’ is associated with diagnosis but importantly it is not defined by it, as to start the thriving cycle it is important to reconceptualise autism from the ‘deficit’ model presented at diagnosis to a ‘neurodivergent’ model. The insights given by this study are relevant, not least because they provide impetus, direction and a framework for the design of much needed post-diagnostic support. The study also places prominence on the fundamental importance of listening to autistic people regarding their experiences, as they are autism experts. Additionally, and perhaps more far reaching, it emphasises the fundamental importance of acceptance and understanding of autistic people.

As this study was focused on providing a platform for the voice of autistic participants, it seems fittings that I conclude this thesis with the words from one of the participants. Peter eloquently and accurately summarises what has the most impact on autistic wellbeing:

> *If you’re looking for me to encapsulate in one word… acceptance…that’s what makes the difference with children, that’s what makes the difference for young people and that’s what makes the difference to move forward… acceptance is the way… acceptance is the one thing that will make the difference, it’s the only thing that will make the difference.* (Peter/M/55/7)

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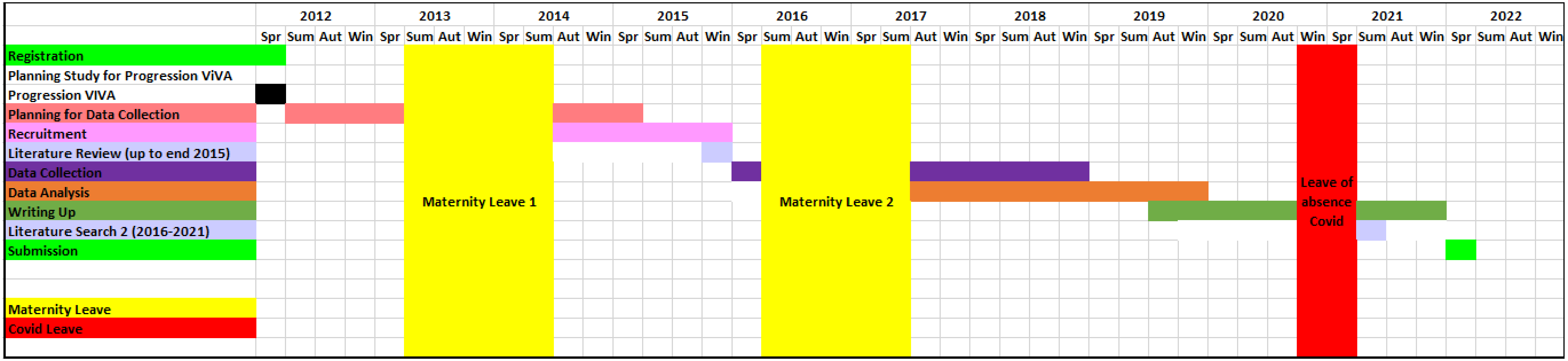
Appendix one: Literature Search 2 (2016-2021)

<table>
<tr><td>Search Terms #S1
(In Title or Abstract)</td><td colspan="2">Autis* OR ASC OR ASD OR Asperger*
AND
Qualitative OR Interviews OR Lived experience* OR narrative OR autobiographical OR biographical OR Life</td></tr>
<tr><td>Date range:</td><td colspan="2">2016 to 2021</td></tr>
<tr><td>Language:</td><td colspan="2">English – This was selected due to resource issues</td></tr>
<tr><td>Age range:</td><td colspan="2">Adult 16+ This was selected as I am interested in research done on older adults. I included all adults over 16, due to the lack of research with older autistic adults.</td></tr>
<tr><td>Source</td><td colspan="2">Peer Reviewed Journals only – As a preliminary search I am interested specifically in research done in this area and therefore I have limited my search to academic journals only.</td></tr>
<tr><td>Inclusion criteria:</td><td>Methodological filters
• Qualitative research
• Primary data</td><td>Topic based filters
• ‘Wellbeing’ issues
• Experienced based
• Adults</td></tr>
</table>

Database/source	**Search Terms**	**Stage 1 (Matches)**	**Stage 2 (Matches) Discounting Duplicates**	**Stage 3 (Matches)**
PubMed	See Table 1	1193	30	19
CINHAL	See Table 1	285	15	5
Cochrane Review	“Autism”	0	0	0
PSychInfo	See Table 1	1053	12	2
Autism (Journal)	“Qualitative”	22	1	0
Research in Autism Spectrum Disorders	“Qualitative”	206	5	2
Journal of Autism & Developmental Disorders	“Qualitative AND Adults”	488	7	5
Disability & Society	“Qualitative AND Autism”	109	2	2
Autism in adulthood	Qualitative	69	6	6
References list searching	n/a	0		
				41

Appendix two: study timeline



Appendix three: Adapted Critical Appraisal Skills Programme. Checklist

(for Qualitative Studies)

Research Paper for appraisal

Huws, JC. & Jones, RSP. (2008) *Diagnosis, Disclosure, and Having Autism: An Interpretative Phenomenological Analysis of the Perceptions of Young People with Autism.* Journal of Intellectual & Developmental Disability, 33(2) 99-107

Participants:

- Semi-structured interviews were conducted with nine young people with high functioning autism
- IPA was used
- Nine students (three female and six male)
- Ages ranged from 16– 21 years,
- they had attended the college for between 1 and 4 years.

