AN EXPLORATION OF SUICIDE AND AUTISM: QUANTITATIVE, QUALITATIVE AND AUTOETHNOGRAPHIC PERSPECTIVES

by

Margaret Louise Dean

Canterbury Christ Church University

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Abstract

In this study I explored the experience of suicidal autistic adults from the perspective of an insider researcher. I used mixed methods, within an interpretative paradigm, that focused on three methods of data collection. The first study used quantitative and thematic analyses to interpret data from 74 autistic adults collected using an online survey. Demographic characteristics highlighted that not all who have planned suicide have experienced depression, not all who have attempted suicide have been diagnosed with depression, and that autistic adults have attempted suicide without making a plan. Quantitative analysis results indicated suicidal plans are experienced by those with diagnosed depression, and suicidal ideation and suicidal plans are experienced by those who have experienced depression but have not been diagnosed with depression. A thematic analysis identified themes relating to the various suicidal behaviours, the reasons for these behaviours, and the effect of NHS/Mental health teams on suicidal autistic adults. The second study used interpretative phenomenological analysis (IPA) to elicit the experience of seven suicidal autistic adults. Using email to undertake the interviews was an innovative approach for suicide research. I adapted the IPA method to suit the perceived autistic strengths and weaknesses of the participants, in addition to my own. Their experiences identified six super-ordinate themes including the roles of autistic well-being, support, the autism diagnosis, the community, and the impact of gender. The third study focused on my lived experience. It took the form of an innovative autoethnographic study, analysing the personal experience of a suicidal autistic adult. The results resonated with those of the second study, whilst also highlighting that the option of suicide never recedes. As a priority of the autistic community, this study made recommendations to prevent suicide, including correctly identifying depression, anxiety, autistic burnout, and other co-occurring conditions, by using specific autism-friendly tools.

Acknowledgements

> “Resisting hate, practising solidarity, and transforming society to be inclusive and just is suicide prevention in its most radical form because social injustice, hate, stigma, and oppression create the conditions that make the horrors of suicide possible”
> (Reynolds, 2016, p. 184).

I would like to thank all those who made this research possible.

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List of Abbreviations

ABA	Applied Behaviour Analysis
ADAT-A	Autistic Depression Assessment Tool - Adult
ADHD	Attention Deficit and Hyperactivity Disorder
AFAB	Assigned Female at Birth
Anx.	Anxiety
APA	American Psychological Association
AQ	Autistic Spectrum Quotient
ASA-A	Anxiety Scale for Autism - Adults
ASC-ASD	Anxiety Scale for Children with Autism Spectrum Disorder
ASD	Autism Spectrum Disorder
BAI	Beck Anxiety Inventory
BPD	Borderline Personality Disorder
CA	Content Analysis
CAMHS	Child and Adolescent Mental Health Service
CAT-ANX	Computerized Adaptive Test for Anxiety
CAT-Q	Camouflaging Autistic Traits Questionnaire
CBT	Cognitive Behavioural Therapy
CES-D	Centre for Epidemiological Studies - Depression Scale
CMHT	Community Mental Health Team
CPN	Community Psychiatric Nurse
CRHT	Crisis Resolution and Home Treatment
CV	Curriculum Vitae
DASS-21	Depression, Anxiety and Stress Scale-21 Items
DBT	Dialectical Behaviour Therapy
DH	Department of Health
DHSC	Department of Health and Social Care

Dl.	Dyslexia
Dp.	Dyspraxia
DSM	Diagnostic and Statistical Manual of Mental Disorders
dx.	Diagnosis
EDS	Ehlers-Danlos Syndrome
EQ	Empathy Quotient
EUPD	Emotionally Unstable Personality Disorder
GAD	Generalised Anxiety Disorder
GCSE	General Certificate of Secondary Education
GDPR	General Data Protection Regulation
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HAM-A	Hamilton Anxiety Rating Scale
ICD	International Classification of Diseases
IMV	Integrated Motivational-Volitional
IPA	Interpretative Phenomenological Analysis
IPTS	Interpersonal-Psychological Theory of Suicide
JH	Joint Hypermobility
LeDeR	Learning from Deaths of People with a Learning Disability and Autistic People
LSAS	Liebowitz Social Anxiety Scale
K10	Kessler Psychological Distress Scale
K-ANX	Korean Anxiety Assessment Tool
MEd	Master of Education
NAS	The National Autistic Society
NCTE	National Center for Transgender Equality
NHS	National Health Service
NHSE/I	NHS England and NHS Improvement

NICE	National Institute for Health and Clinical Excellence
NSSI	Non-Suicidal Self-Injury
OASIS	Overall Anxiety Severity and Impairment Scale
OCD	Obsessive Compulsive Disorder
OED	Oxford English Dictionary
ONS	Office for National Statistics
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
PGCE	Post Graduate Certificate in Education
PhD	Doctor of Philosophy
PHQ	Patient Health Questionnaire
PIP	Personal Independence Payment
PSWQ	Penn State Worry Questionnaire
PTSD	Post-Traumatic Stress Disorder
SBQ-ASC	Suicide Behaviours Questionnaire for Autism Spectrum Condition
SBQ-R	Suicide Behaviours Questionnaire-Revised
SIB	Self-Injurious Behaviour
SPSS	Statistical Package for the Social Sciences
STAI	State Trait Anxiety Inventory
TA	Thematic Analysis
TS	Tourette’s Syndrome
UK	United Kingdom
URL	Uniform Resource Locator
USA	United States of America
VEQ	Vulnerability Experiences Quotient
WHO	World Health Organisation

List of Statistical Abbreviations and Symbols

CI	Confidence interval
H_0	Null hypothesis
H_1	Alternative hypothesis
M	Population mean
N	Population size
n	Sample size
p	Calculated probability
SD	Standard deviation
$\bar{x}$	Sample mean
α	Cronbach’s alpha
χ^2	Chi-square

Preface

Notes on terminology and language use

I am autistic and have been suicidal, therefore I am an insider researcher. This thesis represents an autistic person's interpretation of autism. The findings of this thesis represent the experience of previously suicidal autistic adults and enables the autistic voice to be heard. The style of my writing may be an outward representation of the effect of my autistic traits. Identity-first language is used, and person-first language is avoided in this thesis, other than in quotes of researchers, to reflect the preference of the autistic community (Kenny *et al*., 2016). Identity-first language is frequently preferred as it is, "associated with improved well-being, self-esteem, and quality of life" (Gernsbacher, 2017, p. 859), corresponding with the purpose of this research.

Within the thesis I refer to two self-administered questionnaires that have been used to assess autistic traits in the general population. They are the autism-spectrum quotient (AQ) (Baron-Cohen *et al*., 2001), and the empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004).

Throughout this research I use the terminology of IPA as outlined by Smith, Flowers, and Larkin (2009) in their detailed account of the theoretical foundations, and practices, published in *Interpretative Phenomenological Analysis: Theory, Method and Research*. In December, 2021, prior to the submission of this thesis, a second edition was published that included updated terminology. Quotes from the online survey's respondents, and the participants interviewed, are included as written in the online survey or in the email correspondence. This is particularly relevant in Chapters Three and Four.

Chapter 1. Introduction

This first chapter introduces the issue of suicide in autistic adults. I outline the history of autism, and the changes in diagnostic criteria in the diagnostic manuals. I describe the characteristics and life experiences of autistic people and the prevalence, and the assessment, of suicidal thoughts and behaviours within the autistic population. I discuss the risk and protective factors that influence autistic individuals. I also discuss several suicide theories and models that may be relevant to the autistic adult. Finally, I describe the gaps in suicide research in relation to autistic adults and define the research questions.

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1.1 The research

This research aims to explore the interface of suicide and autism in a group of autistic adults. In 2021, the International Society for Autism Research published a policy brief, recommending the ten top autism community's priorities to prevent suicide (Cassidy *et al.*, 2021c). This thesis explores the first part of one of these priorities, "What is the experience of suicidality in autistic people?" (Cassidy *et al.*, 2021c, p. 3), and discusses some of the other ten priorities within the thesis. I achieve this exploration in four ways. Firstly with a review of literature, based mainly on the research of non-autistic researchers, and by using three data collection methods, based on the autistic voice. I include a quantitative study and a thematic analysis of data gathered from a group of autistic adults, most of whom have experienced suicidal behaviours. This research also includes two further qualitative studies exploring the lived experience of people who have exhibited suicidal behaviours through interpretative phenomenological analysis and an autoethnographic study.

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1.2 Autism

To aid the exploration of suicide and autism, I introduce information about the history of autism and autistic characteristics that places a suicidal autistic adult into an overall context. Therefore, after briefly outlining the history of autism and development of the diagnostic criteria that have occurred, I describe the possible cognitive and behavioural characteristics of autistic adults. Finally, I describe the potentially problematic life experiences that may increase the vulnerability of autistic adults to tend towards suicidal behaviours.

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1.2.1 The history of autism

Eugene Bleuler (1857-1939), the Swiss physician and expert in mental illness, was one of the first people to write about autism (Asperger, 1944/1991). He, however, was using the term to explain the various autistic symptoms of schizophrenia. The term derives from the Greek, *autos* meaning self and *-ism* denoting a condition; the word therefore signified a condition of being alone. The term autism had been used in earlier writings, such as those of German priest, Martin Luther (1483-1546) (Wing, 1997), and of Jean-Marc Itard (1774-1838), famous for his work into intelligence testing and theory (Chamak *et al.*, 2008). Autism was, therefore, in usage to describe a person as different from normative cognitive functionality (Milton, 2013a) though there is little written evidence explaining Luther’s or Itard’s understandings. As one autistic author suggested,

> “right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its

> appearances, and not from the inside according to how it is experienced" (Williams, 1996, p. 14, original emphasis).

In the late 1930s and the 1940s, together with the theory behind such developmental disorders, infantile autism and Asperger's syndrome were being researched and discussed by people born in the Austro-Hungarian Empire. Leo Kanner (1896-1981) was a psychiatrist and Hans Asperger (1906-1980), a paediatrician. After serving in the First World War, Kanner moved to the United States of America (USA) in 1924, publishing his first work in English in 1943. Asperger stayed in Austria and published his first work in German, four months later in 1944. Despite emanating from the same geographical area there is no account that these two men knew of each other's work. However, Silberman (2015) questions this as Frankl, Asperger's chief diagnostician, was rescued from the Holocaust by Kanner and he started working for Kanner in the USA in 1938.

Rather than labelling people with schizophrenia, Asperger explained how he chose the label autism in an attempt to describe the basic trait of aloneness (Asperger, 1944/1991). The name *autism*, devised by Bleuler, "is undoubtedly one of the great linguistic and conceptual creations in modern nomenclature" (Asperger, 1944/1991, p. 38). The British psychiatrist and researcher, Lorna Wing (1928-2014), created the term *Asperger's syndrome* (Wing, 1981). In describing this aspect of autism, she highlighted the wider, "range of intellectual and language skills" (Howlin, 2021, p. 2), demonstrated by some autistic people. To further complicate matters, in the 1980s, Wing, together with the psychiatrist Christopher Gillberg, coined the phrase *autism spectrum* attempting to explain that there are many variants of the condition (Wing, 1981; Gillberg, 2007).

Only a small proportion of the population born from 1936 to 1970 were diagnosed as being autistic (Warrier and Baron-Cohen, 2021). This is probably due to this sample being born when autism was more readily diagnosed in children with moderate to severe intellectual disability (Howlin, 2021). Both Kanner, in his work of 1973, and Asperger, in his work of 1944, identified that some autistic individuals were able to achieve success in areas of their lives (Howlin, 2021). Prior to 1994, higher ability children may not have been diagnosed as autistic, although not having an intellectual disability is not indicative of an autistic person's functionality in their daily living skills (Alvares *et al*., 2020). Studies also suggest that only about one in every five autistic adults are, "well integrated" (Howlin, 2021, p. 4293), into the general society, and half of the outcomes of autistic individuals are described as poor or very poor (Mason *et al*., 2021). It is stressed that favourable and negative outcomes are the views of neurotypical researchers and, "are not necessarily endorsed by everyone in the autism community" (Howlin, 2021, p. 4302). Being rated as having a *negative* outcome may be related to the impact on autistic adults of having a poor mental health, rather than the impact of their autistic traits (Howlin, 2021). Also, a delay in diagnosing autism in autistic adults may increase the risk of depression (Cassidy, 2015). In addition, negative outcomes may also arise as autistic adults are diminished and stifled by being a part of a minority group (Chapman and Carel, 2022). As is reflected upon later, suicidal behaviours may be preceded by depression. Therefore, early diagnosis of autism may be required to reduce the risk of suicide (Zahid and Upthegrove, 2017).

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1.2.2 Changes in diagnostic criteria

The *Diagnostic and Statistical Manual for Mental Disorders* (DSM), published by the American Psychological Association (APA), focuses on all mental health diagnoses, whereas the *International Classification of Diseases* (ICD), published by the World Health Organisation (WHO), relates to all health disorders, and is used to classify and monitor causes of injury and death (Apter, 2019). Consequently, due to differences in the perspectives of the two organisations, both diagnose autism differently (First *et al*., 2021). The ICD is mandated for use in the National Health Service (NHS), in the UK (United Kingdom). Researchers, though, frequently use the DSM diagnoses as a base of their research (Apter, 2019).

Autism was neither described in the first edition of the DSM published in 1952 by the American Psychological Association (APA), nor in the DSM-II (APA) published in 1968. Nevertheless, childhood autism was included within the DSM-III (APA), published in 1980, within the section describing Childhood Onset Schizophrenia (Rapoport *et al.*, 2009). At this juncture, autism was only viewed as a childhood condition (Howlin, 2021). Asperger's syndrome was included in the DSM-IV (APA, 1994) using diagnostic criteria (Molloy and Vasil, 2002). Since its publication more people, including adults, have been able to be diagnosed with Asperger's syndrome or autism. Individuals diagnosed as autistic were described as those without speech until later than their peers compared to those diagnosed with Asperger's syndrome who had developed *typically*, including their speech (DSM-IV, APA, 1994). This differentiation has been dropped from the diagnostic criteria in the DSM-5 (Howlin, 2021), which uses the term autism as an umbrella term, and describes it less clinically but more functionally (Volkmar and Reichow, 2013). Although not binding in the UK, the DSM-5 is very influential (Carrington *et al.*, 2015).

In the ICD 10 (WHO, 1994), *Childhood autism*, *Atypical autism* and *Asperger's syndrome* were mentioned under the heading F84, Pervasive Developmental Disorders. Also under this heading were other disorders including pervasive developmental disorder - unspecified. In 2018, the ICD 11 (WHO) was published, and autism has its own heading *6A02 Autism spectrum disorder*. This is described with other neurodevelopmental disorders, such as disorders of intellectual development and attention deficit hyperactivity disorder.

There is a difference in the diagnostic criteria for autism between the DSM-5 (APA, 2013) and the ICD 11 (WHO, 2018). In the DSM-5 (APA, 2013) a person has to satisfy a number of criteria to achieve a diagnosis of autism, such as having persistent deficits in three areas of social communication and interaction, and having restricted, repetitive behaviours; whereas in the ICD 11 (WHO, 2018) clinicians derive a diagnosis using the, “spirit of guidelines” (Buckley, Lister-Brook and Stewart, 2019, p. 2), which amongst other aspects takes cultural values and diversities into consideration (WHO, 2010). Prior to the 1980's gaining an autism diagnosis was very rare (Atladottir *et al*., 2015; Nyrenius *et al*., 2022). It is now recognised that autism is a lifelong condition that affects those in older age, as well as the young (Howlin, 2021).

Autism may be diagnosed using one of several diagnostic tools. Although however autism is diagnosed, autistic adults generally self-diagnose, and identify as autistic, prior to seeking a diagnosis (Lewis, 2016). General practitioners

(GPs) are generally the gatekeepers to specialised services for an autism assessment (Foley and Trollor, 2015). This may add to the lengthy delays prior to diagnosis (Crane *et al.*, 2021). The impact of a diagnosis in adulthood can be, "huge" (Crane *et al*., 2021, p. 892), lead to an improvement in self-awareness, and be a, "positive and beneficial experience" (Stagg and Belcher, 2019, p. 358).

Nevertheless, the diagnostic manuals recognise groups of people, "who share similar forms of marginalisation and oppression" (Chapman, 2021, para. 10), and many describe autism as a disability. Differences in autistic people might only be disabling, if they live without the correct support, and if their particular abilities are not valued (Bottema-Beutel *et al*., 2021), or if the environment in which they live is intimidating (Krieger *et al*., 2018). Some autistic adults camouflage (Lai *et al*., 2017) and attempt to pass as non-autistic, thereby, "minimising the importance of impairment in their lives, perhaps by concealment" (Shakespeare, 1996, p. 100).

Some non-autistic parents of autistic children recurrently use the terminology that their child *suffers* from autism (Huws and Jones, 2011). The medical model of disability focuses, "suffering ... on the self" (Shakespeare, 1996, p. 99), and the individual in a position of, "coming to terms with the loss" (p. 98), in this case the loss of not being a *non-autistic* person without any impairment. This can also be described as a personal tragedy model of disability (Swain and French, 2000). The medical model usually assumes, "that disability is inherently inferior to nondisability" (Bottema-Beutel *et al*., 2021, p. 21), and that the *suffering* stems from being autistic (Chapman and Carel, 2022). However, the perception of autism as an impairment of the individual may lead autistic people to conceal, or to camouflage, their impairments to fit into the non-autistic community. Furthermore, some people may desire to improve the autistic person, or *cure* them of their autism, which is anathema to most autistic people (Bagatell, 2010).

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1.2.3 Cognitive and behavioural characteristics of autistic adults

Classifying autism in the diagnostic manuals groups the various diagnostic characteristics of autistic people. Autism may typically affect a person's social communication, social interaction, and social imagination[1], including different patterns of behaviour, interests, or activities (Crowe and Salt, 2015). To discern whether their sample has autistic traits and deficits in social skills, attention switching, attention to detail, communication, and imagination many researchers have used the autism-spectrum quotient questionnaire (AQ) (Baron-Cohen *et al.*, 2001).

In 2011, it was claimed that about 1.1% of the population were autistic (Brugha *et al.*, 2011; Pilling *et al.*, 2012), with about half of autistic people having co-occurring intellectual disabilities (Emerson and Baines, 2010). At that time there would be approximately 700,000 diagnosed autistic people in the UK. This proportion of autistic people in the population has been put into doubt by research in South Korea, where Kim *et al*. (2011) suggest that autistic people represent approximately 2.5% of the population. This higher rate is supported by research undertaken relating to children and young people in the UK, rather than the adult population. In English state schools 1.76% of under 21s are

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[1] Social imagination - includes difficulties in interpreting other people's thoughts, feelings and future actions (Bolton Adult Autism Support, 2022).

autistic (Roman-Urrestarazu *et al*., 2021), and in Northern Ireland 4.5% of the school population are autistic (Rodgers and McCluney, 2021). The proportion of the autistic under 21s in English state schools with co-occurring intellectual disability has reduced, and is now approximtely one fifth (18.1%) (Roman-Urrestarazu *et al*., 2021). In other autistic people, autism co-occurs with severe depression, and a higher risk than average to tend to suicidal behaviours (Cassidy *et al.*, 2014; Hirvikoski *et al.*, 2016).

These differences, or impairments, an autistic person demonstrates are based on the *Triad of Impairments* (Wing and Gould, 1979), impairments within the autistic individual's cognitive system, in their social acts of interaction, their imagination, and their communication. Rather than an impairment in the autistic person, Milton (2012) explains this being, "a disjuncture in reciprocity between two differently disposed social actors" (p. 884), describing it as the *double empathy problem*. Williams (2021) further explains that misunderstandings in communication between autistic and non-autistic people are the result of, "mutual" (p. 122), failures.

The understanding of autistic individuals has evolved over the past fifty years. Once being considered as a rare childhood disorder of more boys than girls, frequently with intellectual impairment, being autistic is now seen as a more common lifelong difference and more equally found across the genders and cognitive abilities (Happé and Frith, 2020). Previously, "'impaired' pragmatic abilities" (Williams, 2021, p. 127, original emphasis), could be traced back to a deficit in an autistic person's Theory of Mind[2] (Baron-Cohen, 1988). However, this breakdown in communication is understood by autistic researchers to be related to a mismatch of cognitive environment[3], rather than to an impairment of Theory of Mind (Gernsbacher and Yergeau, 2019; Williams, 2021).

Autistic traits or characteristics may also be described as being advantageous (Russell *et al*., 2019). If deficits become a focus of attention, the strengths of autistic people can lack acknowledgement (Brown et al., 2021), and the possibility that autistic adults can flourish may be missed (Chapman and Carel, 2022). Nevertheless, having a *deficit* in making transitions between tasks may be due to the potentially positive autistic characteristic of hyperfocus[4] (Russell *et al*., 2019).

Despite the removal of Asperger's syndrome from DSM-5 (APA, 2013), some researchers continue to use the term, as it remains in the ICD 11 (WHO, 2018) as a subtype of autism. Parsloe and Babrow (2016) describe four differences between autism and Asperger's syndrome. Controversially, they describe autistic people as being withdrawn from social interaction, fixated by numbers and colours, experiencing severe language delay, and being diagnosed in early childhood. In comparison, Parsloe and Babrow's (2016) description of people with Asperger's syndrome is those who attempt to interact with other people, are fixated on intellectual pursuits, adopt a, "particular communication style"

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[2] Theory of Mind - the ability to think of others' beliefs, desires and emotions, as well as our own (Baron-Cohen *et al*., 2007).

[3] Cognitive environment - the environment in which a person acquires knowledge through experience of the world (Williams, 2021, p. 126).

[4] Hyperfocus - whilst performing an engaging task having, "an intense state of sustained... attention... [with] a diminished perception of non-task relevant stimuli" (Ashinoff and Abu-Akel, 2021, p. 14).

(p. 485), and are diagnosed later in childhood or as an adult. They indicate that they feel as if Asperger's syndrome is definitely, "a distinct condition" (Parsloe and Babrow, 2016, p. 485). However, other researchers focus upon the similarities between autism and Asperger's syndrome. Although some people describe autistic people without intellectual disabilities as 'high functioning', this term has never been formally recognised (Alvares *et al*., 2020; Crane *et al*., 2021). Kozlowski, Matson and Sipes (2012) propose that children with, "high functioning autism" (p. 360), are in many ways similar to children with, "Asperger's Disorder" (p. 360). The use of the term *high functioning* can also lead to misunderstandings in that any autistic individual may still be, "significantly impaired in terms of social skills" (Dover and Le Couteur, 2006, p. 540). This can be defined as having a, "spiky profile of skills and abilities" (Department of Health (DH), 2015a, p. 7), describing when autistic people have varying abilities in activities in daily living.

One advantage of the Asperger's syndrome label is the increase in profile of autistic people and that the *autistic voice* is heard, particularly in the areas of education, employment, and research (Howlin, 2021). In addition, autistic individuals are now more frequently actively involved in autism research, not only as participants but as guides to achieve shared goals through organisation and co-production (Fletcher-Watson *et al*., 2019), or through autism research as the researcher (Jones, 2021). Whereas some researchers have used the skills of autistic people in positive ways, this involvement may in some cases have been deemed *tokenistic* (Benevides *et al*., 2020).

Autism has been found to be more prevalent in men and boys than in women and girls (Baron-Cohen *et al*., 2011). However, there is an increasing awareness that autistic girls and women are not being recognised as autistic, and therefore may lack a diagnosis (Gould and Ashton-Smith, 2011; Rynkiewicz, Janas-Kozik, and Słopień, 2019). Also emerging in the literature is the suggestion that it may be more difficult to diagnose autism in women and that the causes for their stress might be different from those identified in autistic men (Gould and Ashton-Smith, 2011).

This section describes the characteristics of autistic adults that many non-autistic researchers define as being a *deficit*. Despite this negative understanding, other researchers are reporting the more positive aspects of autism (Nicolaidis, 2012; Russell *et al*., 2019; Williams, 2021). Chapman and Carel (2022) suggest that the diversity of having autistic individuals is, "desirable and valuable for humanity" (p. 5). Autistic people have made important contributions to society and to research, and it is possible for an autistic individual to, "flourish in the right social environment" (Russell *et al*., 2019, p. 130).

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1.2.4 Life experiences of autistic adults

Autism is an invisible disability (Kourti and MacLeod, 2019), although not everyone, "who identifies as autistic also identifies as 'disabled'" (Graby, 2012, p. 3, original emphasis). Many autistic adults prefer the term *neurodivergent*[5], replacing the use of, "phrases such as disability, deficit or disorder" (Bottema-Beutel *et al*., 2021, p. 23). Neurodevelopmental conditions, being neither

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[5] Includes those who experience differences in neurological thinking, including attention deficit and hyperactivity disorder (ADHD), dyslexia, dyspraxia, and others who describe themselves other than neurotypical (OED, 2020b)

physical nor mental illnesses, and being present from birth, may also be described as differences rather than as a disability (Broderick and Ne'eman, 2008).

In the 1970s there was a paradigm shift in the understanding of disability, from the medical model to the social model (Oliver, 2017). The social model locates, "disability in social structures and attitudes" (Mertens *et al.*, 2010, p. 197), and that, "disability is no longer a personal tragedy but a basis for social oppression" (p. 197). In autistic terms, this social oppression comes from a general assumption that it is the autistic person's lack of ability to understand the non-autistic person, rather than the non-autistic person's inability to understand the autistic person.

Baron-Cohen (2017) suggests that society needs to accept, "difference and diversity" (p. 745), and should make, "reasonable" (p. 745), adjustments. Yet, he adds that the term *disability* should only be used in autism,

> "when the person falls below an average level of functioning in one or more psychological or physical functions, and where the individual needs support or intervention" (Baron-Cohen, 2017, p. 746).

For some autistic people, the consideration of the *spiky cognitive profile*, helps them describe themselves as capable in some areas relating to their daily living, whilst finding that they have impairments in other areas (Milton, 2017).

The social model of disability recognises that the individual is in an environment that has barriers, where the person may be oppressed, potentially by social policy (Shakespeare, 1996). As Shakespeare and Watson (2001) suggest, many people, "downplay the significance of their impairments, and seek access to a mainstream society" (p. 20). An autistic person frequently *downplays* their autistic traits by masking, or camouflaging (Lai *et al*., 2017).

Autism is seen by some autistic people as an identity, in such a way as race, ethnicity, sexuality, gender, or nationality are seen as identities. This explains why many autistic people prefer the use of the identity first term *autistic*, rather than the person first term *person with autism* (Kenny *et al*., 2016).

Autistic people may be potentially vulnerable to traumatic life events (Griffiths *et al*., 2019), such as being on the receiving end of bullying (Balfe and Tantam, 2010; Richa *et al*., 2014), unemployment (Pilling *et al*., 2012), financial problems (Howlin and Moore, 1997), relationship problems (Howlin *et al*., 2004), including domestic abuse (Griffiths *et al*., 2019), and sexual abuse and rape (Rynkiewicz, Janas-Kozik and Słopień, 2019). Autistic lives are also complicated by feelings of anxiety (Rydén and Bejerot, 2008) and impulsivity (Aleman and Denys, 2014; Licence *et al*., 2020). These factors may play a role in the perceived increase in suicides amongst the autistic population.

The Autism Act (2009), "placed a duty on the Secretary of State for Health to introduce a strategy for improving outcomes" (Pellicano and Stears, 2011, p. 271), for autistic adults. One of the aims of the Autism Act (2009) was to aid autistic adults find employment. Employing autistic adults can be seen as an asset to some companies, rather than as a disability (Russell *et al*., 2019). Seeking information from approximately 300,000 people in the Annual

Population Survey, the Office for National Statistics (ONS) found that in the 6 months ending in June 2020, autistic people had the lowest employment rate of any disability group at 21.7%, though these results should be treated with caution due to there being a small sample size (ONS, 2020a).

Being vulnerable to trauma, autistic individuals may experience anxiety and depression, whether separately or together, for either short bouts or longer lasting experiences (Griffiths *et al*., 2019). Whilst developing the Vulnerability Experiences Quotient (VEQ), Griffiths *et al*. (2019) requested information from 426 autistic adults regarding their experience of education. They compared this data with that collected from a non-autistic sample. One hundred and ninety-nine autistic adults (47%) reported missing at least two weeks of education due to anxiety or depression; this was over three times the rate of the non-autistic sample (Griffiths *et al*., 2019). Likewise, the autistic individuals avoided stressful lessons at school at a rate of three times that compared with the non-autistic sample. The autistic students were also five times more likely than the non-autistic students to be excluded from their educational establishment (Griffiths *et al*., 2019). Exclusions may be due to the school not being able to cope with the more challenging behaviours, that some autistic individuals demonstrate (Barnard, Prior and Potter, 2000). Overall, the number of autistic adults who had *dropped out* of school, further or higher education was twice that of the non-autistic sample (Griffiths *et al*., 2019). Nineteen percent of the autistic sample explained that their parents or carers had failed to get the autistic individual their required additional support whilst at school. Although 62% of their autistic adult sample had university degrees many of these adults, “reported experiences of difficulty with education” (Griffiths *et al*., 2019, p. 1525). These difficulties in education, for the autistic individual, were recorded alongside difficulties with employment, finances, social services, and the criminal justice system, as well as difficulties regarding victimisation and domestic abuse (Griffiths *et al*., 2019). Griffiths *et al*. (2019) also report that 60% of their autistic sample had made suicide plans and that 41% had attempted suicide. These high rates of suicidal behaviours may not solely be related to difficulties in education, nevertheless it is an important element within the VEQ (Griffiths *et al*., 2019).

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1.2.5 Summary

This section includes aspects of autism relating to the use of the term *autism* in history, the changes that have occurred within the diagnostic criteria for autism, the characteristics of autistic adults, whether described negatively or more positively, and the vulnerability to common traumatic life experiences of autistic adults that may increase the risk of suicidal ideation and behaviours.

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1.3 Suicide in autism

To achieve this research, I sought to place it in the context of the literature that is available relating to suicidal autistic adults. I also acknowledge literature that solely relates to the suicidal or to the autistic experience. As the research has progressed the relevancy of some research has waned, whilst other research has gained importance. To set a basis for this research on the experiences of suicidal autistic adults, I identify the necessity of undertaking such research by outlining the prevalence of suicidal thoughts and behaviours in autistic adults. I outline how the suicidal experiences of adults may be assessed, and report adaptations being made for autistic adults. I introduce the characteristics of autistic adults that may develop into suicidal risk and protective factors. I include an outline of various suicide theories and models, that other research into suicidal adults or suicidal autistic adults have found relevant.

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1.3.1 Prevalence of suicidal thoughts and behaviours

There is a high rate of suicide in autistic adults. Six papers regarding suicidal ideation, suicidal attempts and actual suicides suggest rates that are consistent with each other. These papers are based on studies within the UK (Cassidy *et al*., 2014; Cassidy *et al*., 2022), Canada (Paquette-Smith, Weiss and Lunsky, 2014), Japan (Kato *et al*., 2013), the USA (Hand, Benevides and Carretta, 2020), and Sweden (Hirvikoski *et al*., 2016). Four of the papers suggest that suicidal ideation and attempted suicide over a lifetime is between nearly eight and ten times greater in autistic adults than in the general non-autistic population (Kato *et al*., 2013; Cassidy *et al*., 2014; Paquette-Smith, Weiss and Lunsky, 2014; Hand, Benevides and Carretta, 2020). The fifth paper is a large study that reports the deaths of a Swedish region's population, including those by autistic people taking their own lives. They find that the autistic suicide rate is again nearly eight times greater than the suicide rate in the non-autistic population (Hirvikoski *et al*., 2016). The sixth paper reports that, using information from coroners' reports, 10.7% of those who had died by suicide in England, from 2014 to 2017, were autistic or who had elevated autistic traits (Cassidy *et al*., 2022). Due to the methods used by coroners this figure may be an underestimate (Cassidy *et al*., 2022). Following interviews with the deceased's next of kin, 41.4% of those who had died had demonstrated, "elevated autism traits indicating possible autism" (Cassidy *et al*., 2022, p. 6).

Cassidy *et al*. (2014) studies the people who were attending a clinic, based in Cambridge, for assessment of Asperger's syndrome. Sixty-six percent of their sample had experienced suicidal ideation during their lifetime. As Cassidy *et al*. (2014) explain, this is, "more than nine times higher than in the general population in England" (p. 145). Their sample of 374 adults also suggests that 35% had experienced suicidal plans or attempts. This rate is similar to that of the 50 adults with Asperger's syndrome studied by Paquette-Smith, Weiss and Lunsky (2014) in Ontario, Canada, who conclude that the 36% of their sample who had attempted suicide was just under eight times greater than the 4.6% lifetime prevalence of attempted suicide in the general Canadian population. The results of Hand, Benevides and Carretta's (2020) study, based in the USA, suggest that suicide attempts are 6.5 to 10 times more common, in their sample of autistic adult *Medicare* beneficiaries, than in the general American population. Their study is based on a large sample of 21,792 adults, which includes those with intellectual disabilities, who they suggest do not have suicidal ideation, but have made suicidal attempts.

A paper with a similar sample size to Hand, Benevides and Carretta's (2020) study is by Hirvikoski *et al*. (2016). It is based on a population study carried out in Sweden, over 22 years. Hirvikoski *et al*. (2016) calculate how, during the study, 24,358 people had died by all means, 706 of them having been diagnosed as autistic, this being 2.6% of their study's population. According to this paper, the death rate for suicides in the general population is 0.04%, whereas within the autistic population it is almost eight times that number, with 0.31% of the deaths of autistic people being attributed to suicide (Hirvikoski *et al*., 2016).

Kato *et al*. (2013) discover that 43 (7.3%) of the 587 consecutive suicidal patients seen in a clinic were autistic. This result is between six and seven times higher than the normal levels of autism found within the population, which was generally accepted to be approximately 1.1% (Brugha *et al.*, 2011) when Kato *et al.*'s (2013) study was published. Despite their different research locations, and methods of data collection, the five papers, by Kato *et al*. (2013), Cassidy *et al*. (2014), Paquette-Smith, Weiss and Lunsky (2014), Hirvikoski *et al*. (2016), and Hand, Benevides and Carretta (2020), provide relatively consistent results.

Hirvikoski *et al*. (2016) suggest that autistic people with intellectual disabilities die, on average, 30 years prematurely, whereas those without intellectual disabilities die 16 years prematurely. Suicide is the only specific cause of death where autistic people without intellectual disabilities is greater than for those with intellectual disabilities (Hirvikoski *et al.*, 2016). Those with intellectual disabilities have greater levels of mortality due to a variety of specific causes, such as epilepsy and ischaemic heart diseases, but also include suicide amongst the cause of death (Hirvikoski *et al.*, 2016). Hirvikoski *et al*. (2020) suggest that the risk of suicide may be lower for autistic adults with intellectual disabilities, as supported housing may provide many with social support whilst decreasing the access to means of attempts.

In addition to the above papers, a study comparing the Interpersonal Theory of Suicide in autistic and non-autistic people, with an aim of understanding the suicide risk in autistic adults, was undertaken using 695 adults by Pelton *et al*. (2020a). Their results again demonstrate that there are higher rates of suicidal behaviour in the autistic population than the non-autistic population. Pelton *et* *al*.'s (2020a) results attest that only 4.7% of autistic adults have no suicidal thoughts or behaviours compared with 31.7% of non-autistic participants. Their results include 38.3% of the autistic adults who had attempted suicide compared with 10.5% of the non-autistic population (Pelton *et al*., 2020a). Furthermore, Takara and Kondo (2014) explain that 29% of all suicide attempters eventually received an autism diagnosis. These rates of suicidal behaviours in autistic adults compare with McManus *et al*.'s (2016) report that in the general population of the UK 6.7% have, "made a suicide attempt at some point" (p. 302).

Moreover, autistic adults are more likely to be successful in their first suicide attempt than would be expected in the non-autistic population (Kato *et al*., 2013; Carbone *et al*., 2018). This might be as the methods used are more lethal (Kato *et al*., 2013; Takara and Kondo, 2014; Carbone *et al*., 2018). Consequently, the suicide risk for autistic adults is higher than for non-autistic adults.

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1.3.2 Assessment of suicide risk in autistic adults

In non-autistic people suicide risk can be assessed using the Suicide Behaviour Questionnaire-Revised (SBQ-R) (Osman *et al*., 2001). It was one of the fourteen suicide tools reviewed by Cassidy *et al*. (2018b). Of these fourteen tools, the SBQ-R was one of four that were assessed in greater depth. The SBQ-R (Osman *et al*., 2001) is a robust self-report tool used to determine whether participants are at risk of suicide (Cassidy *et al*., 2018b). Comprising of four questions, each assessing a different dimension of suicide risk, the SBQ-R assesses lifetime suicidal behaviours, together with the frequency of such behaviours, whether the threat of suicide has been communicated to others (Osman et al., 2001) and the, "likelihood of attempting suicide someday in the future" (Cassidy *et al*., 2020a, p. 3478). Cassidy *et al*. (2018b) highlight the briefness of the four question SBQ-R in comparison with the more expensive and longer assessment tools. The SBQ-R was prepared for use in the general population, and suggest that the SBQ-R is not,

> "interpreted and responded to in the same way by autistic adults, and did not include items relevant to autistic adults experience of suicidality" (Cassidy *et al*., 2020a, p. 3485).

The SBQ-R (Osman *et al*., 2001) had been used in prior research pertaining to autistic adults. Three hundred and thirty-three adults completed an interview, including 164 autistic adults (Cassidy *et al*., 2018c). Using the SBQ-R, Cassidy *et al*. (2018c) find no significant difference between the results of autistic males and autistic females. However, the results for non-autistic males and non-autistic females in the SBQ-R are significantly different, the non-autistic women scoring significantly lower (Cassidy *et al*., 2018c). Overall, the autistic adults score more highly on the SBQ-R, and are, "significantly more likely to score above the psychiatric cut-off for suicide risk" (Cassidy *et al*., 2018c, p. 6).

To determine the limitations when using the SBQ-R (Osman *et al*., 2001) with autistic adults, Cassidy *et al*. (2020a) interviewed 15 autistic people and asked them to respond to the SBQ-R questions. The participants were asked to, "think aloud" (Cassidy *et al*., 2020a, p. 3481), whilst answering the questions, so that a comparison with non-autistic adults could be made. In contrast to non-autistic people, Cassidy *et al*. (2020a) suggest that autistic people, "interpret and respond differently" (p. 3478), to the questions asked in the SBQ-R. Therefore, using the SBQ-R with an autistic population may be problematic (Cassidy *et al*., 2020a).

One of the autism community's top ten priorities for future suicide research enquired as to how suicidal thoughts and behaviours can be identified and assessed in both research and clinical practice (Cassidy *et al*., 2021c). A new innovative approach was desired. To identify those at risk of suicide an autistic assessable tool is required (Wagner *et al*., 2020). Previously, autistic adults have been excluded from studies validating suicide screening tools (Jager-Hyman *et al*., 2020). As a result of their research regarding the SBQ-R (Osman *et al*., 2001), Cassidy *et al*. (2021b) designed and tested a tool, the SBQ-ASC, for use by both the autistic and the possibly autistic people who have yet to receive a diagnosis. Their results, whilst testing the SBQ-ASC, show that for autistic people it is, "more appropriate for use in suicidality research" (Cassidy *et al*., 2021b, p. 17), than the original SBQ-R. Nevertheless, Cassidy *et al*. (2021b) suggest that the SBQ-ASC should not be used by clinicians to identify possible future suicide attempts, but use it instead to, "identify suicidal thoughts and behaviours" (p. 19), in both the autistic and the potentially autistic adults.

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1.3.3 Characteristics of suicidal thoughts and behaviours in autistic adults

There is evidence that the characteristics of suicidal thoughts and behaviours in autistic adults are different to those found in the non-autistic population, particularly the connection between autistic characteristics and specific suicide risk markers. Some risk markers found within the non-autistic population, are amplified within autistic people (Cassidy *et al*., 2020c). These risk markers include low mood or depression (Cassidy *et al*., 2014; Zahid and Upthegrove, 2017; Cassidy *et al*., 2018b), perseveration[6], including repetitive behaviours and rumination (Arwert and Sizoo, 2020; South *et al*., 2020), impulsivity (Licence *et al*., 2020), alexithymia[7] (Costa, Loor and Steffgen, 2020) and having a low self-esteem (Arwert and Sizoo, 2020; Cassidy *et al*., 2020c). A poor self-esteem, unemployment, and the perception of feeling a burden, are also particularly associated with requiring an increased level of support (Pelton and Cassidy, 2017).

In contrast to data collated by the ONS (2020b) from the entire population which demonstrates that men are at greater risk of suicide than women, research suggests there is a higher level of suicidal behaviours amongst autistic women compared to autistic men (Hirvikoski *et al*., 2016; Kirby *et al*., 2019). However, other researchers report that there is no significant difference between the rates in autistic adults (Cassidy *et al*., 2018c; Pelton *et al*., 2020a). Affecting suicidal women with autistic traits, South *et al*. (2020) show that anxiety, in addition to depression and stress, is an important feature related to suicidal behaviours.

Research has been undertaken to assess whether some theoretical suicide models, and allied theories, are relevant to the autistic population (Pelton and Cassidy, 2017; Botha and Frost, 2020; Pelton *et al*., 2020a; Pelton *et al*., 2020b). Studying one such model, the Interpersonal-Psychological Theory of Suicide (Joiner, 2005), Pelton *et al*. (2020a) propose that autistic people have frequent

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[6] Perseveration - repeating or prolonging an action, thought, or word after the stimulus that prompted it has ceased (OED, 2022e).

[7] Alexithymia - lacking ability to understand and communicate one's own emotions and mood (OED, 2022a).

feelings of not belonging and perceiving that they are a burden on others. These feelings lead to suicidal feelings, which may also be associated with experiencing more lifetime trauma than non-autistic people (Pelton *et al.*, 2020a). The interaction of autistic traits and depressive symptoms predicts thwarted belonging, although separately they predict perceived burdensomeness (Pelton and Cassidy, 2017).

Being burdened can also be a real, rather than a perceived, experience through inaccessibility, lack of accommodations, stigma, bias, and ableism (Mansfield, 2021). There are also barriers to belonging that marginalise, stigmatise, and exclude autistic individuals (Chapman and Carel, 2022). A suggestion that the increased tendency for an autistic individual to perseverate thinking could increase the risk of feeling entrapped with the only possible escape route being suicide (Lai, Rhee and Nicholas, 2017; South *et al.*, 2020; Arwert and Sizoo 2020). This is redolent of the Baechler's 1979 theory describing suicide as an escape.

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1.3.4 Risk factors

The autistic population is vulnerable to suicidal behaviours (Raja, Azzoni and Frustaci, 2011). The second priority of the autism community concerned with suicide prevention relates to the risk and protective factors across the lifespan (Cassidy *et al.*, 2021c). Various researchers have attempted to identify the risks involved, to protect the autistic community. However, these risk factors are numerous and wide ranging. In the general non-autistic population unemployment, depression, anxiety, and financial strain or insecurity, are amongst the risk factors for suicidal ideation and behaviours (Zortea *et al.*, 2020). However, in the autistic population there may be different risk factors, as autistic individuals, "may perceive and experience their context, social situations, and communication differently" (Hirvikoski *et al*., 2020, p. 1473). The factors that have been recognised to raise the risk of suicide for autistic individuals include depression (Segers and Rawana, 2014; Takara and Kondo, 2014; Cassidy *et al*., 2018a; Hedley *et al*., 2018a; Arwert and Sizoo, 2020), anxiety (Doering *et al*., 2019), autistic camouflaging (Cassidy *et al*., 2020b; Pearson and Rose, 2021), gender (Hirvikoski *et al*., 2016; Howlin and Magiati, 2017; Kirby *et al*., 2019), and misdiagnosis of mental health issues (Au-Yeung *et al*., 2019; South, Costa and McMorris, 2021; Suckle, 2021), including psychosis (Raja, Azzoni and Frustaci, 2011; Upthegrove *et al*., 2018). In addition, loneliness (Hedley *et al*., 2017; Hedley *et al*., 2018a; Hedley *et al*., 2018b), thwarted belonging and perceived burdensomeness (Pelton and Cassidy, 2017; Cassidy *et al*., 2020b), as well as being autistic or having autistic traits (Cassidy *et al*., 2018c), also increase the risk of suicide. Employment is sometimes recognised as a protective factor, although Kirby *et al*. (2019) and Kõlves *et al*. (2021) both identify it as a risk factor.

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1.3.4.1 Autistic characteristics

Being autistic, in itself, is a risk factor for being suicidal, as various autistic traits have been identified as being risk factors for suicidal behaviours (Takara and Kondo, 2014; Cassidy *et al*., 2018c; Hedley *et al*., 2018a). These traits include difficulties with executive functioning[8], that some autistic people experience,

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[8] Executive functioning - "the cognitive processes that help people to regulate, control and manage thoughts and actions. It includes planning, working memory, attention, problem solving, verbal reasoning, inhibition, cognitive flexibility, initiation and monitoring of actions" (Bennie, 2018, para. 3).

which may lead to suicidal ideation (Hirvikoski and Blomqvist, 2015). Similarly, in non-autistic people one element of executive functioning that, “directly increases suicidal behaviour” (Conner *et al*., 2020, p. 3546), arises from having poor emotion regulation.

Autistic traits, such as difficulties with social interaction, communication, and behaviour might lead to victimisation, loneliness, and camouflaging (Richards *et al*., 2019). The autistic traits of a person being cared for may negatively impact the caregiver in such a way that they become abusive to the autistic person (McDonnell *et al*., 2019). Any such victimisation may lead to suicidal behaviours in the autistic adult (Warrier and Baron-Cohen, 2021). Avoiding bullying and victimisation may lead to an attempt to avoid social interaction (Ee *et al*., 2019), so reinforcing the first descriptions of autism, which recognised that autistic people may be alone (Capps and Sigman, 1996). Some researchers suggest that in autistic people aloneness may lead to loneliness (Kasari and Sterling, 2013), which in turn may lead to depression and onto suicidal ideation (Hedley *et al*., 2018a; Hedley *et al*., 2018b). Loneliness, isolation, and a possible yearning for interpersonal connection, may affect any autistic adult (Pelton and Cassidy, 2017; Hickey, Crabtree and Stott, 2018; Ee *et al*., 2019). Due to the realisation of being different autistic individuals may fail, “to reach their full potential” (Hickey, Crabtree and Stott, 2018, p. 5). One method used to attempt not to appear different, is to camouflage, one of the autistic coping mechanisms (Hull *et al*., 2017) that may result in suicidal ideation and behaviours (Cassidy *et al*., 2020b; Pearson and Rose, 2021).

One speculated pattern of autistic thinking is described as *cognitive inflexibility*[9] (Storch *et al*., 2013; Richards *et al*., 2019; Rodgers and South, 2021). This inflexibility is associated with anxiety in autistic children (Hollocks *et al*., 2019; Rodgers and South, 2021). It is possible that if an autistic adult feels threatened by either an internal or an external stimulus then fear, rather than anxiety, may be elicited (McVey, 2019). This fear may limit the number of perceived options available to an autistic person, leaving the thought of suicide uppermost. Furthermore, due to cognitive inflexibility, and a possible lack of empathy, autistic people may not be able to, "consider alternative courses of action than suicide" (Richards *et al*., 2019, p. 3), or understand the impact of their suicidal death upon their family and friends.

Additionally autistic characteristics increase the vulnerability to depression and anxiety, both of which are recognised as risk factors for suicidal ideation and behaviours (Richards *et al*., 2019). Added to this are the long-term consequences of chronic stress that may lead to the increased risk of suicidal ideation (Hirvikoski and Blomqvist, 2015). Furthermore, the consequence of receiving a potentially misdiagnosed mental health diagnosis, may lead to contemplation of suicide or death (Au-Yeung *et al*., 2019; South, Costa and McMorris, 2021; Suckle, 2021).

Autistic adults with intellectual disabilities have a lower rate of suicide than those with higher levels of cognitive functioning (Hirvikoski *et al*., 2016; Hedley

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[9] Cognitive inflexibility - "the tendency to focus on one's own perspective, thoughts, interests and behaviours with consequent impact on flexible problem-solving, the ability to inhibit prepotent responses and adapt in a flexible way to changing circumstances and situations" (Rodgers and South, 2021, p. 726).

and Uljarević, 2018). However, autistic adults with intellectual disabilities have an almost three-fold increased rate of suicide than that found in Hirvikoski *et al.*'s (2016) control population.

One of the associated risks concerning suicide in autistic adults is, "reduced social communication abilities" (Hedley and Uljarević, 2018, p. 71), which may affect those with or without intellectual disabilities. It is also frequently recognised that autistic individuals may have difficulty in communicating with their non-autistic peers (Paquette-Smith, Weiss and Lunsky, 2014; Lai, Rhee and Nicholas, 2017; Richards *et al.*, 2019; Hooijer and Sizoo, 2020; Dow *et al.*, 2021; Warrier and Baron-Cohen, 2021). Salvatore *et al*. (2016) continue this theme of impaired social communication, whilst observing that autistic traits, "can interfere with comprehension and cognition" (p. 3). Communication difficulties may be the reason why suicidal autistic adults refrain from seeking assistance (Paquette-Smith, Weiss and Lunsky, 2014; Richards *et al.*, 2019). In addition to recognising that some autistic adults are non-speaking, Williams (2021) suggests that autistic adults use more pragmatic language, which may result in a breakdown in communication with non-autistic people. However, this *breakdown* may be equally due to the non-autistic person failing to understand and empathise with an autistic person and exacerbating the differences in language use and comprehension (Milton, 2012).

Deliens *et al*. (2018) explain that, following their study on autistic pragmatism, autistic adults less readily adopt other people's perspectives. Their study was influenced by that of Baron-Cohen (1988) who explains that autistic individuals have deficits in social skills, including pragmatic skills. Whilst Pijnacker *et al.*

(2009) agree that autistic adults have pragmatic deficits, their autistic participants used their own, “verbal intelligence to compensate” (p. 615), for these deficits. Deliens *et al.*’s (2018) findings suggest that autistic adults, rather than experiencing difficulties with the interpretation of indirect questions as suggested by previous research in pragmatism, were more likely to answer them correctly, though slower, than their non-autistic participants.

Contrary to the general negative reporting of communication for an autistic adult, Bennett (2016) does not emphasis this difficulty, and impresses upon researchers the importance of interviewing autistic adults about depression and their experiences of suicidal ideation. Although, one element of communication is interacting directly with other people, a difficulty possibly affecting autistic adults with and without intellectual disabilities (Cummins, Pellicano and Crane, 2020), the risk of suicide may be alleviated if it is possible for, “non-autistic people to more effectively interact with autistic people” (Cassidy *et al.*, 2020b, p. 3645). This is important as people may assume that it is the autistic person’s responsibility to seek help in communicating with non-autistic people.

It is also highlighted that autistic people may not spontaneously communicate their suicidal thoughts to others, including significant people in their lives (Carbone *et al.*, 2018; Cassidy *et al.*, 2018b). This may explain why the third question relating to communication in the SBQ-R, “have you ever told someone that you were going to commit suicide, or that you might do it?” (Osman *et al.*, 2001, p. 454), may be difficult to use with the autistic population (Cassidy *et al.*, 2018b). In particular, there are two significant problems in the SBQ-R (Osman *et al.*, 2001) when used with autistic people (Cassidy *et al.*, 2018b). Firstly, that autistic individuals may not spontaneously communicate, “their suicidal intent to others” (Cassidy *et al*., 2018b, p. 64), and therefore not inform, “someone” (Osman *et al*., 2001, p. 454), that they are planning a suicide attempt. Secondly that, “difficulties in imagination and abstract thinking” (Cassidy *et al*., 2018b, p. 64), may cause autistic people to misinterpret the fourth and final question relating to, “attempting suicide in the future” (p. 64).

Alongside differences in communicating with others, research also suggests that autistic adults may be different in the way they internally communicate (Zener, 2019; Costa, Loor and Steffgen, 2020; South *et al*., 2020). Autistic adults may focus upon their internal thoughts by ruminating, that correlates with having suicidal behaviours within the autistic population (Dell’Osso *et al*., 2019; Arwert and Sizoo, 2020). Autistic adults may be more likely to ruminate due to the autistic trait of, “repetitive thinking” (Dell’Osso *et al*., 2019, p. 37).

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1.3.4.2 Alexithymia

Alexithymia is the difficulty to identify and describe one’s own emotions (Nemiah, Freyberger and Sifneos, 1976). This may include difficulty identifying feelings and further compounded by a difficulty in describing the feelings to other people (Poquérusse *et al*., 2018). Sifneos first introduced alexithymia into psychiatry in 1972 (Lopez-Munoz and Pérez-Fernández, 2020). Though alexithymia is a term used in psychiatry, it is, “not identifying a personality disorder *per se* but a personality trait” (Poquérusse *et al*., 2018, p. 2). There is a 10% incidence of alexithymia in the non-autistic population (Bird and Cook, 2013) and is found to be relatively common in autistic adults (Poquérusse *et al*., 2018) and in those with psychosis (Upthegrove *et al*., 2018). The alexithymia hypothesis suggests that disproportionate number of autistic adults experience alexithymia, and that perceived deficits in, “emotion recognition and empathy” (Bird and Cook, 2013, p. 3), are attributable to alexithymia rather than being a, “characteristic of autism” (p. 3).

A discrepancy has been found between the rates of suicidal ideation and depression in autistic adults; more experienced suicidal ideation in comparison to depression (Cassidy *et al*., 2014; Hooijer and Sizoo, 2020). This phenomenon may be due to alexithymia (Cassidy *et al*., 2014). This may mean that firstly, the autistic adult may be depressed and unable to identify their emotional state, or that secondly, they may not be depressed, but still have a difficulty in identifying their actual emotional state, or that thirdly, they may be extremely overwhelmed and unable to communicate any feeling to others (Costa, Loor and Steffgen, 2020; Hooijer and Sizoo, 2020). Nevertheless, however the alexithymia presents itself, it still represents a high risk for suicidality.

A further possible consequence of alexithymia is not detecting the emotional state of anxiety in autistic women prior to their diagnosis. This may be as these women are not aware of the symptoms of anxiety and, “how they manifest” (Zener, 2019, p. 5). Hence, Zener (2019) claims that without an autism diagnosis, with its benefits of raising awareness of potential co-occurring diagnoses, autistic women are more at risk of, “depression, anxiety and suicidality” (p. 11).

Alexithymia is not only present in women. A perceived difference in communication skills of a 21-year-old autistic man, may have been due to alexithymia (Carbone *et al*., 2018). The man seemed unable to describe his feelings or to communicate his suicidal thoughts to the significant people in his life (Carbone *et al*., 2018).

Not being able to identify and name an emotional state may be detrimental (Costa, Loor and Steffgen, 2020), and alexithymia may, in part, explain the, "under-reporting of depression" (Cassidy *et al*., 2014, p. 146). Alexithymia may partially explain why some autistic women find that social situations leave them confused or exhausted (South *et al*., 2020). Despite alexithymia being a risk factor for suicide for many autistic adults, whether experiencing alexithymia or not, Bennett (2016) suggests, the autistic adult may be able to, "describe their lived experience of depression and suicide" (p. 1493).

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1.3.4.3 Depression

Depression is feeling, "persistently sad for weeks or months, rather than a few days" (NHS, 2021a), and ranges from relatively minor to severe, when a person can feel suicidal. Many researchers assume that suicidal behaviours in autistic adults are related to depression (Sterling *et al*., 2008; Richa *et al*., 2014; Takara and Kondo, 2014; Hedley *et al*., 2018a; Livingston, Shah and Happé, 2019; Costa, Loor and Steffgen, 2020; South *et al*., 2020). This assumption is because a relationship has been identified between suicidal behaviour rates and the rates of major depression within the autistic population (Sterling *et al*., 2008), as well as being evidenced within the general non-autistic public (Oquendo *et al*., 2001; Richa *et al*., 2014). Dow *et al*. (2021) suggest that autistic adults experience depression at higher rates compared to the non-autistic adult population, with Cassidy (2015) demonstrating that up to 90% of autistic adults who had died by suicide had co-occurring depression. Depression is therefore also classified as a risk factor for suicidal thoughts and behaviours amongst autistic adults (Cassidy *et al.*, 2014; Zahid and Upthegrove, 2017; Cassidy *et al.*, 2018b). However, there is also evidence that more autistic people may experience suicidal behaviours than depression, in Cassidy *et al.*'s (2014) paper more autistic people reported suicidal ideation (66%) than reported being depressed (31%). This phenomenon is described as, "puzzling" (Cassidy *et al.*, 2014, p. 146). They give two explanations for this discrepancy. Firstly, that there is, "a different process for suicidal ideation" (Cassidy *et al.*, 2014, p. 146), taking place for autistic adults, in this sample those with Asperger's syndrome, or secondly, that this discrepancy is due to the, "under-reporting of depression" (p. 146), related to alexithymia.

There is also the possibility that depression, though sometimes experienced, may be a false description of an autistic person's mental state in some circumstances (Costa, Loor and Steffgen, 2020). Studies have taken place where autistic adults without a diagnosis of depression have been prescribed antidepressants by psychiatrists and GPs (Wichers *et al.*, 2019). Wichers *et al.* (2019) found that psychiatrists prescribed antidepressants as they are effective in *normalising* behaviours associated with differences in executive functioning, that they reduce repetitive behaviours, and improve social communication. Costa, Loor and Steffgen (2020) explore the relationship between suicidality, depressive symptomatology, and alexithymia, and find that 25% of autistic adults are prescribed antidepressants.

Depression in autistic adults is still understood to be greater than in the non-autistic population. Using the Centre for Epidemiological Studies - Depression (CES-D) Scale (Radloff, 1977), Costa, Loor and Steffgen (2020) find that autistic adults had significantly higher depression scores than non-autistic adults, 67% of their autistic group had depressive symptoms in comparison to 14% of their non-autistic group. The large percentage of depressive symptoms found within the autistic sample may have been due to the nature of the CES-D assessment used, that includes statements that accord with autistic experiences, as well as depressive symptoms, such as the following: “I felt that everything I did was an effort”, “I thought my life had been a failure”, “people were unfriendly”, and, “I felt that people dislike me”, in addition to the phrase worded more positively to reduce the acquiescent response bias[10], “I felt hopeful about the future” (Radloff, 1977).

False positives for depression may occur as the characteristics of autism make it difficult for the clinician, or researcher, to distinguish between the affect, the observed emotional state, and the mood, the self-reported internal feelings, of an autistic person (Lai, Rhee and Nicholas, 2017). False negatives may also result if the depressed autistic individual has a, “difficulty with expressive language” (Lai, Rhee and Nicholas, 2017, p. 191), making it difficult to describe their emotional, “state” (p. 191), upon which many of the depression measuring tools rely. This may result in depressed autistic individuals not being considered to be depressed. Due to these difficulties, Lai, Rhee and Nicholas (2017) question the

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[10] Acquiescent response bias - “is the tendency for survey respondents to agree with research statements, without the action being a true reflection of their own position or the question itself” (Qualtrics, 2020).

use of depression scales designed for the non-autistic population within the autistic population.

Two studies further suggest that depression may not be at the root of autistic behaviours in autistic adults. This is particularly clear in one case study of a 21-year-old suicidal autistic male, the researchers found no depressive symptoms (Weiner *et al*., 2019). In the case study of two suicidal 16-year-old boys, who were both initially diagnosed with depression and were prescribed antidepressants, their medication was withdrawn on them being diagnosed as autistic as receiving the alternative diagnosis improved their mood (Kocourkova, Dudova and Koutek, 2013), suggesting that depressive symptoms may have been secondary to their autism. For one of the patients their suicidal behaviours were rooted in a disturbing sense of being different (Kocourkova, Dudova and Koutek, 2013).

In addition to the data found in Cassidy *et al*.'s (2014) study, the phenomenon of not all suicidal autistic adults being depressed, is also found in the research of Hedley *et al*. (2017) and Hooijer and Sizoo (2020). The Hooijer and Sizoo (2020) study, based on a Dutch autistic population of 74 adults connected to one particular hospital; report a lower rate of severe depression (33.8%) in comparison with that of suicide ideation (70.3%). Supporting Cassidy *et al*.'s (2014) suggestion, they surmise that this phenomenon is due to the underreporting of depression, owing to the autistic participants having deficits in communication skills and in expressing feelings (Hooijer and Sizoo, 2020). Whether or not depression is clearly demonstrated to a clinician or perceived by the suicidal autistic adult, Hedley *et al*. (2017) maintain that depression is the prerequisite for suicidal behaviours in autistic adults. However, in their data there is a slightly greater incidence of self-reported anxiety, 39.5%, than self-reported depression, 36.8% (Hedley *et al*., 2017).

Sterling *et al*. (2008) investigate whether there are co-occurring, or other, psychiatric diagnoses alongside the occurrence of depressive symptoms in suicidal autistic adults. Their results suggest that depressed suicidal autistic adults are prone to obsessive compulsive disorder (OCD), and that those who are not depressed, but suicidal, are prone to anxiety (Sterling *et al*., 2008).

As a result of identifying that the characteristics of autism and the symptoms of depression may overlap, Cassidy *et al*. (2021a), with the assistance of autistic adults through interviews and focus groups, developed the Autistic Depression Assessment Tool - Adult (ADAT-A). In addition to using some depression indicators used with non-autistic adults, this tool also uses depression indicators that are solely, “autism specific” (Cassidy *et al*., 2021a, p. 6), such as measures relating to increases in, “difficulties in social situations... social withdrawal... adapting to change, and... sensory hyper-sensitivity” (p. 6).

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1.3.4.4 Anxiety

Lai, Rhee and Nicholas (2017) consider whether there are other explanations, other than depression, for suicidal ideation in the autistic adult. These explanations may include social and environmental pressures, alongside difficulties in relationships (Lai, Rhee and Nicholas, 2017). Lai, Rhee and Nicholas (2017) recognise that Storch *et al*. (2013) and Paquette-Smith, Weiss and Lunsky (2014) do not make a causal link between anxiety and suicidality in autistic adults. However, they qualify this by identifying that anxiety may have a different presentation in autistic adults, than is recognised in the non-autistic population (Lai, Rhee and Nicholas, 2017). Anxiety is a troubled state of mind arising from a worry or concern over the future or about something with an uncertain outcome (OED, 2021). Nevertheless, autistic adults record higher anxiety scores than non-autistic adults (Ee *et al*., 2019). In a non-autistic population anxiety is a risk factor for developing psychiatric diagnoses and suicidal ideation later in life (Khan *et al*., 2002), which is compounded by having a diagnosis of autism or attention deficit and hyperactivity disorder (Doering *et al*., 2019). Rowland (2020) explains that autistic adults do not process emotions but use their intellect to experience the physiological response of anxiety. Rowland seems to reignite Charles Letourneau's 19th Century proposal that emotions are linked with the use of certain cell groups in the brain (Steimer, 2002). Steimer (2002) explains that anxiety has cognitive aspects, most particularly the role of uncertainty.

As one of the mental health diagnoses, anxiety is frequently discussed as either co-occurring with, or as a consequence of, depression (Sterling *et al*., 2008; Takara and Kondo, 2014; South *et al*., 2020). Sterling *et al*. (2008) find that many of their autistic sample show anxiety, whilst Takara and Kondo (2014) write about agitation, which may be a sign of anxiety (OED, 2020a). Being anxious can have a wide-ranging detrimental effect on daily living and as a consequence affect an autistic person's quality of life (Rodgers *et al*., 2016; Rodgers *et al*., 2020), and may lead to suicidal thoughts and behaviours (Richa *et al*., 2014; Zener, 2019; Costa, Loor and Steffgen, 2020).

The significance of anxiety may, to some extent, illuminate Cassidy *et al.*'s (2014) proposition that in some cases there is an alternative, "process" (p. 146), other than depression, leading to suicidal ideation for autistic adults. Costa, Loor and Steffgen (2020) find that 38% of their suicidal autistic group had been diagnosed with anxiety compared to 11% of their non-autistic control group. Therefore, one of the processes that Costa, Loor and Steffgen (2020) conclude may lead to suicidality in autistic adults is anxiety.

