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HOW AUTISTIC ADULTS EXPERIENCE BEREAVEMENT: AN INTERPRETATIVE PHENOMENOLOGICAL STUDY

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Submitted to the New School of Psychotherapy and Counselling and Middlesex University Psychology Department in partial fulfilment of the requirements for the Doctorate by Professional Studies in Counselling Psychology and Psychotherapy

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I dedicate this research to the loving memory of my late mother, Linda. Thank you for showing me the meaning of unconditional and everlasting love; and for teaching me how to live with courage and determination. This work is also dedicated to my “little sister”, and my children. You inspire me to dare to try a little harder, and to love a little deeper, every day.

I will forever be indebted to the participants who so generously gave their time and effort for this study. I hope that I have done their stories and experiences justice. They were simply wonderful contributors, and I obviously could not have realised this project without them.

Thank you also to my autistic advisers, Damian, and Monique, for helping to educate this non-autistic novice researcher and assisting with setting this project in motion. I appreciate the conversations we had, and the insights you shared with me.

ABSTRACT

Bereavement is a stressful life event that disrupts a person's world on relational, practical, and spiritual levels. The aim of this study is to elucidate what it is like for autistic individuals, who characteristically desire predictability and continuity, to experience the death of a loved one. Individual in-depth interviews were conducted with 5 autistic adults and the transcripts analysed using Interpretative Phenomenological Analysis. Four inter-related group experiential themes are presented: 'Impacts of change, loss and uncertainty', 'Marginalisation: the sociocultural context of autistic grief', 'Adapting to change and loss: meaning and connection', and 'Stories and scripts: making sense of it all'. Consistent with existing grief literature, participants' grief reactions included affective, physiological, cognitive, and behavioural changes and were individual and varied with each loss. Participants also reported autism related grief reactions such as changes in sensory processing, increased masking, and an increase in autistic inertia, shutdown, and meltdown. The findings provide preliminary data on how the demands of bereavement, including the burden of minority stress, may increase the risk of autistic burnout for autistic survivors. Bereavement instigated a narrative reconstruction of the autistic survivors' life stories and identities. This process was social, including talking about the deceased, reflecting on their biography and legacy, and creating a sense of continued connection and relationship with the deceased in their ongoing lives. The findings are discussed in relation to extant literature and implications for psychotherapy and Counselling Psychology are raised.

STATEMENT OF AUTHORSHIP

This dissertation is written by Joanna Pang and has research ethics approval from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University. It is submitted in partial fulfilment of the requirements of the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University for the Degree of Doctor of Existential Counselling Psychology and Psychotherapy. The author reports no conflicts of interest and is alone responsible for the content and writing of the dissertation.

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Key abbreviations

ASD:	Autism Spectrum Disorder
AS:	Asperger’s Syndrome
NT:	Neurotypical
IPA:	Interpretative Phenomenological Analysis
UK:	United Kingdom

1. INTRODUCTION

1.1 Motivation for the study

The motivation for this research is drawn from my clinical and personal interest in bereavement together with the experience of living with a sibling who was diagnosed with Asperger syndrome (AS). An experience of bereavement in my late twenties was the catalyst to embark on training in Counselling Psychology. The intensity of my grief and the existential questions that came with the bereavement were totally unexpected. A desire to find out about others' experiences of bereavement led to the discovery of the work of Irvin Yalom (1980, 1999 & 2001) and thereafter to the study of existential philosophy and psychotherapy.

The inspiration to combine an interest in bereavement with autism research comes from my family experiences. Supporting my autistic sister has been a central concern over the years. We had sense of her difference from infancy, and I wanted to understand more about how she experienced the world and how we could support her. My sister's life has been touched by bereavement from a young age and my curiosity and concern for how she might be affected by our mother's death was one of the driving factors behind this project.

I have understood my privilege through witnessing the struggles my autistic sister faced because of her neurodivergence, and this motivated me to work in learning disability services. I was introduced to psychological theories of autism in my undergraduate psychology lectures back in the 1990's. That was my first exposure to the "enigma" of autism (Frith, 1989) and it had me returning home with the knowledge that we needed to seek an autism assessment for my sister so that she could be better understood and supported in school. I clearly recall the reaction of one family member to my suggestion: anger, suspicion, and ignorance. They were horrified and did not speak to me for weeks. This was my first witnessing of the stigma and discrimination experienced by autistic people.

At the beginning of my career, I worked as a carer at a residential home for older adults with physical and/or learning disabilities, some of whom were autistic. Most of the residents found themselves institutionalised because there were no remaining family that were able to care for them. In all cases, residents had previously lived with family, and many had been bereaved of their parents immediately before moving into the unit. It struck me how nobody talked about or acknowledged their loss, not just of their mother or father but also of their home, routines, and freedom. Often their behaviour would be described as 'challenging' or anti-social. I wondered about their grief processes and what was really going on for them; how their emotional worlds were colliding with this new life they never chose. I felt that there was a tacit assumption that autistic people do not grieve, or that if they do so, there is no support that we can offer because we do not fully understand what it is like from their perspective due to struggles with communication. At times, it seemed that people did not truly care, and this was deeply troubling to me.

The above personal and professional experiences also brought my attention to the lack of specialist provision for counselling and therapy for autistic adults. As Aston (2003) notes, there are more psychological support services for parents of autistic children than there are for autistic adults. As a result of the Autism Act 2009, the UK Government produced a strategy for autistic adults (DOH, 2010) and statutory guidance on how to implement the strategy (DOH, 2010). The Government aims to foster change at a local level and expects each area of the UK to develop and commission a plan for services for adults with autism based on the vision that:

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

I support the view of autistic voices being fundamental to such plans but am sceptical as to the success of this aim. Until recently, I lived and worked in a region where there was no service for autistic adults who did not also have a formal diagnosis of learning difficulties. There was also no diagnostic pathway for adults requiring an autism assessment. This was long after the above strategy was in place and unfortunately, access to support can be a lottery for many.

As Tantam (2014) asserts, “the power to change one’s life is necessary for life satisfaction, but not everyone has that power” (p.167). Resources are not consistently going to autistic people in need who, it could be said, are being treated as if they are ‘lower quality persons’ (Ibid.). This study aims to contribute to the raising of awareness of autistic individuals’ experiences of bereavement and inform clinical practice in services supporting autistic adults. For autistic adults to live rewarding and fulfilling lives “within a society that accepts and understands them” (DOH, 2010; P.6), research that investigates and promotes the lived experiences and concerns of autistic adults has an important role to play in this aim.

1.2 The research aims

This study aims to contribute to the raising of understanding and awareness of autistic individuals’ lived experiences of bereavement and to inform clinical practice in services supporting autistic adults. Interpretative phenomenological analysis is an appropriate method for the exploration of a under-researched subject seeking a detailed exposition of autistic participants’ experiences and lifeworlds (Smith et al., 2022).

1.3 Key terms

1.3.1 Bereavement, grief, and mourning

For the purpose of this thesis, distinctions will be made between the key terms bereavement, grief, and mourning.

Bereavement refers to the situation or fact of the death of someone significant. Grief will be used to refer to the emotional experience of the psychological, functional, physical, social, and behavioural responses a person may experience when bereaved. Mourning will more specifically refer to the different ways of expressing grief that are influenced by social, religious, and cultural beliefs and include rituals such as funerals, wakes, memorial services, and the visitation of graves.

1.3.2 Autism spectrum disorder and Asperger's Syndrome

Autism Spectrum Disorder (ASD) is a lifelong severe neurodevelopmental disorder with a considerable functional and financial impact on both the individual and their family (Roth & Rezaie, 2011). The primary characteristics of ASD are deficits in social communication and social interaction. These deficits present with restrictive or repetitive patterns of behaviours or interests and sensory abnormalities.

Previously, the diagnostic category for autism was divided into four sub-types: autistic disorder (autism), Asperger's Syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (DSM-4; APA, 1994). This research was originally planned to explore the experiences of individuals with a diagnosis of Asperger's syndrome. However, these four disorders were subsumed by the DSM-5 name of autism spectrum disorder or "ASD" (DSM-5; APA, 2013).

Most recently, the International Statistical Classification of Diseases and Related Health Problems 11th Revision (ICD-11; WHO, 2019) has mirrored this change in criteria. Both diagnostic systems utilise ASD as the unitary classification of core symptoms, though the systems differ in their approaches to describing within-group differences (Rosen et al. 2021). The ICD-11 is the recognised system for diagnosis in the UK and participants in this research will have received their diagnosis before the latest changes. However, people diagnosed under the old classification system are likely to meet the new, updated diagnostic criteria (Huerta et al., 2012). For consistency therefore, the term ASD will be used throughout this report when referring to diagnoses of autism.

1.3.3 Formal diagnosis

The term formal diagnosis refers to a diagnosis that was given by a suitably qualified clinician following a thorough clinical assessment.

2. LITERATURE REVIEW

A large body of research exists for both topics of autism and bereavement and this review will focus on providing a selected overview of the literature. Autistic people experience difficulties and differences in aspects of social interaction and communication and bereavement is an inherently relational and social life event. This section therefore aims to present current thinking in both autism and bereavement so that relevant connections can be made across fields that might illuminate understanding of autistic adults' lived experiences of bereavement. The key theories in the field of autism are presented and critiqued first, providing some historical and cultural context to how autism has come to be defined and understood. A review of the bereavement literature follows, tracing the development of models of grief and studies on what the experience of bereavement and grief is like. The chapter concludes with a summary of material specifically related to the experiences of autistic individuals who have suffered bereavement which leads to the demonstration of a gap in the literature in support of the rationale for the study.

2.1 Search method

Electronic searches were used to gather articles and publications using the following key search terms: Asperger's syndrome, autism, autism spectrum disorder, high functioning autism, AS, ASD, diagnosis, psychological, treatment, cognitive, bereavement, loss, grief, death, models of grief, resilience, qualitative research, IPA, and adults. The above search terms were used in different combinations to search a variety of sources.

The following academic databases were searched: PsycINFO, PsychArticles and Medline (PubMed). A search for academic books was made in the Middlesex University Library Catalogue. Internet searches were made on Google search engine and Google Scholar.

Blogs and bulletin boards that contained any relevant references or links to publications were reviewed. Uta Frith's research and publications were reviewed on her site, https://sites.google.com/site/utafrith. Grey literature was searched in the catalogue for the National Autistic Society's reference library, called 'Autism Data' and government and NHS websites.

2.2 Autism literature

2.2.1 ASD definition and diagnostic criteria

The definition of autism and its diagnostic criteria have evolved several times since it was first included in the DSM-III as a pervasive developmental disorder in 1980. Autism was first described by Kanner (1943) in his work with children exhibiting unusual behaviour from birth or before age 30 months. Kanner labelled what he observed as 'early infantile autism'. Almost simultaneously, Hans Asperger published a paper on what he called 'autistic psychopathy' (1944) which shared considerable overlap with Kanner's description of autism (Wing, 1991) but with children displaying higher language and intellectual abilities and appearing to have a milder form of autism.

A 'triad of impairments' in social interaction, social communication and social imagination were later identified by Wing and Gould (1979). These social impairments tended to cluster together and were associated with a narrow, repetitive pattern of activities. For example, rituals, special interests, compulsions, and repetitive, one-sided communication. They were said to occur in a very wide range of manifestations of autistic syndromes representing what was then considered a spectrum of autistic disorders.

The label AS was widely recognised and in use from 1981 when Wing published a paper in English on Asperger's work. She proposed the label of AS to raise awareness of this form of autism and as a less stigmatising label for the individual. AS was differentiated from classic autism by the lack of clinically significant delay in speech or cognitive development, self-help skills or interest in the environment and is associated with average or above average IQ. There has been uncertainty surrounding the diagnostic validity of AS, and whether it is different to 'high functioning autism' (Klin, 2006). Milton & Moon (2012) describe the categorisation of low and high functioning as a "disabling narrative" because in the context of the uneven cognitive skill profiles common in autism, it "leads to the underestimation of the abilities of the low functioning and an often over-estimation of some of the abilities of the high functioning" (p.3).

There is a strong genetic association between autistic traits and intelligence quotient or 'IQ' (Nishiyama et al., 2009), with approximately 70% of children with classic autism having an intellectual disability (Chakrabarti & Fombonne, 2005) and 8% of children with intellectual disabilities having autism (Emerson, 2003). However, some children diagnosed with autism with average IQ will struggle with adaptive behaviour (Charman et al., 2011).

To reduce the inconsistencies and account for the lack of clear distinction between the subcategories, all subgroups of autism have been merged into a single ASD diagnosis. The triad of impairments has also been merged into two core domains of i) deficits in social communication and reciprocal social interactions and ii) restricted, repetitive and inflexible patterns of behaviour, interests, and activities (ICD-11; WHO, 2019). There has been criticism of the new criteria for ignoring impairment in social imagination, perceived by many as the most disabling consequence of being autistic (Wing et al., 2011).

The first core domain relating to social communication and reciprocal social interactions includes limitations in:

- Understanding of, interest in, or inappropriate responses to the verbal or non-verbal social communications of others.
- Integration of spoken language with typical complimentary non-verbal cues, such as eye contact, gestures, facial expressions, and body language. These non-verbal behaviours may also be reduced in frequency or intensity.
- Understanding and use of language in social contexts and ability to initiate and sustain reciprocal social conversations.
- Social awareness, leading to behaviour that is not appropriately modulated according to the social context.
- Ability to imagine and respond to the feelings, emotional states, and attitudes of others.
- Mutual sharing of interests.
- Ability to make and sustain typical peer relationships.

The second core domain relating to restricted, repetitive, and inflexible patterns of behaviour, interests and activities includes limitations in:

- Lack of adaptability to new experiences and circumstances, with associated distress, that can be evoked by trivial changes to a familiar environment or in response to unanticipated events.
- Inflexible adherence to particular routines.
- Excessive adherence to rules.
- Excessive and persistent ritualized patterns of behaviour.
- Repetitive and stereotyped motor movements.
- Persistent preoccupation with one or more special interests, parts of objects, or specific types of stimuli (including media) or an unusually strong attachment to particular objects (excluding typical comforters).
- Lifelong excessive and persistent hypersensitivity or hyposensitivity to sensory stimuli or unusual interest in a sensory stimulus.

To meet the ICD-11 criteria for diagnosis, a person is required to show persistent deficits and difficulties in both domains that began in early childhood. It is recognised that some characteristic symptoms may not fully manifest until social demands exceed capacities later in life. A person's symptoms must also cause significant impairments in important areas of functioning such as family, social, employment and education.

2.2.2 Epidemiology

The global prevalence rate for autism is estimated as 103.5 per 10,000 or 1.035% (Mackay et al., 2018). For adults in England this estimate is 1.1% (Brugha et al., 2012) with the last Adult Psychiatric Morbidity Survey reporting approximately 1% (MacManus et al., 2016). Rates are higher for males than females at a ratio of 4:1 for autism and 15:1 for AS (Brughart et al., 2009). However, more recent research has found, a male-to-female ratio of ASD in children closer to 3:1 (Loomes et al., 2017). There appears to be a diagnostic gender bias, with girls who meet criteria for ASD at disproportionate risk of not receiving a clinical diagnosis. It is also suggested that autism is under-diagnosed in gender-fluid and non-binary people (George et el., 2019) and those from ethnic minorities (Hussein et al., 2019).

Prevalence rates rose dramatically by five times throughout the 1990's and appear to have plateaued from 2004 to 2010 (Taylor et al., 2013). This has been attributed in part to broadening diagnostic criteria, increased awareness, and social influences. However, the precise reason for the fluctuations is unknown. A recent study by Newcastle and Cambridge Universities of more than 7 million children found that prevalence rates among boys was 2.8% and 0.65% for girls (Roman-Urrestarazu, et al., 2021). Their overall prevalence rate of 1.76% of children in the UK is higher than previously reported rates. The cohort study also found higher prevalence rates in pupils of racial and ethnic minority groups and varying rates across different geographical areas in England.

2.2.3 Aetiology: biological and genetic theories of autism

Kanner originally posited that in addition to genetic and biological defects, autism was caused by cold and aloof parenting (Kanner & Eisenberg, 1956). This theory has since been discredited and current consensus is that environmental factors do play a role but to a lesser degree than neurobiological differences (Bartoluci & Bremner, 2008). The exact aetiology of autism is unknown, although research has focused on the areas of genetics, neurology, and psychology.

Autism is considered one of the most heritable 'neurodevelopmental disorders'. Some twin and family studies estimate the heritability of autism to be as high as 90% (Bailey et al., 1995). Cederlund and Gillberg (2004) found a very high rate of male relatives with autism spectrum problems. However, they also found that those diagnosed with AS frequently had a combination of genetic, prenatal, and perinatal risk factors. It is unclear whether prenatal, perinatal, and postnatal factors play a causal or secondary role in autism (Wang et al., 2017). While genetic factors play a role in risk for ASD, there is not absolute concordance for diagnosis in monozygotic twins (Hodges et al., 2020).

The strongly familial cases of ASD can be explained by a two-factor theory of autism in which both a genetic predisposition and environmental factors are necessary (Tantam, 2013). A study by Hallmayer et al. (2011) highlights the significant influence of shared environment over moderate genetic heritability in both AS and classic autism in dizygotic twins. Ultimately, research continues to reveal factors that correlate with autism risk, but no causal determinates have been found (Hodges et al., 2020).

2.2.4 Diagnosis

A combination of clinical observation of behaviour and developmental history are employed in the identification of ASD (Falkmer et al., 2013). Diagnostic assessments can take several forms, all of which are required to be carried out by trained persons in a multidisciplinary team.

The earliest age at which autism is formally diagnosed is 2 years (Constantino & Charman, 2016) with the average age of diagnosis in the UK being around 4.5 years (Brett at al., 2016). Children diagnosed earlier tend to show language and skills regression or delay. There is no biological test for autism.

Despite ASD being a developmental disorder, significant difficulties may not present until adolescence and young adulthood when accomplishments in life are more dependent on successful social relationships (Tantam, 1991). Some researchers have suggested that comorbidity is to be expected in ASD (Gillberg & Billstedt, 2000) and ASD is highly associated with anxiety, depression, attention deficit hyperactivity disorder (ADHD), bipolar disorder and tic disorders (Mazzone et al., 2012).

2.2.5 Psychological theories of autism

Several psychological theories of autism have been researched to explain the co-occurrence of the triad of impairments in terms of a single underlying impairment. Most theories of a fundamental impairment in autism are based on cognitive psychological research. A small number of cognitive mechanisms are said to explain a large number of phenomena (Frith, 2012). One such mechanism is that of 'central coherence', explaining the strong bias towards detail in the skills of autistic people. Information processing with 'weak central coherence' (Frith, 2002) means that an autistic person has a deficit in global processing, focusing on a wide variety of details whilst lacking the ability to see the global meaning. Difficulties in integrating information also make it harder to contextualise and to interpret information and events in terms of their overall meaning. Creating and understanding stories is also said to be difficult for autistic individuals (Joliffe & Baron-Cohen, 2000).

Executive function deficits have been described to explain some of the cognitive weaknesses seen in autism. Executive function is the collective term for the cognitive capacities of planning, mental flexibility, inhibition, and generativity (Hill, 2008). Autistic children have inflexible thinking and will often perseverate, repeating a redundant response or continuing with a strategy that has already failed to solve a problem (Sainsbury, 2000).

There has been less research into the difficulties faced by autistic adults with higher level executive functions although neuropsychological studies have found that people with high intellectual ability and autism also show executive deficits (Turner, 1997). Autistic adults seek sameness and routine, often requiring someone to remind them when to do something. In even slightly unexpected situations autistic individuals are likely to need guidance about the appropriate action to take and find it difficult to override routine responses. It has also been observed that a clearly structured environment and external prompts regarding unusual tasks are facilitative (Frith, 2004). Jacobsen (2004) suggests that weak executive functioning seen in AS also impacts a person's ability for awareness (of themselves and others) and perspective taking due to the difficulties in attentional focus.

A psychological explanation of the challenge of perspective taking for autistic people is that a lack of the underlying mental process called 'theory-of-mind' (Baron-Cohen et al., 1985), impacts upon impairments in communication and social skills. Theory-of-mind is the ability to recognise that another person's belief is based on their knowledge or experience and not on what I know to be true. Autistic people purportedly lack the ability to perform the 'mind-reading' that is automatic and implicit for NT's when making sense of another person's behaviour (Frith, 2004).

The frequent observation that autistic children do not engage in imaginative or pretend play led to the proposition of a meta-representational deficit in autism (Leslie, 1987). False belief tests were developed to test whether a child can use mental states to predict and explain another person's behaviour (Wimmer & Perner, 1983; Baron-Cohen at al., 1985). This failure in 'mentalising' is said to lead to an inability to reflect on the mental states of self and others and was proffered as an explanation of the triad of impairments. It has been argued by Happé (2003) that a typically developing child's knowledge of their own mental states and knowledge of the mental states of others occurs at the same time and shows the same difficulties in both abilities. What follows from such a deficit is the inability to represent intentions, or recognise statements as interpretations of the speaker's thoughts, characteristic of the communication impairments of autism (Frith, 1989).

The 'mind-blindness' theory asserts that autistic children are delayed in the development of their theory of mind (Baron-Cohen, 1995). This leaves them with degrees of mind-blindness that can result in other people's behaviour seeming confusing and even frightening. Signs of impairment on theory of mind tasks reduce with age (Ziatus et al., 1998). It is possible that older children's impairment is being camouflaged using logical inference rather than being less severe (Frith, 2003).

A network of brain regions has been identified as activated during tasks that take account of other's mental states. Higher functioning autistic individuals have been found to show decreased activation in this mentalising system which might in part be due to weak connectivity between brain regions (Castelli et al., 2002). Brain-imaging studies have also differentiated between the neurocognitive processes involved in theory of mind and those underlying empathy (Blair, 2005; Jones et al., 2010). However, Happe (1994) reported how "in every study testing autistic children's performance on mentalising tasks, some proportion of subjects is found to pass" (p.219). This undermines the mentalising-deficit theory of autism, a theory which also has poor explanatory power for other features of autism.

The relationship between mentalising, empathy and emotion is highly complex. Baron-Cohen (2009) has proposed the 'empathizing-systemizing' theory to describe how autism may demonstrate a discrepancy between a person's capacity for affective empathy (below average) and their drive for 'systemizing' or drive to analyse and construct systems (above average). The ability to mentalise is crucial for intentional, or affective empathy, requiring the ability to orientate oneself to another's mental states, understand the reasons for their sadness and to have the appropriate emotional response to their thoughts and feelings (Davis, 1994). This skill can be considered as distinct from the capacity for sympathy and a lack of mentalising does not mean that autistic people do not resonate with other's feelings (Frith, 2002).

Williams & Happé (2009) found that for autistic children, self-awareness of mental states is more impaired than for awareness of mental states in others. They suggest this is because autistic people can watch and learn rudimentary behaviour rules about the regularities of other people's actions but are not able to visually assess their own behaviour. However, autistic individuals do not show the same impairments in awareness of their physical body as they do in reflecting on their 'psychological selves', pointing to a specific deficit in self-awareness (Williams, 2010).