Aim:
Exploring participant’s perceptions of autism and their diagnosis experiences

Methods: Semi structured interviews. IPA

Location: Wales

	Yes	No	Can’t tell
Was there a clear statement of the aims of the research?		x	
There was not a clear statement of the research aims but included in the discussion the paper outlines the focus being participant’s perceptions of autism and their diagnosis experiences.			
Is a qualitative methodology appropriate?	x		
It would not be appropriate to use any other methodology.			
Was the research design appropriate to address the aims of the research?	x		
Not completely as there was no autistic expertise in construction of the research tools or involved in data analysis. There is no acknowledgement from the authors that their thinking might be different from the participant’s. However, this study predates the ‘double empathy problem’ paper (Milton, 2012). These factors should be considered when interpreting the findings.			

Was the recruitment strategy appropriate to the aims of the research?			
All the participants came from a college for autistic children. They are all therefore exposed to similar experiences and similar ideas about autism. As this study is interested in the perception of autism, it is biased in that there would be reason to believe that all the participants may have the same influences.			
Was the data collected in a way that addressed the research issue?	x		
This data was collected through the use of three open ended questions about the perception of autism. In that way the research was not constrained by specific questions that could potentially miss valuable data.			
Has the relationship between researcher and participants been adequately considered?		x	
Data was collected in a way that addresses the research issue, however the paper states that interviews were conducted in an office within the school. It does not explain that additional efforts were made to ensure that the researcher's role was sufficiently clarified. As participants are potentially familiar with having meetings with teachers and other education and social care professionals, the researcher role could well have been misconstrued and therefore the findings flawed. Again, this must be taken into account when examining the findings.			
Have ethical issues been taken into consideration?		x	
There is no mention of ethical issues.			
Was the data analysis sufficiently rigorous?	x		
Data analysis procedures were significantly rigorous, but potentially flawed by not involving autistic people to hep guard against interpretation problems. There was no mention of member checking or clarifying meaning.			
Is there a clear statement of findings?		x	
Mixed, there are some clear findings that are not translated to discussion.			
How valuable is the research?			
This research is very valuable as it is one of the first pieces of research that explores autistic adolescence experience through first hand qualitative accounts. There may be flaws in some of the design and the fact that autistic people were not included. This could have led to misinterpretation of the data, but the study raises interesting points and starts conversations and for this reason remains highly cited.			