In their meta-analysis of autistic people aged from 16 years of age, Hollocks *et al*. (2019) suggest that 42% of their autistic sample had a lifetime prevalence of being diagnosed with anxiety, compared to 37% having been diagnosed with depression. This compares with 71.3% of a sample of 505 autistic adults who self-reported having been formally diagnosed with anxiety (Rodgers *et al.*, 2020). Maisel *et al*. (2016) also identify that autistic people, "experience increased levels of anxiety" (p. 692), due to the perceived inability to understand emotions.

Rates of anxiety may be overlooked as tools validated for use within the non-autistic general adult population may not capture the, "autism-related presentation of anxiety" (Rodgers *et al.*, 2020, p. 25). Nevertheless, tools have been developed to explore anxiety both in autistic children (den Houting *et al.*, 2018) and in adults (Rodgers *et al.*, 2020). The Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD) is completed by parents of the autistic child (Rodgers *et al.*, 2016; den Houting *et al.*, 2018), and developed from this is the Anxiety Scale for Autism - Adults (ASA-A) (Rodgers *et al.*, 2020) which is a self-report tool.

Hollocks *et al*. (2019) include post-traumatic stress disorder (PTSD) and OCD, together with generalised anxiety disorder (GAD), panic, agoraphobia, and specific phobias, within the remit for anxiety as these, "disorders" (p. 560), had been organised under anxiety disorders within the DSM-IV-TR (APA, 2000). Other studies, including Kim *et al*. (2018), choose to focus upon GAD as, "its central features... are common aspects shared by anxiety disorders" (p. 1054). The symptoms of the above *disorders* within the non-autistic population may become confused with characteristic autistic behaviours. Repetitive behaviours and interests may be difficult to differentiate from symptoms of OCD, and social withdrawal can be difficult to differentiate from elements of social anxiety (Kaim, 2022). Anxiety for autistic adults may be linked with, "violation of logical rules or the unpredictability of the social environment" (Rodgers *et al*., 2016, p. 1205). Additionally, autistic adults may be unable to differentiate the symptoms of anxiety from the effects of sensory overload (Rodgers *et al*., 2016).

The perceived prevalence of anxiety in the suicidal autistic population may depend upon the interpretation of the common symptom of agitation. The agitation that Takara and Kondo (2014) witnessed, in the patients for their paper regarding suicide in autistic adults, is described as a, "specific psychopathology of depression" (p. 2), however one definition of agitation is, "anxiety or nervous excitement" (OED, 2020a). In contrast, Takara and Kondo (2014) appear to link agitation to depression, particularly during depressive episodes. They only mention the term *anxiety* twice in their text whilst recognising that co-occurring depression and anxiety is more prevalent in suicidal autistic adults than in non-autistic adults (Takara and Kondo, 2014).

There are few papers focusing upon anxiety in autistic adults in suicide research. However, one paper shows that 52% of the diagnosed autistic population had been diagnosed with anxiety disorder, although 17% of their sample claimed that this was a misdiagnosis (Livingston, Shah and Happé, 2019). Anxiety in adolescence is generally a risk factor for developing psychiatric diagnoses and suicidal ideation later in life (Doering *et al*., 2019). The rate of suicidality within the autistic youth is high, as suicide is described as, "a viable option to relieve distress" (Storch *et al*., 2013, p. 2454). Nevertheless, results show that non-autistic youth, who experience anxiety, have higher suicide rates than the autistic children and young people experiencing depression and PTSD (Storch *et al*., 2013). A nation-wide study, based in Sweden, investigated anxiety in those aged 15 and suggests that there is a need for further investigation into anxiety and neurodevelopmental differences, of which autism is one, leading into adverse outcomes later in life, one of which is suicidal ideation (Doering *et al*., 2019).

Undiagnosed autistic women may also experience anxiety, as they realise their characteristics differ to others within their community (Zener, 2019). Despite experiencing anxiety, they may not be aware of either its internal symptoms or its external manifestations (Zener, 2019). Furthermore, these autistic women without an autism diagnosis, or in the process of seeking an autism diagnosis, are also at risk of depression and suicidal behaviours (Zener, 2019).

Differentiating between anxiety and depression is understood to be important for treatment (Cosci and Fava, 2021). However, five of the tools that differentiate depression from anxiety have been developed to be used within the general population, and therefore are not specifically designed for autistic adults. Nevertheless, there is evidence that in research with autistic children traditional forms of assessment for anxiety may be useful (Lecavalier *et al*., 2014; Wigham and McConachie, 2014).

As Costa, Loor and Steffgen (2020) recognise that anxiety may be one of the processes leading to suicidality in autistic adults, autistic adults should be assessed for chronic anxiety. Within the DSM-5 (APA, 2013) chronic anxiety is one of the nine core diagnostic criteria for the diagnosis of GAD. However, only one anxiety assessment tool has been developed and validated for use in autistic adults, the Anxiety Scale for Autism - Adults (ASA-A) (Rodgers *et al*., 2020).

Five of the fourteen assessment tools that assess anxiety are also designed to assess depression (Table 1.1). These are the Hamilton Anxiety Rating Scale (HAM-A) (Hamilton, 1959), the Depression, Anxiety and Stress Scale-21 Items (DASS-21) (Lovibond and Lovibond, 1995), the four item Patient Health Questionnaire for anxiety and depression (PHQ-4) (Kroenke *et al*., 2009), the Hospital Anxiety and Depression Scale (HADS) (Snaith and Zigmond, 1994) and the Kessler Psychological Distress Scale (K10) (Kessler *et al*., 2002).

Scale	Excessive anxiety and worry	Difficulty in controlling worrying	Restlessness	Fatigue	Difficulty concentrating	Irritability	Muscle tension	Sleep disturbance	Impairment of functioning
ASA-A	✓						✓		
HAM-A	✓		✓	✓	✓		✓	✓	✓
PSWQ	✓	✓							
BAI	✓		✓			✓	✓		
DASS-21	✓						✓		
GAD-7	✓	✓	✓	✓		✓	✓		
PHQ-4	✓	✓							
HADS	✓	✓	✓				✓		
OASIS	✓		✓		✓				✓
LSAS	✓								✓
STAI	✓	✓	✓						
K10	✓	✓	✓	✓					
CAT-ANX	✓		✓		✓				
K-ANX	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 1.1
DSM-5 Generalised Anxiety Disorder core diagnostic criteria in the diagnostic anxiety tools

ASA-A: Anxiety Scale for Autism-Adults (Rodgers *et al*., 2020); HAM-A: Hamilton Anxiety Rating Scale (Hamilton, 1959); PSWQ: The Penn State Worry Questionnaire (Meyer *et al*., 1990); BAI: Beck Anxiety Inventory (Beck *et al*., 1988); DASS-21: Depression, Anxiety and Stress Scale-21Items (Lovibond and Lovibond, 1995); GAD-7: Generalised Anxiety Disorder Scale-7 items (Spitzer *et al*., 2006); PHQ-4: The four-item Patient Health Questionnaire for Anxiety and Depression (Kroenke *et al*., 2009); HADS: Hospital Anxiety and Depression Scale (Snaith and Zigmond, 1994); OASIS: Overall Anxiety Severity and Impairment Scale (Barlow, Ellard and Fairholme, 2010); LSAS: Liebowitz Social Anxiety Scale (Liebowitz, 1987); STAI: State Trait Anxiety Inventory (Spielberger *et al*., 1983); K10: Kessler Psychological Distress Scale (Kessler *et al*., 2002); CAT-ANX: Computerized Adaptive Testing - Anxiety Inventory (Gibbons *et al*., 2014); K-ANX: Korean Anxiety Screening Assessment (Kim *et al*., 2018).

Of the five tools that are capable of differentiating anxiety from depression, the HAM-A (Hamilton, 1959) is one of the oldest, measuring the severity of anxiety, and is used in both clinical and research settings. It measures mental agitation and psychological distress, as well as physical complaints related to anxiety, using a scale from zero, not present, to four, severe. The DASS-21 (Lovibond and Lovibond, 1995) uses a self-report 4-point Likert scale to measure depression, anxiety and stress, each mood being assessed by seven different statements. In four instances, anxiety is measured using physical symptoms. The PHQ-4 (Kroenke *et al*., 2009) uses a self-report 4-point Likert scale from 0, not at all, to 3, nearly every day, to screen for problems experienced over a two-week period. It is, “ultra-brief” (Kroenke *et al*., 2009, p. 613), with the first two questions screening for anxiety and the remaining two questions screening for depression. The HADS (Snaith and Zigmond, 1994) contains seven statements relating to anxiety and seven relating to depression in the general population. It is used in both clinical and research settings to assess the rates of anxiety and depression over the latest week. This tool has been used for an autistic sample within research (Uljarević *et al*., 2018). It demonstrates statistically similar properties in both autistic and non-autistic individuals (Richdale *et al*., 2020). Limited to the clinical environment, the ten item K10 (Kessler *et al*., 2002) was developed to be used as a screening tool to monitor distress, in the forms of both depression and anxiety. Requested to remember feelings over 30 days the respondent may score 1, none of the time, to 5, all of the time, for each of the ten items.

Eight tools only assess anxiety within the non-autistic population, and each has its own benefits. The Penn State Worry Questionnaire (PSWQ) (Meyer *et al*., 1990) uses a self-report, 5-point Likert scale, with five of the sixteen questions reverse scored, to determine a *worry* score. Excessive anxiety and worry together with difficulty controlling worrying, are two of the nine symptoms outlined for GAD in the DSM-5 (APA, 2013). However, the remaining seven symptoms of GAD are not covered by the PSWQ. The Beck Anxiety Inventory (BAI) was initially aimed to distinguish anxiety from depression in patients with depressive disorders (Kim *et al*., 2018). It uses a self-report 4-point Likert scale to assess the measure of anxiety a person has experienced over the period of a week. Many of its elements relate to the physical effects of anxiety upon the individual. The Generalized Anxiety Disorder 7-item scale (GAD-7) (Spitzer *et al*., 2006) was developed for the purpose of identifying GAD as described in the

DSM-IV (APA, 1994). It, therefore, does not cover the diagnostic domains of *difficulty concentrating*, *sleep disturbance*, or *impairment of functioning*, as stated relating to the diagnosis of GAD in the DSM-5 (APA, 2013). The Overall Anxiety Severity and Impairment Scale (OASIS) (Barlow, Ellard and Fairholme, 2010) requests information relating to anxiety and fear. Consisting of five questions, each scored from zero to four, the OASIS aims to determine the physical and social aspects of anxiety experienced over seven days. Similarly, the Liebowitz Social Anxiety Scale (LSAS) (Liebowitz, 1987) assesses the social aspect of anxiety. The LSAS assesses Social Anxiety Disorder, described as social phobia. The respondent is required to assess their fear or anxiety presented by each of 24 situations, and their element of avoiding that situation, using a score of 0, none or never, to 3, severe or usually. The State Trait Anxiety Inventory (STAI) (Spielberger *et al*., 1983) is used in both clinical and research settings to study the effects of anxiety. Of the 20 items in the self-report assessment, nine are reverse coded. Anxiety items relating to *state* include the phrases, *I feel tense*, *I am worried*, *I feel calm*, and I *feel secure* and trait anxiety items include, *I am presently worrying over possible misfortunes*. The Computerized Adaptive Test for Anxiety (CAT-ANX) (Gibbons *et al*., 2014) was also based on the DSM-IV (APA, 1994) description of GAD. With the use of a computerised program, different responses from the respondents generate different questions asking about their anxiety. Due to its complexity, the CAT-ANX is solely used in clinical settings where it can be administered, "in a couple of minutes over the internet" (Gibbons *et al*., 2014, p. 192). Finally, an anxiety screening tool (K-ANX) has been designed using the DSM-5 (APA, 2013) definition of GAD. It was developed in Korea and seeks responses from respondents relating to each of the GAD symptoms described.

In contrast, the ASA-A (Rodgers *et al*., 2020) is a determinant of anxiety for use with autistic adults and, therefore, does not rely upon the descriptors of GAD. The tool was developed from the ASC-ASD (Rodgers *et al*., 2016), a paediatric instrument developed to measure anxiety in the younger autistic population. In addition to a factor of general anxiety, the ASA-A specifically assesses anxious arousal, social anxiety, and uncertainty (Rodgers *et al*., 2020). Being adapted, "through consultation with autistic adults and professionals working with autistic people" (Rodgers *et al*., 2020, p. 24), it introduces anxiety elements only relevant to the autistic population, such as *I worry about changes to my surroundings or my routine*, *I worry about making mistakes during social interactions*, and *I suddenly shut down and become unable to think, speak or do things*.

Cosci and Fava (2021), after highlighting that depression and anxiety need to be separated, outline the advantages and disadvantages of different treatment approaches for anxiety, depression, and for when they co-occur within the general, non-autistic population. Likewise, these conditions may need treating within the autistic population as they are recognised as risk factors for suicidal behaviours (Zener, 2019; Costa, Loor and Steffgen, 2020; South, Costa and McMorris, 2021). As an additional significant risk factor, Takara and Kondo (2014) state that agitation should also be treated. One treatment, cognitive behavioural therapy (CBT), is a recommended psychological therapy to help with anxiety symptoms in both non-autistic adults (Ainsworth *et al*., 2020), and in autistic adults (Foley and Trollor, 2015). However, its use within the autistic population may be problematic (Frith and Happé, 1999). South and Rodgers

(2017) propose that the therapy be adapted, if used with autistic adults, to incorporate the improvement of alexithymia and the tolerance of uncertainty, as well as increasing emotional acceptance. Nevertheless, Robertson *et al*. (2018) suggest that older autistic adults, “are more practiced at trying to prevent anxiety” (p. 15), than younger autistic adults, as they had a greater number of strategies to cope with life’s unpredictabilities without the use of additional therapy.

Other than the papers by Zener (2019) and by Costa, Loor and Steffgen (2020), and those that also refer to depression, there is a lack of literature associating anxiety with suicidal behaviours in the adult autistic population.

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1.3.4.5 Gender

In the general population of England and Wales, registered suicide deaths for men are three times that for women (ONS, 2020b). This contrasts with the rates of suicide attempts in the Swedish autistic population, where autistic women are twice more likely to attempt suicide than autistic men (Hirvikoski *et al*. 220). However, neither of these data sets include data relating to non-binary individuals.

Gender is an important consideration for many autistic adults as some research has found an association between gender dysphoria and autism. Van der Miesen, Hurley and de Vries (2016) find that approximately 20% of people attending clinics for gender dysphoria have co-occurring autism. The feeling of distress, or dysphoria, of experiencing a different gender from an assigned sex may lead to mental health issues (de Freitas *et al*., 2020). In addition to autistic adults identifying with the experience of gender dysphoria, autistic adults who describe themselves as female and male, and conform to their sex at birth, can also experience pressures that lead to suicidal behaviours (McQuaid, Lee and Wallace, 2022).

Six times more autistic adults describe their gender other than the binary male and female than is found in the non-autistic population (Heylens *et al*., 2018). However, only a few research papers, related to suicide in the autistic adult, define gender other than solely male and female (Camm-Crosbie *et al*., 2019; Pelton *et al*., 2020a; Raymaker *et al*., 2020), although some acknowledge the additional complexity that gender dysphoria brings to suicidal autistic adults (South, Costa and McMorris, 2021).

There may be different stresses that push an autistic woman into suicidality than an autistic man (McQuaid, Lee and Wallace, 2022). One of the autism community's priorities for future research seeks to enquire why autistic women are at greater risk of suicide than autistic men, who are also at risk greater of suicide than the non-autistic population (Cassidy *et al*., 2021c). Ascertaining how suicidal thoughts and behaviours are linked to autistic traits in women, South *et al*.'s (2020) results show that depression, anxiety, and stress affect all suicidal women with autistic traits, whatever their autistic trait score.

Using the Suicide Behaviour Questionnaire-Revised (SBQ-R) (Osman *et al*., 2001), Cassidy *et al*. (2018c) found that 42.4% of the autistic females had made a suicide attempt during their lifetime, compared with 32.3% of the autistic males (Cassidy *et al*., 2018c). This compares with 13% of non-autistic males and 6.1% of non-autistic females having made a suicide attempt (Cassidy *et al*., 2018c).

Autistic females might face a variety of extra challenges, such as abuse or the conflict between a feminine identity and typical autistic traits (Kirby *et al*., 2019). Women on their journey to an autism diagnosis may become anxious, as they are aware that they are different to non-autistic women (Zener, 2019). Autistic females camouflage their autistic behaviour in a wider variety of settings than autistic males (Cassidy *et al*., 2018c). However, Arwert and Sizoo's (2020) findings suggest that gender does not affect either rumination or self-esteem.

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1.3.4.6 Camouflaging

Autistic people, and those with autistic traits, attempt to fit into the non-autistic population, and therefore may camouflage their autistic traits (Hull *et al*., 2017). Rather than camouflaging, some researchers refer to masking (Pearson and Rose, 2021). Camouflaging is the, "conscious or unconscious suppression of natural responses" (Pearson and Rose, 2021, p. 53), to arrest social exclusion. Bradley *et al*. (2021) question whether camouflaging is beneficial. Generally, camouflaging leads to negative consequences for mental health, and may prompt suicidal thoughts and behaviours (Cassidy *et al*., 2018c; Cassidy *et al*., 2020b; Bradley *et al*., 2021). Contrastingly, some autistic adults highlight the benefit of camouflaging which enables them to, "access the social world" (Bradley *et al*., 2021, p. 327), particularly in relationships, and protects them from bullying or other types of harm. Furthermore, there may be an assumption that camouflaging is predominantly a female experience (Fombonne, 2020), with a consequence that camouflaging males may not be recognised, leading to possible detrimental mental health (Bradley *et al*., 2021).

The theory of stigma and social identity was applied by Goffman in 1963, by suggesting that those who are different in behaviour, or attribute, from the majority are stigmatised (Milton, 2013a; Perry *et al*., 2022). When meeting other people any individual, whether autistic or not, will continually adjust their behaviour to the response of the other individual, presenting, "themselves in a meaningful way" (Milton, 2013b, p. 4). Tajfel's 1978 Social Identity Theory (Tajfel and Turner, 2004) proposes that people might attempt to *pass* into a higher status group. To eliminate any stigma the autistic person may attempt to camouflage their autistic behaviours, and camouflaging may be an unintentional process to move from an autistic group into a non-autistic group (Carr and Tchanturia, 2022). In comparison, some autistic individuals are openly autistic, which may be linked with fewer camouflaging behaviours, although some having, "an internal conflict between high autistic identity and fear of discrimination... may feel resigned to camouflaging" (Cage and Troxell-Whitman, 2020, p. 337).

Alongside camouflaging or masking autistic traits, autistic individuals may use the strategy of compensating, which is the generation of new behaviours, such as attempting to make, "eye-contact" (Livingston, Shah and Happé, 2019, p. 772), or making, "small talk" (p. 772). Compensating may enable individuals to perform daily tasks, such as communicating and being employed (Livingston, Shah and Happé, 2019). Although, the costs of this compensation for some may be anxiety, as well as depression and suicidal ideation (Livingston, Shah and

Happé, 2019). Both camouflaging and compensation may lead to a delay in the diagnosis of autism (Livingston and Happé, 2017; Fombonne, 2020).

To camouflage, autistic people may require, “insight” (Cassidy *et al*., 2018c, p. 11), into their own difficulties, and have to develop, “explicit strategies” (Hull *et al*., 2017, p. 2526), to disguise their autistic traits. There is evidence that autistic females camouflage their autistic behaviour in a wider variety of settings than autistic males (Lai *et al*., 2017, Cassidy *et al*., 2018c; Sedgewick, Hill and Pellicano, 2019; Beck *et al*., 2020).

Researchers explain the relationship between increased suicidality and camouflaging in at least two ways. The first recognises that camouflaging in social settings may result in, “increased feelings of thwarted belonging” (Cassidy *et al*., 2020b, p. 3644), whilst feeling alone and isolated and attempting to, “fit in” (Cassidy *et al*., 2022, p. 1). The second suggests that camouflaging also adds stress and social anxiety to the level of overall health (Perry *et al*., 2022). Similarly, there is an increased level of anxiety and depression related to compensating behaviours for the autistic adult, which in turn may lead to suicidal ideation (Livingston, Shah and Happé, 2019). Autistic individuals who are professionally diagnosed use similar compensatory or camouflaging strategies to those people who are self-diagnosed (Livingston, Shah and Happé, 2019).

In addition to autistic adults who camouflage, Cassidy *et al*. (2020b) acknowledge that some non-autistic people similarly attempt not, “to stand out from the crowd” (p. 3644), and for both groups the result may be a feeling of thwarted belonging. Thwarted belonging elevates the risk of suicide according to the Interpersonal-Psychological Theory of Suicide (Van Orden *et al*., 2010).

To address the well-being of the camouflaging autistic adult, Hull *et al*. (2019) developed the Camouflaging Autistic Traits Questionnaire (CAT-Q) to assess, "measures of social anxiety, anxiety, and depression" (p. 830). This assessment tool, based on autistic adults', "own experiences of camouflaging" (Hull *et al*., 2019, p. 830), is not biased to those of a particular gender, and can also be used for those without an autism diagnosis. Engelbrecht (2022) suggests that a high camouflaging score from the CAT-Q may account for low scores on diagnostic autism tests, resulting in a camouflaging person with many autistic traits not receiving an appropriate autism diagnosis.

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1.3.4.7 Autistic burnout

Burnout, described by Freudenberger in 1974, is exhaustion from, "excessive demands on energy, strength, or resources in the workplace" (p. 159). In comparison, autistic burnout differs, "in severity and breadth of symptomology" (Higgins *et al*., 2021), may resemble depression, and can result in suicidal ideation and behaviours (Raymaker *et al*., 2020). It is, "a response to coping with the basic demands of everyday life" (Higgins *et al*., 2021, p. 2357). Although it resembles depression, Raymaker *et al*. (2020) strongly believe that autistic burnout, "is a distinct condition" (p. 141). Raymaker *et al*. (2020) base their definition of autistic burnout on that of *burnout* as defined in the ICD 11 (Higgins *et al*., 2021), and therefore describe it as,

> “characterized by pervasive, long term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus” (Raymaker *et al.*, 2020, p. 140).

The *loss of function* may be wide ranging from loss of speech and memory capacity to loss of executive function and self-care capabilities (Higgins *et al.*, 2021). Autistic burnout may result from, “chronic life stress and a mismatch of expectations and abilities without adequate supports” (Raymaker *et al.*, 2020, p. 140). Higgins *et al.* (2021) suggest that *appropriate* rather than *adequate* support is required for recovery. Rose (2018) describes the chronic life stress of autistic burnout from his personal experience, a time when he attempted suicide wanting to remove himself from the stressful environment.

Raymaker *et al.* (2020) outline *life stressors*, as potentially leading to autistic burnout. These stressors include camouflaging or masking, the expectations of family and society, disability management and the stress of transitions. Similarly, *barriers to support* may precipitate autistic burnout. These barriers include a lack of external support services and poor self-advocacy, resulting in, “self-injury, suicidal thoughts, or suicide attempts” (Raymaker *et al.*, 2020, p. 140). Importantly, any intervention related to autistic burnout must include a suicide risk assessment and be able to manage any suicide risk (Raymaker *et al.*, 2020).

Potential solutions to autistic burnout include accepting that the autistic individual is autistic, accepting social support and more formal support, in addition to reducing the normal load that has to be borne (Raymaker *et al.*, 2020). Amongst other solutions to autistic burnout are elements that include attending to autistic needs, withdrawing socially, not camouflaging or masking, allowing the individual not to give eye contact, and using the autistic person's strengths and skills (Raymaker *et al*., 2020). Overall, there is a need to reduce stressors, and to address social issues and the sensory environment that can lead to autistic burnout, which in turn may lead to suicidal ideation and behaviours for autistic individuals (Higgins *et al*., 2021).

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1.3.4.8 Employment

Autistic adults may have a complicated relationship with employment. Despite there being the potential for challenges associated with social interaction, employment may provide a protective factor through the routines that it provides (Hedley, Uljarević and Hedley, 2017), although this protective factor is much less evident in the autistic population (Kõlves *et al*., 2021). Nevertheless, in their study of autistic suicidal behaviours in Denmark, Kõlves *et al*. (2021) find that unemployed autistic adults have a suicide attempt rate of 2.24 times the rate of autistic employed adults. However, there is evidence that when these familiar routines are disrupted, an autistic adult may become anxious with an associated negative impact on mental health (Hedley, Uljarević and Hedley, 2017). Finding employment can additionally enrich the lives of the autistic adult, as well as their family and the wider society (Hedley, Uljarević and Hedley, 2017). Meaningful employment can reduce the dependency on governmental benefits, whilst adding to the overall economy by paying various taxes, and can also reduce the risk of co-occurring health conditions, thereby leading to a reduction of both the time and financial burdens upon the health system (Hedley, Uljarević and Hedley, 2017). Despite these positive attributes of employment, for autistic adults there may be negative consequences.

Employment is considered a risk factor as several studies draw attention to its negative effects on autistic adults (Hedley, Uljarević and Hedley, 2017; Kirby *et al.*, 2019). Kirby *et al.*’s (2019) study shows that 49% of all autistic suicide deaths were of people in employment, or they were studying with the aim to enter employment. Autistic adults may question the meaningfulness of their employment, as many are employed, “in low paid jobs that are often well below their qualification level” (Hedley, Uljarević and Hedley, 2017, p. 300), or are, “‘malemployed’ (in jobs for which they are expressly unsuited)” (Baldwin, Costley and Warren, 2014, p. 2440). Employment could be beneficial if the frequently found autistic skills of attention to detail are used.

Autistic traits may be the cause of the high rates of unemployment within the autistic community (Kirby *et al.*, 2019). Despite strong motivation, and willingness to work, many autistic adults are, “unsuccessful in gaining suitable employment” (Hedley, Uljarević and Hedley, 2017, p. 297). The work environment has been shown to be particularly problematic for autistic adults (Griffiths *et al.*, 2019). Griffiths *et al.* (2019) demonstrate that 43% of autistic adults had at least two months signed off from work due to anxiety, depression or another mental health reason, leading to a, “lower life satisfaction” (p. 1516). An even greater number, 73% of their sample, had left a particular employment, being unable to cope with either the work environment or the demands of their job (Griffiths *et al.*, 2019).

As autistic adults may be underemployed, in part-time roles, or in roles not in keeping with their level of training or education, this may create potential stress and financial challenges (Petty *et al*., 2022). This may lead onto financial insecurity, and poverty, for older autistic adults who may not have had the opportunity, “to save for a pension” (Michael, 2016, p. 516). Older autistic adults may also experience age-related cognitive decline, making their work more difficult, and increasing their, “risk of mental health problems and suicidality” (Roestorf *et al.*, 2019, p. 7).

Suitable employment may provide a place for autistic adults to interact with non-autistic people in a positive environment and provide an income that can be used to provide material needs. One of Cassidy *et al*.’s (2019) results, suggesting future interventions for suicidal autistic adults, emphasises the important role of effective interaction between non-autistic and autistic people.

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1.3.4.9 Misdiagnosis

Some researchers suggest that their autistic participants claim they have incorrect mental health diagnoses (Dossetor, 2007; Gould and Ashton-Smith, 2011; Carbone *et al*., 2018; Livingston, Shah and Happé, 2019). Amongst the data of diagnosed autistic participants in Livingston, Shah and Happé’s (2019) study, 21 have a co-occurring diagnosis of an anxiety disorder, of which 10 (47.6%) believe this is a misdiagnosis. Furthermore, 12% of their participants also claim to have been misdiagnosed with co-occurring depressive disorders, and 5% with schizophrenic disorders (Livingston, Shah and Happé, 2019). Misdiagnosing mental health conditions prevents people receiving appropriate support (Au-Yeung *et al*., 2019).

Delaying an autism diagnosis may negatively affect a person’s mental health (Cassidy *et al*., 2018c), as an autism diagnosis may provide access to an, “alternative culture... [with] information and support (Stagg and Belcher, 2019, p. 357). Females may be underdiagnosed as autistic through missed opportunities for diagnosis or through misdiagnosis (Gould and Ashton-Smith, 2011; Rynkiewicz, Janas-Kozik, and Słopień, 2019). The misdiagnosis may be with a mental health condition, sometimes with eating disorders or BPD (Gould and Ashton-Smith, 2011), or with schizoaffective disorder (Carbone *et al*., 2018). Some autistic characteristics, such as, “difficulties with emotional regulation and self-injurious behaviours” (Au-Yeung *et al*., 2019, p. 1513), may be, “confused with symptoms of a mental health condition” (p. 1513), such as BPD. Similarly, autistic anxiety may be confused with OCD (Hollocks *et al*., 2019). Also demonstrating a negative consequence of a delayed diagnosis of autism in autistic people, Rydén, Rydén and Hetta (2008) find that those adults who are initially diagnosed with BPD and subsequently with autism, have a greater number of suicide attempts than those solely diagnosed with BPD.

Misdiagnosis frequently occurs when clinicians attribute a person’s autistic traits to a condition they regularly diagnose, such as anxiety (Pezzimenti *et al*., 2019; South, Costa and McMorris, 2021). In research studies, those not agreeing with their diagnoses are mostly autistic, or possibly autistic, participants (Au-Yeung *et al*., 2019). Within the quantitative element of the Au-Yeung *et al*. (2019) mixed-methods paper, 86.5% of the non-autistic participants agree with their mental health diagnoses, contrasting with 58.2% of the autistic participants agreeing with their mental health diagnoses, and 45.6% of the possibly autistic participants agreeing with their mental health diagnoses. Au-Yeung *et al*. (2019)

conclude that their autistic participants reported that their, “healthcare professionals gave priority to treating mental health conditions” (p. 1515), rather than addressing their autistic needs and providing post-diagnostic support.

The importance of detailed history taking, for correct diagnosis, is recognised in the case-study of a 21-year-old autistic man, who was unable to describe his feelings, or to communicate his suicidal thoughts, to the significant people in his life (Carbone *et al*., 2018). He had been diagnosed and treated for three years for schizoaffective disorder (Carbone *et al*., 2018). Following the detailed history being taken, he received his autism diagnosis (Carbone *et al*., 2018).

Researchers have found several explanations for mental health misdiagnoses in autistic adults. Non-suicidal self-injury is often attributed to people with BPD (Titus and DeShong, 2020), similarly autistic adults may show a high rate of non-suicidal self-injury (Maddox, Trubanova and White, 2017), leading to a misdiagnosis of BPD (Au-Yeung *et al*., 2019). Dell’Osso and Carpita (2022) suggest that autistic adults experience more stressful and traumatic events, leading to unrecognised PTSD symptoms. Furthermore, they hypothesise that autistic females with a history of trauma are, “more frequently misdiagnosed with BPD” (Dell’Osso and Carpita, 2022, p. 2). Mental health diagnoses, which are not accurately diagnosed, may lead to contemplation of suicide or death (Au-Yeung *et al*., 2019). Furthermore, Luciano *et al*. (2014) find that if mental health diagnoses are not be recognised by an autistic person as being relevant, and the treatment is considered an, “intolerable intrusion” (p. 7), this can lead to suicidal behaviours.

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1.3.4.10 Non-suicidal self-injury

Research pertaining to suicide in autistic adults frequently use the terms self-injurious behaviour (SIB) and non-suicidal self-injury (NSSI). SIB is described as causing direct and deliberate harm to oneself, and includes NSSI, suicidal behaviours, and suicide (Hamza, Stewart and Willoughby, 2012). In autistic adults SIB, and NSSI, may persist from childhood (Summers *et al.*, 2017), as there appears to be a strong association between, “sensory processing and self-injurious behaviours” (Shkedy, Shkedy and Sandoval-Norton, 2019, p. 2). However, autistic self-injury may, “serve a different function” (Maddox, Trubanova and White, 2017, p. 413), to NSSI in non-autistic individuals. Research relating to NSSI has frequently excluded autistic individuals (Dickstein *et al.*, 2015). In non-autistic individuals NSSI may reduce emotional distress and is frequently identified as being a characteristic of BPD (Turner *et al.*, 2015). In autistic people SIB, or NSSI, may similarly be a response, “to bring about relief from or gain control over intense negative emotions” (Summers *et al.*, 2017, p. 2), in addition to being reported as a restricted, repetitive behaviour (Maddox, Trubanova and White, 2017). Maddox, Trubanova and White (2017) find that over 50% of their 21 autistic adult participants related to NSSI, with more women than men endorsing a history of NSSI. This is consistent with more autistic women attempting suicide than autistic men (Croen *et al.*, 2015). Both Maddox, Trubanova and White (2017) and Cassidy *et al.* (2018c) find NSSI to be more significant for autistic individuals than is generally found within the non-autistic population. Cassidy *et al.* (2018c) report that, “NSSI significantly predicted suicidality in autistic adults” (p. 12), and, “must be addressed in its own right” (p. 12). Although referring to non-autistic adults, Butler and Malone (2018) suggest that NSSI may result from particular needs not being addressed and may lead to suicide.

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1.3.4.11 Summary of risk factors

In this section I introduce several risk factors that autistic adults may experience. These risk factors include being autistic, alexithymia, depression, anxiety, gender, camouflaging, autistic burnout, employment, misdiagnosis, and non-suicidal self-injury. Many of these risk factors result from the experience of being autistic, a minority in a majoratively non-autistic population. Autistic women are at a higher risk of suicide than autistic men (Hirvikoski *et al*., 2016; Kirby *et al*., 2019). Some researchers observe that delayed autism diagnoses, and misdiagnoses of co-occurring mental health conditions, hinders access to appropriate support. Other than autism being defined within the various editions of the DSM, suicide for the autistic adult may result with or without a co-occurring mental health diagnosis (Kõlves *et al*., 2021).

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1.3.5 Protective factors

The second priority of the autism community concerning suicide prevention includes protective factors across the lifespan (Cassidy *et al*., 2021c), the characteristics that reduce the likelihood of attempted suicides (Hedley *et al*., 2017). There is a paucity of research into the protective factors in both the non-autistic population (McClatchey *et al*., 2019), and the autistic population (Segers and Rawana, 2014). Ideal protective factors for non-autistic adults, “may not necessarily be in the best interests of” (Hedley *et al*., 2017, p. 3674), the autistic person, who may have a different set of protective factors due to their response to the social environment (Hirvikoski *et al*., 2020). The protective factors for an autistic individual include, raising self-esteem (Arwert and Sizoo, 2020), receiving social support (Hickey, Crabtree and Stott, 2018; Camm-Crosbie *et al*., 2019; Zener, 2019), and receiving material support (Hedley *et al*., 2017), in addition to the possibly protective factor of religion (Segers and Rawana, 2014; South *et al*., 2020).

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1.3.5.1 Self-esteem

The Interpersonal-Psychological Theory of Suicide (IPTS) (Joiner, 2005; Van Orden *et al*., 2010) identifies perceived burdensomeness as a risk factor for suicide. One of the core components of the observable behaviour of perceived burdensomeness is a lack of self-esteem (Pelton and Cassidy, 2017). Autistic people may have low self-esteem due to feelings of isolation through repeated serious social failures (Raja, Azzoni and Frustaci, 2011). Interventions to reduce camouflaging, aiming to normalise behaviour to that found in the non-autistic population, may decrease self-esteem whilst increasing anxiety (South, Costa and McMorris, 2021). Van Orden *et al*. (2012) suggest that any perceived burdensomeness, or thwarted belonging, is, “dynamic and amenable to therapeutic change” (p. 198). Consistent with this, improving an autistic person’s self-esteem may be possible and become a protective factor (Arwert and Sizoo, 2020). This can be achieved through good social support (Segers and Rawana, 2014; Raymaker *et al*., 2020), especially through maintaining friendships (Hedley *et al*., 2018a), and addressing traumatic life events (Pelton *et al*., 2020a).

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1.3.5.2 Social support

Social support has been found to decrease the risk of suicide attempts in non-autistic suicidal adults (Kleiman and Liu, 2013). Likewise, “improving inclusion” (Pelton and Cassidy, 2017, p. 1900), may be instrumental in reducing death by suicide in those adults with autistic traits. Receiving an autism diagnosis can alleviate social isolation and loneliness by opening access to both local, and online, support groups (Hickey, Crabtree and Stott, 2018). Camm-Crosbie *et al.*’s (2019) participants described that their diagnosis enabled them to access positive treatment and support, resulting in improved, “mental health and well-being” (p. 1437). In a study of a suicidal adolescent, Kocourkova, Dudova and Koutek (2013) explain that antidepressants were prescribed, as no autism condition had been considered. However, during a period of hospitalisation the adolescent’s autism was identified and diagnosed, and the medication was withdrawn (Kocourkova, Dudova and Koutek, 2013). Weiner *et al.* (2019) studied a 21-year-old man who had no psychiatric diagnosis, nevertheless, he was suicidal, and prescribed antidepressants. His autistic, “features” (Weiner *et al.*, 2019, p. 3), were later identified, he received a diagnosis, and his antidepressants were discontinued. An earlier detection of autism and the receipt of a diagnosis, enabling access to appropriate support, may reduce the co-occurring mental health conditions that may lead to suicidal thoughts and behaviours (Zener, 2019).

It is recognised that most autistic adults initially self-diagnose, or self-identify, and realise that they are autistic prior to seeking a clinical autism diagnosis (Lewis, 2017). Self-diagnosed autistic individuals have similar autism-spectrum quotient scores to those who are professionally diagnosed (Livingston, Shah and

Happé, 2019). South *et al*. (2020) give equal validity to clinically diagnosed and self-diagnosed women in their paper focusing on depression and suicide in women with autistic traits. For adults, self-diagnosis starts the journey towards diagnosis, and its access to social support (Lewis, 2016).

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1.3.5.3 Material support

Within the general population, Cohen and Wills (1985) identify that financial aid and material resources are protective against stressful events. Hedley *et al*. (2017) propose that suicidal autistic people may also, “benefit more from the availability of material support than other forms of social support” (p. 3675). However, one of the participants of Camm-Crosbie *et al*.’s (2019) study explained that “people like me don’t get support” (p. 1434), although they do not define the type of support they would appreciate. Hedley *et al*. (2017) suggest that providing social support also provides an element of tangible support. They explain that having a perception that material support is available, reduces a person’s depression, and has “an indirect effect on suicidal ideation” (Hedley *et al*., 2017, p. 3674).

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1.3.5.4 Religion

Religion is frequently described as a suicide protective factor in relation to suicidal ideation and attempts in non-autistic adults (Dervic *et al*., 2004; Segers and Rawana, 2014; South *et al*., 2020). Some religions have, “strong cultural prohibitions against suicide” (South *et al*., 2020, p. 3614). South *et al*. (2020) undertook research in one such area, Utah, USA, where the dominant religious population are members of The Church of Jesus Christ of Latter-day Saints, who declare that suicide is, “wrong” (Church of Jesus Christ of Latter-day Saints, 2021, para. 2). Despite this declaration the, “highly religious sample” (South *et al*., 2020, p. 3614), of autistic women in their study report suicidal plans and attempts.

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1.3.5.5 Summary of protective factors

In this section I examine the factors that may protect an autistic person from the risk of suicidal thoughts and behaviours. These factors include raising an autistic individual’s self-esteem, and providing both social and material support. Receiving an autism diagnosis is identified as a prerequisite for receiving suitable support. The perceived protective role of religion in non-autistic adults seems inaccurate for autistic women.

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1.3.6 Theories of suicide

Researchers agree that suicide is a complex and, “highly contextual phenomenon” (Hjelmeland and Knizek, 2020, p. 168). Suicide occurs within a context of history, society, economy, politics, ideology, culture, or relationship to gender. (Hjelmeland and Knizek, 2020). Some researchers have devised suicide models and theories with the aim to improve the understanding of why people engage with suicidal behaviours. Cassidy *et al*. (2021c) state that it is necessary to understand how models of suicidal behaviour relate to the autistic individual, being one of the autism community’s top ten priorities for future suicide research. Studying psychological theories of suicidal thoughts and behaviour may contribute to efficient suicide interventions to reduce the overall rate of suicide in the autistic community (Franklin *et al*., 2018). I describe several suicide theories and models, some of which have been related to suicidal autistic adults.

The earliest model, Durkheim's (1897) sociological model of suicide, describes suicide being based on an imbalance of social integration and moral regulation (Milton and Moon, 2012), or as a, "collective breakdown of society" (Mueller *et al*., 2021, p. 2). Rather than identifying suicide as being a result of the disintegration of society, more recent models recognise an element of deficit in the suicidal individual, either being stressed, or being thought of as a burden. These models and theories propose that suicidal ideation may lead onto a suicidal action, such as found in the Interpersonal-Psychological Theory of Suicide (Joiner, 2005), the Integrated Motivational-Volitional Model (O'Connor, 2011), and the Three-Step Theory (Klonsky and May, 2015).

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1.3.6.1 Suicide as Escape

Baechler's 1979 theory of *Suicide as Escape* is viewed as a logical means of problem solving when stress becomes too much (Baumeister, 1990). Baechler theorises that suicidal behaviours are escapist, either alleviating painful internal states, such as anxiety, shame, or guilt, or resulting from loss of external states, such as the loss of a close relative or friend, social status, or of independence through aging (Gunn and Lester, 2015).

Baechler's work prompted other researchers to develop further theories and was the foundation for Baumeister's (1990) *escape theory* of suicide. Baumeister (1990) describes suicide as being aggressive, oblative, or ludic. The intension of aggressive suicide is to make other people remorseful, through vengeance, crime, blackmail, or appeal (Abbas *et al*., 2018). Oblative suicide occurs where the person values salvation more than life, and ludic suicide describes a person risking their own life, through ordeal or as a game (Abbas *et al.*, 2018). Baumeister (1990) suggests that a person fails to reach a self-imposed standard, leading to self-blame, feeling inadequate, and negative emotions, so seeking an escape, potentially resulting in the undesirable behaviour of suicide.

Leenaars (1999) also theorises about suicide as being an escape. He investigated suicide notes originating from all regions of the world producing a model that included 35 protocol sentences (Leenaars, 1999). Leenaars (1999) describes two classifications to explain suicide. The first resulting from unbearable psychological pain, hopelessness, and overpowering emotions, and the second resulting from the impact of relationships (O'Connor and Leenaars, 2004).

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1.3.6.2 Cry of Pain model

Williams' (1997) *Cry of Pain* model proposes that suicidal behaviour is reactive, and is a response to a stressful situation, "perceiving life events as defeating" (Taylor *et al.*, 2009, p. 795), and from where there is no escape or rescue. Williams (1997) suggests the suicide reaction is predominantly caused by a lack of efficient memory in a depressed suicidal person. Information processing takes longer, or may not occur at all, in an extremely depressed person (Williams, 1997; Hunter and O'Connor, 2003). Anger and rage, together with hopelessness and despair, may become evident in a person whilst having, "feelings of entrapment" (Williams, 1997, p. 218), eventually leading to a person seeking a means, "of escape" (p. 218). The resultant suicidal behaviour is dependent upon the availability of suitable methods, and whether possible substance abuse has impaired the person's judgment (Williams, 1997). Furthermore Rasmussen *et al.* (2010) suggest that, in this model, the wish to die, "may have a communicative motive” (p. 17). J.M.G. Williams has followed up this research with his development of *mindfulness*, maintaining it is a useful element to recover from this cry of pain (Williams, 2014).

In non-autistic people poor emotion regulation, “directly increases suicidal” (Conner *et al*., 2020, p. 3546), behaviours, especially as negative emotions are, “inescapable” (p. 3546). A suicidal behaviour is the potential emotional response to poor emotion regulation (Rasmussen *et al*., 2010). Autistic people are found to have difficulties in emotion regulation, redolent of BPD (Conner *et al*., 2020). However, the Cry of Pain model, and the link between emotion regulation and suicidal behaviour, have not been fully explored in autistic people.

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1.3.6.3 Interpersonal-Psychological Theory of Suicide

Diathesis-stress frameworks distinguish suicidal ideation from other suicidal behaviours, one of which is the Interpersonal-Psychological Theory of Suicide (IPTS) (Joiner, 2005), also referred to as the Interpersonal Theory of Suicide (Van Orden *et al*., 2010). The theory suggests two processes are essential for a suicide attempt (Joiner, 2005; Van Orden *et al*., 2010). The first is having feelings of being alone, described as thwarted belongingness, and of perceived burdensomeness on others, which lead onto a feeling of never changing hopelessness (Joiner, 2005). Adding to this feeling of hopelessness is the second requirement, an acquired capability for suicide gained through painful experiences (Joiner, 2005).

Autistic characteristics of difficulties with social communication, loneliness and camouflaging may lead to contemplation of suicide (Richards *et al*., 2019). Studying the IPTS in relation to autistic adults, Pelton and Cassidy (2017) report that to reduce premature death by suicide in people with high levels of autistic traits there needs to be inclusion, and a sense of belonging, and independence. In addition, they highlight that autistic people may be unable, “to see that one’s death will affect others” (Pelton and Cassidy, 2017, p. 1893).

The IPTS model requires an alternative interpretation for autistic adults, in that thwarted belongingness and perceived burdensomeness may be, “experienced and expressed differently by autistic adults” (Pelton *et al*., 2020a, p. 3632). Whilst analysing the Interpersonal Needs Questionnaire, a self-report scale used to measure suicide risk, Pelton *et al*. (2020b) suggest that perceived burdensomeness remains a risk factor for autistic adults. Furthermore, Pelton and Cassidy (2017) suggest perceived burdensomeness arises from difficulties in communication, and may result in, “unemployment, physical illness, family burden, low self-esteem and agitation” (p. 1893).

Autistic adults have a difference in communication skills, or as described in the DSM-5 (APA, 2013), a deficit. Thwarted belonging may arise due to communication issues (DiBlasi *et al*., 2020), and is associated with, “loneliness, few social supports, relationship breakdown” (Pelton and Cassidy, 2017, p. 1893). Dow *et al*. (2021) suggest that, for autistic adults, thwarted belonging and perceived burdensomeness may result in the experience of high rates of, “depression and anxiety” (p. 11). A lonely, isolated, and depressed autistic person is more at risk of suicidal thoughts and behaviours (Hedley *et al*., 2018a).

Pellicano and Stears (2011) focus on the term burden and express that autism is a condition, “which places considerable burdens on... society” (p. 271). Nicolaidis (2012), as a physician and also as a mother to an autistic child writes, “Do I want him to grow up in a world that sees him as a burden... ?” (p. 505). Nicolaidis (2012) reflects the thoughts of many of the autistic community when she explains that rather than focusing on deficits that, “need to be fixed” (p. 503), recognise autistic people as being in possession of, “a complex combination of strengths and challenges” (p. 503).

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1.3.6.4 The Integrated Motivational-Volitional model

O’Connor (2011) developed the Integrated Motivational-Volitional (IMV) model to explain why some people are more predisposed to suicide than others. O’Connor, Rasmussen and Hawton (2012) developed the IMV model after reviewing other models, and it was further refined by O’Connor and Kirtley (2018). O’Connor, Rasmussen and Hawton (2012) reported the results from studying the background factors and triggering events of suicidal behaviours, together with the people who have thoughts of self-harm, the ideators, and the people who engage with suicidal behaviour, the enactors. O’Connor, Rasmussen and Hawton (2012) reviewed, the Diathesis-Stress Model (Schotte and Clum, 1987) that recognises that stressors makes individuals vulnerable to suicidal ideation, the Theory of Planned Behaviour (Ajzen, 1991) that suggests the intention to carry out suicide is the strongest predictor of a suicidal behaviour, the Cry of Pain Theory (Williams, 2001) that describes the roles of defeat, arrested flight, and entrapment with no means of escape, and finally the Differential Activation Hypothesis (Teasdale, 1988) that suggests feelings of distress and depression are associated with suicidal ideation, and are easily reactivated.

The IMV model suggests that diathesis[11], the environment, or stressful life events are seen as being negative (O’Connor, 2011). This leads to the motivational phase of feeling defeat or humiliation, which in turn leads to a feeling of being entrapped, which can then lead to suicidal ideation, especially if there is a low level of support or few positive future thoughts, such as a feeling of thwarted belongingness or perceived burdensomeness (O’Connor, 2011). These are outlined in the second part of the model, the motivational phase (O’Connor, 2011). The third part of the model, the volitional stage, includes a, “distinct group of factors that increase the risk that an individual will act on their suicidal thoughts” (O’Connor, Rasmussen and Hawton, 2012, p. 330). For those who have already attempted suicide, suicidal ideation will continually lead to suicidal behaviours, rather than returning to the start of the model with the formation of intent (O’Connor, 2011). Using the IMV model, it may be possible to predict the distinguishing factors between those who have suicidal ideation, but do not attempt suicide, and those who attempt suicide (O’Connor, 2011).

Within the pre-motivational phase of the IMV model (O’Connor, 2011), the autistic adult may have had an increased risk of traumatic early life events (Huckridge, 2020), and also have aversive sensory experiences to the environment (van Elst *et al*., 2013). These background factors lead to the motivational phase where differences in rumination (Crane, Goddard and Pring, 2013), and difficulty accessing suitable support (Camm-Crosbie *et al*., 2019)

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[11] Diathesis - a tendency to have a medical condition (OED, 2022b).

may lead to defeat, possible humiliation, and entrapment. Entering the volitional phase the autistic adult may be more impulsive (Licence *et al*., 2020), and have a greater than average access to people who have attempted suicide (O’Connor, 2011).

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1.3.6.5 The Three-Step Theory

The Three-Step Theory (Klonsky and May, 2015) was inspired by the Interpersonal-Psychological Theory of Suicide (Joiner, 2005), and the Integrated Motivational-Volitional model (O’Connor, 2011). Klonsky and May (2015) suggest that their Three-Step Theory explains the relevancy of depression, self-criticism, personal experiences or personality traits, when explaining suicide. The first step is related to psychological, emotional, or potentially even physical, pain although intentionally they do not specify its source (Klonsky and May, 2015). This pain could be related to Durkheim’s (1897) lack of social integration, Joiner’s (2005) thwarted belongingness and burdensomeness, or O’Connor’s (2011) defeat and entrapment. Having any pain may be experienced as punishment, and, “decrease a person’s desire to live and... initiate thoughts about suicide” (Klonsky and May, 2015, p. 117). Pain needs combining with hopelessness to motivate the individual towards suicidal ideation (Klonsky and May, 2015). An individual having hope may not consider suicide (Klonsky and May, 2015). The second step towards suicide involves a lack of connection to the individual’s activities of daily living, as connections may become a protective factor (Klonsky and May, 2015). If a person experiences both pain and hopelessness, and have no connection with activities of daily living, then they may have suicidal ideation and desire to die (Klonsky and May, 2015). In the third step the individual will act on the desire, and make a suicide attempt (Klonsky and May, 2015).

Klonsky and May (2015) further outline that three components are required for suicidal ideation to become an attempt; a dispositional component such as pain sensitivity, an acquired component such as NSSI or a relative's suicide, and a practical component such as the, "knowledge of and access to a lethal means" (Klonsky and May, 2015, p. 119).

This theory has been studied, "across different genders and age groups" (Klonsky and May, 2015, p. 126). Although no studies seem to link the Three-Step Theory with autistic adults, there seems to be a possibility that autistic adults may be prone to the psychological, emotional or physical pain, mentioned in the first step. A decreased, "desire to live" (Klonsky and May, 2015, p. 117), may be due to external pressure to change an individual's behaviour to social exclusion, or aversive stimuli. Therefore, to reduce the risk of suicide this theory would suggest that the experience of feeling pain needs to be reduced, an element of hope needs to be encouraged, a connectedness with activities of daily living needs to be stimulated, and the capacity of carrying out suicide needs to be reduced.

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1.3.6.6 Minority stress theory and model

The dominant culture of society exerts a powerful force upon an individual to conform (Meyer, 1995). To provide a theoretical explanation for the negative stress on the mental health of specific sexual minority groups, Meyer (1995) developed the minority stress theory. Autistic people are an identity-based marginalised group, sometimes being presented as, “abnormal, defunct or impaired” (Pearson and Rose, 20201, p. 54). Tajfel’s Social Identity Theory (1978) suggests that people also desire to move into a higher group, which can lead to autistic people trying to compensate for their potential differences and attempt to camouflage (Meyer, 1995). In addition, environmental or social stressors, whether described as a, “physical, mental or emotional pressure, strain or tension” (Meyer, 2003, p. 675), are exerted upon minority groups in the form of prejudice and discrimination (Meyer, 2003). Individuals from minority stigmatised groups, such as non-binary or autistic individuals, are affected by conflicts with the dominant culture (Botha and Frost, 2020). The stigma can have long lasting effects that can lead onto internalised social rejection, the individual having a greater number of stressful situations together with a fewer number of coping resources (Botha and Frost, 2020).

The minority stress theory, therefore, speculates that minorities face unique and hostile stressors related to their minority identity, and consequently, these stressors have negative effects on their health (Meyer, 2003). The theory was developed within the lesbian, gay and bisexual populations alongside the poorer health outcomes that these groups experienced (Meyer, 2003). The theory has also been used to highlight the negative physical outcomes of African American populations (Williams and Williams-Morris, 2000), as well as those individuals with physical disabilities in the United States of America (Brown, 2017).

Meyer (2003) describes two approaches to alleviate the stress of being in a minority grouping. The first alleviates stress by placing the burden on the individual and introducing interventions to change, “the person’s way of evaluating their condition" (Meyer, 2003, p. 697), and therefore encouraging resilience. The second places the burden on society by altering, "the stress-inducing environment" (Meyer, 2003, p. 697). Meyer (2003) highlights the 1997 work by Kitzinger, who maintains that the stressed *victim* is not the *problem*, whilst at the same time not denying the work of other researchers who endorse the importance of increasing an individual's resilience to stress.

Being autistic also places an individual into a minority grouping within the overall population, with the potential for victimisation, including emotional bullying (Weiss and Fardella, 2018), and highlights the relevancy of Meyer's (2003) minority stress theory. Botha and Frost (2020) developed this theory into a model to include, and understand, the various mental health problems experienced by the autistic population, similar to the disparities in access to mental health services experienced in socially disadvantaged populations (Schwartz and Meyer, 2010). In addition to being more commonly minority gendered, autistic adults have higher rates of mental health issues, and are more prone to suicidal thoughts and behaviours (Botha and Frost, 2020). Therefore, rather than depression, anxiety and suicidal ideation being attributed to autistic traits (Kamio, Inada and Koyama, 2013), Botha and Frost (2020) associate these due to the stressors with being autistic and a member of a minority group.

In addition to the negative effect of the general demographic factors such as gender, race, and ethnicity, autistic adults are also vulnerable to stress factors that are, "potentially preventable" (Botha and Frost, 2020, p. 28). Autistic adults face rejection, and poor mental health, leading to acts of discrimination and being negatively stereotyped (Botha and Frost, 2020). To compensate for being in the minority group, an autistic individual may camouflage to fit in with the larger non-autistic majority (Bradley *et al*., 2021). This camouflaging may result in being exhausted and isolated, and create, “unreal perceptions and expectations of their abilities” (Bradley *et al*., 2021, p. 8). In turn, these unrealistic expectations may result in poor mental health (Bradley *et al*., 2021), and onto suicidal thoughts and behaviours in autistic people (Cassidy *et al*., 2020b).

The minority stress theory (Meyer, 2003) potentially explains the high risk of suicide in autistic adults and may provide autistic people with dignity in a manner resembling that of the deaf community (Jaarsma and Welin, 2012). Meyer (2003) surmises that growing up within a minority group enables resilience to be built within a child and young person, therefore alleviating the risk of increased mental health problems. However, resilience built through interacting with adverse experiences may also have an emotional cost. The, “detrimental effects of an autism-incompatible and autism-phobic society” (Jaarsma and Welin, 2012, p. 28), may result in more mental health issues for autistic adults than for non-autistic adults. This may explain the higher rates of, “depression, suicidality, PTSD, and poorer mental health” (Botha and Frost, 2020, p. 23), within autistic adults. Lai *et al*. (2019) identifies that 70% of autistic adults have at least one co-occurring mental health condition.

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1.3.6.7 Summary of theories and models of suicide

This section describes six models or theories generated to describe suicidal experiences of the general, non-autistic population. However, these models and theories may also be useful to attempt to explain why an autistic adult may turn to suicide. Whereas Baechler's model proposes that suicide is a logical freedom of choice, most of these models, or theories, assume that suicide prevention requires the correction of a personal *defect* or *deficit*. Contrastingly, the minority stress model explains that suicide in autistic people could be a response to social injustice and living with the stress of camouflaging in a majoratively non-autistic environment.

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1.3.7 Summary of suicide in autism

In this section the high prevalence of suicidal thoughts and behaviours in the autistic population is outlined. A suicide assessment for use with autistic adults is presented, the SBQ-ASC (Cassidy *et al*., 2021b). The characteristics of autistic individuals that may lead to suicidal thoughts and behaviours are also discussed. Various risk and protective factors that may affect autistic adults are described. Several theories or models explaining why the general population may consider suicide are described, which generally place suicide as an issue related to society, or an issue within the suicidal person. In 1897, Durkheim described suicide as resulting from a societal breakdown (Mueller *et al*., 2021), and Meyer (2003) and Botha and Frost (2020) suggest suicide may result from being in a societal minority. In contrast, the authors of the other models place suicide as relieving the deficiency of a person, whether to relieve a painful internal state (Baechler, 1979), failing to reach a self-imposed standard (Baumeister, 1990), needing to escape psychological pain (Leenaars, 1999), feeling entrapped (Williams, 1997), escaping the feelings of thwarted belongingness and perceived burdensomeness (Joiner2005; Van Orden *et al*., 2010), or, feeling defeated or humiliated (O'Connor, 2011). The, "hard realities" (Hjelmeland and Knizek, 2020, p. 171), of being a burden, and not belonging, link with the external suicide risk factor of unemployment, alongside those associated with being autistic, such as autistic characteristics, alexithymia, misdiagnosis, and autistic burnout. These *real* experiences of hard reality for an autistic adult seem to conflict with the *perceived* experiences as described in Joiner's (2005) IPTS model.

Emotional experiences in autistic adults may be misrepresented owing to differences in communication and insight (Dow *et al*., 2021), or due to alexithymia (Cassidy *et al*., 2014; Carbone *et al*., 2018). Autistic adults may, contrastingly, experience a physiological response (Rowland, 2020). Nevertheless, the concerns of autistic adults must be heeded when seeking mental health support regarding suicidal behaviours (Dow *et al*., 2021).

Owing to the higher percentage of autistic people attempting suicide, any person attempting suicide should be assessed for autism (Kato *et al*., 2013; Kocourkova, Dudova and Koutek, 2013). A diagnosis of autism must also be considered where the motivation for a suicide attempt is difficult to understand or evaluate (Kocourkova, Dudova and Koutek, 2013). Likewise, all clinicians assessing depressed patients, who are at risk of suicide, might encounter those with autistic traits (Takara and Kondo, 2014). Similarly, there are elevated autistic traits in adults who have attempted suicide more than once, and autism may be underdiagnosed in those who have attempted suicide (Richards *et al*., 2019).

All autistic people should be screened for suicidal behaviours (Richa *et al*., 2014), as the prevalence of suicidal thoughts and behaviours are much higher than those found in the non-autistic population (Kato *et al*., 2013; Cassidy *et al*., 2014; Paquette-Smith, Weiss and Lunsky, 2014; Hirvikoski *et al*., 2016; Hand, Benevides and Carretta, 2020; Cassidy *et al*., 2022). As many suicidal autistic adults have been found to be depressed, all autistic adults should also be assessed for depression (Hedley and Uljarević, 2018). Similarly, Zahid and Upthegrove (2017) combine both of these ideas and advise that everyone who is diagnosed as autistic ought to be screened for depression, and that those diagnosed with depression ought to be screened for autism. Autistic people, who are depressed and suicidal, may require support dealing with material needs to address any bullying (Hedley *et al*., 2017; Camm-Crosbie *et al*., 2019), and may require accommodations and support to cope with the effect of autistic burnout (Raymaker *et al*., 2020).

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1.4 Summary of research

Many of the studies I review relate to autism, suicide, or the association of autism and suicide, and are quantitative in nature or use mixed methods. I am drawn to several innovative studies pertaining to the suicidal autistic adult, from the immense quantity of data in Hirvikoski *et al*.'s (2016) and Doering *et al*.'s (2019) quantitative research, to the case studies of two single men by Carbone *et al*. (2018) and Weiner *et al*. (2019). I am encouraged by the use of an online survey by Paquette-Smith, Weiss and Lunsky (2014). Although others may have used a similar method to gather their data, Camm-Crosbie *et al*. (2019) and Livingston, Shah and Happé (2019) specify the use of the internet for their data collection. Four qualitative studies, using thematic analysis, mention suicide in autistic adults (Crabtree and Stott, 2018; Camm-Crosbie *et al*., 2019; Livingston, Shah and Happé, 2019; Raymaker *et al*., 2020). Qualitative research is important as it provides a deeper understanding of experiences and phenomena, and places the research into a context (Cleland, 2017). There seems to be a gap identifying the lived experience of the suicidal autistic adult using Interpretative Phenomenological Analysis (IPA). IPA specifically aims to provide detailed examinations of personal lived experiences (Smith, Flowers and Larkin, 2009).

Rather than attributing suicidal thoughts and behaviours to depression, Raymaker *et al*. (2020) suggest that although autistic burnout resembles some elements of depression, it is a, “distinct condition” (p. 141). Dora Raymaker is an autistic researcher, who works alongside non-autistic researchers, with members of the autistic community directing and participating, “in all aspects” (p. 134), of their study. Good participatory research includes autistic individuals in research (Fletcher-Watson *et al*., 2019; Poulsen *et al*., 2022). Bennett (2016) impresses upon researchers the importance of interviewing autistic adults about depression and their experiences of suicidal ideation. Cassidy *et al*. (2018c) used a steering group of autistic adults who framed the research. Au-Yeung *et al*.’s (2019) questionnaire was set up with autistic steering groups, and an autistic focus group. Cassidy *et al*.’s (2020b) research involved an online survey that was undertaken by 371 adults, 188 of whom were autistic, followed by interviews with a sub-group of 15 autistic adults. Continued input by autistic individuals should be encouraged to ensure that any questionnaires, “are accessible and understandable” (Roestorf *et al*., 2019, p. 4). These pieces of participatory research offer direct access to the experiences of suicidal autistic adults, in comparison to Conner *et al*.’s (2020) study where the access is indirect as the parents of the autistic youth were surveyed regarding their offspring’s suicidality.

The recruitment method for participants in studies including suicidal autistic adults may be significant. Costa, Loor and Steffgen (2020) assess autistic traits using the AQ-short (Hoekstra *et al*., 2011), where they state within their limitations, that 30% of the *non-autistic* group have significantly high scores on the AQ-short, demonstrating autistic traits. This non-autistic group may not entirely have consisted of non-autistic participants, as Costa, Loor and Steffgen (2020) recruited the two groups of participants using two different methods. The autistic group was recruited through autism groups, whilst the non-autistic group was recruited through social media, describing the research as a mental health study (Costa, Loor and Steffgen, 2020). Some of the *non-autistic* group may, therefore, have been autistic.

Autistic stakeholders have been asked to rank their top priorities for research (Cassidy *et al*., 2020c; Cassidy *et al*., 2021c). As well as identifying risk and protective factors associated with suicide, the autistic stakeholders identified that it is also necessary to, "understand the experience of suicidality in autistic people" (Cassidy *et al*., 2021c). From literature, it is found that the overall experience of suicidality in autistic people is relatively frequent (Kato *et al*., 2013; Cassidy *et al*., 2014; Paquette-Smith, Weiss and Lunsky, 2014; Hirvikoski *et al*., 2016; Hand, Benevides and Carretta, 2020), and that risk factors may be related to depression (Cassidy *et al*., 2014; Zahid and Upthegrove, 2017; Cassidy *et al*., 2018b), or misdiagnosis (Au-Yeung *et* al., 2019; South, Costa and McMorris, 2021; Suckle, 2021), or to the autistic characteristics of anxiety (Richa *et al*., 2014; Doering *et al*., 2019; Zener, 2019; Costa, Loor and Steffgen, 2020), autistic burnout (Raymaker *et al*., 2020), camouflaging (Cassidy *et al*., 2018c; Cassidy *et al*., 2020b), alexithymia or to gender (Kirby *et al*., 2019;

Zener, 2019). Likewise, suicide protective factors include having a raised sense of self-esteem (Arwert and Sizoo, 2020) and social and material support. An autism diagnosis enables access to support (Hickey, Crabtree and Stott, 2018). The autistic stakeholders outlined that one of the top ten community priorities was to, “examine how well existing models” (Cassidy *et al*., 2021c), of suicide related to autistic people. Several models and theories were examined in relation to the autistic adult, from the theory of S*uicide as Escape* (Baechler, 1979), through the *Cry of Pain* model (Williams, 1997), the *Interpersonal-Psychological Theory of Suicide* (Joiner, 2005; Van Orden *et al*., 2010), the *Integrated Motivational-Volitional model* (O’Connor, 2011), the *Three-Step Theory* (Klonsky and May, 2015), to the *Minority stress theory* (Meyer, 1995) and *model* (Botha and Frost, 2020).