Whilst findings point to a possible impairment in the metacognitive process central to self-awareness including mentalising, autistic individuals can experience instinctive sympathy and can be extremely upset by suffering (Frith, 2002). The presence of these basic emotional responses, accompanied by autonomic responses, mark out autism as distinctive from psychopathy. Psychopaths do not show sympathy responses but have good mentalising skills whereas, autism is characterised by poor mentalising with the capacity for sympathy (Blair et al., 1996; Blair, 1999).

In a neuroimaging study (Hill, Berthoz & Frith, 2004), it was participants' bodily awareness of feelings that separated those with alexithymia from those with autism. Alexithymia is a personality trait characterised by difficulty in recognising and expressing emotions, limited fantasy life and a lack of thinking about inner life (Kooiman et al., 2002). It can appear similar to autism in terms of difficulties with social interaction, unusual language use, affective interaction, non-verbal behaviour, and factual thinking style (Fitzgerald & Bellgrove, 2006). In the case of autistic people, they may not be attuned to the emotional influences of those around them and can appear to be lacking emotion. Tantam (2009) suggests that without direct knowledge of the autistic person's emotions, a parent or caregiver cannot teach the person how to label them. With their emotions remaining hidden, the person is prevented from being taught the words to name and describe them.

Evidently, autistic people have emotions and are affected by the distress of others despite the 'aloof' stereotype. The expression of their feelings is however, diminished or not considered typical. This is particularly so when an appropriate emotional response is part of social communication such as embarrassment or modesty (Frith, 2002). The mind-blindness theory may offer an explanation to how autistic people lack the ability to think about their own thoughts and feelings as well as others. In this context, Happé and Frith (1995) liken the world of autistic people to being like, "strangers in a foreign land, because the world we inhabit is a social world" (p.193).

Another explanation for the experience of autistic people as outsiders in a social world is given in Tantam's (2009) theory of impaired non-verbal communication. Neurotypicals are said to share an "automatic, nonintentional connectedness" (Ibid; p.100) via a network likened to those wirelessly linking computers. This automatic connection is referred to as the 'interbrain' and is mediated by non-verbal communication. In Tantam's theory, the fundamental impairment in autism is an absent interbrain connection. Autistic individuals are 'offline' and effectively cut off in some ways from other people. Those with AS can to an extent, connect with others through language. Neurotypicals with the interbrain connection have automatic responses to other's gaze and can look at a person's eyes and make inferences about what they are looking at. People with AS do not receive these signals as strongly and are not shaped by social feedback because they have impaired imitation and mutual gaze. Such impairments in joint attention are one of the earliest signs of autism, relating to outcome in later life (Charman, 2004) and reflecting processes that are central to the developmental aetiology of autism (Mundy, Sullivan & Mastergeorge, 2009). This capacity to share the gaze of a social partner is “fundamental to our aptitude for learning, language, and sophisticated social competencies throughout life” (Mundy & Newell, 2007; p.269).

Murray et al. (2005) proposed the theory of monotropism as an explanation for the core features of autism. In this theory, atypical strategies for the distribution of attention are seen as the core of autistic experience. The amount of attention available to individuals is understood to be quantitatively limited or scare and moderated by brain metabolites. A person’s strategies for how they use attention are said to be normally distributed and largely determined by genetics. Murray et al., (Ibid) describe the ‘monotropic’ tendency of autistic people to have few interests highly aroused, whereby their attention is tightly focused over a narrow range of subjects. At the other side of the distribution, a ‘polytropic’ tendency refers to the strategy of having many varied interests that are less intensely attended to.

The theory of monotropism (Murray et al., 2005) offers an explanation for all diagnostic features of autism. For example, the “patchy and partial awareness that results from monotropic focus” (p.148) prevents autistic individuals from learning how to participate socially, accounting for qualitative impairments in social interaction. The term ‘attention tunnel’ is used to describe how a monotropic interest is far more closed than a typical one, with the potential for the individual’s attention to become absorbed in a single action or thought repetitively to the inclusion of all else.

Monotropism is one of the only theories based on autistic lived experience rather than inferences made about accounts of behaviour, therefore offering a model of autism from the “inside-out” (Milton, 2016; p.7). It accounts for aspects of autistic experience that have been overlooked by other psychological theories. For example, it explains how an autistic person might be either enthusiastically interested in something or entirely lacking interest in it at all. Issues related to executive functioning such as difficulties with shifts in the object of attention and initiating or stopping tasks, described in the autistic community as ‘autistic inertia’ or by Murray et al. (2005) as ‘getting stuck’ and struggling to move on without prompting, can also be understood as resulting from “extreme task focus” (Ibid, p.144).

Spiky profiles of cognitive ability may occur when an autistic person is highly motivated to direct high levels of attention to something that results in them being able to do it exceedingly well, while other interests are left unattended. Through the monotropic lens, it becomes more accurate to speak of difficulties rather than incapacities (Murray et al., 2005). The model helps us to understand how individual patterns of interest, borne out of what people spontaneously give attention to, lead to such varied range ways of being that allow for “infinite neurodiversity” (Murray, 2018).

The sensory differences experienced by autistic people can also be understood as atypical allocation of attention. Murray et al. (2005) propose that there is usually hyper-awareness within the attention tunnel and hypo-awareness, characterised by a lack of expectation, outside it. This corresponds with the hyper- and hypo-sensitivity in response to sensory input that characterise autistic sensory integration difficulties. Monotropism accounts for the difficulties experienced with dividing attention between the senses which requires a great deal of energy and can go beyond the person’s available processing resources. Focusing attention uses up significant resources and managing extraneous stimuli can create intense discomfort and pain for autistic individuals.

Psychological theories offer intrapersonal explanations of autism whereas Milton (2012) adds a sociological perspective and positions the difficulties faced by autistic people in how the relations and interactions that people have can lead to a sense of social disconnection when there is an absence of a shared social reality. Thus the ‘double empathy problem’ (Ibid), describes how problems in reciprocal empathy occur between people with different “dispositional perceptions of the lifeworld” (Ibid, p.885). In the interactions between non-autistic and autistic people there is a high likelihood of a breakdown in mutual understanding because of they have such different dispositions.

The double empathy problem can arise in any dyad with the success of social interactions dependent on “two people sharing similar experiences of ways of being in the world” (Milton at al., 2022; p.1901). Bi-directional differences in cognitive and communication styles, interests and experiences create a double empathy gap and reciprocal misunderstanding. This opposes the dominant theoretical assertions that difficulties in social interaction and communication are down to deficiencies in the autistic person. Autistic people have been shown to communicate well, empathise, and experience high interactional rapport when interacting with other autistic people (Crompton et al., 2020a and 2020b).

Milton is an autistic autism researcher who derived the concept of the double empathy problem through a combination of their personal experience, anecdotal accounts and the scant qualitative available at the time (Milton 2022). This theory highlights the inherent problems in normative assumptions that pervade dominant autism theory and research, challenging us to question the “idealised normative view of social reality” (Milton, 2012). The double empathy problem provides a cogent countertheory to the hitherto stigmatising portrayal of autistic people as ‘mindblind’ or poor ‘mentalisers’. In a review of the empirical evidence for the assertion that autistic people lack a theory of mind, Gernsbacher & Yergeau (2019) found that it fails in its specificity, universality, replicability, convergent validity, and predictive validity. They concluded that claims that autistic people lack a theory of mind is “empirically questionable and societally harmful” (Ibid., p.1), contaminating autistic people’s understanding of themselves and others. Despite the evidence, this claim persists in teaching and education about autism and is promoted in over 75% of the top 500 articles indexed in Google Scholar for “theory of mind” and “autism” (Ibid). In Milton’s original (2012) paper on the double empathy problem, he highlights the power of defining autistic people as abnormal to enable harmful othering and stigma, while also placing responsibility for social difficulties with autistic people. These normative views, when imposed on the other, also create a form of internalised oppression (Ibid).

2.2.6 Critique of the medical model of autism

Most of the existing autism literature subscribes to the medical model of disability. Inclusion in the ICD-11 and DSM-V as ASD means that autism is treated as a medical problem caused by biological differences and psychological deficits. Classifying autism as pathology with a physical cause has enormous implications for how we deal with it, influencing research to focus on the discovery of causes and development of 'treatments'. As Rezneck(1987) states:

> The classification of a condition as a disease carries many important consequences. We inform medical scientists that they should try to discover a cure for the condition. We inform benefactors that they should support such research. We direct medical care towards the condition, making it appropriate to treat the condition by medical means such as drug therapy, surgery, and so on. (p.1)

Psychological research and theories of autism have focused on proposals for causal accounts of psychological deficits that have explanatory power in accounting for the "syndrome-specific impairments in socialisation, imagination and communication" (Happe, 1994, p. 215). Such parameters are a product of autism having come to be diagnosed through the behavioural classification of impairments. The dominant psychological theories are therefore predicated on the assumed validity of the classification of autism as a disorder, something that many autistic people find offensive. Autistic voices are undervalued by and notably absent from biomedical models that largely focus on cognitive explanations of autism. The implications for autistic people of being portrayed as cognitively deficient are wide reaching, resulting in detriments to the well-being of autistic people in society (Milton,2011). The nature of positivistic research production works against autistic people, studying them as 'objects' of study, as 'other':

> The power embedded in the knowledge produced by research based upon positivistic ontological and epistemological axioms can profoundly affect the lives of those being researched, especially when those being researched are a recognised vulnerable and marginalised group within society with little political voice of their own (Milton & Moon, 2012: p.6)

Autism is framed as a disability caused by a medical problem residing in the individual with ‘sufferers’ offered treatments aimed at ameliorating or curing symptoms. This view presents autistic people as needing to be changed or fixed rather than examining the conditions that might be contributing to their ‘disability’ (Kasser & Lytle, 2005). This essentialist view of autism locates disability within autistic individuals themselves and sees them and their families as responsible for overcoming the disadvantages that being atypical brings (Baker, 2011).

Alternatively, the social model of disability acknowledges that how society responds or fails to respond to people’s needs is fundamental to how ‘disabled’ a person is viewed (Baker, 2011). This is a much more inclusive way of describing disability and autism, with the emphasis on how disabling a role society plays for autistic people when accommodations are not made to match their cognitive style and needs (Kenny et al., 2016).

Despite much of the autism research to date seeking to understand autistic people in terms of biological differences and explanations, there is a need to find a way of synthesising biological and experiential perspectives (Tantam, 2013). Kenney et al. (2016) found that autistic people and their support networks reported finding it necessary to adopt both the medical and social models of disability for achieving different aims. Ultimately, medical descriptors are needed to access services and support, and moving toward an integrated model of autism is suggested. Their study also highlighted the ethical importance of the consideration of context and personal preference when researchers and clinicians work with autistic individuals.

Our knowledge and understanding of autism is constantly changing and evolving and this process ought to be reflected in how we perceive, understand, and refer to it in society (Ibid).

Beliefs about autism impact on the terms we use to describe it. ‘Person-first’ language was put forward in the early 1990’s when individuals began being referred to as ‘people with disabilities’, borne out of a desire to not equate people with their disability (Halmari, 2011). However, this can be construed as implying that ‘having autism’ is negative and members of the autism community have objected to such language. Autistic people and their families more often use identity-first language (Kenny et al., 2016). Sinclair (2013), objects to the idea that he can ever be separated from his autism and that being autistic is so bad people need to use that language to remind themselves he is still a person.

2.2.7 An existential-phenomenological approach

Existential perspectives are aligned with an integrated approach to autism. They reject the medical principles of diagnosis, focusing on how a person experiences the world and exploring what meaning any diagnosis might hold for them. Diagnostic categories and ‘treatments’ are viewed as forms of knowledge that exert power over ‘patients’. They are not held as scientific truths but are instead seen as useful ways of speaking about a person’s problems and enabling access to services and support systems. An existential-phenomenological stance accommodates the exploration of highly individualised experiences of being autistic in a relational and socio-political context. Rather than describing autism in terms of a medical disorder that implies a person’s being is somehow deficient, it seeks to understand all human experience in a holistic, non-reductionist way.

Existential psychologists face the task of how to work within a mental health system based on medical, reductionist principles whilst remaining true to humanistic values and validating the totality of autistic clients’ experiences. Cooper (2009) proposes that there are many, perhaps most, clients in clinical settings that wish to be engaged with as distinct individuals, with a depth and complexity far exceeding their diagnoses. He suggests “professionals are needed who can engage with people in this way, who can hold labels lightly and meet people, first and foremost, as people" (Ibid. p. 10).

2.3 Bereavement literature

2.3.1 Attachment theory and stage models of bereavement

Attachment theory was devised to explain the distress arising from mother-infant separation. Extending his theories of attachment, separation and loss, Bowlby (1969) described grief as an adaptive and predictable emotional response to bereavement. He argued that the loss of attachment figures, with whom early affectional bonds had ensured security and survival, would result in distress. A person's particular attachment style was said to correspond with their response to grief and whether it resulted in pathology. He identified four stages: shock and numbness, yearning and searching, despair and disorganisation and reorganisation or recovery. To Bowlby, grieving was a biological drive and process to attempt to reunite with the deceased that was at odds with the reality of the loss.

The stage-based models of grief that followed Bowlby's work have been hugely influential in bereavement counselling and became part of the mainstream understanding and discourse on grief. The Kubler-Ross (1969, 2005) stages of dying and grief (shock and denial, anger, bargaining, depression, acceptance) describe a person's confrontation with their own death and have been applied universally to emotional reactions to loss. The goal here is to aid the sufferer in fully resolving each stage and transition to the next rather than 'getting stuck' in a particular phase or cycling between one unresolved phase and another.

Like Bowlby (1969), Parkes (1972), suggested sequential phases of grief that inevitably involve intense emotional pain during some phases before grief is finally resolved and homeostasis is achieved. However, Parkes and Prigerson (2010) later suggested dropping the concept of the 'phases of grief' for its lack of utility and acknowledgment that phases can overlap without the need for one to end before the other begins. More recent theories of grief have indeed moved away from this approach. Some have questioned whether phases of grieving exist at all (Wortman & Silver, 1989) and few attempts to validate such theories have been undertaken (Holland & Neimeyer, 2010).

There is scant support for stage or phase models of grief with a consensus that theories of fixed stages of grief are of limited utility (Stroebe et al, 2001). Stage and phase models of grief have also been criticised for presenting grieving as a rather passive process of moving through grief, omitting the way the bereaved often must make an active effort to struggle through grieving (Stroebe & Schut, 2010). Despite this, Bowlby's ideas remain influential, with attachment security appearing important in the prediction of adjustment to bereavement (Mikulincer & Shaver, 2013).

2.3.2 Task models of grief

Freud first proposed the concept of 'grief work' in his seminal 1917 essay on *Mourning and Melancholia*. His theory describes mourning as an intensely painful but necessary process of working through grief to relinquish attachment to a loved one. Once this is achieved, libido can be redirected to other relationships and activities. While Freud's theory of libidinal energy might not be as popular today, his idea of grief as being part of the work of reconstructive processes has been carried forward.

Worden's (1992) four tasks of mourning: accepting, acknowledging, adjusting, and reinvesting make up a grief process that enables the bereaved to find an appropriate place for the deceased in their emotional lives. The tasks overlap, requiring a person to 'work through' the emotional pain of their loss, concurrently adjusting to changes in life circumstances, roles, status, and identity. Integrating the loss into their life and letting go of attachments to the deceased is said to allow the bereaved to invest in their present and future. The active working through of one’s loss and expression of grief have since been demonstrated as unnecessary for many bereaved individuals (Bonnano, 2001).

2.3.3 Dual process model

Stroebe and Schut (2010), proposed the dual process model to address some of the shortcomings of task models of grief which were based upon the central construct of grief work as the mechanism for adaptive coping in bereavement. They criticised stage models for neither acknowledging the need for ‘dosage’ of grief nor accounting for the benefits of denial and non-confrontation with grief tasks.   Stage models also do not account for individual and cultural differences in ways to work through grief in the way that the dual process model purports to allow for.

Stroebe and Shut’s (1999) model of coping with bereavement integrates attachment and cognitive stress theories to explicitly define two categories of stressors associated with bereavement: loss versus restoration. Loss-orientation refers to processes focused on the loss experience such as the painful dwelling on or searching for the lost person. Restoration-orientation refers to the bereaved’s focus on their struggle to reorient themselves in a changed world without the deceased. Both orientations can cause distress and anxiety for the bereaved and can be either confronted or avoided in a regulatory process of oscillation between coping behaviours. Taking ‘time out’ from grieving completely is also emphasised as beneficial, acknowledging how exhausting grieving can be.

2.3.4 Continuing bonds

Klass et al. (1996) suggest that grief following bereavement is never fully resolved or reaches a point of ‘recovery’. They suggest that rather than letting go of attachments to the deceased, the purpose of grieving can be to maintain a continued bond with them. This view emphasises the interdependent nature of our existence and the reality that grief is never fully resolved. Their theory permits previously pathologised reactions to bereavement as acceptable and challenges long established attachment theory-based models of grief (although some authors would argue attachment theory can accommodate this conceptualisation i.e., Field et al., 2005). However, evidence is divided as to the benefit of continuing bonds in every case (Field & Friedrichs, 2004), once again pointing to the individuality and specificness of grief for each person.

Bonanno’s (2004) theory of adult resilience in the face of loss and trauma also challenges traditional recovery models in which ‘recovery’ occurs following symptomology that overwhelms normal functioning and can last a matter of months or years. Resilience to loss is not a sign of pathology but a common and healthy adjustment that does not lead to delayed grief. Contrary to Bowlby’s (1980) assumption that individuals exhibiting little, or no grief were either lacking in attachment, or cold and unfeeling, Bonnano et al.’s (2002) study found that some individuals are simply resilient enough to maintain a steady equilibrium following significant loss. Individual differences in grief responses exist with some survivors who feel chronically overwhelmed and others who struggle for several months before recovering Bonanno et al., 2011). Resilient grievers, continue functioning at usual levels even soon after the death and demonstrate a stable trajectory of healthy adjustment across time (Bonanno, 2004).

2.3.5 Cognitive constructivist approaches to bereavement

Much of the existing literature and models of bereavement and grief persist with the notion of grief as a universal experience, describing prescriptive and restrictive definitions of what constitutes the ‘healthy’ way to grieve. Stage and task models assume a start and end point in the grieving process, while grief work approaches promote the idea that intense emotional distress and a working through of feelings is necessary for resolution of one’s grief. These stances fail to fully capture the complexity and individuality of the grieving experience.

Approaches to understanding bereavement are moving toward less universally defined responses and away from imposing assumptions about what is ‘normal’ upon the bereaved. Constructivist approaches highlight the multiple truths constructed by each bereaved individual. In constructivism, our reality is continually constructed in coherent narratives that encapsulate our sense of identity, connection, and purpose (Bruner, 2004). A person’s identity and sense of self is constructed out of the stories we construct about ourselves and share with others. Our assumptive world is the world in which we assume to exist based upon our experience of life (Janoff-Bulman, 1989), enabling us to function effectively by providing expectations about ourselves and the world.

A major loss or life event can challenge or invalidate parts of our assumptive world, inciting a process of psychosocial transition. The death of a loved one may challenge the validity of our core beliefs and undermine the coherence of self-narrative (Neimeyer et al., 2010). The emphasis being on the role of meaning making in the adaptation to bereavement, with grieving as a process of reconstructing a world of meaning that has been challenged by loss (Neimeyer et al., 2006).

2.3.6 Grief reactions and the classification of grief

The fact that grief is a ubiquitous experience, one that will undoubtedly touch most people's lives at least once if not several times over, does not make it a painless or easy experience. People speak of 'suffering' a bereavement and the death of a loved one is a highly stressful event. Holmes and Rahe (1967) weighted the death of a spouse as the life event requiring the most intense readjustment in their social readjustment scale (SSRS). The items in the SSRS are "change events, that is events that precipitate movement from one equilibrium or steady state to another" (Ibid. p.216). Although the SSRS has been widely criticised and subsequently revised, death and dying are consistently found to be the chief stressful life events with a consistent and significant relationship to health outcomes in the stress literature (Hobson et al., 1998; Scully et al., 2000; Turner & Wheaton, 1995).

Despite the challenges of bereavement, most people are able to successfully navigate and adapt to their loss, ultimately recovering their ability to engage in ongoing life (Zisook et al., 2014). There is enormous variability in people's experiences of grief which is "different for every person and every loss" (Zisook & Shear, 2009, p.68). Bonnano and Kaltman's (2001) review of empirical evidence of the phenomenological features, longitudinal course and possible diagnostic relevance of grief found that:

> Most bereaved individuals showed moderate disruptions in functioning during the first year after a loss, while more chronic symptoms were evidenced by a relatively small minority (p.705)

Their review found "ample evidence" that most bereaved people show nonpathological grief with between 50% and 80% of the bereaved participants in the studies falling into a "common grief pattern consisting of moderate disruptions in cognitive, emotional, physical or interpersonal functioning during the initial months after the loss" (Ibid, p.709). The review also emphasises the individual differences in how intensely and long people grieve, demonstrating that most bereaved individuals appear to have returned to their baseline levels of functioning one year after the death although some disruptive manifestations of grief may continue for several years.

For the majority of the bereaved, the grieving process does not reach a point of completion or ending, but Shear and Mulhare (2008) make the distinction between ‘acute’ and ‘integrated’ grief. Acute grief occurs in the early aftermath of bereavement and is often emotionally painful, intense, and debilitating. Individuals experience emotions and behaviours that are outside of their usual everyday life such as crying and intense sadness, dysphoric moods that might be unfamiliar to the bereaved, difficulties with concentration, preoccupying thoughts about the deceased, reduced interest in other people and usual activities of day-to-day life, and neurovegetative experiences (fatigue, sleep disturbance, reduced appetite).

A transition from acute grief to ‘integrated’ or ‘abiding grief’, begins a few months after the death in which the bereaved slowly begin to assimilate the reality of the death and engage again with pleasurable activities and relationships. Although the authors propose a “general progression from numbing and disbelief to painful acknowledgment and ultimate integration of loss and grief”, they caution that “discrete stages cannot be discerned” (Ibid, p.662). Over time, there is integration of the loss into autobiographical memory and meaning is found in the death. Adjustment to the loss occurs despite continued memories of the deceased, sadness and missing them and the rekindling of periods of acute grief.