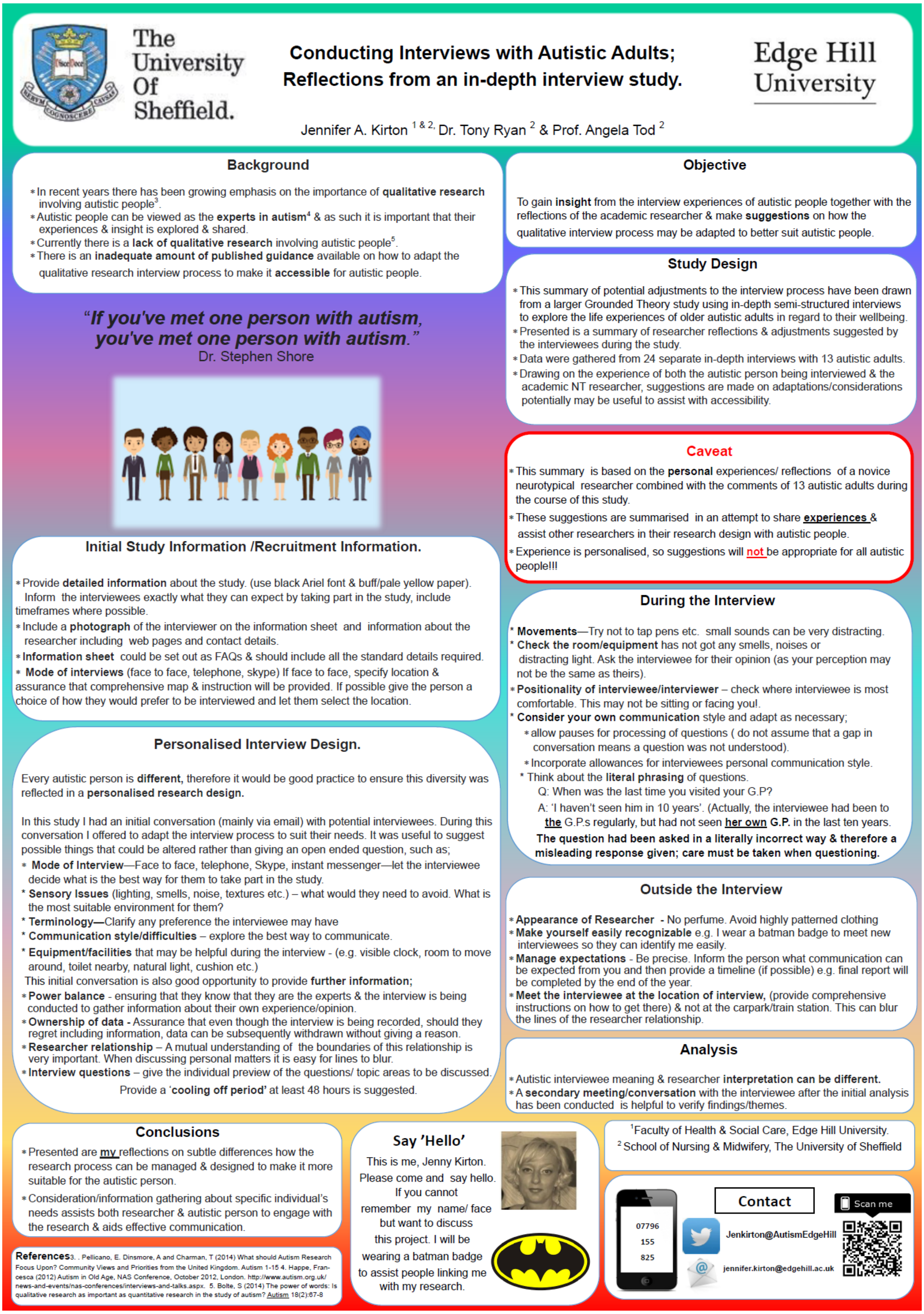
Appendix four: data extraction table for studies included in the literature review

Source & Location	Aim	Methods	n	Age	Gender		Location & Recruitment
					M	F	
**Hurlbutt & Chalmers (2002)	To describe perceptions of their life experiences.	In depth interviews. Follow up by phone and email.	3	31-61 (31,35,61) (μ= 42.3)***1	2	1	USA: Purposively recruited via attendance at National Conference
**Hurlbutt & Chalmers (2004)	To explore autistic adults' experiences regarding employment.	In depth interviews. Follow up by phone and email.	6	25-65 (25,35,39,43,56,65) (μ= 43.8)***2	3	3	USA: Purposively recruited via attendance at National Conference & Autism chat support
Portway & Johnson (2005)	The risks of having a non-obvious disability,	Life stories; unstructured interviews	18	18-35	21	4	England: Purposively recruited through autism services.
*Huws & Jones (2008)	To explore the perceptions of diagnosis, disclosure & having autism.	semi structured interviews.	9	16-21	6	3	Wales: Purposively through a gatekeeper in a college for autistic students.
Muller *et al* (2008).	To explore perspectives regarding social challenges & supports	Interviews, coding member checked & autistic core team	18	18-62 (μ= 37.2) ***3	13	5	USA: Contact through ASC & support groups.
Punshon *et al* (2009)	The examination of the experiences autistic adults receiving their autism Dx.	Interviews	10	22-45 median 31	7	3	England: Contact through local service for autistic adults.

Griffith et al (2012)	To explore the support needs of autistic individuals.	Interviews	11	37-57 μ= 46.36 ***3	7	4	Wales : Advertisements on autism charity web page. Inclusion ->35
Krieger *et al.* (2012) ‘	To explore factors which contribute to successful labour market participation	In depth Interviews	6	30-45	4	2	Switzerland : Healthcare gate keepers only inclusion: in employment for 18 months
Smith & Sharp (2013)	To investigate how unusual sensory experiences, affect autistic adults’ lives.	Interviews via instant messaging software.	9	25-39	6	3	England : Local service for HFA/AS adults with experience of USEs
*Huws & Jones (2015)	Exploring the use of social comparisons when describing their experiences of Dx.	Semi structured interviews.	9	16-21	6	3	Wales : Purposively recruited Through a gatekeeper in a college for autistic students. Inclusion: Dx of AS
Nicolaidis*. et al. (2015)*	To obtain understanding of autistic adults’ experiences with healthcare	Participatory study employing interviews:	39	19–64 μ= 35	22	17	USA : Via local & national autism related organizations & disability services
Robertson & Simmons (2015)	To explore the unusual sensory experiences	Focus Group	6	24 -51 μ= 32	5	1	Scotland: All parts. were highly able, worked for a local company that employed adults with ASC
			139	Only 10 Participants >50****	94	46	

*Denotes two papers that used the same data set.
** Denotes two papers that used the same participants within the study. The second study used the same participants as the first study with an additional 3 participants also.
***The number of participants in the sample over 50 (if known)
**** excluding Nicolaidis (2015)

Appendix Five: Scottish Autism Conference in 2018 (Kirton 2018) Poster



The University Of Sheffield.