I determine a gap in the knowledge, also commented upon by Doering *et al*. (2019), specifically relating to the effect of anxiety and its relationship to suicidal thoughts and behaviours in autistic adults. A further gap in knowledge, mentioned by Cassidy *et al*. (2020a), relates to the reason why autistic people are more likely to contemplate suicide than those in the non-autistic population.

This research resonates with one of the priorities set by the autism community in that I explore, “the experience of suicidality in autistic people” (Cassidy *et al*., 2021c). Assessing the literature reveals the importance of the use of mixed methods to gain an understanding of the quantitative nature of the characteristics of a study group, and to delve to seek a deeper understanding of the phenomena of the lived experiences of suicidal autistic adults through qualitative methods. In addition, I appreciate the use of the internet for researchers to gather data, for the benefits it affords to autistic participants. To carry out the exploration, I probe three research questions.

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1.5 Research questions

Through preliminary research, attempting to find support and information relating to being a suicidal autistic adult, I identified that most research into suicide and autism was quantitative, and possibly undertaken by non-autistic researchers. Furthermore, the research included little information that I was seeking regarding the lived experience of suicidal autistic adults. To support other suicidal autistic adults, and those who had not yet been affected by suicidal thoughts, I sought to address this lack of experiential information. It was, therefore, paramount to know what other autistic adults had experienced, and through interviewing, *hear* the *voice* of suicidal autistic adults. This led to the development of the research question, what is the lived experience of the suicidal autistic adult?

Through further preliminary research, I recognised the importance of gaining a broader understanding of more suicidal autistic adults, as interviews with suicidal autistic adults would give me very detailed information relating to just a few specific people. Initial research that I found focused on the experience of depression, contrasting with anecdotal evidence that I was finding suggesting that there were other issues causing suicidal behaviours in autistic adults. I therefore developed an exploratory study seeking characteristics of a larger group of suicidal autistic adults. I identified that I could recruit the interview participants from this larger group. I therefore developed the research question, what are the characteristics of the suicidal autistic adult?

Whilst continuing further preliminary research, I understood that as an insider researcher my experience would probably bias the results. To address this, and to acknowledge my own lived experience, I found other insider researchers had used autoethnographic methods to demonstrate their positionality in relation to the research and included their own experience as an integral part of their research. This led to the development of the research question, what is my experience of being a suicidal autistic adult?

For the study to be progressive, I therefore reordered the sequence of research questions, to initially seek the broader range of experiences, through those of the smaller interview group, to my own.

The research encompasses three areas, by answering the three research questions. These questions are researched using different research methods.

1. An exploratory study, answering the question *what are the characteristics of the suicidal autistic adult*?
2. A phenomenological study, answering the question *what is the lived experience of the suicidal autistic adult*? and,
3. An autoethnographic study, answering the question *what is my experience of being a suicidal autistic adult?*

The first question is researched using data collected from an online survey, analysed quantitatively, and qualitatively using thematic analysis. The second question is examined through the data gathered using phenomenological interviews analysed by means of interpretative phenomenological analysis. The third question is analysed using an autoethnographic method, reflecting upon my own data of being an insider researcher.

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1.6 Thesis overview

This thesis is organised into six chapters. The next chapter is the methodology and locates the research in the interpretative paradigm. The research design is identified as mixed methods, and a justification of the methods used is provided. The third, fourth and fifth chapters report, analyse, reflect and examine the data responding to the three research questions. Chapter Three examines the characteristics of suicidal autistic adults though the quantitative data gathered from 74 respondents, and through a thematic analysis of the qualitative data provided by 36 of the respondents. Chapter Four is an exploration of the data gathered from interviewing seven participants about their experience of being a suicidal autistic adult, analysed using interpretative phenomenological analysis. Chapter Five uses an autoethnographic approach to reflect upon being an insider researcher, and my own experience of being a suicidal autistic adult. Chapter Six is the conclusion of the thesis, and being the interface of this mixed-methods research, I draw together the results of the three empirical chapters. I discuss the findings and how they resonate and add to literature, discuss the strengths and limitations of the research, and I make recommendations for policy and practice based.

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1.7 Conclusion

This chapter introduces the history of autism, and its diagnostic features. It presents the characteristics of autistic people and their life experiences. This chapter also introduces the vulnerability of the autistic population to suicidal behaviours. The prevalence of the various suicidal behaviours is described, and various assessment methods are explored. In addition, the chapter presents the risk and protective factors that are relevant for the autistic population. Several theories or models of suicide are introduced, including the role of the minority stress model. The research pertaining to the suicidal autistic adult is summarised, and the research questions examined are introduced. The next chapter focuses upon the methodology.

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Chapter 2. Methodology

In this research I aim to explore the characteristics of the suicidal autistic adult, to explore the lived experience of a group of autistic people who have exhibited these suicidal behaviours, and to reflect upon my own lived experience. Therefore, in this second chapter I present the research design and scrutinise the methodology of the research. I explain the use of sequential explanatory mixed methods that I use within the interpretative paradigm. I also outline my axiological, ontological, and epistemological assumptions, and how they are influenced by being an insider researcher undertaking a study through autistic and disabled lenses.

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2.1 Mixed methods

This study is based on a sequential explanatory mixed-methods approach (Tashakkori, Teddlie and Sines, 2012; Schoonenboom and Johnson, 2017). As this approach initially uses quantitative and subsequently qualitative data the advantages, and disadvantages, of both methods are assumed.

Mixing methods became popular in education with Creswell in the United States of America, in management with Bryman in the United Kingdom, in nursing with Morse in Canada, and in sociology with Brewer and Hunter (Leech and Onwuegbuzie, 2009). These researchers were trying not only to use quantitative and qualitative methods for a study, but in combining them they bring a greater depth to their research (Creswell and Plano Clark, 2011), and create a, “dialogue” (Maxwell, 2010, p. 478), between the different results, particularly when synthesising the findings.

Quantitative research has advantages as it can draw conclusions from large numbers of people, it can analyse data efficiently, it can be more easily bias controlled, and it can demonstrate relationships between variables (O'Cathain, 2010). The criteria for quantitative researchers should be, "validity, reliability, replicability and generalizability" (O'Cathain, 2010, p. 533). Nevertheless, quantitative research can be seen as dry and impersonal, as it is largely researcher motivated, and there may be limited understanding of the context of the participants (Creswell, 2013).

Qualitative research also has advantages, such as incorporating detailed perspectives of a few people. It is usually constructed from the views of the participants, not the researcher, and the participants' experiences can be understood in context. Its criteria are, "credibility, confirmability, transferability, and dependability" (O'Cathain, 2010, p. 534). The limitations of qualitative research are that: the data can be seen as *soft*; fewer people are studied and therefore it is not as easy to extrapolate as quantitative data; it can be highly interpretive; and it generally relies on the participant and therefore minimises the researcher's expertise (Creswell, 2013). This research uses two distinct qualitative methods, IPA and autoethnography. IPA studies examine individual participant's complex and detailed experiences (Smith and Osborn, 2015), whereas autoethnographic studies use the views of the insider researcher and maximise their expert knowledge.

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2.1.1 Mixed-methods typology

Mixed-methods typology[12] is the classification system of mixed-methods designs. A formative article by Greene, Caracelli and Graham (1989) described the first classification system for mixed-methods designs. Subsequently, more classification systems have been developed: by Tashakkori and Teddlie in educational psychology; by Creswell and Plano Clark in education; and by Morse in nursing. Schoonenboom and Johnson (2017) suggest that all mixed-methods research must have at least one qualitative and one quantitative element, the core element being able to, “stand on its own” (p. 112), in addition to being, “implemented rigorously” (p. 112). Guest (2013) proposes that these descriptive typologies are, “not capable of capturing the complexity and iterative nature” (p. 141), of some studies.

Morse (1991) introduces a notational system, where she uses the abbreviations *qual* for qualitative and *quan* for quantitative. She identifies simultaneous and sequential triangulation. A simultaneous design occurs when the qualitative and quantitative data are collected concurrently and are symbolised using a +. The sequential design develops when the qualitative and quantitative data are collected, and analysed, separately and sequentially, symbolised using a →. Morse (1991) also introduces the concept of dominance in her mixed methods; *QUAL* and *QUAN* are used as the dominant phase, whereas *qual* and *quan* are used as the minor phase. Mixed-methods research usually focuses upon four main designs, sequential, parallel, conversion, and fully integrated (Tashakkori, Teddlie and Sines, 2012). There are two sequential designs. The first design has

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[12] Typology - the way in which different objects can be placed into groups of different types (Leech and Onwuegbuzie, 2009).

the quantitative (QUAN) strand followed by the qualitative (QUAL) strand, known as a sequential explanatory mixed-methods design. The second design has the qualitative (QUAL) strand followed by the quantitative (QUAN) strand, known as the sequential exploratory mixed-methods design (Creswell *et al.*, 2003). This research is described as using a sequential explanatory mixed method, *quan → QUAL*, as it uses one quantitative element followed by a linked qualitative thematic analysis, and which precede the two distinctive qualitative elements of an IPA study and an autoethnographic study. Following the collection, analysis, and evaluation of the initial quantitative data from the online survey, a thematic analysis is performed using the online survey's qualitative data. The results of these findings are used to develop a pre-planned approach to the second phase of data collection, initially through interviewing previously suicidal autistic adults and analysing the data using IPA, and then through an autoethnographic study.

Sequential explanatory mixed-methods designs may sometimes emphasise quantitative research and the direction of the research is generally set in the first phase (Creswell *et al.*, 2003). However, this study has three qualitative analyses, all following the quantitative analysis, and the emphasis is on the qualitative aspect of the study. The strengths of a sequential design include being straightforward to describe, implement, and report, and that the final thesis can be written in distinct phases (Creswell *et al.*, 2003).

The participants of the second phase were recruited from the respondents of the online survey. One complication of a sequential explanatory design is the order in which the research ought to be completed. The challenge of this sequential design was that the questions for the second phase needed to be written prior to seeking permission from the ethics committee, however, owing to time constraints, this process occurred as the initial data was still being collected and analysed. Hence, rather than following this mixed-methods outline precisely, in this research I chose to follow the Schoonenboom and Johnson (2017) understanding of mixed methods, in that the study has independent quantitative and qualitative sections. Consistent with this, I formulated the questions for the second phase of data collection, the phenomenological interviews, and sought the relevant ethics approval for prior to completing the analyses of the online survey. The study may continue to be described as sequential, as online survey's data were collected, and analysed, prior to undertaking the interviews and analysing their data. Furthermore, the interview data were also collected, and analysed, prior to the autoethnographic study commencing.

Guest (2013) explains that the focus of a mixed-methods study should be, "the points of interface" (p. 146), between the different elements, rather than forcing research into, "an inadequate classification system" (p. 146). The system generally describes the elements of mixed-methods studies being dependent on one another, where the second element is dependent upon the results of the first (Schoonenboom and Johnson, 2017). Nevertheless, independent mixed-methods studies where the, "two research components are *independent*" (Schoonenboom and Johnson, 2017, p. 114, original emphasis), are accepted if there is a point of interface where, "the qualitative and quantitative components are brought together" (p. 115). In this research the three chapters collect data, relating to suicidal autistic adults, from different perspectives. The point of interface occurs in the final chapter where I bring together the findings of the three chapters, together with their connections to literature.

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2.2 Paradigms

The interpretative paradigm[13] of this research (Wright and Losekoot, 2010), is approached from a particular axiology, the nature of ethical values and biases; ontology, the nature of reality; epistemology, including the nature of knowledge; and methodology, the appropriate approach to systematic enquiry (Mertens, 2010a). I explore these philosophical components individually.

The paradigm was paramount when I chose the methodology. Kuhn (1970) defines a paradigm as, “what the members of a scientific community share” (p. 176). In this study I use an interpretative paradigm (Mertens, 2010a; Chowdhury, 2014), consistent with the aim of exploring the lived experience of the suicidal autistic adult, reported upon in Chapters Four and Five. The interpretative paradigm is developed from, “the philosophy of Edmund Husserl’s phenomenology” (Mackenzie and Knipe, 2006, p. 195), and the general study of hermeneutics[14] by other German philosophers. The research can, therefore, be described as idiographic, as it focuses on the uniqueness of the individual. However, Wright and Losekoot (2010) suggest that the interpretative paradigm should not be used with quantitative studies, although they accept that, “interpretative and positivistic approaches can work together with one supporting the other” (p. 418), if mixed methods are used for the research.

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[13] The paradigm or world-view - the set of beliefs and feelings the researcher has about the world and how it should be understood and studied (Kuhn, 1970).

[14] Hermeneutics - the interpretation of texts (OED, 2022d).

Although the transformative paradigm could have underpinned this research, as it approaches the, “issues of social justice and marginalised peoples” (Mackenzie and Knipe, 2006, p. 195), the interpretative paradigm was chosen due to the experiential nature of the second and third data collection phases. Nevertheless, this research does highlight the needs of a marginalised population (Mertens, 2011), namely the autistic adult population affected by suicidal behaviours. Using an interpretative paradigm enables some previously suicidal autistic adults to have a *voice* to explain their position. This research is completed *within* the autistic community, rather than the research being undertaken *on* the autistic community, as I am an insider researcher.

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2.2.1 The insider researcher

As a member of the autistic community, who has experienced various suicidal behaviours, I can describe myself as an insider researcher (Merton, 1972). There are both advantages and disadvantages to this. The first advantage is that as an insider researcher, I do not have to worry about orienting myself, “with the research environment and/or participants” (Greene, 2014, p. 3), and that I have a, “pre-existing knowledge of the context of the research” (Greene, 2014, p. 3). A second advantage is that the interaction between myself and the participants was more natural, and I was, “less likely to stereotype and pass judgement on the participants under study” (Greene, 2014, p. 3). Insider researchers usually attain in-depth knowledge (Bell, 2005), as the participants welcome, “the opportunity to discuss issues with someone who understands” (Greene, 2014, p. 4). A third advantage is that I may have found easier access to respondents (Chavez, 2008).

Limitations of insider researchers come when the researcher has become too subjective. Aguiler (1981) argues that insider research is a, “deterrent to objective perception and analysis” (p. 15), and as themes are too familiar the, “researcher may become normalized to an extent that threatens to impede analysis” (Greene, 2014, p. 4). Chavez (2008) draws attention to pressure exerted on an insider researcher to collude with participants’ answers when they say, “You know what I mean” (p. 485). If I encountered this collusion, I had to be disciplined to probe more deeply. A further disadvantage was raised by Merriam *et al*. (2001), who suggest that I, the insider researcher, would be too biased, being too close to the subject being researched, and not be able, “to raise provocative questions” (Greene, 2014, p. 4). However, a similar warning can be made to *outsider* researchers, or non-autistic stakeholders, who may have preconceived ideas of the community being researched, also limiting their questions. Being an insider researcher may also have added difficulty to the analysis of the phenomenological interviews, where findings should not be, “weighed down by my own experience” (Goldspink and Engward, 2019, p. 295). Alternatively, my experiences may provide, “new ways of understanding the data” (Goldspink and Engward, 2019, p. 295), with resultant new findings.

I approach this research using both the autistic and disabled lenses. Therefore, the review of literature and all aspects of methodology, together with the collection and interpretation of data, is *seen* through the experience and, “informed judgement” (Hayes *et al*., 2022, p. 493), of a disabled autistic adult.

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2.2.2 The respondents and participants

To focus this research on the autistic voice, it was vital to only include autistic respondents and participants. Non-autistic stakeholders were, therefore, not recruited for this study, and is a significant paradigmatic shift to that of previous research. In the first phase I recruited 74 autistic respondents to define the characteristics of suicidal autistic adults. In the second phase of data collection, it is the lived experiences of the suicidal autistic individual that is sought, not a non-autistic person's understanding of the suicidal autistic person's life experiences; I interviewed seven of the 74 respondents. In the third phase I am the sole contributor, being an autoethnographic study.

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2.3 Axiology

Axiology, the study of my own values and their effect on research outcomes, has been brought to attention by such researchers as Creswell (2007), Heron and Reason (1997), and Mertens (2007), but is not mentioned by Guba and Lincoln (1994). Due to the nature of insider research, insight into my own values, intuition, and biases, affect and inform my interpretation of all research data, and are an integral part of the study (Chavez, 2008). I aim to use language that is positive towards autistic people. I also determined to use only potentially ableist terms, such as *high functioning autism*, whilst reporting on work of other researchers. Axiological considerations are also relevant in the use of other people's questionnaires, such as the autism-spectrum quotient (AQ) (Baron-Cohen *et al*., 2001) and the empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004) questionnaires. I assume that the writers of these questionnaires are not autistic.

I approach the research trying to achieve the aims of Mertens (2007). She is explicit that in research, “every person must be treated with dignity and respect” (Mertens, 2007, p. 222), and any harm must be avoided. To be able to meet this aim several criteria are embedded in the design: that social justice and human rights are improved; that cultural groups are respected; that reciprocity is provided with the autistic adults; that discrimination and oppression of the autistic adults is challenged; that relationships are based on trust; and, that power inequalities are explicitly addressed (Mertens, 2011).

My own values may have influenced this research in various ways, both positively and negatively. Nevertheless, I sought to, and continually seek to, treat all participants with respect and dignity (Mertens, 2007). However, in the first phase, to ascertain whether respondents were autistic they were asked for their AQ (Baron-Cohen *et al*., 2001) and EQ (Baron-Cohen and Wheelwright, 2004) scores, as well as any physical or mental health diagnoses. I regret asking the respondents about diagnoses, with the assumption that this would draw out the autism or Asperger’s syndrome diagnosis, as this places the research back into the medical model. After initially assuming that the AQ and EQ questionnaires were valid and reliable, I now understand that these questionnaires may under identify autistic women and some autistic men, and therefore may be flawed (van der Aa *et al*., 2016). It is also possible for people, who have completed these AQ and EQ questionnaires on more than one occasion, to *know* the autistic answer and answer accordingly. Following psychometric analyses of the AQ and EQ, English *et al*. (2020) suggest that, “the use of total-scale scores” (p. 45), are not recommended for research use, but instead their sub-scale scores by used.

Clarke (2009) proposes that interpretative phenomenological analysis (IPA) outcomes are, "influenced by the researcher's own experiences, values and pre-understandings" (p. 38). This is also impacted by the double hermeneutic explained by Smith and Osborn (2008) as, the participants who are trying to make sense of their world and,

> "the researcher is trying to make sense of the participants trying to make sense of their world" (p. 53).

One factor enabling this *making sense* is that both the participants and I, the researcher, are autistic. However to add complexity, and where misunderstanding may occur, the analysis is written to be read by both non-autistic and autistic people.

My own values are evident in the third phase of data collection, the autoethnographic study, where I reflect upon my positionality, together with the personal narrative, and the echoes and resonances I had noted during the analyses of data collected from the online survey and phenomenological interviews.

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2.4 Ontology

Ontology is the study that defines a reality that is fixed, measurable, and observable (Guba and Lincoln, 1994). To achieve good research, Mertens (2007) poses ontological questions such as, "how is reality defined? By whom? Whose reality is given privilege?" (p. 216), and, "How can mixed methods shed additional light on the capture and interpretation of reality?" (p. 216). Undertaking research in the deaf community, Mertens (2007) describes communication as a social construct, as some people, “occupy a position of greater power” (p. 216), and do not make allowances for the way in which deaf people communicate. Similarly, not making allowances for the different ways in which autistic people communicate may lead to a sense of powerlessness in comparison to non-autistic people. Both the DSM-5 (APA, 2013) and the ICD 11 (WHO, 2018) suggest that social communication may be different for autistic people. The autistic individual may prefer to use written communication and, in so doing Mertens (2010b) explains, will be able to define what is ontologically real. In this study there is a depth of research to find the nature of reality, the potential antecedents of suicidal behaviours within some adults of the autistic community. IPA does not aim to seek the truth but aims to uncover the meaning and reality of individual people’s experiences (Vicary, 2017). To enable the autistic voice to be heard without discrimination or oppression, the interviewing took place using email, a method that is acceptable to autistic participants (Benford, 2008).

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2.5 Epistemology

Epistemology is the study of knowledge. It can be also defined as the relationship between the researcher and the research, particularly when knowledge is acquired through the, “subjective experiences” (Creswell and Poth, 2013, p. 21), of the participants. The researcher must have an objective detachment from the research to find out the reality of the research (Guba and Lincoln, 1994). However, having an objective detachment is very difficult, or impossible, for me as an insider researcher. Especially as the experiences of the participants in the phenomenological interviews resonate with my own experience, and furthermore, as I am also the subject of the autoethnographical study.

The interpretative paradigm has an epistemological collaboration, as researchers actively involve their participants as their data source. In this study, the level of the participants' involvement was influenced by the need to create an environment that enabled them to be at ease. This meant, for example, that the phenomenological interviewing was one-to-one, and in a place where the participant felt easiest to discuss their experiences. This could have been through face-to-face interviews, telephone interviews or by email interview. I gave the participants the three options, their preferred method of interview was by email. This removed any barriers of communication between the autistic participants and me, the interviewer (Chown *et al*., 2016). Using email also reduced my stress and anxiety levels, in addition to those of the interviewees (Benford, 2008).

To study the knowledge gained some researchers, using Husserl's methods in IPA, would assume that I would have to be detached from the data gathered (Smith, Flowers and Larkin, 2009). Husserl used three different expressions, bracketing, *epoché* and phenomenological reduction, to refer to the process of reflection where the researcher's opinion and prejudice are suspended, so they can focus on the phenomena (Koch, 1995). In this study, despite using an interpretative paradigm, I could not follow Husserl's phenomenological method.

As an insider researcher I could neither detach myself from the data collected, nor suspend my opinion and prejudice. I, therefore, acknowledged the life circumstances I had experienced in relation to the data I needed to collect, that of being a suicidal autistic adult, and being a human in the world, that Heidegger describes as, "*Dasein*" (Koch, 1995, p. 831). As Heidegger (1962) explains, the researcher must work out their, "fore-structures" (p. 195). The fore-structure I possess is due to being an insider researcher and having an understanding of the participant's engagement with being a suicidal autistic adult. Heidegger (1962) suggests that this is acquired in three parts, by possessing fore-having, fore-sight, and having a fore-conception. Firstly, by having been immersed in the activities that I interpret from the participants' interviews, I possess a fore-having (Warnke, 2011). Secondly, as I have an insight into some of their experiences and having a personal viewpoint, I possess a fore-sight (Geanellos, 1998; Warnke, 2011). The third element that I have is fore-conception, as I have created expectations of possible interpretations of the participants' lived experiences (Geanellos, 1998).

Gadamer highlights that a researcher must look, not only closely at the results, but also beyond the results to a horizon which gives a broader view (Nenon, 2016). In hermeneutic theory, the concept of the horizon explicitly explains how a researcher's own intellectual understanding and their personal experience interpret the routine perceptions of the unanalysed data and enrich the findings (Nenon, 2016; Howard, Katsos and Gibson, 2019).

The research, therefore, acknowledges my personal experience of being a suicidal autistic adult, and is underpinned by my experience of action research in education. During interviews I needed to focus on having a curious attitude, with a critical self-appraisal, in order not to guide any participant's answers

(Goldspink and Engward, 2019). Without this critical self-appraisal, I may have unintentionally influenced the research (Goldspink and Engward, 2019).

In IPA the personal perceptions and understanding of the researcher are drawn upon in the analysis of each participant's life experience (Smith, Flowers and Larkin, 2009). Smith, Flowers and Larkin (2009) suggest that journaling gives the space and time required to develop interpretative ideas that otherwise would have been lost. Therefore, to develop my interpretation of the interviewees' comments, I recorded my own reflections in a notebook throughout the interviews and analyses. I considered these reflections as I developed the emergent themes throughout the analytical process.

Similarly to the axiological consideration, as the researcher I am aware of the double hermeneutic (Smith and Osborn, 2008). I have to be aware of the epistemological approach of me making sense of the participants making sense of their own experience. In contrast to other IPA research, there is an additional consideration within this thesis. The autistic adults are making sense of their own suicidal experiences, the autistic researcher is attempting to make sense of the autistic participants' experiences, and, additionally, the researcher then has to report the findings to a non-autistic reader of the text. This additional layer is one that Milton (2012) describes as the double empathy problem.

It is suggested that both the text of the autistic participant and the interpretation by an autistic researcher belong to the same Gadamerian horizon (Vessey, 2009). The meaning of the written word lives in the *fusion of horizons*, where the researcher interacts with, and interprets, each participant's text (Vessey, 2009).

IPA has its origins in both phenomenology and hermeneutics, although van Manen (2017) claims that IPA is not totally in line with phenomenology. IPA is based on lived experience, and therefore requires an amalgamation of both the phenomenological insights and the interpretational, or hermeneutic, insights. Smith, Flowers, and Larkin (2009) suggest that phenomenology is crucial to IPA, as without it, “there would be nothing to interpret” (p. 37), and without any interpretation the individual lived experiences of people, and potential learning opportunities, would not be shared with others.

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2.6 Justification of methods

To achieve an exploration of autism and suicide the methods I use are quantitative, and qualitative through thematic analysis, IPA, and autoethnography. The aim is to solely use the autistic voice for this exploration. I, therefore, set up an online survey to be undertaken by autistic adults which is analysed quantitatively, through hypothesis testing, and qualitatively, through thematic analysis. A small group was recruited from the online survey’s respondents to undertake interviews relating to their experiences of being a previously suicidal autistic adult, analysed through IPA. Finally, in the autoethnographic study, I respond to the resonances that I experienced as I reviewed literature, undertook the online survey and the seven interviews, whilst adding the data of my own experience. The three parts of the thesis combine to meet the overarching aim of the exploration of autism and suicide.

The axiological, ontological, and epistemological considerations determined the methodology used. Methodology is the justification of the methods, in this case, the reason for carrying out data collection from autistic people who had previously exhibited suicidal behaviours by ideation, planning or attempt. The methodology explains why I gather data from 74 participants for the first phase of data collection, and from only seven participants for the second phase. Whereas the larger sample for the first phase aims to explore the characteristics of suicidal autistic adults, the smaller and purposive sample for the second phase illuminates the autistic experiences in a new light, unable to be achieved using other qualitative approaches (Howard, Katsos and Gibson, 2019).

Following the Schoonenboom and Johnson (2017) understanding of mixed methods, the explanatory sequential mixed-methods design (Creswell *et al*., 2003) was chosen to gain an insight into the emotional landscape of suicidal autistic adults.

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2.7 Rigour and addressing potential bias

Rigour is important in research, with the identification of specific factors that increase rigour and reduce bias. Some researchers suggest that rigour implies, “rigidity and inflexibility” (Baillie, 2015, p. 36), whilst appropriate in quantitative research, and may not lend itself to qualitative research. I recognise the significance of validity for the online survey, by using reliable and valid research tools. I explain the importance of trustworthiness in the IPA study’s data collection and analysis. Finally, I describe the complexity of rigour for an autoethnographic study.

Finlay (2021) focuses on achieving rigour in thematic analyses but the themes she identifies are important for all research, “rigour, resonance, reflexivity and relevance" (p. 104). Rigour provides the guidelines that help researchers, "provide a path to expertise" (Le Roux, 2017, p. 195), by using the correct tools. When using mixed methods, Creswell and Plano Clark (2011) advocate that the rigour of both the quantitative and qualitative research methods be developed. One problem in achieving rigour, with mixed-methods research, is that the qualitative and quantitative elements need to be completed concurrently, and independently, if triangulation is desired (O'Cathain, 2010, p. 538). However, as this study uses sequential mixed methods, triangulation is not possible (Schoonenboom and Johnson, 2017). To redress this and to gain rigour, O'Cathain (2010) suggests that there ought to be transparency in the rationale and the planning, and that there should be sufficient time for the study to be completed. Therefore, to achieve rigour, I outline the rationale and the processes I undertook to gather the data for the online survey in Chapter Three, and for the phenomenological interviews in Chapter Four.

To evaluate qualitative research, Finlay (2006) assesses the clarity, credibility, contribution, communicative resonance, and caring elements of her research. I, therefore, also achieve rigour by responding affirmatively to the following questions: does the qualitative research make sense? Is it convincing? Does the knowledge add to an issue? and, Have I shown respect to the participants?

Within the online survey phase of data collection, to ensure rigour and validity, I use tools that have been proved reliable and valid in previous research (Heale and Twycross, 2015), the Suicide Behaviours Questionnaire-Revised (SBQ-R) (Osman *et al*., 2001), the autism-spectrum quotient (AQ) (Baron-Cohen *et al*., 2001), and the empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004).

Osman *et al*. (2001) validates the first part of the SBQ-R, detailing it as, "high in support of the criterion-related validity" (p. 250). Within the Baron-Cohen *et al*. (2001) study, that introduced the AQ, the Cronbach's alpha coefficients are all moderate to high (communication = .65; social = .77; imagination = .65; local details = .63 and attention switching = .67). The EQ (Baron-Cohen and Wheelwright, 2004) has, "reasonable construct and external validity in having a high alpha coefficient" (p. 171). The validity of both the AQ and EQ is further verified as the two quotients are inversely correlated (Baron-Cohen and Wheelwright, 2004).

To promote the robustness of the quantitative findings I use a bias-corrected and accelerated bootstrap to provide 95% confidence intervals that adjusts for both bias and skewness (Efron, 1987). The bootstrap results are based on 1000 samples, using the Statistical Package for the Social Sciences (SPSS-24.0) software (version 24.0).

Using the validated tools, the SBQ-R (Osman *et al*., 2001), the AQ (Baron-Cohen *et al*., 2001), and the EQ (Baron-Cohen and Wheelwright, 2004), in the online survey further reduced potential bias. Nevertheless, advertising an online survey mainly on the internet through a social media site, automatically excluded anyone without internet access. I attempted to address the bias of online advertising through recruitment in face-to face sessions at local autism groups. However, any respondent still required access to the internet to take part. I am also aware that some potential participants did not participate in the online survey. They sought total anonymity, rather than confidentiality.

Potential respondents had to provide details of their name and contact details on the consent form, before being given the online survey's access details. Furthermore, data collection bias may have occurred if my personal beliefs, relating to the suicidal autistic adult influenced the data collection (Smith and Noble, 2014).

Many qualitative methods require saturation of the sample, a criterion developed explicitly for use with theoretical sampling (Saunders *et al*., 2018). However, IPA uses purposive sampling, where saturation is not required, as the method seeks to focus on the unique lived experience of several participants (Hale, Treharne and Kitas, 2008) who can offer meaningful insight on the subject being studied (Rai and Thapa, 2015).

Within the IPA study the positivist terms of *reliability* and *validity* can be replaced with *trustworthiness* (Rodham, Fox and Doran, 2015). Mason (2012) describes trustworthiness as data generation and analysis that is, "thorough, careful, honest and accurate" (p. 188). In phenomenological interviews respondent validation of the analysis is impossible, as the emergent and super-ordinate themes are expected to be the researcher's own interpretation of the participants' comments (Smith, Flowers and Larkin, 2009). The comments the participants make are also their own interpretation of events that happened. Validation can be sought from participants by asking them to check that their responses are accurately recorded, which also ensures trustworthiness.

Shinebourne (2011) interprets the studies by Yardley (2000) and Elliott, Fischer and Rennie (1999), to describe four stages where IPA can be assessed for rigour.

The first is, “sensitivity to context” (Shinebourne, 2011, p. 26). Shinebourne (2011) explains that by choosing the IPA method, participants would be recruited, “from a particular context” (p. 26), bringing a sensitivity to their lived experience. In this research the context is suicide and autism, therefore, I recruited previously suicidal autistic adults as the participants. The second stage Shinebourne (2011) describes encourages, “commitment and rigour” (p. 27), demonstrated by the researcher being immersed in the, “data of the research” (p. 27). To be immersed in their data, and to address the idiographic nature of IPA, I undertook most of the interviews sequentially, giving three weeks to each participant, and whilst analysing the data, I engaged, “extensively and thoughtfully” (Yardley, 2008, p. 267), with each participant’s script for two weeks, before moving to the next. I address Shinebourne’s (2011) third area of rigour, that of, “transparency and coherence” (p. 27), by clearly describing in detail the processes involved, such as selecting the participants, conducting the interviews, and explaining the stages of analysis. Shinebourne’s (2011) fourth stage to assess an IPA study for rigour, is the, “impact and importance” (p. 27), of the final piece of work, that the analysis is coherent, and informs the reader of, “something interesting, important or useful!” (Smith, Flowers and Larkin, 2009, p. 183). I anticipate this to be the case as, during the process of researching, and gaining confidence and knowledge, my views have been sought in several different forums that aim to improve the response, and the support offered, to suicidal autistic adults.

I reduced potential bias in the IPA study by sending the questions to the participants prior to seeking the responses. This gave each participant time to think about their response (Love, Vetere and Davis, 2020). To ensure that the process was as robust as possible I undertook training in the use of IPA as a method and discussed the findings with other researchers experienced with the method (Love, Vetere and Davis, 2020). After the completion of the interviews there was also an opportunity for each participant to add any information that they thought I had not included (Love, Vetere and Davis, 2020).

Achieving rigour in autoethnographic research is complex; autoethnographers have different opinions of rigour, although most agree that it is important. Ellis (2000) suggests that any narrative should engage with the feelings of the reader, whereas Medford (2006) recommends that the narrative needs to be accountable, credible, and dependable. Loh (2013) proposes that the narrative must, “ring true” (p. 7), and that it ought to produce knowledge to aid solving problems. In contrast, Ragan (2000) suggests that an autoethnographic study cannot be appraised, as the method of autoethnography is, “neither methodical nor systematic” (p. 230).

Although I do not include a full personal narrative within this thesis, I aim for the autoethnographic study to engage with the reader (Ellis, 2000), and provide a credible account (Medford, 2006) that rings true (Loh, 2013). Even though I act reflexively by journaling and therefore attempt to reduce bias, as a white educated adult I have to be aware that I cannot totally eliminate bias, but only aim to reduce it (Kahl, 2011). To promote the robustness of the findings I wrestle with the partly ethical thought of whether I am being too open about my experience of being a suicidal autistic adult (Winkler, 2018). An autoethnographic study contrasts to other more *traditional* research, where the researcher’s role is, “objective, neutral, rational and definitely not visible in the text" (Winkler, 2018, p. 243). Contrastingly, it requires a personal lived experience on which to reflect, revealing the deep connection between myself and the subject (Goodall, 2000).

If researchers aim to empower and support others, rigour, "must explicitly address ethical and power dimensions" (Finlay, 2006, p. 325). This supports Henwood and Pidgeon's (1992) attributes of good qualitative research, including reflexivity, where, "the role of the researcher needs to be acknowledged and accounted for in the documentation of the research" (Finlay, 2006, p. 321). As the research questions developed from seeking to support other autistic adults experiencing suicidal behaviours, I ensure rigour by addressing the ethical principles of the entire research, and the ethical considerations of each particular study individually.

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2.8 Ethics

Ethics is doubly important in this thesis, as it addresses two areas of ethical concern, suicide and autistic adults. Ethics committees have concerns regarding research related to suicide (Lakeman and FitzGerald, 2009; Dazzi *et al*., 2014; Blades *et al*., 2018; Andriessen *et al*., 2019). A committee may be cautious as they have less, "knowledge of the population" (Lakeman and FitzGerald, 2009, p. 16), being studied, and anticipate that the research may, "increase an individual's risk of suicide" (Blades *et al*., 2018, p. 2), or other potential harm (Andriessen *et al*., 2019). To reduce any perceived risk, if a participant suggests that they are suicidal, researchers need a, "contingency plan" (Lakeman and FitzGerald, 2009, p. 17), with statements required allowing a breach of confidentiality in the consent form. This is important when it is impossible to predict suicidal behaviours whilst conducting research (Andriessen *et al*., 2019). In addition, Lakeman and FitzGerald (2009), in their study regarding suicide-based research, found that a quarter of ethics committees had concerns regarding the safety of the researcher. This was particularly related to the potential of emotional harm if a participant died by suicide following the research process. To reduce any psychological risk to researchers debriefing supervisions are advised to process the information disclosed by the participants (Lakeman and FitzGerald, 2009). In general, ethics committees seek evidence that any such research will not cause increased suicidal ideation and behaviours amongst the participants. Over half of Lakeman and FitzGerald's (2009) sample of ethics committees mentioned that the researcher had a, "duty of care" (p. 16), for the participants. A much smaller percentage of ethics committees suggested that it was unethical to undertake research on a suicidal sample without the further offer of, "care or treatment" (Lakeman and FitzGerald, 2009, p. 16). However, in the non-autistic population suicide research has been shown to lead to reductions in suicidal ideation, suicidal attempts, and overall distress (Blades *et al*., 2018). Recalling suicidal behaviours may reduce suicidal ideation (Dazzi *et al*., 2014), and may be described as beneficial (Rivlin *et al*., 2012; Biddle *et al*., 2013). The reduction in suicidal thoughts and behaviours may be due to the nature of interviewing in the research studied, as participants are given the rare opportunity to recount in depth, and confidentially, their suicidal experiences (Blades *et al*., 2018).

Research in a suicidal, or previously suicidal, sample have been found to have benefits for both the researcher and the participants (Lakeman and FitzGerald, 2009). Ethics committee members suggest that further benefits include making a contribution to help other suicidal people, gaining an insight into an individual's suicidal thoughts and behaviours, and by realising that they are not the only person having suicidal thoughts and behaviours (Lakeman and FitzGerald, 2009). The researchers may increase their understanding regarding the suicidal, or previously suicidal, sample and it may also, "improve public knowledge of suicide" (Lakeman and FitzGerald, 2009, p. 15). Furthermore, after considering the involvement of the ethics committee, researchers beneficially altered their ethics applications (Andriessen *et al*., 2019).

Nevertheless, fears of concern for either the participant or researcher need to be addressed (Dazzi *et al*., 2014). Although Dazzi *et al*. (2014) reports on the results of suicide related research in non-autistic people, similar research with autistic people may cause concern, as perseverative thinking may prompt suicidal ideation, and therefore create a particularly vulnerable population (Lai, Rhee and Nicholas, 2017). This concern is possibly addressed by Biddle *et al*. (2013), who researched vulnerable people's experiences, "of participating in suicide... based research" (p. 356). Within their findings they emphasise that, "a self-selecting group" (Biddle *et al*., 2013, p. 361), of vulnerable people may benefit from participating in, "in-depth qualitative" (p. 361), studies. The results also generate successful interventions (Biddle *et al*., 2013). Also addressing this possible risk, new autism focused suicide assessment tools have since been developed (Cassidy *et al*., 2021b). To reduce any negative impact of taking part in suicide focused research, I designed the research and then discussed it with other more experienced researchers (Lakeman and FitzGerald, 2009).

It is significant to reflect upon the ethics of person-orientated research (Israel and Hay, 2006). This is particularly important in relation to autism-based research, where autistic people have experienced alienation and marginalisation in the past (Pellicano and Stears, 2011; Gowen *et al*., 2019) due to coercion and, "discomfort in the research process" (Cascio *et al*., 2020, p. 1677). Whereas ethics based on non-autistic individuals may encourage an accessible consent process and address potential imbalances of power between the researcher and the researchee, within the autistic population there is a need for the researcher to commit to the experiences of anxiety and communication differences, in addition to high ethical standards (Cascio *et al*., 2020). Cascio and Racine (2018) suggest that, in addition to their research in autistic adults, their *person-oriented research ethics* model can be used with all groups of research participants. Based on five principles, the development of the model was assisted by autistic adults, in addition to the researchers and other professionals (Cascio *et al*., 2020). The first *guide-post* is that the research should meet the needs of individual participants. I achieved this in the research by initially accepting different forms of consent, other than the scanned forms, which contained the same information; by determining through consensus the best way to achieve the interviews with the seven participants; and by respecting the language used by the participants, especially in relation to gender (Cascio *et al*., 2020). Achieving the second principle, related to the acknowledgement of the respondents' lived world, meant that trust had to be developed so that they knew that no harm would come to them (Pellicano and Stears, 2011; Cascio *et al*., 2020). In acknowledging the lived world of the research participants research ethics emphasises intersectionality to halt any exclusion or marginalisation (Cascio, Weiss and Racine, 2021; Mallipeddi and VanDaaalen, 2021). The third area outlined by

Cascio and Racine (2018) suggests that autistic people may be excluded from relevant participatory research due to barriers that may arise because of their age, socioeconomic status, “sex, gender, language, ethnicity, [or] level of support needs” (Cascio, Weiss and Racine, 2021, p. 33). Enabling empowerment in the decision-making process (Cascio *et al.*, 2020) led to some people not taking part in the online survey as they sought anonymity, and I required names and addresses of the respondents to be able to seek medical assistance if it was required. Nevertheless, once I took out all identifying information from the text in the IPA study, the participants read their interview scripts, and approved them for use. Furthermore, I wanted to offer a route for suicidal autistic adults, “to direct the course of research as a way to impact policy” (Cascio, Weiss and Racine, 2021, p. 103), through research providing access to the autistic voice. I respected the fourth principle, that of, “holistic personhood” (Cascio and Racine, 2018, p. 177), by accepting that some of the respondents would be self-diagnosed and would not have an official autism diagnosis. To meet the specific needs of autistic adults, I identified the use of the internet for recruiting the respondents and collecting data (Benford, 2008). To provide autonomy, self-confidence, and self-determination I provided specific dates before which the participants could withdraw from the study.

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2.9 Conclusion

This research uses an explanatory sequential mixed-methods model to explore autism and suicidal behaviours in autistic adults. Each of three data collection methods enables the autistic voice to be heard through quantitative, qualitative and autoethnographic methods.

The purpose of this chapter is to present the research design and analyse the methodology, defining sequential explanatory mixed methods. I discuss the interpretative paradigm and the relevancy of being an insider researcher, and thereby researching through autistic and disability lenses. I outline the axiological, ontological, and epistemological considerations of the research. I explain how I approach rigour, attempt to reduce bias, and the ethical concerns related to researching the experience of suicidal autistic adults. The third, fourth and fifth chapters detail the data collection, results, and analyses.

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Chapter 3. An exploratory study of the characteristics of the suicidal autistic adult

The overall aim of this research is to explore the characteristics of suicidal autistic adults. I, therefore, start to address the first part of the seventh of the ten autism community's priorities to aid suicide prevention, "what is the experience of suicidality in autistic people?" (Cassidy *et al*., 2021c, p. 3).

In this chapter I outline the research question and summarise the key aims of this first part of the study; the conditions of data collection, together with an outline of the ethics approval; the measures that I use to gather the data in the online survey, the process of respondent recruitment, and the procedure through which the data is gathered; and, the methods used to analyse the data. I report the demographic characteristics, including descriptive statistics, of the respondents. The results of quantitative analyses are reported, followed by a thematic analysis of the additional comments that respondents made in the online survey. The chapter culminates with a discussion of the findings drawing upon literature by other researchers.

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3.1 Research question

The research question for this first exploratory phase of the mixed-methods research is *what are the characteristics of the suicidal autistic adult*? The three suicidal behaviours, suicidal ideation, suicidal plans, and suicidal attempts, are analysed separately through the examination of various *a priori* hypotheses in relation to age and gender, experience of depression, and diagnosed depression.

I assess whether having a history of diagnosed depression, suicidal ideation, plans, or attempts in autistic adults in associated with gender, and then with age, by examining the following hypotheses:

- H_0 - suicidal ideation is independent of gender
- H_0 - having a suicidal plan is independent of gender
- H_0 - suicidal attempt is independent of gender
- H_0 - diagnosed depression is independent of gender
- H_0 - the age of suicidal ideation is independent of gender
- H_0 - the age of suicidal plans is independent of gender
- H_0 - the age of suicide attempts is independent of gender
- H_0 - the age of adults diagnosed with depression is independent of gender

I assess the association of the various suicidal behaviours in autistic adults with the reported experience of depression, by examining the following hypotheses:

- H_0 - suicidal ideation is independent of experienced depression
- H_0 - suicidal plans are independent of experienced depression
- H_0 - suicidal attempts are independent of experienced depression

I address the association of the various suicidal behaviours in autistic adults with a reported history of diagnosed depression, by examining the following hypotheses:

- H_0 - suicidal ideation is independent of diagnosed depression
- H_0 - suicidal plans are independent of diagnosed depression
- H_0 - suicidal attempts are independent of diagnosed depression

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3.2 Data collection

A convenience sample was selected of the most readily available subjects, due to the ease of availability, that it is inexpensive, and it is time considerate. Therefore, the respondents may not be representative of the total population, there is a possibility of the data being biased, and there may be a high rate of sampling error. The results cannot be generalised, although trends in the data can be identified.

I undertook several calculations to calculate the approximate sample size I required for the online survey. An estimated number of autistic people in the United Kingdom at the time of the survey was approximately 700,000 (National Autistic Society (NAS), 2017). I determined to seek a confidence level of 95% (p = .05). The results indicated that a sample size of approximately 120 would give a margin of error of approximately 9%. A margin of error between 4% and 8% is usually acceptable by most survey researchers (Schulz, 2011).

The tools I used, particularly the autism-spectrum quotient (AQ) (Baron-Cohen *et al*., 2001) and empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004), were prepared for use for those without intellectual disabilities. To keep the information within the questionnaire confidential, exclusion criteria also included being unable to fill in the information required without assistance. As the study focuses upon the suicidal autistic adult, I excluded those who were not autistic.

The homogeneity of a single population is important to enable quantitative tests to be performed (Kupczynski, 2015). This is especially pertinent when using a convenience sample (Jager, Putnick and Bornstein, 2017). Homogeneity is provided as all the respondents are self-identified as adults and are diagnosed as being autistic or having Asperger's syndrome. Although using a convenience sample, I acknowledge that the respondents may present a particular subset within the population of autistic adults.

Using an online survey to gather data from a group of autistic adults regarding various aspects of their suicidal thoughts and behaviours had the benefits of its ease of use, its lack of cost, and its accessibility through a uniform resource locator (URL) link, sent to each respondent. Additionally, it could be completed at the respondents' convenience and at their own pace, however, access was denied to those who did not have internet access (Ball, 2019).

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3.2.1 Ethics approval

In this first phase of data collection the online survey results are anonymous, which pose a problem if assistance is required for a suicidal person (Lakeman and FitzGerald, 2009). Some ethics committee members have suggested that providing details of support services may not be sufficient for a depressed person who requires medical or emotional assistance (Lakeman and FitzGerald, 2009). Therefore, in addition to providing details of support services I requested contact details of all the respondents. Through their numeric identifier it was possible to identify a respondent if assistance was required. Nevertheless, to maintain the requirements of the General Data Protection Regulations (GDPR), measures were in place to ensure that personal data was protected. Some potential respondents wanted to remain totally anonymous so were excluded from the study.

For the first phase of the study, ethics approval was obtained from the Faculty of Health and Wellbeing Research Ethics Panel, Canterbury Christ Church University, Ref. 17/FHW/17 006 (Appendix A).

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3.2.2 Measures used to collect data

To determine the characteristics of suicidal autistic adults, prior to setting the questions of the online survey, I had to define the type of data I wanted to collect. In addition to confirming that the respondents were autistic, I sought information relating to depression, as this co-occurring condition is frequently mentioned in literature relating to autistic suicide (Cassidy *et al*., 2014). As personal experience demonstrated that depression may not be diagnosed prior to a suicide attempt, I highlight the importance of data related to experienced depression. If the two questions seeking depression data were both answered negatively, this would generate a third variable, that of not having experienced, or been diagnosed, with depression. I sought data relating to autistic traits through the collection of the respondents' AQ and EQ scores. I sought data relating to gender, as I was aware that autistic females are more at risk of suicide than autistic males (Hirvikoski *et al*., 2016), and added *non-binary* to the gender classification for the results. Furthermore, I had a concern that autistic adults may have other risk markers that precipitate suicidal behaviours. I therefore sought information relating to other co-occurring conditions, and I designed a question to ascertain this information.

Within the online survey I sought demographic characteristics of the respondents, and used several published tools used within autism and suicide research. I used an adapted question from the Suicidal Behaviours Questionnaire-Revised (SBQ-R) (Osman *et al*., 2001), and two unadapted measures, the autism-spectrum quotient (AQ) (Baron-Cohen *et al*., 2001) and the empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004). The AQ and the EQ help determine the level of autistic traits demonstrated by the responding autistic adults. It is acknowledged that these questionnaires may be biased and dated and may not be an ideal indicator of autistic traits for most autistic women and for some autistic men (van der Aa *et al*., 2016; Agelink van Rentergem, Lever, and Geurts, 2019; Brown *et al*., 2020). However, gathering data from the AQ and EQ enabled me to confirm that the respondents had autistic traits as identified by the quotients.

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3.2.2.1 The Suicide Behaviours Questionnaire-Revised

To seek the suicidal characteristics of suicidal autistic adults, I developed the first question of the Suicide Behaviours Questionnaire-Revised (SBQ-R) (Osman *et al*., 2001), itself developed from The Suicide Behaviours Questionnaire (SBQ) (Linehan, 1981). Rather than using the questionnaire's first question (Figure 3.1), I constructed three succinct questions that sought information about the respondents' previous suicidal thoughts, plans, and attempts, 'have you ever thought about killing yourself?', 'have you ever planned to kill yourself?' and 'have you ever attempted to kill yourself?'. If any respondents had never thought about, planned, or attempted suicide, they were able to answer *no* to each of the questions. As I was not seeking to assess suicide risk, I did not attempt to adapt, or include, any further questions from the SBQ-R.

1. Have you ever thought about or attempted to kill yourself?
(Circle only one):
1 = Never
2 = It was just a **brief** passing thought
3a = I have **had a plan** at least once to kill myself but **did not** try to do it
3b = I have **had a plan** at least once to kill myself and really wanted to die
4a = I have **attempted** to kill myself, but **did not** want to die
4b = I have **attempted** to kill myself, and really hoped to die

Figure 3.1
Question 1 of the SBQ-R (Osman *et al*., 2001)

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3.2.2.2 The autism-spectrum quotient

The autism-spectrum quotient (AQ) (Baron-Cohen *et al*., 2001) has been widely used in research and clinical practice to quantify autistic traits. The AQ highlights self-reported autistic traits in a person. It is a 50-item self-evaluation questionnaire assessing personal preferences (Baron-Cohen *et al*., 2001). The participants rate to what extent they agree or disagree with the statements on a 4-point Likert-type scale forced-choice format. Responses are scored using a binary system, where an endorsement of the autistic trait, either slightly or definitely, is scored as *+1*. The opposite response is scored as a *0*. The maximum score of the AQ is 50. The AQ items are counterbalanced to avoid a response bias, with half of the *agree* responses and half of the *disagree* responses endorsing the autistic trait. The AQ is not suitable for individuals with an intellectual disability, a low verbal ability or a language impairment, as it is a self-report questionnaire and relies on the understanding of each question (Ruzich *et al*., 2015). The fifty items are divided into five domains of ten items each (Table 3.1), which assess the strengths and difficulties related to autism as described in the diagnostic manuals. These five domains are communication, social skills, imagination, attention to detail, and attention switching or tolerance of change (Auyeung *et al*., 2008). A score of 32 or greater is seen as indicative that a person's autistic traits would suggest an autism diagnosis (Ruzich *et al*., 2015). The AQ has satisfactory internal consistency with Cronbach's α varying from .63 (Baron-Cohen *et al*., 2001) to .78 (Kurita, Koyama and Osada, 2005).

Domain	Question number
Communication	7, 17, 18, 26, 27, 31, 33, 35, 38, 39
Social skills	1, 11, 13, 15, 22, 36, 44, 45, 47, 48
Imagination	3, 8, 14, 20, 21, 24, 40, 41, 42, 50
Attention to detail	5, 6, 9, 12, 19, 23, 28, 29, 30, 49
Attention switching *or* Tolerance of change	2, 4, 10, 16, 25, 32, 34, 37, 43, 46

Table 3.1
The fifty items of the autism-spectrum quotient by domain
(Baron-Cohen *et al*., 2001; Auyeung *et al*., 2008)

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3.2.2.3 The empathy quotient

The empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004) is designed to be, "short, easy to use and easy to score" (p. 166). Similar to the AQ, it is in a 4-point Likert-type scale forced-choice format. The EQ comprises 60 questions; 20 filler questions, 20 questions that an autistic person would probably score *agree* and 20 questions an autistic person would probably respond *disagree*. The responses can either be classified as *definitely agree* or *definitively disagree* where the responses score 2 points, and *slightly agree* or *slightly disagree* responses score 1 point. No points are scored for the filler question responses. In the original study the research team checked the results of the answers for bias (Baron-Cohen and Wheelwright, 2004). A score of 30 or less is seen as indicative that the respondent would be diagnosed as autistic (Baron-Cohen and Wheelwright, 2004).

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3.3 Respondent recruitment

I regularly advertised the study via the internet, using an internet social networking service (Figure 3.2), and through face-to-face support groups for autistic adults in a county in South-East England. This online survey was available for approximately 6 months, from 7th August, 2017 to 31st January, 2018.

Are you Autistic?
Do you have Asperger's Syndrome?

If yes, do you have a few minutes to answer an anonymous survey about suicide?

For more information about the PhD survey by an autistic researcher,
Contact: *email address removed*

Figure 3.2
Post advertising study on 7th August, 2017

A further advertisement (Figure 3.3) was added to the internet social networking site towards the end of the study period, on 20th January, 2018, which generated more responses.

10 days left for #actuallyautistic people to complete my PhD survey. Please email *email address deleted* for consent form. The topic is related to suicide in autism. I'm autistic myself and need your help. (20 Jan 2018)

Figure 3.3
Post re-advertising study on 20th January, 2018

Prospective respondents were sent an introductory letter (Appendix B), a participant information sheet about the study (Appendix C), and a consent form (Appendix D), by email. The inclusion criterium for the respondents of the online survey of having an autism diagnosis was determined through self-reporting, by signing the consent form. Other inclusion criteria were to be 18 years of age or over, to not have an intellectual disability, and to be able to fill in the form without help. On return of the completed consent form I sent the respondent a link to the online survey. Respondents were invited to take part voluntarily in the questionnaire, had to understand the purpose and procedures of the study, and were informed that they had the right to a copy of the results at the completion of the entire thesis. There were no direct benefits of the study for the respondents, other than knowing that the study would result in an exploration of people who had been in a similar position to themselves, previously suicidal.

Although the online survey was anonymous, the respondents were allocated a number, which was recorded within the online survey results. To maintain confidentiality, on transferring the information to the SPSS-24.0 package for analysis the respondent's number was not recorded. Additionally, digital copies of the consent forms were kept in a password protected data file, and emails, both sent and received, were deleted. Furthermore, data would be used only for the stated purpose of the research and not passed onto any third party. The data gathered is to be kept for a reasonable period of time, until the award of the final qualification or for five years, whichever is longer.

During this initial phase of communication, all respondents were asked if they would be willing to assist in the second, interview phase of the research. The personal details of these volunteers were transferred to a separate data collection site to maintain the confidentiality of data from the online survey.

At the start of the online survey, respondents were informed of various sources of help, including a reminder of their own support network that could comprise of their own GP or mental health team (Figure 3.4). They were also advised that they could contact NHS 111, or the Samaritans via their national number, or through their text service that was available at the time of the online survey. Information relating to the charity Papyrus was offered, specifically for those aged under 35. Papyrus is a charity with resources to help young people who may have suicidal thoughts. For those requiring more support about autism, the National Autistic Society's website was offered, alongside details of their helpline. This information was repeated on completion of the online survey.

Support

Suicide can be a difficult subject to talk about and to think about for many people. If you would like support around this topic then please seek further help from your local GP, Mental Health Team, qualified physician, or speak to NHS 111. You may also contact either of these support organisations.

You may contact Samaritans for free, confidential support to anyone in crisis (24 hour service) on 116 123, jo@samaritans.org, or at samaritans.org.

If you are aged under 35 and having thoughts of suicide you may contact Papyrus (www.papyrus-uk.org), a confidential support and advice service, by telephone 0800 068 4141, by text 07786 209 697 or email pat@papyrus-uk.org (this service is only open 10am-10pm weekdays and 2pm-10pm weekends and 2pm-5pm on bank holidays).

For more general support

National Autistic Society www.autism.org.uk or speak to the Autism Helpline 0808 800 4104 (this service is available Mon to Thurs 10am-4pm and Fri 9am - 3pm).

Figure 3.4
Information regarding support that was advertised prior to the respondents commencing the online survey

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3.4 Procedure of data gathering

The first four questions (Figure 3.5) of the online survey were designed to gather the demographics of the sample. Question 1 was designed to elicit the response of autism, alongside other medical diagnoses. The respondent's gender was sought to determine if gender had any effect on suicidal behaviours. The respondent's age, and the level of attained education, were sought to attempt to determine the socio-economic mix, and general demographic, of the population studied.

1. What physical or mental health diagnoses do you have?

Response box used for answer of any length

2. How would you describe your gender?

Response box used for answer of any length

3. What is your age?

	Age range *Required*						
	18-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65-74 years	75+ years
Age	■	■	■	■	■	■	■

4. What is your highest educational level? *Required*

■ Entry Level
■ Level 1 (GCSE grades D to G)
■ Level 2 (GCSE grades A* to C)
■ Level 3 (A-Level or equivalent)
■ Level 4 (Professional award)
■ Level 5 (Foundation degree, HND, DipHE)
■ Level 6 (Bachelor’s degree, Grad. Certificate)
■ Level 7 (Master's degree, PGCE, PGDip, PGDE)
■ Level 8 (PhD, DPhil, Higher doctorate)

Figure 3.5
Questions gathering demographic information

As research generally associates depression with suicidal behaviours, the demographic questions were followed by questions relating to depression. These questions sought information relating to whether the respondent had diagnosed depression, or whether they had experienced depression but had not received a diagnosis (Figure 3.6).

5. Have you ever experienced being depressed? Required
■ Yes ■ No

6. Have you ever been diagnosed with depression? Required
■ Yes ■ No

Figure 3.6
Questions seeking information about experienced and diagnosed depression

Subsequently, there were three questions seeking information concerning the respondent's previous suicidal behaviours. Questions 7, 8 and 9, (Figure 3.7) were based on the first question of the SBQ-R (Osman *et al*., 2001). Asking three distinct questions, relating to ideation, plans, and attempts, provides the information relating to the respondents' suicidal characteristics.

Suicide can be a difficult subject to talk about and to think about for some people. Please be aware that the following three questions ask about suicidal thoughts, and behaviours.

7. Have you ever thought about killing yourself? Required
■ Yes ■ No

8. Have you ever planned to kill yourself? Required
■ Yes ■ No

9. Have you ever attempted to kill yourself? Required
■ Yes ■ No

Figure 3.7
Questions regarding suicidal behaviours developed from the SBQ-R
(Osman *et al*., 2001)

A text box enabled respondents to elaborate on any of their previous responses (Figure 3.8), adding brief comments or more lengthy responses.

10. Please use this space if you wish to add comments regarding the questions above.

Response box used for answer of any length

Figure 3.8
A text box provided for additional comments

The 50 questions AQ (Baron-Cohen *et al*., 2001) were split into two pages of 25 questions each (Figure 3.9) and were placed after the questions relating to depression and suicide.

Please answer the following 50 questions as truthfully as possible. The test was developed by Simon Baron-Cohen at the Autism Research Centre at the University of Cambridge.

The 50 questions will be split onto two pages of 25 questions each.

Figure 3.9
Request to fill in the 50 questions of the AQ (Baron-Cohen *et al.*, 2001)

The EQ questionnaire was administered after the AQ questionnaire. The questions of the EQ were split into three pages of twenty questions each (Figure 3.10).

Please answer the following 60 questions. The test was developed by Simon Baron-Cohen at the Autism Research Centre at the University of Cambridge.

The 60 questions will be split onto 3 pages of 20 questions each.

Figure 3.10
Request to fill in the 60 questions of the EQ
(Baron-Cohen and Wheelwright, 2004)

Following the two tools for eliciting the level of the respondents' autistic traits was a message thanking the respondents for their time in completing the questionnaire (Figure 3.11). The page relating to appropriate support was repeated at this stage, after the completion of the entire questionnaire.

Thank you for taking your time to complete this questionnaire.

Figure 3.11
Statement thanking respondents

The readability of the main questions in the questionnaire, using the Flesch Reading Ease Test, was 62.2 (Flesch, 1948). Scores for easily understood Plain English should be between 60 and 70, the higher the number the easier the reading ability (Flesch, 1948).

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3.5 Data analysis methods

Following descriptions of the various demographic characteristics, the data gathered is analysed through quantitative investigations of *a priori* hypotheses and through a thematic analysis.

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3.5.1 Quantitative analyses

In hypothesis testing, with a $p = .05$, there is always the probability that 5% of the null hypotheses (H_0) are falsely rejected, known as a *type I error*. The analyses I undertook were hypothesis driven, in that they were formed prior to the questions of the online survey being written and, therefore, before the data were collected. This method of hypothesis writing is the preferred protocol and is referred to as *a priori* (Streiner and Norman, 2011).

As I test multiple hypotheses, and some simultaneously, the significance or the error rate of individual tests would no longer represent the error rate of the combined set of tests, and the analyses must be interpreted cautiously (Sainani, 2009). I could have corrected for multiple testing, using either the Bonferroni correction (Streiner and Norman, 2011) or a modified version of the correction, the False Discovery Rate (Haynes, 2013). Using a Bonferroni correction can increase the risk of not noticing a true relation, described as a *type 2 error* (Groenwold *et al*., 2021). Streiner and Norman (2011) add to Sainani's (2009) proposal, and also suggest that, "it is better to tolerate findings that may later prove to be false than to prematurely discard potentially useful observations" (p. 17).

I use descriptive statistics, a Pearson's correlation calculation, and examine the various hypotheses using calculations including Chi-square (χ^2) analyses. To increase the quality of the calculations regarding the smaller observed values I use Yates' correction (χ^2_{Yates}) for expected observed values from 5 to 10, and I use Fisher exact probability tests for expected observed values of less than 5. To help correct bias and to improve the robustness of calculations I use a bias-corrected and accelerated bootstrap calculation using SPSS-24.0, to provide confidence intervals of 95%.

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3.5.2 Thematic analysis

Following the quantitative analysis, I continue the exploratory study into *what are the characteristics of the suicidal autistic adult?* using thematic analysis (TA), which is an iterative and reflexive process (Quadt *et al*., 2021). Although I decided to use TA, I also had considered using content analysis (CA) for the evaluation of this data. Either method of analysis would have enabled me to evaluate the data efficiently, although TA is more interpretative and CA is more descriptive (Crowe, Inder and Porter, 2015). However, on appraising all the conditions relating to both methods, I evaluated that TA was the better method of analysis to include the experience of the autistic voice described within the data, as the method is accessible and flexible, and is mostly inductive (Braun and Clarke, 2012).

I identify themes using the respondents' data derived from the open-ended question in the online survey, seeking any additional information that they thought was relevant (Braun and Clarke, 2012). Although TA is inductive, due to being an insider researcher and using an autistic lens, there is an essence of deductiveness as I draw out the themes. To conduct TA, Braun and Clarke (2006) outline the following six stages, becoming familiar with the data, generating initial codes, searching for potential themes, reviewing these themes, naming them, and writing the report.