In a review of the empirical date on the relationship between bereavement and physical and mental health, Stroebe et al. (2007) reported on the increased risk of mortality in the first weeks and months following a bereavement. Mortality was related to declines in physical health and psychological distress; deaths had various causes including suicide. The authors also noted the acute suffering in the early phase of bereavement, similar to those described above by Shear and Mulhare (2008), including an increase in depressive symptoms. The review findings suggest that many people with intense grief fail to consult with doctors when they need to. Grief reactions were diverse with cultural differences in grief and grieving. The nature of reactions to bereavement were affective (e.g., despair, distress, anxiety, longing, shock), cognitive (e.g., intrusive ruminations on the deceased, lowered self-esteem, sense of presence of the deceased, concentration difficulties), behavioural (e.g., agitation, restlessness, fatigue, overactivity, crying, withdrawal), physiological-somatic (e.g., loss of appetite, energy loss, disturbed sleep) and immunological and endocrine changes (e.g., susceptibility to illness, disease and mortality).

Risk factors for poor bereavement outcomes related to the circumstances of the death, intrapersonal risk or protective factors, interpersonal resources and protective factors, strategies, and processes (Stroebe et al, 2007). In the latter category, whether an individual engaged in grief work, disclosure or sharing was a poor predictor of outcome and grief avoidance was not necessarily detrimental. In fact, some who did not work through their grief often recover as well as or better than those who do not. Emotional regulation and appraisal was found to be a more beneficial coping process. Inadequate social support is a general risk factor but when specifically looking at outcomes for bereaved individuals, those with greater social support did not fare better than those with low support (Ibid).

Counselling was reviewed as a formal level of social support with the conclusion that "professional psychological intervention is generally neither justified nor effective for uncomplicated forms of grief" (Ibid., p.1969). Some benefit was found in grief interventions at a primary level where professional support was available to all bereaved individuals but only when initiated by the person themselves. The authors noted that these finding concurred with those of Parkes (1998) who highlighted the lack of evidence for the benefit of routine referral for bereavement counselling. While the review by Stroebe et al. (2007) was comprehensive, much of the evidence was based on studies of spousal loss as research up to that point had focused very little on other forms of bereavement.

While grief is a natural response to the death of a loved one (Bandini, 2015), with most people adjusting to their loss without professional intervention (Stroebe et al., 2007), there has been intense debate over the diagnosis and medicalisation of “abnormal” grief reactions. The third edition of the DSM differentiated between uncomplicated and complicated grief reactions (APA, 1980). Certain severe grief reactions e.g., “morbid preoccupation with worthlessness, prolonged and marked functional impairment, and marked psychomotor retardation” (APA, 1980), became “symptoms”, transforming the conceptualisation of grief from a natural process to a potential disease (Granek, 2014a).

Subsequent DSM editions have attempted to discriminate between grief and depression, with the DSM-5 (APA, 2013) allowing a diagnosis of major depression to be made two weeks following bereavement. Proponents contend this permits the bereaved to access early treatment for depression, but the move has been extensively criticised for pathologising grief, raising concerns about future norms for “appropriate” grief (Bandini, 2015). The APA have recently incorporated criteria for the diagnosis of prolonged grief disorder into the DSM-5 for bereaved individuals who meet the diagnostic criteria at least twelve months after the death of someone close. At least three out of eight symptoms of identity disruption, disbelief, avoidance, emotional pain, difficulties moving on, numbness, a sense that life is meaningless, and loneliness must be present with intense yearning or preoccupation.

In the ICD-11 (WHO, 2018) prolonged grief disorder is included under the heading of “disorders specifically associated with stress”. The diagnosis is a “disturbance” accompanied by “a persistent and pervasive grief response characterised by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain” (WHO, 2018). It can be diagnosed from six months after a bereavement if the individual experiences marked functional impairment. When widowed parents were asked their opinion of the above diagnosis of grief, they believed that being diagnosed at six months post loss was far too early (Holmgren, 2022a). Grief was seen as often taking more time than society expects and in

Holmgren's participants' circumstances, undeniably longer than six months. Numerous other examples of grief that remained intense six months after a loss and subsequently naturally reached a satisfactory resolution can be found in the literature (e.g., Horowitz et al., 1997).

Lund (2021) describes the diagnosis of prolonged grief disorder in the ICD-11 as an attempt to control grief which has become a disorder requiring psychiatric treatment to hastily return the bereaved back to productivity. Cultural factors in the diagnosis of prolonged grief disorder have been included in the ICD-11 by virtue of a condition for the individual's grief response to clearly exceed "expected social, cultural or religious norms for the individual's culture and context" (WHO, 2018). This does not however account for variation within cultures (Doka & Martin, 2010). It also does not account for neurodiversity as a dimension of grief reactions.

2.3.7 Existential perspectives on bereavement

Meaning-making approaches such as social constructionist, narrative and constructivist models are most consistent with existential approaches to counselling. In existential counselling, the practitioner conceptualises and works with psychological disorders by focusing on existential themes rather than diagnostic categories (Sharf, 2012). Two givens of human existence are drawn into focus by bereavement: death and relatedness (De Santis & Finlay, 2018). Relationships come with the risk, unpredictability, and inevitability of loss which in turn confronts us with our own mortality.

Bereavement as a confrontation with our own mortality is central to Yalom's (1980) approach to existential therapy. He suggests there are two ways that death is important in psychotherapy: 'boundary situations' (events that confront us with our existential situation such as bereavement or a diagnosis of a terminal illness) and death as a primary source of anxiety. Despite the challenges and pain of grief, Yalom asserts that bereavement can be transformational for many people due to their awareness of death through which they begin to live more fully in the present, realising that “existence cannot be postponed. And that there is still time for life” (Ibid:162).

Yalom asserts that the death of others always increases death awareness and brings an existential dimension to therapy. Grief can be an ‘awakening experience’, making us mindful of our being (Yalom, 2011). This is a view shared by Young (2009), who notes how the theme of facing up to our mortality recurs in bereavement work, “the death of another can bring us face to face with our vulnerability and mortality” (p.169). Yalom (1980) gives the example of losing a parent and how it brings us in contact with our vulnerability, compared with the loss of a spouse that might arouse the issue of basic isolation.

The potential for death to enrich our lives was also elucidated by Heidegger (1927) who suggested that mortality is an existential given that we have not chosen but are free to respond to in one way or another. Death offers us the certainty of the possibility of no further possibilities. The future is finite, and we are constantly projecting ourselves toward death (‘being-toward-death’) in a process of becoming. Heidegger viewed time existentially, as a web of experiences between birth and death as opposed to a line from past to future. Dasein is ‘temporal’, the source of time. Our existence is constantly unfolding and changing, moving between past, present, and future. The moment we are born we are “at once old enough to die” (Ibid:289), death is a part of being and something we are aware of. We are thrown into the world and projected towards death with an awareness of the finiteness of our existence. We experience anxiety about the possibility of Nothing, or “the possibility of the non-existence of everything” (Warnock, 1970:61) and become aware of our concern for our being-in-the-world and how things matter to us.

Heidegger describes his conception of death as that “possibility which is one’s ownmost, which is non-relational, and which is not to be outstripped” (Ibid:294). Possibility is the technical term Heidegger uses to refer to the ways in which Dasein can project itself (Cerbone, 2008). ‘Being-toward-death' is a way to be so that, rather than being an event that happens to me, death can be a way to live.

Heidegger differentiates between anticipating and awaiting the certainty of death. Awaiting for death to happen is to consider it an event (dying) that is feared will occur at some future time. He argues that the deaths of others confounds the illusion that death happens somewhere off in the distance, at the end of life. We tell ourselves that "one dies too, sometime, but not right away" (Ibid:299) and it is this "evasive concealment in the face of death" (Ibid:300) that helps us to think of death as something that happens to others. In doing so, we have fallen in with the 'they', into the anonymous mode of 'everydayness', so that we might flee from death and the reality that we are already dying. The death of others neither gives us the answers to our own experience nor captures our own death; it is merely a generalised experience of death (Rennie, 2006).

Anticipation of death on the other hand, is authentic being-toward-death and it not only confronts death but also embraces it as one's ownmost possibility. This is an ever-present way of projecting ourselves that welcomes anxiety. Anticipation of death brings Dasein:

> …face to face with the possibility of being itself, primarily unsupported by concernful solicitude, but of being itself, rather, in an impassioned freedom towards death – a freedom which has been released of the illusions of the 'they' and which is factical, certain of itself, and anxious (Heidegger, 1927:311).

Facing up to the inevitability of death can therefore make people aware of their freedom and invoke existential anxiety. The death of others is seen by Heidegger as adding to the illusion that death is something that happens at a distance rather, than to us. However, it is possible for people to experience their grief as an 'awakening experience' (Yalom, 2011) that brings them face to face with their vulnerability and mortality (Young, 2009).

Once we face up to the reality of our mortality with an attitude of 'resoluteness', we become passionately aware of our freedom. Accepting death and freedom causes us existential anxiety yet this is not to be viewed as a weakness. Existential anxiety is an ontological and inevitable part of existence, it lacks the definite object of fear can be experienced as general apprehension (Cohn, 1997). It is essential in order for us to be aware of our possibilities and it confronts us with having to make choices. Anxiety is usually viewed as pathological and something to be cured, whereas Heidegger reverses that therapeutic theory and stresses that it is the defining feature of authentic living (van Deurzen, 2010).

2.4 Bereavement and autism

2.4.1 Autistic adults' experiences of bereavement

From an existential perspective, bereavement is a de-centring experience causing discontinuity in a person's autobiography and an opportunity for them to "reflect on their situation in the world, their givens of existence and their responsibility for their life" (Adams, 2006; p.277). It can be responded to in a myriad of ways. Bereavement and loss pose challenges to the informational processing styles and capabilities of autistic adults. Cashin (2008) describes how intense stress and anxiety is often experienced by autistic adults in novel situations and during periods of transition. Difficulties in adapting to the changes associated with loss are noted by Paxton & Estey (2007). They emphasise that the grieving of an autistic individual may go unnoticed when emotions are expressed in a different way to non-autistic expression. Instead, an autistic person might engage in 'odd behaviours' because of heightened anxiety.

Operating on the level of the social dimension, or Mitwelt (Van Deurzen, 2010), poses unique issues for autistic adults. Autism "represents a different way of being in the world that is associated with a higher frequency of anxiety disorders and depression" (Cashin, 2008, p.48). Ramsay et al. (2005) suggest that unlike social anxiety experienced by non-autistic people when they misinterpret a situation, autistic people simply cannot interpret a social situation and anticipate what may happen. Thus, social conventions around death and dying are potentially difficult to comprehend and participate in for autistic people.

There is often an assumption that relationships are not important for autistic adults, especially when their behaviour is interpreted as appearing cold or aloof. In the absence of close friendships, autistic people can be perceived as lacking emotional warmth and/or the capacity for intimacy (Tantam, 2009). While interpersonal relationships can be somewhat of a mystery to them, autistic individuals are still “often attached to people in their lives” and “pleased or upset when they please(d) or disappointed others” (Jacobsen 2004, p.570). Research has found that autistic children have been shown to develop attachment bonds that can be evaluated using the Strange Situation (Rutgers et al., 2004). Young autistic people may become particularly attached to a grandparent and experience bereavement in their early teens (Tantam, 2013). It has certainly been my experience that autistic individuals value relationships, desire to feel socially connected and care deeply about others.

Doka (1989) wrote about disenfranchised grief and the particular elements of bereavement that can be disenfranchised. He said that some bereaved individuals may not be recognised as being capable of grieving such as very young children, people with learning disabilities and those with dementia. In later writing (Doka, 2002), he also included the ways in which people grieve as potentially being disenfranchised when their way of expressing grief does not conform to expectations or societal norms. Relatives of autistic people are often upset by the autistic survivor’s apparent lack of grief response however, depression following a loss is a reality for many autistic people (Tantam, 2013). I propose that some autistic adults may experience disenfranchised grief and a resulting lack of empathy and appreciation for their experience.

Gradually, resources and literature regarding experiences of bereavement for autistic people are increasing. These are predominantly found online with more aimed at supporting children than adults. Such guidelines and articles are provided by: Carol Gray (2003), Autism Digest (2009), Child Bereavement UK (Koehler, 2011), Faherty (2008), Beytien (2010), Autism West Midlands (2020), Autism Speaks (2021) and COMPASS (2021). Two surveys have been undertaken of people supporting autistic individuals with intellectual disabilities in residential settings following bereavement (Allison, 1992; Rawlings, 2000). From the results of those surveys, Allison (2007) has written a code of practice for staff in residential settings.

The National Autistic Society (NAS, 2020) offers a guide called "Bereavement" with information for adults, parents or carers and professionals. In the section written for professionals, the NAS notes:

> There is limited research, information or guidance about what bereavement and grief is like for autistic people or about the effects it might have on them (NAS, 2020)

When you click on the "article sources" tab, it is empty. Links to further resources take you to two online blogs written by autistic women (Fisher, 2012; Purple Ella, 2018).

Much of the literature pertaining to the experience of bereavement for autistic adults is indeed based on anecdotal evidence and grey literature on web-based sources. For example, Lipsky is an autistic woman who has written a book about how autistic people grieve (Lipsky, 2013). Lipsky rejects stage models of grief as unhelpful for autistic individuals:

> I felt that the majority of autistic individuals out there would experience such a myriad of individual different reactions to grief that it would be hard to categorize them into stages (Ibid, p.32)

Other such autistic first-person accounts include that of an American graduate called Elizabeth Graham (2019) who has written about how they were affected by the death of their mother as a child. Graham took to signing online obituary guest books of people who died in similar ways to their mother to alleviate feelings of isolation. This aspect of the death became a new interest for them which Graham explains in the context of the autistic feature of perseveration on topic of interest. Rather than talking about their feelings, they read books on grief. The combination of these interests promoted healing for them. Graham recommends that parents teach autistic children about death and loss in concrete ways so that they can be better prepared for it.

Julie Esris (2012) is another autistic person entreating parents of autistic children to speak openly and without fear about death to their children. Her magazine article is called “An aspies’ view of death” and describes how her fascination with the biological processes of death was heightened following bereavement. She believes that a person focusing on the biological process of death might appear strange or macabre to neurotypical individuals.

Christopher Barber (2022) is an autistic nurse, writer and lecturer who wrote an article on his experience of anticipatory grief when caring for his late wife. Barber describes how he struggled with feelings of “hopelessness and failure” (p.381) in his role as grieving carer and felt mostly ignored. His emotions intensified the anticipatory grief that he was experiencing which was occasionally expressed through impatience and ill temper with the community nurses. This behaviour was misinterpreted as aggression and met with “criticism, judgement, neglect and ignorance” (Ibid, p.382). Barber writes that his behaviour was in fact an expression of anticipatory grief, a sense of injustice, and a wish for his wife to receive appropriate care. This occurred despite the community nursing team’s awareness that he is autistic. What he needed was “compassion and the opportunity to talk, to share my experiences, to be listened to, to be understood, to be validated, to be cared for and to have a shoulder to cry on” (Ibid, p.381).

The reviewed articles and grey literature describe some autism specific differences in the experiences of bereavement and emphasises a need for further support for bereaved autistic people. While the grey literature is not published, peer-reviewed work, it provides some useful and hard to find information from first person accounts of marginalised voices. The lack of research and evidence base for knowledge about autistic adults’ lived experiences of bereavement supports the justification for the current research.

2.4.2 Situating the study in the literature

Bereavement is a universal yet idiosyncratic experience which has been researched widely but the specific experience of autistic adults is hard to find. Most of the above literature is based upon stage models of grief and pertaining to children. While the above resources are certainly informative, none are based on research examining the experiences of autistic people. The first-hand perspective of autistic adults who have experienced bereavement has not been found in existing research.

The authors of a resource called “Autism and Loss”, describe difficulties in providing resources on grief specific to autistic people:

> “…there is virtually no literature on bereavement and autism we refer first to the research in the general population and on learning disability to inform us of these issues” (Forrester-Jones & Broadhurst, 2007; p.155).

The above authors did acknowledge that several autistic people’s stories and insight were sought as contributions to their book. However, the resource also uses the stage model of grief which is an outdated and unsubstantiated framework of bereavement. Frith’s words remind us that extending theories from a neurotypical population might not be the best approach:

> “The person with autism does not just have the behavioural features of autism, but has different cognitive machinery and hence sees and experiences the world differently at a very central and personal level” (2012, p.12).

I have been unable to locate any studies of the lived experience of bereavement of autistic adults and believe that there might be a gap in the literature for this study. This project aims to stimulate further research in this area and to contextualise the experience of autistic people in the extant grief literature.

3. METHODOLOGY

3.1 Research aim

This research aims to make an original contribution to the Counselling Psychology literature via the qualitative exposition of autistic adults' lived experiences of bereavement within an existential-phenomenological framework. It asks the question, "how do autistic adults experience bereavement?", and is interested in what it was like for participants when a loved one died. The study of 'Lived experience' encompasses "experiences as they are lived by an embodied, socio-historical situated person" (Eatough & Smith, 2017, p.195).

3.2 Overview of methodology: rationale for a qualitative approach

Implicit in delimiting the research method is the researcher's worldview, their perception of reality and how they believe it is best studied:

> To ensure a strong research design, researchers must choose a research paradigm that is congruent with their beliefs about the nature of reality (Mills, Bonner, & Francis, 2006, p. 2).

The current author personally subscribes to a constructionist-interpretivist paradigm that has influenced the choice of research topic and methodology. Qualitative methodologies are aligned with the constructivist belief that there is no single reality, rather that the researcher elicits participants' individual views of reality (Bergman et al., 2012). Reality can be different for each person based on their unique understandings of the world and their experiences of it (Berger & Luckman, 1966).

The constructionist worldview argues that reality is socially constructed; knowledge of the world is constructed between people and social interaction of all kinds, and particularly language, is of interest (Burr, 2003). However, a middle ground is adopted by this study in that it assumes a critical-realist position, acknowledging that there is a ‘real world’ even if the data gathered cannot provide direct access to this reality (Willig, 2021).

Rather than adopting a realist, reductionist stance for this qualitative bereavement study, an attitude of openness is adopted in order to study phenomena as they present themselves and rather than imposing pre-conceived ideas or hypotheses on them (Dahlberg et al. 2008). By employing an inductive approach to studying rich descriptions of autistic people’s experience, we can hope to understand them in new ways.

Utilising an interpretative phenomenological analysis (IPA) approach allows participants’ lived experiences to take centre stage. In most of the prior research of autistic experience, “the one voice that has been traditionally silenced within the field is that of autistic people themselves” (Milton, 2014, p.12). This IPA study is committed to “the phenomenological requirement to understand and ‘give voice’ to the concerns of participants; and the interpretative requirement to contextualize and ‘make sense’ of these claims and concerns from a psychological perspective” (Larkin et al., 2006, p.102).

Research in the field of psychology has historically predominantly been undertaken using quantitative or positivist empirical methods. The world seen through the positivist paradigm is something ‘out there’ that can be objectively apprehended. If it is possible to observe and describe the world from an objective viewpoint then it is possible to draw generalisable conclusions about the world from observations made in experiments (Levin, 1988). Subsuming to scientific epistemology means that research is viewed as value-free with the object and subject of study being detached from one another (Polkinghorne, 1983).

Contrastingly, the epistemological focus in qualitative research is on subjective experience and the impact of the researcher on the study. Qualitative research can produce descriptions based on subjective accounts that tell us something about everyday lived experience. It is interested in the meanings that research participants attribute to events, attending to ‘the quality and texture of experience’ as opposed to ‘the identification of cause-effect relationships’ (Willig, 2021, p.9). This marries with a constructivist approach to research that does not begin with a theory but rather an aim to “generate or inductively develop a theory or pattern of meanings” (Cresswell, 2003, p.9).

According to Howitt & Cramer (2011), the use of a qualitative research method is more appropriate than a quantitative method in the following circumstances:

i) There is a lack of research into a particular topic
ii) When aiming to understand complex phenomena in a natural setting

This study fits both the above criteria, providing further justification for a qualitative approach.

Exploring how autistic people experience bereavement is the priority in this study. That priority, taken with the philosophical stance that subject and object influence and co-constitute each other, means that IPA is the preferred method in this instance. The hermeneutic method of interpretative phenomenological analysis (IPA) will examine individual lived experiences of bereavement, merged with a subjective and reflective interpretation that leads to insight into participants’ experience and perception (Reid et al., 2005). IPA is a suitable qualitative analysis to employ when researching the complexity and meaning of a personal issue such as bereavement.

3.3 Phenomenology

Phenomenology is both a methodology and a method being an umbrella term for a philosophical movement and a range of qualitative research methods. It refers to the study of human experience and how things are perceived as they appear to consciousness (Langdridge, 2007). The main concern is “the appearance of things, as contrasted with the things themselves as they really are" (Spinelli, 2005, p.2). This means that rather than being able to know an objective reality, we understand the world from the point of view of our individual perception. Finlay (2009) highlights the shared features of phenomenological approaches:

> Phenomenological research characteristically starts with concrete descriptions of lived situations, often first-person accounts, set down in everyday language and avoiding abstract intellectual generalisations (..) Phenomenologists also concur about the need for researchers to engage a 'phenomenological attitude'. In this attitude the researcher strives to be open to the Other and to attempt to see the world freshly, in a different way (p.10).

This methodology aligns with the current study which starts with first-person accounts of bereavement adopting an open attitude to the autistic participants' experiences. Phenomenology also accords with my epistemological stance.

3.3.1 Descriptive phenomenology

Descriptive phenomenological methods are based on Husserl's phenomenological psychology (1913/1970, 1929/1977) and his method of identifying the essential structures of experience by turning attention back to knowledge of 'the things themselves'. Husserl's method aims to clarify how objects are experienced and present themselves to consciousness. Things in phenomenology are things of experience including abstract objects such as bereavement and grief.

Husserl outlined a series of steps for moving away from an everyday perception of phenomena in the 'natural attitude' toward a phenomenological attitude of critical reflection. This involves Husserl's 'phenomenological method of reduction' in which "common-sense notions, scientific explanations and other interpretations or abstractions that characterize most other forms of understanding" (Willig, 2008) are put aside, or bracketed. Husserl's transcendental phenomenology aims to strip away preconceptions and biases and through a series of reductions arrive at the *whatness*, or invariant structure of an experience (Eatough and Smith, 2017).

A question debated by phenomenological psychologists is whether it is possible to truly transcend subjectivity when we are so practically engaged with the world. This was as times contradicted by Husserl himself who conceptualised the world as concretely lived as the 'lifeworld' (Husserl, 1936/1970). The lifeworld is the experiential world that we perceive and act in, it "appears meaningfully to consciousness in its qualitative, flowing given-ness; not an objective world "out there", but a humanly relational world" (Todres, Galvin & Dahlberg, 2007, p.55). Husserl grounded his later works in the concept of the lifeworld which placed them at odds with a transcendental position. Despite this, he maintained his stance on bracketing aspects of consciousness to see things as they really are.

Phenomenological psychology is now less concerned with the Husserlian identification of essences than it is with the multiplicity of human experience (Spinelli, 2005) and few phenomenological researchers would claim it possible to suspend all biases and presuppositions in the analysis of a phenomenon (Willig, 2021). The phenomenological reduction is however regarded as a valuable method for exposing some of the ways in which the natural attitude conceals understandings of human nature despite it being an imperfect process (Dahlberg, Drew & Nystrom, 2001).