Conducting Interviews with Autistic Adults; Reflections from an in-depth interview study.

Edge Hill University

Jennifer A. Kirton [1 & 2], Dr. Tony Ryan [2] & Prof. Angela Tod [2]

Background

- In recent years there has been growing emphasis on the importance of **qualitative research** involving autistic people[3].
- Autistic people can be viewed as the **experts in autism**[4] & as such it is important that their experiences & insight is explored & shared.
- Currently there is a **lack of qualitative research** involving autistic people[5].
- There is an **inadequate amount of published guidance** available on how to adapt the qualitative research interview process to make it **accessible** for autistic people.

> ***"If you've met one person with autism, you've met one person with autism."***
> Dr. Stephen Shore

Initial Study Information /Recruitment Information.

- Provide **detailed information** about the study. (use black Ariel font & buff/pale yellow paper). Inform the interviewees exactly what they can expect by taking part in the study, include timeframes where possible.
- Include a **photograph** of the interviewer on the information sheet and information about the researcher including web pages and contact details.
- **Information sheet** could be set out as FAQs & should include all the standard details required.
- **Mode of interviews** (face to face, telephone, skype) If face to face, specify location & assurance that comprehensive map & instruction will be provided. If possible give the person a choice of how they would prefer to be interviewed and let them select the location.

Personalised Interview Design.

Every autistic person is **different,** therefore it would be good practice to ensure this diversity was reflected in a **personalised research design.**

In this study I had an initial conversation (mainly via email) with potential interviewees. During this conversation I offered to adapt the interview process to suit their needs. It was useful to suggest possible things that could be altered rather than giving an open ended question, such as;

- **Mode of Interview**—Face to face, telephone, Skype, instant messenger—let the interviewee decide what is the best way for them to take part in the study.
- **Sensory Issues** (lighting, smells, noise, textures etc.) – what would they need to avoid. What is the most suitable environment for them?
- **Terminology—**Clarify any preference the interviewee may have
- **Communication style/difficulties** – explore the best way to communicate.
- **Equipment/facilities** that may be helpful during the interview - (e.g. visible clock, room to move around, toilet nearby, natural light, cushion etc.)

This initial conversation is also good opportunity to provide **further information;**

- **Power balance** - ensuring that they know that they are the experts & the interview is being conducted to gather information about their own experience/opinion.
- **Ownership of data -** Assurance that even though the interview is being recorded, should they regret including information, data can be subsequently withdrawn without giving a reason.
- **Researcher relationship** – A mutual understanding of the boundaries of this relationship is very important. When discussing personal matters it is easy for lines to blur.
- **Interview questions** – give the individual preview of the questions/ topic areas to be discussed.

Provide a '**cooling off period'** at least 48 hours is suggested.

Objective

To gain **insight** from the interview experiences of autistic people together with the reflections of the academic researcher & make **suggestions** on how the qualitative interview process may be adapted to better suit autistic people.

Study Design

- This summary of potential adjustments to the interview process have been drawn from a larger Grounded Theory study using in-depth semi-structured interviews to explore the life experiences of older autistic adults in regard to their wellbeing.
- Presented is a summary of researcher reflections & adjustments suggested by the interviewees during the study.
- Data were gathered from 24 separate in-depth interviews with 13 autistic adults.
- Drawing on the experience of both the autistic person being interviewed & the academic NT researcher, suggestions are made on adaptations/considerations potentially may be useful to assist with accessibility.

Caveat

- This summary is based on the **personal** experiences/ reflections of a novice neurotypical researcher combined with the comments of 13 autistic adults during the course of this study.
- These suggestions are summarised in an attempt to share **experiences** & assist other researchers in their research design with autistic people.
- Experience is personalised, so suggestions will not be appropriate for all autistic people!!!

During the Interview

- **Movements**—Try not to tap pens etc. small sounds can be very distracting.
- **Check the room/equipment** has not got any smells, noises or distracting light. Ask the interviewee for their opinion (as your perception may not be the same as theirs).
- **Positionality of interviewee/interviewer** – check where interviewee is most comfortable. This may not be sitting or facing you!.
- **Consider your own communication** style and adapt as necessary;
  - allow pauses for processing of questions (do not assume that a gap in conversation means a question was not understood).
  - Incorporate allowances for interviewees personal communication style.
  - Think about the **literal phrasing** of questions.