To achieve the TA, I followed Braun and Clarke's (2006) stages, initially analysing and making notes on the 36 comments made by the respondents. I then summarised, described, and interpreted the respondents' comments, to provide succinct terms used as *codes,* and finally, I sorted the codes into thematic groups (Braun and Clarke, 2006). I followed the six stages of generating themes before reporting the results.

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3.6 Results

There were 121 requests for the introductory letter, participant information sheet and consent form. Eighty-one people returned their consent forms. Two people found difficulty giving consent electronically, one wrote a letter which they photographed and emailed to me, and the other person wrote the contents of the consent form within an email message. Seventy-four people completed the survey, a response rate of above 61%. The data from the individuals' AQ and EQ scores were transcribed onto a score sheet, scored, and then recorded within the SPSS-24.0 package. I was prepared to use an equation for any missing AQ or EQ data[15]. One respondent did not complete the AQ and EQ information.

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[15] Total domain score + (mean domain item score x number of missing items in domain).

3.6.1 The demographic characteristics

The respondents' demographic characteristics reported relate to their age, gender, and attained educational level, in addition to their AQ and EQ scores, and their co-occurring conditions. I also report the history of suicidal behaviours and depression in the 74 respondents.

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3.6.1.1 Age of respondents

The respondents' ages were sought in ranges (Table 3.2), with ages potentially ranging from 18 to 24 years to 75+ years. No data were gathered from anyone in the 65 to 74 or the 75 years+ age categories. Most respondents are aged from 35-44, with the overall mean age of 37.54 years. The mean age for males is 44.91, for females is 36.03, and for non-binary adults is 30.47.

Age	*N*	Percentage
18-24	11	14.9%
25-34	19	25.7%
35-44	21	28.4%
45-54	17	23.0%
56-64	6	8.1%
65-74	0	0%
75+	0	0%

Table 3.2
Age of the online survey respondents

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3.6.1.2 Gender of respondents

Within the first 16 surveys, five described their gender as male, five as female, and six described their gender as other than either male or female. The National Center for Transgender Equality (NCTE) (2018) suggest that the term *non-binary* can be used to describe genders that do not fall into either of the two binary categories of male or female. Therefore, I use the term *non-binary* to group all those who used other terms than male or female in Question 2. Results for *non-binary* were added to the results tables. The final results for the respondents' gender are 37 female, 22 male, and 15 non-binary (Table 3.3). Non-binary respondents used various terms including *transgender*, *agender*, or *non-binary*, as well as *gendervague*, *genderqueer*, *androgyne*, *gender neutral*, *polygenderflux*, and *broken* or *fluid*. None of these terms have exactly the same meaning, but the respondents all have an experience of gender that is neither male nor female.

Gender	*N*	Percentage
Male	22	29.7%
Female	37	50.0%
Non-Binary	15	20.3%

Table 3.3
Gender of the online survey respondents

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3.6.1.3 Respondents' levels of educational attainment

The educational levels attained by respondents are wide ranging, from Level 0 (1 respondent) to Level 8 (5 respondents) (Table 3.4). Level 0, Entry Level, is designed for people with and without intellectual disabilities who cannot access GCSE's or their equivalent and is itself split into three levels. Four people had GCSEs as their highest educational award, two at Level 1 and two at Level 2. Twelve people had A-Levels, or equivalent as their highest educational award, however, a few of these people explained that they were in their final year of a bachelor's degree or a Level 6 course. Forty-seven people (63.5%) had already completed a bachelor's degree, with 18 people having bachelor's degrees, and some working towards their postgraduate degree. Twenty-four respondents are educated to Level 7, master's degree level, and five have PhD's, Level 8.

Level of educational attainment	*N*	Percentage
0 - Entry level	1	1.4%
1 - GCSE Grade D to G	2	2.7%
2 - GCSE Grade A* to C	2	2.7%
3 - A Level (& equivalent)	12	16.2%
4 - Professional Qualification	4	5.4%
5 - HND (& equivalent)	6	8.1%
6 - Bachelor Degree (& equiv.)	18	24.3%
7 - Master Degree (& equiv.)	24	32.4%
8 - PhD (& equivalent)	5	6.8%

Table 3.4
Level of educational attainment of the online survey respondents

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3.6.1.4 Autism-spectrum quotient scores

The maximum score for the AQ (Baron-Cohen *et al.*, 2001) is 50. The observed scores of the AQ questionnaire (Figure 3.12) show that the majority of the scores are greater than 32, usually indicative of autism (Baron-Cohen *et al.*, 2001; Ruzich *et al.*, 2015). Four scores are lower than the expected cut-off of 32. Three of these scores, 21, 23, and 27, are recorded by respondents who also indicate that they have a diagnosis of autism or Asperger's syndrome. The fourth, with the AQ score of 9, indicates that one person answered the survey may not be autistic. However, as the introductory letter (Appendix B) and information participation sheet (Appendix C) requested that the respondents were autistic, the result has been included for some analyses. One respondent did not answer the AQ questionnaire.

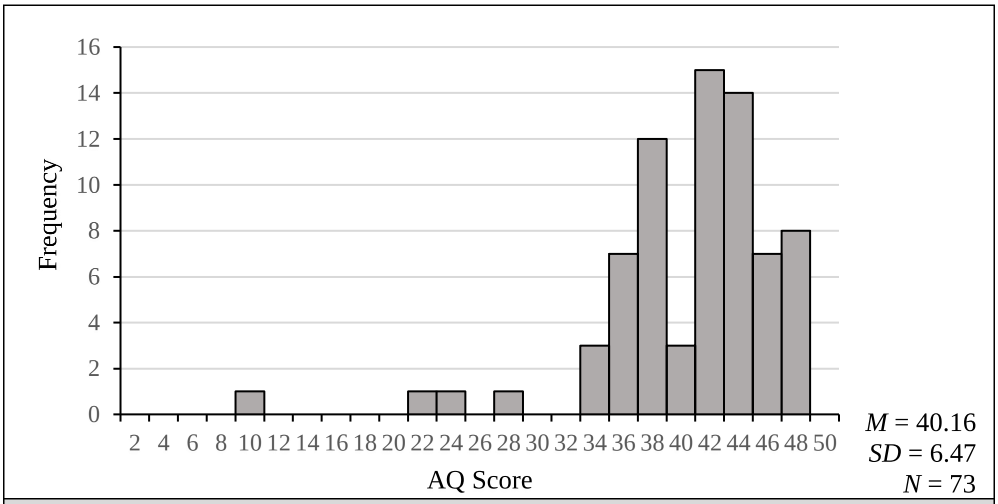

Figure 3.12
A histogram of autism-spectrum quotient (AQ) scores from all respondents

The AQ scores range from 21 to 48 for the male respondents, 34 to 48 for the female respondents, or 9 to 48 if the outlier is included, and, 23 to 48 for the non-binary respondents. The mean AQ score is 40.16, the male respondents scoring higher (41.29) than either the female (40.00) or the non-binary respondents (39.00). However, if the outlier datum is removed the overall mean increases (40.60), with the female mean (40.86) greater than the overall mean.

The mean AQ scores for experiencing suicidal ideation (40.21) and having made plans (40.91) are higher than for those who had not had these experiences (ideation = 38.50; plans = 37.50). In contrast, the mean AQ scores for those having made suicide attempts are lower (40.09) than for those who have not made attempts (40.23). The mean AQ score for those with diagnosed depression (40.52) is higher than that for those without diagnosed depression (39.16).

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3.6.1.5 Empathy quotient scores

The maximum score possible for the EQ questionnaire is 80 (Baron-Cohen and Wheelwright, 2004). On average, most non-autistic females score approximately 47, and most non-autistic males score approximately 42 (Baron-Cohen and Wheelwright, 2004). Most people having a diagnosis of autism, or Asperger’s syndrome, score less than 30 (Baron-Cohen and Wheelwright, 2004).

In this sample of autistic adults, the mean EQ score for the 73 respondents is 22.67, the mean score for male respondents (19.05) being lower than that for either non-binary (23.13) or female (24.54) respondents. The mean score for females drops to 23.44 when the outlier score is removed. Eight people have scores just above the critical score of 30, in the range of 31 to 33 and six scores are greater than 42; 43, 44, 48, 52, 60 and 64 (Figure 3.13). Five of these respondents have reasonably high AQ scores, indicative of being autistic. However, one of the scores is from the person with the very low AQ score, an indication that they may not be autistic.

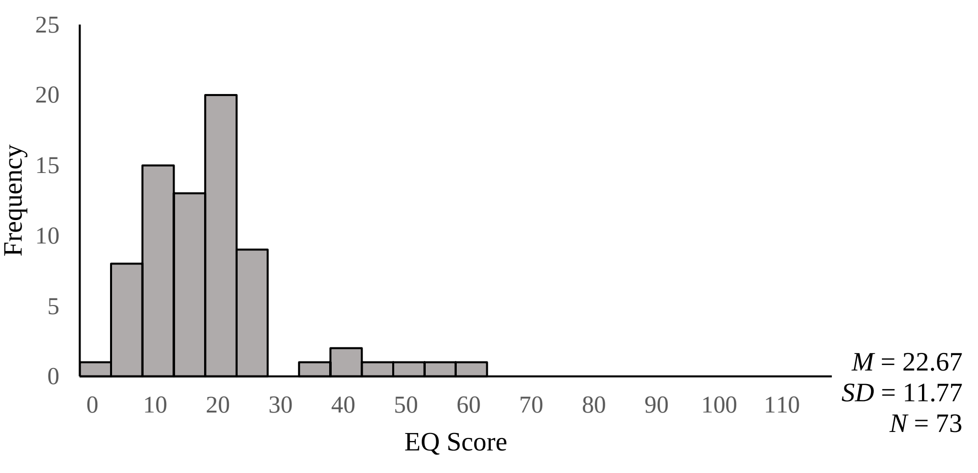

Figure 3.13
A histogram of empathy quotient (EQ) scores from all respondents

The EQ scores range from 8 to 44 for the male respondents, 3 to 48 for the female respondents, or 3 to 64 if the outlier is included, and, 10 to 60 for the non-binary respondents. The mean EQ score for those who have experienced suicidal ideation (22.68) is slightly higher than for those who have not experienced suicidal ideation (22.50). In contrast, the mean EQ score for those having made suicidal plans (21.68) is lower than for those who have not made suicidal plans (26.19). Similarly, the mean EQ score for those who have attempted suicide (22.59) is lower than for those who have not made suicidal attempts (22.74). The mean EQ score for those with diagnosed depression (22.72) is slightly higher than for those without a depression diagnosis (22.53).

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3.6.1.6 The correlation of AQ and EQ scores

The results of a Pearson's correlation calculation, conducted using SPSS-24.0, demonstrates that the AQ scores and the EQ scores are moderately to strongly negatively correlated, *r* (71) = -.54, *p* < .001 (Figure 3.14).

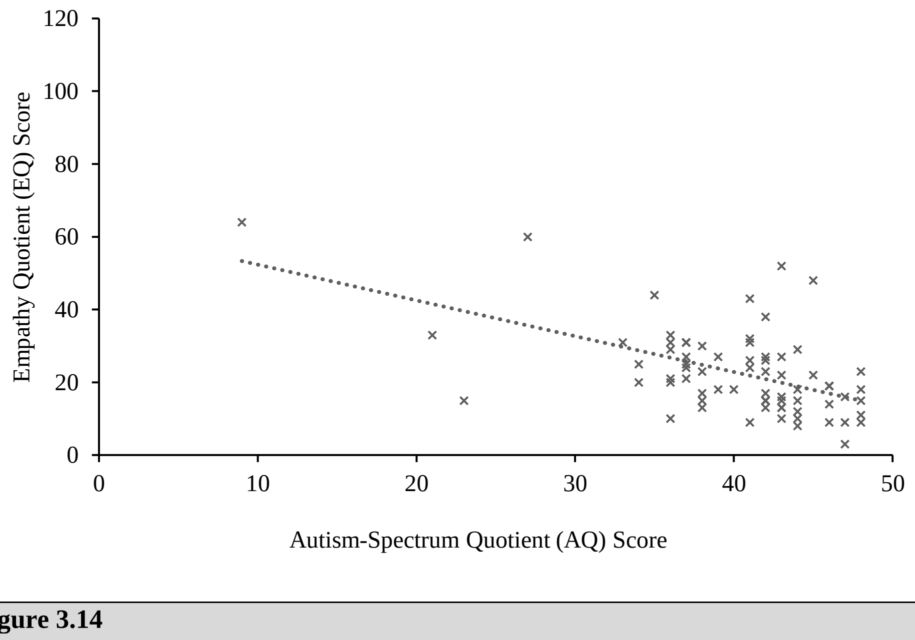

Figure 3.14
A graph showing the negative correlation of the respondents' AQ and EQ scores

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3.6.1.7 Co-occurring conditions

The online survey's first question, concerning physical health and mental health diagnoses, was designed to elicit whether the respondents have an autism diagnosis. Although 15 respondents did not record either autism or Asperger’s syndrome, all the data is included in the analyses. The respondents could include any condition or diagnosis. Some responses included, “none”, others were left the section blank, whilst 55 wrote an extensive list of various co-occurring conditions (Table 3.5).

	Co-occurring Conditions									
Gender	OCD	ED	ADHD	TS	BPD	Dp.	Dl.	JH†	PTSD	Anx.
Male (*n* = 22)	0 (0)	0 (0)	1 (5%)	0 (0)	1 (5%)	1 (5%)	1 (5%)	0 (0)	3 (14%)	6 (27%)
Female (*n* = 37)	2 (5%)	1 (3%)	5 (14%)	0 (0)	4 (11%)	0 (0)	2 (5%)	4 (11%)	1 (3%)	15 (41%)
Non-Binary (*n* = 15)	3 (20%)	0 (0)	4 (27%)	1 (7%)	0 (0)	0 (0)	0 (0)	2 (13%)	4 (27%)	5 (33%)
Total (*N* = 74)	5 (7%)	2 (3%)	10 (14%)	1 (1%)	5 (7%)	1 (1%)	3 (4%)	6 (8%)	8 (11%)	26 (35%)

OCD	Obsessive Compulsive Disorder
ED	Eating Disorder
ADHD	Attention Deficit Hyperactivity Disorder
TS	Tourette’s Syndrome
BPD	Borderline Personality Disorder
Dp.	Dyspraxia
Dl.	Dyslexia
JH	Joint Hypermobility
PTSD	Post-Traumatic Stress Disorder
Anx.	Anxiety

Table 3.5
Number (percentage) of respondents with co-occurring conditions, stratified by gender († and Ehlers-Danlos syndrome)

The co-occurring conditions include: post-traumatic stress disorder (PTSD); obsessive compulsive disorder (OCD); attention deficit hyperactivity disorder (ADHD); borderline personality disorder (BPD) or emotionally unstable personality disorder (EUPD); eating disorders; Ehlers-Danlos syndrome (EDS) and joint hypermobility; in addition to the neurodivergent conditions of dyspraxia, dyslexia and Tourette’s syndrome.

The most frequently mentioned co-occurring condition is anxiety, described either as *anxiety*, or within the term *generalised anxiety disorder*. Anxiety, as a specific condition, is experienced by 26 respondents, 35% of the total. The findings also show respondents reported the following co-occurring conditions, PTSD (10.8 *n* = 8), OCD (6.8% *n* = 5), and ADHD (13.5% *n* = 10). EDS is specifically mentioned by three respondents; however, another three respondents also include *hypermobility* and *joint hypermobility* amongst their co-occurring conditions. As EDS can be described as joint hypermobility, I combined the conditions. This group comprises 8.1% (*n* = 6) of the respondents.

Borderline personality disorder, also known as emotionally unstable personality disorder, is mentioned by five people (6.8%), although four of the five specifically indicate that this diagnosis followed a suicide attempt, preceding their autism diagnosis. Furthermore, two of these four respondents indicate that the BPD diagnosis is no longer relevant or should have been removed from their medical history. Generally, more females seem to have co-occurring conditions than the males, however, the results for PTSD show that a few more male (13.6% *n* = 3) and non-binary respondents (26.7% *n* = 4) report co-occurring PTSD than the female respondents (2.7% *n* = 1).

During the data analysis I noted two characteristics that would benefit from further investigation; that co-occurring anxiety may be associated with suicidal planning, and that co-occurring PTSD may be associated with suicidal attempts.

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3.6.1.8 The frequency of a history of depression, suicidal ideation, plans, or attempts in autistic adults

Very few of the online survey's respondents recorded that they had not been affected by either suicidal behaviours or depression. Four respondents (5.4%) had neither experienced, nor had been diagnosed, with depression (Table 3.6), two (2.7%) of whom had experienced suicidal thoughts or behaviours. Only two people answered the questionnaire who had neither experienced any form of suicidal thought, plan, or attempt, nor experienced depression.

Depression		Suicidal behaviours			Frequency	
Experienced	Diagnosed	Ideation	Plans	Attempts	count	%
X	X	✓	✓	✓	1	1.35
X	X	✓	✓	X	0	0
X	X	✓	X	X	1	1.35
X	X	X	X	X	2	2.70
✓	X	✓	✓	✓	5	6.76
✓	X	✓	✓	X	4	5.41
✓	X	✓	X	X	6	8.11
✓	X	X	X	X	0	0
✓	✓	✓	✓	✓	28	37.84
✓	✓	✓	✓	X	19	25.68
✓	✓	✓	X	X	7	9.46
✓	✓	X	X	X	0	0
✓	✓	✓	X	✓	1	1.35

Table 3.6
The frequency of respondents who demonstrate (✓) or not (X) a history of depression and suicidal behaviours

Fifteen respondents (20.3%) have experienced depression, without receiving a diagnosis. The majority of respondents (74.3% *n* = 55) have both experienced and have been diagnosed with depression. Of this group, eight (10.8%) have experienced suicidal ideation, a larger number have experienced making suicidal plans (25.7% *n* = 19), but the largest number of respondents have made suicidal attempts (39.2% *n* = 29). Importantly, I note that one person who has made a suicidal attempt has not experienced making a suicidal plan.

The findings of a 97.3% (*n* = 72) lifetime experience of suicidal ideation, a 78.4% (*n* = 57) lifetime experience of planned suicide, and a 47.3% (*n* = 35) lifetime experience of attempted suicide suggests that these are common occurrences within this sample of autistic people. Depression had been diagnosed in 74.3% (*n* = 55) of the respondents, although a further 20.3% (*n* = 15) wrote about experiencing depression without a diagnosis. None of the respondents mention that they have been diagnosed with depression without experiencing depression.

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3.6.1.9 Report of demographic characteristics

Seventy-four autistic adults responded to the questionnaire, with 73 of the respondents completing the AQ (Baron-Cohen *et al*., 2001) and EQ (Baron-Cohen and Wheelwright, 2004) questionnaires. The characteristics of the respondents are: most (92%) are aged from 18 to 54, with a few (8%) aged from 55 to 64; 50% of the respondents are female, 29.7% male and 20.3% non-binary; 39.2% are educated to master's degree level or above; the mean AQ score is 41.3; and, the mean EQ score is 22.7. The data demonstrate that the AQ and EQ scores are negatively correlated. The most frequently mentioned co-occurring condition is anxiety, with 26 respondents (35%) recording the condition. Anxiety is more prevalent in the female respondents (41%), than either the male (27%) or non-binary (33%) respondents.

One of the noticeable results is that not all the autistic adults who have attempted suicide have planned suicide. One respondent specified that they have experienced suicidal ideation and have made a suicide attempt but had not planned their suicide attempt. In addition, not all the respondents who have suicidal thoughts or behaviours have experienced, or been diagnosed with, depression. Having neither experienced depression nor having been diagnosed with depression, two people have experienced suicidal thoughts, with one also having made a suicide attempt. Fifteen adults have experienced depression without being clinically diagnosed as depressed, five having attempted suicide.

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3.6.2 Investigations of quantitative data

The data gathered to test the various *a priori* hypotheses are analysed in three main groups. Firstly, the depression and suicidal behaviours data of all 74 respondents are analysed. Secondly, the data of the 70 respondents who have experienced depression is analysed. The third analysis is of the data of the 55 respondents with a diagnosis of depression.

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3.6.2.1 History of diagnosed depression, suicidal ideation, plans, or attempts in autistic adults

The data collected concerns the various suicidal behaviours and diagnosed depression from all 74 respondents. Data is presented stratified by age and gender for the responses received relating to diagnosed depression, suicidal ideation, plans, or attempts (Table 3.7).

Within the male and non-binary populations there is a 100% experience of suicidal ideation. The two respondents, who have never experienced suicidal ideation, were both female. Therefore, the female result of suicidal ideation is slightly lower, at 94.6%. Overall, 97.3% (n = 72) of respondents have previously had thoughts of suicide.

	18-24 Years	25-34 Years	35-44 Years	45-54 Years	55-64 years	65-74 Years	Missing	Total
Male (*n* = 22)								
Suicidal ideation	0 (0/0)	100% (3/3)	100% (7/7)	100% (8/8)	100% (4/4)	0 (0/0)	0 (0/22)	100% (22/22)
Suicidal plans	0 (0/0)	67% (2/3)	71% (5/7)	100% (8/8)	75% (3/4)	0 (0/0)	0 (0/22)	82% (18/22)
Suicidal attempts	0 (0/0)	67% (2/3)	29% (2/7)	88% (7/8)	50% (2/4)	0 (0/0)	0 (0/22)	59% (13/22)
Depression (dx)	0 (0/0)	67% (2/3)	57% (4/7)	100% (8/8)	50% (2/4)	0 (0/0)	0 (0/22)	73% (16/22)
Female (*n* = 37)								
Suicidal ideation	100% (5/5)	92% (11/12)	91% (10/11)	100% (7/7)	100% (2/2)	0 (0/0)	0 (0/37)	95% (35/37)
Suicidal plans	60% (3/5)	75% (9/12)	73% (8/11)	71% (5/7)	100% (2/2)	0 (0/0)	0 (0/37)	73% (27/37)
Suicidal attempts	20% (1/5)	33% (4/12)	45% (5/11)	43% (3/7)	50% (1/2)	0 (0/0)	0 (0/37)	38% (14/37)
Depression (dx)	40% (2/5)	84% (10/12)	82% (9/11)	71% (5/7)	100% (2/2)	0 (0/0)	0 (0/37)	76% (28/37)
Non-Binary (*n* = 15)								
Suicidal ideation	100% (6/6)	100% (4/4)	100% (3/3)	100% (2/2)	0 (0/0)	0 (0/0)	0 (0/15)	100% (15/15)
Suicidal plans	100% (6/6)	75% (3/4)	67% (2/3)	100% (2/2)	0 (0/0)	0 (0/0)	0 (0/15)	87% (13/15)
Suicidal attempts	67% (4/6)	75% (3/4)	0 (0/3)	50% (1/2)	0 (0/0)	0 (0/0)	0 (0/15)	53% (8/15)
Depression (dx)	84% (5/6)	75% (3/4)	100% (3/3)	0 (0/2)	0 (0/0)	0 (0/0)	0 (0/15)	74% (11/15)
All Adults (*N* = 74)								
Suicidal ideation	100% (11/11)	95% (18/19)	95% (20/21)	100% (17/17)	100% (6/6)	0 (0/0)	0 (0/74)	97% (72/74)
Suicidal plans	82% (9/11)	74% (14/19)	71% (15/21)	88% (15/17)	84% (5/6)	0 (0/0)	0 (0/74)	78% (58/74)
Suicidal attempts	44% (5/11)	47% (9/19)	33% (7/21)	65% (11/17)	50% (3/6)	0 (0/0)	0 (0/74)	47% (35/74)
Depression (dx)	64% (7/11)	79% (15/19)	76% (16/21)	76% (13/17)	67% (4/6)	0 (0/0)	0 (0/74)	74% (55/74)

Data are *n*/*N* (%), for which *n* is number of respondents who answered yes to the survey question, and *N* is number of respondents who answered survey question.

Table 3.7
The history of diagnosed (dx) depression, suicidal ideations, plans, or attempts in autistic adults, stratified by age and gender

Analyses, through the examination of the *a priori* hypotheses, were undertaken on the information relating to suicidal behaviours and gender. Results from a series of Chi-square analyses, and Fisher exact probability tests, show that there are no significant associations between suicidal behaviours and gender. For example, the null hypothesis, H_0, suicidal ideation is independent of gender, is examined[16] ($N = 74$ $p = .699$). As $p > .05$ suicidal ideation is independent of gender in this sample.

Likewise, the H_0, having a suicidal plan is independent of gender, is examined[17] and the result shows no significant dependency ($N = 74$ $p = .609$), so the null hypothesis is accepted. Similarly, the H_0, suicidal attempt is independent of gender, is examined and was likewise not found to be significant (χ^2 (2, $N = 74$) = 2.78 $p = .250$), along with the H_0, diagnosed depression is independent of gender, that is tested (χ^2 (2, $N = 74$) = .07 $p = .964$).

I conducted further analyses on the information relating to suicidal behaviours, gender and age, using the null hypotheses: the age of suicidal ideation is independent of gender (χ^2_{Yates} (8, $n = 72$) = 11.60 $p = .170$); the age of suicidal plans is independent of gender (χ^2_{Yates} (8, $n = 58$) = 12.92 $p = .115$); and the age of suicide attempts is independent of gender (χ^2_{Yates} (8, $n = 35$) = 10.39 $p = .239$). The resulting p values indicate that, neither suicidal ideation, nor suicidal plans, nor suicide attempts are associated with either age or gender.

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3.6.2.2 Suicidal ideation, plans, or attempts in autistic adults who reported experiencing depression

Seventy respondents (94.5%) responded to questions regarding depression, and answered that they had experienced depression. The resultant data are presented

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[16] Using Fisher exact probability test

[17] Using Fisher exact probability test

stratified by age and gender for the responses received relating to suicidal ideation, plans, or attempts (Table 3.8).

	18-24 Years	25-34 Years	35-44 Years	45-54 years	55-64 years	65-74 Years	Missing data	Total
Male (*n* = 21)								
Suicidal ideation	0 (0/0)	100% (2/2)	100% (7/7)	100% (8/8)	100% (4/4)	0 (0/0)	0 (0/21)	100% (21/21)
Suicidal plans	0 (0/0)	50% (1/2)	71% (5/7)	100% (8/8)	75% (3/4)	0 (0/0)	0 (0/21)	81% (17/21)
Suicidal attempts	0 (0/0)	50% (1/2)	29% (2/7)	88% (7/8)	50% (2/4)	0 (0/0)	0 (0/21)	57% (12/21)
Female (*n* = 34)								
Suicidal ideation	100% (5/5)	100% (11/11)	100% (10/10)	100% (6/6)	100% (2/2)	0 (0/0)	0 (0/34)	100% (34/34)
Suicidal plans	60% (3/5)	73% (8/11)	80% (8/10)	0% (5/6)	100% (2/2)	0 (0/0)	0 (0/34)	76% (26/34)
Suicidal attempts	20% (1/5)	36% (4/11)	50% (5/10)	50% (3/6)	50% (1/2)	0 (0/0)	0 (0/34)	41% (14/34)
Non-Binary (*n* = 15)								
Suicidal ideation	100% (6/6)	100% (4/4)	100% (3/3)	100% (2/2)	0 (0/0)	0 (0/0)	0 (0/15)	100% (15/15)
Suicidal plans	100% (6/6)	75% (3/4)	67% (2/3)	100% (2/2)	0 (0/0)	0 (0/0)	0 (0/15)	87% (13/15)
Suicidal attempts	67% (4/6)	75% (3/4)	0 (0/3)	50% (1/2)	0 (0/0)	0 (0/0)	0 (0/15)	54% (8/15)
All Adults (*N* = 70)								
Suicidal ideation	100% (11/11)	100% (17/17)	100% (20/20)	100% (16/16)	100% (6/6)	0 (0/0)	0 (0/70)	100% (70/70)
Suicidal plans	82% (9/11)	71% (12/17)	75% (15/20)	94% (15/16)	75% (5/6)	0 (0/0)	0 (0/70)	80% (56/70)
Suicidal attempts	45% (5/11)	47% (8/17)	35% (7/20)	69% (11/16)	50% (3/6)	0 (0/0)	0 (0/70)	49% (34/70)

Data are *n*/*N* (%), for which *n* is number of respondents who answered yes to the survey question and *N* is number of respondents who answered this survey question.

Table 3.8
Suicidal ideation, plans, or attempts in autistic adults who reported experiencing depression, stratified by age and gender

Analyses were undertaken to explore the relationship between experiencing depression and suicidal behaviours. Two of the results are found to be significant; that those autistic adults who have experienced depression have experienced suicidal ideation, and the autistic adults who have experienced depression have experienced suicidal plans.

Details of the analyses are as follows: the null hypothesis, H_0, suicidal ideation is independent of experienced depression, is examined[18] ($N = 74$ $p = .002$). Therefore, the alternative hypothesis, H_1, that suicidal ideation is associated with experienced depression, is accepted. The H_0, suicidal plans are independent of experienced depression, is examined (χ^2 (1, $N = 74$) = 7.11 $p = .008$). Again, the p value < .05 suggests that the H_0 can be rejected and the alternative hypothesis, H_1, that suicidal plans are associated with experienced depression, accepted. The H_0, suicidal attempts are independent of experienced depression, is examined (χ^2 (1, $N = 74$) = 0.83 $p = .358$). Here the H_0 is accepted as the p value ($p < .05$) indicates that suicide attempts are not associated with the experience of depression.

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3.6.2.3 Suicidal ideation, plans, or attempts in autistic adults who reported diagnosed depression

Fifty-five respondents (74.3%) stated that they had been diagnosed with depression. Data for those who had diagnosed depression is presented stratified by age and gender for the responses received relating to suicidal ideation, plans, or attempts (Table 3.9). One result was found to be significant, the relationship between making suicidal plans and having a diagnosis of depression.

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[18] Using Fisher exact probability test

	18-24 Years	25-34 Years	35-44 years	45-54 years	55-64 years	65-74 years	Missing data	Total
Male (*n* = 16)								
Suicidal ideation	0 (0/0)	100% (2/2)	100% (4/4)	100% (8/8)	100% (2/2)	0 (0/0)	0 (0/16)	100% (16/16)
Suicidal plans	0 (0/0)	50% (1/2)	75% (3/4)	100% (8/8)	100% (2/2)	0 (0/0)	0 (0/16)	88% (14/16)
Suicidal attempts	0 (0/0)	50% (1/2)	25% (1/4)	88% (7/8)	50% (1/2)	0 (0/0)	0 (0/16)	63% (10/16)
Female (*n* = 28)								
Suicidal ideation	100% (2/2)	100% (10/10)	100% (9/9)	100% (5/5)	100% (2/2)	0 (0/0)	0 (0/28)	100% (28/28)
Suicidal plans	50% (1/2)	80% (8/10)	89% (8/9)	80% (4/5)	100% (2/2)	0 (0/0)	0 (0/28)	82% (23/28)
Suicidal attempts	0 (0/2)	40% (4/10)	56% (5/9)	60% (3/5)	50% (1/2)	0 (0/0)	0 (0/28)	46% (13/28)
Non-Binary (*n* = 11)								
Suicidal ideation	100% (5/5)	100% (3/3)	100% (3/3)	0 (0/0)	0 (0/0)	0 (0/0)	0 (0/11)	100% (11/11)
Suicidal plans	100% (5/5)	100% (3/3)	67% (2/3)	0 (0/0)	0 (0/0)	0 (0/0)	0 (0/11)	91% (10/11)
Suicidal attempts	60% (3/5)	100% (3/3)	0 (0/3)	0 (0/0)	0 (0/0)	0 (0/0)	0 (0/11)	55% (6/11)
All Adults (*N* = 55)								
Suicidal ideation	100% (7/7)	100% (15/15)	100% (16/16)	100% (13/13)	100% (4/4)	0 (0/0)	0 (0/54)	100% (55/55)
Suicidal plans	86% (6/7)	80% (12/15)	81% (13/16)	92% (12/13)	100% (4/4)	0 (0/0)	0 (0/54)	85% (47/55)
Suicidal attempts	43% (3/7)	53% (8/15)	38% (6/16)	77% (10/13)	50% (2/4)	0 (0/0)	0 (0/54)	53% (29/55)

Data are *n*/*N* (%), for which *n* is number of respondents who answered yes to the survey question and *N* is number of respondents who answered this survey question.

Table 3.9
Suicidal ideation, plans, or attempts in autistic adults who reported a diagnosis of depression, stratified by age and gender

The null hypothesis, H_0, suicidal ideation is independent of diagnosed depression, is examined[19] ($N = 74$ $p = .063$). As $p > .05$ the H_0 is accepted. The H_0, suicidal plans are independent of diagnosed depression, is examined (χ^2_{Yates} (1, $N = 74$) = 8.06 $p = .005$). The H_1 is accepted, that there is a relationship between making suicidal plans and diagnosed depression. A further

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[19] Using Fisher exact probability test

null hypothesis is tested, H_0, suicidal attempts are independent of diagnosed depression (χ^2_{Yates} (1, N = 74) = 1.76 p = .185). Again, the H_0 is accepted.

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3.6.2.4 Report of quantitative investigations

The data show that there is statistical evidence that those autistic adults who have experienced depression have experienced suicidal ideation and have experienced suicidal plans. There is also evidence that those autistic adults who have diagnosed depression have experienced making suicidal plans.

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3.6.3 Results - Thematic analysis

Thirty-six respondents elaborated on their responses to the questions relating to demographics, depression, or suicidal behaviours (Appendix E), and these are analysed using thematic analysis (TA). Fourteen codes were generated identifying three main themes, suicidal behaviours, reasons for suicidal behaviours and NHS / Mental health teams (Figure 3.15).

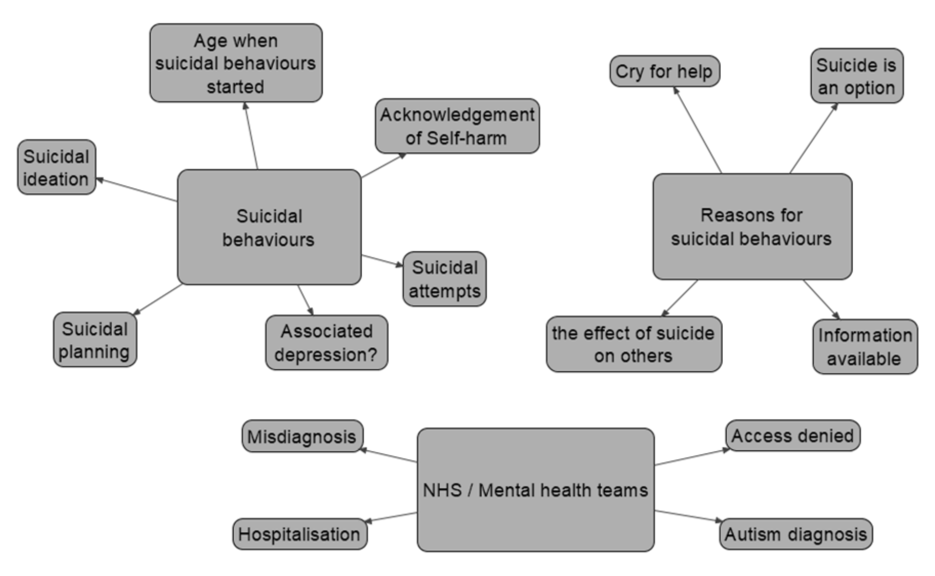

Figure 3.15
Thematic map showing the three main themes, with codes

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3.6.3.1 Suicidal behaviours

I generated the theme suicidal behaviours from six codes. Being immersed in the data, I initially identified the three codes of suicidal ideation, suicidal planning, and suicidal attempts. Three further codes linked with these, as I formed the thematic map, age when suicidal behaviours started, acknowledgement of self-harm, and associated depression?

Suicidal ideation is mentioned in ten responses. The responses include comments regarding frequency, from, “I think about suicide a lot at the moment” (Response 3), and, “many years of suicidal thoughts” (Response 18), to more general responses including, “I have thought about how I might kill myself” (Response 4), and, “I have *wanted* to kill myself” (Response 26, original emphasis). Some responses showed confusion understanding the terms *ideation* and *planning*. One respondent suggests, “suicidal ideation is about method, so... it is planning” (Response 17). This is consistent with the response, where the respondent proposes that, “by planning I... have thought about... it” (Response 34). These suicidal thoughts are potentially negative, but only one person seemed to make this clear with their use of the word *struggle*, where they write, “I... struggle with thoughts of suicide” (Response 22). One person who had wanted to kill themself wrote, “I’m just too discombobulated... to come up with a plan” (Response 26), suggesting that they were too confused within themself to plan or attempt suicide.

Suicidal planning is mentioned by six people. Again, there is confusion about the difference between suicidal ideation and planning. Attempting to describe their confusion, one person suggests,

> "By planning, I mean I have thought about, ruled out different ways to do it and settled on the way I'd do it" (Response 34).

Another response, raising confusion over the understanding of ideation and planning, suggests that they had planned suicide, but had not thought of the method, which would be usual in making a plan. This respondent also suggests that they thought of the effect suicide would have on their place of employment and their students.

> "I did plan suicide to some extent, but I never came to the part of deciding about actual method. I just planned how I would give notice to my working place so that my long distance students would not have to travel to classes in vain" (Response 12).

Other responses that involve suicidal planning include telling other people about their plans, as one person recounted that they have, "ended up in a secure unit for plans to commit suicide" (Response 19).

Although one respondent had made plans, they detailed that their actual suicidal attempt had been unplanned, writing, "The plans did not result in the attempt. The attempt was spontaneous" (Response 27). This theme is validated by a further respondent who suggests,

> "I have attempted suicide... but this wasn't planned. I have planned alternative methods of suicide but these didn't lead to attempts" (Response 29).

Again, one respondent reinforces this idea of spontaneity suggesting that their suicidal thoughts and plans have not led to attempts, but that their attempt was a, "spur of the moment event" (Response 24).

More people wrote about suicide attempts, than either suicidal ideation or suicidal plans. There are thirteen different responses suggesting the respondent has attempted suicide. These include seven people explaining the method they have used attempting suicide. One respondent explained that they have made, “multiple suicide attempts” (Response 6), whilst another wrote that they have, “attempted suicide on multiple occasions” (Response 14). Rather than taking suicidal action themself, one respondent has put themself at sufficient risk of being killed, “in the hopes of it being taken out of my hands” (Response 28).

The age at which the respondents had these suicidal thoughts and behaviours are varied. One person suggests that their, “suicidal ideation began when I was 10 and has been ongoing” (Response 5). Similarly, a second respondent suggests that this was the age when they first attempted suicide when they wrote, “attempted suicide at age 10” (Response 30). Whilst others explained that their attempts were when they were, “aged 15-18” (Response 5), “age of 16” (Response 6), and, “in my teens and twenties (Response 11). Nevertheless, suicidal behaviours are also experienced by older respondents. One person wrote about having made suicidal plans whilst having a dependent child (Response 20).

The code, acknowledgement of self-harm, arose as one person did not describe their past actions as any suicidal intent, but as non-suicidal self-injury, as a way of dealing with the emotional pain, “in the years I suffered with depression” (Response 10).

Associated depression? arose as one person explained that although they had been prescribed antidepressant, they, “do not have a piece of paper that says, ‘This person is depressed,’” (Response 8). Interpreting their response, I questioned whether they were depressed or not, which generated the question mark within the code. Another two respondents also suggest that they may no longer be depressed whilst writing, “in the years I suffered with depression” (Response 10), and, “the depression I have experienced was in my teens and twenties, I am now happy” (Response 11).

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3.6.3.2 Reasons for suicidal behaviours

I generated three codes from the respondents’ comments explaining the reasons they have experienced suicidal behaviours: cry for help; suicide as an option; and, information available. The fourth code is effect of suicide on others. This is included in the theme as respondents explained it affected their suicidal behaviours.

I generated the code, cry for help, from one response. They wrote about suicidal ideation and planning being when they are in a mental state, such as depression, from which they want to escape. However, they continue that it is not a cry for help, writing,

> “It is usually around the sense of escape from this mental state, a fantasy if you will. It is not a cry for help.” (Response 17).

The code, information available, was generated from two responses. One older respondent suggested that if they had information available, that younger people have today through the internet, they may have made an attempt at an earlier age. They explained that the suicide method that was usually, “portrayed on telly” (Response 7), was impossible for them as they did not have access to the elements required. A second respondent confirms this, as they wrote, “I googled how to do it painlessly” (Response 35).

The third code, suicide as an option, was generated as three people explained that suicide was always an option for them. One respondent wrote,

> “For me contemplation of suicide is normal... it is simply a logical option of activity for each day, it is always a possibility... I still consider suicide an option every day” (Response 11).

A second respondent takes,

> “a very matter of fact view of this, I’ve thought about killing myself many times as a logical solution when I can’t think of any other logical solutions” (Response 25).

A further respondent has interfering thoughts, “I have intrusive thoughts about suicide which... never fully go into remission” (Response 16). These responses suggest that the respondents experience perseverative thinking.

I generated the fourth code, the effect of suicide on others, from the responses that related to the effect that each respondent’s suicide would have on others. This was mentioned several times, with one person clearly stating that they did not want to attempt suicide in a, “way it could affect others” (Response 7). In addition to the respondent who thought about the effect suicide would have on their students’ travel arrangements (Response 12), another respondent recounted that composing a suicide note is never easy, as, “I try to compose a suicide note in my mind, but it will never satisfactorily explain things to those I care about”

(Response 17). Whereas the respondent with a dependent child, could not carry out a planned suicide attempt as, “I had agreed to take... for his... assessment” (Response 20).

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3.6.3.3 NHS/Mental health teams

I generated the third theme from four codes, as a few respondents wrote about times when interventions have been made by health and public services. These include autism diagnosis, hospitalisation, misdiagnosis, and access denied.

I generated the code, autism diagnosis, from three responses. Two respondents included their diagnosis within more detailed responses, “my autism diagnosis” (Response 8), and, “my asd diagnosis” (Response 31). Nevertheless, one respondent suggests that the benefits of being assessed, and potentially receiving an autism diagnosis, would have had too great an, “emotional cost” (Response 1).

I generated the code, access denied, as one respondent described that their autism diagnosis denied them access to mental health professionals, as it was,

> “difficult to be accepted by a doctor/psychiatrist/psychologist as a patient and not turned away because of autism” (Response 33).

One respondent reported being misdiagnosed due to their suicidal behaviours, therefore I generated the code, misdiagnosis. They wrote,

> “Before my asd diagnosis... my attempts at suicide got me labelled with BPD even tho I met none of the other criteria for bpd” (Response 31).

Despite these two respondents being denied specific mental health support for a suicidal autistic person, others had been, “a psychiatric inpatient” (Response 6), had been stopped by the police with a Section 136 of the Mental Health Act (1983), “removed and s136 by police” (Response 14), received care in, “Intensive Care” (Response 18), or had been placed, “in a secure unit” (Response 19) after planning suicide. From these responses I generated the code, hospitalisation.

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3.6.3.4 Thematic analysis report

The thematic analysis of the respondents’ comments drew out three themes: suicidal behaviours; reasons for suicidal behaviours; and, the NHS/mental health teams. Within the theme of suicidal behaviours are six codes: acknowledgment of self-harm; associated depression?; suicidal ideation; suicidal planning; suicidal attempts; and, age when suicidal behaviours started.

Hand, Benevides and Carretta (2020) explain that the characteristics of autistic adults who experience suicidal ideation are similar to those of autistic adults who attempt suicide or self-inflict injury. However, the data for this thematic analysis (TA) only provide evidence of one person relating to non-suicidal self-injury (NSSI). Autistic adults who undertake self-harm or NSSI are also more at risk of suicidal ideation and suicidal attempts (Maddox, Trubanova, and White, 2017). This may be due to the increase of tolerance of pain and the decrease in fear of death (Moseley *et al.*, 2020). Although not evidenced within this study, it is reported that NSSI may affect half the autistic population (Maddox, Trubanova, and White, 2017).

Despite there being evidence in this TA that not all of the previously suicidal respondents felt that they had been depressed, in non-autistic adults depression is perceived to be a precursor to suicidal thoughts and behaviours (Sterling *et al*., 2008; Richa *et al*., 2014; Takara and Kondo, 2014; Cassidy, 2015; Hedley *et al*., 2018a; Livingston, Shah and Happé, 2019; Costa, Loor and Steffgen, 2020; South *et al*., 2020). The code of associated depression? was therefore included within the theme of suicidal behaviours. Additional comments from seven of the 36 autistic respondents reported some form of depression. One of these adults explained that they have been prescribed an antidepressant but had not formally been told that they have depression. This ambiguity concerning depression is counterbalanced by another respondent describing that their suicidal ideation increases in severity during depressive episodes. Two further respondents clearly aligned the depth of their depression with the efficacy of their suicidal planning. Another two responses suggest that even though depression may diminish, suicidal thoughts linger, and that the daily thoughts never going into remission.

Although ten of the respondents mentioned the code suicidal ideation, not all had developed these thoughts into plans. One of these respondents explained they could not order their thoughts sufficiently to make a plan, or make an attempt, whilst another explained they had experienced suicidal thoughts for many years.

The code of suicidal planning arose from comments made by six respondents, with one respondent confirming that their plans had not led to any attempt. In contrast, another of the respondents denied that they had planned their attempted suicide, as their attempt was a spontaneous reaction. A few respondents demonstrated that they were confused trying to determine the difference between suicidal ideation and suicidal planning. The confusion also arises in research where different researchers use different terms, whilst describing similar, if not identical, suicidal processes. Klonsky, May and Saffer (2016) explain that, in the USA, suicidal planning is included in one definition of suicidal ideation, defining it as, “thinking about, considering, or planning suicide” (p. 309). Whereas other researchers, including Liu, Bettis and Burke (2020), describe suicidal ideation as ranging from passive ideation, where the desire is to be dead, to active ideation, where the desire to kill yourself.

The responses relating to the suicide attempts code were more numerous. Thirteen respondents had attempted suicide, with six explaining the method that they had used in their attempt. Richards *et al*. (2019) recognised that more autistic adults, with a diagnosis, had attempted suicide more than once compared to those who had attempted suicide only once. Whilst explaining that this phenomenon increases autistic adults’ vulnerability of risk to suicide, they include results that demonstrate, “that autistic traits are associated with attempting suicide” (Richards *et al*., 2019, p. 32).

The code, age when suicidal behaviours started, was generated from a number of responses. Two people explained that their first suicide attempt had been when they were aged 10 years, whilst another respondent had three suicide attempts when they were aged 15 to 18. Other respondents indicated that their suicide attempts had been later in life. Both findings are supported by literature. Hunsche *et al*. (2020) confirm that autistic children demonstrate, “high rates of suicidality” (p. 3506), with 15% of parents suggesting their autistic children have attempted to kill or harm themselves. Hand *et al*. (2020) also highlight that older autistic adults, aged 65 years and older, were, “11 times more likely” (p. 757), to receive medical assistance for suicidal behaviours than the matched group with whom they were compared.

Most respondents did not explain the reasons for suicidal behaviours. However, four significant codes generated this theme. These codes were, cry for help, the effect of suicide on others, information available, and suicide is an option. The first code is entitled cry for help. Since the publication of the book entitled *Cry for Help* (Farberow and Shneidman, 1961), referring to suicide prevention and therapeutic approaches for suicidal adults, members of the public have frequently seen a suicide attempt as an attention seeking behaviour (Maple *et al*., 2020). However, a respondent emphasised that their suicide ideation and planning were not cries for help but explained that thinking of suicide provides a relative feeling of escape. This feeling of escape is illustrated by accounts of non-autistic suicide survivors (Maple *et al*., 2020), and is redolent of Baechler’s 1979 theory of *Suicide as Escape*, and of Williams’ (1997) *Cry of Pain* model.

Within the theme of explanations for suicidal behaviours, four diverse responses related to the second code, the effect of suicide on others. Whilst one person did not want to adversely affect another person with their suicide, another respondent demonstrated how committed they were to the people in their workplace, and a third had attempted, without success, to explain their potential suicide to their family and friends. The fourth respondent wrote about the effect suicide would have had on their son, who they supported in various ways. These comments relating to others' feelings accord with research by autistic researchers (Gernsbacher and Yergeau, 2019), but appear to conflict with the theory that autistic adults lack a Theory of Mind (Baron-Cohen *et al.*, 2007).

The third code, information available, was generated as one respondent described the quantity of information available regarding methods of suicide on the internet. However, they mentioned that when they had been suicidal, they were a child and saw suicide being portrayed in one specific way on the television. As the respondent did not have all the items required at the time for this particular method, they admitted that they were unable to make an attempt. This respondent was also troubled by the availability of suicide-based information on the internet. They highlight the potential vulnerability of autistic adults who are drawn to research using the internet.

Relating to the fourth code, suicide is an option, three respondents described reasons for their suicidal behaviours. One person described the perseveration of suicidal thoughts, even when times of mental ill-health have subsided. Two respondents wrote about continual presence of suicide being an option without using the term, one describing suicide as, “a logical solution” (Response 25), and the other describing that their intrusive suicidal thoughts never reduced.

The third theme has four codes and considered the role of the NHS and mental health teams. I merged these two potentially separate themes, as I generated them both from the same responses. The first code is autism diagnosis. Only two people confirmed their autism diagnosis, one explaining when they received their diagnosis, whilst the other mentioned their diagnosis in relation to another coding. In contrast, one respondent wrote that the benefits of being assessed, and potentially receiving an autism diagnosis, would have been too emotionally costly. This respondent neither outlined what they perceived as the benefits of an autism diagnosis, nor did they explain the emotional cost. However, there can be barriers involved with the diagnostic process, and a lack of post-diagnostic support (Crane *et al*., 2018). It is recognised that diagnosis can be arduous, challenging, and traumatic for the autistic individual and for any family members involved (Crane *et al*., 2018; Leedham *et al*., 2020).

The second code, within this theme, is misdiagnosis. The one comment, within this code, related to borderline personality disorder (BPD). There is some evidence that people with BPD and autistic people have a similar level of autistic traits, when measured using the AQ (Dudas *et al*., 2017). The respondent outlined that their BPD diagnosis was only from attempting suicide. Nyrenius *et al*. (2022) explain that misdiagnosis can occur as clinicians diagnose co-occurring psychiatric disorders due to, “significant diagnostic overshadowing” (p. 8), rather than acknowledging autistic characteristics.

Within the theme relating to the NHS and mental health teams, I generated the third code, access denied, as one of the respondents found that their autism diagnosis made it difficult for them to receive any mental health support. They found it difficult to access support from doctors, psychiatrists, or psychologists. Camm-Crosbie *et al*. (2019) provide evidence that this lack of mental health support is due to autistic adults seeming to be, “too complicated” (p. 1435). Brice *et al*. (2021) suggest that the barriers to accessing appropriate mental health provision for autistic adults are at an “individual-level... provider level...

and system level" (p. 2). They describe difficulties with professionals' communication, and their, "lack of 'autism awareness'" (Brice *et al*., 2021, p. 2), and the, "convoluted referral pathways" (p. 2), of those providing mental health support.

The fourth and final code, within this theme, is hospitalisation. It appears that for some respondents, their poor mental health had to deteriorate to a point where emergency intervention had to occur. Four respondents referred to being hospitalised. Two of them described that suicide attempts resulted in them being a psychiatric inpatient, or in a secure unit. One respondent mentioned being removed by the police to a place of safety for a mental health assessment using Section 136, of the Mental Health Act (1983). Although this act enables a police officer to remove a person from a public space to a place of safety, police frequently feel unprepared to assist an autistic individual due to a lack of training and have to resort to using their intuition (Swan and Perepa, 2019).

The Mental Health Act (1983) also suggests that any autistic person can be detained, solely for being autistic (NAS, 2021a). However, a governmental White Paper and a public consultation in 2021 propose that the UK parliament amend this mental health legislation (Department of Health and Social Care (DHSC), 2021a). The suggested changes include,

> "reducing the reliance on specialist inpatient services for people with a learning disability and autistic people and to developing community alternatives" (DHSC, 2021a, Chap. 9, para. 1).

The long-term change requires participation of the various concerned bodies including the,

> “national health and social care organisations, NHS mental health services, local authorities, the courts and the police, and the third sector” (DHSC, 2021b, para. 69).

Whilst the three previous respondents wrote about potential hospitalisation within mental health services, one respondent wrote about receiving emergency care in a hospital caring for physical needs, explaining their need of intensive care, following a suicide attempt. For autistic people, many factors can contribute to increased levels of distress whilst in hospital, especially within intensive care. These might include, “hypersensitivity to auditory, visual, or other sensory stimuli” (Iannuzzi *et al.*, 2015, p. 1097), found throughout the hospital. Autistic people may have no control over these sensory stimuli, and some may be, “unable to consciously process information” (Robertson and Simmons, 2015, p. 582).

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3.7 Discussion

In this discussion I explore the characteristics of suicidal autistic adults. I discuss how the demographic characteristics, the findings of the quantitative analyses, and the thematic analysis illuminate previous research, and how existing literature supports these findings.

Prospective respondents were either advised of the study through an advertisement on an internet social networking service, or within a few face-to-face autism support groups. The survey information was accessed through email with me, the researcher. Of the people who had requested the initial information pack, 68.6% returned their completed consent form, and were sent the link to the online survey. Eight people, who had completed a consent form, did not access the survey, or stopped the survey before an answer was recorded. One person postponed their completion of the survey and attempted to access it once the survey had closed. The response rate for the completed surveys was 61.2%. Response rates of over 60% are seen as being, “the goal of researchers” (Fincham, 2008, p. 1). The online survey was completed by 89.1% of the people who had completed their consent form, only one person, who started the survey, did not complete the questionnaires assessing their autistic traits. Their remaining data were included in the analyses.

All the respondents signed a consent form that stipulated they had understood inclusion criteria, which included the requirement of being autistic. To demonstrate the level of their autistic traits, information relating to AQ (Baron-Cohen *et al*., 2001) and EQ (Baron-Cohen and Wheelwright, 2004) scores were gathered and analysed. One set of scores indicate that one respondent may not be autistic. However, as the individual completed the consent forms with the inclusion criteria for the study, their data is included in most statistical analyses. The thematic analysis highlights one respondent deciding against getting a formal autism diagnosis, as the emotional costs for them would outweigh the potential benefits. It is unknown whether the person providing the outlier results was this person not seeking an official diagnosis.

The demographic characteristics data suggest that the greater the autistic traits, shown by a higher AQ score, the more likely an autistic person is to have had suicidal ideation and to have made suicidal plans. Similarly, lower EQ scores are indicative of greater autistic traits with the data suggesting that lower EQ scores are linked with suicidal planning and attempts. This supports literature demonstrating that adults with higher AQ scores are more likely to make suicidal plans (Hedley and Uljarević, 2018), and have histories of suicidal planning and attempting suicide more than once (Richards *et al*., 2019).

Ages were sought through groups and were generally organised in ten-year blocks leading up to the retirement age of 65 in 2017, when the data collection started. This results in a smaller age group of seven years for those aged 18 to 24. Provision was made for respondents in the 65 to 74 age range, and in the 75+ age range, however, there were no respondents in these age groups. Fewest respondents were in the 55 to 64 age range. There may be various explanations for this lower rate of participation, including a lack of diagnosis in this age group. Only since the publication of the DSM-IV (APA, 1994) people in this age group, and without an intellectual disability, have been diagnosed as autistic. A further explanation may be due to premature mortality in autistic people (Hirvikoski *et al*., 2016). Hirvikoski *et al*. (2016) suggest that their non-autistic control group died at a mean of 70.20 years whereas autistic people, without intellectual disabilities, died at a mean of 58.39 years. One of the explanations for this lower age was found to be due to suicide in the autistic population (Hirvikoski *et al*., 2016). Furthermore, autism may only be diagnosed once co-occurring mental health issues arise, particularly in those without cognitive, or language, impairments (Dell'Osso, Dalle Luche and Carmassi, 2015). Many adults find accessing an autism diagnosis difficult as they are used to their camouflaging their autistic traits, or they find that, "clinicians used to diagnosing mood and anxiety disorders miss additional signs of autism" (South, Costa and McMorris, 2021, p. 1). Although autistic adults have been found to die at younger ages, some autism research has been found to exclude older autistic adults (Howlin and Moss, 2012; Michael, 2016).

In this study the data for gender are described using three categories, male, female and non-binary. The response rate for females is high, with 50% of the respondents being female. Females are more likely to fill in questionnaires than their male counterparts (Korkeila *et al*., 2001; Smith, 2008). The diagnosis of autism in the female population has been generally found to be lower than for that of males (Baron-Cohen *et al*., 2011). A Finnish study suggests that a male to female ratio in autistic adults is 1.7:1 (Mattila *et al*., 2011). In this study the male to female to non-binary ratio is 1.5: 2.5:1. This higher number of females responding to the questionnaire may be, as Santor *et al*. (2007) suggest, that non-autistic, "females are more likely to rely upon the internet for interaction and self-help" (George and Stokes, 2018, p. 139). The overrepresentation of females in the data set is also consistent with the general higher response rates of autistic females compared to autistic males participating in research (Byers and Nichols, 2014).

The online survey question related to gender was open-ended. Just over a fifth of the respondents (20.3%) are non-binary. George and Stokes (2018) report that 30.8% of their study's response, relating to gender identity and sexual orientation in autistic adults, describe themselves as, "non-heterosexual" (p. 139). Answers to this question also included *trans*, which refers to those whose gender, "differs from societal expectations of their assigned sex at birth" (Bailey, Ellis and McNeil, 2014, p. 209). Most of the non-binary respondents described themselves using the term *non-binary*, others described themselves as *gendervague* or *agender*, where the respondents possibly do not identify with either gender, and one respondent described themselves as *androgyne*, identifying themselves with both binary genders at the same time. Suicide risk in transgender populations is found to be higher than in the heterosexual, non-autistic population (Tebbe and Moradi, 2016). Meyer (1995) explains that those who do not conform to the dominant culture, by being in a sexual minority group, experience stress, which can negatively affect their mental health.

Many theories are proposed into the causes of autism and its link with gender diversity. One theory suggests that, "basic gender identity begins to develop within the first three years of life" (Jacobs *et al*., 2014, p. 278), linking with Baron-Cohen *et al*.'s (2007) study where autistic children are described as lacking a Theory of Mind. Another theory, Baron-Cohen's extreme male brain theory, suggests that autism may be caused by prenatal testosterone exposure (Baron-Cohen, 2002; Glidden, 2016). This theory does not explain those assigned male at birth, but later identify themselves as transgender or non-binary (Glidden, 2016; Heylens *et al*., 2018). Whether or not these theories are correct, the DSM-5 (APA, 2013) stipulates that for an autism diagnosis there should be *deficits* in social communication and social interaction, and these difficulties have also been found in people with gender dysphoria (Heylens *et al*., 2018). However, van der Miesen, Hurley and de Vries (2016) conclude that their systematic search of literature confirms that there is no agreement amongst researchers to explain the link between autism and gender dysphoria.

The minority stress theory (Meyer, 1995) developed by Botha and Frost (2020) to incorporate autistic people, may partially explain why the suicide attempt rate is higher within this study’s sample. Additionally, as 20.3% of the respondents are non-binary this classifies them as multi-marginalised.

The demographic characteristics show a higher response rate for those with a higher level of education, comparable with the findings of Griffiths *et al*. (2019). Those people who have completed higher degrees were also more active in reposting the request for respondents. Due to the continual analysis of the online survey site, when the response rate was seen as being skewed towards those with a higher educational level, the request for respondents was advertised within a county’s autism support groups. This also resulted in people with higher degrees responding. This characteristic differs from other studies suggesting that, in general, autistic people have low levels of educational attainment (Nicolaidis *et al*., 2015; Cooper, Smith and Russell, 2017).

The demographic characteristics data for this group of autistic adults show that there is evidence that further research should be undertaken into the association between anxiety and suicidal planning in autistic adults. Affective disorders, such as depression and anxiety, are seen to be more frequent within the autistic population (Cath *et al*., 2008; Mazefsky, Folstein and Lainhart, 2008; Lever and Geurts, 2016). Within the data from 55 of the respondents, there is evidence that anxiety is the most extensive co-occurring condition, with 26 respondents writing anxiety as part of the term *general anxiety disorder* or solely as *anxiety*. Trembath *et al*. (2012) explain that the symptoms of anxiety include physiological arousal and panic, which, “can greatly interfere with [autistic people’s] daily lives” (p. 213). In addition to the factors that lead to the development of anxiety in the non-autistic population, the possible difficulties in, “social awareness and social understanding” (Trembath *et al*., 2012, p. 214), in autistic people might exacerbate anxiety. The consequences of anxiety may include the inability to cope with, “everyday stressors” (Trembath *et al*., 2012, p. 214). Being unable to tolerate stress and anxiety can lead to autistic people finding their own solutions, including suicidal behaviours (Michael, 2016).

Difficulties with social skills may be associated with the severity of the autistic person’s anxiety (Bellini, 2004). Increased stress and anxiety can be caused by the atypical sensory functions of autistic adults and can be expressed by the person being either over-responsive or under-responsive (Michael, 2016; South and Rodgers, 2017). Autistic people may experience alexithymia that may also contribute to the sense of anxiety (South and Rodgers, 2017). Furthermore, having an intolerance of uncertainty can also lead to anxiety in autistic people (South and Rodgers, 2017). Having an intolerance of uncertainty may be a result of having autistic traits, including having atypical sensory functioning, alexithymia, or demonstrating a rigidity of thought (Boulter *et al*., 2014; South and Rodgers, 2017). In non-autistic populations, intolerance of uncertainty is a risk factor for, “clinically significant anxiety” (Carleton, 2012, p. 939). Research undertaken on autistic children suggests an association of being intolerant of uncertain situations and, “higher levels of anxiety” (Boulter *et al*., 2014, p. 1397). Nevertheless, the measurement of the intolerance of uncertainty, within autistic individuals, may be complicated owing to it capturing features of restrictive and repetitive behaviours, typical of autism (Boulter *et al*., 2014).

The data for this group of autistic adults also show that depression is associated with suicidal behaviours. In particular, the findings demonstrate that if experiencing depression an autistic adult may have suicidal ideation and make suicidal plans, and that if diagnosed with depression an autistic adult may make suicidal plans. The data show a high percentage of individuals having a history of experienced depression or diagnosed depression, and suicidal thoughts and behaviours. Only four of the 74 respondents have not experienced depression. Of particular note is that two of these people have experienced suicidal thoughts, and one of these adults has also made a suicide attempt. Therefore, depression cannot be assumed if an autistic person has suicidal thoughts. In addition, 15 other respondents experienced depression, but have not received a diagnosis of depression, despite all having had suicidal thoughts. Furthermore, nine of this group have also planned suicide and five have attempted suicide. The finding that diagnosed depression is associated with suicidal planning, is supported by the thematic analysis where one respondent wrote, “the degree of my planning relates to the degree of my depression” (Response 17). Whilst another respondent wrote that they, “suffered with depression” (Response 10), a further respondent was uncertain whether they had a depression diagnosis, as they did not have a certificate providing confirmation.

It is important to emphasise that the data of demographic characteristics demonstrate that one person has attempted suicide without making any suicidal plans. The thematic analysis also demonstrates that a respondent recounted having made an attempt that had not been planned but was spontaneous. In non-autistic adults it is assumed that a suicidal person has a suicidal thought, and then makes a plan before attempting suicide (Large *et al*., 2017). This is an important inclusion within the data, as other autistic adults may also go directly from having suicidal thoughts to a suicidal attempt. Within the thematic analysis it is noted that autistic adults have perseverative suicidal thoughts that are not linked to depression. These factors affect those medical professionals, family, and friends, who attempt to put into place suicide prevention plans.

Large *et al*. (2017) counter the usual classification of those having suicidal thoughts as low risk, and those having attempted suicide as high risk. Their results show that some of those classified as low risk are denied treatment, and have taken their own life (Large *et al*., 2017). These findings support those of Large *et al*. (2017) and suggest that all who present with suicidal ideation and behaviours should receive an, “individually negotiated treatment plan” (p. 2), and should not be stratified into low, medium, or high risk.