Descriptive phenomenological methods were appraised as unsuitable for the current study as the notion of extracting an object's 'universal essence' is at odds with my interpretivist epistemological position. As Langdridge (2013) states, a researcher's attempts at objectivity are ultimately flawed due to the inevitability that their subjectivity will influence the analytical process in multiple ways. This study is concerned with the diversity and variability of autistic individuals' experience of bereavement, rather than identifying 'essences' in the Husserlian sense.

3.3.2 Interpretative phenomenology

The Husserlian foundations of phenomenology were extended by existentialists concerned with fundamental questions regarding existence (Langdridge, 2007). The theory of interpretation and meaning, known as ‘hermeneutics’, is a practical philosophy derived from a wide range of traditions and theorists. Whereas phenomenology is the description of pure experience, hermeneutics is the interpretation of experience via ‘text’ or some symbolic form (Van Manen, 1990).

Interpretative phenomenology draws from the Heideggerian hermeneutic and ontological approach (Heidegger, 1927/1962). Heidegger’s conceptualisation of a person, or ‘Dasein’, as ‘being-in-the-world’ highlights the fundamental nature of existence as relational. We are thrown into the world to face the facticity and situatedness of our existence. This world is one of objects and relationships and of always moving toward death. Interpretation is a basic structure of our being-in-the-world rather than a separate procedure. Individual and experience co-exist to the extent that understanding is a mode of being. In the hermeneutic process, understanding and interpretation reveals to us what is hidden.

To Heidegger (1927/1962), absolute bracketing is impossible because people cannot stand outside the pre-understanding and historicity of their experience; “Interpretation is grounded in something we have in advance – in a fore-having” (Ibid; p.191). My understanding is therefore connected to a given set of ‘fore-structures’, including my historicity, that I am not able to eliminate from the interpretation:

> In interpreting, we do not, so to speak, throw a ‘signification’ over some naked thing which is present-at-hand, we do not stick a value on it; but when something within-the-world is encountered as such, the thing in question already has an involvement which is disclosed in our understanding of the world, and this involvement is one which gets laid out by the interpretation (Ibid; p. 190).

Thus, the role of the researcher changes from observer to co-creator and hermeneutic phenomenology encompasses the role of a person's preunderstandings in the interpretative work: their prior experiences, assumptions, and preconceptions. Deep engagement with and the understanding of texts is achieved through a hermeneutic circle of moving back and forth between the detailed parts of experience and the whole of experience.

Gadamer (1975/2004) saw interpretation as a fusion of horizons with the expectations of the researcher and the meaning of the text interacting with one other. He posited that "The horizon is the range of vision that includes everything that can be seen from a particular vantage point" (1989; p.301). The horizon of our present perspective is continually taking shape and cannot be separated from the horizon of our past and the tradition that we come from. Gadamer referred to Heidegger's fore-structures as 'prejudices', saying that all understanding involves some prejudices or biases of our openness to the world. The researcher is describing not their own personal experience, but how the participant makes sense of their experience via the 'double hermeneutic process'. As Gadamer (1986) states, "when we interpret the meaning of something we actually interpret an interpretation" (p.68).

The researcher's preconceptions change and evolve throughout the process of interpretation as their horizon, or worldview is expanded or revised through dialogue with other horizons. Understanding between minds occurs in this process of fusing horizons, a process that bridges the gap between them to reach a common understanding (Gadamer, 1927/2004). Applied to the context of this study, Gadamer's theory suggests that understanding autistic participants' understanding of their bereavement experiences does not require me to enter into their horizon or attempt to become one with their worldview. Rather, the fusion of horizons requires me to look beyond what is close at hand, to discern the principles at work in participants' accounts and uncover their deeper meaning beyond historical circumstances. Through the encounter with each participant, old and new horizons fuse and both the participants and I will leave with changed horizons. Gadamer's ideas are particularly relevant to interpretative research with autistic individuals as they prompt me to consciously expose the tension between my neurotypical understanding and theirs. They also describe a method for new understandings with living value to be reached without an allistic researcher needing to attempt to assimilate the participants' horizons.

3.3.3 Reflexivity

Reflexivity is a vital ingredient of rigour in hermeneutic research (Ethrington, 2004), Finlay (2003) defines it as the:

> …process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes. (p.108)

However, including researcher reflexivity does not mean that 'anything personal goes' (Ethrington, 2004). The researcher must remain focused on the phenomenon, "dancing between bracketing pre-understandings and exploiting them as a source of insight" (Finlay, 2008). Rather than focusing on following certain steps in interpretative phenomenology, the researcher of human experience focuses on moving beyond assumptions to allow the meaning of a phenomenon to show itself in unexpected ways (Dahlberg et al. 2008).

In recognition of the role that the researcher plays in making sense of participants' experience, the researcher should try to discern which of their pre-conceptions might be relevant or impact the study. However, Heidegger (1927/1962) also states that it is important to prioritise the object of study rather than attempting to lay out one's fore-structures in advance of interpretation. It might be the case that the researcher will only come to see what their preconceptions about the data are, once interpretation is in progress. Therefore, while it is important to be aware of one's preconceptions and how they might affect the research, one must give precedence to the data rather than becoming absorbed in attempts to identify all preconceptions at the outset.

3.3.4 IPA

Husserl's methods for focusing upon experience itself and describing it in terms of its particular and essential features were greatly influential un the development of IPA (Smith, Flowers & Larkin, 2022). However, IPA does not attempt to transcend the particular by focusing on the structure of the phenomenon; rather, it "aims to grasp the texture and qualities of the experience as it is lived by an experiencing subject" (Eatough et al., 2017, p.3).

IPA is committed "to understanding phenomena of interest from a first-person perspective and its belief in the value of subjective knowledge for psychological understanding", (Eatough & Smith, 2017, p. 193). It's three key features are: experience, interpretation and idiography (Eatough & Smith, 2017). Experience is explored in its own terms by focusing on events that matter in people's lives and engaging with participants' reflections on their significance. Major life transitions and decisions interest IPA researchers who are interested in understanding participants' lifeworld. IPA recognises the researcher and participant are both sense-making creatures and is an explicitly interpretative task. The in-depth examination of each person's account before analysing the next exemplifies the "meticulously idiogaphic" (Smith, 2015, p.644) nature of IPA.

Exploring how autistic people experience bereavement is the priority in this study. That priority, taken with the philosophical stance that subject and object influence and co-constitute each other, means that IPA is the preferred method. The hermeneutic method of IPA will examine individual lived experiences of bereavement, merged with a subjective and reflective interpretation that leads to insight into autistic participants' experience and perception (Reid et al., 2005). IPA is a suitable qualitative analysis to employ when researching the complexity and meaning of a personal issue such as bereavement. IPA also explicitly acknowledges the researcher's fore-conceptions which is deemed important as I am aware of my personal interest in the research. In IPA research, participants are facilitated to give detailed accounts of their lived experiences, allowing for the inherently different experiences of people experiencing the same phenomenon to emerge. While there is no single right way of collecting data in IPA (Smith, 2015), the most common method is in-depth, semi-structured interviews.

3.3.5 Alternative qualitative methodologies

As previously started in section 3.3.1, descriptive phenomenology was rejected as my stance is that interpretation is a basic structure of our being-in-the-world rather than a separate procedure. Giorgi's (1989) descriptive method would be implemented in research seeking to clarify "the phenomenon in a broadly traditional, normative and scientific sense" (Finlay, 2011, p.96). It is not a description of an individual's experience per se that would be sought but a description of the more general phenomenon of bereavement. This method would aim to identify the underlying structures of meaning, or *essences,* of the experience of bereavement for autistic people. Giorgi (2002) critiqued IPA for lacking validity and not meeting the criteria of a 'scientific method'. However, attempts at turning philosophy into a rigorous science have been described by some as Cartesian in their ideas and focus (Koch, 1995). Rather than searching for 'true' and fixed meanings via descriptive phenomenology, I prefer, like other phenomenological researchers, to embrace ambiguity and a relational unfolding of meanings that incorporates an intersubjective view of knowledge (Finlay, 2009).

Research carried out using the discourse analytic method (Potter & Wetherell, 1987) is focused on how participants use available discursive resources and what the interactional effects are. The types of data that are analysed include text and talk, from natural conversations to the language used in a poster. In discursive methods, the function of language is primary to its content, they investigate what participants are doing with their talk (Willig, 2015) in relation to its social context. Foucauldian discourse analysis looks at how discourse shapes participants' experiences and ways of being, uncovering the relationship between language and power. Language here is not a reflection on people's inner realities, it "does not explain the world as much as produces it" (Dunn & Neumann, 2016: 2).   The social constructionist epistemology of discourse analysis views knowledge and reality as socially, culturally, and historically constructed which does not marry as closely with my critical realist stance as do the underpinnings of IPA.

While discourse analysis can play a role in exposing the ways that cultural discourse constructs knowledge and 'truth' about autistic people's experiences, and how this is implicated in marginalisation and oppression, that is not the aim in this study. Hermeneutic phenomenological methods such as IPA also consider the role of language in communicating meaning. This is done with an awareness of the ambiguity of meaning in language and with an understanding that people are discursive entities (Heidegger, 1927/1962). The coding and analytic processes in IPA attend closely to the detailed linguistic aspects of accounts and their relationship to the multiple meanings, interpretations, and contexts of the participants' experience (Smith et al, 2022).

Narrative analysis is another method borne from social constructionism that was considered and rejected for the current study. While it also does not marry with my critical realist position, it does share some cross-over with IPA insofar as it is interpretative and focuses on participants' meaning-making of their experiences through narrative (Bruner, 1987). People are said to make sense of their experience through storytelling and in narrative research, the focus is on the content or structure of participants' stories as a whole rather than identifying themes or deconstructing them into discourses (Murray, 2003).   Narrative approaches fall somewhere between discursive psychology and IPA (Smith at al., 2022) and this type of analysis would investigate the types of story structure and/or content that autistic participants use to describe their experiences of bereavement. IPA was the preferred method as it allows participants to disclose any other processes and objects of concern that are salient to them (Ibid). It is flexible enough to also allow the researcher to incorporate detailed analyses of the participants' self-narratives and the influence of broader cultural narratives should they show themselves to be meaningful in participants' experiential accounts (Ibid).

There is considerable overlap between IPA and grounded theory (GT), which is an alternative exploratory qualitative method that aims to elicit experience (Glaser & Strauss, 1967). GT focuses is on fitting individuals' accounts into existing theoretical constructs thereby constructing theories and explanations of social processes. While IPA research can contribute to theory development, its contrasting focus on the in-depth idiographic understanding of the lived experience of a small number of participants is more fitting for the aims and constraints of the current study. GT is less interested in the personal meaning making of key experiences. IPA's explicitly reflexive approach from a hermeneutic and phenomenological foundation are also preferred in this case.

3.4 Design

3.4.1 Sampling

A small, homogeneous, and purposively selected sample was recruited in line with the orientation of IPA (Smith et al., 2022). This enables the analysis to be in depth and idiographic and for patterns of convergence and divergence with the data to emerge. For example, the type of bereavement and relationship to the deceased was stipulated in the inclusion criteria so that meaningful insight into the experience of a specific phenomenon could be analysed.

An IPA study sample size of between four and ten data points for professional doctorates was suggested by Smith at al. in 2009. More recently, between six and ten was described as a typical number in doctoral studies (Smith at al., 2022). The emphasis here is on the data points or interviews rather than recommending a specific sample size. A sample size of five was therefore deemed appropriate for the current study as one participant emailed me following the interview with additional written data, making a total of six data points. All the interviews yielded rich data and it was decided, in consultation with research supervisors, that the quality and quantity of data (10 hours of interview and a written account) meant that further interviews risked inhibiting the depth and quality of the analysis and were not required. As Smith et al. (2022) explain, the optimum number of participants partly depends on: "the degree of commitment to the case study level of analysis and reporting; the richness of the individual cases; and the organisational constraints one is operating under" (Ibid., p.46). Large data sets can be inhibitive of the time, reflection and dialogue required for successful analysis and do not necessarily indicate 'better' work' (Ibid.).

3.4.1.2 Inclusion criteria

1. Age eighteen or over at the time of the bereavement.
2. Self-reported formal diagnosis of autism without learning disability before the bereavement.
3. Either secondary or tertiary education received in English. This was to ensure that understanding of the English language was sufficient to enable engagement in discussion with the researcher.
4. The deceased was a member of the close family (e.g., parent, grandparent, or sibling), somebody they considered important to them.
5. The death was not defined as traumatic, sudden, or totally unexpected (e.g., not death by suicide, murder, or loss of a child).
6. The death occurred a minimum of twelve months and maximum of ten years prior to participation. This is to give a socio-political context to the interviews and a more homogenous sample.

3.4.1.3 Exclusion criteria

1. Being known to the researcher in a dual capacity.
2. Not being able to give consent or lacking the capacity to consent. Capacity to consent for one participant was assessed by a referring autism service. The remaining participants were deemed to demonstrate capacity by virtue of their ability to

appropriately respond to the research advert, self-evaluate their suitability with the inclusion criteria and communicate back and forth with me regarding participation.

3. Individuals currently seeing a doctor for a mental health problem (excluding autism and associated problems) or receiving care for acute mental illness at the time of participation were not invited to interview. This was to ensure that findings are representative of the experience of being autistic rather than reflecting co-morbid diagnoses and to avoid aggravating any difficulties associated with co-morbidities. This criterium also excluded persons for whom an acute mental health condition might affect capacity to consent.

3.4.1.4 Participants

Five participants were recruited through various streams. The study was advertised on the social media pages of four branches of the National Autistic Society and several other autism charities in the British Isles. I also joined an online autism social group meeting in my local community to answer questions about the research. This generated interest from four potential participants who unfortunately did not meet the inclusion criteria. However, three participants responded to a direct email with the research flyer and participant information sheet attached. Those three individuals received the email via either the autism research mailing list of a UK autism community or through an autism consultant who was a professional contact of the researcher. One participant responded to the research advert listed on the website for a charity that offers counselling to autistic people. One other participant was recruited in collaboration with an autism service who acted as a ‘gatekeeper’ to what is a hard-to-reach population (Namageyo-Funa et al., 2014).

Recruitment was constrained by the small number of suitable and willing participants available during the timeframe of the project. During recruitment, twelve people contacted me enquiring about participation but only six people met the criteria. One participant withdrew consent the day before their interview due to concerns about talking about an upsetting experience and how that might affect their wellbeing. All five participants that were interviewed had had prior experience of counselling or therapy and/or participating in previous research which I believe was a facilitating factor in their willingness to take part.

Table 3.1: Participant demographics

Participant Pseudonym	**Luke**	**Luisa**	**Sara**	**Gillian**	**Marco**
Deceased	Mother	a. Father b. Partner	a. Mother b. Father	a. Maternal Grandmother b. Paternal Grandmother	a. Father b. Mother
Age at Diagnosis	54	45	54	25	30
Age at Bereavement	55	a. 45 b. 47	a. 50 b. 52	a. 27 b. 32	a. 36 b. 41
Age Range of Participants	34 – 60				

3.4.2 Interviews

The interview process was designed to accommodate the potential needs of autistic adults and a detailed consideration of the relevant issues was submitted for ethical approval of the study. The interview schedule was tested in a pilot study , the data from which was integrated into the final analysis. Feedback on the study design was also sought from two autistic consultants (an autism researcher and lecturer, and an autism consultant) which included their review of the interview schedule questions. Their suggestions for ensuring the interviews were autism friendly were incorporated into the design and added to the participant information sheet. For example, my attention was brought to the fact that participants might ruminate on the interview and be anxious at the thought of missing something important out of the conversation, or needing to correct something that they told me. The study design and information was therefore updated to advise participants that they were free to email me for up to a week after their interview to add or amend to what was discussed.

Other accommodations included explicitly stating in the study information that participants were welcome to stim or fidget, and that raising a hand would be understood as signalling a need to pause the interview. One of the questions on the original interview schedule asked how participants perceived being autistic to have affected their experience of bereavement. This was removed after discussion with one of my consultants who raised the fact that being autistic is a way of being that participants might not necessarily be able to reflect on in the way the question implied. Everything discussed in the interview was from participants' experience as autistic people and the nuances and implications of this was for me to uncover in the analysis.

The interview schedule was provided to participants by email together with the participant information sheet. The rationale for this was to reduce the uncertainty and anxiety about the social interaction that was the interview. Care was taken to explain that the schedule was merely an example of the types of topics we might discuss in the interview and that I was interested to hear what participants felt were the important aspects of their experiences. Feedback from participants was that they appreciated how comprehensive the participant information and preparation for the interview was. A copy of the final interview schedule is included in Appendix 3.

A semi-structured webcam interview was conducted to collect data as it permitted flexibility in how the participant's exploration of their experience of bereavement was facilitated (Eatough & Smith, 2017). Semi-structured interviews bring a level of consistency to data collection whilst enabling an interaction which allows participants to tell their own stories, in their own words (Smith et al. 2010). Thus, the pre-set interview questions were used as a guide rather than a strict script and the participant was encouraged to speak about the topic with minimal prompting from me as per Smith and Osborn's recommendations (2003). I remained open and receptive to unexpected and novel issues raised by participants, something that one of the autistic advisors noted might appear like 'going off tangent'. This is an important task for IPA researchers who are 'enablers', supporting participants in the bringing to life of their experiences (Eatough & Smith, 2017). Accommodations for autistic participants such as asking closed and concrete questions where necessary and allowing sufficient time for formulating responses were integrated into the interviewing technique.

3.4.3 Process of analysis

The interviews were digitally recorded and transcribed verbatim then pasted into Excel with columns on either side of the text to make analytic comments. Each participant's account was analysed on a case-by-case basis. During the process of transcription, the audio recording was listened to several times and some descriptive notes were written on my initial response to the account. The transcript was then analysed according to the steps of IPA analysis as detailed by Smith, Flowers & Larkin (2022).

In Step 1 the transcript was read and re-read to become immersed in the data. This was a phase of active engagement with the data and notes were made of initial observations and responses including the emergence of narratives and structure of the interview. Exploratory coding took place in Step 2 which involved a close, line by line reading of the transcript and annotating anything of interest. These comments remained close to the participant's meaning. Noting was descriptive (initial notes on key words, phrases and the objects that structured the participant's thoughts and experiences), linguistic (the way something was said, functional language, repetition, metaphor etc) and conceptual (interpretation of meaning and interrogation of the data).   Exploratory notes focused on what was important to the participant.

In the construction of experiential statements in Step 3, the volume of data was reduced by analysing exploratory notes and creating phrases that reflected both the researcher's interpretation and the participant's original words and thoughts. This involved moving back and forth between the detail of the account and the whole of the interview in a manifestation of the hermeneutic circle.

In Step 4, connections across the experiential statements were established so that personal experiential themes (PET's) could be formed. The experiential statements were printed and cut out into strips of paper and worked with on the floor to map the connections between them. Some experiential statements were worded differently but were in fact related to the same aspect of experience. This meant that in the process of clustering it was possible to reduce the statements down to a more manageable number.   Those that clustered together were given a label that attempted to capture the essential quality of what was discovered. It was important that the PET's and their relationship to each other could be traced back to what was said by the participant. I kept track of this by colour coding the PET's and filtering and sorting the data in the spreadsheet by PET. This meant that across each row containing a PET, it was clear which line of transcript was being assigned to it and all my prior notes and coding were there to track my interpretative process. An example of the single case analysis is shown in Appendix 5.

The above steps were repeated for each participant's transcript so that an in-depth analysis was carried out for each case. I constructed a table of PET'S and subthemes for each participant's data, then began the cross-case analysis. The tables were pasted into a single sheet in Excel where I could view them simultaneously. I also found it helpful at this stage to draw mind maps with different configurations of clusters of the PET's into Group Experiential Themes (GET's) and subthemes. This made it easier to visualise different connections between them and draw out the convergence and divergence between the accounts.

Once the table of GET's had been constructed, the results of the analysis were written up. This became another step in the iterative process of analysis and led to a further reconfiguration of the themes. It was during write up that the theme of 'stories and scripts' emerged as being a central theme rather than its components being subthemes. Another example of this process in the analysis is given in the following section on reflexivity.

3.4.4 Personal reflexivity

Reflexivity is a vital ingredient of rigour in hermeneutic research (Ethrington, 2004), Finlay (2003) defines it as the:

> …process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes (p.108)

Examining the quote above, I can see that I am invested in this research because of my care for my autistic sister. At the planning stage of the study, I was interested in understanding how she might be affected by the death of our mother. As the eldest child and her 'big sister', my role had always been to support her and I knew that one day our mother would die, but would might than mean for us?

Little did I know, that shortly after I gained preliminary approval for the study, my mother would be diagnosed with an aggressive cancer. She died eighteen months later. I paused the study while I grieved for her. I become a mother and lost my mother during that time, and my grief reaction included what was at times crippling death anxiety. It was a time of confrontation with all the existential givens, similar to my previous experiences of bereavement but far more intense. I have attempted to stay tuned into my own grief process throughout the analysis and not assume that participants' grief would be the same as mine. In the analysis, existential themes are present and noted, but they are certainly not the main event in the same ways as they were for me.

Perhaps more importantly, I have also reflected on how my perception of my sister's experience of bereavement might be implicated in the research process. Her experience was very hard, and I so often felt powerless to help her. She needed support that was not forthcoming. I cried in meetings with social workers in exhaustion and despair at the total lack of support and care for her. I wrote letters, made phone calls, challenged doctors and attended meetings. I witnessed her falling apart at the seams and at one point suicidal. She lost her job, an event that was directly connected to our mother's death. Nobody seemed to understand or to 'get it'. When I was analysing Gillian's transcript where she describes her experiences with the label 'high functioning', it reminded me of what some people said to my sister when our mother died. These people did not understand her distress and wanted her to 'move on' from her loss and be more independent, telling her "You're not autistic, you've got Asperger's", as if such ignorance could somehow jolly her along.

During this research process, I have attempted to bracket my experiences and assumptions and be open to the participant's description of their experience and the potential for it to be different to that of my sister. There is a risk that the personal impact of witnessing the difficulties in her experience might have somehow closed down the analysis by expectations of what would be discovered. The first participant I interviewed described a personal journey of positive growth after their bereavement and I welcomed it. I realised that I was not necessarily seeking to confirm prior (second hand) experience, that I could hold my fore-conceptions flexibly and not assume the worst.

I have kept a research journal since the proposal stage of the research and made notes on the experience of meeting the participants, the interviews, and the impact the data and process of analysis has had on me. I was also in personal therapy whilst I was conducting the interviews and analysis and was able to use the sessions as an additional reflective space. In the description of some my reflective process, I hope to demonstrate how I have been "conscious of and reflective about the ways in which [my] questions, methods and very own subjective position (as white/black, middle class/working class, heterosexual/homosexual, insider/outsider etc.) might impact on the psychological knowledge produced in this research study" (Langdridge, 2007, p. 58-59).