Q: When was the last time you visited your G.P?

A: 'I haven't seen him in 10 years'. (Actually, the interviewee had been to the G.P.s regularly, but had not seen her own **G.P.** in the last ten years.

The question had been asked in a literally incorrect way & therefore a misleading response given; care must be taken when questioning.

Outside the Interview

- **Appearance of Researcher** - No perfume. Avoid highly patterned clothing
- **Make yourself easily recognizable** e.g. I wear a batman badge to meet new interviewees so they can identify me easily.
- **Manage expectations** - Be precise. Inform the person what communication can be expected from you and then provide a timeline (if possible) e.g. final report will be completed by the end of the year.
- **Meet the interviewee at the location of interview,** (provide comprehensive instructions on how to get there) & not at the carpark/train station. This can blur the lines of the researcher relationship.

Analysis

- Autistic interviewee meaning & researcher **interpretation can be different.**
- A **secondary meeting/conversation** with the interviewee after the initial analysis has been conducted is helpful to verify findings/themes.

Conclusions

- Presented are my reflections on subtle differences how the research process can be managed & designed to make it more suitable for the autistic person.
- Consideration/information gathering about specific individual's needs assists both researcher & autistic person to engage with the research & aids effective communication.

References 3. . Pellicano, E. Dinsmore, A and Charman, T (2014) What should Autism Research Focus Upon? Community Views and Priorities from the United Kingdom. Autism 1-15 4. Happe, Francesca (2012) Autism in Old Age, NAS Conference, October 2012, London. http://www.autism.org.uk/news-and-events/nas-conferences/interviews-and-talks.aspx. 5. Bolte, S (2014) The power of words: Is qualitative research as important as quantitative research in the study of autism? Autism 18(2):67-8

Say 'Hello'

This is me, Jenny Kirton. Please come and say hello. If you cannot remember my name/ face but want to discuss this project. I will be wearing a batman badge to assist people linking me with my research.

[1]Faculty of Health & Social Care, Edge Hill University.
[2] School of Nursing & Midwifery, The University of Sheffield

Contact
07796 155 825
Jenkirton@AutismEdgeHill
jennifer.kirton@edgehill.ac.uk
Scan me

Appendix six: study information sheet

Research into the Wellbeing of Older Autistic Adults: An Interview Study

Participant Information Sheet

You are being invited to take part in an interview study which aims to explore the perspectives of older autistic adults on personal wellbeing. This research is interested in your own personal account and personal reflections on events in your life, and what are the most important factors in regarding your own wellbeing.

Please take the time to read this information carefully and talk to others about the study if you wish before deciding whether or not to take part.

What is the purpose of this study?

This study aims to gain insight into the life experiences of autistic older adults regarding their own personal wellbeing. Specifically looking at factors which promote or inhibit maintaining personal wellbeing.

A secondary aim of the research is to use a novel approach to conducting this research. The research will be conducted in an individualised way allowing each person to tailor their involvement in the research to suit their own needs. As such you can take part in the interview in a way that best suits you. You can be involved in a face to face interview, and online real time interview, a telephone interview, an email interview, a skype interview or any other mode of communication you feel most comfortable with. The way that the interview is conducted will also be individualised, you can tell the researcher what the most comfortable way for you is to engage with the research and it will be tailored to meet your personal needs.

It is hoped that the new knowledge gained in this study may help to develop better support for autistic people.

Why have I been invited to take part?

You have been invited to take part as you have an autism diagnosis and are aged 50 or over.

Do I have to take part?

No, it is up to you to decide if you wish to take part. If you agree to take part in the study you are free to withdraw from the study at any time, without having to give a reason.

What will happen to me if I take part?

If you decide to take part, we will have an initial contact (phone/text or email) with me where we can discuss the research project. This is an opportunity for me to provide you with further information about the research and your own specific needs and then decide if you wish to take part.

The research will involve having an interview with me (approximately 2 hours although it could be more or less depending on individuals) where we will discuss your experiences regarding personal wellbeing. Our conversations will be digitally recorded and transcribed. I will then analyse the transcriptions to look for themes. We will then have further contact to clarify meanings that have been taken from the interview. You are free to decline to take part in an interview at any time point, or to delay the interview.

What are the possible disadvantages and risk in taking part?

A possible risk is that you may discuss experiences that you find upsetting. If this happens, we can move on to another subject, end the interview or return to the interview on another day. You will direct the conversation during the interviews and so if there are matters that you do not wish to discuss you can omit these.

What are the possible benefits?