The data gathered to describe the demographic characteristics of the respondents describe autistic respondents having other co-occurring neurodivergent conditions. Other than autism, neurodivergent conditions include ADHD, Tourette’s syndrome, dyslexia, dyscalculia, and dyspraxia (Dalton, 2013). In this study, ADHD is found to be co-occurring in 13.5% (*n* = 10) of the respondents. Until the DSM-5 (APA, 2013) was published, ADHD was unable to be diagnosed together with autism (Hollocks *et al*., 2019; Rynkiewicz, Janas-Kozik and Słopień, 2019). Sinzig *et al*. (2008) suggest that almost a half of autistic children have co-occurring, “hyperactivity, inattention and impulsivity” (p. 1). Within this study, Tourette’s syndrome, dyspraxia, and dyslexia are all found to have a co-occurrence of 4% or less.

Co-occurring PTSD is experienced by 11% (*n* = 8) of the respondents, affecting more non-binary respondents than either male or female respondents.. This is also the only co-occurring condition where more males are affected than females. PTSD is frequently mentioned by autistic individuals with late diagnosed autism (Dell'Osso, Dalle Luche and Maj, 2016). As PTSD may result from distressing or traumatic experiences (NHS, 2020b), this co-occurring condition may explain the potential difficulties, "in interpersonal relationships and the inability to cope with conflicts" (Dell'Osso, Dalle Luche and Carmassi, 2015, p. 436).

The inability to cope with excessive stimuli may result in being over-responsive and experiencing meltdown[20], or being under-responsive and experiencing shutdown[21]. This is typically seen in some autistic adults and can lead onto a diagnosis of BPD (Dell'Osso, Dalle Luche and Carmassi, 2015). Co-occurring BPD is found in five respondents, four females and one male. Within the co-occurring conditions data, two respondents stated that their BPD diagnosis was prior to their autism diagnosis. This is supported by the findings of the thematic analysis, which also recognises that one respondent's BPD diagnosis was prior to their autism diagnosis. Rydén, Rydén, and Hetta (2008) find that 15% of their BPD patients, "had a co-occurring ASD" (p. 27), and those with both autism and BPD are, "worse off" (p. 28), and have a higher rate of suicidality. There is a chance of misdiagnosis, or possible diagnostic overshadowing, as there are similarities between autistic traits and some of the symptoms of personality disorders (Strunz *et al*., 2015, Hollocks *et al*., 2019; South, Costa and McMorris, 2021; Nyrenius *et al*., 2022). Strunz *et al*. (2015) suggests that BPD is

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[20] Meltdown - an intense response to overwhelming circumstances and a person may show extreme behaviours (Autism West Midlands, 2017).

[21] Shutdown - when a person may either partially or completely withdraw from the world around them (Autism West Midlands, 2017).

sometimes misdiagnosed prior to an autism diagnosis. Differentiation between the two conditions is required to identify appropriate treatment. Self-injurious behaviour in autism may be due to, “sensory overload” (Strunz *et al.*, 2015, p. 4028), whereas in BPD the behaviour may be due to, “interpersonal reasons” (p. 4028).

The results relating to BPD in this study highlight the need for correct history taking when a diagnosis is made. Autistic females are more frequently diagnosed with BPD, rather than autism, due to the effect of traumatic experiences (Dell’Osso and Carpita, 2022). Most diagnostic autism assessments are based on the traits of autistic males and may not be adequately sensitive to recognise an autistic female presentation (Hollocks *et al.*, 2019). Although crisis points involving suicidal behaviours may resemble one another, the medical histories of people with BPD and autistic people may be very different. This difference may be explained by their contrasting reactions in a crisis. The person with BPD may feel an emotional dysregulation (Glenn and Klonsky, 2009), whereas the autistic person may be overwhelmed by sensory overload (Pellicano and Burr, 2012). Brickman *et al.* (2014) suggest that NSSI is present in 65-80% of adults with BPD. Although NSSI may affect half of the autistic population (Maddox, Trubanova and White, 2017), the only evidence I find in this study is one response mentioning NSSI in the thematic analysis.

Obsessive compulsive disorder (OCD) occasionally co-occurs with autism (Martin *et al.*, 2020). Seven per cent of the respondents (*n* = 5) in this study record having co-occurring OCD. Due to some similarities in presentation, NICE (2018) include autism within the differential diagnoses that must be considered when making an OCD diagnosis. The OCD diagnostic criteria include arranging objects and repetitive tapping (Cath *et al*., 2008). These behaviours can also be defined as autistic self-stimulatory behaviour (*stimming*), or as restricted and repetitive behaviours (Wigham *et al*., 2015; Kapp *et al*., 2019). Autistic individuals may use restricted and repetitive behaviours to manage their anxiety, and, "exert some control over the environment" (Wigham *et al*., 2015, p. 950).

Other co-occurring conditions recorded may not directly link to the development of suicidal behaviours, although there may be a partial connection for autistic adults. Six (8.1%) of the respondents suggest that they have joint hypermobility or EDS, four are female and two are non-binary. Rocchetti *et al*. (2021) describe that people with EDS have, "a high prevalence of autistic traits" (p. 8), and delays in diagnosing EDS increases the risk of attempting suicide.

The high response rate of respondents having experienced suicidal behaviours may have been due to desiring to fill in a questionnaire relating to suicide in autism and, therefore, the results need to be interpreted accordingly. Only two autistic adults, who have not been affected by suicidal thoughts and behaviours, responded to the request for respondents. In literature, reasons given for not participating in research include having little or no interest in the topic (Korkeila *et al*., 2001; George and Stokes, 2018), or due to the sensitive, and potentially *triggering*, nature of the topic. In this case, the study subject of *suicide in the autistic population* was advertised on every occasion. This was deliberate in order not to attract those who would prefer not to answer questions on suicidal behaviours.

Finally, the thematic analysis' findings indicate that having an autism diagnosis resulted in difficulty accessing appropriate support from mental health professionals, until hospitalisation was required either through sectioning, or the need for care following a suicide attempt.

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3.8 Conclusion

To conclude, this chapter considers the methods and results of the first phase of data collection of a mixed-methods study. The results determine the answer to the question, *what are the characteristics of the suicidal autistic adult*?

Seventy-four questionnaires were completed using the online survey, representing a response rate of 61.2%. Gender is described in three ways; male, female and non-binary, with females completing half of the responses, and 20.3% by the non-binary population.

The demographic characteristics demonstrate that autistic adults do not need to have planned suicide before making an attempt. Additionally, not all autistic adults who have attempted suicide have experienced depression. These results have implications when assessing the risk of a suicidal autistic adult. For the autistic adults within this study, the significant findings show that suicidal ideation and suicidal planning are associated with experienced depression; and, that suicidal planning is associated with diagnosed depression. The thematic analysis highlights: that an autism diagnosis may be arduous in attaining; that an autism diagnosis sometimes denies access to mental health professionals; that there can be misdiagnosis; that respondents demonstrate that depression made their suicidal thoughts worse; that suicidal thoughts are not always linked with depression; that NSSI is rarely mentioned; and, that autistic people have attempted suicide from young ages.

Seventy-four percent of the respondents indicate that they have diagnosed depression. Over one third of respondents indicate anxiety as a co-occurring condition. The data confirms literature suggesting that depression is potentially a precursor to suicidal behaviours (Sterling *et al.*, 2008). However, I find evidence that not all adults exhibiting suicidal behaviours have experienced depression. Suicidal autistic adults may, or may not, experience depression, and may, or may not, be diagnosed with depression. They may experience anxiety.

Only autistic adults could participate in the online survey, confirmed through the signing of the consent form. Although autism diagnoses were not checked, questionnaires were used to assess autistic traits. The AQ (Baron-Cohen *et al.*, 2001) and EQ (Baron-Cohen and Wheelwright, 2004) scores suggest that all, except one person, are autistic.

Within the limitations that should be considered when interpreting the results and analysis, was the demographic characteristic that respondents have a relatively high standard of education. I attempted to address this by advertising the study in local autism support groups, which again drew in more respondents who had higher level degrees.

The characteristics of the suicidal autistic adult are wide ranging. Suicidal autistic adults, whether having experienced suicidal ideation, planning, or attempts, can be any age or gender, have attained any level of education, and may have experienced depression or received a depression diagnosis. Alongside an autism diagnosis, they may have other co-occurring mental health conditions, physical health conditions, or a combination of the two. Over one third of respondents indicate anxiety as a co-occurring condition, confirming literature suggesting that anxiety is also potentially seen as a precursor to suicidal behaviours (Khan *et al*., 2002). Although mentioned by only a few people, there appears to be confusion over the assessment of autism in an adult, with the possibility of being misdiagnosed with borderline personality disorder.

In the next chapter I explore the lived experience of seven previously suicidal adults, including the nature of their suicidal behaviours, and the care and support the respondents received. Following individual interviews, the qualitative method analyses the participants' responses using interpretative phenomenological analysis, seeking to respond to the question, *what is the lived experience of the suicidal autistic adult?*

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Chapter 4. The lived experience of the suicidal autistic adult

This chapter examines the lived experiences of seven autistic people who have previously been suicidal. It, therefore, continues to address a part of one of the autism community's top ten priorities for suicide prevention, to understand, "the experience of suicidality in autistic people" (Cassidy *et al.*, 2021c, p. 3). In this study accounts of others are not considered, such as those of parents, partners, children, or friends, of the suicidal autistic adult. It is important that in all areas of the research autistic people are interviewed. This is particularly important, as autistic people are frequently ignored when decisions are made about them, or about their behaviours (Milton, 2014).

In the previous chapter I find that, in autistic adults, having suicidal thoughts and making suicidal plans were associated with experiencing depression, and that there is also a relationship between making suicidal plans and diagnosed depression. I also find that suicidal thoughts worsen whilst an autistic adult is depressed, and that these thoughts may linger once the depression has subsided. In this phase of the study, I explore how the co-occurring conditions of depression, anxiety, and PTSD, may be related to suicidal thoughts and behaviours in autistic adults. I also explore the roles of an autism diagnosis, possible misdiagnosis, gender, and the support an autistic adult receives.

After stating the research question, I explain the suitability of the method of data collection and the background and process of the analysis. I then describe the method of recruitment, the process of using email as a method of data collection, and a summary of the participants' key demographics. I briefly outline how I adapted the method of data analysis. I report the results and discuss this data drawing upon literature.

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4.1 Research question

This phase of the study explores the second research question, *what is the lived experience of the suicidal autistic adult?* This question helps to address this lack of experiential information regarding the lived experience of suicidal autistic adults and allows the *voice* of previously suicidal autistic adults to be heard.

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4.1.1 Choice of analytical approach

I examined various qualitative analysis approaches for an appropriate method to analyse the data gathered; grounded theory, case study, ethnography, thematic analysis, and phenomenology (Beteta, 2008).

A grounded theory approach was rejected, as the purpose of the study was to develop deeper understanding of a particular population of the community, rather than to develop theory (Locke, 2001). Whilst a case study may have suited this study, an exploration of several participants' lived experiences was desired to focus on shared phenomena. Therefore, the case study approach was dismissed. An ethnographical approach was also contemplated, as the research would focus on the significance of actions, communication, and relations amongst a, "culture-sharing group" (Creswell, 2007, p. 68). I rejected the ethnographical approach, as the intent was not to examine the actions of suicidal adults, but to obtain a deeper understanding of their lived experiences. However, an autoethnographical approach was considered and chosen for the third phase. Additionally, the narrative approach was evaluated. Thematic significance was desired, rather than individual theorisation that accompanies the narrative approach (Bell, 2003). Whilst narrative passages are included within the analysis, I rejected the narrative approach.

Finally, I selected phenomenology as its heuristic approach enables the researcher to discover something for themselves, exploring for significance and nature in, “human experience” (Douglass and Moustakas, 1985, p. 40). Despite an initial attempt to place my experiences to one side, I had to acknowledge that my personal experiences are important, and underpin all the analysis (Goldspink and Engward, 2019). One disadvantage of phenomenological interviewing, perceived by researchers using other methods of research, is the smaller sample size due to purposive sampling, and the findings cannot be generalised (Smith, Flowers and Larkin, 2009).

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4.1.2 Interpretative phenomenological analysis - background

Through phenomenology, IPA develops a researcher’s understanding through an exploration of *what* a participant has experienced, and *how* they have experienced it (Brocki and Wearden, 2006; Creswell, 2007). Phenomenology stems from the work of the German mathematician, Edmund Husserl, and was expanded by Heidegger, Sartre and Merleau-Ponty. Despite their individual differences of understanding of the term, all agreed that phenomenology is the study of the lived experience (Creswell, 2007).

Husserl believed that it was possible to entirely bracket off one's preconceptions when exploring a phenomenon (Horrigan-Kelly, Millar, and Dowling, 2016). Heidegger was more cautious, believing that all observation includes an interpretation by another person (Horrigan-Kelly, Millar, and Dowling, 2016). Being interpretative, IPA is more aligned with Heidegger's clarification (Horrigan-Kelly, Millar, and Dowling, 2016). Whilst researchers, in general, should take care to acknowledge and make note of possible preconceptions, so their preconceptions do not unduly bias the research, there is also an acceptance that research is a co-construction in which the researcher is making sense of the participants' sense making (Smith, Flowers and Larkin, 2009). Generally, the researcher has an understanding of the situation of the participant’s experience, and in interpreting the content of the interview determines the, “underlying structures” (Moustakas, 1994, p. 13). Giorgi (1979) explains that the participant’s experience can only be understood by reading the entire content of the interview script during the analysis. Therefore, it is necessary to read, and reread, each participant’s script to define their experience. Each script is transformed into a version detailing its revelations, and the researcher learns from what had been revealed (Moustakas, 1994).

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4.1.3 Interpretative phenomenological analysis - process

IPA uses the description of participants’ comments, and their linguistic use, alongside conceptual remarks, to tease out emergent themes from each individual’s interviews. IPA usually uses face-to-face interviewing (Charlick *et al.*, 2016) or telephone interviewing (Spiers *et al.*, 2016), with face-to-face interviewing usually seen as the *gold standard* in non-autistic research (McCoyd and Kerson, 2006; Ison, 2009; Bowden and Galindo-Gonzalez, 2015). I sought to seek a more autistic-friendly method for this study. Email interviewing has been used in various studies using IPA (Brocki and Wearden, 2006), however, prior to this research, IPA has not been used to analyse interviews relating to previous suicidal experiences.

IPA typically seeks a homogenous sample who share a set of, “demographic characteristics” (Larkin, Shaw and Flowers, 2019, p. 182). Hamilton and Bowers (2006) deliberate that it has to be considered, “how well the internet population ‘fits’ the research question” (p. 826, original emphasis). The autistic population frequently use the internet to communicate (Finkenauer *et al.*, 2012). Therefore, this population of internet users *fit* the requirements of the research question.

Several researchers have outlined the advantages of using email interviews for use in studies using other research methods. Benefits include enabling the interviews to occur in segments, thereby reducing tedium, fatigue, and other distractions (McCoyd and Kerson, 2006). Autistic participants have mentioned the benefits of online interviewing: the permanence of the question permitting, “extra processing time” (Benford, 2008, p. 277); being, “under less pressure” (p. 276); having, “more time to process and construct messages” (p. 276); and bypassing, “the disabling effects of autism” (p. 276). Face-to-face interviews can lead to participants having difficulties in the areas of social interaction and communication, and less control over the interview process (Benford, 2008; Burke, Kraut and Williams, 2010).

Notwithstanding the positive aspects of interviewing using email, there may also be limitations. The interviewer has to be careful of any power hierarchy (Madge, O’Connor and Wellens, 2004), as the researcher sets the agenda, asks the questions, and benefits from the whole interview process. Non-autistic people generally use nonverbal cues in face-to-face interviews, which would be missing in any online interviewing, making rapport difficult to attain (Benford, 2008). However, rapport may still be able to be developed over the time of the email interview process (McCoyd and Kerson, 2006), to build trust between each participant and the researcher (Bowden and Galindo-Gonzalez, 2015). Kivits (2005) suggests that active listening, demonstrated by, “the simple gestures of nodding, agreeing or eye interrogation” (p. 42), is not possible whilst using email. Contrastingly, Mann and Stewart (2000) explain that, in email correspondence, active listening needs, “to be expressed as words, not silence” (p. 141). A logistical issue, regarding email correspondence, is not being able to verify if the participant is, “who they say they are” (Bowden and Galindo-Gonzalez, 2015, p. 81). One suggested verification strategy is to evaluate how a participant’s story is constructed, and to appraise the consistency of their story between emails. This evaluation ensures trustworthiness (Bowden and Galindo-Gonzalez, 2015). Bampton and Cowton (2002) propose that the length of time it takes to conduct an interview using email can result in a loss of spontaneity, and a loss of richness of data. However, this potential loss is counteracted by the suggestion that data collected from a person being in a familiar environment will be richer due to the possibility of greater self-disclosure (Benford and Standen, 2011). Any added time delay, due to the asynchronous communication, enables the incorporation of reflexive answers to be produced, ideal for an IPA study (Bagatell, 2010; Bowden and Galindo-Gonzalez, 2015).

There are no formal rules about sample size for using IPA (Smith, Flowers and Larkin, 2009). Generally, the sample size is dependent upon the depth of each individual participant’s analysis; the richness of their responses; how the participants are compared by the researcher; or, by the restrictions under which the researcher is working (Pietkiewicz and Smith, 2014). In this study the sample size was restricted by the total number of autistic people who had volunteered and for whom the experience of suicidal thoughts and behaviours was relevant.

Although there is no stipulated method for conducting IPA (Pietkiewicz and Smith, 2014), there is suggested five-step route to analyse the data collected for those who are, “doing IPA for the first time” (Smith, Flowers and Larkin, 2009, p. 81); reading and rereading; initial noting; developing emergent themes; searching for connections across emergent themes; and looking for patterns across the cases, so that, “the participant becomes the focus of analysis” (p. 82).

In the third step emergent themes develop, reflecting the, “participant’s original words” (Smith, Flowers and Larkin, 2009, p. 92), in addition to the comments made through my interpretation. In IPA, due to purposive sampling, the point of saturation, where no new information is discovered, does not need to occur (Brocki and Wearden, 2006; Saunders *et al*., 2018).

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4.2 Data collection - Phenomenological interviews

I used semi-structured phenomenological interviewing to collect the data from a small group of previously suicidal autistic adults, exploring their lived experiences, as it complements existing work by adding personal accounts and participants’ views of the *reality* leading to depth and meaning (Mertens, 2010a). Following an analysis of the online survey’s data, I prepared an interview schedule covering four main areas of investigation, the first three being namely: the participant's diagnosis of autism; their suicidal behaviours; and their recovery process. The aim of the questions about their recovery process was to positively remind them of their support network, especially if they had been negatively affected by the interview. The fourth, and final area, determined whether the participants were aware of their autistic traits, and whether they thought these affected their suicidal thoughts and behaviours.

Personal security and the participant's control of information were necessary for richer data within this study. A safe, confidential place to write was required by the participants, so that they could write freely about their personal events. Being held within a familiar environment, the interview could result in enhanced self-disclosure, as participants may have felt, "safer about sharing their personal experiences" (Bowden and Galindo-Gonzalez, 2015, p. 80), and therefore, could positively affect the richness of the resulting data (Benford and Standen, 2011). Online questions also reduce any bias for which the presence of a researcher may be responsible (Ball, 2019; Camm-Crosbie *et al*., 2019). In addition, the email interview method eliminates the potential for errors in transcribing, with no transcription required. Furthermore, email interviewing affords, "a more equal research relationship" (James, 2016, p. 160), between the researcher and participant, as it gives time and space for the participant to write without interruption from the researcher. Sending each participant the questions and planned agenda enabled them to maintain some control over their responses and enabled their voice to be heard for this research.

To increase credibility, I kept a reflexive journal throughout the interviewing, and during the analysis process (Goldspink and Engward, 2019). This enabled me to record my responses to participants' comments without influencing their future replies to questions.

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4.2.1 Adaptation of phenomenological interviews

Taking Benford's (2008) research findings into account regarding the benefits of using email to interview autistic participants, I determined to give the participants' time to reflect on the question, with the intention for them to add deep, reflective, and expressive responses. Having the question permanently available enabled each autistic participant to have control over their own emotional responses, how they presented themself and what personal information they disclosed (Benford, 2008; Finkenauer *et al*., 2012). IPA uses open-ended questions to allow participants to describe, and make sense of, their experiences using their own terminology. However, autistic adults may experience difficulty defining the intention of an open-ended question (Nicolaidis *et al*., 2015). To address this, I made the questions specific, whilst maintaining the essence of IPA.

The more structured interviews provided reliability for me, together with an element of control. I had aimed for the control to be with the participants and, therefore, may have missed out aspects that they may have thought important and that I had not considered (Smith and Osborn, 2008).

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4.2.2 Ethics approval

The ethics committee had some concerns regarding the potential vulnerability of the prospective participants of this second phase of the research. They felt this vulnerability would be amplified if I used the internet to recruit, communicate with, and collect data through email interviews. The ethics committee felt that I, the researcher, may also find myself emotionally impacted by gathering data related to suicidal behaviours, and I was invited to discuss these issues with the Faculty Ethics Panel. Therefore, ethics approval for this second part of the study was problematic.

As Biddle *et al*. (2013) explain, all research involving participants who have been suicidal is, “important but ethically challenging” (p. 356). Biddle *et al*. (2013) propose there is a fear, “that discussion of sensitive issues or past trauma may exacerbate distress or otherwise cause harm” (p. 356). This research sample, being previously suicidal autistic adults, can therefore be described as a vulnerable population. The perceived fears of the ethics committee may have been assuaged with the knowledge that, “acknowledging and talking about suicide may in fact reduce... suicidal ideation” (Dazzi *et al*., 2014, p. 3362), and that, “vulnerable people may in fact derive benefit from participating in well-conducted research” (Biddle *et al*., 2013, p. 361), as they gain greater insight whilst recalling their suicidal experiences. Furthermore, Mathias *et al*. (2012) confirm that in non-autistic participants, “inquiring about suicidal ideation is not generally associated with later increases in suicidal thoughts” (p. 348). Rivlin *et al*. (2012) endorse benefits of, “taking part in research related to personal suicidal behaviour” (p. 61), include precursors to suicide attempts, illustrated by a possible improvement of participants’ mood levels.

The addresses and telephone numbers of the participants for this second phase of the study were collected, so that if anyone showed signs of suicidal behaviour, outside help could be sought. The use of this breach of confidentiality was outlined in the consent form that each participant signed.

To address the concerns of the ethics committee relating to my own welfare, I met each week with my mentor. They had developed their role supporting me through all aspects of the study over time and were well-placed to identify if I needed further emotional support.

Ethics approval, for this second part of the study, was attained from the Faculty of Health and Wellbeing Research Ethics Panel, Canterbury Christ Church University, Ref: 18-006 (Appendix F).

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4.2.3 Participant recruitment

A purposive sample of seven were interviewed. All the respondents of the online survey had been invited to participate in the interviews. This invitation (Figure 4.1) had been included within the Introductory Letter (Appendix B) emailed to each of the respondents of the online survey, which had been advertised on an online social network service and in local autism support groups. The inclusion criteria are therefore similar to those described in Chapter Three, that the participants were at least 18 years of age, not having an intellectual disability, being able to communicate without the assistance of another person, being autistic or having Asperger’s syndrome, and being able to provide informed consent.

> Would you be willing to be contacted in the future? The next stage will comprise of a further questionnaire or an interview in the next 12 to 24 months. Please let me know if you would be prepared to take part in the next part of my study on suicide prevention in autistic people.

Figure 4.1
Interview invitation reproduced from the Participants' Introductory Letter to the online survey (Appendix B)

All the participants needed to have experienced suicidal behaviours, whether through ideation, plans, or attempts, but they also required a stable mental health demonstrated by not having made suicidal plans or attempts within the last two years. These inclusion criteria could only be assessed through the self-confirmation of the participants, using the consent form (Appendix I). Sixteen of the 74 respondents originally agreed to be interviewed. Possibly due to the lengthy process of gaining ethics approval, when I was ready to start this part of the study, only nine confirmed their decision. One of these nine did not return their consent form, and one had neither had suicidal thoughts, nor had made plans or attempts. These two people were therefore withdrawn from the study. Consequently, seven participants were recruited for the interviews.

The IPA requirement of homogeneity was provided in several ways. Firstly, all but one of the participants had an official diagnosis of Asperger's syndrome or autism, the other participant self-identified as autistic and was waiting for a diagnosis by a registered clinician. All had experienced suicidal thoughts, planning or attempts.

Similarly to the conditions of taking part in the online survey, the participants had the right to a copy of the results, at the completion of the entire thesis.

Likewise, there were no direct benefits of the study for the participants, other than understanding that their knowledge and expertise would result in an exploration of autistic people who had experienced suicidal thoughts, plans, or attempts.

Aiming to adhere to the best ethical principles, the participants being interviewed had to have a stable mental health. This was defined on the Participant Information Sheet as not having made suicidal plans or attempts within the last two years (Appendix H). However, there may still have been a slight risk to the participants, and they were encouraged to seek their normal support structure and were given advice about nationally recognised organisations. My role was to protect the participants from any physical or mental harm as a consequence of participating in the study (Canterbury Christ Church University, 2014). The participants were frequently furnished with sites from where advice could be obtained including their GP, the NHS 111 telephone number, the Samaritans telephone and text numbers, or their regular caregiver. A direct question about suicide would have been asked if I had felt that any of the participants was suicidal. There were exclusions for people aged under 18, those determined as having an intellectual disability, as well as those who had experienced a recent suicidal behaviour.

Interviews were carried out from the 12th September, 2018, until 31st March, 2019. In accordance with the best fit preference of this sample the interview was undertaken using email, and a separate, research specific, university email address was opened. Prospective participants were sent information about the study, including the envisaged questions (Appendix G), and were provided with a participant information sheet (Appendix H). They were given the opportunity to ask any questions they may have had. Finally, I sent each participant a consent form (Appendix I). They signed their consent forms and received a copy for themselves to retain that I, as the researcher, had signed. The aim was to conduct each interview separately, allowing a three-week window for communication with each participant. With each participant's agreement, if an email had not received a response after three days, a further email would be sent.

To benefit the autistic participants, and to elicit the richest data, I sought their preferred interview methods. Prior to the interviews starting, an email was sent to the seven participants to ascertain whether they would prefer face-to-face, telephone, or email interviews. Five opted for email as their first option (Table 4.1), with three writing that email was the only option. The remaining two participants put email communication as their second choice, one putting face-to-face as their first choice and the other choosing telephone communication as their first choice. I made the decision to interview everyone using email communication, as this was the best fit to this sample's preference and provided uniformity of data collection. This method would also avoid any additional stress and anxiety (Ghaziuddin, 2005), which could have arisen from synchronous interviews (Benford and Standen, 2011). One of the aims of this research was to eliminate aspects of the social environment that would disable the participation of autistic participants. Furthermore, email correspondence accorded well with my own preferred method of communication.

Interview Method	1st choice	2nd choice	3rd choice
Email	5	2	0
Face to face	1	1	2
Telephone	1	1	2

Table 4.1
Choice of interview method

Four of the participants are non-binary, two female, and one male (Table 4.2). Six of the participants are aged in the twenties and thirties with the seventh participant aged in their late forties. Six of the participants had also been, or are being, educated at bachelor’s or master’s degree level, or equivalent. The educational background of the seventh participant is unknown. All the participants live independently, either with partners/spouses or on their own. Only one participant has children. Due to the nature of the study, only individuals who could write and be able to give informed consent could participate.

<table>
<tr><th colspan="12">Descriptions of participants</th></tr>
<tr><td colspan="12">Age</td></tr>
<tr><td colspan="4">20s</td><td colspan="4">30s</td><td colspan="4">40s</td></tr>
<tr><td colspan="4">4</td><td colspan="4">2</td><td colspan="4">1</td></tr>
<tr><td colspan="12">Gender</td></tr>
<tr><td colspan="4">Male</td><td colspan="4">Female</td><td colspan="4">Non-binary</td></tr>
<tr><td colspan="4">1</td><td colspan="4">2</td><td colspan="4">4</td></tr>
<tr><td colspan="12">Preferred pronouns</td></tr>
<tr><td colspan="4">He/him</td><td colspan="4">She/her</td><td colspan="4">They/them</td></tr>
<tr><td colspan="4">1</td><td colspan="4">2</td><td colspan="4">4</td></tr>
<tr><td colspan="12">Occupation</td></tr>
<tr><td colspan="3">Employed</td><td colspan="3">Previously employed</td><td colspan="3">Student</td><td colspan="3">Other/Unknown</td></tr>
<tr><td colspan="3">2</td><td colspan="3">2</td><td colspan="3">5</td><td colspan="3">1</td></tr>
</table>

Table 4.2
Characteristics of the participants

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4.2.4 The interview process

After receiving the returned signed consent forms, I sent an approximate timeline of the interview process. I introduced myself and engaged each participant in a written exchange about work, hobbies, and their age, aiming to develop a rapport with them and to place them at ease (Kivits, 2005; Bowden and Galindo-Gonzalez, 2015). To keep the questions visible, I embedded the questions within the text of the email rather than sending them as attachments (Bowden and Galindo-Gonzalez, 2015). Other questions (Appendix J) were introduced in succeeding interviews (Bampton and Cowton, 2002).

Over the following three weeks emails were sent to, and received from, the participant. I would read each reply, and the following morning would send the next question, or set of questions. The responses would occasionally be quick, and in other instances would take several days to arrive. As suggested by Bampton and Cowton (2002), all these replies were equally valid. However long the interval between responses, the participants frequently started their response with an apology for the delay, to which I generally reassured them that there was sufficient time scheduled for each interview. I appreciated that more time may be needed for some participants to retrieve personal memories (Goddard *et al*., 2007). During the interview I only asked the questions as planned, enabling consistency, comparison between the participants' responses, and a depth of detail across the interviews (Hamilton and Bowers, 2006). The aim was to let the participants shape the interview. Although I responded to the participant's previous answers, to demonstrate active listening, I attempted not to influence the responses to any question, and only asked additional questions if participants did not cover the broad areas, or if more detail was required.

I drew the interviews to a close after three weeks, acknowledging that if the interviewing process was too protracted, the participants could lose interest, and lack motivation to respond to emails. Most of the interviews were detailed, but one particular interview was quite short. As mostly lengthy email conversations ensued, to enable recall of what had already been written, a record of the interview script, in chronological order (Ison, 2009), was kept in a word-processed document. This up-to-date document was attached in all the email exchanges with six of the participants. The seventh participant attached photographs of their handwritten responses. To confirm that I had transcribed their handwritten answers correctly, I inserted their entire transcribed script into one email.

Participants' interviews were different lengths. The briefest interview involved seven emails, four from me including an expression of gratitude for their participation, and three from the participant. The longest interview involved 17 emails. Some emails included lengthy responses by the participants, whereas others included many brief answers. Most participants only answered the questions, forming the majority of the data. Occasionally the participants included other information, not directly connected to the question. This data was also analysed if it was included within their text. One participant attached links to articles to their email; although I read these articles they were not included within the analysis. The maximum delay of a participant's response to my email was three days, with some responses being almost immediate, an hour after I sent the next set of questions. I generally sent their next email the morning after I had received the response to the previous email. There were two instances of responses taking three days, in each case the participant felt unwell. To ensure trustworthiness I evaluated each participant's factual responses and sets of words and phrases, determining that they were consistent. The participants were reminded that they could withdraw from the study at any stage during the interview process, or until 31st December, 2019.

During the interviews I kept to asking the planned questions and did not seek clarification of specific comments made, or specific words used. I had aimed for the control to be with the participants and, therefore, I may have missed out on aspects that the respondent may have considered important, and that I had not considered (Smith and Osborn, 2008).

As email was used to conduct the interviews, I protected the confidentiality of the participants in various ways. The participants chose or were given a pseudonym, I pasted their anonymised email messages into individualised word-processing documents, then deleted their emails, emptied the *recycle bin* on my device, and defragmented the computer's hard drive. The participants were also encouraged, if they so desired, to delete emails using the same process, and to keep their device under password protection. The data for all methods of interview was kept on a password protected pen drive and stored in a locked box, out of sight in a drawer or cupboard. For added confidentiality, email addresses and the participants' pseudonyms were stored in separate data files. The data gathered is to be kept for a reasonable period of time, until the award of the final qualification or for five years, whichever is longer.

One beneficial consequence of this study is that previously suicidal autistic adults had a platform to respond to a phenomenological interview, without the frequently found barriers related to communication or environment.

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4.3 Method of data analysis

To use the strengths of my autistic traits, I adapted the processes involved throughout the entire IPA study, from the development of the semi-structured questions, the method of data collection, through to the process of analysis and the reporting of the data. IPA is a fluid process, and researchers can be creative in their analysis (Noon, 2018), however due to my autistic traits I prefer to follow guidelines.

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4.3.1 Interpretative phenomenological analysis - An adapted process

I followed the suggested five-step route for those analysing data (Smith, Flowers and Larkin, 2009); reading and rereading; initial noting; developing emergent themes; searching for connections across emergent themes; and looking for patterns across the cases. Each participant became my, “focus of analysis” (Smith, Flowers and Larkin, 2009, p. 82).

As IPA usually uses face-to-face interviews, linguistic emergent themes generally focus upon the participant’s use of expression. Relying upon written information meant that these emergent themes focus upon the meaning of the words used (Jeong and Othman, 2016). However, rather than acquiring evidence from the tone of the participant’s voice, tone was interpreted as the participants used capital letters, asterisks, inverted commas, parentheses, rapid repetition of words, very brief sentences, and emoticons. Some of these were used more frequently as rapport was built.

I further adapted the analytical process by adding an extra step. Near the completion of the analysis, I compiled extracts from each participant’s script relating to each individual super-ordinate theme, enabling me to confirm that the accuracy of the super-ordinate themes and whether I had included all the relevant comments relating to the experiences of having been a suicidal autistic adult.

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4.3.2 Interpretative phenomenological analysis - Process of analysis

IPA provides a comprehensive descriptive report of the main emergent and super-ordinate themes of the participants' experiences (Smith, Flowers and Larkin, 2009). I started the data analysis after the completion of the final interview. Focusing on the lived experiences of the previously suicidal autistic participants the analysis initially felt overwhelming, so as suggested by the guidelines, I kept a record of my thoughts in a notebook to which I could refer (Smith, Flowers and Larkin, 2009). I studied each of the participants' interviews, individually, for a period of two weeks, to allow myself to truly understand their experience through what they had written.

The emails went through four stages to analyse the data. The first three stages of gathering each individual's data into one file, anonymising and validating the data, then saving the script using each person's pseudonym, were followed by the fourth stage of preparing the interview scripts for IPA. The lines of each script were shortened, enabling analysis to take place on the right-hand side of the page, and for the emergent themes to be placed on the left side of the page (Smith, Flowers and Larkin, 2009). The lines were numbered, using Microsoft Excel (2013), enabling quotes from the participants to be found.

To immerse myself into the data collected, as the first step of analysis, I read and reread each participant's entire script, familiarising myself with the data, ensuring that individually they were the focus of the analysis. Copious notes were written in the second step, and I started to generate comments line by line.

Some aspects of the text necessitated several analytical comments, whereas other areas of the text were void of these analytical comments. Alongside the descriptive comments were remarks interpreting why the participant may have made these particular comments. In conjunction with the many descriptive comments were fewer interrogative and linguistic analysing comments (Smith, Flowers and Larkin, 2009). However, these led to the further interpretation and meanings being found within the participant's text, especially from the usage of punctuation and symbols. Although laughter was noted, pauses and degree of fluency were impossible to gauge owing to the interviews having taken place via email. The linguistic notes single out few metaphors within the interviews, but they are used.

After reading, and making notes, themes developed from both the participant's words and from my interpretation of their comments. I searched for connections between the emerging themes. After compilation of all 727 emergent themes, it was noticed that one is repeated 29 times, and another is mentioned on 21 occasions. I produced thematic maps to visualise the emergent themes, and their connections to the super-ordinate themes (Smith, Flowers and Larkin, 2009).

Although I originally attempted to follow Husserl's phenomenology and bracket my personal experience (Koch, 1995), as an insider researcher I realised this was impossible. I recognised the importance of my own experience in the interpretation of the participants' accounts, consistent with Heidegger's phenomenological approach. I more easily recognised some emergent themes as they aligned with my own experience, other emergent themes took longer to recognise. I noted the themes that resonated with my own experience in my notebook for particular mention within the next autoethnographic chapter.

As I was faced with the entirety of the printed-out interviews, 178 A4 sides from all of the participants, the process of drawing back from the main themes enabled me to notice other significant details. To aid the analytical process I compiled extracts from each of the participants' responses for each of the emerging super-ordinate themes. This process clarified the evidence for the choice of super-ordinate themes.

For the fifth step I sought patterns to determine the super-ordinate themes. Although noting the frequency of how often an emergent theme is mentioned threatened to quantify the data, the frequency of the emergent themes is taken as significant in determining the relative significance of each emergent theme. Nevertheless, I also gave relative significance to some infrequently mentioned emergent themes, as I interpreted their impact to be significant. This is considered important due to contextual considerations. Eatough and Smith (2006) describe this process as, "a magnet with some of the themes pulling others in and helping to make sense of them" (p. 487). Some emergent themes were dropped as they did not fit within the super-ordinate theme structure.

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4.4 Positionality

As an insider researcher I am aware of my own experience of being a suicidal autistic adult. However, in this phase of the study my intention is to report the voice of other autistic adults who have also experienced suicidal behaviours. One benefit of being an insider researcher is that, as both the participants and I are autistic, there may have been fewer instances of potential misunderstandings in communication (Grant and Kara, 2021). Communicating using email ensured that neither the participants nor I were exhausted (Pearson and Rose, 2021), and that questions and responses were always visible during the interviews (Benford, 2008). With the aim not to influence any responses, I used a semi-structured questionnaire. In addition to being an insider researcher, and having some commonalities with the participants, I am also white, female, heterosexual, and cisgendered[22]. Although I acknowledge the benefits of these societal privileges, in this chapter I focus on equity for each participant by recognising the barriers they encounter from their own perspective (Kintzinger, 2021). To demonstrate equity, I used each participant's preferred pronouns, and enabled one participant without access to word processing technology to send hand-written responses.

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4.5 Results

All the participants used a pseudonym to maintain confidentiality, and to anonymise their data. Whilst writing, I use each participant's preferred pronouns. All quotations within this text are *verbatim*.

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[22] Cisgender - refers to those whose gender aligns with their assigned physical sex (Tan *et al*., 2020).

I analysed the text of all the participants using the five-step process (Smith, Flowers and Larkin, 2009), and I initially found five super-ordinate themes. As four of the seven participants are non-binary, I added the super-ordinate theme of impact of gender (Table 4.3). Only Avien, Dylan and Peter made comments in each of the super-ordinate themes. Galina made comments in four of the super-ordinate themes. Coco, Eliza, and Sage made fewer comments that only related to three super-ordinate themes.

	Sections				
	4.5.1	4.5.2	4.5.3	4.5.4	4.5.5
Number of participants mentioning each super-ordinate theme	7	7	6	5	3
Section	Section Title				
4.5.1	Autistic well-being				
4.5.2	Emotional and practical support				
4.5.3	Financial support				
4.5.4	Autism diagnosis				
4.5.5	Autistic community				
4.5.6	The impact of gender				

Table 4.3
Super-ordinate themes

Despite most of the participants choosing email interviewing as their first choice, there are also difficulties with this method, as it is well acknowledged that autistic people find *reading between the lines* difficult (Baron-Cohen *et al*., 2001). Regarding the first question, “Can you tell me about yourself?”, one participant explained the importance of my own introduction before answering the open-ended question, and added,

> “These sorts of open-ended questions are a bit of nightmare in terms of ‘reading between the lines’ and knowing how to pitch the answer” (Peter: lines 91-94).

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4.5.1 Autistic well-being

Autistic well-being encompasses the themes of depression, autistic burnout, anxiety, camouflaging/masking, and the option of suicide. I use an all-encompassing title as these five emergent themes were discussed by the participants almost interchangeably. In addition, phrases relating to depression were discussed alongside phrases associated with suffering, researching, and environmental issues.

Two of the participants introduced themselves as depressed people. Initially Dylan introduced themself to me as a person with depression, “I’m a queer, agender, autistic person with chronic depression” (Dylan: lines 72-75), using both identity-first and person-first language in the same phrase. Galina also introduced themself as being depressed, “As well as being autistic, I’m also depressed and anxious, having been on antidepressants” (Galina: lines 51-54). I interpreted that Galina’s *depression* may not have resulted from feeling depressed, but that they took prescribed antidepressants. Sage responded to the entire set of questions without mentioning the term depression once. Contrastingly, Peter explained depression as, “I sank into a deep and tortuous depression” (Peter: line 214), and explained at the culmination of his thoughts, “I don’t think I’m doing it justice here... it altered the course of my whole life” (Peter: lines 225-227). Despite this, he reported that his GP had told him that there was, “no reason to be depressed” (Peter: line 249), and Peter wrote later in his writing, “I can find a thousand very good, very well evidenced reasons to be depressed” (Peter: line 605).

Connecting their suicidal feelings with depression, both Dylan and Peter experienced these whilst aged in their twenties. Dylan wrote, “The suicidality I experienced as an adult is most likely a ‘natural’ consequence of my chronic depression” (Dylan: lines 218-220). Peter also linked the thought of suicide and depression, writing,

> “I have struggled with recurrent depression and suicidal thinking
> since my first significant depressive episode in my early twenties”
> (Peter: lines 125-128).

Highlighting the word *episodes*, on several occasions Avien explained that they have, “depressive episodes” (Avien: lines 147; 198; 208), that they are not depressed all of the time, but that the depression coincides with times of planning suicide.

In relation to depression, suffering was mentioned by Coco, Eliza, Galina, and Peter. Coco suggested the idea of suffering from depression when she wrote, “My mother also suffers from depression” (Coco: lines 201-202). Peter used a similar phrase when he wrote, “I have suffered so many years of depression” (Peter: lines 297-298). In addition, Eliza explained that her suffering had been for many years, “I have suffered from anxiety and depression since I was 11 years old” (Eliza: lines 83-86). It may be that in many people’s vocabulary the term *suffer* precedes the term *depression*. In the written text it was not clear how Coco, Eliza and Peter suffered, except that the depression led onto thoughts of suicide. Nevertheless, Galina wrote about suicide in relation to, “something needed to end the constant suffering” (Galina: lines 341-342).

Whilst being depressed, the participants would undertake research. I draw this theme out in the super-ordinate theme of autism diagnosis. Yet importantly here, Avien gave a glimpse of why they researched when they wrote, “When I’m in deep planning mode during episodes of depressions I spend a lot of time researching” (Avien: lines 173-175).

One observation, within this super-ordinate theme, was the association between depression and anxiety. Four of the participants wrote about anxiety being linked with their depression. As with Eliza’s use of *suffering*, she also experienced anxiety for many years, “I have suffered from anxiety and depression since I was 11 years old” (Eliza: lines 83-86). Coco also linked depression and anxiety, and also associated her anxiety with stress, “I am very prone to stress and anxiety as well as depression” (Coco: lines 68-70). This situation led to Coco having feelings of tiredness and hopelessness, and an outward manifestation of emotional outbursts. Anxiety may arise from a stressful life, and so may coexist with stress in all of the participants who wrote about anxiety. Additionally, Galina’s anxiety also coincides with their depression, writing, “As well as being autistic, I’m also depressed and anxious, having been on antidepressants” (Galina: lines 51-54). Peter wrote in great detail about his depression and anxiety, but he also wrote about the help of the various antidepressants he had been prescribed. He wrote, “I live with the often-debilitating relapses into depression, constant anxiety” (Peter: lines 109-111), although one particular antidepressant helped, “with the constant anxiety” (Peter: line 255). Furthermore, Peter explained that, “when I’m not depressed I’m often in the grip of anxiety” (Peter: line 273).

Autistic burnout aligned with both Avien’s and Peter’s depression. In one email Avien explained the overlap of depression and the periods of autistic burnout writing, “I think my depressive episodes frequently overlap with periods of autistic burnout” (Avien: lines 198-201). Peter also explained that the autistic burnout occurred whilst experiencing depression, “at about 30 I burned-out” (Peter: lines 266-267), due to his job, and he added, “I collapsed into depression” (Peter: line 268). Although not directly mentioning autistic burnout, Eliza mentioned over stimulation which in many autistic people may result in burnout (Raymaker *et al*., 2020). She explained that the stimulation led to dropping out of society, which in turn led to depression, and onto her suicidal thoughts,

> “due to becoming overwhelmed by social stimuli and I would drop out, that would then lead to be becoming depressed then suicidal” (Eliza: lines 190-195).

The effect of social media was significant in the development of depression for Galina. They wrote,

> “I was tired of being so depressed all the time and social media was magnifying that so I tried to create more positive social spaces for myself” (Galina: lines 236-238).

Galina did not explain whether the social media was connecting with autistic or non-autistic communities, however I analyse the role of the autistic community. Drawing together three of the themes in this super-ordinate theme, Avien additionally aligned depression with masking, or camouflaging, and with autistic burnout. They wrote,

> “I was trying to hold down a stressful job that involved a TON of masking, that led to periods of burn out/depressive episodes” (Avien: lines 206-208).

The home or work environment was instrumental in the development of chronic depression for Dylan, Avien, Peter, and Eliza. Explaining the effect of a detrimental home environment Dylan wrote,

> “My chronic depression is likely the outcome of growing up in an environment that was hostile towards most parts of me.” (Dylan: lines 86-88).

Elsewhere in their emails Dylan claimed that this hostility was due to their chosen gender identity, and their undiagnosed autism. Dylan explained that identifying other than binary drew particularly hostility, as their family were evangelical Christian’s and opposed, “Queerness in any form” (Dylan: line 196). The work environment affected Avien and Peter, with both attributing it to the cause their depression. Furthermore, Avien used the term *stress* whilst describing their work environment,

> “I was trying to hold down a stressful job... that led to periods of burn out / depressive episodes” (Avien: lines 206-208).

Peter explained that he collapsed into depression due to his, “intensely people-focused job” (Peter: line 267). Eliza also described one environment as being overstimulating due to, “social stimuli” (Eliza: line 191). It appears that living, or working, in detrimental environments can be overwhelming for an autistic adult.

Depression was seen by the participants as being an acceptable explanation for their experience of suicidal thoughts, plans, or attempts. Only Coco explained how other people's thoughts about depression impacted on her life.

> "The least helpful thing that people have done for me is... openly criticise other people for their depressive symptoms" (Coco: lines 212-216).

Here she wrote about how people spoke about others' depressive symptoms within her hearing. It was not clear whether she felt that these comments were being made about her, or whether the comments were being made about depressed people in general. I noticed that she did not define her depressive symptoms.

In addition to Galina and Peter, Dylan also stated that they took antidepressants to cope with their anxiety associated depression. For Peter these antidepressants had mixed results, resulting in him changing his medication several times. In contrast, Dylan had a positive outcome using medication, where their chronic depression, "reacts very well to antidepressants" (Dylan: line 221). Despite this positive element of taking antidepressants Dylan concluded, "I will experience depressive episodes my whole life" (Dylan: line 283). For some of the participants antidepressant medication seemed to be a long-term method of coping with their depression and associated anxiety.

There is further evidence that depression, having affected six of the seven participants, has had, and will probably continue to have, an effect on the rest of their lives. Galina was uncomplaining of the situation, and identified that something has changed forever, as they wrote, "Accepting that I will never be the person before the depression" (Galina: line 265). Peter hinted at a way that could have reduced the likelihood of his depression, as he finished his responses with a comment about when he had first felt suicidal,

> "Maybe if I'd heard someone being more open about their depression I would have sought help in my early twenties" (Peter: line 733).

I also noticed that participants' suicidal attempts were not always linked with depression. Avien explained that suicide attempts were also due to their Bipolar 2 Disorder, during their hypomanic episodes,

> "Almost always these have been during depressive episodes, but a few have been during hypomanic episodes" (Avien: lines 147-149).

The emergent theme of autistic burnout was closely linked to that of depression. Dylan's various reflections supported this. They explained that their burnout triggered suicidal thoughts twice whilst being a teenager writing, "I likely had my first burn out at 14 and another at 17" (Dylan: lines 213-214). These burnouts may have resulted from Dylan continuously having, "to perform the role that was expected from me" (Dylan: lines 208-209), a role that was alien to being agender and autistic. They continued writing that other periods of suicide were probably related to depression. Similarly, Avien linked periods of autistic burnout and depression writing, "I think my depressive episodes frequently overlap with periods of autistic burnout" (Avien: lines 198-201), continuing, "one will often trigger the other" (Avien: line 204).

Peter seemed to write about mental breakdown and burnout interchangeably. Initially, he used both terms within the same sentence, “I haven’t worked for several years following a severe and protracted ‘burn out’ or mental breakdown” (Peter: lines 105-108). Perhaps following on from our email conversation, when I validated that what he said concerning burnout resonated with my own experience, Peter was more forthright with his views concerning this phenomenon, “autistic burnout... it basically explains the entire journey of the last six years of my life” (Peter: lines 655-657). On reflection, my comments may have skewed the results, however these comments elicited further information from Peter. Possibly linking autistic burnout with the term breakdown, Galina explained that their response to breakdown was to consider suicide, “I had a breakdown and considered overdosing” (Galina: lines 186-187).

I interpreted one of Sage’s comments as reflecting Raymaker *et al.*’s (2020) definition autistic burnout, as they wrote, “Sometimes the thoughts are responses to current situations that are too difficult to deal with” (Sage: lines 176-178). Reflecting on autistic burnout, Peter explained, “one... thing I wish I’d heard about sooner” (Peter: line 654), and recalled that, “at about age 30 I burned-out in my intensely people-focused job” (Peter: lines 266-267). After his Personal Independence Payment (PIP) benefit was rescinded he, “completely fell apart” (Peter: line 364), which I interpreted as being the result of autistic burnout. Peter’s response was to move back to his mother’s home for a week to be in a safe environment. However, at the time of the interview he was, “in a better position” (Peter: line 407), and not as, “I was in the depths of my burnout” (Peter: line 407).

Neither Eliza nor Coco made explicit comments mentioning autistic burnout or breakdown. Nevertheless, Coco explained that her suicidal episodes coincided with, “an increase in tiredness, a high level of anxiety and difficulties in social relationships” (Coco: lines 342-345). These difficulties correspond with some of Raymaker *et al.*’s (2020) definition of autistic burnout. Furthermore, Coco wrote of feeling, “completely overwhelmed” (Coco: line 151), and described episodes when, “everything has gone terribly wrong” (Coco: line 139). To cope in these circumstances, her response was to get, “to a private and quiet place” (Coco: lines 170-171).

Autistic burnout seemed to be significant for most of the participants, whether they mentioned the specific term, or not. Explaining how autistic burnout is understood by the autistic community, Peter explained its effects need to be understood by the wider community, especially medical professionals.

Anxiety was also frequently mentioned, sometimes being linked with depression, but at other times mentioned on its own. As stated previously, Peter wrote, “when I’m not depressed I’m often in the grip of anxiety” (Peter: line 273). In this phrase he differentiated the difference between depression and anxiety, and highlighted that anxiety was a significant issue. Peter amplified this point writing, “My thoughts of suicide are... more like a reactive response to anxiety” (Peter: lines 276-278). Anxiety drove his suicidal ideation, and he explained that it may not necessarily have been huge issues that triggered this suicidal ideation. For example, suicidal ideation was a result of self-criticism when making, “a minor misunderstanding when driving” (Peter: line 283). In one email Peter explained that he had not been aware of the anxiety, until trying a new medication,

> “which helped a lot - especially with the constant anxiety that I had not yet realised I live with” (Peter: lines 254-256).

Not realising that he lived with, “constant anxiety” (Peter: line 255), may be fundamental in Peter developing suicidal thoughts. Following Peter’s, “‘burn out’ or mental breakdown” (Peter: lines 107-108), and before his autism diagnosis, he lived with, “often-debilitating relapses into depression, constant anxiety” (Peter: lines 109-111). It seemed as if, even though he identified that the anxiety led to his suicidal thinking, he was ill-equipped to move out of the suicidal zone, as he always kept suicide, “in my back-pocket” (Peter: line 239). Further focusing on anxiety as a contribution to their suicidal thoughts Galina wrote, “Anxiety - I was perpetually in a state of fight or flight” (Galina: lines 387-388). They did not elucidate what they meant by, “fight or flight” (Galina: line 388). Although Galina described that they had been on antidepressants for, “nearly a year” (Galina: line 55), they had experienced depression and anxiety, “for much longer” (Galina: line 56). In contrast, mentioning anxiety only once, Eliza explained that she had, “suffered from anxiety and depression since I was 11 years old” (Eliza: lines 84-86). However, when she was asked about her past suicidal thoughts, plans, and attempts and about what had generated them, her response was, “I strongly believe it was/is my autistic traits that triggered my suicidal thoughts and plans” (Eliza: lines 177-181). Eliza neither classified these autistic traits, nor the processes that led from them to her suicidal behaviours. Whilst also responding to the question relating to what had contributed to their suicidal thoughts, plans, or attempts, Coco made comments concerning her anxiety, writing, “an increase in tiredness, a high level of anxiety and difficulties in social relationships" (Coco: lines 343-345). I interpreted that her anxiety seemed to have a greater effect on her, compared to either the increase in her tiredness, or her difficulties with relationships.

Within the analysis of the participants' interviews, as anxiety is a reaction of stress, the link between the words *stress* and *anxiety* is too close to ignore. I elicited the emergent theme of anxiety as Dylan wrote about episodes of depression and suicidal ideation that were, "triggered by severe stress" (Dylan: line 232). They gave examples, such as when they, "wrote my bachelor's thesis" (Dylan: line 234), and when they had, "emotional troubles like a break-up" (Dylan: lines 235-236). Stress was also mentioned by Avien, yet their responses Avien did not elicit any analytical notes or emergent themes regarding anxiety. Sage also refrained from using the term *anxiety*, when writing about suicidal thoughts and they used the phrase, "ending my life", rather than the word *suicidal*. These thoughts about ending their life, "have been about ending ongoing traumas" (Sage: line 159), with Sage continuing, "sometimes the thoughts are responses to current situations that are too difficult to deal with" (Sage: lines 176-178). However, I interpreted that the situations that *are too difficult to deal with* could have been interchanged with the phrase *would create too much anxiety*.

The fourth element discussed in this super-ordinate theme of autistic well-being is camouflaging, or masking, being mentioned by most of the participants. Although Peter described his employment as causing his autistic burnout, he explained that his appearance was typical of a stress-free employee, writing, "My job was so unbearable, but you'd never have known it from looking at me"

(Peter: lines 443-444). Peter claimed, this was from being, “a very proficient ‘masker’” (Peter: line 182), and continued, “I learned from a very young age how not to stand out in the wrong way” (Peter: lines 183-185). Whilst talking with his psychiatrist, Peter appears to have masked and demonstrated a state of mental stability, and in one email he wrote, “I sometimes feel that I don’t ‘perform’ my distress well enough” (Peter: lines 326-327). Furthermore, Peter claimed that he masked his emotions so well that the only way to communicate his anguish to his mental health team would be to attempt suicide.

Although not mentioning camouflaging, Dylan wrote their aversion to performing like a non-autistic person, that I interpreted as camouflaging, “I... had to perform the role that was expected from me” (Dylan: lines 208-209). This performance, “got more draining the older I got” (Dylan: line 211), and they continued, “I just wanted to escape and sleep forever” (Dylan: lines 216-217). The intent of suicide was not to end their life, but to escape the situation, and the accompanying fatigue.

For Avien camouflaging was associated with the themes of burnout and ableism. Similar to Peter’s situation, Avien’s masking was related to employment, they wrote, “I was trying to hold down a stressful job that involved a TON of masking” (Avien: lines 206-207). They explained that their camouflaging led to burnout and depressive episodes, which in turn triggered suicidal thoughts. Avien also placed some of the responsibility for their suicidal thoughts onto their co-occurring PTSD (Avien: line 191) and bipolar disorder (Avien: line 210).

Contrastingly, Galina wrote about camouflaging so that they were able to go out with people and pass as non-autistic. When asked about whether autistic traits contributed to their suicidal behaviours, Galina wrote about forcing themself to go out with other people, “in the hope it would make me feel better” (Galina: line 376). However, this socialising would backfire and, “I’d make some kind of mistake that everyone else picked up on and I’d feel even worse” (Galina: lines 377-379). Camouflaging is seen as stressful, but in this case the alternative result of failing to camouflage, was also identified as stressful. Whereas Galina would attempt to socialise, Eliza preferred staying at home. Eliza explained that failing to mask her autistic traits triggered her, “suicidal thoughts and plans” (Eliza: lines 180-181). She described her, “struggle to fit in to life” (Eliza: line 183), and further described her coping mechanism as retreating, “into my own little world” (Eliza: line 201). Camouflaging was not mentioned by either Coco or Sage, but the strategy of *retreating* may also have resonated with Coco’s handling of stressful situations. Although she mentioned she has, “strong emotional outbursts” (Coco: line 72), which I interpreted as experiencing autistic meltdowns, in later emails Coco detailed how she handled stressful social situations by, “getting to a private and quiet place” (Coco: lines 170-171). If she did not retreat she would experience a, “strong negative emotional reaction” (Coco: line 176).

Camouflaging is a strong theme for most participants, either being mentioned directly, or found through the interpretation of their script. Dylan and Peter explicitly described the experience as having to perform, but this linked with the experiences of Galina and Coco attempting to socialise.

The final theme of autistic well-being relates to the participants' comments regarding suicide as an option. Peter kept the option of suicide in his, "back-pocket" (Peter: line 239). In a similar way, Sage demonstrated that suicide is an option by using it as, "a safety net" (Sage: line 168). Similarly focusing upon suicide as an option, Dylan's comment referred to wanting, "to escape and sleep forever" (Dylan: line 217).

This section has raised the impact of the environment, whether positive or negative, at home or at work. The theme of suffering from depression was referred to by a few of the participants. Generally, the experience of the suicidal autistic adult, in this participatory sample, is that they had suicidal thoughts, plans, and attempts. This analysis revealed that the participants describe themselves as depressed for a number of reasons, either; they were told that they were depressed; they had been given antidepressants to deal with the symptoms of depression; or they were actually depressed. Autistic traits may confuse the diagnosis of depression. This study did not intend to determine the extent to which the participants were depressed.

Throughout the seven interviews the emergent themes of depression and anxiety seemed to be interchangeable. Through the interpretation of their scripts, the participants revealed the connection between autistic burnout and camouflaging, and were described as being a result of depression or anxiety. Within this super-ordinate theme of autistic well-being, no ameliorating themes were identified. The consequence of all these aspects of autistic well-being was the contemplation of suicide, specifically mentioned by three as continually having the option of suicide.

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4.5.2 Emotional and practical support

During the detailed analysis of each set of emails, I noted that Avien and Peter wrote more about support than the other participants. Sage added an extra dimension to the super-ordinate theme, the emergent theme of support for assisted suicide.

I classified support as either emotional support or practical support to help the participants complete an activity. This support was referred to in many ways, some participants relied upon support from family, whereas others relied upon friends, paid peer support workers or other professionals. Avien and Peter also wrote about supporting others. Avien supported those who are, “questioning their gender” (Avien: line 298), and Peter supported his mother. Peter explained this using the term *help* rather than support, “the help I provide with her physical disability” (Peter: lines 371-372).

There were statements about the role of supporting family. Coco explained that she lived with her, “family... who are very supportive” (Coco: lines 57-58). Throughout her interview Eliza wrote about her husband’s support. Peter had family support and explained, “I am lucky to have the support from my mother and a sibling” (Peter: lines 120-121), but he worried about the time, “once mum is gone” (Peter: line 123), “her being my main support for my mental health problems” (Peter: line 293). Although he also reflected,

> “Sadly, my mental health has taken a toll on these relationships and my sister and I aren’t as close as we used to be” (Peter: line 670).

Peter also added that a negative implication of support was, “turning all of my friendships and family connections into ‘support’ relationships” (Peter: line 671).

Avien did not mention their family. Dylan experienced an absence of family support. They explained briefly, “My family did not support me” (Dylan: line 437), however, Dylan had received and appreciated support from their friends. Whilst Dylan had struggles with their family, reparation of family relationships does appear to occur. Galina explained that initially their family was, “unsupportive” (Galina: line 247), whereas at the time of the interview they wrote that their support came from, “My mother who I make a conscious effort to talk to at least twice a week” (Galina: lines 283-286). A particular type of positive family support was available to Sage, who had discussed their potential autism diagnosis with their family, and had received their support to progress with the assessment.

Peter attempted to widen the source of support. He wrote, “I attend local autism groups, which has been a huge support emotionally” (Peter: lines 544-545). Nevertheless, in widening the theme he confirmed the importance of family support during episodes of poor mental health when he added,

> “it wasn’t my new connections to the autistic community that kept me going through this period - it was my mum” (Peter: lines 556-557).

For the participants, support from outside the family came in different forms, from professional support to that of friends. Eliza wrote about the support of her general practitioner (GP) (Eliza: line 199), and her husband's, "extremely supportive boss who understands issues" (Eliza: lines 211-213). Professional support, in the form of therapists, was mentioned by both Avien and Dylan. Although they both received some support from therapists, it sometimes required augmenting. Avien remarked upon their therapist's help, especially in identifying if they needed more support. They wrote they, "can help me figure out whether I'm safe or whether I need more support" (Avien: lines 596-597). Similarly, Dylan acknowledged that they were supported by, "a few friends" (Dylan: line 433), in addition to the support received from their therapist and other health care employees. Avien received support from friends by receiving lifts, "to hospital" (Avien: line 618), and when *hospitalised*, the friends looked after their cat and washed their clothes. On other occasions, their friends looked after their medications, "to help with overdose risk" (Avien: line 641). The support of friends was also significant to Galina. Their friends' support provided alternating positive and negative experiences, "One of my oldest friends" (Galina: line 288), supported me, although Galina continued, "We stopped talking for a year or two... now we're stronger together" (Galina: lines 289-290). At the time of the interview Peter also had thirty hours of support from a charity, which was available to him over six months.

The role of therapists seemed significant in the analysis of support. Both Avien and Dylan were advised to seek an autism diagnosis from a therapist. Similarly, Coco was guided to have an autism diagnosis after contact with a therapist, but the therapy was not supportive. Neither Eliza nor Sage mentioned therapy.

Both Avien and Dylan had some very positive experiences of therapy, although they both explained that the process of finding a therapist was difficult. Dylan explained,

> "it took me about 6 months to find a therapist who was able and willing to work with a trans person" (Dylan: lines 262-264).

Dylan would have preferred to have a therapist from a marginalised group, and described their therapist as, "a white hetero abled cis man" (Dylan: line 320). Likewise, Avien mentioned, "It is really frustrating to try to find competent care when you're multiply marginalized" (Avien: lines 335-337). Dylan's therapy sessions resulted from an episode of severe depression. The therapist, "After a few months of therapy... asked me if I was ever tested for autism" (Dylan: lines 110-113). This comment directed Dylan towards a beneficial autism assessment, and diagnosis. Similarly, Avien's therapist suggested they might be autistic, "I was in my early twenties, said I had Aspergers or maybe PDD-NOS" (pervasive developmental disorder - not otherwise specified) (Avien: lines 73-76). Avien had good relationships with their therapists and saw them quite frequently, in comparison to their other health professionals, "my therapists... know me best from seeing me more often" (Avien: lines 581-583).

The participants also described the limitations of receiving support from a therapist. Despite the positives, Avien also explained, "I can't say accessing treatment is easy or comfortable a lot of the time" (Avien: lines 338-339). Galina described their negative experiences of therapy. Originally they had therapy organised by the child and adolescent mental health services (CAMHS), and Galina explained that after having eight therapy sessions, the sessions were, "rescinded without warning" (Galina: line 245). Galina added that they had to be responsible for their own recovery, because after the initial sessions, "I wasn't getting any professional help" (Galina: lines 218-219). Galina closed their responses on therapy with further negative comments, possibly relating to online CBT therapy writing, "Online therapy made me feel even worse" (Galina: lines 279-280), and briefly acknowledging, "I almost wish they never gave me therapy sessions" (Galina: lines 276-277). Coco did have CBT, together with other types of talking therapy. She explained that,

> "After a period of major depression including suicidal thoughts and trying a few different antidepressants I was referred to a therapist for CBT" (Coco: lines 92-95).