Being a cisgender, neurotypical researcher and counsellor means that I have a position of power in the interview and overall research process. I have reflected on how this might affect participants' thoughts and feelings about interacting with me and that this could lead to them feeling judged or anxious and vulnerable. I am an outsider and that was made very clear to me during the research process. For example, I was met with hostility and suspicion by several organisations that I contacted about recruitment. One did not trust me to understand autistic people's psychological or emotional needs, and another was outright angry that I was excluding participants with learning difficulties from participation which destroyed any possibility of trust and collaboration. During interview, a participant checked that I was "not autistic" as we began our conversation, and this re-aligned the power dynamic somewhat. I needed those experiences; they taught me important lessons in humility and sensitivity. It was somehow as if being pushed further outside gave me insight into the inside experience of being autistic. I have since wondered why we're not all talking about 'neurotypical guilt', in the age of Black Lives Matter and #metoo, is there a place for similar discourse around the oppression of autistic lives?

I have also considered the power of my words in the writing of this thesis and I have found myself saying, that I wish to "do this justice", particularly after transcribing the interviews and beginning the analysis. I was so moved by the participants' accounts and the generosity and good will that they extended me, and I felt a responsibility to respectfully convey what they had expressed to me in ways that could make a genuine contribution.

The above reflections brought my attention to how important social justice is to me as a personal as well as professional value. When reflecting on how this might affect the research, I could see how this is potentially a positive, as social justice is at the heart of existentialism and something that motivates me to be part of social change. On the other hand, there was the risk that I could impose my beliefs on the data and make interpretations that were not congruent with participants' lived experiences. I went back and forth over the GET related to marginalisation because of this, which began life as a subtheme, then I removed it from the themes altogether. However, when I began the process of writing up the analysis findings, I realised that it was indeed an important theme and there was such rich data to support it that it would be remiss not to foreground it as a GET and show how it permeates all the other themes across the accounts.

3.4.5 Quality and validity

The validity criteria of objectivity, reliability, and statistical generalisability that are applied to quantitative studies, are inappropriate for most qualitative studies (Yardley, 2015). In qualitative research there are no set criteria in assessing the validity of a study as those employed depend on the epistemological assumptions of the researcher. Yardley (2000, 2015, 2017) suggests four broad principals to ensure quality and validity: sensitivity to context; commitment to rigour; transparency and coherence: and impact and importance.

Sensitivity to context refers to how the researcher has allowed for meanings and patterns to emerge from the study. In the current research, there is sensitivity to the theoretical context of the study and findings from previous research. A good qualitative study ought to also be sensitive to the perspective and socio-cultural context of participants and the relationship between the researcher and the participants. It is important that participants are allowed to talk freely and express their personal views. This study offered participants the choice to provide written notes and accounts to the researcher to allow people to express themselves in a medium that was potentially more accessible to them and lessened the intensity of interacting with me (a neurotypical researcher with greater power in the dyad). In the analysis, sensitivity to the participants' position and socio-cultural context was carefully considered and ultimately elucidated in a standalone GET. Sensitivity to the data was achieved through my reflexivity in the research process and grounding the interpretation of the raw data in quoted extracts from participants' accounts.

The second and third of Yardley's (Ibid) criteria relate to the requirement for thoroughness in data collection, analysis and reporting of findings. Substantial time and commitment has been given to engaging with the topics of autism and bereavement for this study. This pertains not only to the time period of the study, but also to the many years prior of working in the field, training, and studying the topics in different contexts. As a novice researcher in IPA, I attended a two day 'London IPA Training' workshop run by Birkbeck University in addition to studying the key texts and guidelines for IPA and reading examples of IPA research to ensure competence. The sampling (detailed above), data collection process and analysis were thorough, systematic and 'rigorous'. Significant time was spent immersing myself in the complexity of the data, circling between the detailed micro-analysis of the transcripts, emerging themes, relevant theory and philosophy so that the final interpretation transcends a superficial understanding and description of the data.

The coherence of qualitative research is "the extent to which it makes sense as a consistent whole" (Yardley, 2015; p.267). This study demonstrates consistency and compatibility between the theoretical approach adopted, research question and methodology and the analysis and interpretation of the data. The current research presents a transparent report of the research with clear and detailed descriptions of the stages of the process. Interpretations made in the analysis are traceable to the participants' words and the researcher's initial response to the text (Smith and Osborn, 2003). The results of this study offer a persuasive interpretation of the data and are presented clearly and cogently with tables summarising the themes (Yardley, 2015). The criterion of transparency is similar to Ricoeur's (1981) analogy to the judicial process where evidence is interrogated. Results are more likely to be persuasive if the reader can see evidence of how data were collected and analysed, original data in support of the claims made and a discussion of reflexivity to clarify the influence of the researcher on the outcome of the analysis. All such evidence is provided in this study.

The fourth of Yardley's (2000) criteria, 'impact and importance' appraises the value of a piece of research in terms of its utility. Gaining ethical approval for this research involved demonstrating its importance and potential for impact. This study has implications for clinical practice and future research in the field of counselling psychology and psychotherapy. I also believe that it may influence the way that autistic people and their experiences of grief are positioned in society. However, as Langdridge (2007) asserts, judging the validity of research on its practical utility is problematic. This research will be judged on an ongoing basis by different readers who may find it important and impactful on their thinking (and therefore valid) without it necessarily bearing practical implications for them.

Confidence in the validity of qualitative research can be strengthened through 'independent audit' (Smith et al., 2022) or a 'paper trail' of the analysis (Flick, 1998). The data for the analysis in this study has been presented in a way that allows the reader to follow the process from the raw data to the final write up. The paper trail was provided to my research supervisors for them to conduct 'mini-audits' (Smith et al., 2022) of my work. The data were imported to Excel where I highlighted text in different colours and used columns to record the initial notes, exploratory coding, experiential statements, personal experiential themes, and group experiential themes. GETs were colour coded for ease so that all transcript data and notes could be filtered by theme. This enabled my supervisors to trace the GETs all the way back to my original 'annotations' using an electronic trail of evidence thus reassuring them that the study was carefully and professionally documented.

3.5 Ethical considerations

3.5.1 Consent, confidentiality, and anonymity

Participants did not have learning difficulties however, as autistic individuals who experiences social and communication difficulties, a level of potential vulnerability existed in the population group. Considering this, a thorough and clearly communicated consent process was followed. Participants were sent the details of the study, which was written in plain language, ahead of either an initial phone call or subsequent email exchanges allowing people time to review it and formulate questions. A minimum period of one-week between the initial contact and subsequent interview was ensured, allowing time for the participant to further weigh up taking part and withdraw their consent if necessary. This is in line with a two-step informed consent process (National Institutes of Health, 2009). I believe that above processes gave the participant the opportunity to make an informed decision about participating and respected their autonomy and dignity, in keeping with the BPS ethical guidelines (2014).

Prior to arranging interviews, I confirmed with participants either via email or phone that they were comfortable with the study information and parameters of taking part. They gave their written consent to voluntarily participate and I asked each participant again at the start of the interview whether they had any questions or concerns. Participants were advised that they could withdraw from the study at any time. The participant that was recruited via an autism service had been assessed by the service manager (a specialist psychologist) as suitable for participation. It was understood by this participant that their participation in the study did not affect any care or services they may have been receiving. Individuals were not remunerated for taking part.

All records pertaining to the participant were stored digitally on a personal computer which is password protected and used only by the researcher. Any identifying information pertaining to the participant, the deceased and others in the interview transcripts were anonymised. Restricting direct contact with participants to a brief initial phone call or email exchanges and one interview session assisted in making participation more anonymous and emphasised the boundaries of the research context of the relationship.

3.5.2 Risk of harm: sensitivity of interview material

The goal in the interview was striking a balance between minimising distress, harm avoidance and allowing space for the participants to express their emotions and experiences of grief. Participation in the study could have brought difficult thoughts and feelings to the surface both during and after the interview. It was possible that a participant might not have spoken about their loss before which was potentially an emotive subject to talk about. It was expected that some participants might feel a little sad or upset at times during a discussion of bereavement, but this is different to people being in a harmful situation.

The interviewees were not at physical risk of harm when talking about their loss, but it could have been emotionally painful to describe their experience. The researcher observed body language for physical signs of distress but was aware that it might not have been possible to tell by outward appearances whether the participant was becoming overwhelmed or distressed and therefore offered the participants breaks regardless.

Measures were taken to adapt the interview process to accommodate the interaction, communication and behavioural needs of autistic participants as has been discussed above. The ‘Guidelines for Conducting Ethical Bereavement Research’ by Parkes (1995) were also consulted when considering how best to safeguard participants. Although it is difficult to foresee all potential risks, the risk involved in this study does not appear to be more than minimal, as defined in the BPS (2014) Code of Human Research.

The inclusion criteria contained a safeguard for reducing the risk of harm by only selecting those people who had sufficient time before interview to recover from acute grief related to their loss satisfactorily enough to be able to safely reflect upon it in interview. Whilst there are no definitive data regarding the time frame for acute grief, studies suggest that by six months, the transition to integrated grief is usually well underway (Zisook et al. 2010). In a study into the effectiveness of bereavement counselling by Newsom et al. (2017), bereaved adults who had not received specific bereavement support showed a consistent levelling of grief symptoms from 12 months post bereavement. Thus, this timeframe was incorporated into the inclusion criteria by stipulating a minimum of twelve months between the death and data collection, allowing a reasonable timeframe for participants to not be in the acute grief that can occur immediately after and in the months following, a bereavement (Zisook et al. 2014).

Participants were invited to speak about their experience of the interview when it ended. A de-briefing letter was provided which included the academic address for the researcher and their supervisor. Some individuals might have required support following participation and the letter also contained information regarding how to access counselling, including bereavement counselling, should they need to. If it had been appropriate, one of the participants could have been referred to their referring autism service for support.

It is hoped that as McLeod (2003) suggests, the experience of being part of the research was empowering for the participants. Parkes (1995) advises that spontaneous expression of emotion in research interviews ought not be blocked, as “Expressing grief can be a very therapeutic experience” (p.174-175). In a qualitative study of grief and marital tension following the death of a child, Riches and Dawson (1996) discovered that talking about painful experiences did not cause participants distress. Instead, they responded by using it as an opportunity to ‘tell it like it is’ and to explore confusing and intimate memories. Positive feedback in the current study included that the interview was “a good conversation” (Luisa), and that it was rewarding to talk about the deceased (Gillian).

4. RESULTS

4.1 Introduction

This chapter presents the findings of the interpretative phenomenological analysis of the five participants' accounts in narrative form. This will be achieved by systematically explicating each of the four themes and related subthemes; inviting the reader into the hermeneutic dialogue so that a coherent and cogent picture of the participants' sense-making is created (Smith et al. 2022). The analysis was an inductive process, creating meaning from the idiographic level of each participant's personal experiences of bereavement.

An overview of the findings will be given together with an abbreviated table of the Group Experiential Themes ("GETs"), followed by a detailed examination of each GET. Quotations from the interview transcripts will be provided in each instance to illustrate how interpretations in the identified themes and subthemes are grounded in the data and thus derive from the participants' lived experience. A comprehensive table depicting how each participant's account relates to the individual themes and subthemes, with illustrative quotes from the transcripts, is provided in Appendix 6.

4.2 Overview

As one would expect when exploring experiences of the death of somebody close, all the participants spoke about the loss of meaningful relationships and their bereavements were significant life events for all of them. Participants showed a high level of engagement in the interview process and were generous with their time and courage in sharing complex experiences with me. One participant also emailed additional reflections following the interview which were included in the analysis. This resulted in a rich and evocative data set and due to the word limitations of the thesis, the analysis process necessarily condensed the data to include what emerged as the most salient themes. Within each theme, several subthemes were developed which provide in-depth elucidations of the participants' lifeworld and personal experiences of bereavement, grief, and loss.

Table 4.1: Master table of Group Experiential Themes and Subthemes

Group Experiential Theme	Subtheme
Theme 1 **Impacts of change, loss, and uncertainty**	a. So much change: the gradual processing of change and loss b. Depletion of resources: social, emotional, and physical demands
Theme 2 **Marginalisation: the sociocultural context of autistic grief**	a. Experiences of stigma, discrimination, and alienation b. Am I doing it right: internalised ableism, subordination and concealment c. Finding inclusion, belonging and emotional safety
Theme 3 **Adapting to change and loss: meaning and connection**	a. Social support and the healing power of talking b. Enduring love: continued connection c. Meaning-making and adaptive coping
Theme 4 **Stories and scripts: making sense of it all**	a. Life Story: the biography of the deceased b. Death and Dying Story: including scripts for 'a good

death' and 'biological processes of death'

c. My Story: reconstructing who and how I am

Table 4.2: Table of occurrences of themes across participants

Group Experiential Themes	**Luke**	**Luisa**	**Sara**	**Gillian**	**Marco**
Theme 1	✓	✓	✓	✓	✓
Theme 2	✓	✓	✓	✓	✓
Theme 3	✓	✓	✓	✓	✓
Theme 4	✓	✓	✓	✓	✓

During the iterative process of analysis, the most compelling theme that emerged related to participants' personal meaning making of their bereavement experiences through storying. However, the following findings are ordered in a broadly chronological fashion to produce a "full narrative account" (Smith et al., 2022) so that the first theme to be presented is "impacts of change and uncertainty". Theme one assists the reader in understanding what participants coped with following the death of a loved one. This depiction of how people were impacted, will hopefully set the scene for what follows.

A major theme of marginalised experiences was located across all participants' stories, providing an important context to how they made sense of grief experiences and self-concepts. This second theme, "marginalisation: the sociocultural context of autistic grief", connects across all the other themes. The analysis then explores the theme "adapting to change and loss”, depicting how people adapted to their losses by finding a place for the deceased in their ongoing lives and creating positive meaning from their bereavement experiences. The final theme, “stories and scripts: making sense of it all”, draws together how participants navigated their new, post-bereavement worlds and identities through the healing power of storying.

4.3 Group Experiential Theme 1 – Impacts of change, loss, and uncertainty

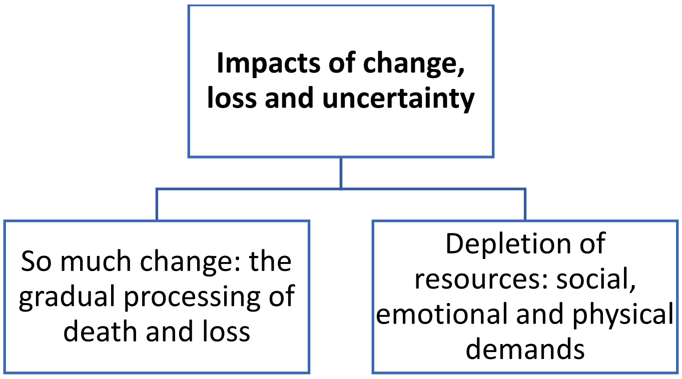

Figure 1: Group Experiential Theme 1, “Impacts of change and uncertainty”

Consensus exists that bereavement is a stressful and demanding experience, and accordingly, it affected participants in a myriad of ways. This first theme articulates how participants were impacted by the death of a loved one and the challenges that bereavement presented. A trajectory of grief emerged in the interviews, from being in a shock-like state to a gradual acknowledgement and processing of the loss. This theme is called *Impacts of change and uncertainty*, because it was the sudden change to participants’ worlds and what that meant in terms of introducing uncertainty which was a major defining aspect of their experience. Managing the demands of bereavement was exhausting and the significance of the depleting nature of the aftereffects of death and loss for autistic survivors will be examined before taking an in depth look at the part that sensory issues played.

4.3.1 Subtheme 1a – So much change: the gradual processing of death and loss

Participants were invited to talk about bereavements that are considered "non-traumatic" or as Gillian said in her interview, bereavement resulting from "natural" deaths. Despite this, it was clear that expecting an aging relative to die did not prevent the loss from being experienced as a shocking and intense experience. As Luke and Gillian described, even a long-awaited anticipated death, when it comes, can happen quickly, and take you by surprise:

> I had no idea she wouldn't be around for much longer because she was sitting down and going to attempting to make conversation. And then the shock sort of the shock, even though, you know, they're going, they're going to pass away (Luke)
>
> So everyone's older, so it's kind of it's all somewhat natural, but at the same time it's kind of been you still don't expect it. So when it happens, it's still kind of like, Oh, it's a shock (Gillian)

Above, Luke was reflecting on the last conversation he had with his mother on the day that she died, which followed a period of illness and mental decline. He left for work as usual, knowing that his mother had very little time left before she would die. Yet in his daily, moment to moment experiencing, he somehow was not expecting that eventuality to happen. While he was still at work, he received the news of her death and returned to the house to face the fact that she had passed away. For Gillian, the death of grandparents was also experienced as sudden and shocking. She wrestled with the sudden loss of routines established over a lifetime of her grandmother being an integral part of family life:

> So. You know, it's it's mostly that loss, I think, that hit the most the realization that this lifelong set of routines we'd always done was completely gone. Yeah. And I think that was the hardest hitting part (Gillian)
>
> And then all of a sudden it's like she's suddenly been snapped out of existence and she's not there. It's like, how do you deal with the fact that this person who's been constantly present is in an instant gone? Yeah, and there's no more of those occasions anymore. There's no more Christmas, no more birthdays with them, and you've suddenly got to put that all into. You know, it's a lifetime of routine, essentially in one way. (Gillian)

Death is something that snaps loved ones out of existence, fracturing the safe, familiar routines of old and breaking the template for the future. In an instant, Gillian was left bewildered with the task ahead of her, unsure how she would adapt to so much change. Everything about this situation was unpredictable, and managing such change was “the hardest hitting part”. This part was also emphasised by Sara when she clarified what she would have liked from her bereavement counsellor:

> I think the other thing is, is like the change in routine as well, that I found that hard to sort of come back to and get back to the routine [...] I think I would have liked her to appreciate how the disruption to my routine was derailing (Sara)

Sara’s allistic bereavement counsellor was unaware of Sara being autistic which contributed to Sara not feeling understood and validated. Sara spoke not only about the change related to the loss of her parents, but also about the secondary changes that come with bereavement. When a relative is ill and after they die, daily life revolves around tasks such as caring, funeral arrangements and dealing with estates. Returning to everyday life and work after these events also requires significant and challenging adjustment for the autistic survivor.

The fact that one of the main adaptations in the counselling that Sara cited as missing was a full appreciation of the disruption to her routine, is very telling. While participants spoke of emotional pain and loss as part of the bereavement experience, change to routine was paramount, it was “derailing”. The significance of coping with impacts of change and uncertainty was not restricted to routines, it was also felt regarding the unpredictability of their own grief responses. This was alluded to in Gillian’s extract above where she asked, “how do you deal with the fact” that somebody is so suddenly non-existent? When her mother died, one of Sara’s immediate responses was feeling “panic” about, “What do I do now?” This aspect of the bereavement experience was also communicated in participants’ observations of how having experienced one bereavement, knowledge they gained about their personal grieving style was helpful in coping with subsequent bereavements:

> I knew what to expect. So that being prepared in advance helped (Sara)

> I took it very differently when [they] died because I'd had the chance to sort of. Go through all of that (Marco)

For Sara, having a sense of predictability about her own process that she gleaned from the death of her mother meant that she felt better equipped to cope with the loss of her father two years later. During Marco's interview about the death of their mother, toward the end of the conversation they told me that it felt important, to reflect and compare all the way back on their first ever bereavement and how subsequent losses were influenced by those that came before. The role of change and uncertainty in participants' experiences held such weight that it seemed to act as a mediator of participants' grief responses.

As we've seen, death means disruption to routine on a grand scale, and a finality that is beyond an individual's control and even beyond comprehension in the immediate aftermath of bereavement. Out of the experience of change, ending, and uncertainty about a future in a new world, emerges a trajectory of grief. Luisa very much wanted me to understand this aspect of her bereavement experiences, and we spent much of her interview exploring how change impacted her and the gradual processing it necessitated:

> So get, get the news and it's, it's kind of. Yeah, I, okay I know that. And then. It. It takes a while before. I guess [...] it is, is the fact that it is a, it is a change in my little my little world, my little circles around myself [...] In the end, it was just kind of the fact that. That was quite a large. Yeah. A large part of my life. And. There was that sense of. Ending. It was a very final sort of thing. (Luisa)

Again, the significance of change is expressed by Luisa, who places her bereavement in the context of the small number of people close to her in her "little world". The way that she said "Ending" conveyed the power and finality of death to close a whole chapter of her life. Luisa went on to talk about and emphasise, the lag that she and other autistic informants had experienced at the beginning of their grief trajectories, between the death, or news of the death and the emergence of grief related emotions and feelings:

> Some of my autistic friends have also mentioned […] there's this kind of delay between getting the news and. See the emotions kind of catching up that that's a gap that kind of delayed reaction (Luisa)
>
> *Adjusting mentally. It doesn't happen instantly [...] It's becoming used to the new idea. So the new idea then becomes normal [...] So there's a period of adjustment period. It's like. Yeah. I suppose like with any new situation, you. You. Kind of adapt to it. And.*

> As, best you can. So, I mean, some certainly somebody close dying, somebody who's been part of your life for however long. If they're no longer there, then that is a significant change in your situation in and. Yeah, it would be hard to sit down and work out all the ways that that could affect what you do and. From that point on. *(Luisa)*
>
> Maybe not straightaway, but eventually at some point emotions come [...] it's not a sudden sensation of anything. And. It's something that kind of creeps in very slowly (Luisa)

Luisa understood her grief response as related to a drive to create a sense of predictability and familiarity in her changed world, a desire to predict the manifold ways that things will be different in light of loss. There is so much to comprehend and absorb that emotions are at first absent but there's a sense of foreboding and threatening about grief that "creeps in very slowly". This perceived absence of feeling immediately after the death was also described by Luke who was quite explicit about what was, in his view, a delayed reaction to his loss. When a loved one dies, Luke described how the impact is physical, it "hits you". He used the word "numb" or "numbness" five times during this part of his interview discussing what it was like after his mother died. Rather than referring to an emotional numbness, it was more specifically related to an arrest of cognition in his "brain" and "head", rendering his mind held in "neutral":

> I suffered from delayed reaction, sort of shock of sort of that. She's not there anymore […] before my mother died and after mother died, well my brain was just completely neutral […] It's something that hits you. It's a shock to the system, and your brain will be numb for some considerable time [...] Numbness of the head *(Luke)*

When the impact of loss was at its most intense, it plunged participants into an acutely stressed state that had the power to overwhelm them. There were significant cognitive effects of bereavement such as loud, racing thoughts and a sense of being in survival mode, just going through the motions of daily life and being swept along by everything that was happening. Here Luisa uses the metaphor of "turbulence" in her brain:

> Turbulence churning kind of, you know. Any thoughts are just. You know, being whirled around so fast that you. You can't really become aware of erm things. Everything is just moving too fast [...] I kind of fall back on instinct. I'm not. Not really consciously directing what I'm doing. It's just. You know, a much more visceral thing. [...] And I don't want to say animal, but not not a you know, it's not not consciously responding. It's kind of just being carried along. Yeah. By it. And whatever happens, happens *(*Luisa)
>
> The brain is too noisy to think about what I'm doing, but at the same time […] It's not exploding outwards. Yeah. It's much more centred, much more an internal thing (Luisa)

This experience is internal and “visceral”, implying that those around Luisa were unlikely to realise what she was going through. She describes it as something like an animalistic sort of state, rather than having access to higher order mental processes, she was running on survival instincts. Luisa was impacted so strongly by bereavement that she was almost taken over by it, thrown into a tornado of thoughts and feelings, “not really consciously directing” herself. The impact of the changes brought about by her mother’s death had a similar effect on Sara:

> I had a fall and hurt my elbow. I was in a lot of pain but put it aside because there was so much going on and I'd had such a change to my routine, not knowing what would happen next [...] All the time my elbow was fractured. I don't how this happened but I think it was all a blur at the time and I wasn't with it but trying to function and hold it together. (Sara)

Sara’s extract also discloses the sense of not being fully aware of herself, to the point where she didn’t realise that she had suffered a fractured elbow before her mother’s death. It wasn’t until some weeks following the funeral that she sought medical attention. Repeated here is the significance of change to routines and uncertainty in underpinning her experience. She was “trying to function and hold it together”, giving a sense like Luisa, of merely surviving this period. Gillian uses the descriptor, “haze of disbelief” regarding the state she was in whilst trying to cope with the initial impact of her grandmother’s death:

> It was sort of like being in a haze of disbelief [...] Then the disbelief kind of went and it started to go more into like. Okay, so. She's definitely dead, but not really knowing how to process the fact she's gone. It was that initial. She's not here anymore. Sort of mental processes is the only way I can explain it. It was like. I knew she was dead. I knew she'd gone. But there was a part of my mind that was sort of like dazed over and still couldn't quite believe it, even though I knew it [...] And then slowly, I think it was after the wake, slowly it sort of started to get a little bit more, I suppose you'd say bearable (Gillian)

Like Luisa, Sara, and Luke, in the above extract Gillian tried to make sense of what was happening to her on a cognitive level and the impact on her “mental processes” that meant her mind was “sort of dazed over” with shock and disbelief. She emphasised the slow and gradual nature of the intensity of the survival period easing which, as will be discussed below, led into the processing of difficult grief related emotions and feelings.