It is unlikely that there will be personal benefits from taking part in the research, although some people may find it interesting to discuss their life experiences. The main benefits will be to add to our understanding of the factor that are important in the wellbeing of older autistic adults.

What is will my relationship with the researcher be?

The relationship that you have with the researcher for the course of the research will be different from any other relationship you might have. Some professionals you meet might be teachers and you'd have a teacher - student relationship with them, the teacher is the expert and would be helping you with your study. Some professionals might be doctors, and you'll have a doctor - patient relationship with them where the doctor is the expert and the doctor would help you with your health concerns. In both cases with teacher and doctor their role in the relationship would be to help/assist you. This research relationship is different than those relationships because the researcher is not proposing to help you; actually you are helping the researcher by being part of the research. You are the person with all the knowledge and therefore the expert, and the researcher is the learner. It's more like an informant - researcher relationship. Once the research is finished that will signify the end of the researcher relationship.

Will my taking part be kept confidential?

Yes. Any personal information about you, family members, colleagues or friends will be removed from the transcripts so that anonymous quotations are used in any final reports. Any audio recordings will be kept secure and then destroyed after 5 years and any written information will be kept strictly confidential. However, we are creating your own life experience account and therefore if you so choose you can be named in the ultimate research report/publication.

Only if the researcher uncovers information that suggests that you, or others, are at risk of coming to any harm, will they break this confidentiality. The procedures for handling, processing, storage and destruction of data from the study are compliant with the Data Protection Act 1998.

What are you going to do with the results of the study?

The results of this study will be published in academic journals, and presented at conferences, and a final thesis will be written and submitted to The University of Sheffield as part of my doctoral studies. You will not be identified in any publication, unless you wish to be.

Who is organising and funding the research?

There is no funding attached to the research.

Who has reviewed the study?

This study has been given favourable ethical opinion by the School of Nursing & Midwifery, Sheffield University Research Ethics Committee (31.07.13). This means that the study has been scrutinised to ensure that it is planned in a way that ensures that both the interviewees and the researcher are safe and not at risk of harm due to their involvement in the study.

What if there is a problem?

If you are unhappy with the research in any way please tell me. Or if you would prefer to talk to my supervisory team please contact them;

Dr Tony Ryan, t.ryan@sheffield.ac.uk 0114 222 2062 or

Professor Angela Tod a.tod@sheffield.ac.uk 0114 2222057

The University of Sheffield, The School of Nursing and Midwifery, Barber House, 387 Glossop Road, Sheffield S10 2HQ

My Contact Details; If you would like to ask any other questions regarding the research, or what is expected from you, please contact me Jennifer Kirton 07796 155 825 (Monday to Friday 9am - 5pm)
or email Jennifer.kirton@edgehill.ac.uk
Please view my research profile: https://www.edgehill.ac.uk/eprc/jennifer-kirton/

Thank you for taking the time to read this information. Jenny

The batman logo is added to this information sheet as I will wear a batman badge if we meet for a face to face interview to help you recognise me.

Research into the Wellbeing of Older Autistic Adults: An Interview Study

Jennifer A. Kirton, Dr Tony Ryan & Prof Angela Tod

Privacy statement for the handling of data in the above research study

The University is committed to ensuring compliance with current data protection legislation and confirms that all data collected is used fairly, stored safely, and not disclosed to any other person unlawfully. The University is a data controller and, in some instances, may be a data processor of this data. At Edge Hill, we are committed to respecting and protecting your personal information. Certain individuals from the University and regulatory organisations may look at your anonymised research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. To find out more about how we protect your data, please see https://www.edgehill.ac.uk/about/legal/privacy.

Only Jennifer Kirton will have access to the original interview recordings and personal contact details; these will not be passed to anyone else or the University. Jennifer Kirton will only use personal information as needed, to contact you about the research study, and to send you a summary at the end of the study if you have requested one. You can request the removal of your personal data at any time by contacting Jennifer Kirton.

When the interviews are transcribed to word documents, all identifying features such as individual's names or names of organisations will be removed. Transcripts will be labelled with unique participant identifiers such as ID1, ID2, etc. Anonymised data from the interviews will be shared only within the research team to support analysis.

All information that is collected during the research will be kept strictly confidential and stored in a locked cabinet at Edge Hill University, and password protected computer files. The interview audio files will be kept until the Study ends in 2022 and then destroyed. All other information will be stored electronically and kept securely for up to 10 years. The exception to the maintenance of confidentiality would be solely where unsafe or poor practice by a registered nurse or other registered professional was highlighted. If any incidents are highlighted these will be discussed with you so you are aware that an issue has been identified. The issue will then be reported to the trust so the appropriate policies and procedures can be followed.