Similarly to the experiences of Avien and Dylan, this therapist introduced to Coco the possibility that she was autistic. I therefore understood that Coco undertook CBT before her autism diagnosis. However, her experience of therapy was also negative, and wrote, "I have not found CBT or other types of talking therapies to be particularly helpful to me" (Coco: lines 186-188). Coco explained this negativity as arising from a perceived fault in herself, rather than a fault in the type of therapy. Perhaps experiencing perseverative thinking, Coco explained that she thinks too much, and that CBT, and any talking therapies, encourage thinking. Adding further negative consequences of CBT, Peter was very explicit about his experience, writing, "CBT was... damaging" (Peter: line 597), explaining, "It made me much more suicidal and took months to recover from" (Peter: line 452). He was also very descriptive when he commented, "It felt like straightening roof tiles on a burning house" (Peter: line 456). Peter explained that he understood the principles of CBT, "but I don't think... my problems come down to identifying a mistaken belief" (Peter: line 604). Peter further complained that, whilst undertaking CBT he was forced to camouflage, and there was,

> "no scope to say during the process, 'I'm working hard on this, I'm doing the exercise, and I'm getting worse'" (Peter: lines 600-601).

He also explained the negative role of the therapist, "there was this unconscious coercive pressure to say that it was helping me when it wasn't" (Peter: line 602).

Avien described the difficulty of professional support coming to an end, when they came too old to access the provision, as they wrote, "I felt... supported by them" (Avien: lines 605-606). Avien contrasted the benefits of peer support and relationships with peer providers with professional provision. They wrote, "I have generally gotten way more out of relationships with peer providers than I have with professionals" (Avien: lines 507-510). This dichotomy may be explained by the problems Avien encountered attempting to communicate with emergency health care staff following a suicide attempt. As a user of augmentative and alternative communication, Avien explained,

> "I'd hope they would have been more supportive of me using whatever communication method was best for me" (Avien: lines 464-467).

Following suicidal episodes, Avien consequently had to take a friend to support their communication within health care settings.

Whilst most of the participants received outside support, Coco's social difficulties hindered her from seeking other people's support and left her isolated. She wrote,

> "Because of my social difficulties it is also very hard for me to ask for help or feel any sense of support or understanding from other people" (Coco: lines 361-364).

Avien identified that there is insufficient support when visiting hospitals. They introduced the concept of autistic people supporting other autistic people with their needs, by suggesting the use of autistic advocates to support hospital visits. Avien wrote that autistic people need, "WAY more peer support options than we do" (Avien: lines 505-506), and added,

> "it would be helpful to have an autistic advocate who has experience supporting people in healthcare settings" (Avien: lines 532-535).

Avien explained that anxiety could be alleviated, together with any potentially detrimental effects, if either an autistic person, or a non-autistic person with specific training, could support an autistic healthcare patient.

All the participants discovered the initial study through an internet networking service, and Peter mentioned the internet as a way of keeping in contact with people. Avien mentioned the role of the internet as providing positive emotional support, whilst writing, "I have many long distance friends who support me" (Avien: lines 691-692).

In relation to emotional support for suicidal adults, Sage introduced the completely different element, the aspect of assisted suicide for themself. Sage hoped that in the future society would accept and support, "those who have chosen to end their life" (Sage: line 203). However, Sage did not elaborate on this in their script, but attached articles that were outside the scope of the analysis.

Within this super-ordinate theme of emotional and practical support, the two emergent themes of support and therapy demonstrate that the role of therapists may be controversial for autistic suicidal adults. For four of the participants the role of the therapist brought about the helpful suggestion of seeking an autism diagnosis, whereas others found therapy harmful. Family are important to some, whereas friends are important to others. This super-ordinate theme was mentioned by all the participants.

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4.5.3 Financial support

I classified the two emergent themes of receiving governmental financial benefits and employment together into one super-ordinate theme, as both provide financial support.

Peter commented that he desired to support himself financially. He continually referred to the negative effect that the lack of employment had on him, whilst equally elaborating on the stress of receiving financial support through government benefits. Avien also acknowledged receiving benefits. Coco, Dylan, Eliza and Galina all worked, either part-time or full-time, and were more able to financially support themselves. Sage mentioned neither employment nor the receipt of benefits in their interview.

Employment was mentioned by Peter whilst explaining his burnout, “in my intensely people-focused job” (Peter: line 267). He later described that the work was perhaps not as damaging as he had first described, as he reminisced that, "the job wasn't even that bad" (Peter: line 445).

Peter wrote very strongly, and negatively, about the experience of being on benefits. He explained that he had received benefits, had them rescinded, and successfully appealed to have them reinstated. He described the experience as, "just surviving the abusive terror of the benefits system" (Peter: line 610). Peter also used a very descriptive phrase to explain the feeling of being on benefits, writing it was,

> "like being underwater and having someone arbitrarily cut off your air supply whenever they feel like it" (Peter: line 386).

At the time of the interview Peter was back in receipt of financial benefits, and explained,

> "I just wish I wasn't always looking over shoulder, waiting for my benefits to be taken away" (Peter: line 433).

Avien also described having to receive benefits as affecting them detrimentally. Avien explained that in the past they had been, "trying to hold down a stressful job" (Avien: line 206), but were, at the time of the interview, "on a ton of benefits... in order to survive" (Avien: lines 223-224). This prompted Avien to raise the theory of ableism, where there is discrimination in favour of non-disabled people. They wrote, "Ableism certainly instills the idea that I am a burden - at this point I can't work" (Avien: lines 220-222). Avien continued this theme commenting about being worthless, in that they are, "using up resources without contributing to society" (Avien: lines 227-228), and, "have internalized a lot of ableist nonsense about 'work ethic'" (Avien: lines 211-213). Seeking to counteract this Avien added, “I tell myself not to believe it” (Avien: line 231), as they are, “unable to work due to disability” (Avien: line 55).

In their emails, Coco, Dylan, Eliza, and Galina, wrote about how they are employed, have been employed, or are going to be employed in the future. Coco, at the time of interview, described her employment as, “currently work part-time” (Coco: line 56). Dylan was looking forward to imminently starting their, “first ‘proper’ job” (Dylan: line 77). Galina had worked in retail at Christmas, to improve their future prospects for employment, as they were aware their, “CV was lacking” (Galina: line 86). Eliza was, “now self employed” (Eliza: line 61). She clarified the reason for this by preceding the statement with, “I’ve never had a steady job due to my autism” (Eliza: line 59). Previous employment conflicted with her autistic traits and led to suicidal thoughts. She explained that,

> “my inability to hold down job as I would be bullied due to me ‘being weird’... I would drop out... becoming depressed then suicidal” (Eliza: lines 187-195).

Despite this, for Coco, Dylan, Eliza and Galina, at the time of their interviews, their autistic characteristics did not seem to be a permanent barrier to employment, whether this was full-time or part-time, permanent or seasonal, or being self-employed.

Although presenting challenges, all the study’s participants recognised that work has its advantages. Peter wrote negatively about his experience of work, but positively about the importance of work. He identified employment being related to his poor mental health, and explained, “I haven’t worked for several years following a protracted ‘burnout’ or mental breakdown” (Peter: lines 105-108), and further elucidated, “my job was so unbearable” (Peter: line 443). Peter highlighted that he had little hope about future employment, explaining that he had neither confidence nor mental resiliency to work, “even if I could find a job” (Peter: line 436). He continued that the thought of possible future employment falsely raised his hopes, as if, “it’s the answer to all of my problems” (Peter: lines 438-439). The thought that employment should improve his mental well-being recurred in Peter’s response to the question regarding whether he had any helpful thought processes or beliefs. He wrote that if he could uncover,

> “my mind’s faulty-logic... I can fix myself and become an economically productive member of society” (Peter: lines 564-566).

Nevertheless, Peter had previously seemed quite realistic about future employment when he wrote, “I still have no plan to move forward, to get back to the workforce” (Peter: lines 423-424). Sage did not mention any paid employment, though they explained that they had raised a family.

In this super-ordinate theme of financial support, the participants fell into two groups, those who were supported by benefits, and those for whom employment provided financial support. Some participants had experienced poor employment environments, which led Avien and Peter to receive benefits, and Eliza to become self-employed.

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4.5.4 Autism diagnosis

I combined the emergent themes of an autism diagnosis and research into one super-ordinate theme. One trait recognised in many autistic people is having a special interest (NAS, 2021c), and for many autistic adults this focused interest is research (Ghaziuddin, 2005). Although research is an element of education neither Coco nor Eliza, who were both studying, mentioned researching in their interviews. This may have been as research is an integral part of their course.

Diagnosis and research were integrally linked when Peter responded to receiving his autism diagnosis by, “diving headlong into researching autism” (Peter: line 414). In a later email he explained the benefit of research as getting, “passionately interested in something” (Peter: line 483), and losing, “myself in researching it” (Peter: line 483). In a similar vein, prior to their diagnosis, Sage’s own research into autism had resulted in them seeking an autism diagnosis as, “An acquaintance who had autistic adult close relatives suggested I was autistic” (Sage: lines 146-148). Likewise, Galina also self-diagnosed, as their family had not informed them of their autism diagnosis in childhood. They explained they researched autism whilst writing, “I was about 16 when I started learning more about autism” (Galina: lines 72-73). Furthermore, Dylan’s research of autism explained, “a lot of my symptoms” (Dylan: line 117). Although not mentioning *research* directly they added, “I continue to understand and learn more about myself” (Dylan: lines 124-125). Dylan added that one of the special interests of autistic people, is frequently research, particularly the, “aspects that are rarely studied” (Dylan: line 406). Dylan also implied that health professionals should undertake more research relating to autism, commenting, “health care providers would seek out that knowledge and implement it into their care” (Dylan: lines 408-410). Furthermore, without his own research into autism Peter, “could still be stumbling around the dark” (Peter: line 419). He added that it is perhaps, “that buzz of intellectual curiosity as you research it" (Peter: line 585), that gives him such a fillip, and improves his mental health.

Researching autism before their diagnosis was important to Peter, Sage, Galina, and Dylan; and after diagnosis, researching was important to Avien and possibly to Eliza. Having a diagnosis of autism, or Asperger's syndrome, seemed to be a positive identification for most of the participants, although Coco did not write about her autism diagnosis. This may have been as a result of her previously having major surgery for a life-threatening condition, so diminishing the relevant significance of Coco's diagnosis of autism.

The waiting time for autism assessments varied between areas, as did the time taken for its completion. Dylan waited for 14 months for an assessment, and similarly, Eliza waited for, "a little over 1 year" (Eliza: line 123). Eliza's appointment was approximately two and a half hours, having interviews with both a psychiatrist and an occupational therapist. Galina's was initially diagnosed in childhood by CAMHS. It was only when they self-diagnosed at 16, they found out about the earlier diagnosis from their family. Despite the earlier diagnosis by CAMHS, Galina sought their GP's assistance to request an assessment to confirm their diagnosis. They waited nine months for the assessment. Peter explained that he had waited for two years for the assessment, which then lasted for five hours with a psychologist. At the time of their interview, Sage was still on the path to having an autistic assessment. Avien claimed that they would initially have been more positive about their diagnosis if their health care professionals had explained the typical difficulties autistic people experienced. Avien had previously experienced doubts regarding their autism diagnosis, “until I had enough contact with the community to realize how much it fits” (Avien: lines 90-92). In this instance research and diagnosis were definitely linked.

Eliza demonstrated that she had researched suicidal behaviours in autistic adults, and linked her suicidal behaviours with her Asperger’s syndrome and autistic traits. She explained that her, “traits... would trigger it all” (Eliza: lines 184-185). This seemed positive, as if she could blame the suicidal thoughts on her Asperger’s syndrome. Similarly, having an autism diagnosis was positive for Galina. They explained that their diagnosis, “made me happy” (Galina: line 140). Galina’s research into autism occurred before their official diagnosis, “when I started learning more about autism... it seemed to fit me perfectly” (Galina: lines 73-74). They wrote about the benefit of being autistic explaining, “I fulfilled the criteria for autism spectrum disorder [which] made me happy” (Galina: lines 138-140). They concluded, “There was finally a reason as to why I am the way I am” (Galina: lines 141-142). The sound of Galina’s delight on receiving an autism diagnosis came through in the email. Likewise, Dylan wrote about their exploration of autism, “and realised that autism would explain a lot of my symptoms” (Dylan: lines 116-117). Using the word *symptom* makes autism resemble an illness, which conflicts with the rest of their writing describing autism as an identity. After being advised to research autism by an acquaintance who had recognised their autistic traits, Sage refrained from saying which autistic traits they recognised in themself. However, they added that they had,

> "read articles about 'female' presentation later diagnosed autistic people and after much research realised that I was autistic" (Sage: lines 150-153).

Amongst those who had researched autism before diagnosis was Peter. He wrote that the autism diagnosis explained, "so much" (Peter: line 170). Peter had waited two years for his assessment, and whilst waiting, "did considerable reading into autism and Asperger's" (Peter: line 165). Explaining his response to the assessment Peter stated,

> "I would have felt devastated if my assessment had not found that I was autistic as the condition seems to explain so much of my personal history and difficulties" (Peter: lines 167-171).

Dylan's, "symptoms" (Dylan: line 117), appear to equate to Peter's, "personal history and difficulties" (Peter: line 171). As with Galina's diagnosis, Peter's contentment with his diagnosis could be felt within his email.

Research was not only about autism, with both Avien and Sage researching different aspects of suicide. Avien mentioned that their research is associated with invalidation of gender identity, indicating, "that material is established elsewhere" (Avien: line 486). However, Avien had also spent time researching suicide methods associated with overdoses, "I spend a lot of time researching lethal doses of medications online" (Avien: lines 175-177). This comment suggests that research can possibly have negative consequences, as well as being positively influential in the lives of suicidal autistic adults. Sage demonstrated that they researched by attaching a couple of articles that they thought I ought to read, however, without the addition of further comments I could not add the content to the analysis. The articles concerned assisted suicide and Sage's comments would have been of interest.

In this super-ordinate theme it seemed that a diagnosis of autism, or Asperger's syndrome, and the participant's associated research, are important to explain some of the difficult experiences of the suicidal autistic participants. Receiving an autism diagnosis enabled some to blame their autistic traits for their suicidal behaviours.

If this cohort of suicidal autistic adults is indicative of all suicidal autistic adults, investigating autism appears to be the main subject researched. The diagnosis also provided entry into the community of autistic adults, which is discussed in the next section.

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4.5.5 Autistic community

Coco, Eliza, Galina, and Sage only mention the autistic community in relation to developing their understanding of their autistic experiences. In contrast, Avien, Dylan, and Peter seemed to engage more directly with the online, or face-to-face, autistic community.

Confirming the importance of the online autistic community, when given their autism diagnosis, Avien wrote, “I didn't really accept or believe I was autistic for sure” (Avien: lines 88-89), until they had made contact with the autism community, “to realize how much it fits” (Avien: line 92). Dylan went into detail expressing, “I've found a very helpful community of autistic people online” (Dylan: lines 127-128), as, “they had first-hand experience with many of the issues I was dealing with" (Dylan: lines 397-398). The online autistic community have helped Dylan with their issues because, "many... are also queer or otherwise marginalized" (Dylan: lines 392-394). The issues Dylan was, "dealing with" (Dylan: line 398), may have also included their suicidal thoughts, these being the basis of our email communication.

In addition to the online community, the participants also made links in face-to-face situations. Peter described making connections in the *real world* as well as online, although sometimes I found it difficult to discern about which autistic community he was writing. For example, he wrote about the time following his diagnosis, "I'm finally making community connections and meeting more people" (Peter: lines 392-393). Whist positive, these relationships did not remediate his poor mental health. He rapidly followed this particular comment with, "I still have no hope... and every moment thinking about suicide" (Peter: lines 396-397). The community may not have been providing Peter with what he needed to stop his suicidal thoughts. Nevertheless, he later wrote, "Meeting other autistic people... has helped immensely" (Peter: line 463), and explained this comment by adding,

> "I can finally understand that my problems are part of wider pattern of problems faced by a community of which I am a member" (Peter: line 464).

At the time of the interviews, Peter looked forward to, "an autistic meet-up" (Peter: line 490), which he described as a time that, "really helps" (Peter: line 490). He did not explain whether these *meet-ups* were at a regular face-to-face, or online, support groups. Nevertheless, in a later email, Peter added that he, “can make an effort to attend local autism groups, which has been a huge support emotionally” (Peter: lines 544-545). Explaining this he wrote,

> “Being able to make connections with people who have had similar journeys to me means everything and helps me conceptualize my own problems” (Peter: lines 546-547).

The autistic community has been generally beneficial to Peter.

The autistic community, whether online or in person, was of particular support to Avien, Dylan and Peter. The other participants had received some benefit from the autistic community whilst developing their understanding of their autistic experiences.

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4.5.6 The impact of gender

The sixth super-ordinate theme is included owing to its importance within the initial online survey, and that four of the participants identified as non-binary. Three of the participants aligned their gender with their sex at birth; two, Eliza and Coco, were female and one, Peter, was male.

Immediately I started the first interview Avien chose their own pseudonym (Avien: line 31), and asked me to use the non-binary pronouns of them/their (Avien: line 32). In the second email, they briefly answered the second question that related to gender, “I am trans - non-binary/neutrois” (Avien: line 64). Dylan described themself as, “agender” (Dylan: line 91), and added the explanation, “which means I don’t feel like I have a gender at all” (Dylan: line 91). They clarified that they, “simply don’t experience it” (Dylan: line 93). Neither Avien nor Dylan gave any information relating to gender at birth. Galina explained that they were assigned female at birth. At the age of 14 they started identifying as a, “demiboy” (Galina: line 61), “partially as a rebellion against gender stereotypes” (Galina: line 62). They now consider themself as, “genderqueer”[23] (Galina: line 63), although they are also now, “more comfortable with femininity” (Galina: line 64). However, Galina wrote that this description of being comfortable, “fluxes” (Galina: line 65). I assigned the term non-binary to Sage as they considered themself agender, “neither male nor female” (Sage: line 143). They later explained that they had raised a family after being in a long-term marriage, but did not elaborate further. They are now in a relationship with a, “long term partner” (Sage: line 139). Nevertheless, they informed me that when they researched autism in relation to themself they, “read articles about ‘female’ presentation” (Sage: line 150).

I placed both Avien and Dylan in the non-binary category within this research gender categories, despite Dylan’s response that they have no experience of gender. Nevertheless, both described one of the motivations for their suicidal behaviours being related to gender identity, or lack of it. Both of these participants outline the oppression and hostility that they felt. Avien wrote,

> “living in the world as a trans/queer person - similar experiences of internalized oppression, plus intense body dysphoria in and of itself can make me tempted to kill myself” (Avien: lines 233-236),

and Dylan explained,

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[23] Genderqueer - designating a person who does not subscribe to conventional gender distinctions, and identifies with neither, both, or a combination of male and female genders (OED, 2022c).

> "My chronic depression is likely the outcome of growing up in an environment that was hostile towards most parts of me" (Dylan: lines 86-88).

Dylan later described that their suicidal behaviours were the result of their chronic depression.

For some participants gender identity was a significant part of their experience relating to their suicidal ideation, planning or attempts.

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4.6 Discussion

The aim of this discussion is to explore the super-ordinate themes in relation to previous literature. I determined the super-ordinate themes whilst exploring *what is the lived experience of the suicidal autistic adult?* I discuss how the findings resonate with previous research, and how existing literature supports these findings. This study explores the lived experience of seven previously suicidal autistic adults by analysing the responses to a set of questions (Appendix J). Six super-ordinate themes emerged from the interpretative phenomenological analysis. The complex nature of the super-ordinate themes means that some of the participants' comments were explored in more than one theme. The super-ordinate themes are *autistic well-being*, *emotional and practical support*, *financial support*, *autism diagnosis*, *autistic community*, and *the impact of gender*.

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4.6.1 Autistic well-being

Within the super-ordinate theme of autistic well-being were five emergent themes: depression; anxiety; camouflaging; autistic burnout; and, the option of suicide. Depression featured quite prominently in the findings. Depression is identified as being a precursor to suicidal behaviours within both the non-autistic population (Richa *et al*., 2014) and the autistic population (Cassidy *et al*., 2014; Zahid and Upthegrove, 2017; Cassidy *et al*., 2018b). Yet, there is evidence from the results that this is not always apparent. Sage never referred to depression. Galina deduced that they were depressed as that they were prescribed antidepressant medication. This may be consistent with South, Costa and McMorris' (2021) suggestion that autistic traits can be misinterpreted as depression through diagnostic overshadowing. The results also show that there is evidence linking stress, autistic burnout, anxiety, and depression in the autistic suicidal adult. It seemed as if Coco associated depression with stress, whereas Eliza and Peter associated depression with anxiety. The NHS (2020b) link stress and anxiety in their description of PTSD, adding that flashbacks and anxiety is a consequence of a previous traumatic experience. However, of the participants in this sample, only Avien acknowledged being diagnosed with PTSD. Higgins *et al*. (2021) link stress and anxiety in the autistic adult with autistic burnout, mentioned by both Peter and Avien. Raymaker *et al*. (2020) highlight that autistic burnout may be mistaken for depression.

Whilst depression may not have been identified by all the participants, the results from this participatory group appear to disagree with Au-Yeung *et al*.'s (2019) findings, that, “depression may still be under-diagnosed” (p. 1508), in autistic adults. Six of the seven participants in this study had been diagnosed with depression. Sage was the only participant who did not mention depression. Peter described himself as having been very depressed, despite his GP's reported comments that he had no reason to be depressed. Yet, Peter also mentioned that he was always anxious, and interpreted that he may have associated his anxiety with depression. This was particularly evident when Peter wrote, “when I’m not depressed I’m often in the grip of anxiety” (Peter: line 273). In this phrase I interpret that he reacts to difficult situations by becoming anxious, from the *grip* of which he cannot escape. Depression and anxiety need to be recognised and differentiated in autistic adults. They also need identifying and differentiating in the undiagnosed autistic adults currently, “over represented in mental health services” (Hollocks *et al.,* 2019, p. 570), so that correct support can be proffered.

There is also evidence that anxiety is a trigger for suicidal planning in autistic adults. Peter described that his suicidal thoughts were reactive responses to anxiety, and Galina attributed their anxiety as contributing to their suicidal thoughts. Anxiety in autistic adults may not be recognised by mental health professionals, as the tools used for non-autistic adults may not identify anxiety as experienced in autistic adults (Rodgers *et al*., 2020). As a response, the Anxiety Scale for Autism - Adults (ASA-A) (Rodgers *et al*., 2020) has been developed to assess anxiety within autistic adults. This is significant as autistic adults are considerably more likely to experience anxiety (42%), compared with the general population (16.6%) (Rodgers *et al*., 2020). However, the Hospital Anxiety and Depression Scale (HADS) (Snaith and Zigmond, 1994), although designed for a non-autistic population, may also be a useful tool. It uses two sub-scales to differentiate depression from anxiety (Snaith and Zigmond, 1994). Although the HADS has been used in research related to autistic adolescents and young adults (Uljarević *et al*., 2018), it fails to assess the entire spectrum of anxiety witnessed within the autistic population (Rodgers *et al*., 2020).

The number of participants affected by anxiety may have been greater than expected in this part of the study. Maisel *et al*. (2016) suggest that due to alexithymia autistic adults may have higher levels of anxiety as a negative reaction to an emotional experience. In the non-autistic population anxiety subtypes may overshadow OCD (NHS, 2021b), and some of the, “symptoms of OCD” (Hollocks *et al*., 2019, p. 569), overlap with autistic traits (Buck *et al*., 2014). In this study none of the participants referred to OCD during the interviews.

In one email Galina wrote about their anxiety, describing it as, “fight or flight” (Galina: line 388). This effect increases the amount of adrenaline produced by the body to assist with either fighting or fleeing (OED, 2021). The heart rate and blood pressure increase, and the already alert autistic senses become hyper-alert (Bracha, 2004). Coco’s tiredness could also have been attributed to the effect of adrenaline wearing off, after the hyper-vigilant effect of her anxiety which led to her emotional outbursts, or autistic meltdowns. Although only Galina mentioned, “fight or flight” (Galina: line 388), most of the participants’ statements about anxiety evoked these thoughts as emergent themes. However, there was evidence that, instead of fleeing or staying to fight, the autistic person may respond by having suicidal thoughts and behaviours.

The participants provided evidence that being autistic in a non-autistic world was stressful and anxiety laden. Autistic people may camouflage their internal autistic features, to cope with living as a minority within a non-autistic environment (Lai *et al*., 2017; McQuaid, Lee and Wallace, 2022). The result of living in a hostile environment meant that the participants had to sometimes mask, or camouflage, their autistic traits. For Dylan, this was in their evangelical Christian home, for Peter this was in his previous employment; and for Avien this was in hospital settings. Camouflaging may have added to their suicidal thoughts and behaviours, as they attempted to escape the oppressing environment.

Bedrossian (2015) explains that autistic people may have emotional meltdowns, as a means of escaping stressful situations. Storch *et al*. (2013) also suggest, that due to a lack of coping strategies, the means of escape may result in suicidal thoughts or behaviours. Camouflaging was a common coping mechanism for several of the participants in this study. This was particularly evident for Peter, Dylan, and Avien. Peter had learnt to camouflage at a young age to fit in and described himself as highly proficient in this skill. Peter’s camouflaging may have been too proficient, as when referring to working with the psychiatrist he explained that he did not sufficiently perform his distress. Similarly, Dylan explained that they had to perform the role of not being agender or autistic whilst living with their family. Avien also had to perform by camouflaging to maintain a position in their previous employment. Galina described going out with their friends where it appears that they initially camouflaged. However, this strategy was not successful as Galina explained that their friends would notice a mistake they had made leaving them with negative feelings.

In autistic adults, camouflaging is linked with generalised anxiety, social anxiety, and depression, in addition to autistic burnout that can eventually lead to suicidal behaviours (Hull *et al*., 2021). The findings of Hull *et al*. (2020) consistently found, in their study on camouflaging, that, “autistic females had higher camouflaging scores than autistic males" (p. 360). This contrasts with my findings. There were no comments regarding camouflaging from either of the two female participants, Coco and Eliza, whereas, the male participant, Peter, camouflaged his autistic traits. Bargiela, Steward and Mandy (2016) explain that males frequently camouflage due to the social expectations upon them. The effect of camouflaging for males may result in having a, "greater impact on [their] mental health" (Hull *et al*., 2020, p. 361). The effect of camouflaging on Peter was damaging to his mental health. The non-binary autistic participants in the Hull *et al*. (2020) study were also at, "risk of the negative outcomes associated with camouflaging" (p. 360). They describe these risks as anxiety, exhaustion, and suicidal thoughts (Hull *et al*., 2020). Avien's and Dylan's accounts both attest to this assertion. Non-binary autistic adults demonstrate more compensatory elements of camouflaging, which include using skills learned from the media, when interacting with people (Hull *et al*., 2020). Owing to the method of data collection, I gathered no data relating to the participants' interactions with other people, other than those they described within their text.

Literature confirms that camouflaging is witnessed more in adult-diagnosed autistic adults than in autistic adults diagnosed in childhood, or in their early teenage years (McQuaid, Lee and Wallace, 2022). This is pertinent particularly for Sage and Peter, being older when they recognised that they were autistic. Although Peter mentions the disadvantages of camouflaging, Sage mentions neither camouflaging nor masking within their text, nor did they elicit either behaviour as an emergent theme.

When autistic adults do not camouflage, and openly disclose their autism, they may also become the focus of discrimination (Botha and Frost, 2020), which if in the workplace may result in bullying and unfair dismissal (Baldwin, Costley and Warren, 2014). Autistic adults can therefore experience minority stress, whether camouflaging or not, having a negative impact on their mental health, and leading to suicidal thoughts and behaviours (Botha and Frost, 2020).

There may be additional complications associated with camouflaging. Cassidy *et al.* (2020b) suggest that, “camouflaging one’s autistic traits” (p. 3644), led to a negative feeling, “of thwarted belonging” (p. 3644). Likewise, Raymaker *et al.* (2020) suggest that masking is, “the most prominent life stressor” (p. 137), that contributes to the negative outcome of autistic burnout. Whilst not mentioning camouflaging, Eliza recognised that she did not fit into the non-autistic world, so much so that she had suicidal thoughts. Although she appeared to experience thwarted belonging, which is redolent of IPTS suicidal model (Van Orden *et al*., 2010), her resultant suicidal thoughts evoked emergent themes suggestive of autistic burnout.

Three of the diagnostic features of burnout, in the non-autistic population, are the feelings of exhaustion, detachment, and a sense of ineffectiveness (Maslach and Leiter, 2016, p. 103), that resemble some of the diagnostic descriptors of depression. Burnout in autistic people may have different antecedents and can result in having suicidal thoughts and behaviours (Raymaker *et al*., 2020).

Discussing autistic burnout is necessary as it played a part in the lives of at least three of the suicidal autistic adults in this study, Avien, Dylan and Peter. Avien allied their autistic burnout with depression, whereas Peter wrote about his burnout being a mental breakdown. In addition, Dylan recognised two stressful times in their life when they experienced burnout. Therefore, only diagnosing and treating depression may not effectively address an autistic person's suicidal thoughts and behaviours (Raymaker *et al*., 2020). Raymaker (2019) gives examples of specific times when autistic burnout can occur. These are mainly during periods of life transitions, when autistic people, "felt incapable of taking action on their feelings" (Raymaker, 2019, p. 28). These may be the times when autistic people experience the, "mismatch of expectations and abilities without adequate supports" (Raymaker *et al*., 2020, p. 140), resulting in the, "pervasive, long term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus" (p. 140). Suicidal responses by an autistic adult may be, therefore, as a result of autistic burnout and being overwhelmed by a hostile environment. This is supported by the evidence of Dylan, who wrote about living in such a hostile environment. They expressed that their desire was to escape the situation, they did not specifically seek to end their life, but needed the life they were experiencing to stop. This is not to deny that some of the participants had depression. However, many of the emergent themes were more consistent with autistic burnout, as described by Raymaker *et al*. (2020), than with those of depression, as outlined by the NHS (2021a).

Although *suicide* was mentioned by every participant, the theme could not be used as a super-ordinate theme as the entire study is about suicidal thoughts and behaviours in the autistic adult. Nevertheless, the thought of suicide always being in some of the participants' daily lives was seen as aligning with the autistic trait of perseverative thinking (Lai, Rhee and Nicholas, 2017). In addition to Dylan, the theme of escape was also mentioned by Peter. Baechler (1979) attributed his suicide model to feelings of sadness, anxiety, or guilt. As neither sadness nor guilt were focused upon by any participant, I attributed the feeling of anxiety as a precursor to their suicidal thinking. Sage, Peter, and Dylan wrote about the persistence of their suicidal thoughts. In his writing Peter claimed suicide was a contingency plan as it was in his, “back-pocket” (Peter: line 239). Similarly, Dylan described the reflex of suicidal ideation, and that they had wanted, “to escape and sleep forever” (Dylan: line 217). Likewise, Sage described suicide as a, “safety net” (Sage: line 168). These phrases could all be interpreted as keeping suicide as an option for future use.

Analysing the use of language I particularly noticed some of the comments by Dylan, Eliza and Peter. Dylan used both identity-first language, preferred by the autistic community (Kenny *et al*., 2016), and person-first language, frequently used within research to maintain scientific rigour and reduce bias (Dunn and Andrews, 2015). They introduced themself as an, “autistic person with chronic depression” (Dylan: lines 74-75). Eliza and Peter used the term *suffering*. In many people’s vocabulary the term *suffer* goes before the term *depression*. In 1961, Beck analysed these phenomena whilst examining the hypothesis, “there is a significant association between manifestations of the need to inflict suffering on the self and the clinical state of depression” (Beck, 1961, p. 164-165). However, his conclusion demonstrates that, “the unpleasant subjective state of the depressed person” (Beck, 1961, p. 169), does, “not necessarily imply that there is a motivation to suffer” (p. 169). Similarly in this study, it appears that Peter who claimed to have *suffered* from depression, was only suggesting that he had depression, and was not necessarily inflicting suffering on himself.

Contrastingly, Eliza explained that she suffered with depression, and needed an exit strategy from the suffering. In her case this was through thoughts of suicide.

The environment also had a negative effect on the participants. Dylan explained that the evangelical Christian home in which they grew up was hostile towards their identity. Peter wrote about the negative environment in which he had worked. Avien also described their prior work environment as stressful. Eliza also described one environment as being overstimulating. These diverse negative environments all resulted in suicidal thoughts and behaviours.

Although there is literature to support most of the emergent themes that arose through this super-ordinate theme of autistic well-being, there was no literature that supported the finding that autistic adults have the option of suicide, such as that experienced by Peter, Sage, and Dylan. This is an important finding of this second stage of this study.

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4.6.2 Emotional and practical support

Social support for autistic adults should address, "what each individual would appreciate as a support" (Ee *et al.*, 2019, p. 191). Nevertheless, despite the Autism Act (2009) celebrating its 10th anniversary in 2019, 71% of autistic people who were questioned about its effect, declared that they did not have sufficient support (NAS, 2020). In addition, the Care Act (2014), also relevant to autistic adults, delineates the local authorities' duties in relation to assessing people's needs, and their eligibility for publicly funded care and support. Local authorities are particularly attempting to put support into situations where autistic people are at risk of being hospitalised (DH, 2015b). Yet, it is reported that autistic adults do not receive the correct support, and do not know where to go to seek the relevant support (Camm-Crosbie *et al*., 2019). This is confirmed by the findings of the All Party Parliamentary Group on Autism (2019) who suggest that autistic children, students, and employees, in addition to those who stay at home, lack support. These findings are further supported by many of the comments made by the seven participants in this study. Coco found her family was supportive. However, she indicated that she particularly found it difficult to ask for support and, when she did receive emotional and practical support, also found it difficult to be supported. Raymaker *et al*. (2020) acknowledges this initial difficulty in asking for support as an additional barrier to receiving the relevant support.

Support by family and friends, which may be emotional and practical in nature, is described as a protective factor against suicidal thoughts and behaviours (Segers and Rawana, 2014; Hedley *et al*., 2017). The experience of the suicidal autistic adults, in this study, was that they received practical support from many people. Though many of the participants received support from their family, where the participants were estranged from family, friends became the major support. Only Peter and Eliza seemed to mention emotional support, which in both cases was through close family members. There is evidence that support by family and friends also had social and emotional costs. Peter described the stressed relationships with his sibling. Galina described the difficult ending of a relationship they had with one particular friend. These relationships may have been negatively influenced by difficulties in communication between autistic and non-autistic individuals (Cummins, Pellicano and Crane, 2020).

The Autism Act (2009) and the Care Act (2014) have placed more emphasis on local authorities to support autistic people within their own community. Avien, Dylan, and Peter received some practical support, and possibly emotional support, from paid support workers and therapists.

Therapy was the turning point for Avien, Coco and Dylan, as all three participants received their autism diagnosis following comments made by their therapists. Therapy sessions were organised for Dylan as they were chronically depressed. Their therapist identified their autistic traits and suggested that they have a diagnostic assessment. Knowing that they are autistic may result in Dylan having a better quality of life. However, both Avien and Dylan described the difficulties of working with therapists, as they had both been looking for those who had experience of working with minority gendered people. Dylan specifically sought, without success, a therapist from a marginalised group, which would have given them confidence in potentially not experiencing, “ableism and discrimination” (Chapman, 2021, para. 12).

Given that a few of the participants had started therapy before their autism diagnosis, it is possible to highlight the vulnerability of as yet undiagnosed autistic individuals undertaking therapy for a misdiagnosed mental health condition. CBT may be one such therapy. For the non-autistic population, the talking therapy of CBT may be routinely used to treat a, “wide range of mental health disorders” (Spain *et al*., 2015, p. 153). CBT originally focused on helping depressed adults with their spontaneous negative thoughts (Capp, 2021), and integrates the,

> “cognitive and behavioral approaches for making specific targeted changes in thoughts, feelings or behaviors” (Attwood and Scarpa, 2013, p. 27).

An autistic person may find the reliance upon self-reflection required in CBT problematic (Frith and Happé, 1999). Coco provided evidence of this difficulty, as she claimed she thinks too much. However, her excessive thinking suggested an emergent theme of the autistic trait of perseverative thinking, rather than self-reflection. As suggested by the National Institute for Health and Care Excellence (NICE) (2012), CBT has limited use for autistic adults, and may be potentially harmful, as was found by Peter. Nevertheless, there is some evidence of its effectiveness in aiding anxious autistic children and adolescents (Foley and Trollor, 2015). However, if CBT is used with autistic people owing to the differences in, “socio-communication” (Spain *et al.*, 2015, p. 154), tolerating changes, and alexithymia, the approach requires altering (Spain *et al.*, 2015). A modified CBT, with the provision of more sessions, may enable autistic people to take part in therapy (Attwood and Scarpa, 2013; Spain *et al.*, 2015). An autistic friendly CBT method may also reduce the percentage of autistic people using psychotropic drugs (Murray *et al.*, 2014). However, the evidence from Peter’s and Galina’s experiences of CBT demonstrates that this therapy method creates further distress which corresponds with the NICE (2012) advice.

Further support mechanisms were mentioned by Dylan, Avien, and Peter. Dylan found support regarding identifying as agender via an internet social networking service. They particularly found the autistic community was knowledgeable about this specific issue. Avien introduced the idea of having peer support workers, where support could be given by autistic people who are aware of the needs of other autistic people. Avien appreciated support with communication in medical appointments. Avien also supported others who were exploring gender issues. Peter supported his mother helping her with practical needs.

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4.6.3 Financial support

The participants received financial support through benefits, and through full-time or part-time employment. Those who were in full-time education did not refer to their financial circumstances other than mentioning part-time jobs. In the UK, the Equality and Human Rights Commission (2010) requires employers to, “provide tailored workplace adjustments” (Petty *et al*., 2022, p. 1), for autistic people. Peter explained that his employment had led to his autistic burnout. This may have been due to some of the barriers encountered by autistic employees including those that Petty *et al*. (2022) identify, such as, “busy and distracting environments” (p. 2), with, “unwritten rules” (p. 2), and, “unpredictable demands” (p. 2), that result in, “bullying or harassment” (p. 2).

Since January 2020, the Office for National Statistics (ONS) have sought details concerning the number of autistic people in employment (ONS, 2021). The ONS (2021) data show that 25.4% of autistic people are economically active. Of the economically active, approximately half (52.1%) were in full-time employment (ONS, 2021). Both economically active and inactive autistic adults may apply for financial assistance through different benefits schemes in the UK (NAS, 2021b). Although it is recognised that poverty may be an issue for older aged autistic adults (Michael, 2016), there is a dearth of research regarding the role of poverty and debt for working age autistic adults, especially in relation to suicidal behaviours. Only a few studies have highlighted that autistic individuals frequently have difficulties applying for disability benefits owing to their sensory issues, camouflaging behaviours, or difficulties with mental health, being hidden from the medically trained assessor (Autistica, 2019). After explaining the negative effect employment had on him Peter also explained that he was in receipt of benefits but hoped to support himself financially in the future. Peter clarified the devastating effect of having his benefits being rescinded at one point, however following an appeal, they had been reinstated. Eliza was self-employed and could fit her schedule around herself, working when she was able and doing less when necessary. Whether working as an employee or being self-employed, autistic people need to be aware that the stressors of employment can precipitate a mental health crisis (Stephan, Li and Qu, 2020), leading to suicidal thoughts and behaviours (Toivanen *et al*., 2016). In contrast, European studies with non-autistic people demonstrate that it is usually unemployment that causes the stress and anxiety that lead to potential suicide (Yur'yev *et al*., 2012). The social expectation of being employed may add to the life stressors and cumulative load of an autistic adult (Raymaker *et al*., 2020). This expectation has been found to lead to autistic burnout, which in turn can be responsible for suicidal feelings (Raymaker *et al*., 2020).

Also eliciting emergent themes relating to financial support were the terms *burden* and *worthless*. Avien's idea of being, "a burden" (Avien: line 221), is redolent of the suicide models where the perception of being a burden is one aspect that leads to peoples' suicide (Joiner, 2005). However, to Avien being a burden was real and not perceived. To clarify this idea Avien wrote about consuming resources and burdening society, which resulted in them feeling a, "failure" (Avien: line 217), and, "worthless" (Avien: line 219). I similarly interpreted that Peter felt a burden to society when he considered *fixing* himself to become, “an economically productive member of society” (Peter: line 566). Feeling a failure appears to come from the autistic person judging and comparing themself with a mainly non-autistic community.

This super-ordinate theme relating to financial support is important for all autistic adults, whether diagnosed or not. The evidence of the participants wanting to be financially independent demonstrates the importance of employment with suitable support and adjustments. Making adjustments for autistic adults in the workplace, and providing sufficient financial support, may lower the suicide risk in autistic adults.

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4.6.4 Autism diagnosis

Researching autism was an important and useful activity for several of the participants, whether this was before or following their autism diagnosis. Many descriptions of autistic people focus upon special interests (Klin *et al*., 2007) and for many autistic people research is this focused interest (Nowell *et al*., 2021). In the cases of Avien, Coco and Dylan, therapists had suggested that the participants were autistic, which led them to research. Contrastingly, other participants, Galina, Peter, and Sage, had researched autism and had identified themselves as autistic. Dylan explained that they wanted health care providers to use the knowledge that the autistic adult had acquired, especially regarding aspects that were rarely studied. Research also linked with using the internet and being online with the autistic community. This use of the internet meant that some of the participants, especially Avien and Peter, were aware of the theory surrounding autistic burnout, despite it not having a wide acknowledgment in literature at the time of the interviews.

Having an autism diagnosis was helpful for the six participants who had such a diagnosis. Sage was looking forward to receiving a diagnosis in the future. To reduce the potential of autistic burnout, it may be beneficial to get an autism diagnosis earlier in life (Raymaker *et al*., 2020). However, there was evidence from the participants that diagnoses could follow years of delay for an assessment.

Having an autism diagnosis opened the possibility of support from the autistic community, whether this is online or in person. Additionally, as Peter acknowledged, and Stagg and Belcher (2019) claim, “receiving a diagnosis later in life can be a positive and beneficial experience” (p. 358). Nevertheless, there is also a claim that being a part of a minority grouping may be disadvantageous as difficult social situations may cause stress for minority individuals, which over time may result in long-term mental health deficits (Meyer, 2003). There is therefore a sense of tension for the autistic adult. Being openly autistic may in one situation be therapeutic, but in another context may be considered a risk (Botha and Frost, 2020). This dichotomy may lead to more mental distress for the autistic adult, which itself may lead onto suicidal behaviours.

Within this super-ordinate theme, the importance of the autism diagnosis is recognised. There is evidence that research using the internet may be a focused interest, and that it provides access to a potentially supportive autistic community.

4.6.5 Autistic community

Communities have a role to play in keeping a person from feeling isolated (Trout, 1980). Galina reported that their suicidal thoughts and behaviours were rooted in being isolated. Coco also wrote about experiencing isolation, and how difficulties with social relationships contributed to her suicidal thoughts and behaviours. Subsequently, Coco admitted that she did not always realise how many people cared about her. These relationship difficulties may be defined as *loneliness* when there is, “a discrepancy... between one’s desired and perceived actual relationship” (Ee *et al*., 2019, p. 183). Loneliness may increase an autistic person’s vulnerability to depression and anxiety (Quadt *et al*., 2021). However, Galina made contradicting comments relating to the cause of their suicidal thoughts and behaviours. They explained that it was isolation that led to such behaviours, whilst also maintaining that social situations led to their suicidal ideation. Nevertheless, they described their socialising as sometimes being traumatic, which may have added to their isolation. Literature supports this experience. Hedley *et al*.’s (2018) research supports the suggestion that autistic characteristics lead to social isolation, and possibly suicidal behaviours. The research by Ee *et al*. (2019) suggests that socialising with non-autistic adults can be, “exhausting, challenging or anxiety provoking” (p. 183), which Quadt *et al*. (2021) explain can possibly be due to the associated overwhelming environment.

Rather than writing about relationships with the non-autistic community, some of the participants wrote emails reflecting on the role of the autistic community. All seven participants had some connection with the online autistic community. They had found, and responded to, the original request for autistic adults for the online survey through an internet social networking site. There is evidence that Avien found the autistic community helpful, when given their autism diagnosis, to identify elements of their traits that were autistic. Similarly, Peter made connections with other autistic people who had similar experiences to him which helped him put his own difficulties into context. The positive experiences of being in a community, whether online or in person, included being shown acceptance and being connected to others, alongside the characteristics of independence, autonomy, and self-understanding (Camm-Crosbie *et al*., 2019).

This sample of autistic adults wrote more about community than about loneliness, although I had not asked specific questions relating to either. The autistic community was mainly mentioned in responses relating to who provided support.

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4.6.6 The impact of gender

The theme of gender has been significant in autism studies for many years. The publication of *The extreme male brain theory of autism* by Baron-Cohen (2002) reinforced, “cultural stereotypes of gender” (Bumiller, 2008, p. 973). However, from an autistic perspective gender may be very different or may be, “barely present at all” (Davidson and Tamas, 2016, p. 61). For autistic people gender is a, “ghost” (Davidson and Tamas, 2016, p. 61), that neither settles nor shapes interactions in the way that it may do in non-autistic people. This was evidenced in this study as neither Dylan nor Sage experienced gender. Sage described themself as, “neither male nor female” (Sage: line 143), and Dylan described themself as, “agender” (Dylan: line 91). Dylan clarified that they “don’t feel like I have a gender at all” (Dylan: line 93), reflecting the research by Kourti and

MacLeod (2019) that considered, “the perceptions of gender within autistic adults raised as girls” (p 52).

There may be implications for clinical practice as autistic people questioning their gender may need advice and support from specialised gender teams (Walsh *et al*., 2018). A study on gender in those assigned female at birth (AFAB) suggests that autistic AFAB adults had to camouflage their autism, as they conformed to neither the non-autistic representation of being female, nor to the male-orientated vision of being autistic (Kourti and MacLeod, 2019).

From the evidence of these seven participants, I suggest that autistic people who are minority gendered, being non-binary, may be more at risk of suicidal thoughts and behaviours. Within this small sample four described themselves as non-binary, Avien, Dylan, Galina, and Sage. In particular, Avien and Dylan were quite explicit that others’ responses to their gender was one of the motives for their suicidal thoughts. Avien highlighted this whilst explaining the external oppression they experience being a, “trans/queer person” (Avien: line 233), and the possibly unconscious internal oppression of their body dysphoria. This is supported by Tan *et al*. (2020), who explain that minority gendered adults report a higher rate of suicide attempt. In response to the question, seeking information concerning triggering elements for suicide, Dylan described the experience of growing up in a family that opposes any form of gender deviation, and explained that suicidal thoughts provided them with the opportunity to gain some self-control.

Avien identified PTSD as being a trigger for their suicidal behaviours. During the analysis, I interpreted that their PTSD may have resulted from the lack of acceptance by other people to their gender identity, in addition to their own feeling of gender dysphoria. Dell'Osso, Gesi and Carmassi (2016), despite confirming the role of PTSD in non-autistic suicidal behaviours, identify difficulties with understanding how trauma is manifested in autistic adults. They further suggest that there is a low incidence of PTSD within the autistic population (Dell'Osso, Gesi and Carmassi, 2016). This suggestion contrasts with Rumball's (2019) report of PTSD in an autistic group of individuals, where PTSD co-occurs, "at a similar or greater rate" (p. 294), compared to that found in the non-autistic population.

Suicidal behaviours have been seen to be manipulative, or socially controlling (Williams, 1997), a form of regulating the responses of other people in the suicidal person's life (Manning, 2012). The evidence of Dylan suggests that they did not seek to manipulate or gain control over their family, it rather suggests the reverse. Dylan's family exerted pressure or control on them, resulting in Dylan experiencing suicidal thoughts and behaviours. Similarly, Sage seemed to want to gain control over their own life, and not endure negative experiences inflicted by others. They suggested that their suicidal thoughts were there for the correct time, and added that suicide is their, "safety net" (Sage: line 168). Sage did not explain what it was they were having to *endure*, whether this was a response to their autistic traits, to their gender, or to something that had not previously entered the discussion.

Galina responded to the question regarding the triggers of their suicidal thoughts and behaviours with phrases relating to isolation and the feeling of absolute despair. Although these statements may have arisen due to loneliness, I interpreted that they could also have arisen from their gender. I made this interpretation, as in an earlier response Galina described their suicidal planning had been caused by, "being abandoned by the one person who I thought understood me" (Galina: lines 169-171). It has been recorded that, "the typical conflict that produces suicide is a conflict between spouses" (Manning, 2012, p. 214). Manning (2012) further describes a potential suicide as, "moralistic" (p. 214), if the suicidal person is in conflict with someone who is socially close, and they have an interdependency with each other. Galina may, or may not, have been in a very close relationship, however, I interpreted their feeling of abandonment being similar to that found in an unsuccessful spousal relationship.

The gender of the participants was an important element of the responses of Avien, Dylan, Galina, and Sage, although this was not always mentioned as a direct reason for their suicidal behaviours. It is acknowledged that non-binary adults demonstrate a higher rate of mental health issues compared to cisgendered adults, with anxiety being found in 68% of the non-binary population compared to 18% within the binary population (Tan *et al.*, 2020). All people, both autistic and non-autistic, may experience discomfort or distress when their assigned gender is different from the gender with which they identify (Jacobs *et al.*, 2014). This discomfort, or distress, is known as gender dysphoria (Jacobs *et al.*, 2014). There is evidence that Dylan went through a period of distress in their teenage years, whilst living with their parents. Their distress appears to be associated with gender dysphoria, or being minority gendered.

Although the minority stress model suggests that autistic adults are at greater risk of suicidal behaviours (Botha and Frost, 2020), the initial focus of the model demonstrates that those who are non-heterosexual are more at risk of mental health problems (Meyer, 2003). Therefore, people who describe their gender as *non-binary* may have similar issues with society and may be similarly at risk of mental health problems. Being autistic, the non-binary participants, Avien, Dylan, Galina, and Sage, belong to two minority groups, and as such may be doubly at risk of suicidal behaviours.

The role of gender may also impact binary gendered autistic adults. Lai and Szatmari (2019) suggest that cisgendered females camouflage their autism, resulting in later autism diagnoses, that affect their mental health, and lead to, "exhaustion, strain, anxiety, depression and suicidal risk, and even loss of identity" (p. 120). Segers and Rawana (2014) identify that being male can also be one of the risk factors for suicidal behaviours. However, in this autistic sample it appears that whilst all autistic people are at risk of suicidal behaviours, this risk may increase for those who are non-binary.

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4.7 Conclusion

The contributors to this part of the study, *what is the lived experience of the suicidal autistic adult?* were two females, one male and four non-binary participants. Six of the participants were already diagnosed as autistic, with either autism or Asperger's syndrome, the seventh participant was progressing towards a diagnosis. All the participants had experienced suicidal thoughts, although it was not clear whether they had all experienced suicidal plans or attempts. Peter and Avien gave very in-depth replies, whilst Sage’s replies were much shorter owing to limitations with their technology.

Although the study required a stable mental health, demonstrated by not having planned or attempted suicide within the last two years, this was only assessed through self-confirmation, whilst signing the consent form. Having studied all the participants’ responses, it is unclear whether all the participants had been free of suicidal plans and attempts for the previous two years. Nevertheless, during the interviews all the participants demonstrated having a stable mental health, as none of them expressed being suicidal during the email interviews.

This was a small qualitative study gathering experiential data from a purposive sample. Although it may not represent the full diversity of the suicidal autistic adult population, it enables the autistic voice to be heard. The participants were self-selecting, and as such, may have been more engaged and motivated to give time and thought over their responses. The method of sampling used is appropriate for use in IPA studies, as it ensures that the experiences investigated are of significance to the participants (Smith, Flowers and Larkin, 2009).

The main findings for these participants are: that a lack in autistic well-being, including the detrimental effect of camouflaging, may lead to suicidal thoughts and behaviours; that financial support is necessary, but employment may lead to stress and suicidal thoughts and behaviours; that an autism, or Asperger’s syndrome, diagnosis is important to explain some of the participant’s traits and characteristics; that despite CBT not being useful, therapy may be beneficial to highlight the possibility of an autistic diagnosis for those as yet undiagnosed;

that the role of community is significant, whether as the autistic community, or a supportive non-autistic community, although both could exist together; and, that many autistic adults describe themself as non-binary. Importantly, there is the finding that suicide is always an option, either being a *safety net, being kept in the back-pocket,* or as a means of *escape*.

The answer to the research question, what is the lived experience of the suicidal autistic adult? includes both beneficial and detrimental experiences. An autism diagnosis, including self-identifying, was fundamental to seeking a positive outcome, although part of the experience included keeping suicide as an option. The experience also included elements of autistic well-being, such as being depressed and anxious, in addition to the experiences of camouflaging and autistic burnout. In this sample, all the participants were autistic, and therefore a minority grouping. The majority of the participants were also from a minority gender group, being non-binary. There was evidence of all participants experiencing stress, as predicted by Botha and Frost’s (2020) minority stress model. All participants experienced support, whether practical, financial, or emotional, which for some was beneficial. For some participants the experience of support was positive, as it provided financially for them, and led them towards their autism assessment. However, the experience of support sometimes led to negative consequences for their mental health, whether by receiving inappropriate therapy, or when benefits were rescinded.

One limitation I encountered was giving each participant three weeks to answer all the questions. This time started when I sent their first email, after receiving and returning their consent form. Rigorously keeping to this three-week schedule resulted in two of the participants feeling rushed. One participant was initially recovering from influenza, and although they provided detailed emails, they occasionally mentioned their tiredness. Another participant did not own a computer, and wrote their responses, photographed them, then sent them to me as email attachments. These processes were time consuming. If this work was to be repeated, I would seek more time from the ethics panel, to enable the completion of longer interviews.

The next chapter continues with a qualitative study, using an autoethnographic method. I continue to explore the experiences of being a suicidal autistic adult, and include resonances from literature and from the interviews of the seven participants.

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Chapter 5. An autoethnographic study

In this chapter I examine my own lived experience of being a suicidal autistic adult, and therefore continue to address the understanding of, "the experience of suicidality in autistic people" (Cassidy *et al*., 2021c, p. 3). Examining my own experience maintains the element of only using the experiences of autistic adults. By using an autoethnographic approach I undertake an analysis of my own narrative, and my responses to the questions I had asked the previously suicidal autistic adult participants of the IPA study. Autoethnography enables me to engage with the first of the ten priorities, that includes the identification of, "barriers that autistic people encounter when seeking help, which may increase their risk of suicide" (Cassidy *et al*., 2021c, p. 3). Reflecting upon my own experience of being a suicidal autistic adult, I analyse this experience alongside reference to various literature and the accounts of the participants in the second phase of the research. I also reflect upon being an *insider researcher*, and how my positionality and approach to autism and suicide may have influenced different aspects of the study, from the recruitment and data collection to the analysis, whilst including the strengths and limitations of such an approach.

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5.1 Research question

The question for this phase of the research is *what is my lived experience of being a suicidal autistic adult*? I, therefore, use an autoethnographic method to examine and analyse my own experience, and how it resonates with literature and the interview responses of the seven participants in the IPA study.

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5.2 Method of data collection

As a source of data autoethnographic study researchers can either use self-introspection, observing their own thoughts and feelings, or self-examination, assessing their own behaviours and motives (Ellis, 1991). I, therefore, systematically reflect upon my personal behaviours to understand some of the experience of being a suicidal autistic adult. Most autoethnographic studies concerning suicide to date have been in relation to the surviving parent (Matthews, 2019), or surviving partner (Wheeler, 2016). This autoethnographic study adds an extra dimension, as I write as the surviving subject of the suicidal thoughts, plans, and attempts.

The aim of the autoethnographic researcher is, “to describe cultural experience” (Holman Jones, Adams and Ellis, 2013, p. 23). Through offering personal insight of a researcher’s experience, the autoethnographic approach is, “a courageous moral act... [to] bear witness” (Lapadat, 2017, p. 591), and help others with, “their struggles” (Bochner and Ellis, 2006, p. 111). Having been a suicidal autistic adult, I address the three aims of *describing the cultural experience*, *offering insight*, and *bearing witness* to the *struggles* of this minority group of adults.

There are several approaches to writing an autoethnographic study. Chang (2013) categorizes autoethnographic studies into three forms, those that are: descriptive and self-affirmative; analytical and interpretive; or, confessional and self-critical. All categories of autoethnography encompass, “personal narrative and lived experience” (Holman Jones, Adams and Ellis, 2013, p. 20), and as such will, “present an intentionally vulnerable subject” (Holman Jones, Adams and

Ellis, 2013, p. 24). The autoethnographic approach broadly follows the analytical and interpretative form. Autoethnographic studies flourish in such areas of study as education and health studies (Holman Jones, Adams and Ellis, 2013). As a former teacher, with a history of research in education, and as a student within a broad health faculty, the method sits within my fields of research.

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5.2.1 Autoethnography - background

Autoethnography originated in 1979, and was first used by David Hayano (Wall, 2006). Similar to IPA, autoethnography is interpretative (Doloriert and Sambrook, 2011). The autoethnographical method describes a personal experience whilst also analysing that same experience (Ellis, Adams and Bochner, 2011). As this thesis was undertaken due to personal experiences of suicidal behaviour as an autistic adult, an autoethnographic study acknowledges and accommodates my own influence on the research (Ellis, Adams and Bochner, 2011, p. 274). Ellis and Bochner (2000) refer to the autoethnographic method as, “action research for the individual” (p. 754), and Wall (2008) suggests that autoethnographic studies link, “literature to the narrated personal experience” (p. 39). Therefore, it is possible to research the, “role of self” (Doloriert and Sambrook, 2011, p. 586), within the context of the research study.

Autoethnographic studies concentrate on, “producing meaningful, accessible, and evocative research grounded in personal experience” (Ellis, Adams and Bochner, 2011, p. 274). Ellis, Adams and Bochner (2011) suggest that the process of sharing personal experiences helps the, “cultural members” (p. 275), and also helps the understanding of the cultural experience by the, “cultural strangers” (p. 275). The autoethnographical nature of the text produces accessible text that, “may be able to reach” (Ellis, Adams and Bochner, 2011, p. 277), a wider audience than, “traditional research” (p. 277).

The autoethnographic study, “must be accompanied by a critical reflection” (Pitard, 2019, p. 1829). I critically analyse and reflect upon my own resonances, although for ethical reasons, I do not include the detailed narrative upon which the reflection and analysis is based. Autoethnographic studies are criticised as not being sufficiently rigorous or analytical and sometimes too emotional and therapeutic, and encompassing subjectivity (Ellis, Adams and Bochner, 2011; Campbell, 2016). In comparison, Wall (2006) suggests that an autoethnographic study gives the researcher, “freedom... to speak as a player in a research project” (p. 148), and that the researcher’s own experience, blended with that of others, “is precisely what is needed to move inquiry and knowledge further along” (p. 148). This *freedom to speak* is important for me as an insider researcher, so that I can recount my own experience, and how it resonates with those of the participants, and with literature. Similar to Richards (2015), I realise that as participants have expressed their feelings during this research, I have an opportunity to express myself. I am able to explore the *epiphany* of my own suicidal experiences that resonate with those of the participants. As Denzin (2014) suggests, “epiphanies... are interactional moments and experiences which leave marks on people’s lives” (p. 52).

Chang (2008) suggests that, in autoethnographic studies, the cultural interpretation could be forgotten with the emphasis being on the researcher. However, I advocate that the emphasis in this study is dispersed over the three distinct phases of data collection. The narrative, and its analysis, seek to achieve cultural interpretation through reflection and acknowledging the echoes and resonances with the participants' experiences and with literature.

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5.2.2 Autoethnography - ethics

As an autoethnographic study is a qualitative inquiry, where the researcher recounts their own narrative and is both subject and researcher (Lapadat, 2017), the ethics of autoethnographic studies are complex and challenging (Sikes, 2015). Autoethnographic studies frequently concern difficult life events which are normally kept private (Lapadat, 2017). Nevertheless, a successful autoethnographic study reveals the vulnerability of the researcher whilst exposing their personal experience (Doloriert and Sambrook, 2009). Doloriert and Sambrook (2009) explain the importance of an autoethnographic study used in a PhD thesis as a response to triggering life events.

Some autoethnographers are criticised for their lack of following ethical guidance (Tolich, 2010). An autoethnographic study can be either evocative, analytic, or on a spectrum between the two (Anderson and Glass-Coffin, 2013). Recounting my own experience could involve other people, nevertheless, the narrative is told from my own perspective and is my interpretation of events (Sikes, 2015). I only include a brief narrative within this thesis which does not specifically identify other people. The ethical implications that I have to be aware of are, protecting the people whose lives are the focus of the study, being alert to misuse of power over people mentioned within the autoethnographic study, and respecting their voluntary participation within the study, and to treat the information included as permanent, and anticipate my own and others', "future vulnerabilities" (Sikes, 2015, p. 2). I, therefore, reflexively deliberate all the ethical considerations (Lapadat, 2017). Although the writing can be therapeutic, both the researcher and the reader may need to debrief after raising strong emotions and memories (Bochner, 2007). With all these factors in mind I only include a brief narrative within this thesis. However, during the autoethnographic analysis I include some personal details as they resonate with themes found in the IPA study.

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5.3 Method of data analysis

I read many autoethnographies to find a suitable method to follow to complete an autoethnographic study. However, I found that there was no agreed method for producing an autoethnographic study. Nevertheless, all the autoethnographic methods emphasised the importance of the autoethnographer being a part of the culture about which they are writing (Ellis, Adams and Bochner, 2011).

I followed the examples of autoethnographers who detail their own stories (Ellis, 2000; Wall, 2006; Hughes, 2012; Crean, 2020). This approach fulfils the need to analyse the data, and to compare this data with other, "cultural members" (Ellis, Adams and Bochner, 2011, p. 276). An autoethnographic study has to be reliable, valid, and evoke, "a feeling that what [had] been represented could be true" (Ellis, Adams and Bochner, 2011, p. 282). The writing also has to be relatable to people's own experience, or the experience of others they know (Ellis, Adams and Bochner, 2011). I approached this autoethnographic analysis in a similar manner to that of the interpretative phenomenological analysis, in that I answered the questions that I had asked the seven interviewees, and analysed them, whilst only including a short personal narrative within this study.

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5.4 Reflection upon positionality

I am a heterosexual, autistic woman. I acknowledge the privilege of being white, being a part of the UK's dominant culture, and well-educated (Robertson *et al*., 2017), in addition to having an autism diagnosis. I do not resemble the typical autistic person as characterised as "a little white boy" (Giwa Onaiwu, 2020, p. 270). Neither in the online survey nor in the interviews did I seek the racial demographics of the participants, and therefore do not "address disparities stemming from under-representation in research" (Maye *et al*., 2021, p. 1). Being a suicidal autistic adult I am part of the marginalised group being studied.

The autoethnographic study allows my own experience to reflect upon the data gathered from other suicidal autistic adults in this research. I recruited the initial online survey respondents from an online social media site, of which I was a member. When I wrote messages on the social media site asking for autistic adults to respond, I always mentioned that I was autistic, and that the theme of the research was suicide. This was to sensitively warn people of a difficult subject, so as not to cause distress. Autistic people seem to be confident using such sites (Benford, 2008), and 74 autistic people finished the online survey relating to their suicidal thoughts and behaviours. Whilst one person responded with a question asking if there were any non-suicidal autistic people, two people responded to this study who had not experienced suicidal thoughts or behaviours. The seven participants of the phenomenological interviews were self-selecting, being those who offered to be interviewed and had been suicidal.