While Marco didn't explicitly describe being in a mental haze during the period around their mother's death, something of that nature was implied in the way that his recollections of details and the order of events were themselves hazy in the interview. Interjections such as, "Yeah. No, I mis-remembered that" were peppered throughout our conversation. Marco's grieving process was marked by feelings of loss and emptiness:

> I felt a pretty intense sense of loss. Um. Kind of emptiness at times. Thought about her a lot [...] I'd had a bit of counselling. Ten years or so before. Um. I think partly it was about sort of getting more in touch with my emotions (Marco)

The counselling that Marco had engaged in some years before their mother's death had helped them to improve emotion processing, implying that this has been an issue for them, and it is in this context that they experienced an "intense sense of loss". That fact that Marco raised the emotion focused work of the counselling while we were discussing the emotional impact of their bereavement, discloses its implied relevance here. Marco didn't verbalise much about their emotions and grief related feelings save for what has been quoted above, although there had been several opportunities to do so. However, talking about the bereavement during interview had brought Marco in touch with them. At the end of the interview when we checked in with their feelings, Marco reported:

> I've got that sort of dealing with difficult emotions feeling [...] A bit in my stomach. And. My face. Uh, and. I think maybe generally feeling just a little bit shaky (Marco)

Despite the scant articulation of emotions, Marco had been emotionally engaged in the interview, connected with their sense of loss and was also experiencing some anxiety (shakiness). Dealing with the impacts of bereavement inevitably involves "dealing with difficult emotions" and if like Marco, an autistic person doesn't feel inclined or able to talk about them, that does not mean that the person is not experiencing them. It was a similar picture for Gillian, who told me that she felt disconnected from her embodied sense of self and relied on her partner to identify how she was feeling. Unless Gillian's feeling crossed a high threshold of intensity, they remained somewhat of a mystery while her partner would assess her body language for cues:

> And he can tell physically how I'm going to be in any situation before I get the mental and the feeling memo [...] I can't keep track of that really unless it's as obvious as a brick. It's kind of hard to know (Gillian)

In Luisa’s interview, as she was reflecting on how she processed her loss, she spoke about how hard it can be to identify and makes sense of the feelings that arose whilst acknowledging that it is also a helpful thing to do in coping with grief. Here Luisa affords us some insight into her personal journey toward better understanding of her feelings:

> Talking about feelings isn't necessarily very easy. Even understanding feelings and. It's. Yeah. I mean, I. It's something I've had to work on learning through my life is. You know, emotions are primarily very much sort of physical sensations. And putting the label onto that is a matter of kind of doing the algebra, sort of working out. It's like, well, you know, these things have happened. You know, I've got these sensations. Yeah, that I'll be feeling such and such that that's that kind of works out. Then you've got a label on it. It. Let labels help you understand things (Luisa)

Understanding feelings was not an instinctive skill for any of the participants. Luisa has developed a way of doing so which is actively “doing the algebra, sort of working it out”. For Sara, the period after her mother’s death was so emotionally intense that she desired to be on her own and “private”, although she didn’t get much opportunity for that. Her inner world of dreams was a channel for her to process difficult and distressing emotions:

> I was still having those awful dreams. And they, they were so vivid. And it was the same thing that I still have them now, but they're not as intense. But I was having real strong emotions in those dreams and waking up in a bit of a panic. (Sara)
>
> And at a time when it's so emotional, I want to be private. I just want to be there with my thoughts and wanted other people to go away. I just wanted to be there with my partner (Sara)

Autistic survivors experience a gamut of emotions as will any bereaved individual, but this poses additional challenges when the task of understanding them is difficult, complex, or sometimes out of reach. Gillian compared how it was to be intensely grieving and feeling emotional to aspects of her experience of depression, noting that it was similar in some ways but ultimately different and unique. Bereavement for everyone I interviewed created feelings that were hard to express, it was a singular experience that is “not an easy thing to describe” (Marco), even to themselves let alone communicate to others.

Luke used a metaphor of being a balloon full of the “Feelings in your emotional shock” to articulate the emotional impact of loss while Sara talked of a “void” that felt as if it were trying to turn her “inside out”. The struggle to articulate it was heard in the false starts she made, “It's a kind of kind of void kind of emptiness”. Their metaphors bore some striking similarities:

> It's like you're compressing a balloon is being compressed all the time and suddenly the balloon will just open up [...] You were like a balloon being compressed and compressed and suddenly burst and everything breaks out and you're able to express yourself (Luke)
>
> And with the most intense feeling. Is. Oh, it's. It's a kind of kind of void kind of emptiness. It's. And there's. This great gap inside and that. Um, it's. Kind of the space that should have been filled by the person [...] it's like a an emptiness inside that's almost trying to. I don't know. Turn you inside out. It's that it's really powerful sensation. And. You know, the. It just. Uh. And no, no clarity of thought. It's it's dominated by this. Erm. It's not like a sort of physical injury pain, but it is a. It is a pain. And it it's hard to find the words to describe. It's something that I don't know, want. Feel like you want to simultaneously sort of curl up in a tight little ball and explode out in all directions. And the tension between those and it's just this great tension and tightness. Yeah. Overwhelming (Luisa)

Both participants conjure the sense of their embodied experience of overwhelming grief, the feelings within them creating an intense pressure. For Luke, the balloon of feelings was “being compressed all the time” until it burst open, and he regained his ability to express himself. If we connect this with what Luke said about his delayed reaction, it’s as if the release of emotion has freed his “head” out of being stuck in “neutral” and we hear his sense of relief at this in the metaphor. Luisa also references not being able to have any “clarity of thought” while her emotional pain was causing such “tension and tightness”. Her description of the “void” is as if there’s an empty space where the deceased once occupied in her body. The intense discomfort they both felt is palpable and for Luisa, it seems as if the emptiness might almost have the power to obliterate or consume her.

Four of the participants referred to feeling a sense of “strangeness” following bereavement. Feeling strange was particularly striking at the time of death or upon hearing the news. For example, Luisa noted there was *“*a kind of calm, but like almost like a chill as well. It's a funny feeling” that came over her during the phone call in which she was told her father had died.

The coldness of the chill was likened to blood draining from her body, "almost like sucked away from the inside" while emotionally she was "flat". Being present for her mother's dying moment resulted in Sara also experiencing a sudden cold "chill" and sense of strangeness:

> And we were with her and. Oh, well, that was a strange aura in the room. And it it went really cold […] It was like a chill. It was just like a sudden drop in the room temperature and. I know there was just a strange aura about the room (Sara)

A sudden drop in body temperature is commonly experienced during intense anxiety and stress yet neither participant made that connection. Both intimated that their experiences might not be rationally explained, with Sara making sense of it as a paranormal "aura" in the room. Luke described not being able to make sense of how he felt when he went into the room where his mother's corpse lay, "the doctor was with me [...] and that was sort of it was a strange thing at the time. I didn't. I didn't know what to ponder about the whole thing".

Both Luke and Luisa felt a sense of strangeness in themselves at their mothers' funerals when hearing the deceased being described in eulogies. Luisa encountered a "kind of feeling [...] that was strange" upon hearing the officiant speak about her late mother and for Luke, there were "one or two strange things" that he felt on hearing anecdotes about the deceased. The closest comparison that Luke could find for his experience was as if he was "ill", but ultimately, words to pin down the strange affliction of grief escaped him:

> A bit of crying here and there. Certainly felt a bit ill sometimes. Yeah, just just emotions and feeling a little bit ill from time to time. Um, not sickness, but. I suppose even I would be a bit strange [...] Well, but I felt you're not quite yourself, but you don't know why. I think that's the best way of describing it (Luke)

What does Luke mean when he says he didn't know why he felt that way when he clearly connects his above feelings to the loss of his mother? He's talking about a peculiar and unusual feeling in a world that has been changed by the sudden non-existence of his mother. Everything else about his world, in the physical sense, remains as it was before her death. Hearing familiar anecdotes of his mother's life felt at odds with something, the room with her corpse was the same as it was when he left that day, yet he had a deep sense that something was fundamentally unfathomable and disturbing. The other participants' descriptions of feelings of strangeness share these characteristics including the following from Gillian's depiction of her grandmother's death:

> And we were all sat downstairs in the house literally for about half an hour after they'd taken her body out and it was weird to be sitting in her house without her there because it was still her house. But you almost felt like something had left with the body, almost like there. […] It was her house, but she wasn't there anymore in that way, and it didn't feel homey anymore […] Yeah, it was weird. [...] And then in the instant when she'd gone, it just felt like a husk, like the light had gone out the house and it felt like there was like it was just gone. It didn't feel like the same anymore. It didn't feel like home in that sense. So. It was weird (Gillian)

Her grandmother's "husk" of a house no longer felt cosy and familiar and Gillian repeats how "weird" she felt. She had been there before when her grandmother was out of the building, but this felt different. It had an eeriness to it that she struggled to make sense of and got close to something meaningful when she alluded to it being like homesickness. These descriptions of an indecipherable 'strangeness' illustrate just how unsettling and anxiety-provoking an experience bereavement was. Suffering bereavement meant that participants were left struggling to understand their embodied experiences.

Managing the initial impacts of change, loss and uncertainty meant dealing with a sudden disruption to participants' worlds and these intense, difficult, and singular feelings that all five participants reported. This went from surviving the haze of shock and overwhelm into what was considered a natural process that participants experienced as happening organically if given space and time:

> But it's it just seems to be something that happens and. I think just over time [...] Let it happen in its own time [...] Just go easy on yourself. Give yourself time and space as much as you need (Luisa)
>
> Do whatever you need to do and. And just give yourself plenty of time and space and if you can. And. To try and pace yourself, going back to routine […] Give, give your mind space (Sara)

The concept of necessary "space" was reiterated when Marco talked about the counselling they had in the aftermath of their bereavement being helpful because, it "Cleared some space for dealing with the the loss". These descriptions imply that in order to adapt to their new post-loss worlds, they needed to find room in their life on practical and embodied levels to focus on what they were going through, without undue distraction or harrying.

Participants made sense of the temporal nature of their grief experiences, with everybody in consensus that while grief changes over time, it doesn’t have a cut and fast end point. Gillian shared with me a metaphor that a friend told her, with grief being a ball in a room with a button. The ball is so large at first that it triggers the button all the time then:

> … as the time goes on, the ball gets smaller and smaller and you'll be doing something and it will be bouncing all over the room and then all of a sudden it'll hit the button and you'll get tearful and you'll get upset. And it's like even years later, it's probably about the size of like a tiny little bit of marble. It still hits the button, it still gets you upset, but it's not as frequent or as big as it used to feel. You've kind of grown accustomed to it. And it doesn't it doesn't happen as often or with the same intensity (Gillian)

Gillian has come to accept that grief is part of her life now, describing there still being “moments where I feel sad about her and things, but it's not like it was in the beginning”*.* Her grandparents are in her thoughts “at least once a day, if not more” which she had become habituated to and felt assured by. Marco reflected on how much they missed their mother, “Not like all the time. I think about her quite a lot […] I do miss my mum from time to time.” Marco found this aspect of ongoing grief rather “annoying” as it is a difficult feeling that they were not accustomed to.

Luke and Luisa had contrasting experiences of grief over time, with Luke describing his grief as, “Very low, God, can't really describe it now, it's sort of it. It's out of 100. It's probably nought point one percent now.” This was despite him telling me that he thought about his mother all the time and missed her deeply, implying that his grief was not experienced as troublesome or painful anymore. While Luke’s grief was at a minimal level, he still experienced it and maintained an ongoing relationship with his late mother (this will be discussed further in later themes). For Luisa however, she cited her grief feelings as having “become more intense as time goes on”*,* specifically each year around the anniversary of her mother’s death which is something she now plans for. She was very aware that there will also be other grief triggers that will catch her unawares:

> It's you know, it's not one time when it's done. There can be any number of triggers for the feelings. And it's usually some some kind of association [...] It keeps coming back and it can be unexpected. And, you know, there's there's not a there's never a good time for it to hit you, but it's when it's unexpected because it can kind of catch you out. (Luisa)
>
> I mean sometimes it just kind of almost overwhelmed me. I've. You know, I've ended up I've just gone curled up on the bed, hugging a stuffed toy or something and just let the tears flow. And sometimes, yeah, just kind of break down like that. And then that'll sort of pass subside and carry on again. But yeah, sometimes, yeah. Just, just hits me, comes over me like that and I just need to give it time and let it run its course (Luisa)

For Luisa, when her grief is triggered, the feelings can be just as intense as they were around the time of the initial bereavement. The language she uses to describe tears flowing and the grief coming over her before subsiding, calls to mind the power of the sea, with grief coming in waves. There is a passivity in her description of letting her grief “run its course”. Her experience of loss and grief sits at the other end of the continuum from somebody in Luke’s position, yet neither expression is right nor wrong. The participants’ trajectories of grief were highly individual, variable, unpredictable and without end. The nature of grief acts as another source of uncertainty that survivors are challenged to find ways of adjusting to and integrating into their post-loss worlds.

4.3.2 Subtheme 1b – Depletion of resources: social, emotional, and physical demands

Bereavement is a demanding life event for those who experience it, and participants were no exception to this. When a close relative dies, family and friends are also grieving, there are arrangements to make and affairs to organise. The social dynamics and sheer number of decisions and interactions are inherently stressful for autistic people to navigate. This subtheme will clarify what participants found demanding and demonstrate the intense level of stress and overwhelm they experienced.

Four out of the five interviewees made specific reference to the exhausting nature of bereavement for example, Luke repeated how he felt “drained of energy”. Gillian also described the intense fatigue of bereavement that was in part caused by lack of sleep, “I wasn't sleeping no matter how hard I tried, I just could not get off to sleep”. However, participants focused mostly on aspects of bereavement which, as a fundamentally social experience, posed particularly distressing demands from an autistic perspective.

The concept of a requirement for ‘space’ to process bereavement was also heard in this theme. Participants described at times the overwhelm of it all and in Gillian’s case, that bereavement “filled my head completely”, “taking up everything and all the room and everything”, leaving no space for her to think about anything else to the point where she “couldn’t function”. Gillian also described how in any usual week, she might lack the capacity or space to manage coming into contact “with another human being” and would go hungry if her cupboards were empty to avoid the overwhelm of social interaction. This illustrates how autistic survivors start from a disadvantage as they are already managing the extra demands that autism places on their day-to-day existence.

In usual circumstances, Sara said she struggled to keep on top of managing personal finances which get overlooked while she is “trying to sort of manage with everything else in life”. Her mother made her joint executor, but Sara was “just in such a state” that she was not involved in matters of the estate because she “had no capacity left to deal with it”. After a very upsetting and disappointing experience of counselling, Sara began the process of complaining to the supervisor, but “didn't have the energy at the time to sort of deal with it or anything”. Participants spoke of feeling mentally and physically ‘full up’ with bereavement and of lacking resources and ‘running on empty’ from “the demands of it all” (Sara).

Some of the most demanding and depleting aspects of bereavement that participants described were the associated social and sensory demands. For example, the environment of the hospital where her mother died posed overwhelming social and sensory challenges for Sara. There was an expectation that she would assist with the care of her mother doing tasks such as wiping saliva from her face with swabs. Managing the bodily functions of a dying person was nauseating and distressing and she found herself “privately gagging”. The social aspect of being at the hospital disturbed her because “people think they're being kind by hugging” but that created further discomfort, “Yeah, I don't want it”. While palliative care wards are ostensibly quiet places, for an autistic person, this means that “you tend to sort of notice things, sensory triggers in the environment” like the “beeping of the machines” (Sara). For Sara, sensory sensitivities were heightened both in the lead up to the death and in the initial period of her bereavement. Coupled with a protracted and distressing stay in the hospital, this has had a lasting detrimental effect on her wellbeing:

> Everything seemed to be amplified in the noises, the sounds of the breathing that the rattle, you know, the death rattle and everything (Sara)
>
> And I had all of the sensory stuff, the sensory experiences of the hospital and all the interaction and everything. And I just I found that incredibly difficult. And I think I may have got PTSD after it [...] I could hear the sounds of the hospital. I could smell the smells. Like when my mum pulled up her covers, the sound of bed covers moving triggered an emotional response for me (Sara)

Sara felt traumatised, haunted by the sounds of the hospital which she found triggering and led to her avoiding any reminders of the period around the death. Her description of that time was tortuous, repeating how she waited for “the end” for ten long days throughout which she was “flitting between shutdown and meltdown”.

Sensory issues were also affected for Gillian when she was bereaved of her grandmother except that she experienced hyposensitivity in which her senses “kind of got shut down completely or really low”. This was very different from her usual way of experiencing herself interacting with the world with sensory sensitivities. None of her senses were “working to the peak optimum efficiency it usually works at”. Food tasted of nothing, her hearing was dulled and her bodily interoception was so poor that she described it as failing to alert her to basic physical needs because parts of herself had been “shut up”. Despite this, Gillian did engage in self-soothing when her anxiety and emotional distress levels were high following her grandmother’s death. This was done through stimming which automatically increased in severity and frequency and occasionally resulted in self-injurious behaviour. The shift in Gillian's stimming began once she began to process the reality of the death and she said the change was "very, very, very, very significant" and at times it felt constant:

> And then a couple of days after that, it started to sort of sink in a bit more and a bit more. And the stimming got worse as well around that period. The lead up to the funeral was probably it was getting steadily up and increasing (Gillian)
>
> But doing that kind of keeps me on the on the level, right? It's like when I stim it's kind of like it's because this sort of motion is happening in my brain, but when I stim, it kind of helps me keep it to that flat line and that regular (Gillian)

As Gillian described the "motion" in her "brain", she traced in the air the shape of undulating waves to visually express the kinetic way that she felt this embodied experience of over-stimulation. Stimming brought her back to the calming "flat line" of nervous system equilibrium through repetitive, predictable sensory input.

Gillian's account of stimming can be understood in its relation to the demands that bereavement presented in her social world. When a close relative dies other family members are also grieving and this poses challenges to autistic people who find it hard to know how to respond to other people's distress. Gillian said, "I don't know how to behave with those people" yet regularly had to manage the stress of being in social situations with the bereaved. Faced with all the social interaction that follows a bereavement, Gillian found herself masking her way through these situations which came at great personal cost to her:

> And it really felt like as much as I was trying to keep it in control around other people when I was on my own, it was kind of like taking the pin out of a grenade (Gillian)
>
> …spending those days gritting my teeth [...] I didn't know how I was coping with it (Gillian)

Masking to the level that Gillian was doing was very physically, emotionally, and psychologically demanding exercise. She only felt able to release her emotions in private, where it was an explosion of pent-up emotions and suppressed feelings. Both Gillian and Sara described how masking took up valuable resources in coping with the social demands of bereavement. For Gillian, the emotional suppression of masking worsened an existing health condition, and she was aware that expressing herself naturally is far better for her wellbeing then "if I'm constantly holding back and holding back, I make myself worse and make my symptoms worse". When she was masking after her bereavement, it was as if "somebody took the light […] the battery out" of her. Sara described her experience:

> The whole process. Right the way through. From the time that she first started getting ill, right through to sorting everything out in the funeral and everything. So, like my camouflage, I felt that I had to use all of my camouflaging resources and. And there was no let-up (Sara)

> Up to [after the funeral], it had been all of the masking, the camouflaging and the just trying to survive through it and get through it. And that was the point of. I don't know. Just I had mind collapse (Sara)

The quotes above illustrate how draining, intense, and unrelenting bereavement can feel for autistic people who are motivated to participate in the caring of dying loved ones and in the mourning rituals that follow. When the extra-ordinary social demands were finally over, Sara was burnt-out with "mind collapse", an expression that captures how totally depleted and unable to function she felt.