Jennifer Kirton

Jennifer.kirton@edgehill.ac.uk

Appendix seven: recruitment table and personalised requests for accommodations at interview

Participant	**Recruited from**	**Date**	**Mode of Interview**	**Location of Interview**	**Duration of interview**	Examples of personalised accommodations to the interview process requested (unanticipated)
Theo	Snowball from conference delegate	12.04.16 & 27.04.16	F2F	Home	1.15 & 1.48 (total 3.03)	Theo had precise start and finish times allocated for the interview, so it was important we adhered to them. He has wanted sight of a clock. Although I had previously delineated start and finish times, I had not previously considered taking a clock. I did this for subsequent interviews.
Ralph	Snowballing autism group	22.03.16 & 20.04.16	F2F	Home	1.49 &1.23 (total 3.12)	
Christine	Snowballing autism group	13.03.18 27.03.18	F2F	Home & University	3.13 & 2.35 (total 5.48)	It was an unusually hot spring day on our second interview and the University office window was open. When checking with Christine that she was comfortable, she shared with me that the window being open was distracting due to the low level noise and so we closed it to aid her concentration.
Peter	University weekly news	19.04.18 & 21.06.18	F2F	His Office	3.40 & 2.56 (total 6.36)	Peter wanted to conduct the interview with the main lights off and just a small lamp on as the lights were hurting his eyes.
Yvette	Snowballing from Peter	14.08.18	F2F	University	3.38	Yvette disclosed to me prior to the interview that she was quite often late for meetings. We decided that would be fine and I would go to our meeting location at the allocated time with work to get on with and she could arrive when she could without worrying that she was late.

Gary	Staff email	20.09.18	F2F	University	2.35	
Amy	Twitter	26.09.18	phone	Phone	1.29	
James	Snowball from conference	09.10.18	F2F	Home	2.01	James halfway through the interview mentioned a topic but then told me that he did not want to talk anymore about that subject, and we moved away from it. He also took the invited opportunity to contact me after the interview and ask me to remove another conversation out of the transcript, which I did.
Shelia	Twitter	4.10.18	phone	Phone	2.14	
Catrina	Snowball from autism group	16.10.18	F2F	Home	1.53	Catrina shared with me that she found low level noises very distracting. We agreed that I would be mindful not to tap or fidget and I asked her to inform me if I was making any distracting noises that I was unaware of.
Sophia	Facebook	23.10.18	phone	Phone	2.33	
Sylvia	Facebook	25.10.18	F2F	Rented Office in community HUB	1.52	Sylvia shared that she was prone to long digressions. We discussed this and I asked her what the best way for me would be to alert her that I suspected she was digressing and that we needed to return to the topic. We agreed on a signal of a raised hand.
Emma	Facebook	6.11.18	Phone	Phone	1.53	In a phone conversation Emma informed me that she would be playing a game on her phone throughout the conversation as that would make her feel more relaxed and enable her to concentrate better on our discussions.
Walter	Conference delegate	30.10.18	F2F	University	1.59	Walter informed me that he did not find it easy to look at people in the eye so he would prefer not to do that as he would be more comfortable. Given my knowledge on this subject it seemed appropriate that I offered to look away too. He was happy with this, and we conducted the interview neither looking directly at each other.

Appendix eight: Example extract from field notes post interview are given below:

“I thought it went really well ...conducting the interview, I went in and I was slower in my speech and calmer in my tone…There were no social niceties… I’m not saying that it was unfriendly because he certainly wasn’t, but no offering of a drink, no ‘oh you’re expecting a baby [I was heavily pregnant at time of interview] nothing like that. It felt really odd for me and unnatural, but it clearly was the right way to do it. …he spoke about recurrent negative thoughts from 20 odd years ago, similar to Theo, so I need to check back on that and certainly something to explore in the next interview. He did not seem to know much about autism, but he’s been diagnosed for a long time but has totally shut off from learning about it”.

(Field Notes made on 22.03.16 after Ralph Interview)

“Really interesting guy, clearly a very organised gentleman, bottle of water, glass on the table in preparation, had thought about where I was going to sit, so I didn’t have to talk about where he felt comfortable, or anything like that because he had already orchestrated where I was going to sit. He was very organised with his wellbeing rituals and really self-aware of what was good for him, I need to explore... he is so well attuned to his wellbeing... what is going on there? Is that because hes been to counselling? Has that helped? He was very reflective. Something to ask in him when member checking”.

(Field Notes made on 12.04.16 after Theo Interview)

Appendix nine: – Examples of different uses of memos during analysis

Coding Task Memo

Walter talked about modifying himself to ‘fit in’ but actually it just made him stand out. There were also comments similar in Sophia and Sheila’s interview about how trying to fit in made them stand out. James talked about artificially learning strategies and him not liking that idea.

- Look back on the impact of this.is there any evidence of how this made them feel and what the impact of these unsuccessful strategies were?