As the first phase of the study progressed, my own positionality relating to various questionnaires assessing autistic traits developed. I became aware of the male-orientation of some of the questionnaires (van de Aa *et al*., 2016), and questioned the content and relevance of some of their autistic trait statements. It is possible that incorporating the AQ (Baron-Cohen *et al*., 2001) and EQ (Baron-Cohen and Wheelwright, 2004) questionnaires within the online survey may have reduced the number of respondents, due to difficulties they may have with it. One difficulty that Gernsbacher, Stevenson and Dern (2017) identify is that autistic adults deliberate over answering many of the AQ questions owing to them lacking “context” (p. 4).

I had sought to find support for suicidal autistic adults through finding information relating to their lived experience which tends towards a qualitative approach. However, to gain a broader understanding from a larger number of respondents, I initiated the research with a quantitative study. My approach to the data analysis of the quantitative data was methodical and leant towards my previous mathematical and statistical background. Subsequently, I delved into qualitative analyses facilitating the exploration of lived experiences.

My experience of the vulnerability of being a suicidal autistic adult influenced the second phase of data collection in the IPA study. The recruitment to the second phase of the research was initiated through emails to a small group of respondents, who in the first phase had indicated that they would be interested in taking part in an interview relating to the suicidal thoughts and behaviours. This is seen as a particularly autistic friendly approach (Benford, 2008). Approximately half of this small group of people did not respond to the email. I did not contact them again, as I wanted to respect their decision of not responding. This was a response to invitations I have received to participate in research, where follow-up emails have made me feel the researchers are forcefully expecting me to take part. I did not want this feeling of potential bullying to be felt by any suicidal autistic adult. Being an insider researcher, I anticipated not being seen as a stranger to the participants of the second phase, and hopefully gained their trust and acceptance (Bonner and Tolhurst, 2002). Despite this presumption, one participant did assume I was not autistic in one of their replies.

Throughout the analysis I sought to be rigorous, relevant, and reflexive, in addition to highlighting resonances (Finley, 2006). I responded consistently to the comments the participants had made, aiming to demonstrate that I had *heard* what they had written. So as not to influence the participants' responses when I resonated strongly with them, I processed my own experiences by keeping my remarks separate in a notebook.

Some autism research has damaged the reputation of autism researchers for autistic individuals. The research undertaken on house mice and zebrafish, together with other genetic research seeking a cure for autism, is not welcomed by many autistic adults (South, Costa and McMorris, 2021). Raymaker (2017) describes the autistic community as, "a community which is suspicious of researchers" (p. 270), and advises that insider researchers, "may help to build trust towards scientists" (p. 270). Some participatory research has attempted to undertake research *with* autistic people to stop the person being researched feel like a *guinea pig*. However, participatory research aims to "bring together the respective expertise" (den Houting *et al*., 2021, p. 149) of the academic partners, the research professionals, or students, with that of the community partners, the autistic people, though not integrate the two roles. Nevertheless, autism research is now being conducted *by* autistic people, rather than, "on" (Jones, 2021, p. 206), or only, "with autistic people" (p. 206). Autistic researchers are valued for their autistic insight and experience, and can use their possible autism-related skills, "such as attention to detail, intellectual curiosity, and passionate focus" (Jones, 2021, p. 206).

I chose to include an autoethnographic study in the thesis as, being an insider researcher, it was important to identify my own thoughts and reflections relating to the research, rather than being solely a passive observer (Matthews, 2017). Being able to add themes after reflecting on the analysis of my own responses, in addition to acknowledging the experiences of the participants, adds depth to the understanding of being a suicidal autistic adult (Crean, 2020).

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5.5 A brief narrative

Following years of teaching children and young people with additional needs, including autistic children and young people, I became suicidal, and later I suspected that I, too, was autistic. Being suicidal was a reaction to what I now understand to be autistic burnout (Raymaker *et al*., 2020). This was probably a response to camouflaging my differences and, "failing to communicate my needs" (Hannam-Swain and Bailey, 2021, p. 3), and my needs, therefore, not being met. My autistic burnout was similar to that of other autistic adults, characterised by dropping out of paid employment, and experiencing suicidal thoughts and behaviours (Raymaker *et al*., 2020). Initially I was diagnosed with

BPD and reacted to this by researching. As I researched, I realised that my symptoms did not fulfil the criteria for this personality disorder, and I believe I was misdiagnosed. In response to my suicidal behaviours the GP prescribed antidepressants, so I assume I was also diagnosed with depression. Following this possible depression diagnosis, I investigated depression and found the HADS (Snaith and Zigmond, 1994) assessment tool which indicated that rather than depression I was experiencing anxiety. As I searched the internet I found autistic people, especially females, who described my experience exactly. On completing the AQ questionnaire (Baron-Cohen *et al*., 2001), I realised that my high AQ score indicated that I had many of the autistic traits that it assesses. I was supported by family to seek an autism diagnosis. Nevertheless, as I continued this research, I found literature that suggested that being autistic was outlined as being defective and disordered (DSM-5, APA, 2013; ICD 11, WHO, 2018). Furthermore, I read literature that described non-autistic people as typically developed or healthy (Lawson, Mathys and Rees, 2017; Dow *et al*., 2021).

Autism is described within the manuals for the assessment and diagnosis for mental disorders. The accompanied stigma and marginalisation of having a mental disorder diagnosis can be harmful to the autistic individual (Chapman, 2021). Nevertheless, removing all differentiating language and claiming all people are neurodiverse (Timimi, 2021) erases the, “autistic voice, culture, and solidarity and reduces disabled groups to suffering individuals” (Chapman, 2021, para. 12).

Whereas much research on autistic adults is based on scientific psychology, this entire study has foundations in health and education that draws upon different research methods. These methods include action research, where using an insider perspective is anticipated (Stringer, 2008). Gillespie-Lynch *et al*. (2017) find that, “autistic people are autism experts through their lived experience” (p. 10), and that listening to their experiences may, “address and counter” (p. 10), the stigma and marginalisation with which autistic adults are familiar.

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5.6 Reflection, echoes, and resonances

As I reflect on, and analyse, my own experiences I am aware how they echo the responses of the participants, and likewise understand how their responses resonate with my own experience. I know about my own experience of being a suicidal autistic adult, and when I interviewed the participants some of their experiences were reminiscent of my own history. The themes that I discuss within this autoethnographic study come from my own experience, and are based on autistic well-being, misdiagnosis, research, community, alexithymia, emotional and practical support, an autistic environment, gender, and the option of suicide.

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5.6.1 Autistic well-being

In this chapter autistic well-being incorporates four foci: autistic burnout; depression; anxiety; and, camouflaging. Anxiety and depression both relate to a person’s perception of their own worth (Cooper, Smith and Russell, 2017) and frequently lead to a lower self-esteem, which itself can invoke suicidal thoughts and behaviours. Autistic burnout may have been the experience of autistic people misdiagnosed with depression (Raymaker *et al*., 2020). In the IPA study

I found evidence that the terms *depression* and *anxiety* may be used interchangeably to describe feelings prior to suicidal ideation and behaviours. Furthermore, camouflaging autistic traits may lead to autistic burnout, anxiety, depression, or any combination of the three (Hull *et al*., 2017; Raymaker *et al*., 2020).

My suicidal thoughts occurred when I was anxious about situations and when I collapsed with fatigue, not when I deteriorated into depression. I now understand that I was experiencing autistic burnout. Autistic burnout is as a pervasive, long-term exhaustion, together with a loss of function, and reduced tolerance to stimuli (Raymaker *et al*., 2020). It is described as a response to, "coping with the basic demands of everyday life" (Higgins *et al*., 2021, p. 2357), and from living in an environment which is not suitable for the autistic person (Raymaker *et al*., 2020). In contrast *burnout* in non-autistic people originated to, "describe the state of emotional, physical, and mental exhaustion that develops over time from job-related stress" (Mantzalas *et al*., 2022, p. 53). Whilst work related stress is included in the DSM-5 (APA, 2013) and the ICD 11 (WHO, 2018), it is not included as a specific medical condition (Higgins *et al*., 2021). My experience of autistic burnout was initially gradual, then becoming massive and catastrophic. This is redolent of the research undertaken by Mantzalas *et al*. (2022) who suggest alexithymia in autistic adults may impair interoception[24], and therefore fail to recognise, "burnout symptoms until it is too late" (p. 10). Prior to my autistic burnout I was employed in a learning environment that appeared to be conducive for autistic children and teenagers, however, I found

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[24] Interoception - the ability to perceive internal states such as hunger, muscle tension and heart rate (Mantzalas *et al*., 2022, p. 61).

the environment exhausting, and had to camouflage. This experience contrasts with my experience within the autistic community who are very accepting of the person who has been burnt out due to *masking* or *camouflaging* (Higgins *et al*., 2021). After having worked in what I describe as a *hostile* environment, it was a release to resign from employment and seek to avoid similarly stressful environments. Yet, this journey returning to a *normal* and autistic friendly life is a lengthy process, and I realise that many autistic adults do not regain, "their preburnout capabilities" (Mantzalas *et al*., 2022, p. 61).

From both the online survey and the IPA study, depression, either diagnosed or assumed, has been found to be an important factor in relation to suicidal behaviours. Amongst the non-autistic population, there is a very strong correlation between an individual having a diagnosis of depression, or expressing that they are depressed, and a person having suicidal thoughts (Malone *et al*., 1995). Despite the evidence of experienced and diagnosed depression from the online survey and the phenomenological interviews, and given my own experience of being treated for depression, I query the reliability of depression diagnoses for some of those in this study. Reflecting on my own experience makes me consider that some respondents may have thought themselves depressed as they were prescribed antidepressants. This reflection is confirmed by one online survey respondent stating,

> "my doctor prescribed an SSRI... I do not have a piece of paper that says, 'This person is depressed,' the way I do for my autism diagnosis" (Response 8).

During the data analysis of the online survey, I found that all those respondents who had been diagnosed with depression reported that they had experienced depression. However, this is not my experience. Although I received a diagnosis of depression, probably as a consequence of attempting suicide, having self-administered the hospital anxiety and depression scale (HADS) (Snaith and Zigmond, 1994) I realised that I experienced anxiety rather than depression. My experience, therefore, supports the evidence of the quantitative analysis, which demonstrates that two of the people who had suicidal behaviours had neither experienced nor been diagnosed with depression.

Several participants in the IPA study used the terms anxiety and depression together, for example Galina introduced themself as, “depressed and anxious” (Galina: lines 52-53). Coco also used both terms in the same sentence when describing how they were, “prone to stress and anxiety as well as depression” (Coco: lines 68-70). In addressing the needs of a suicidal autistic adult clarity is needed to differentiate between depression and anxiety.

The use of the Anxiety Scale for Autism - Adults (Rodgers *et al*., 2020) may now determine how anxiety is assessed in autistic adults, but there remains a difficulty in addressing whether depression or anxiety is dominant in the suicidal autistic adult. One tool frequently used by the NHS to identify depression is the PHQ-9 (Kroenke, Spitzer and Williams, 2001), in which the answers to nine questions are sought. Arnold *et al*. (2020) indicate that the PHQ-9 is “appropriate and useful” (p. 2224) for use in autistic adults. However, for the autistic person this tool may be flawed as the criteria assessed resemble some autistic characteristics. These similarities include, having sleeping difficulties (Yates and Le Couteur, 2009), having little energy (Stewart *et al*., 2006), over or under eating (Gillberg and Råstam, 1992), feeling like a failure (Hull *et al*., 2017), fidgeting so other people notice (Nolan and McBride, 2015), and having suicidal thoughts (Cassidy *et al*., 2014). Scoring the PHQ-9 with these autistic characteristics is consistent with a possible diagnosis of moderate to severe depression (Kroenke, Spitzer and Williams, 2001).

Rather than having been assessed using the PHQ-9 (Kroenke, Spitzer and Williams, 2001), that was available at the doctor's surgery, I may have benefited from using a modified HADS (Snaith and Zigmond, 1994). This tool differentiates the effects of anxiety from the effects of depression (Cameron *et al*., 2008). The narrative suggests that the use of this tool would have identified my high anxiety score, and my low depression score, assisting clinicians to provide appropriate treatment, and avoiding the need for antidepressants.

My reflection suggests that when I was suicidal, rather than being depressed, I camouflaged and experienced anxiety that resulted in autistic burnout.

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5.6.2 Misdiagnosis

There is evidence from the respondents to the online study, from the seven interviewees, and from literature, that misdiagnosis is a regular occurrence (Lai and Baron-Cohen, 2015; Fusar-Poli *et al*., 2020; Kentrou *et al*., 2021). Missed diagnoses frequently occur as autistic individuals develop coping strategies and may result in neither having been referred to psychiatric services for an autism assessment as a child, nor as an adult (Geurts and Jansen, 2012; Happé *et al*., 2016; Fusar-Poli *et al*., 2020). Diagnoses with which autistic adults disagree may also occur over a lifetime (Au-Yeung *et al*., 2019; Kentrou *et al*., 2021). These may include, “personality disorders, psychoses, anxiety disorders, obsessive-compulsive disorders" (Fusar-Poli *et al*., 2020, p. 2). Additionally, a psychiatric condition may be present, and partially cover any autistic traits (Fusar-Poli *et al*., 2020; Gesi *et al*., 2021). Psychosis is characterised by, "social isolation, socially inappropriate behaviors, and low social insight" (Fusar-Poli *et al*., 2020, p. 8), and these characteristics may mask autistic traits. Similarly, autistic self-injurious behaviours may be misdiagnosed as borderline personality disorder, and social withdrawal may be misdiagnosed as depression (Fusar-Poli *et al*., 2020). As these psychiatric *disorders* may be foremost in the mind of psychiatrists, they assume the presence of these diagnoses and miss the autistic traits (South, Costa and McMorris, 2021; Nyrenius *et al*., 2022). Furthermore, in addition to the data from the online study and the IPA study, Fusar-Poli *et al*. (2020) suggest that prior to receiving an autism diagnosis, autistic adults may be diagnosed with, "anxiety, attention deficit-hyperactivity disorder, mood disorders, and personality disorders" (p. 2). A missed autism diagnosis, and misdiagnosis of other psychiatric conditions, occurs most frequently amongst the female autistic population (Gould and Ashton-Smith, 2011; Lai and Baron-Cohen, 2015; Gesi *et al*., 2021). Females, in particular, may internalise the difficulties of their autistic traits and experience anxiety and depression, potentially leading to a misdiagnosis of depression, anxiety, or personality disorders (Bargiela, Steward and Mandy, 2016). This internalisation may result from experiencing sensory overload (Gesi *et al*., 2021). Autistic adults may also pay a greater attention to detail, and this may lead to a misdiagnosis of obsessive compulsive disorder (OCD) or, if food related, to a possible misdiagnosis of an eating disorder (Gesi *et al*., 2021). In contrast, a more male representation of autistic traits may be externalised, leading to possible misdiagnoses of attention deficit hyperactivity disorder (ADHD), psychosis, or a conduct disorder (Fusar-Poli *et al*., 2020).

Whilst gathering all the data relating to the suicidal autistic adult, I kept notebooks with my own thoughts and reflections that arose due to resonances with the 74 respondents and seven participants. One such resonance related to others being misdiagnosed. For me misdiagnosis was a terrible experience. It was difficult to challenge my misdiagnosis of BPD. The more I denied the diagnosis of BPD, the more the community mental health team (CMHT) said that I had BPD. This diagnosis led me to join a therapeutic community for people with BPD for a year, which met three times a week. A misdiagnosis, as in my case, can also cause a lengthy delay in appropriate support or treatment. On reflection the one benefit of the expensive treatment in a community for people with BPD, though inappropriate, was that it created an appreciated routine. Soon after the culmination of the year's BPD programme, and following a detailed medical history being taken by a psychiatrist and diagnostic interviews undertaken by a clinical psychologist, I was diagnosed as autistic.

From my experience the suicidal behaviours of the autistic individual may be misinterpreted as BPD traits by medical professionals. In a time of crisis, the emotions of a person with BPD may shift very quickly, the suicidal BPD person may experience extreme sadness, anger, and anxiety (NHS, 2020a). This may be due to feeling abandoned by the people they care about, who are the people who give them *emotional* support (Palihawadana, Broadbear and Rao, 2019). This contrasts with the experience of an autistic person, where anxiety may occur if they do not receive routine practical support (Zener, 2019), which is generally provided by a friend or family member (Herrema *et al*., 2017). The suicidal behaviours may resemble those of the person with BPD, but they arise from a different cause. The autistic person may be afraid that the people they care about will abandon or leave them without the required *practical* support (Hedley *et al*., 2017). This may lead to an autistic person being misdiagnosed with BPD. From the findings there is a suggestion that misdiagnosis may be possible. Two of the 74 respondents seemed to be misdiagnosed with BPD, and another two gave more detail and explained that they were diagnosed with BPD following a suicide attempt and prior to their autism diagnosis.

My relationship with the CMHT was varied, sometimes the relationship was good, and at other times it was under strain. Experiencing alexithymia and being unable to explain my emotions, I spent countless hours talking to the CMHT, and when suicidal, attempting to explain how I felt to the Crisis Resolution and Home Treatment (CRHT) team. However, these communication attempts failed and the CRHT team would suggest, “have a bath”, “light some fragrant candles”, or, “relax”. I find sensory stimuli overloading, and if the advice had been followed, would have used up the little energy I had remaining. Nevertheless, one helpful intervention was that the CMHT organised a gym group that met once a week. Ee *et al*. (2019) suggest that focusing on sport and recreational activities may assist autistic people to socialise. I enjoyed this group, going to the gym, counting how many calories I had utilised on the cycle machine or the treadmill. This synchronised with one of my autistic traits, my love of facts and figures.

Within the provision of the CMHT, for eight years I had a community psychiatric nurse (CPN). I had several, as they moved on to other teams, or became ill for a long time. However, having someone with whom to discuss things through was quite useful. The CPN would listen to me and help me get my thoughts straight. Over time, as they got to know me, they wanted me to succeed in life, rather than just survive. They reiterated that taking my own life was my own decision, and pointed out the devastating effect my death would have on my family. Nevertheless, I felt that I required more appropriate support rather than the guilt-trip and ignominy I sometimes experienced through this advice. One of the roles of the CPN was to assist putting in interventions before I attempted suicide. However, I resonated with the response of a respondent from the first data collection phase who was stopped from attempting suicide by nearby people. A similar response by Galina concerning a suicide attempt that was thwarted also resonated with me. They were preparing themself to attempt suicide and someone came to them and started a conversation. Likewise, one of my suicide attempts was stopped by someone coming over to speak with me. This is an important detail for those involved with suicide prevention, as the people who intervened in each case initially started a conversation with the suicidal person before the emergency services were involved.

Following my autism diagnosis, I was told by the CMHT that the mental health NHS trust could no longer help me, and they withdrew my CPN. Autism turned out to be an excluding factor for me. I have found this situation to have been familiar to other autistic adults, with one respondent in the first phase of data collection stating,

> “It was difficult to be accepted by... [medical professionals] and not turned away because of autism” (Response 33).

It seemed as if the CMHT felt that other teams were better equipped to deal with those diagnosed as autistic. Nevertheless, the other NHS team, whose aim it was to work with autistic individuals, was for those with an intellectual disability, and at the time only worked with those who satisfied this strict criterion.

Misdiagnosis, including diagnostic overshadowing, prioritises treatment for a mental health condition whilst harmful autistic experiences are left unaddressed (Au-Yeung *et al*., 2019; Nyrenius *et al*., 2022). However, mental health issues may co-exist alongside autism, and these co-occurring mental health conditions need to be treated to alleviate any suicidal thoughts and behaviours (Au-Yeung *et al*., 2019).

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5.6.3 Research

Due to systematic research, and lived experience, some autistic people are understood to be experts in autism (Gillespie-Lynch *et al*., 2017). Due to their own research autistic individuals may find characteristics that they share with the wider autistic community and feel a part of the wider group. This social identification results in lower depression scores (Cooper, Smith and Russell, 2017), and may contribute to lower rates of suicidal thoughts and behaviours. Research has greatly aided my own recovery of being a suicidal autistic adult. I get lost in the process of researching; hours can go by without me realising. Knowing that other autistic people have had suicidal thoughts confirmed that I was not unique and provided me with the motivation to become an insider researcher.

Despite the positive elements of research, the process has meant that I have had to come to terms with people using what I consider to be offensive language. Autism is frequently described as a list of deficits, rather than also outlining the positive attributes of an autistic individual (Gillespie-Lynch *et al.*, 2017; Botha, 2021). Some non-autistic researchers dwell on the use of differentiating their non-autistic participants from their autistic participants by describing the former as *typically developed* (Dow *et al*., 2021) or as *healthy* (Lawson, Mathys and Rees, 2017). One problem in describing autistic people as not being properly developed or unhealthy, is that some research seeks to cure, or remediate, the autistic person (Botha, 2021).

Researchers also seek to improve suicide prevention for the autistic community. After consulting over one thousand autistic people and their supporters, Cassidy *et al*. (2021c) made seven immediate priority recommendations to remove barriers to mental health services, with eight additional recommendations to improve assessment and treatment, alongside the top ten community priorities for suicide prevention that are crucial for future policy and clinical practice in addition to research. The first additional recommendation suggesting that anyone being told by an autistic person that they are suicidal, should be believed, “even if such information comes in a different or unexpected manner” (Cassidy *et al*., 2021c, p. 3), particularly resonated with me. When I reported feeling suicidal, my external appearance could be quite cheerful, having a smile on my face. The smile is perhaps a result of a lifetime of camouflaging, and I indicate that I am thriving even when I am not well.

Gillespie-Lynch *et al*. (2017) recognise, that for autistic adults, research may be a focused interest. Thirty-nine percent of the online survey's respondents demonstrated that they were interested in researching, as they were educated to a level requiring research, 24 having a master's degree, with a further five having received PhD's or equivalent. In the IPA study, Peter was specific about the benefits of research. He did his own research into his nephew's autism diagnosis and realised that an autism diagnosis would probably explain his own difficulties with mental health. Since his diagnosis, research has greatly aided Peter's recovery, "The best thing I can do is get passionately interested in something and lose myself in researching it" (Peter: line 483). Similarly, I experience getting lost in the process of research, which is positively stimulating. I appreciated and resonated with Peter's comments when he culminated his thoughts about the recovery of the suicidal autistic adult by writing,

> "there will be a point soon where you get interested in something again and get that buzz of intellectual curiosity as you research it" (Peter: lines 584-585).

Mason *et al*. (2018) suggest that autistic adults take part in research, as describing their lived experiences identifies future "support strategies" (p. 1145) for the autistic community. In this study the respondents may similarly have recognised the value of taking part in research relating to suicide in autistic adults.

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5.6.4 Community

Bagatell (2010) questions how an autistic community can exist, "given that, from a biomedical perspective, autism is characterized by significant social and communication deficits" (p. 34), as well as other deficits, that would seem to assume that autistic people, “lack the skills essential for the establishment and maintenance of a community” (p. 34). Whilst recognising the paradox, Bagatell (2010) acknowledges the existence of the autistic community. The autistic community mainly emerged due to the inclusion of more people with the ICD 9 (WHO, 2012) and DSM-IV (APA, 1994), the development of self-advocacy as a part of the disability rights movement, and the use of the internet and computer technology (Bagatell, 2010). One benefit of using the health disorder classifications, as expressed in the diagnostic manuals, is the provision of solidarity, and a culture and community for minority disabled groups (Chapman, 2021). Zener (2019) demonstrates the support of belonging to the online autistic community.

Prior to my major autistic burnout, I attempted to be a member of the general, usually non-autistic, community, and I continuously camouflaged. This was very draining, and I returned from social events exhausted and requiring space from people. Following my autistic burnout and having suicidal thoughts and making suicidal plans, as previously mentioned I attended a local mental health gym group using the local leisure centre. The regular meetings, with the same group of people, meant that I had *normal* conversations with a group of non-autistic adults, who were also experiencing a period of negative mental health. Once the CMHT withdrew their support I had to find a different support structure. I found the local autism support groups, and they grew in importance to me, as did the autistic community that I found on the internet using social media.

I have gained greatly from being a member of the online autistic community; I have access to research that has been undertaken by autistic researchers; I understand more fully the role of anxiety in everyday autistic life, and the negative effects that it plays in my life; and, I have developed as a person, not having to camouflage in discussions relating to myself.

Experiencing being a part of a minority community and having the positive social identity of being autistic can enhance an autistic individual's self-esteem (Cooper, Smith and Russell, 2017). I have developed a more positive self-identity, which has resulted in raising my self-esteem, through recognising that I belong to the autistic community.

Furthermore, I also belong to a faith community. Contrasting with the expectation that a religious belief is a protective factor against suicidal behaviours (Segers and Rawana, 2014), I found that having a faith did not preclude me from suicidal behaviours.

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5.6.5 Alexithymia

From my own experience it is difficult to deduce what mental state I am experiencing. Consistent with alexithymia, I struggle to identify feelings and emotions. Rather than feeling emotions, I frequently experience bodily sensations, such as nausea. This physiological response may be a reaction to anxiety (Rowland, 2020). I also experience the difficulty of communicating within myself, and I am not usually aware of the feelings I have. If, due to alexithymia, a person does not experience emotions, they may have no story to tell about their own destructive behaviour and may find it difficult to receive therapeutic help (Muller, 2000). I believe that this was my situation. Whilst attending sessions with my CPN I would explain that I felt fine, and would be smiling, but at the same time be considering how I could bring my life to an end. This situation is very different from the non-autistic, non-alexithymic, representation where people are supposed to be “eager to discuss” (Muller, 2000, para. 14) their self-destructive behaviours. High levels of alexithymia may be a risk factor for depression, anxiety, substance abuse, eating disorders, and various personality disorders (Preece *et al*., 2018). I particularly relate to alexithymia being a risk factor for anxiety.

Alexithymia was referred to by Avien. Although they did not use the technical term, they wrote, “I have trouble identifying my emotion” (Avien: line 316). None of the other participants wrote about the difficulty of identifying emotions, but they did demonstrate that they had difficulty in defining different mental states, notably depression and anxiety.

One description of alexithymia suggests that autistic people struggle to use metaphors or figures of speech (Poquérusse *et al*., 2018). However, Peter, in his responses, was very eloquent in his descriptions, using such phrases as, “Having someone arbitrarily cut off your air supply” (Peter: line 386), “Straightening roof tiles on a burning house” (Peter: line 456), “I sank into a deep and tortuous depression” (Peter: line 214), “Diving headlong into researching autism” (Peter: line 414), and, “carried suicide around in my back-pocket” (Peter: lines 239). Unlike Peter, I rarely use metaphors.

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5.6.6 Emotional and practical support

As a suicidal, autistic adult I require support. In this chapter I combine two of the different elements of support, the emotional and the practical. To maintain some confidentiality, I refrain from making personal comments regarding financial support.

I find that there is confusion in some autism related services concerning the difference between intervention and support, where *support* receives a wide variety of use. I have received inappropriate support, redolent of Applied Behaviour Analysis (ABA), where the power and control are in the person supporting, rather than in the person receiving the support. The term *support* may be used in reports referring to autistic adults, such as, we *supported* [name] to return to the work area, which induce feelings of forceful movement. This may dismiss the reason why the autistic person originally left the area, whilst failing to recognise the importance of the role of the supporter to ameliorate the environment. Similarly, there are health care providers who claim to provide support by actively trying to manipulate an autistic child's, or adult's, behaviour through social skills intervention (Crowell *et al*., 2020), using ABA (Kirkham, 2017). This is particularly unusual in the non-autistic population as, "purely behavioural treatments are not generally in medical favour today" (Kirkham, 2017, p. 109). The general aim of ABA practitioners is to, "extinguish 'undesirable' behaviours and to promote 'pro-social' ones" (Kirkham, 2017, p. 109, original emphases), including the increase of eye contact and verbal communication in the autistic person. This therapy is particularly contentious for autistic adults (Kirkham, 2017).

I find that practical support for autistic adults is frequently delivered by an organisation limited to the facilitators' skills and is not tailor-made to directly support the needs of the autistic person. This may be due to a lack of funding. Nevertheless, there is post-diagnostic support for parents with autistic children, support for autistic children in schools, and support for young people transitioning to adult services (Kapp, 2018). Post-diagnostic support for autistic adults may include recommendations for: care and follow-up of autism, the non-medical condition; managing risks; overall health care; managing in a crisis; the need to have a Health Passport[25]; and, specialist care for health and medical problems (Scattoni *et al*., 2021). However, a European study found that 67% of autistic adults experienced none of these recommended features of post-diagnostic autism support (Scattoni *et al*., 2021). With my support from the CMHT stopping when I received my autism diagnosis, I resonated with the comments made by the online survey's respondent who explained that their access to mental health professionals was denied on the receipt of their autism diagnosis.

As an undiagnosed child and teenager, I did not receive any tailored support, although my family and various educational establishments provided some relevant support. In comparison, since my diagnosis, I have received practical support and emotional support from close family members, as well as through online social media. When I was younger, there were possibly times when I felt alone and knew I did not fit into society. However, I never felt the loneliness that Quadt *et al*. (2021) suggest may have increased my vulnerability to depression and anxiety, which in non-autistic individuals could eventually lead

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[25] Health Passport - important health information about the person's needs and care (NAS, 2022).

to suicidal ideation (Hedley *et al*., 2018a; Hedley *et al*., 2018b). It can be questioned whether the aloneness I experienced and appreciated, equates to loneliness. As Gallitto and Leth-Steensen (2015) suggest, it may have been the result of attempting to distance myself from aspects of "relationships with others" (p. 66). Furthermore, it can also be questioned whether this aloneness increases suicidal risk. From my experience, I also question whether receiving social support reduces social isolation, and its allied risk of depression and suicidal ideation (Hedley *et al*., 2018a), and whether the programmes targeting loneliness increase inclusion and mental well-being (Hedley *et al*., 2018b).

Although I appreciate being alone, in medical appointments I value the emotional and practical support of someone to help me communicate the important information that a clinician requires. This is redolent of the comments made by Avien, though our needs are different, the requirement for help with communication is similar. The support I need is specific for particular situations. I require appropriate emotional and practical support to assist in appointments where communication is important. Support is appropriate when it leaves the power in my control. Without the emotional and practical support that I have received, and continue to receive, I may have succumbed to the option of suicide.

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5.6.7 An autistic environment

Further examination is required into the origins of suicidal ideation and behaviours for an autistic person. My experience suggests that once the environmental stressors are removed, the suicidal ideation disappears, with the consequential antidepressants no longer being prescribed. Therefore, there is evidence that one source of my suicidal ideation was trying to exist in a non-autistic environment. Removing similar stressors may also remove the sources of suicidal ideation for other autistic individuals. However, I identify an added complication, the difficulty of identifying the external stressors. It is often only after the stressor has been removed that I realise its past negative effect. For me, the practical support in identifying potential stressors is helpful.

Following the report of my suicidal ideation to my general practitioner I was offered support by the CMHT. One member of the CMHT attempted cognitive behavioural therapy (CBT) and dialectical behaviour therapy (DBT) with me. Both techniques are used with suicidal adults, as they are designed to help change a person's thinking and behaviour (Mind, 2021), through analysing antecedents, behaviours, and consequences (Kirkham, 2017). Furthermore, to train resilience in suicidal people, and to diminish, "the probability of suicidal outcomes" (Collins *et al*., 2018, p. 100), some therapists use mindfulness. One particular mindfulness exercise in DBT is the raisin meditation (McKay, Wood and Brantley, 2019). The exercise focuses the person undertaking the therapy on reliving the sensory effect of holding and tasting the raisin and focusing on breathing. As with many autistic people, my experience of the meditation was that the exercise was overstimulating, as I am hyper-alert to all the senses within the environment. Unfortunately for some autistic people, overstimulation and sensory overload can lead to anxiety and depression (Francis, Duke and Chiu, 2017), associated with further suicidal ideation and behaviours (Richa *et al*., 2014; Dow *et al*., 2021).

An autistic friendly environment is extremely necessary for me. In order not to experience sensory overload, I seek a quiet environment with few stimuli. I also appreciate space. However, I also acknowledge that other autistic people may require a bright environment with many stimuli. Identifying the necessity of living in an autistic friendly environment has been life changing. Following my autism diagnosis, and affirming my autistic traits, my life changed by not having to camouflage at social events, by not making difficult decisions on a daily basis, by spending the majority of the day researching, and by limiting my level of interaction with other people. Although the definition of an autistic friendly environment may be different for everyone, some factors may be common. Being aware of both social engagement and environmental factors is important for most autistic individuals. Camouflaging yields a, “mismatch between external observable features and the internal lived experience of autism” (McQuaid, Lee and Wallace, 2022, p. 552). For me, attaining an environment without stressors reduced my suicidal thoughts and behaviours. Choosing the correct autistic friendly environment may result in a decrease in camouflaging, fewer mental health issues and the allied propensity to tend towards suicidal behaviours.

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5.6.8 Gender

Consistent with the findings of the online survey many autistic adults are non-binary, however, I am female and align with my sex at birth. Much research to date regarding suicidality in autistic adults, categorises participants by sex or binary genders. Identifying a participant’s sex may be more relevant for research concentrating on prepubescent autistic children, whereas the inclusion of non-binary adults in autistic research is becoming more established.

Both sex and gender have been found to be important in the provision of assessments for autism diagnoses (Goldman, 2013; Lai *et al.*, 2015). Girls are less likely to be diagnosed as autistic than boys, unless they have significant behavioural problems (Duvekot *et al.*, 2017; Gould, 2017), as there is, “a male bias” in society’s perception of autism (Dean, Harwood, and Kasari, 2017). Females, in particular, have found that they have received their autism diagnosis later in adulthood (Leedham *et al.*, 2020). From childhood, girls may camouflage and conceal their autistic traits from adults, seemingly maintaining engagement in playground activities, and thus are less likely to receive any positive intervention or support (Dean, Harwood and Kasari, 2017). This camouflaging of autistic traits may also exacerbate, “difficulties with mental health” (Leedham *et al.*, 2020, p. 143). However, these mental health difficulties do not necessarily culminate with an autistic diagnosis. Having endured a life of being assumed to be non-autistic, on receiving their diagnosis some women experience intense pain, and express grief accepting how their life pre-diagnosis could have been different (Leedham *et al.*, 2020). Equally, some older, late-diagnosed women feel vindicated having previously experienced shame following social misunderstandings (Leedham *et al.*, 2020).

I was relieved when I received my diagnosis as an adult. I resonated with the findings of those researching missed diagnosis and misdiagnosis (Gould and Ashton-Smith, 2011), as despite having autistic traits from early childhood, I received my autism diagnosis later in life. As a child I had ordered my belongings so that they were ranged from small to large, in alphabetical order, or in the order of preference. Perhaps observers would have recognised my restrictive and repetitive behaviours that I would perform at home, as being autistic characteristics. My favourite childhood toy was my space hopper that I now consider provided me with proprioceptive input. This input can be calming when a person is particularly overwhelmed by sensory stimulation (McCrohan *et al.*, 2019). Space hoppers are now sold as sensory toys and as therapeutic aids for autistic children. However, I camouflaged and attempted to *fit in* and conform to the society norms, perhaps using my intellect, rather than instinct, to learn the rules of society (Gould, 2017).

The minority stress theory originally focussed upon those who were in the sexual or gender minority (Meyer, 1995). Subsequently, the model has been developed to describe the social disadvantage and marginalisation of other minority groups, such as the autistic community (Botha and Frost, 2020). Additionally, and consistent with the original focus of the minority stress theory, the autistic community encompasses more people who describe their gender other than binary. One of the seven participants in the second phase of data collection, Dylan, grew up in an environment that was hostile to their recognised expression of lack of gender. In Dylan’s case, having their autism and non-binary status recognised enables them to belong to the intersection of two minority groups. Rather than being negative for a person’s mental health (Meyer, 2003), belonging to one or more minority groups may improve an individual’s self-esteem, their mental health, and reduce their suicidal tendencies (Cooper, Smith and Russell, 2017).

By being female, I was possibly affected by gender as my autism was late diagnosed. Although when I was born autism was not recognised in children without co-occurring intellectual disability, similarly aged autistic males received their diagnosis at an earlier age to me.

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5.6.9 The option of suicide

Suicide is still an option that I have. Despite living in a more autistic friendly environment, when faced with stressful situations I am still tempted by the rational option of suicide, although I am much more aware of the effect it would have on my family. This suicidal ideation arises when I am very anxious and would rather escape a situation rather than stay in that stressful environment. More particularly, I have also considered suicide as a logical response to being bullied and wanting to be in a peaceful environment.

My response of seeing suicide as both rational and logical is reflected within the data of the online survey. The findings demonstrate that 47% of respondents had attempted suicide, with 78% having made suicide plans. One online survey respondent suggested that contemplation of suicide is a normal, daily event, and did not specifically link suicidal thoughts with a negative mental health issue. Two other respondents used the word *logical* in describing their suicidal thoughts. Being rational or logical would not normally be a cause of concern, nevertheless other solutions to stressful situations were not visible to these particular autistic adults.

Resembling my own experience of keeping suicide as a rational option, rather than an emotional response, were four responses in the IPA study: Peter keeping suicide in his, “back-pocket” (Peter: line 239); Sage suggesting they would contemplate suicide again, “once I am ready to die” (Sage: line 167), and immediately describing dying by suicide as, “a safety net” (Sage: line 168); Dylan thinking that, “suicidal ideation has become like a reflex” (Dylan: line 175); and that when asked about their suicidal behaviours Galina writing that, “something needed to end the constant suffering” (Galina: lines 341-342). I particularly resonated with the comments made by Peter, Sage, and Dylan. If suicide is kept in the, “back-pocket” (Peter: line 239), is a, “safety net” (Sage: line 168), and is a reflex route of, “escape” (Dylan: line 216), it may suggest a quicker recourse to suicide without the stages of mental deterioration, as described in non-autistic adults. From the online survey, the analysis of interviews, and my own experience, I suggest that once suicide has been considered as an option for the suicidal autistic adult, it will always remain an option.

Keeping suicide as an option is redolent of Baechler’s 1979 theory of *Suicide as Escape*, focusing on the general type of *escape* with *flight* from an intolerable situation. As an autistic adult escaping from a negative situation, responding either to emotions or to the environment, enables the capability to enact a suicidal attempt.

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5.7 Conclusion

The overall aim of this chapter is to analyse, and reflect on, my own personal experience of being a suicidal autistic adult, whilst answering the question, *what is my lived experience of being a suicidal autistic adult*? This third phase of gathering data using the autistic voice was achieved by using an autoethnographic style. Reflecting on my answers to the questions I gave to the seven participants highlighted the strong resonances with many of the interviewees' answers. The stories, mine and those of the participants, are complex.

The themes that I highlight from the autoethnographic study are: autistic well-being; misdiagnosis; research; community; alexithymia; emotional and practical support; an autistic environment; gender; and, the option of suicide. Some of these themes are consistent with those reported upon in the IPA study. The autoethnographic study's findings include: that when I experienced autistic burnout I camouflaged, experienced anxiety and was suicidal, rather than being depressed; that initially I was misdiagnosed with BPD and that following on from my autism diagnosis the mental health team withdrew their support; that research has aided my own recovery from suicidal ideation, planning and attempts; that I value being a member of the autistic community, whether in person or online; that I experience alexithymia; that I require emotional and practical support to reduce isolation; that removing stressors and attaining an environment that is suitable for me has reduced my suicidal thoughts and behaviours; that I was affected by gender as my autism was late diagnosed; and, that rather than remaining in a stressful environment, I keep suicide as a rational option, and a means of escape. Although all the findings are important, this final finding is of particular significance.

My lived experience of being a suicidal autistic adult, and therefore answering the research question, includes both beneficial and detrimental experiences. The detrimental experiences include: having been anxious and having to camouflage, that both led to autistic burnout; being misdiagnosed with depression and BPD, and receiving possibly inappropriate treatments; and, having my access denied to the community mental health team when I received my autism diagnosis. Contrasting with these negative experiences are the beneficial experiences that include: having an autism diagnosis that allows me access to the autistic community, in both face-to-face situations and online; receiving support from my family, especially in relation to communication, to assisting with my alexithymia; and, receiving support to improve my personal environment. My experience also confirms that once suicide has been considered, through ideation, planning or attempt, a suicidal autistic adult keeps suicide as an option.

This is the last of the empirical chapters. In the next, concluding chapter I draw together the results of all three chapters focusing on data collection, together with literature.

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Chapter 6. Conclusion

This chapter is the point of interface of the mixed-methods research exploring the experience of the suicidal autistic adult, research regarding one of the autistic community's top priorities to prevent suicide (Cassidy *et al*., 2021c). The research encompasses three areas: an exploratory study of the characteristics of the suicidal autistic adult through a quantitative study and a thematic analysis (TA); the lived experience of the suicidal autistic adult through phenomenological interviewing and interpretative phenomenological analysis (IPA); and, through the analysis of an autoethnographic study of my own lived experience of being a suicidal autistic adult.

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6.1 Summary of findings

The findings from the three distinct methods of data collection, together with the four methods of data analysis, interconnect as they all emanate from the autistic voice. In this section I outline the separate findings and summarise the common themes.

From the data of the online survey, the statistically significant results regarding the characteristics of the suicidal autistic adult show that: suicidal ideation and suicidal planning in the autistic adults within this sample are associated with experienced depression; and, suicidal planning in the autistic adults within this sample is associated with diagnosed depression. The demographic characteristics show that: many autistic adults describe their gender other than binary, 20% of the respondents are non-binary; autistic adults have higher academic attainment, 63.5% have already attained a bachelor's degree or above;

that autistic adults are affected by anxiety, being the most frequently mentioned co-occurring condition; adults with more recognised autistic traits experience making suicide plans, higher AQ scores corresponded with having suicidal ideation and suicidal planning, and lower EQ scores demonstrated having made suicidal plans or had attempted suicide; not all the autistic adults who have attempted suicide have planned suicide; not all the respondents who have suicidal thoughts or behaviours have experienced, or have been diagnosed with, depression; and, some respondents who have attempted suicide do not have diagnosed depression.

The thematic analysis highlights: the role of the NHS and the mental health teams in being misdiagnosed, the length of time to receive an autism diagnosis, and then being locked from appropriate treatment for co-occurring mental health issues; the various elements and possible antecedents of suicidal behaviours, acknowledging self-harm, and whether depression makes suicidal thoughts worse, or if suicidal thoughts are always linked with depression, and the young age when autistic adults first attempted suicide; and finally, reasons why autistic people have either attempted or stopped suicidal behaviours, including the affect it may have on other people, but that it remains an option.

The findings of the second phase IPA study, the lived experiences of suicidal autistic adults, are: a lack in autistic well-being, including anxiety as well as depression, camouflaging and autistic burnout, may lead to suicidal thoughts and behaviours; despite CBT being generally advised as not being beneficial for autistic adults, therapy may be valuable to highlight the possibility of an autistic diagnosis for those who have not yet been diagnosed; financial support may be necessary as employment may lead to stress, autistic burnout, and suicidal thoughts and behaviours; an autism, or Asperger's syndrome, diagnosis is important to explain some of the participant's characteristics; the role of a community is significant, whether as the autistic community or a supportive non-autistic community; the gender of many autistic adults is non-binary; and, suicide is always an option, either being a *safety net*, *being kept in the back-pocket,* or as a means of *escape*.

The findings of the third phase, autoethnographic study of my lived experience of being a suicidal autistic adult are: I was suicidal as I experienced autistic burnout due to camouflaging, and experienced anxiety rather than depression; I was initially misdiagnosed with BPD and my autism was missed; my autism diagnosis resulted in the mental health team withdrawing their support; researching has aided my own recovery from suicidal ideation, planning and attempts; I value being a member of the online autistic community; I experience alexithymia; I require emotional and practical support to reduce isolation; I appreciate the power of support being left in my control; gender may have contributed to my late autism diagnosis; removing stressors and attaining a suitable environment reduces my suicidal thoughts and behaviours; and, I keep suicide as a rational option as a means of escape for potential use in the future.

The themes that were common to the three research studies are: misdiagnosis; anxiety; the effect of gender; suicide always remaining an option; autistic adults who have planned suicide being diagnosed with depression; and the role of the online autistic community.

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6.2 Findings resonating with literature

There are several areas of literature that resonate with the findings, including: the strength of being an insider researcher; the significance of autistic traits in suicidal thoughts and behaviours; the roles of depression, anxiety and gender; the importance of material support; the significance of misdiagnosis; how perseverative thinking may prompt the ongoing option of suicide; and, the use of the minority stress model to explain the experience of suicidal autistic adults.

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6.2.1 Literature resonating with quantitative analysis findings

The experience and diagnosis of depression is found to be extensive in the group of suicidal autistic adults who responded to the online survey, and corresponds with published research (Cassidy *et al*., 2014; Richa *et al*., 2014; Hedley *et al*., 2018; Upthegrove *et al*., 2018; Dow *et al*., 2021). Many studies endorse that depression is a risk factor for suicidal behaviours in autistic adults (Cassidy *et al*., 2014; Zahid and Upthegrove, 2017; Cassidy *et al*., 2018b). Fifty-five respondents (74.3%) had a diagnosis of depression, and a further 15 respondents (20.3%) had experienced depression without receiving a diagnosis.

In relation to depression and suicidal behaviour in autistic adults, the quantitative analyses suggest three distinct findings: the first, that suicidal ideation is associated with experienced depression; the second, that suicidal planning is associated with experienced depression; and the third, that there is a relationship between suicidal planning and diagnosed depression. There is literature that demonstrates that suicidal behaviours in autistic adults is related to depression, ranging from Sterling *et al*. (2008), who describe that one of the characteristics associated with depressed autistic adults is suicidal behaviours, to more recent studies, where Costa, Loor and Steffgen (2020) describe the role of depressive symptomology for suicidal autistic adults. Hedley and Uljarević (2018) suggest that within the autistic population suicidal ideation is one of the most common symptoms leading to a diagnosis of depression.

Rather than depression, Lai, Rhee and Nicholas (2017) consider whether there are other explanations for suicidal ideation in autistic adults, such as social and environmental pressures, alongside difficulties in relationships. One of the demographic characteristics highlights co-occurring anxiety in this sample of mostly suicidal autistic adults. Nevertheless, the data in this study maintains that more suicidal autistic respondents are depressed (74%) rather than anxious (35%), contrasting with the data gathered by Hollocks *et al*. (2019) where 42% had an anxiety diagnosis and 37% a diagnosis of depression. The anxiety experienced may be a physiological response rather than an emotion (Rowland, 2020). Nevertheless, whether physiological or emotional, anxiety has had adverse consequences on the respondents' quality of life and accords with the findings of Rodgers *et al*. (2020). The finding that anxiety, in addition to depression, is associated with suicidal thoughts and behaviours also supports Dow *et al*.'s (2021) findings. Zener (2019) presents the idea that undiagnosed autistic women are at risk of anxiety, and its manifestations, including suicidal behaviours. Half of the respondents of the online survey are female, and 41% of them experienced anxiety. Although Zener's (2019) study concerns undiagnosed autistic women, there remains a strong link with the findings of the online survey, as Livingston, Shah and Happé (2019) suggest that diagnosed and undiagnosed individuals have similar AQ scores. Although all the respondents of the online survey identified as autistic, I am uncertain to the number of females who had received a formal diagnosis and those who remained undiagnosed.

The NHS (2020b) affiliates anxiety with PTSD, describing PTSD as an anxiety disorder that results from experiencing very stressful, frightening, or distressing events. Ee *et al*. (2019) suggest that autistic adults, due to their distinct characteristics, may be bullied and victimised. Richards *et al*. (2019) describe these characteristics as having particular difficulties in social interaction, and similarly suggest that autistic adults may be victimised. Warrier and Baron-Cohen (2021) identify that this victimisation may lead to suicidal behaviours. Compounding the trauma of victimisation, Dell'Osso and Carpita (2022) explain that after experiencing these traumatic events, and experiencing PTSD, autistic adults may be, "frequently misdiagnosed with BPD" (p. 2). Supporting these studies, the demographic characteristics data show that 11% of the respondents described co-occurring PTSD.

Having increased levels of autistic traits has been well evidenced to relate to suicidal behaviours (Kamio, Inada and Koyama, 2013; Kato *et al*., 2013; Cassidy *et al*., 2014; Takara and Kondo, 2014). The AQ assesses the autistic traits of social skills, attention switching, attention to detail, communication, and imagination (Baron-Cohen *et al*., 2001). The data relating to the demographic characteristics showed that the respondents who had made suicidal plans had higher AQ scores. This supports the results of Cassidy *et al*. (2014) who retrospectively analysed, "clinical survey data from adults newly diagnosed with Asperger's syndrome" (Cassidy *et al*., 2014, p. 142), and state that those, "individuals who reported suicidal plans" (p. 145), had significantly higher AQ scores. However, their results additionally suggest that those who reported suicidal attempts also had higher AQ score. This particular finding was not apparent within this study. This finding of the quantitative analysis that associates suicidal planning with higher AQ scores also corroborates Pelton and Cassidy's (2017) results. Their research, relating to the Interpersonal-Psychological Theory of Suicide, confirms that suicidal behaviours are predicted by self-reported autistic traits (Pelton and Cassidy, 2017).

The findings of the quantitative analysis show that 97% (*n* = 72) of the respondents experienced suicidal ideation, and 74% (*n* = 55) had a depression diagnosis. However, a further finding reveals that two respondents (2.7%) had experienced suicidal behaviours, whilst neither had experienced nor been diagnosed with depression. Cassidy *et al*. (2014) similarly report that more of their participants had experienced suicidal ideation (66%) than had a diagnosis of depression (31%).

Most research associated with the autistic suicidal adult fails to recognise those who are non-binary, with only a few papers using the term *other* to describe gender (Camm-Crosbie *et al*., 2019; Raymaker *et al*., 2020; Pelton *et al*., 2020a). I categorised the respondents of the online survey into three gender groups, male (*n* = 22; 29.7%), female (*n* = 37; 50%), and non-binary (*n* = 15; 20.3%).

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6.2.2 Literature resonating with thematic analysis findings

The findings of the TA are divided into three themes: suicidal behaviours; reasons for suicidal behaviours; and, NHS/Mental health teams.

The theme of suicidal behaviours was generated from six codes; associated depression?, suicidal ideation, suicidal planning, and suicidal attempts, in addition to the age when suicidal behaviour started, and the acknowledgement of self-harm. The code of *associated depression?* challenges whether suicidal autistic adults experience depression. One respondent who was prescribed anti-depressants doubted whether they had a depression diagnosis as, unlike their autism diagnosis, they had not received written confirmation. Other research has raised questions about the accuracy of depression diagnoses for suicidal autistic adults. Lai, Rhee and Nicholas (2017) suggest that rather than experiencing depression, a false positive for depression may occur for autistic adults, due to autistic characteristics making it difficult to distinguish between the affect and the mood (Lai, Rhee and Nicholas, 2017). Raymaker *et al*. (2020) describe the distinctness of autistic burnout explaining it may resemble depression and may similarly result in suicidal ideation and behaviours.

The findings suggest that NSSI is significant for one respondent, as a response to emotional pain. NSSI appears to be more significant for autistic individuals than is generally found within the non-autistic population (Cassidy *et al*., 2018c), and may be a response, “to bring about relief from or gain control over intense negative emotions” (Summers *et al*., 2017, p. 2).

The second theme, *reasons for suicidal behaviours*, was generated from four codes, one of which, *cry for help*, resonates with Williams’ (1997) *Cry of Pain* model. The model proposes that suicidal behaviour is reactive, and is a response to a stressful situation, and presents that there is no escape or rescue; and that there is only defeat (Williams, 1997). One respondent wrote about their suicidal ideation, describing it as an escape from a negative mental state, and not a cry for help. Their experience differs from the communicative aspect of the model, that explains that suicidal behaviours are a cry, a form of communication (Rasmussen *et al.*, 2010). This was not the intent of the behaviour for this respondent. However, their response partially accords with the Cry of Pain model, as their suicidal ideation is a response to a stressful situation.

Within the third theme, *NHS/Mental health teams*, three of the codes link with literature regarding the suicidal autistic adult, *misdiagnosis*, *autism diagnosis* and *access denied*. As autistic traits may be confused with symptoms of some mental disorders, misdiagnosis may occur (Gould and Ashton-Smith, 2011). Au-Yeung *et al*. (2019) suggest that autistic characteristics are, “misinterpreted as symptoms of a borderline personality disorder” (p. 1513). The findings suggest that BPD can be a misdiagnosis. One respondent, who had attempted suicide and was diagnosed with BPD, emphasised that they did not meet any of the other BPD diagnostic criteria.

The data relating to *autism diagnosis* in this theme was seemingly contradictory, with one respondent suggesting that the benefits of being assessed, and potentially receiving an autism diagnosis, would have had too great an emotional cost. Botha, Dibb and Frost (2020) recognise that the label of *autism* may be stigmatising, and acknowledge that, “the weight of stigma appeared to out-weigh the perceived benefits of disclosure resulting in concealment” (p. 18), of the diagnosis. Nevertheless, other literature contrasts with this finding, as receiving an autism diagnosis may have a benefit. Hickey, Crabtree and Stott (2018), though not discussing suicide, suggest that after receiving a diagnosis autistic adults can reattribute, “past negative experiences... to autism” (p. 357), rather than being self-critical.

The code, *access denied*, resonates with the findings of Camm-Crosbie *et al*. (2019). One respondent described that they were denied access to mental health services due to their autism diagnosis. Camm-Crosbie *et al*. (2019) find that some autistic adults were, “ineligible for services” (p. 1435), as, “their co-occurring autism and mental health diagnoses... made them ‘too complicated’ (p. 1435).

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6.2.3 Literature resonating with IPA study findings

The findings of the IPA study, *what is the lived experience of the suicidal autistic adult?* are divided into six super-ordinate themes, autistic well-being, emotional and practical support, financial support, autism diagnosis, autistic community, and the impact of gender. Not all the findings resonate with published literature.

The first super-ordinate theme *autistic well-being* comprises of aspects relating to autistic life experiences including depression, autistic burnout, anxiety, camouflaging and the option of suicide.

Literature suggests that in non-autistic adults suicidal behaviours are associated with depression (Hawton *et al*., 2013). Depression is also recognised as a precursor to suicidal behaviours within the autistic population (Sterling *et al*., 2008; Richa *et al*., 2014; Takara and Kondo, 2014; Cassidy, 2015; Hedley *et al*., 2018a; Livingston, Shah and Happé, 2019; Costa, Loor and Steffgen, 2020).

Depression was found to be relevant to six of the seven participants of the IPA study. Although Galina, one of the IPA study's participants, did not write about an experience of depression, they acknowledged that they had been prescribed antidepressants. The studies by Kocourkova, Dudova and Koutek (2013) and Weiner *et al*. (2019) find that antidepressants are not required for autistic adults once an autism diagnosis is obtained.

Autistic burnout, that may be due to stressors in the social and physical environment, is described as having a substantial negative impact on the quality of a person's life, including health and employment, and may lead to suicidal behaviours (Raymaker *et al*., 2020; Higgins *et al*., 2021). In this study Peter suggests his previous stressful job caused his autistic burnout and its allied suicidal behaviours. In recognising the consequences of autistic burnout, Raymaker *et al*. (2020) suggest that suicide prevention programmes need to consider it, rather than focusing on the treatment of depression.

Some literature relates anxiety to the potential development of suicidal thoughts and behaviours in autistic adults (Richa *et al*., 2014; Zener, 2019; Costa, Loor and Steffgen, 2020). Sterling *et al*. (2008), Takara and Kondo (2014), and South *et al*. (2020) recognise that anxiety is frequently discussed as either co-occurring with, or as a consequence of, depression. This is also identified as a finding within the IPA study, as four of the participants, Eliza, Coco, Galina, and Peter, wrote about anxiety being linked with their depression, sometimes whilst introducing themselves to me, and frequently within their subsequent emails. For Peter, discovering the significance of his anxiety was complicated. Peter, experiencing suicidal ideation, could clarify his feeling of deep depression and was prescribed various antidepressants. However, when his antidepressant was changed, he realised that its effect lowered his rate of anxiety, which until then he had not recognised was an issue. Later, he confirmed that he was not always affected by depression, but the continuing presence of anxiety. Recognising that autistic adults experience anxiety differently to the non-autistic population, Rodgers *et al*. (2020) have included autism specific factors within an anxiety assessment tool, the ASA-A, designed specifically for autistic adults. Furthermore, possibly due to the physiological response of anxiety, autistic adults may not recognise emotions unless they are able to process them intellectually (Rowland, 2020).

There are many links connecting the super-ordinate theme of camouflaging to literature. Cassidy *et al*. (2018c), Cassidy *et al*. (2020b) and Bradley *et al*. (2021) all suggest camouflaging may prompt suicidal thoughts and behaviours. All the participants of the IPA study have experienced suicidal behaviours, but camouflaging was particularly relevant for Avien, Dylan, Eliza, and Peter. Avien's initial responses generated the interpretation that the action of camouflaging led onto suicidal behaviours and was confirmed within their later emails. Avien and Peter described the negative effect of camouflaging whilst being employed. Responses by Peter, Eliza, and Dylan also elicited camouflaging as an emergent theme, as they described their attempts to hide their autistic traits and tried to perform as a non-autistic person. This accords with Pearson and Rose (2021) who explain that autistic people camouflage to suppress their usual autistic responses. Camouflaging is needed because autistic people are not readily accepted, principally through lack of societal awareness (Bradley *et al*., 2021). Pearson and Rose (2021) also maintain that camouflaging is a core attribute of autistic females, however, the findings demonstrate camouflaging was found in one male, one female, and two non-binary participants.

One finding of the IPA study addresses emotional and practical support. Ee *et al*. (2019) explain that autistic adults may be bullied, and Dell'Osso and Carpita (2022) describe that this victimisation may lead to trauma and PTSD, Hedley *et al*. (2017) additionally suggest that bullied autistic adults require support to address the resultant isolation. All the research agrees that bullying and victimisation may lead to suicidal behaviours. For Peter and Eliza support was provided by close family members. Dylan's support came from their partner, and the online autistic community. The online community was particularly supportive for Dylan, providing them with support for their autism and their experience of being agender. Avien recognised the support of their friends with communication and in practical ways, particularly when they were suicidal, or in hospital. Ee *et al*. (2019) suggest that support provided should be individualised. The support that these participants received met some of their individual needs. However, Paquette-Smith, Weiss and Lunsky (2014) and Richards *et al*. (2019) find that autistic individuals have difficulty requesting suitable support. Camm-Crosbie *et al*. (2019) add to this, by suggesting that autistic people do not know where to seek support. Raymaker *et al*. (2020) suggest that a lack of adequate support links with the effects of autistic burnout and possible suicidal behaviours. In this study practical support was appreciated but, as foreseen by Hedley *et al*. (2017), emotional support was rarely mentioned.

Financial support was also found to be a significant finding through either employment or the receipt of benefits. Salvatore *et al*. (2016) describe employment as a protective factor, although this is neither corroborated by Kirby *et al*. (2019), nor by the findings of this study. Avien and Peter both described that in the past they had been in employment, but both also admitted that it resulted in negative outcomes. Avien described the camouflaging and the performance required to maintain employment, whilst Peter explained the suicidal effects that his employment caused. Four of the participants, Coco, Dylan, Eliza, and Galina, gained some financial support from employment whether full-time, part-time, or as self-employed. To receive financial support, at the time of the interviews, both Avien and Peter were in receipt of benefits, which also led onto negative feelings. Avien used three distinctively derogatory terms to describe themself. Peter had his benefits stopped, but after them being reinstated described the experience being similar to drowning, and he described an intense feeling of suicide every time he received an official letter.

Avien’s negative feelings of low self-worth, and being a burden, are redolent of the IPTS (Joiner, 2005; Van Orden *et al*., 2010). In discussing this theory of suicide, Pelton and Cassidy (2017) conclude that autistic adults are at increased risk of suicide attempts, due to being, “more likely to experience depression, thwarted belonging, and perceived burdensomeness” (p. 1900). However, Avien’s experience of being a burden was real and not perceived.

A further finding of the IPA study relates to literature concerning the importance of an autism diagnosis, as Zener (2019) finds that having been diagnosed as autistic can be a protective factor against suicidal ideation. She highlights that undiagnosed autistic women are at risk of, “depression, anxiety and suicidality” (Zener, 2019, p. 11). This research by Zener (2019) is particularly relevant to Sage, who stated that they were still undiagnosed. One of their acquaintances suggested that they should use an online self-assessment tool to determine whether they are autistic. Sage explained that they researched the characteristics of female autistic adults, I therefore assumed they were female at birth. After describing their suicidal thoughts, Sage explained that they hoped to have their autism assessment soon after the completion of the interview.

The findings relating to the role of the autistic community to literature is tentative. Galina found the role of a community’s social media was significant in the development of their depression, though did not describe the nature of this community. Nevertheless, Avien, Dylan and Peter wrote about the positive attributions of the online autistic community. On receipt of their autism diagnosis Avien doubted its accuracy, until they had made contact with the autistic community. Dylan found the support of the online autistic community significantly helpful as they shared similar experiences. Peter also wrote that since his diagnosis he is in contact with more autistic people.

The super-ordinate theme, the *impact of gender*, is consistent with the development of Meyer’s (1995) minority stress theory. Although this theory initially provided a theoretical explanation for the negative stress on the mental health of specific sexual minority groups, Botha and Frost (2020) propose that non-binary and autistic individuals are also affected by conflicts with the dominant culture, being minority stigmatised groups. Avien, an autistic non-binary participant, is multiplely marginalised, and recognises their conflict with the dominant binary, non-autistic culture.

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6.2.4 Literature resonating with autoethnographic study findings

The findings of the autoethnographic study are reported within nine themes. In addition to the themes of autistic well-being, community, and emotional and practical support that are also findings within the IPA study, this method of study also highlights the themes of misdiagnosis, research, alexithymia, an autistic environment, gender, and the option of suicide. Not all findings are established in published literature.

Within the theme of *autistic well-being*, the findings demonstrate that my suicidal thoughts occurred when I was anxious about situations, and when I eventually collapsed with fatigue. This resembles the description of autistic burnout, a pervasive, long-term exhaustion, together with a loss of function, and reduced tolerance (Raymaker *et al*., 2020). Raymaker *et al*. (2020) propose a potential association of autistic burnout with suicidal behaviours, and attribute unsuitable environments as one cause of autistic burnout. My autistic burnout may have resulted from camouflaging, particularly in my work environment. Nevertheless, my experience of the online autistic community confirms Higgins *et al*.’s (2021) finding, that autistic people are very accepting of the camouflaging person who has been burnt out.

Bagatell (2010) questions how an autistic community can exist if autistic people have significant deficits in socialising and communication. The autoethnographic study suggests that I particularly appreciate the presence of the autistic community online. Arwert and Sizoo (2020) explain that there is a role for the autistic community in raising an autistic person's self-esteem, and Cooper, Smith and Russell (2017) suggest that a positive autistic social identity may result from being a member of this minority community. This autoethnographic study similarly confirms the enhancement of my self-esteem alongside my autistic identity, through being a member of the autistic community.

Hedley *et al*. (2018a) suggest that loneliness may be a suicidal risk factor and that social support is a protective factor. The Royal College of Psychiatrists (2020) confirm that post-diagnostic support is being considered for autistic individuals in England. My experience confirms Scattoni *et al*.'s (2021) findings that a majority of autistic adults do not receive any post-diagnostic autism support. The autoethnographic finding of *emotional and practical support* is based on the positive support I receive from my family. Although the intent of some support for autistic adults is to decrease loneliness, the autoethnographic study suggests that I have not felt loneliness but have appreciated aloneness.

Misdiagnosis is frequently found in the female autistic population (Gould and Ashton-Smith, 2011; Lai and Baron-Cohen, 2015; Gesi *et al*., 2021). The findings suggest that I was misdiagnosed with depression and a personality disorder. Rather than these diagnoses, the autoethnographic study appears to confirm Gesi *et al*.'s (2021) finding, that I possibly may have experienced sensory overload, and Bargiela, Steward and Mandy's (2016) finding, that due to camouflaging and internalising my anxiety, my autistic traits were not recognised. Fusar-Poli *et al*. (2020) suggest, self-injurious behaviours such as a suicide attempt, may also result in the misdiagnosis of BPD prior to receiving an autism diagnosis. This resonates strongly with these findings. Nyrenius *et al*. (2022) suggest that psychiatric *disorders*, such as BPD, may be foremost in the mind of psychiatrists, through diagnostic overshadowing, resulting in the assumption of the presence of these diagnoses and missing the autistic traits. Literature and the findings of the autoethnographic study support the necessity of taking a detailed medical history to make a correct diagnosis, as described by Carbone *et al*. (2018).