Participating in mourning rituals can come at a high cost for autistic survivors. Gillian was able to justify the personal costs of attending her grandmother's funeral and wake because it meant so much to her to be there, and she was familiar with most of the people at the event. It was more ambiguous as to whether Luke found the benefits to outweigh the costs of attending his mother's funeral. Below he describes how overwhelming it was:

> It's maybe one or two weeks or a month down the line when you can actually, your brain becomes a bit more clearer. But on the day of the funeral, no your brain can't. It can't function [...] You can't think of anything you can't. You just look just following the coffin [...] I just found I just couldn't talk. I could talk very little before the funeral and even after (Luke)

> …because you just said goodbye to someone who you've known for all that time. (Luke)

> A soldier will get used to it, but to you and I civilians who don't see it. You don't see death and destruction. It probably takes an awful lot to handle (Luke)

In Luke's first quote above, he sets his experience of the funeral in the context of the impact of his loss, insofar as he was still reeling from the shock of it all when the time came for the funeral, implying that he was not in a fit state to manage the demands it posed. The social and emotional impact of it was more than he could cope with, and he found it so distressing that he compared it to the “death and destruction of war”. It was too much for a “civilian” like himself to handle. Similarly, Sara experienced her mother’s funeral as overwhelming:

> It was physically painful. Painful round my head, the back of my neck and everything about trying to sort of hold it back and. Not quite cold and shivery and obviously weepy and crying. Um. Felt like a bit of a daze, to be honest [...] Like I wasn't there, almost like it was a dream. Like I was on the outside looking in (Sara)
>
> I wanted the funeral over as quickly as possible. And luckily they're short, you know they're not long. [...] I can't wait to get them over. Just go home and be there with my thoughts (Sara)

Sara suffered the funeral in physical pain and was acutely distressed and anxious to the point of being in a ‘dream-like’ dissociative state. She went on to tell me that she had alternated between feeling present at the funeral, anxious about what was to occur next and “numb”. Afterward she was left feeling “exhausted and in shock”. Being a close family member meant she sat at the front for the service, this caused her great discomfort as she dislikes the feeling of being “watched”. Her father’s funeral took place during the pandemic when there were restrictions on numbers of attendees. This turned out to be an improvement for Sara who “would rather have that. Then have all of that face to face in person interaction”.

Bereavement amounted to an accumulation of stressful and emotionally distressing events and interactions that stretched participants’ resources beyond their capacity to cope. The window of tolerance for shutdown and meltdown became much smaller and Gillian told me their frequency went from once every few months to almost daily. She used a metaphor of “little sticks” to describe what this was like, with each of her anxieties being a stick:

> And it all builds up in little sticks until it gets to the point where I can't take any more and then I have a meltdown. Whereas this just was literally like it was literally like somebody had just thrown a load of sticks onto the mound to start with already. And then one little thing and that was it gone. So it was it was just completely it was a nightmare. Nothing got done because it felt like every 5 minutes one thing would go wrong. I'd forget to turn the plug on for the Hoover. And that was it. Meltdown off we went and that was it (Gillian)

The above quote illustrates how stretched Gillian's resources were and how the bereavement robbed her of her capacity to manage day to day life which felt "like juggling, but with one hand". Shutdown required her to be in total isolation while she was in an incommunicative state, mostly curled up in the foetal position. Immediately after a shutdown, she felt "completely drained", but it was also a way to slowly re-energise and recover.

Having enough 'time and space' to deal with their grief and loss was important to all the participants. Access to time on their own and withdrawing socially was an important way to cope with the immediate demands of bereavement as well as during times when grief was triggered over the longer term. The stress and demands of work required some time away from employment for those who were working. While Gillian was not working, she was clear that she did not think she "could have done any job with the full attention it was due because I was so out of it at the time".

Luke described a process of stepping in and out of grief and how helpful he found it to participate in his hobbies after bereavement. This was an important aspect of his personal sense of a "moving on" part of grieving, which he believed must be carefully balanced with time to "mope and dwell on the whole thing". Luke was very appreciative of his employer giving him four week's compassionate leave with a staged return to work and he found them to be "very wonderful towards the whole thing". Sara was not so fortunate:

> But my manager was putting a lot of pressure on me to go back to work. Yeah, but I didn't. I went in and I just broke down [...] And because I was in such a state, I couldn't even really understand whether that was reasonable or not […] I suppose I have probably had about two or three weeks off work, but I didn't feel I didn't feel that was enough (Sara)

Three weeks wasn't enough time off work for Sara whose job involved meeting people in busy environments. She was still experiencing frequent, disturbing dreams about the circumstances of her mother's death and struggling to recover from the distress and exhaustion of it all. The quote above also shows that she was in a vulnerable state and not able to discern whether she had a right to need and take more leave.

Luisa found working from home accommodated her need for ‘time and space’, “if I ever need to step away for a bit and have a bit of time on my own. I can easily do that”. After her parents died, she was “very distracted finding it difficult to concentrate on things certainly couldn't work” and spent her compassionate leave taking time for herself. Flexible working afforded Luisa greater opportunity for self-care, and she repeatedly expressed how beneficial she finds time on her own. Luisa anticipated her grief reaction to the anniversary of her mother’s death and developed a routine around it. She anticipated having less resources for daily tasks and responsibilities and prepared herself and those closest to her for the time out she was going to need:

> I tell people, you know, for example, it's, you know, it's the anniversary. It's always a difficult time for me. […] I'm going to be a bit quiet. Going to be a bit withdrawn. I might not. You might not hear as much from me. I might not want to. Sort of erm. You know, call or anything [...] it does have an impact on my life and you know the. I might not feel like going out. I might not feel like cooking. Maybe work productivity takes a bit of a nosedive for a couple of days (Luisa)
>
> And if my sleeps alright, everything else tends to be be much better. If, if I'm not sleeping well then my. Yeah. My mood is. Oh. Up and down. Well, mostly down [...] I can get quite a way down before I even realise *(Luisa)*

Coping with grief meant needing to withdraw socially. On the one hand Luisa sounded self-aware about how to manage her wellbeing, that she had learned some strategies for self-care. Yet on the other, she was out of touch with herself and found it hard to intuitively recognise in herself feelings that would signal a more serious shift in her state of wellbeing.

Participants were thrust into a world of change and uncertainty and sought to find ways of managing the accompanying intense, difficult, and often overwhelming feelings. Bereavement was an acutely stressful and singular event that impacted them greatly.

4.4 Group Experiential Theme 2 - Marginalisation: the sociocultural context of autistic grief

Figure 2: Group Experiential Theme 2, "Marginalisation: the sociocultural context of autistic grief"

A theme of marginalised existences and experiences ran through all participants' accounts. The first subtheme describes how participants experienced stigma and alienation in several societal contexts, including the family and how this was also evident in bereavement related situations. Subtheme 2b describes how these socio-cultural contexts have affected participant's beliefs about themselves and how they interacted with their bereavement experiences and grief reactions. The third subtheme describes how participants found a sense of belonging and inclusion as autistic people in a world that is designed by and for neurotypical people.

4.4.1 Subtheme 2a – Experiences of stigma, discrimination, and alienation

Every participant referred to how being autistic means being different, discriminated against, othered, and/or misunderstood. This was on an individual level, in addition to inter-generational experiences of social alienation, discrimination and shame. Autistic people are a minority group, and in the interviews, all the participants were keen to set their stories of loss and grief in their wider societal context. This subtheme describes participants' experiences of stigma, discrimination, and alienation and how they related to a sense of isolation, shame, and vulnerability in their experiences of bereavement.

References to a sense of sameness and difference within their families were made by all the participants, with some describing family as a source of discrimination and shaming. Participants were very aware of difference, a lens through which they made sense of themselves and their experiences. For example, when Marco was describing their mother's illness and death, their description of their family was couched in how the siblings "each had quite different things to contribute". Marco said of their eldest sibling, "I think I felt quite disapproved of by [them]", noticing the sibling's "impatience" with them.

Luisa used the word "different" five times in less than a minute of dialogue when talking about her relationship with her brother, and there was an underlying sense that she did not feel safe in the relationship with him. At the hospital when her father was dying, staff chose to liaise with her brother, marginalising Luisa during a stressful and worrisome time. She was excluded from knowing what was happening to her father, "I didn't really hear a lot. I kept kind of. You know, trying to get more information from my brother", but he was not forthcoming. After their father died, the family did not hold a funeral for him, as this had been his wishes however, Luisa felt that her brother might have been excluding her again:

> I started wondering whether because […] the relationship with my brother's. Not brilliant. So, you know, a little doubt in my head. Sort of thinking. Well, you know, is he just telling me that because he doesn't want me at the funeral or and I start questioning all that and that that's all sort of mixed up with with it [...] I don't know where the doubts came from. Maybe that's just insecurity on my part (Luisa)

In the above quote, we get a sense of how this atmosphere of social alienation in her bereavement experience added to the emotional distress and confusion of what she was coping with, as it is "all sort of mixed up" with her thoughts and feelings about her father's death. Luisa lacked confidence in her feelings and suspicion. However, given the relational context and her previous experiences with her brother, it seems a plausible intuition to have had.

Difficulties in making the connections in the above situation illustrates how Sara prefers to assume the best in a person or situation when she may in fact be vulnerable. Luisa told me how she was not able to “hold a grudge”, which she described as a “character flaw” which also suggested that she might repeatedly put herself in risky situations with others. Luisa did in fact tell me that she had experienced an abusive relationship, something she had worked through in therapy. Luisa also described having had times in her life “where mental health has not been so great and I've needed a little bit of help”, with depression. Mental health diagnoses are a source of additional stigma for autistic people. Gillian also spoke about having received support in the past for mental health issues.

From an early age, Luke had felt a sense of difference and vulnerability in himself, and he also described himself as being “probably more delicate” than his sibling. He told me about being bullied at secondary school where “nobody really understood me too well”. He used the words “jealous” and “jealousy” when he described being threatened or treated abusively. Making sense of abusive treatment as being perpetrated by ‘jealous’ people may well have been an explanation he was given as a child for being bullied. In his account, ‘jealousy’ signified the darker, hostile nature that he had encountered in others; such language implies a naivety in his understanding of the complexity of discriminatory and harmful behaviour, showing another aspect of his vulnerability that he was perhaps unaware of.

Luke’s parents had been victims of stigma and racial discrimination in their local community. This was something that the family later experienced both directly and indirectly through social media. Luke’s mother and grandmother had acted as a buffer between himself and the danger and hostility of the world beyond the family. He told me, “With mother I was molly-coddled in a way, she was trying to protect me from the outside world”. After his mother died, Luke said he “certainly found out about jealousy in the last two, three four years”, particularly on social media and he expressed anger at this increase in his exposure to stigmatising content about his family’s heritage.

Commonly, as in Luke’s account, the experience of being shamed triggers anger. This was conveyed in Sara’s account of the excruciating ten days she spent at the hospital with her mother. For the duration of that time, Sara was holding off an autistic meltdown and managed to conceal her distress:

> I didn't shout or swear or anything like that. And. But I felt a lot of internal unexpressed anger, you know, and. Angst, I suppose, and then feeling guilty because like the nurses, they're only doing their job and they're doing it really well. But I just can't handle this situation (Sara)

In the above quotes, words like “anger”, “angst” and “guilt” convey Sara’s anxiety, distress, and shame about her needs as an autistic person and feeling unable to cope in an inhospitable and overwhelming hospital environment.

During Sara’s bereavement, family could not be relied upon for support and to accommodate her needs. For example, Sara asked her sibling whether she could sleep on the bed furthest from the open door as the bright lights in the ward corridor were left on overnight which was very uncomfortable for her sensory sensitivities. Sara described the sibling’s response as they, “went off on one about ‘it's always about you and your sensory needs and everything’. And it's like, ‘you're just so selfish’”. Sara’s request was for a reasonable adjustment given the circumstances. One can see how this discriminating and shaming interaction might have added to Sara’s distress and sense of alienation, making her believe that she had to maintain a marginalised social position in the hospital for fear of further shame and reprisal. When Sara was feeling incapacitated following her mother’s death and unable to help with the administration of their mother’s estate, Sara found the sibling to be “quite angry with me”. These descriptions of her sibling relationship are clear examples where Sara was shamed for being autistic.

For Gillian, there was an implicit family rule that expressing emotions in public was forbidden as it was “making a scene” and “inconveniencing other people”. This meant that she learned to mask being autistic and suppress her emotions, to “deal with it on your own in your own time”, only letting them out in private:

> And if you get emotional or anything in front of anybody else, it's either you're asking for attention or you're looked down upon because you've made a public fool of yourself and a display of yourself which as you can imagine, when your you have something like autism and you're prone to meltdowns and sometimes in public, I had to learn to shield a lot of that as well. So I have a lot of experience of bottling, holding on and then blowing out when I get into a private place (Gillian)
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> I learnt very early on [...] that a lot of the things that I do to cope with autism are not allowed. So a lot of my stims are hair fiddling, playing with my nails, putting my glasses up all the while and things like that [...] And I think somewhere along the line, emotional outbursts, meltdowns and my stims all kind of gelled into one thing. So I kind of thought anything other than acting like a pretty much a robot in public is frowned upon (Gillian)

Gillian’s quotes illustrate how she was conditioned not to stim or show emotion where societal stigma means that being autistic is not approved of. She felt forced to conceal so much of herself that she operated as a “robot” in public and privately “blowing out”. Behaving otherwise risked being seen as “weird” and inviting public humiliation and shame. Gillian repeatedly described the ways in which she concealed her feelings and needs and how much that costs her. She tried to “do my best to not need any extra help” and endured the isolation of managing her suffering on her own.

Gillian frequently expressed a sense of anger and shame related to the stigma of autistic people being perceived as a hindrance to society. She described having been discriminated against by an ex-employer who put her through a process of constructive dismissal, “because I was struggling with my autism and I wasn't doing everything she asked, like talking to every customer”. Gillian became agitated describing the social injustice of the ‘high functioning autism’ label that had been ascribed to her on many occasions throughout her life:

> And this is what is frustrating about autism in general because people call you high functioning and it's like I am not high functioning. Nothing I do is high functioning. What I'm doing is is surviving to the best of my ability based on what I am allowed by a society

> that people decided hundreds of years ago. And it's unfair to expect those when everything else has changed. But we still keep pushing those (Gillian)

In the above quote, Gillian's speech became more disjointed and repetitive than it was in the rest of her interview, indicating how passionately she felt about this. Her genuine anger and frustration was present as she expressed the harsh feelings of unfairness and discrimination connected to this label. The term was used in a fashion akin to an endorsement or 'gold star' from allistic people for not making a nuisance of herself and by conforming, at a great cost to herself. Being labelled "high functioning" was not a compliment, it was dismissive, insensitive, and demonstrated that her needs and distress were not seen or understood. This excerpt illustrates how harmful it can be when the unequal are treated 'equally' in ways preventing them from accessing empathy, support, and emotional safety. Gillian also condemned the absurdity of outdated social norms privileging non-autistic people and dictating how she must be to be socially accepted.

Marginalisation, trauma, and discrimination were found in most of the participants' family histories. For example, after Gillian told me that after her grandmother died, Gillian discovered the matriarch "had a very tough life" and was institutionalised for post-natal depression where they "gave her electroshock therapy". Sara's discoveries went back over "centuries" when she investigated her late father's family history. She found that "quite a lot of my dad's side of the family ended up in asylums and stuff like that". The history of mental health issues and marginalisation did not surprise her as she reasoned that "probably a lot of them were autistic". This underscores her experiences and belief that autistic lives are fundamentally marginalised existences. When her father was dying, Sara interpreted an ambiguous exchange with him as if he had expressed a deeply embedded sense of victimisation and alienation:

> He said something about he heard some laughter in in the corridor [...] And I thought he was trying to say, 'they're laughing at me'. I don't know whether that was the drugs they were giving him that were making him paranoid or whether it's because of that sort of sense of he felt that he was very much othered and ostracised in his life (Sara)

The fear and expectation that others will laugh at and ridicule you in cruel and shameful ways was something that Sara understood. When I asked her whether feeling othered was something she related to her response was emphatic, “Yeah, completely. I've grown up with it, experience it, still experience it now. And you know, even if it's unconscious bias”. Whether intentional or not, it is evident that being excluded for their differences had a significant negative impact on Sara, her father, and their ancestors. In this bigger picture, it perhaps comes as no surprise that Sara experienced dilemma around disclosing her autistic identity when she was in the hospital:

> I didn't feel that I could say I don't want that. So when people her friends came to visit and all that and the nurses were hugging and I just wanted to push people away [...] I was diagnosed at that point, and I didn't feel that I could tell the nurses that that I'm autistic and, you know, please don't hug me and just be wary that I might need space because, a), I didn't think they'd understand. And b), I thought, well, it's it's my mum they're looking after, not me. So. So I just sort of put up with it. But it was really, really hard (Sara)
>
> Or usually if people haven't had much education about autism, they think that you've got a learning disability as well. And then they start talking slowly and, you know, be patronising and everything. So I didn't I thought that's the last thing I want right now (Sara)

Disclosure is a risky business, so Sara opted to “just try and hide it as much as possible”. She repeated that strategy when faced with a similar hospital situation before her dad’s death in which she again opted not to disclose her diagnosis. In the first quote above, Sara assumed that the staff would not understand what being autistic means, this speaks of her experiences of being misunderstood. Sara felt unable to express her needs, which she believed were not as important as other people’s and didn’t assert herself in the situation. This is something that will be explored further in the following subtheme.

Concealing being autistic through masking was described as an exhausting task that required recovery time afterward. Gillian’s masking had become second nature and she said merely sensing “another presence, I automatically tone [the stimming] down”. In the extract below, Gillian described a conversation with her partner where they were reflecting on what it was like when Gillian prepared to leave the house:

> He says, as soon as you go out the door, it's literally like a switch goes and you're like, boom into social mode, like social interaction mode. [...] as soon as you knew you had to leave the house and somebody else was likely to talk to you or ask you how you were, he said it was almost like you. You'd take this deep breath, square your shoulders, and like you were going out to fight. You said you just pull yourself together and go out (Gillian)

The inner dialogue that Gillian described is like a coach preparing a boxer to enter the ring. Every social interaction is a battle for survival and approval, to not get caught out or hurt. The real Gillian got pushed aside and her feelings were buried, waiting until Gillian was on her own, "then I can deal with whatever it is I'm feeling". This applied to her grief feelings, "I will grieve on my own" and demonstrated that autistic grief can be an isolating and marginalised experience.

The autistic grief and bereavement related suffering described by all the participants was in some way either hard to see, uncommunicated or concealed under duress. Because of Gillian's masking, the full extent of her experience could not be apprehended by others, and she told me that a grieving autistic person "might come across as they're cold and and unfeeling. But the truth is it's not". For Gillian, on the inside "It took over [...] while on the outside I was acting normally". The quote from Luisa below echoes this:

> I'm looking for almost sort of anodyne terms that I might say, you know, I kind of broke down crying, just curled up, sobbing or something like that. But that that's probably as much as it ever as a as I've ever said to anybody. And it doesn't begin to capture the intensity of my experience [...] Kind of what it looked like from the outside, but doesn't begin to convey how it felt (Luisa)

Here Luisa eloquently described the mismatch of what others perceived on the surface and the depth, intensity, and complexity of her inner experiencing. She said that when speaking about grief to others she used "anodyne terms", meaning that she chose terms that were least likely to cause offence or controversy, presenting a dulled down version that hid the extent of her emotional pain.

Bereavement related events such as mourning rituals are social by nature and were another source of exclusion, alienation, and unseen grief. Sara did not believe that funerals accommodated autistic people but felt compelled to attend her mother's funeral out of fear there would be negative social repercussions if she didn't:

> I don't find funerals to be a celebration of someone's life, I think they're morbid and come with too many expectations to do things in a neurotypical way (Sara)

At his mother's funeral, the formality of shaking hands with guests was manageable on a surface level for Luke but he was not able to communicate or connect with the other attendees. Conversing with people was something that he had wished to do:

> We went off to the funeral. I don't know one thing that I just sat in the car. Not dumbstruck, but you know, it's a time when you want to get engaged in the conversation, but somehow you don't know what to say. Your brain's just in totally neutral. The world could blow up. Your brain is still in neutral. (Luke)

There was a desire to engage socially and participate whilst he was stuck on the outside, only able to observe. His brain was "just totally in neutral" and he was helpless to do anything about it, even faced with a life-threatening situation, he would have remained so. There was simply nothing that he felt would have spurred his brain into action. The use of the word "brain" and "neutral" highlights the physical nature of his experience of being mentally stuck and in a vulnerable state of shutdown whilst at the funeral. This whole experience was hard for Luke to describe. He summed the funeral up as strange, "funerals are strange that I have to say, I did, I didn't know what to say or what to do". On balance, the funeral appeared to have largely been an alienating and distressing experience where Luke was trapped on the fringes, feeling confused, helpless, and unable to communicate with those around him.

Unfortunately, one participant, Sara, described their counselling experience as another source of oppression. After her mother's death, Sara had telephone counselling in which she was given advice to socialise which felt the opposite of what she needed:

> I needed space and time to gather my thoughts. I didn't have any energy for socialising or being good company for friends when I was in such emotional pain but it felt like I was being steered in that direction (Sara)

> When I hadn't done [the socialising] because I was exhausted trying to cope, it felt like she was telling me off the next session and she made a comment that I wasn't doing what I should be doing to help myself. I felt I was helping myself by allowing me time to recover. I suppose some acknowledgement and understanding that my way of coping was to spend more time by myself at home, and this was what I needed. (Sara)

Sara went on to tell me that the counselling relationship also did not feel safe enough to disclose her autistic identity. The allistic values regarding the importance of socialising were imposed on her. Sara told me that she did try to follow this advice, which was at best unhelpful and at worst, harmful and oppressive. It created another situation in which Sara was being coerced into attempting something beyond her capacity and against her better interests. The dilemma and risk in disclosing her autism diagnosis played out again in the counselling relationship, Sara called this a “catch 22 situation”:

> So it's this catch 22 situation, should I disclose being autistic and risk getting other assumptions and prejudices that I lack empathy and therefore can't be that upset that my mum has died (when I was totally distraught and didn't know what had hit me), or do I conceal it and her not fully understand [...] Her approach seemed to be on helping me to get back to a 'normal' life but I wasn't ready for it, and wouldn't say I have a 'normal' life in the neurotypical sense anyway (Sara)

4.4.2 Subtheme 2b – Am I doing it right? Internalised ableism, subordination, and concealment

Western culture defines autistic differences in accordance with the medical model and in terms of deviations from social norms, meaning that autistic people occupy a minority and disadvantaged societal position. This subtheme describes the influence of participants’ marginalised existences and experiences of oppression on their sense of self, how these influences were disclosed in the interviews, and their significance to bereavement experiences.

Autistic people face social prejudice for having abilities that differ from the majority in a culture that values ‘able bodies’. Some of the effects of being devalued in this way that were evident in the interviews, this included how participants interacted and expressed themselves in ways suggestive of lowered self-esteem and self-confidence. All the participants regularly used tentative speech that included qualifiers (e.g., “It might have been”, “I’m not sure if I said that right”), hedges (e.g., “kind of”, “sort of”, “probably”, “just”, “maybe”), intensifiers (e.g., “very”, “really, “so” when used superfluously to the content of speech) and generally tentative language which expressed uncertainty and self-doubt. This was particularly pronounced for Luisa who used predominantly tentative language throughout her entire interview. She said the phrase “sort of”, eighty-five times, “kind of” and “just” more than one hundred times each and “you know” more than two hundred and fifty times. Below is an example of this language in her description of how she spent her compassionate leave from work:

> That's really just kind of time to myself and just (Luisa)

This type of speech conveys a lack of confidence and assertiveness and in the above example, it shows how Luisa is unsure whether what she did would be considered ‘appropriate’. Marco’s communication style in the interview was to use minimising language around difficult feelings for example, when describing their grief and sense of loss:

> …pretty intense sense of loss
>
> Whatever that means
>
> Well, I'm not. Quite getting to the actual question yet (Marco)

The language used in the above quotes incorporates marginalising, tentative, and passive phrases that imbue Marco’s speech with a lack of confidence and sense of defensiveness. In the third quote above, we are reminded of when Marco reflected on the impatience and disapproval they experienced from a sibling. Autistic people often need more time to articulate themselves which, as we saw in the previous subtheme, had led to Marco being shamed and now we hear them apologising to me in the interview for not articulating quickly and directly enough. This comment was unprompted as Marco was free to take all the time they needed with me however, their speech disclosed an underlying assumption that I would judge negatively and/or that they were not performing the task well enough.