Theo talks about this positively learning strategies to use in meetings and having a memory of similar situations, so he knows how to behave in certain scenarios.

- Relook at that section of interview for impact.

Peter talked about opting out of situations as it was too stressful.

- Check to see if there are further details about this in his interview.

(Memo attached to Walter’s interview)

Reflective Memo:

Emma spoke about not coming to terms with diagnosis for four years. That she cried every time she spoke about it. She sought diagnosis herself, it was not a surprise, as she suspected that autism was an explanation that fit after learning about autism in her new job role. This meant diagnosis was not a shock, it was anticipated and yet she still struggled to come to terms with it. Shelia talked about this too, she was in denial post diagnosis, despite requesting the diagnosis herself. Gary described a period of turmoil post diagnosis and yet had requested the diagnosis and been put off by the GP earlier so despite expecting a diagnosis they all were really shocked and had a hard time coming to terms with it. Of course, none were offered support!
(Memo attached to Emma’s Interview)

Theoretical Link Memos:

Sheila had a hard time coming to terms with diagnosis but then talks about it all just started to make sense. This was some years post diagnosis she became illuminated to the meaning and the fact that it started to all fit into place. As soon as she started to accept her autism and she engaged with information about autism. *‘in this last couple of years or so, very much so reflecting, and thinking, ah yeah, that makes sense. In fact, it’s been a huge lightbulb moment… It has taken me the last few years to come to terms with this diagnostic bombshell, gain understanding and start moving through a position of acceptance and now, celebration, of my particular difference’.*

Sophia’s life experiences and family started to make sense to her once she learnt more about autism *‘I suddenly went oh my goodness [laughs] I mean I’ve learnt so much since my diagnosis about Autism, about myself’ but it was a process and not straight away. It took many years.* (Memo attached to Shelia’s Interview)

Appendix ten: Ethical approval letter

Dear Jennifer

Re: **'The Autistic Life'. Research into the life experiences of older adults living with autism by means of a Co-Constructed Inquiry (CCI).**

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 31st July 2013 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following document that you submitted for ethics review:

- University research ethics application form (*dated 20th June 2013)*
  - Participant information sheet (*dated 20th June 2013)*
  - Participant consent form *(dated 20th June 2013*)

However, the ethics reviewers have suggested that you consider the following amendments, which you can choose to follow or to ignore:

(i) There are 2 titles – 'The Autistic Life ' which sounds quite labelling – and in the footer "A Life with Autism" which seems preferable and less defining of the person.

(ii) It is suggested that the applicant discuss with her supervisors some reference to dementia – as the sample is older people it is likely that some of these people may also have dementia – would that come into the exclusion criteria? Or perhaps you would want to include people with dementia which may need reference to Mental Capacity.

(iii) Have people with autism advised on the study / info sheet / consent form – would enhance from an ethical and quality perspective.

If during the course of the project you need to deviate from the above-approved document please inform me. Written approval will be required for significant deviations from or significant changes to the above-approved document. Please also inform me should you decide to terminate the project prematurely.

Regards
Lisa Bell

--
Lisa Bell
School Administrator
School of Nursing and Midwifery
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Appendix eleven: Knowledge Transfer and Dissemination

Completed Presentations

Early Career Research Event at Edge Hill University (Ormskirk)	Poster Presentation: *Living with Autism*	September 2015
Scottish Autism Conferences (Glasgow)	Poster Presentation: *Life with autism: Preliminary Results*	October 2018
Scottish Autism Conferences (Glasgow)	Poster Presentation: *Conducting Interviews with Autistic Adults;* *Reflections from an in-depth interview study.*	October 2018
Work in Progress Talks at Edge Hill University (Ormskirk)	Oral Presentation: *The Wellbeing of Older Autistic Adults*	June 2019
Autism Congress (Nice, France)	Poster Presentation: *A VERY late autism diagnosis: The lived experience of receiving a diagnosis over the age of 40 in the UK*	October 2019
Autistica Research Festival (Online)	Oral Presentation: *Surviving or Thriving Post diagnosis: A Grounded Theory Study*	July 2021
Master Class for PGCert Students at Edge Hill University)	Oral Presentation: *The Importance of Positive Constructions of Autism*	March 2022

Completed Knowledge Transfer

Core Capabilities Framework for Supporting Autistic People (London)	Member of Steering Group	2018-2019
Autistica Social Care Summit (Canterbury)	Invited member of Summit	Oct 2019

Planned future Presentations

Autistica Research Festival (Online)	Abstract Submitted	July 2022
Autism Congress (Krakow)	Abstract Submitted	October 2022
Edge Hill University Presentation to Medical, Nursing, and Social Care Trainees	Planned	September 2022