The theme of research links with literature that describes that some autistic people become experts in autism due to both an aptitude to systematically research and to their lived experience (Gillespie-Lynch *et al*., 2017). The autoethnographic study demonstrates that through research I realised that my autistic traits and high AQ (Baron-Cohen *et al*., 2001) score indicated the appropriateness of a diagnosis. The findings also demonstrate that the research has greatly aided my own recovery from being a suicidal autistic adult. It is particularly enlightening knowing that other autistic people have had suicidal thoughts and that I am not unique. Despite this positive element of research, the findings demonstrate that research also led to information that triggered negative feelings. In particular, autism is frequently described as a list of deficits, rather than emphasising the positive attributes of an autistic individual (Gillespie-Lynch *et al*., 2017; Botha, 2021). Most disturbing, and echoing Botha's (2021) experience was research that seeks to cure, or remediate, the autistic person.

Poquérusse *et al*. (2018) explain that alexithymia is frequently found in autistic adults. The findings of the autoethnographic study suggest that although I experience alexithymia, I am aware of anxiety. Preece *et al*. (2018) explain that experiencing high levels of alexithymia may be a risk factor for anxiety. Rowland (2020) suggests that the physiological response of anxiety is a result of being unable to rapidly process emotions. He further suggests that autistic adults may use their intellect to deduce or infer emotions, which may take up to 24 hours (Rowland, 2020).

The autoethnographic study's finding, *an autistic environment*, endorses Raymaker *et al*.'s (2020) conclusion that autistic burnout may result from living in an unsuitable environment. Higgins *et al*. (2021) propose that the sensory environment needs to be addressed for autistic adults, to reduce the stressors that lead to autistic burnout, or suicidal ideation. The findings suggest that the support I received included the alteration of my environment, making it suitable for living, studying, or working.

The final finding within the autoethnographic study, *the option of suicide*, relates to suicide being an escape. Baechler suggests that although suicide may not always be rational, some suicidal people demonstrate an, "internal logic" (Abbas *et al*., 2018, p. 3). The findings suggest that I have kept suicide as an option to escape stressful environments.

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6.2.5 Conclusion of findings resonating with literature

Being diagnosed autistic as an adult, and therefore having been diagnosed with a lifelong disability (Grant and Kara, 2021), I view my life events, past and present, through both autistic and disability lenses. One of the benefits of being an insider researcher, a suicidal autistic adult, was that during interviews the participants and I did not struggle with either of us using neurotypical type communication (Grant and Kara, 2021), and the allied disabling problem of double empathy (Milton, 2012). This particular benefit was achieved by undertaking the interviews using email communication, a method preferred by most of the seven participants interviewed, as well as myself. This ensured that neither the participants nor I were exhausted or debilitated by masking or camouflaging (Pearson and Rose, 2021). The research acknowledges the importance of solely using data from the autistic voice for suicidal autistic adults (Lebenhagen, 2020), whilst partially addressing one of the autism community's priorities to prevent suicide (Cassidy *et al*., 2021c).

Throughout all the findings I recognise that many of the experiences of the autistic adults in this research support the risk factors identified whilst reviewing literature. These risk factors include experiencing alexithymia, depression, anxiety, or autistic burnout, the role of different genders and the possibility of being misdiagnosed, in addition to autistic traits, such as difficulties in social communication. These risk factors may partially explain why autistic people are more likely to contemplate suicide than non-autistic people. Although appropriate support, whether social or material, is recognised by literature as being beneficial and a protective factor, this research suggests that it needs to be tailored to the individual suicidal autistic adult.

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6.2.6 New findings

This research adds to published literature, being the first study to interview previously suicidal autistic adults using email, and the first autoethnographic study that has the suicidal person, whether autistic or non-autistic, as its focus.

The findings of these studies suggest that suicidal autistic adults cannot be stratified according to risk in the same manner as non-autistic adults. Autistic adults may have a suicidal thought and then impulsively attempt suicide, rather than going through the action of planning. The data also suggest that suicidal behaviours, including attempts, may be present in autistic adults who have neither been diagnosed with, nor experienced, depression.

A new finding that traversed the three data collection studies is that the suicidal autistic adult always has an option of suicide. One of the respondents of the online survey wrote that suicide is a daily consideration, three of the interviewees in the IPA study described suicide as being in the back-pocket, a safety net, or a means of escape, and the autoethnographic study suggests suicide remains an option.

I found new risk factors for suicide in autistic adults that included being misdiagnosed with mental health conditions due to be suicidal, and the repercussion of being prescribed medication for the misdiagnosed condition and being assessed and diagnosed as autistic at an older age. The demographic characteristics outlined that autistic adults interested in assisting suicide related research have attained higher levels of education.

Although support for autistic adults has been recognised previously as a protective factor, receiving support designed specifically for autistic people was highlighted as being significant.

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6.3 Discussion of findings

In this section I discuss how the findings of each of the studies link with those of the other studies. I start with the findings linking with the quantitative study and follow this with the findings linking with the thematic analysis. I continue with the findings linking with those of the IPA study, and finally discuss those relating to the autoethnographic study. The demographic characteristics are sometimes included when relevant to specific findings.

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6.3.1 Quantitative analysis findings

The findings of the quantitative analysis link to those of the TA, the IPA, and the autoethnographic study in various ways. I discuss the findings of the quantitative analysis that connect with the findings of each of the other methods of analysis in turn.

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6.3.1.1 Discussion of findings that link the quantitative analysis to thematic analysis

The TA was undertaken using 36 respondents’ elaborations reflecting upon their responses to the online survey, mainly relating to their suicidal behaviours and their co-occurring conditions. The links between the two sets of findings relate to depression and to suicidal behaviours. Within the findings of the quantitative study there is evidence that suicidal ideation is associated with experienced depression. Depression was experienced by 70 (94.6%) of the respondents and suicidal ideation by 72 (97.3%) of the 74 respondents, and suicidal ideation was one of the codes generated within the TA. One respondent described that their ideation ceases once they have attempted writing a suicide note, with another explaining that they only experience suicidal ideation, and had never planned or attempted suicide. The quantitative analysis demonstrated that more respondents had experienced suicidal ideation ($n = 72$), than had experienced suicidal planning ($n = 58$).

The demographic characteristics indicate that all the respondents with a depression diagnosis had experienced depression. Analyses demonstrate the findings that suicidal plans are associated with experienced depression, and suicidal plans are associated with diagnosed depression. Seventy respondents (94.6%) have experienced depression, with 55 (74.3%) respondents receiving a depression diagnosis, and 15 (20.3%) not having a diagnosis. Whilst 12 respondents mention suicidal plans in their comments, four of these specifically mention that they have *not* made plans. Due to the data collection tool used, I was unable to identify the responses made by those with diagnosed depression and separate them from those written by respondents who had experienced depression.

The TA responses included the number of times the respondents had planned suicide, the cause of their plan, and the consequences of having made a plan, as well as the relationship of suicidal plans to suicide attempts. One participant mentioned the number of suicide plans they have made, two others specified that their suicide plans and attempts were not at the same time. The demographic characteristics identify that one person acknowledged having suicidal ideation and attempts, though they had never made any suicide plans. This finding is endorsed within the TA with a respondent writing that although they had not planned one suicide attempt, suicidal planning had not resulted in an attempt. The quantitative findings report 35 respondents (47.3%) having experienced at least one suicide attempt. Within the TA, for the code *suicide attempts*, I analysed 14 responses, ten describing suicide attempts and four suggesting that they have not attempted suicide. Some of the respondents had found other solutions, such as non-suicidal self-injury. The code, suicide attempts, included four categories, age, number, cause, and consequence, with some responses ascribed to two different categories. As one person's suicide attempt resulted in being misdiagnosed with BPD, the code *misdiagnosis* within the theme of *NHS/Mental health teams*. This finding links with the demographic characteristics which records five respondents reporting co-occurring BPD.

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6.3.1.2 Discussion of findings that link the quantitative analysis to the IPA study

There is evidence that the findings of three *a priori* hypotheses within the quantitative analysis relate to the findings of the IPA study; that both suicidal ideation and suicidal planning are associated with the experience of depression, and that suicidal planning is associated with diagnosed depression. The first finding, suicidal ideation is associated with experienced depression, is relevant for five IPA participants, with Peter specifically writing that he struggles with depression and suicidal thoughts. However, Peter's GP claimed there was no cause for his depression. The second finding, suicidal planning is associated with experienced depression, is relevant for five of the participants. Avien connected their depression with suicidal planning. The third finding that links the two studies is that there is a relationship between suicidal planning and diagnosed depression. Coco who described taking anti-depressants, and would therefore have received a depression diagnosis, confirmed this link suggesting that she had planned suicide several times.

The notable occurrence of anxiety and PTSD within the demographic characteristics are reflected within the IPA super-ordinate themes of *autistic well-being* and *the impact of gender*. With 35% of all respondents acknowledging co-occurring anxiety, three of the participants connected suicidal planning to anxiety within the super-ordinate theme of *autistic well-being*. Confirming this link, Coco introduced herself as being anxious, and later attributed her suicidal planning to anxiety, in addition to other difficulties. The demographic characteristics also confirm that half of the respondents acknowledging co-occurring PTSD are non-binary. Four of the seven interviewees for the IPA study were non-binary. However, *the impact of gender* shows that Avien, who is non-binary, was the only interviewee who mentioned PTSD or any associated symptoms, whilst also explaining that their suicide attempts were numerous.

Furthermore, the link describing the respondents’ genders shows that in the online survey 20.3% (n = 15) of the respondents were non-binary, with 50% (n = 37) being female, comparing with the participants of the IPA study, where 57.1% (n = 4) are non-binary, and 28.6% (n = 2) are female. Out of the seven participants, Peter was the sole male in the IPA study, compared with 22 (29.7%) who were male in the initial online survey.

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6.3.1.3 Discussion of findings that link the quantitative analysis to the autoethnographic study

The findings of the quantitative study that resonate with those of the autoethnographic study are associated with the roles of depression and anxiety. The demographic characteristics confirmed that 35% of respondents acknowledged co-occurring anxiety. The quantitative study's findings that both suicidal ideation and planning are associated with diagnosed depression are also supported by the autoethnographic study, which shows I was diagnosed with depression. I believe this possible diagnosis of depression was based on my suicidal ideation and planning. In the autoethnographic study I report that although I did not experience depression, some of my autistic traits are described as depressive symptoms within the diagnostic tools designed for non-autistic adults. The HADS (Snaith and Zigmond, 1994) tool highlighted that I was anxious and not depressed, which resonated with my internal feelings.

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6.3.2 Thematic analysis findings

I discuss the findings of the TA that connect with the findings of each of the other methods of analysis.

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6.3.2.1 Discussion of findings that link the thematic analysis to the quantitative analysis

Codes from the TA theme of *suicidal behaviours* particularly link to the findings of the quantitative analysis. Both sets of findings reflect that not all suicidal autistic adults relate to experiencing depression. The demographic characteristics demonstrate that two respondents had experienced suicidal behaviours, one suicidal ideation, and the other suicidal ideation, plans, and attempts, whilst neither had experienced depression nor were diagnosed with depression. This finding is associated with one response within the TA, indicating that the respondent did not have any mental health issues, despite having suicidal behaviours.

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6.3.2.2 Discussion of findings that link the thematic analysis to the IPA study

The findings that link the TA to the IPA study are numerous. Within the thematic theme of *suicidal behaviours*, most of the codes determining this theme are acknowledged by at least one of the participants of the IPA study. However, as all the participants had been recruited due to their suicidal experiences, *suicidal behaviours* does not appear as a super-ordinate theme. In addition to suicidal ideation, plans, and attempts, a*ssociated depression?* is a code within the theme of suicidal behaviours. The findings of the IPA study indicate that all the participants, apart from Sage, wrote about depression. Three of the comments within the TA suggest that suicidal ideation or planning is associated with depression, and one response suggests that suicidal ideation worsens with the experience of depression. Similarly, Avien, Eliza, and Peter, all wrote about their suicidal behaviours being related to their depression in the IPA study.

The findings from the TA identify two further responses that generated the addition of the question mark within the *depression?* code. One respondent questioned whether they were ever depressed but commented that they had been prescribed anti-depressants. Another respondent acknowledged that they had been depressed in the past, but now have a satisfying career and home life, yet though not depressed they continue to contemplate suicide. This sense of questioning, whether depression was correctly associated with suicidal behaviours, may be pertinent to Sage who never mentioned depression despite being suicidal.

Within the theme of *reasons for suicidal behaviours* one response within the TA generated the code *suicide is an option*, which is congruent with the findings of the IPA study. In the IPA study the option of suicide was linked with escape, a safety net, and being kept in the back-pocket within the super-ordinate theme of *autistic well-being*.

Within the IPA study's super-ordinate theme of *emotional and practical support*, one of the findings link with the response of the TA that generated the theme *the effect of suicide on others*, with the respondent being concerned about the effect their suicide would have on a family member. Similarly, within the IPA study, Peter described how the negative effect of his suicide would impact his family. A further finding of the TA that links with this super-ordinate theme, from the IPA study, is the code of *hospitalisation*, which helped produce the theme of *NHS/Mental health teams*. In the TA, three of the responses indicated stays in hospital, whether in a psychiatric hospital having been sectioned, or in an intensive care unit, following a suicide attempt. The third response only indicated that their suicidal attempt resulted in a hospitalisation, without any further clarification. Two further respondents wrote about times of suicide attempts, with the methods described usually necessitating medical treatment in a hospital. The linked finding, within the IPA study, demonstrates that Avien received support during their frequent hospital admissions which were following suicidal ideation, or attempts.

In the theme of *NHS/mental health teams*, within the TA, two further codes link with the super-ordinate themes of the IPA study. The first relates to having an autism diagnosis. As this was a significant element of both studies, both a code and a super-ordinate theme, were entitled *autism diagnosis*. This super-ordinate theme also includes *misdiagnosi*s, which is also a code within the TA. Peter was one of the five participants of the IPA study who categorised their autism diagnosis as a part of their identity. Avien, Dylan, and Galina used the term *autistic*, acknowledging their traits are a part of their identity. All the participants were positive about an autism diagnosis. Contrasting with this IPA study's finding, the TA found that receiving an autism diagnosis would have been too emotionally costly.

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6.3.2.3 Discussion of findings that link the thematic analysis to the autoethnographic study

Being a focus of the entire study, the term *suicidal behaviours* was not elicited as a theme within the findings of the autoethnographic study. Despite this omission, the findings acknowledge within the theme of *autistic well-being* that I had experienced suicidal ideation, and planning, and had made suicidal attempts. This supports the findings of the theme *suicidal behaviours* within the TA. One respondent in the TA questioned whether they had a depression diagnosis as they did not have the diagnosis in writing, likewise, the findings detail that I was prescribed anti-depressants, was never told I was depressed, and therefore questioned whether I had a diagnosis of depression.

The findings of the TA are also congruent with those of the autoethnographic study within the theme of *reasons for suicidal behaviours*. The findings of the autoethnographic study, in the theme of *the option of suicide*, support those of the TA, that once suicide has been attempted it remains as a rational option despite improved circumstances. In the autoethnographic study, I mention that I became aware of the effect that my potential suicide would have on others especially my family. This finding supports the coding of *the effect of suicide on others* within the TA's theme of *reasons for suicidal behaviours*. The TA findings demonstrate that three people wrote about the effect their suicide would have on other people. The first had considered a method of suicide that necessitated the involvement of another person, and therefore did not make the attempt. Whereas the second wrote that their suicide would have caused a group of students to have had a wasted journey, and the third wrote about how their suicide would affect a member of their family.

Three of the four codes within the TA theme, *NHS/mental health teams*, are supported by the findings within the autoethnographic study. The finding, *misdiagnosis*, was a code within the TA and an autoethnographic theme. Similar to the comment relating to an autistic adult being misdiagnosed with BPD in the TA, the autoethnographic study also acknowledges my misdiagnosis of BPD. Both misdiagnoses were potentially based on the one BPD criterion of having experienced suicidal thoughts and behaviours.

The autoethnographic theme, misdiagnosis, in which I describe the benefits of an autism diagnosis, supports the relevancy of the TA code *autism diagnosis*.

Contrasting with the benefits that I found after being diagnosed as autistic, in the TA these are not recognised, as having an autism assessment, and potentially receiving a diagnosis, would have had too great an emotional cost.

The autoethnographic study findings support those of the TA in relation to the code *access denied*. Once an autistic adult receives their diagnosis, they can have difficulty accessing mental health services. One TA respondent described the difficulty they had accessing mental health services after receiving their autism diagnosis. The autoethnographic study describes that my experience was similar. After many years of using the mental health services, once I received my autistic diagnosis, their support was withdrawn.

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6.3.3 The IPA study's findings

I discuss the findings of the IPA study that connect with the findings of each of the other methods of analysis.

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6.3.3.1 Discussion of findings that link the IPA study to the quantitative analysis

The findings of the IPA study that link to the findings of the quantitative analysis, although partially discussed previously, focus upon the super-ordinate theme of *the impact of gender*. Including this super-ordinate theme was important as gender seemed to be a contributory factor for some suicidal behaviours within this sample. Additionally, the super-ordinate theme acknowledges Dylan's statement that they do not have an experience of gender. Within the IPA study I describe four of the participants as non-binary, two as female, and one as male. The demographic characteristics show that half were female (*n* = 37), 29.7% were male (*n* = 22) and 20.3% were non-binary (*n* = 15). The data indicate that all the male and non-binary respondents had experienced suicidal ideation. Only two females had not experienced any suicidal thoughts. Within the IPA study, all the participants had experienced suicidal behaviours.

The findings within the IPA study that focus upon gender are particularly related to Avien and Dylan. Avien experienced oppression from others, and dissatisfaction with their assigned birth gender, which resulted in intense suicidal thoughts. Dylan attributed their suicidal thoughts to growing up in a very religious home that did not accept their non-binary status.

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6.3.3.2 Discussion of findings that link the IPA study to the thematic analysis

The IPA study was designed to research, *what is the lived experience of the suicidal autistic adult?* Therefore, all the findings relate to the theme of *suicidal behaviours* within the TA. Six of the interviews contained a mention of suicidal ideation to some extent, only Galina did not make a reference to having suicidal ideation before making their suicidal plans. Five participants, Avien, Coco, Dylan, and Eliza in addition to Galina, discussed suicidal planning within their emails. Furthermore, suicidal attempts were also discussed by Avien, Galina, and Sage.

The importance of the TA code, *autism diagnosis*, is acknowledged within the findings of the IPA study and became one of the super-ordinate themes. However, the finding within the TA conflicts with the finding of the IPA study, as one respondent claimed that the benefits of being assessed, and receiving an autism diagnosis, would be too emotionally costly.

The findings of the IPA study include the super-ordinate theme of *autistic well-being* within which the theme of depression partially links with the code *associated depression?* assisting to determine the TA theme of *suicidal behaviours*. However, the findings of the two studies conflict. Within the TA the diagnosis of depression was questioned. Within the IPA study all the participants except for Sage, wrote about depression, but none of the other six participants questioned their depression diagnosis. Eliza linked her depression with suffering, and Peter described his depression as significant and impactful. Despite knowing of Peter's suicidal thoughts, it was the GP who reportedly questioned his depression.

A further IPA study finding within the super-ordinate theme of *autistic well-being* relates to the code *suicide is an option* within the TA. Phrases explaining having suicide as an option were used in both studies; keeping suicide in a back-pocket, as an escape, or as a safety net, were used in the IPA study, whereas suicide is a rational daily option was used in the thematic analysis.

The super-ordinate theme of *emotional and practical support*, one of the findings of the IPA study, links with the code *hospitalisation* within the TA's theme of *NHS/Mental health teams*. Avien wrote about the practical support that they received from friends every time their suicidal planning or attempts resulted in a hospital admission. The support they received included caring for their cat.

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6.3.3.3 Discussion of findings that link the IPA study to the autoethnographic study

The autoethnographic study was analysed independently from the IPA study. However, alongside my reflections, resonances with the IPA study's super-ordinate themes helped generate three themes of the autoethnographic study. The themes in common to both studies are *autistic well-being*, *emotional and practical support*, and *autistic community*. Furthermore, within *autistic well-being*, the findings of both studies relate to the experiences of anxiety, camouflaging, and autistic burnout. However the option of suicide, linked with autistic well-being in the IPA study, became a theme on its own in the autoethnographic study. There is a conflict between the two sets of findings relating to depression. Six of the IPA participants related their suicidal behaviours to depression, whereas in the autoethnographic study these behaviours are linked with anxiety and not the diagnosed depression.

One finding of the IPA study was the *impact of gender*. Four of the participants were non-binary, in addition to being autistic, which recognised them as being multiplely marginalised. In the autoethnographic study, the theme was only termed *gender*, as I undertook this research as a cisgendered female, and my gender may not have influenced my suicidal behaviours. Nevertheless, as a female my autistic traits were overlooked until I received a diagnosis following autistic burnout. This autoethnographic finding, therefore, partly supports that relating to the IPA study.

The IPA study's findings indicate that, for at least three participants, there is a connection between suicidal behaviours and anxiety. Coco, Galina, and Peter mentioned that anxiety, and its effects, contributed to their suicidal episodes. Likewise, the findings of the autoethnographic study explain that my suicidal thoughts occurred when I got anxious, confirmed through using the HADS (Snaith and Zigmond, 1994) tool that differentiates depressive symptoms from those of anxiety.

The findings from the IPA study concerning camouflaging suggest that this autistic trait contributes to suicidal behaviours for two participants. Avien and Peter had camouflaged whilst in employment, resulting in negative experiences. The interpretation of Eliza's and Dylan's scripts led to the conclusion that camouflaging or masking was relevant to them, even though neither used these terms. The findings of the autoethnographic study demonstrate that as a teacher I had to camouflage within the school environment, which I found exhausting. This exhaustion developed into autistic burnout and suicidal thoughts, plans, and attempts. The findings of the IPA study, relating to autistic burnout, are therefore also supported by the findings of the autoethnographic study. Similarly, the comments analysed during the IPA study, describing the *option of suicide* as an escape, a safety net, and in the back-pocket, are supported by the finding of the autoethnographic study, that highlights that suicide remains as an option despite my improved personal environment and self-esteem.

The IPA study's findings are supported by those of the autoethnographic study, relating to *emotional and practical support*. Family were found to be supportive in both studies. Coco, Eliza, and Peter described their close family as supportive. Likewise, in the autoethnographic study, I explain the importance of family support to reduce isolation, and to aid with communication.

The findings of the IPA study relating to the significance of *autistic community* are supported by my experiences highlighted in the autoethnographic study. In the IPA study, Dylan emphasised that the online autistic community are very knowledgeable and helpful, specifically in relation to non-binary issues. In the autoethnographic study, I include the importance of the online autistic community, especially in the areas relating to learning about anxiety, camouflaging and autistic burnout, resulting in an improvement of my self-esteem.

Within the autoethnographic study, I also acknowledge the significance of a faith community. In the IPA study, Dylan found that the experience of living in an evangelical household was hostile. Contrasting with Dylan's experience my home environment is supportive, but I found that my faith did not protect me from developing suicidal behaviours.

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6.3.4 The autoethnographic study's findings

I discuss the findings of the autoethnographic study that support the findings of each of the other methods of analysis.

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6.3.4.1 Discussion of findings that link the autoethnographic study to the quantitative analysis

The findings within the autoethnographic study support findings within the quantitative analysis. One result from an *a priori* hypothesis shows that suicidal planning is associated with diagnosed depression. A finding of the autoethnographic study explains that despite not agreeing that I had experienced depression, I may have been diagnosed with depression as, having made suicidal plans, I was prescribed antidepressants. The findings from both studies also reflect a connection between anxiety and suicidal behaviours in autistic adults. Twenty-six respondents (35.1%) reported anxiety as a co-occurring condition during the online survey, and the autoethnographic study confirms that I also experience anxiety.

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6.3.4.2 Discussion of findings that link the autoethnographic study to the thematic analysis

The findings of the autoethnographic study and the TA include *misdiagnosis*. The finding in the TA demonstrates that one respondent was diagnosed with BPD due to their suicidal behaviours, however, this diagnosis has been retracted. The autoethnographic study demonstrates that, prior to my autism diagnosis, I was also diagnosed with BPD, although I only met one diagnostic criterion for BPD, that of suicidal behaviours. In both studies BPD is identified as a misdiagnosis, hence, the autoethnographic study supports the findings of the TA.

The findings relating to the *option of suicide* in the autoethnographic study generated a separate theme. These supported the TA code, using the same term, relating to the theme of *reasons for suicidal behaviours*. One respondent stressed that suicide is a logical, daily option in three different sentences. In the autoethnographic study I, too, describe that suicide is still an option I have, and particularly as a rational option when I am anxious.

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6.3.4.3 Discussion of findings that link the autoethnographic study to the IPA study

There are several findings, described as themes, within the autoethnographic study that support the findings of the IPA study, demonstrated as super-ordinate themes. The three coinciding findings are associated with the super-ordinate theme of *autistic well-being*; camouflaging, anxiety, and autistic burnout.

Within the autoethnographic study's findings I describe the results of camouflaging as autistic burnout and suicidal behaviours. These support the findings of the IPA study, where Avien, Peter, Eliza and Dylan, all described camouflaging within their scripts, or camouflaging was evoked as an emergent theme. The finding within the autoethnographic study that I realised I experience anxiety, supports the IPA study's findings from Coco, Galina and Peter, who also attributed their suicidal episodes to anxiety. Autistic burnout was also a finding for both studies. The autoethnographic study establishes that I eventually identified the experience of the physical and mental collapse as autistic burnout. Peter, Avien, and Dylan all identified times when they experienced the effects of autistic burnout, although within the IPA study this experience was included within the super-ordinate theme of *autistic well-being*. Peter described autistic burnout as a collapsing due to depression and exhaustion. Avien and Dylan described episodes of depression being concurrent with those of autistic burnout. Nevertheless, the findings of the autoethnographic study diverge from those of the IPA study, in that the autoethnographic study highlights that I experienced autistic burnout, but not depression.

Within the findings of the autoethnographic study one theme relates to *research*. Within the findings of the IPA study, research appears as a response to seeking an *autism diagnosis*. The autoethnographic study's finding clarifies my experience of research as getting lost in its positively stimulating process. This experience supports the IPA finding that suggests that Peter, too, experiences such a fillip whilst researching to fulfil his intellectual curiosity about autism.

Although the participants of the IPA survey were recruited through an online social media site, it was found that only Dylan mentioned the importance of the online autistic community. Within the findings of the autoethnographic study, I express the positive effects on my self-esteem from belonging to such a community. One of these benefits was becoming increasingly aware of the effects of autistic burnout. This led me to assess my autistic traits and seek a late autism diagnosis, aged 50+. Being female, and having a late diagnosis, raised the theme of *gender* within the autoethnographic study. Within the IPA study, nearly all the participants were diagnosed in their twenties and thirties, or earlier. Only Sage was older, and they explained that, although non-binary, they had researched the female presentation of autism. Later autism diagnosis and female presentation of autistic traits may link these two studies.

The findings relating to *emotional and practical support* were similar within both the autoethnographic and IPA studies, as they both demonstrate the importance of family. I appreciate the support of my family, whilst Peter, Coco and Eliza were also supported by members of their close families. I explain that I also received my family's support in communicating, especially in medical appointments. This resonates with, and supports, the findings from the IPA study, where Avien described their need of support to help with their communication and to advocate for their needs, and where Eliza acknowledged the wide-ranging support from her husband.

The final finding where the autoethnographic study supports the findings of the IPA study is the theme of *the option of suicide*. I mention that despite choosing to live in a more autistic friendly environment, suicide remains a rational option. As mentioned previously, Dylan, Sage, and Peter each used different terms to demonstrate that suicide also remained an option for them.

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6.3.5 Synthesis of findings

The findings of the four studies, collected by the three methods, the online survey, the phenomenological interviews, and the autoethnographic study, relate to the experience of the suicidal autistic adult. The quantitative analysis' *a priori* hypotheses find three significant results, the TA finds three themes generated from 14 codes, the IPA study describes six super-ordinate themes, and the autoethnographic study highlights nine themes. The findings of the separate methods of analysis all include the autistic voice in relation to the experience of suicidal behaviours.

The exploration of suicide and autism, through quantitative, qualitative and autoethnographic perspectives, confirms that autistic adults experience suicidal ideation, planning and attempts. The initial findings of the quantitative analysis suggest that the autistic adults who experience either, or both, suicidal ideation and planning also experience depression, and those who have made suicidal plans have been diagnosed with depression. These findings are endorsed by those of the TA and the IPA studies. However, the TA suggests a complex relationship between depression, autism, and suicidality. The autoethnographic study's findings suggest there may be inaccuracy in diagnosing depression, as some of the criteria used in depression assessment tools resemble common autistic characteristics.

The findings relating to depression are complex. Suicidal autistic adults may experience depression, with some receiving a diagnosis, whilst some do not experience depression, but receive a diagnosis. A finding of the autoethnographic study suggests that suicidal autistic adults may not experience depression, even if suicide has been attempted. This is also established within the IPA study, with one person never mentioning depression throughout the interview, and is supported by the online survey respondents' demographic characteristics.

All the studies confirm that suicidal autistic adults receive diagnoses for co-occurring conditions, some of which may be misdiagnoses. The co-occurring conditions include anxiety, ADHD, and PTSD. The autoethnographic study supports the finding of the TA suggesting that autistic adults with a diagnosis of BPD received this diagnosis prior to their autism diagnosis, and that it may be inaccurate. Misdiagnosis may occur when mental health professionals recognise the suicidal thoughts and behaviours, whilst not readily identifying the presenting autistic traits.

The findings of the autoethnographic study supports those of the IPA study suggesting that an autism diagnosis creates opportunities to access the support of the wider autistic community, in face-to-face situations, and through the use of the internet. This contrasts with the finding of the TA, where the finding suggests that seeking an autism diagnosis has too great an emotional cost. Furthermore, the findings of the TA and autoethnographic study also provide evidence that once an adult receives their diagnosis of autism, access to mental health support is denied.

To reduce stress, the study identifies the benefits of ameliorating the personal environment, the roles of emotional, practical, and financial support, in addition to that of research. Despite the experience of these benefits, the qualitative analyses find that suicide is recognised as a rational option for some of the adults in the study.

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6.4 Strengths and limitations

There are several strengths of this research. The first is that it addresses part of one of the autism community's priorities for suicide prevention in that it seeks to understand the suicidal experience of autistic people (Cassidy *et al.*, 2021c). This study may also add to future research related to one of the other autism community's priorities, examining "the development of suicidality that is not associated with other mental health symptoms across the lifespan" (Cassidy *et al.*, 2021c, p. 3). I also advance research relating to the understanding of suicidal thoughts and behaviours through the sole use of the autistic voice in data collection. This is achieved through the responses of autistic respondents to an online survey, from email interviews of autistic participants, and from the analysis of a suicidal autistic adult's autoethnographic study. This research may be the first to use email interviews to explore the experience of the suicidal autistic adult, and supports the use of asynchronous communication to suit the needs of many autistic adults, as proposed by Benford (2008). Emails provide a platform from which autistic adults can respond, without being disabled by any difficulties in communication or environment. This method may have additionally reduced the influence of social desirability bias, in which the participant distorts their experience to meet the expectations of the interviewer (Grimm, 2010; Ball, 2019). This may have been achieved, through email communication, as there was distance between the interviewer and the interviewee. This research is also the first to use an autoethnographic study relating to suicide with the suicidal person as the subject.

Being an insider researcher may have been a strength, as I may have drawn out additional rich data that the interviewees may not have divulged to a non-autistic researcher, and I was able to interpret this data through an autistic lens. However, being autistic may have had a limiting implication, in that I did not pursue supplementary questions to seek clarification of certain data.

I did not verify the autism diagnosis of the respondents, as they self-identified as autistic, through the signing of the consent form. To confirm that the respondents of the online survey had autistic traits, I used the autism-spectrum quotient (AQ) (Baron-Cohen *et al.*, 2001) and empathy quotient (EQ) (Baron-Cohen and Wheelwright, 2004), which are self-administered and self-reported questionnaires. These tools, together with the method of data collection, excluded those with intellectual disabilities and those unable to use technology, which is a limitation of this study. Using the AQ questionnaire had further limitations. Its use is resisted within the autistic community, and it is considered to over-represent autistic traits as possibly found within a young male population (van der Aa *et al*., 2016; Brown *et al*., 2020).

The respondents of the online survey had higher levels of education, than would be expected in a sample from a non-autistic population. This may have been due to the process of recruitment. Moreover, when I advertised in a county's autism support groups, with the aim to address this problem, I again was put in contact with people having higher level degrees. Although people of different educational levels used the online survey, there was a greater number of those with higher levels of education. Respondents may have shared the survey information with their *friends* who had similarly experienced suicidal behaviours, and this may have led to the over-representation of one group of autistic adults with a particular perspective (Ball, 2019). However, this snowball strategy is considered to be beneficial for an IPA study, as it can attract a greater number of suitably experienced participants to the research (Biernacki and Waldorf, 1981; Alase, 2017).

Some of the respondents were confused regarding the difference between suicidal ideation and suicidal planning within the online study. This limitation may have affected their responses to the specific questions relating to suicidal behaviours and may have deterred others from completing the survey. Seven respondents who were sent the link to the survey did not complete it.

I had challenges to overcome in the IPA study. The autistic participants used the terms depression and anxiety almost interchangeably and did not define what they meant by each term. I also did not ask them to define the meanings of their words. Using a tool such as the hospital anxiety and depression scale (HADS) (Snaith and Zigmond, 1994) could have determined whether the participants had experienced anxiety or depression, or indeed both, but my role was to gather data relating to the exploration of the lived experience, not to screen for a mental state. I realised that being an autistic insider researcher, I needed to adapt the IPA process to accord with my autistic characteristics. This may be seen, by some, as a limitation. I found it difficult to look beyond the pre-planned questions and, therefore, did not probe for further information. To address this I could have had more pre-planned questions. The strength of this approach was that it provided consistency, enabling the data from different participants to be more easily compared.

I observed that many autistic people have a difficulty in exploring open-ended questions. Owing to the nature of IPA requiring the use of open-ended questions, I could query whether IPA was a helpful tool for exploring *what is the lived experience of the suicidal autistic adult?* Nevertheless, I believe that this is the most suitable method available to explore lived experiences.

A limitation of using an autoethnographic method, is that as I wrote my responses, I was conscious that other people would read the narrative and that my own inner feelings and thoughts were being exposed (Méndez, 2013). To aid confidentiality I only include a brief narrative within the thesis.

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6.5 Recommendations for policy and practice

Policies and practice relating to the suicidal autistic adult have been developed and adapted due to recognising that this specific population group has, “specific needs and characteristics, that may expose people to more risk factors for suicide" (HM Government, 2021a, p. 31). To highlight the importance of meeting the needs of their suicidal autistic constituents, members of parliament discussed '*Autism Community: Mental health and suicide*', in the House of Commons, on 30th November, 2017 (Hansard, 2017).

In addition to the policies and practices that are already in place, I make recommendations based on the findings of this research.

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6.5.1 Current policies and practices

The various published acts, policies, reports, and clinical guidelines include guidance that could provide support for the suicidal autistic adult:

- The *Autism Act (2009)* makes, "provision about meeting the needs of adults with autistic spectrum conditions; and for connected purposes" (Autism Act, 2009).
- the *Equality Act (2010)* defines disability as, "a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on the ability to do normal daily activities, and this includes people with autism" (Kent Autism Collaborative, 2016, p. 11).
- The clinical guidelines, '*Autism: Recognition, Referral, Diagnosis and Managements of Adults on the Autistic Spectrum*' (NICE, 2012), offer guidance regarding diagnosis, support, and care for autistic adults in relation to physical and mental health.
- The *Care Act (2014)* incorporates the care of autistic people within its remit.

- The ‘*Adult Autism Strategy 2015*’ (DH, 2015b) includes statutory guidance for Local Authorities and NHS organisations regarding preventative support and safeguarding as outlined in The Care Act (2014).
- The policy ‘*Learning from Lives and Deaths - People with a Learning Disability and Autistic People’* (LeDeR) (NHS England and NHS Improvement (NHSE/I), 2021) aims to reduce heath inequalities and prevent premature mortality in people with intellectual disabilities, and since 23rd March 2021, has included autistic people.
- ‘*The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026’* (HM Government, 2021b) aims to improve the services and support for autistic people, by addressing inequalities that autistic people face, so that autistic people can live, “healthier and longer lives” (p. 13).
- The report, ‘*Preventing Suicide in England: Fifth Progress Report of the Cross-Government Outcomes Strategy to Save Lives*’ (HM Government, 2021a), addresses “the wider drivers of suicide and self-harm” (p. 27), and identifies autistic adults as one group with specific needs.

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6.5.2 Recommendations for future practice

From the evidence of the findings of this study, I suggest the following recommendations for future policy and practice to improve suicide prevention strategies for autistic adults. These strategies need to recognise that:

- Autistic adults frequently identify as autistic prior to assessment owing to the extent of research they have undertaken into their *traits*. This self-identification needs to be taken into consideration by clinicians.

- Clinicians and therapists need to be able to recognise autistic traits in undiagnosed adults, so they can direct these adults towards an autism assessment, and appropriate support.
- Autistic adults should be assessed for suicidal behaviours, as these findings suggest autistic adults with higher AQ scores may plan suicide.
- Mental health professionals assessing adults for mood and anxiety disorders may miss autistic traits in a suicidal adult leading to a misdiagnosis.
- There is an association between having made suicidal plans and having a depression diagnosis, so that autistic adults with co-occurring depression should be assessed for suicidal behaviours.
- There is an association between autistic adults having co-occurring anxiety and making suicidal plans.
- Autistic adults may make impulsive suicide attempts without the planning.
- Not all autistic adults who have attempted suicide have experienced or been diagnosed with depression.
- As there are associations for autistic adults between experienced depression and suicidal ideation, between experienced depression and suicidal planning, and between diagnosed depression and suicidal planning, autistic adults for whom depression is a consideration should be assessed for suicidal behaviours.
- Autistic adults may keep suicide as an option, even after suicidal crises have resolved.
- Autistic adults with co-occurring PTSD may attempt suicide.
- Non-binary gendered autistic adults may have co-occurring PTSD.

- Support offered, whether practical or more rarely emotional, is carefully negotiated with the autistic adult.
- Suicidal autistic adults may need financial support.
- Autistic burnout may be the cause of suicidal behaviours in autistic adults, and that associated negative stressors, such as camouflaging, anxiety, or sensory overload, are identified and steps taken to ameliorate them.
- The online autistic community may provide suitable support for suicidal autistic adults.
- Autistic adults are at increased risk of suicide, being part of a marginalised group, and may be multiplely marginalised if they are non-binary.

I further recommend that assessments are undertaken with tools specifically designed for use with autistic adults; suicidal behaviours being assessed using a tool such as the SBQ-ASC (Cassidy *et al*., 2021b), depressive symptoms being assessed using a tool such as the ADAT-A (Cassidy *et al*., 2021a), and for the assessment of anxiety, the ASA-A (Rodgers *et al*., 2020) is advised.

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6.6 Implications for autistic researchers

Autistic researchers may take the following experiences and observations into consideration. Being an autistic researcher involved having to adapt the chosen research methods, particularly IPA, to allow for my autistic traits. To consider all relevant literature, I had to address my negative reactions to research that described autistic people as lacking, having a deficit, or not healthy. Contrastingly, I also found participatory research, either including autistic adults in the development of the research, co-produced with autistic researchers, or being produced only by autistic researchers. Being an autistic insider researcher, and having a similar lived experience to the participants, enabled me to empathise with the participants and cultivate trust. Nevertheless, being an autistic insider researcher may have hindered further probing of the lived experiences of the interviewees.

One feature Baron-Cohen *et al*. (2009) attribute to autistic people is, “excellent attention to detail” (p. 1377). I learnt, whilst reporting the results of the studies, not to include details, that I may have been drawn to, that could possibly identify any contributor to the online survey or the IPA study.

To be able to achieve this research I received emotional support from some neurotypical researchers. I received financial support, emotional support, and suitable adjustments, through the various schemes available for disabled students. Further support was provided by the online autistic community, and more specifically autistic researchers.

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6.7 Recommendations for future research

I recommend that future research involves autistic adults in every aspect of suicide prevention specific to the autistic community, from the planning stage to data collection, and analysing the results. To improve suicide prevention the experiences of suicidal autistic adults in this study highlight the need for further research into the following four areas: risk factors that specifically affect autistic people; raising the awareness of suicide within the autistic community; the awareness of the risk of misdiagnosis; and, the provision of autistic appropriate support.

The demographic characteristics of the respondents of the online survey highlight some potential risk factors for suicidal behaviours in autistic adults. Confirming the results of previous research, this research finds that these autistic adults displayed a high prevalence of co-occurring anxiety and PTSD, and that 20% of the online survey's respondents were non-binary, as were over half of the participants interviewed. Being non-binary adds the risk of being mis-gendered. and due to a paucity of published research in this area regarding autistic adults, I recommend the following future research.

- Research the effect of being misgendered on suicidal behaviours in autistic adults.

My research suggests that, due to social media, some autistic adults are aware of being in a population group who experience more suicidal behaviours. I recommend the following future research in relation to suicide prevention for autistic people.

- Research the effectiveness of different methods of media to reach the autistic community to raise awareness of the importance of seeking appropriate support due to autistic people's increased vulnerability to suicidal thoughts, plans, and attempts.

One common finding of the different studies highlighted the role of misdiagnosis and subsequent inappropriate treatment, which may delay suicidal autistic adults receiving appropriate support and care. I recommend future research to reduce potential misdiagnosis.

- Research the effect of the involvement of autistic people in training health and social care workers on misdiagnosis.
- Research the prevalence of autism in adults with treatment resistant depression and, for those who are autistic, the effect of introducing autistic life improvements.

The findings of my research confirm that of other researchers relating to the importance of appropriate support. The research found that autistic adults may require more emotional, practical, and financial support than is generally recognised, and that appropriate support may help prevent suicidal behaviours. Support is particularly required by autistic adults whose large disparity in functioning skills means that they are unable to meet their requirements for daily living.

- Research the effect of autistic adult's spiky profiles of skills and abilities, specifically the effect of greater differences in amplitude of functioning, on suicidal behaviours.

There are currently two separate programmes available to improve the skills and knowledge of healthcare staff to support autistic people within various settings; The Oliver McGowan Mandatory Training on Learning Disability and Autism, and the NHS England commissioned National Autism Trainer Programme.

- Research the effectiveness and impact of training for NHS staff on the increased awareness of the needs of autistic adults, and of NHS Trusts' specific suicide prevention initiatives aimed at autistic adults.

Additionally, the Care Act (2014) suggests that autistic adults may be eligible for support to complete activities of daily living, due to requiring encouragement, more time, or a different process to reduce anxiety. The Autism Act (2009) sets out duties on local authorities and NHS organisations to support autistic adults. I recommend that future research related to suicide prevention investigates the appropriate support required by autistic adults.

- Research the effect of any discrepancy between the levels of support sought by autistic adults to reduce autistic burnout and lower potential suicidal behaviours and the different levels of support being offered to them.

This study enabled the autistic voice to be heard. To enable the autistic voice to be included in future research, if it is undertaken by non-autistic researchers it is important for it to be co-produced and co-delivered with autistic adults. Research involving interviewing autistic adults should consider using forms of communication adapted for autistic people. For example, email might be a preferred method as this is accessible and has various positive elements, including enabling unlimited time for reflection upon a permanently visible question. Such methods can help researchers gather richer data from this population.

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6.8 Conclusion

In conclusion, this thesis explored the interface of suicide and autism through a variety of methods to enable the voice and the experience of autistic adults to be heard. Previous research had identified that autistic adults are at greater risk of suicidal behaviours than non-autistic adults. The key findings of this research not only confirm this, but also highlight that more autistic adults think about suicide than has previously been recognised, and that suicide remains an option even when stressors are reduced. This is particularly important when suicide prevention is discussed as autistic individuals may experience different risk factors to non-autistic adults. The use of non-autistic specific assessment tools may lead to misdiagnosis, and friends, family, and health and social care workers missing the possible significance of, and requirement for, timely and appropriate assistance for the suicidal autistic adult. This research will remain relevant as long as autistic people live in an environment where needing to camouflage their autistic traits leads to the potential to autistically burn out, which in turn may to lead to suicidal behaviours.

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7. References

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8. Appendices

Appendix A

13th July 2017 Ref: 17/FHW/17
006

Mrs Margaret Dean

Via Email:
[university email address; personal email address deleted]

Dear Margaret,

Project Title: **What is the incidence of suicidal behaviours in autism?**

Your application was reviewed by the Faculty of Health and Wellbeing Research Ethics Committee which concluded on 24th May 2017. The Committee agreed that the conditions set out in the email of the 1st June 2017 should be met before final approval could be given.

As Chair of the Committee, I am content that these conditions have now been met in full, and I am writing to give formal confirmation that you can commence your research. Any significant change in the question, design or conduct of the study over its course should be notified to me as Chair, and may require a new application for ethics approval. You are also required to inform me once your research has been completed.

With best wishes for a successful project

Yours sincerely

J.A.E. Melville - Wiseman

Dr Janet Melville-Wiseman
Chair, Faculty of Health and Wellbeing Research
Ethics Committee Tel: [telephone number deleted]
Email:[email address deleted]

Research Ethics Committee
Faculty of Health and Well Being
Canterbury Christ Church University
North Holmes Campus, Canterbury, Kent, CT1 1QU
www.canterbury.ac.uk

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Registered Charity No: 1098136

Professor Rama Thirunamachandran, Vice Chancellor and Principal

Appendix B

Introductory letter - Phase 1

Dear Participant,

My name is Margaret Dean. I am a PhD student in the Faculty of Health and Wellbeing at Canterbury Christ Church University.

My research is concerned with suicide prevention in autistic adults of working age. It will aim to make recommendations for a new way of caring for autistic people who are exhibiting suicidal behaviours. The questions are therefore being asked of people aged 18 or older, with a diagnosis of autism spectrum disorder. The nature of the questions is that they are aimed at people without a learning disability.

The first part of my study seeks to ask, what is the incidence of previous suicidal behaviours in autism?

If you agree to take part, you will be asked to complete an online questionnaire that comprises a series of closed type questions, with a couple of open-ended questions as well. You will need to follow the on-screen instructions which will carefully guide you through the questionnaire. There are no right or wrong answers. The most important thing that I would request is that you answer all of the questions truthfully and as accurately as possible.

All of the information collected during this research study will be kept strictly confidential. No identifiable information will be collected meaning that your anonymity will be maintained. Further, all of the data collected will be saved on a password protected computer.

The information collected will be analysed with the purpose of understanding the number of autistic people affected by suicidal behaviours so that any recommendations for planned interventions can be effective, feasible and acceptable as possible.

Please fill in the consent form, either by typing or by hand. If done by hand, please scan and the return to me via email, or if by typing please save and return it as an attachment via email. On receipt of the consent form I will send you a link to the questionnaire.

Would you be willing to be contacted in the future? The next stage will comprise of a further questionnaire or an interview in the next 12 to 24 months. Please let me know if you would be prepared to take part in the next part of my study on suicide prevention in autistic people.

Thank you,

Margaret Dean

[university email address deleted]

Canterbury Christ Church University

What is the incidence of suicidal behaviours in autism?

PARTICIPANT INFORMATION SHEET

A research study is being conducted at Canterbury Christ Church University (CCCU) by Margaret Dean.

Background

I am an MPhil/PhD student in the Faculty of Health and Wellbeing at Canterbury Christ Church University. My research is concerned with suicide prevention in autistic adults. It will aim to make recommendations for a new way of caring for autistic people who are exhibiting suicidal behaviours. This first part of my study seeks to ask, what is the incidence of autism linked with previous suicidal behaviours?

What will you be required to do?

Participants in this study will be required to fill in an online questionnaire.

To participate in this research you must:

- To be 18 years of age or over
- To not have an intellectual disability
- Be able to fill in the form yourself
- Be diagnosed with autism spectrum disorder

Procedures

You will be asked to complete an online questionnaire that comprises a series of closed type questions, where you make a choice of answer which best describes your situation. There will also be a few open-ended questions, where you can write your own answer. You will need to follow the on-screen instructions which will carefully guide you through the questionnaire. There are no right or wrong answers.

Feedback

A copy of the final thesis will be made available through the university.

Confidentiality

All data and personal information will be stored securely within CCCU premises in accordance with the Data Protection Act 1998 and the University’s own data protection requirements. Data can only be accessed by Margaret Dean. After completion of the study, all data will be made anonymous (i.e. all personal information associated with the data will be removed).

Dissemination of results

The researcher is planning to present the information at conferences, in journal articles, in conferences through papers and posters and through the final thesis.

Deciding whether to participate

If you have any questions or concerns about the nature, procedures or requirements for participation do not hesitate to contact me. Should you decide to participate, you will be free to withdraw at any time without having to give a reason.

Any questions?

Please contact Margaret Dean at [university email address deleted]

Appendix D

CONSENT FORM

Title of Project: What is the incidence of suicidal behaviours in autism?

Name of Researcher: Margaret Dean

Contact details:

Address:
Faculty of Health and Wellbeing
Canterbury Christ Church University

Tel: [university telephone number]

Email: [university email address deleted]

	Please initial box
1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	☐
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential	☐
4. I agree to take part in the above study.	☐

________________________ ________________ ____________________

Name of Participant Date Signature

__________________________ ________________ ____________________

Researcher Date Signature

Copies: 1 for participant 1 for researcher

Appendix E

Respondents’ comments to Q. 10

1. I have not sought a diagnosis of autism as the benefits of the diagnosis would outweigh the emotional cost to me.

2. I'm working on my bachelor's degree currently, but the highest level of education I have completed is high school/A-level equivalent so I answered accordingly

3. I have taken paracetamol overdose and gone to hospital. I have also cut my wrists very deeply. I think about suicide a lot at the moment and have on and off for years.

4. I have thought about how I might kill myself, but I have never planned it per se--more just the ideation.

5. 3 suicide attempts when I was aged 15-18. Suicidal ideation began when I was 10 and has been ongoing.

6. I have been a psychiatric inpatient numerous times from the age of 16 due to multiple suicide attempts including overdosing and hanging

7. If it had been these days I may have made an attempt. Kids have more access to information via the internet. When I was a kid the only suicide I saw was portrayed on telly. They always showed someone with tablets and alcohol. My parents had plenty of medication, but never had alcohol in the house. So I didn't think I could do it. I didn't want to do it in a way it could affect others (like jumping in front of car/train).

8. Regarding question 6 - my doctor prescribed an SSRI when I described my depressive symptoms to him, and I took that for about two years. I assume that would necessitate a formal diagnosis or something similar from my doctor, but to be clear I do not have a piece of paper that says, "This person is depressed," the way I do for my autism diagnosis.

9. Wording for #7 is odd to me, I suppose I've thought about it in an abstract sense, never considered it though

10. It's difficult to describe my past actions as an 'attempt' or even planned actions. I've self harmed through cutting, I've taken too many pills, my thought process behind these actions are vague to say the least, the cutting was an action towards a divergent of emotional pain in the years I suffered with depression. Unfortunately I can't offer much here.

11. For me contemplation of suicide is normal, it does not indicate mental health problems, it is simply a logical option of activity for each day, it is always a possibility. I am aware of my mental health, I recognise indicators that my mental health is slipping. Considering suicide as an option in life is something I do every day, not just on those days when I feel mentally unwell. The depression I have experienced was in my teens and twenties, I am now happy and well adjusted to life with a satisfying career and home life, I still consider suicide an option every day.

12. I did plan suicide to some extent, but I never came to the part of deciding about actual method. I just planned how I would give notice to my working place so that my long distance students would not have to travel to classes in vain.

13. I do get Seasonal Affective Disorder in the winter, but not Seasonal Depression, so I don't think it counts as a type of depression

14. Have attempted suicide on multiple occasions using overdoses of tablets - paracetamol, co-codamol, diphenhydramine and insulin. Have been removed and s136 by police from high places - railway viaduct in Durham, Beechy Head.

15. I get so low that I no longer wish to be here.

16. I have been suicidal for most of my adult life, with phases of remission lasting between 4 months and a year. I also have intrusive thoughts about suicide which worsen during a depressive episode, but never fully go into remission.

17. Question 8. is hard. Suicidal ideation is all about method, so in that sense it is planning. But more than that it is usually around the sense of escape from this mental state, a fantasy if you will. It is not a cry for help. The degree of my planning relates to the degree of my depression. However once I get past the point in the fantasy where my pain is relieved, I see the pain of those around me. I try to compose a note in my mind, but it will never satisfactorily explain things to those I care about. It is at this point the ideation stops and I am left in the numb pain.

18. Major Attempt May 2016, resulting in resuscitation, 36hrs unconscious in Intensive Care. Attempt brought on by a number of factors after many years of suicidal thoughts.

19. I ended up in a secure unit for plans to commit suicide

20. I had stored all the medication necessary and had a date planned. I could not do straight away as had agreed to take son for his DSA assessment. I was receiving counselling at the time. I did not go through with suicide because my husband did not leave me as he had said he would.

Appendix E continued

21. I think a lot, about a great many things, so I have thought about suicide many times too, but I am also quite optimistic and hope is a powerful thing.

22. I have off and on struggle with thoughts of suicide for over the past three years. I have attempted suicide twice

23. Stopped twice by luck/ chance/ 'fate' rather than design.

24. When I was depressed, I had many suicidal thoughts, but never actually planned to kill myself. When I did overdose, it was always a spur of the moment event.

25. I take a very matter of fact view of this, I've thought about killing myself many times as a logical solution when I can't think of any other logical solutions. I have planned once when I got close to exhausting all other attempted solutions and set a date. I have so far found solutions before resulting in attempting to kill myself.

26. I have *wanted* to kill myself. I'm just too discombobulated when I'm like that to come up with a plan, so I haven't planned it or attempted.

27. The plans did not result in the attempt. The attempt was spontaneous.

28. I did not directly try to kill myself. I indirectly put myself at risk in the hopes of it being taken out of my hands.

29. Q7 is the most common aspect - the idea of not being in emotional pain. I have attempted suicide once through pills but this wasn't planned. I have planned alternative methods of suicide but these didn't lead to attempts.

30. Attempted suicide at age 10.

31. before my asd diagnosis 5 yrs ago...my attempts at suicide got me labelled with BPD even tho I met none of the other criteria for bpd. the bpd diagnosis has now been retracted

32. I have placed my head in a noose twice.

33. It was difficult to be accepted by a doctor/ psychiatrist/ psychologist as a patient and not turned away because of autism. Another problem were assumptions the like that a person with a physical healty seeming body can't have a mental health issue.

34. I have never called it wanting to kill myself- I call it 'wanting to die'. By planning, I mean I have thought about, ruled out different ways to do it and settled on the way I'd do it.

35. I googled how to do it painlessly. I just couldn't see i contribute anything to society.

36. October and November 2017

Canterbury
Christ Church
University

19th September 2018 Ref: 18-006

Margaret Dean

Email: [university email address deleted]

Dear Margaret

Project Title: The connection between autism and the risk of suicide

Your application was reviewed by the Faculty of Health and Wellbeing Research Ethics Panel on 12th September 2018. The Panel agreed that the conditions set out in my email of 29th August 2018 should be met before final approval could be given.

As Chair of the Panel, I am content that these conditions have now been met in full, and I am writing to give formal confirmation that you can commence your research. Any significant change in the question, design or conduct of the study over its course should be notified to me as Chair, and may require a new application for ethics approval. You are also required to inform me once your research has been completed.

With best wishes for a successful project.

Yours sincerely

J.A.E. Melville - Wiseman

Dr Janet Melville-Wiseman
Chair, Faculty of Health and Wellbeing Faculty Ethics Panel Tel: [tel. no. deleted]
Email: [email address deleted]

Faculty Ethics Panel
Faculty of Health and WellBeing

Canterbury Christ Church University
North Holmes Campus, Canterbury, Kent, CT1 1QU Tel +44 (0)1227 767700 Fax +44 (0)1227 470442 www.canterbury.ac.uk

Professor Rama Thirunamachandran, Vice Chancellor and Principal

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Appendix G

Introductory email - Phase 2

Hello,

Can I say thank you to you for responding to my email in March asking if you would consider taking part in the second phase of my research about suicide in autistic adults.

I have received ethics approval to start the second phase of my research.

Could you take a little time to look below at the questions I will be asking? Could you then answer the questions on the consent form, sign it (you can type all the information onto the form) and return it to me via email.

If you consent to taking part in the study, I will send the questions in small batches and may send some extra questions too. Please do not respond to the questions yet.

You will be anonymous in the study. You will be known as a person whose name begins with [a letter of the alphabet] within my writing. You may choose your own name, or I will allocate a name to you.

Many thanks for your help,

Margaret Dean
[university email address for research]

These are the questions that will be asked.

1. Can you tell me about yourself?

2. Can you tell me your gender and, if relevant, the pronouns (he/she/they) you would wish me to use in writing up the accounts.

3. Do you consider yourself to have autism or Asperger's syndrome?

4. Can you tell me about how you got your diagnosis of autism/Asperger's syndrome?

5. Can you tell me about your past suicidal thoughts, plans or attempts?

6. Can you tell me a little more about what may have triggered your suicidal thoughts, plans or attempts?

7. Can you tell me about your recovery process?

8. What did you do? What was helpful? What was unhelpful?

9. What did others do? What was helpful? What was unhelpful?

10. What have been the good elements of your recovery? (Did you have any thought processes or beliefs that helped you?)

11. Is there anything that could have helped you that wasn't thought about at the time or that could have been done differently?

12. Who supported you through this process? Do you keep in touch with them?

Support is available from your GP or, if out of hours help is needed, please phone NHS 111. Support from Samaritans is also available: their telephone number is 116 123, their email address is jo@samaritans.org , and their text number is 07725 90 90 90.

Appendix H

Canterbury
Christ Church
University

What is the connection between autism and the risk of suicide?

PARTICIPANT INFORMATION SHEET

A research study is being conducted at Canterbury Christ Church University (CCCU) by Margaret Dean.

Background

I am an MPhil/PhD student in the Faculty of Health and Wellbeing at Canterbury Christ Church University. My research is concerned with suicide prevention in autistic adults of working age. It will aim to make explore the ways of caring for autistic people who are exhibiting suicidal behaviours. The questions are therefore being asked of people aged 18 or older. The nature of the questions is that they are aimed at people without a learning disability.

The first part of my study has been completed. This asked participants about their autism, their gender, their physical and mental health diagnoses, and whether they had experienced depression. It also asked the participants whether they had experienced suicidal thoughts, plans or attempts. This second part of my study seeks to explore the connection between autism and the risk of suicide?

What will you be required to do?

If you agree to take part, participants in this study will be required to take part in an interview, carried out by email. The interview will comprise of a series of open-ended questions. My most important request is that you answer all of the questions truthfully and as accurately as possible. The interview will take a maximum of three weeks.

To participate in this research you must:

- To be 18 years of age or over
- To not have an intellectual disability
- Be able to fill in the form yourself
- Not made suicidal plans or attempts within the last 2 years
- Provide me with your address and telephone number, for use only in the case of an emergency

Procedures

You will be asked to take part in an interview. This will be completed through email. There will be no right or wrong answers.

Feedback

A copy of the final thesis will be made available through the university.

Confidentiality

All of the information collected during this research study will be kept strictly confidential. During the study, all data will be made anonymous (i.e. all personal information associated with the data will be removed). All data and personal information will be stored securely in accordance with the General Data Protection Regulations (GDPR), the Data Protection Act 2018 and the University’s own data protection requirements. Data can only be accessed by Margaret Dean. However, if a participant has indicated that they are in danger, confidentiality will be broken and the situation discussed with my supervisor.

If, at any stage during the interview process, you feel mentally unwell I will ask that you contact your **own support network**, which may be your **GP**, or that you telephone **NHS 111**. If you need to speak to someone there is also the Samaritans who can be contacted on **116 123**. They can also be emailed at: jo@samaritans.org, or you can text them on **07725 90 90 90.**

I will only use the contact details you have supplied if I think that you are in immediate danger of making an attempt on your own life, and I would always tell you who I am contacting and seek your agreement (though I would have to make the call whether you give your consent or not).

Dissemination of results

The researcher is planning to present the information at conferences, in journal articles, in conferences through papers and posters and through the final thesis. Pseudonyms, in relation to their given gender, will be allocated to participants to protect their anonymity. Only anonymised quotes will be used during the write-up and individual participants will not be identifiable.

Deciding whether to participate

If you have any questions or concerns about the nature, procedures or requirements for participation do not hesitate to contact me. Should you decide to participate, you will be free to withdraw at any time without having to give a reason. If you would like to withdraw at any stage, please email me at [university email address deleted] before 31st December, 2019.

If you would like to continue, please fill in the consent form, either by typing or by hand. Please return the completed form to me by email, preferably within three days. On receipt of the consent form, we will commence the interview. The interview will take no longer than three weeks, with my email responses being made within three days. This delay is to enable me to understand what you have written and to frame the further questions. As this is a research project, I will only respond to emails normally within standard office hours.

Any questions?

If you have any questions, please contact me, Margaret Dean at [university email address deleted]

Appendix I

Canterbury Christ Church University

CONSENT FORM

Title of Project: What is the connection between autism and the risk of suicide?

Name of Researcher: Margaret Dean

Contact details: Address: Faculty of Health and Wellbeing,
[university address deleted]

University Tel. No: [telephone number deleted]

Email: [university email address deleted]

Please initial box

1. I confirm that I have read and understand the participant information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time until 31st December 2019, without giving any reason. ☐
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential. ☐
4. I agree to give my address and telephone number for use only in the case of an emergency. ☐
5. I agree to take part in the above study. ☐

_________________________ ________________ _________________________
Name of Participant Date Signature

Address: ____ Post Code_________

Tel. No.: __________________

__________________________ _______________ _________________________
Name of Researcher Date Signature

Copies: 1 for participant 1 for researcher

Appendix J

Semi-Structured Interview Guide

Introductory Section

1. Can you tell me about yourself?

2. Can you tell me your gender and, if relevant, the pronouns (he/she/they) you would wish me to use in writing up the accounts.

3. Do you consider yourself to have autism or Asperger’s syndrome?

4. Can you tell me about how you got your diagnosis of autism/Asperger’s syndrome?

Main Section - Suicidal behaviours

If the interviewee has not talked about suicidal behaviours then ask:

5. Can you tell me about your past suicidal thoughts, plans or attempts?

6. Can you tell me a little more about what may have triggered your suicidal thoughts, plans or attempts?

Main Section – The recovery process

7. Can you tell me about your recovery process?

8. What did you do? What was helpful? What was unhelpful?

9. What did others do? What was helpful? What was unhelpful?

10. What have been the good elements of your recovery? Did you have any thought processes or beliefs that helped you?

11. Is there anything that could have helped you that wasn’t thought about at the time or that could have been done differently?

Ending Section

To elicit their support network especially if the questioning has been difficult:

12. Who supported you through this process? Do you keep in touch with them ?

Appendix J continued

Further questions, outlined below, were added to determine whether the participant's autism had led to their suicidal thoughts and behaviours. An additional question was also asked to some about the use of email as a technique for gathering data amongst the autistic community.

13. What were you doing at the time of your suicidal thoughts, plans or attempts, which may be different from what you are doing now?
14. Were you able to identify your needs at the time you had your suicidal thoughts, plans or attempts?
15. Can you determine what may have contributed to your suicidal thoughts, plans or attempts?
16. What do you think was the most influential element that contributed to your suicidal thoughts, plans or attempts?
17. Do you think that any of your autistic traits contributed to your suicidal thoughts, plans or attempts?

These additional questions were not answered by most of the responders, as I sent the questions after the interview process had finished, but within the time allocated by ethics clearance.

18. Was answering questions via email an acceptable method of data collection?