Participants’ speaking styles revealed their intrapersonal relationship of self-doubt and internalised lower status. Tentative speech is a way to get along with other people by minimising the risk of causing offence in conversation. Expressing themselves or behaving in ways that are perceived as outside social norms could result in alienation. Gillian described how being autistic means not fully understanding social rules and having to try and predict what might happen in an interaction. The social world is full of risk as every interaction is an opportunity to upset, offend or make a mistake:

> I don't know what the rules are. I have to kind of guess as I go along (Gillian)
>
> I question myself like, did that interaction go well? Did I cock that up? Have I offended somebody? Have I upset somebody? (Gillian)

The above quotes describe Gillian’s rumination and fear of not getting social interactions ‘right’ which is something that caused her immense distress and led to regular self-criticism and self-doubt. Conversing with others successfully to fit and create a sense of belonging often meant suppressing herself to comply with social rules that she did not understand. Gillian was self-critical despite seeing that she was treated unfairly and at one point even compared her grieving style to that of “a normal person”, demonstrating that she had internalised beliefs about herself as ‘abnormal’. This perceived need for self-censorship to avoid exclusion and criticism meant that participants edited what they said or did.

When Sara told be about how distressing it had been for her when caring for her dying mother in the hospital, she prefixed her statement with, “it sounds really horrible to say, but…”. This demonstrates that she believes others will find what she has to say about her experience offensive or odd. Similarly, when she told me how helpful it been to know about the biological processes of dying, she said, “And that sounds a bit sort of morbid, but to me I find that helpful”. Each time she expressed something personal that could have been considered unusual, she was censoring the discourse around it, tentatively putting things forward and undermining the validity of her own experiences. Sara's expectation and fear of negative evaluation was further disclosed in the descriptions of her anxiety and discomfort with being observed at funerals. Sitting in the front row for her mother's funeral service meant being seen which exposed her to being scrutinised and potentially criticised or othered. There was one occasion in the hospital where Sara told the nurses she needed a break:

> And I said, Well, can. Can the nurses come in more? Because I need a break. And I said to her, I said, I'm not on your payroll. I'm not one of your nurses. And she took real offense at that. I knew she did. But it just came out. I was I know it was wrong, but I just I was just sort of at the end of my tether there (Sara)

The above "just came out" when she was too overwhelmed to censor and suppress herself as she usually would. Sara was ashamed to have caused "real offense" by saying something "wrong" yet her plea to the nurses for more support with her mother's care was genuinely and reasonably required. In the written material Sara sent me following her interview, she advised autistic survivors to express their needs so that those around them can be flexible, "But if you feel comfortable telling people, let them know so that they can be more flexible". However, the issue remained that environments and relationships in which Sara herself could feel comfortable and free enough to fully express herself were scarce.

Every participant expressed a deep sense of care for other people's feelings, and how others perceived them mattered to them. Luisa was concerned with ethical decision making when managing the ambiguity of social situations. For example, when considering travelling to visit friends and family after her father's death, shortly after pandemic restrictions were lifted, she described her difficulty in deciding whether it was 'right' to do so and asked, "how do they feel about it?". Luisa's parents had been an external source of validation in her life and after their deaths, she described the difficulty she faced in assessing whether she was getting things right without them, she wondered, "Am I doing well? Am I? Can I parent myself. Can they tell me?"

Analysing the sensitivity that participants showed towards others on a deeper level, revealed how the needs and wishes of others were regularly prioritised over their own. This happened to a degree that was unhealthy or even harmful to participants:

> I will just put everything on the backburner and I will ignore it until it becomes a physical, mental handicap and then I will blow out when I get home. And it's not something I would recommend. It's not something that's healthy, because when the blow outs tend to happen, they tend to be bigger and worse than if you just let it happen in the moment. (Gillian)

In the above quote Gillian described the extreme degree of self-denial she engaged in, putting herself on “the backburner” with everyone else’s needs front and centre. She did so despite knowing how detrimental it was to her wellbeing. From the start of her interview, Gillian was focused on ‘getting it right’; she tried to ascertain what I wanted to know so that she might “go straight to that and sort of help”. She told me how from childhood she had learned to push her own feelings aside. When her grandmother died, Gillian told herself, “You’ve got to hold it together” for the sake of her family. Her language is imperative, an order with no option to deny obeying it. This inability to see choice, self-suppression and denial and focus on what others want, implies that Gillian has come to subordinate herself to the ‘dominant group’ and their allistic social norms. Below is Gillian’s retelling of a conversation with her partner in which they talked about her masking and putting others before herself:

> … it's almost like dealing with a military order. He said, ‘because you don't think you have the right to be any more upset than anybody else. You're always thinking about somebody else’ So when [maternal grandmother] died, it was, ‘I need to keep myself together to be my mum's rock’ (Gillian)

In the above quote, Gillian and her partner used a military reference, with Gillian taking orders from those above her in the social hierarchy. This sense of Gillian being of a lower order was also conveyed when she described her emotions following the death of her partner’s grandfather, “I felt guilty for crying because I didn't know him that well”. This statement implies that Gillian made sense of her experience through a hierarchy of grief. She compared her grief to that of others and was concerned she was grieving too much, believing the grief of the closest relatives to be highest priority. This also influenced her self-denial following her grandmother’s death, when her mother was “most important right now” because “she's lost her mum”. Gillian believed she would only “have every right” to grieve as much as her mother when she loses her own mother.

Sara’s account of her bereavement also discloses a belief that she was of lower importance and that it was more important for her to focus on the needs others than her own. Part of the reasons for Sara to withhold her diagnosis was because she “didn't want to tell them because I didn't want to make a fuss about me”. Sara repeated this idea of not “making a fuss” and “trying to put my needs aside” several times in the interview. In both women’s accounts are descriptions of their intense efforts not to ‘burden’ others with their feelings and needs. This disclosed their underlying self-beliefs of being an inconvenience to society.

Participants demonstrated an awareness of how being autistic meant that there were areas of difficulty for them, such as with social communication and relationships. Both Marco and Luke experienced relationship breakdowns prior to their autism diagnoses:

> I had a difficult relationship with a lady and and then a lady of [a public services department] suddenly noticed something about me, and it was [the psychologist] and a few others who got me into this test (Luke)
>
> And me seeking an autism diagnosis was sort of wrapped up in what went wrong [...] So there were a lot of communication breakdowns and things that I couldn't manage to do [...] Things that I didn't manage to tune into (Marco)

Luke described his romantic relationship as having been “difficult” and it ended just before his referral for an autism diagnosis. Marco more explicitly connects the ending of a significant relationship with things that he “couldn’t manage to do” in the context of realising that he is autistic. Being unable to “tune into” certain aspects of relating gives a sense of how This sense of lacking self-efficacy in relationships and social communication can be undermining and contribute to concern about getting things right. Gillian described herself as “socially useless” while Luisa described herself as “hopeless” regarding certain life skills:

> I was kind of hopeless with all this, [...] I'd have been completely lost, you know, I'd have I'd have had a starting date from work, […] but how do I sort out, get somewhere to live? And I didn't know where to start, really. Just yeah, In fact, I mean, to be honest, even even now, I know there are some things that I struggle with (Luisa)

In the above quote, Luisa is talking about the support that her dad gave her, without which she would have been “lost”. In this example, he had taken Luisa to a job interview and helped her to find suitable accommodation. Luisa is aware that she finds certain tasks difficult and how the death of her parents meant losing the vital support of always having “somebody I could turn to, somebody I could go to”. With bereavement came this significant secondary loss which left her feeling “very vulnerable”. Like Luisa, most of the participants made explicit references to their vulnerability. For example, Sara told me that her partner believed her sibling “probably fleeced you”, when administering their mother’s estate. It was easy to see how it might have been possible to take advantage of Sara in the overwhelmed and vulnerable state she was in following the death.

Bereavement related experiences meant that there were times when participants felt out of their depth and not able to ‘do it’. When I asked Sara how she managed during her bereavement, particularly in the hospital, she told me, “I don't know that I did manage it”. Sara experienced confusion around the ambiguity of what adjustment to bereavement ought to look like and a sense of not having accomplished it. This made it “difficult to be positive” following her bereavement. Marco was also unsure whether they were ‘doing it right’ regarding their grief over their father’s death:

> Obviously everybody is, you know, different after a bereavement. And, you know, they say that you adjust, you learn to adjust. But I don't know if I have I don't know. (Sara)
>
> And I'm not sure that I've ever cried about my dad dying, which I always felt slightly weird about [...] I kind of feel like I should have. You know, I know that. Everyone grieves differently and whatever (Marco)

In the above quotes, both participants had a sense that they had not grieved the ‘right way’, despite knowing bereavement to be an individual experience that’s different for everyone. While the cultural discourse on grief conceptually allows for individual and varied ways of grieving, participants’ sociocultural experiences influenced the construction of their experiences of grieving as invalid.

Bereavement and grief are further life experiences that can bring a sense of shame, of being less-than and not getting it right. This is demonstrated in a quote from the end of Sara's interview, when I asked her what advice she might give to somebody experiencing their first bereavement:

> …if your bereavement seems way out there or really unusual. Just don't feel bad about it at all. [...] don't punish yourself if. If things don't go to plan or if if you have trip ups. And I don't know if that came out right. But if if you think you should be feeling better that you don't feel better, don't punish yourself if you're still having dreams or if. Yeah. If if it's difficult to move on [...] autistic people grieve in different ways. There's no right way to do it (Sara)

In Sara's advice above, the subtext of her own experience is easily found when taken in context. Sara felt that her own bereavement and grief were "really unusual" which caused her distress and confusion. In the quote, she repeats "don't punish yourself", implying that she gave herself a hard time for not recovering quickly enough and believing that she did something 'wrong' in the way that she grieved. This conveys her inner battle with feelings of shame and low self-esteem. It also exemplifies how invalidating experiences and societal stigma around autism and grief can be internalised with harmful consequences for the autistic survivor. This represents the oppression of embodied autistic grief.

4.4.3 Subtheme 2c – Finding inclusion, belonging and emotional safety

In a hostile world where norms are defined by and for the neurotypical majority, participants found social groups and relationships that offered them a sense of inclusion, belonging and emotional safety. This subtheme will describe how family, friendships and romantic partners were sources of inclusion.

When Marco spoke about their family, they described each person's neurological differences. They were related to several autistic people and the family embraced and honoured the "weirdness" of its neurodiverse members, providing an inclusive and supportive environment:

> My life would have been a lot harder if I'd. Being as weird as I am, but grew up in an environment where that was seen as a problem (Marco)

Marco benefited from a family environment of acceptance that provided a sense of belonging on a deeper level than most of the other participants experienced. For Luisa, while she did not share a neurodivergent identity with family, her parents did provide her with emotional safety and support. When she hit hard times and felt overwhelmed by life, she knew that she could stay with them:

> And, you know, it was kind of an almost like an impulse thing. It's like, oh, I can't cope with this. So go home to mum and dad and, you know, at least then somewhere I feel safe and get a bit more space to deal with things (Luisa)

In the above quote we get the sense that being at home with her parents was somewhere that Luisa could truly be herself and attend to her needs in safety. The loneliness and vulnerability that is often part of marginalised lives means that safe spaces and relationships such as these have enormous value for autistic people. As Luisa said, “Sometimes it just helps having someone else” who understands and supports you, whom you can call upon.

Gillian told me that there were relatives in her extended family with an autism diagnosis and while she did find a sense of belonging and social support in being part of a large, close family, she only felt emotionally safe with her partner, “And he's kind of the only person I've got who I can rely on for emotional support”. Since her bereavement, Gillian had formed a friendship with someone whom she was beginning to feel emotionally safe enough with to talk openly about her grief without fear of reprisal:

> You know, it is okay to talk about this and it's been a really weird experience having somebody say you can talk about all the good or the bad and I'm not going to judge you for it. I'm just going to sit here and listen. Yeah, and it's been nice in that way. But it's really weird because I am so not used to it (Gillian)

The above quote shows how novel it was for Gillian to experience a non-judgmental social interaction with a friend who accepted and supported her. This importance of emotionally safe opportunities to talk about grief is discussed further in the next theme.

After Luke’s difficult break-up, he turned to martial arts and found that his instructor opened a “different way of life” and a community in which he could participate and feel a sense of belonging. Luke’s autism identity also brought him a sense of belonging and inclusion, and he made references to “all of us autistic people” throughout his interview. He was optimistic about a more inclusive future for the autistic community, believing that “autism is only just getting it is only just beginning to get [...] understood and accepted now”. While things were less clear cut in Sara’s thoughts, when reflecting on her bereavement experiences, she expressed optimism for a future where “things will get better when people understand more about autism”.

4.5 Group Experiential Theme 3 – Adapting to change and loss: meaning and connection

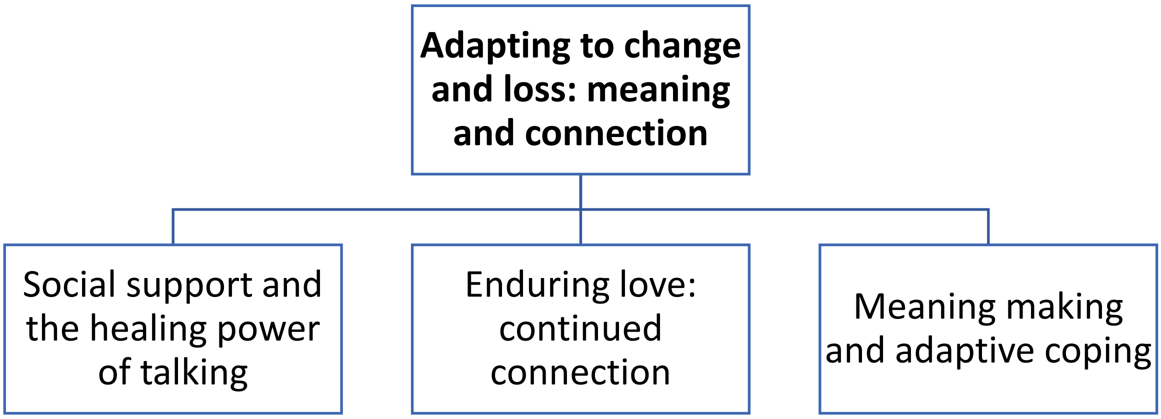

Figure 3: Group Experiential Theme 3, “Adapting to change and loss: meaning and connection”

This theme describes participants’ processes of attributing meaning and purpose to their bereavement experiences. Finding positives in the bereavement, increasing social connection, and forging an ongoing relationship and sense of closeness with the deceased were important ways of adapting to loss. Some of the barriers to adaptive coping for autistic survivors are also explored in this theme.

4.5.1 Subtheme 3a – Social support and the healing power of talking

The value of talking about and storying all facets of the bereavement experience was evident across participants' accounts. This was either explicitly described by participants, for example when Gillian said, "talking about it helps", or implied in what participants said and how they engaged in the research interview process. Luke shared how he found it helpful to actively engage with his grief and talk about it with others. He reached out to those around him for support, advice, and opportunities to express his feelings:

> Well, I think when when it comes to death, you you can't just Jo, when it comes to death. You can't just rub it push underneath the carpet and forget about it.
>
> But if you talk to more and more people about what what's happened, they will tell you, Yes, they lost their mother. They lost their father. They sort of said, well, they just spoke to friends about it.
>
> Let your feelings out about them (Luke)

The above quotes illustrate how Luke valued actively processing bereavement related experiences and talking about his mother and his grief. These were embraced as helpful strategies for overcoming the loss. Luke felt that the death of a loved one needed to be faced explicitly. Talking to others about his bereavement led to many discoveries about the shared experience of parental loss and was a counterpoint to the sense of being alone in the world without his parents and grandmother.

Not all the participants had the level of access to support and suitable people to talk to as Luke did. Sara for example, relied mainly on her partner:

> My partner, who's been a great listener, great support to me. If he wasn't there, I just don't know what I would have done [...] I got a friend who lost her mum about a year or two before mine, and we both she was in that hospital situation as well […] And we were both talking about what it's like to be with someone when they die. So that that was that was supportive (Sara)

Sara’s main source of social support was her partner with whom she felt emotionally safe enough to talk to about her bereavement. There was also a friend she confided in who had shared experience of being bereaved of their mother however, there were only a small number of people she felt comfortable enough to talk about it with. Sara emphasised how important it was for her to feel “comfortable” with somebody when broaching “painful” topics.

Although the interviews covered difficult and emotional subjects, participants were very engaged in the exploration and articulation of their bereavement related experiences. I perceived a sense of satisfaction in the conversations and in the opportunity to tell their stories. At the end of his interview, Luke said he felt “elated” and as we had been speaking, I had a sense that Luke was teaching me. He shared his insights on bereavement and enjoyed having been given the chance to speak about them in detail and be the expert in the conversation:

> Now, that's a very interesting point.
>
> I didn't go, put it this way Jo…
>
> To be honest with you Jo [...] I'll tell you one thing (Luke)

As the above quotes illustrate, Luke was very conversational and collaborative with me, the conversation markers such as, "put it this way Jo" meant the interview felt quite intimate at times. The interview was a co-created account of his experience and he seemed to enjoy talking and confiding with me. For Sara, the fulfilling aspect of the research interview was related to the opportunity to speak about her experience with somebody she could trust to listen and understand what it means to be autistic:

> You know, it's it's helpful. I always think, you know, I've done a number of these research. Participants in research. I find it helpful because researchers are such good listeners, you know, and it's you've been really sympathetic and understood the situation because you understand about autism (Sara)

Implied in the above quote is Sara’s experience of not being understood or met with empathy in her day-to-day life compared with prior positive experiences of research participation. Luisa was also very engaged with the interview, utilising the opportunity to make sense of her bereavements in new ways, and to reminisce about the people she had lost:

> I mean some, some good things I can remember sort of. Oh, we spent the afternoon in…
>
> There's a lot. Yeah. A lot to unpack, a lot to talk about and. You have. Some of it are things I haven't analysed, really.
>
> You know, I wouldn't go so far as to say it's been fun, but it's certainly been interesting [...] A really good conversation (Luisa)

Luisa wanted to tell me, unprompted, about some of the good times that she shared with her late partner. I really felt her desire to do this, that it was meaningful to speak about it with me, to express her loss and share some of her happy memories. Implied in the other quotes is how she has processed and "analysed" her losses and the value of talking it through with me, even if the conversation had touched on complex and emotional subjects.

Talking about her late father was something that Luisa found fulfilling and she described how rewarding it had been to visit her hometown after her he died, as it was a rare opportunity to talk about him:

> It was nice to talk about him with them. It's. And I really. And. The only people I've talked about him with at all (Luisa).

Luisa enjoyed talking to others about shared memories and generally about "the more positive side of things". However, for more emotionally painful or complex bereavement related topics, Luisa said that she preferred to try and work through things in her "own head" before trying to "find a professional to have some sessions with and work through it that way". Talking to a professional meant the other person had specific training in listening and there was greater "emotional distance" (Luisa). However, she was also careful to explain that she realised therapists are still affected by what people tell them as it is impossible for a person to switch off empathy:

> It's hard to try and share the feelings with somebody who I am close to. I find it much easier to talk about with somebody who um. I guess where there is no emotional connection [...] It's not like you're talking to somebody you're close to and. You know, you've you're very aware that you're saying something to somebody you care about

> that is going to potentially upset them. And I find it very difficult to share things that I think are going to be upsetting. [...] Because I don't want to. You know, have somebody showing signs of distress (Luisa)
>
> I mean, you can't we're all human. You can't just switch off any empathy and not feel anything (Luisa)

The above extract illustrates how the potential for the listener to show “signs of distress”, creates a barrier for an autistic survivor to access social support from those closest to them. The quote below from Gillian expands further on this theme, as she describes what it is like to say something that causes the listener to become upset:

> You kind of have to go digging [...] I'm a little bit worried to, in case I cause anybody to get upset [...] Well, I'm waiting on you to introduce them to the conversation, so I know it's okay if you don't bring them into the conversation, I don't know that topic's okay to talk about and I don't want to talk about something that is potentially going to make them feel worse because I can't read the room (Gillian)
>
> …it is like panic station on a submarine. All the red lights start flashing and I'm like, Oh, God, what have I done? I shouldn't have said that. Now I feel bad because I've made you cry and now I feel really bad. And it's like, I don't know how to. I've been the one to upset you, but I don't know if an apology is enough. I don't know if I have to hug you. I don't know if I have to make you a cup of tea. I don't know what the rules are (Gillian)

Gillian’s description above relates to the situation in her family where they have agreed that it is good to talk about relatives who have died. However, she found that family did not bring the subject up very often, certainly not as often is she would prefer. Gillian referred to difficulties in social communication that mean she is unable to “read the room”, fearful of causing upset and feeling socially inept. She described the intense anxiety and confusion of the “panic station” telling her something seriously bad was happening and her assumption that she had broken the rules and got the social interaction wrong with dire consequences. Gillian also later told me that she felt she needed explicit “permission” to talk about the deceased and that, “a cue would be nice”.

Like Sara and Luke, who had found it helpful to speak to others who had shared experience of the death of a parent, Marco said this was also a helpful aspect of processing his bereavement experience. He “had a lot of conversations about, you know, losing a parent you're close to" with somebody who had also lost their mother. Marco's advice to the bereaved was to:

> Make sure you talk about it with someone who understands or at least you know, can understand a bit [...] that they have some insight into how it feels […] preferably someone who is not. Encountered encountering encountering these sorts of experience for the first time in their life, whether that's first or second hand (Marco)

The above quote emphasises the value of talking about bereavement to make sense of it and find one's way through it. Marco was clear that the listener needs to be somebody who understands and has prior knowledge or experience of grief. The quote also underscores how important talking was in Marco's own grief process.

While Marco said that they talked about the bereavement with their partner with whom they lived, which was helpful, it was not necessarily the easiest option, "Partly because they've been the closest". The stress of the lead up to Marco's mother's death had understandably caused strain to their relationship which created complications when talking about their mother's death. It seemed that most of the participants found it difficult, for varying reasons, to speak about their bereavements with some of the people closest to them including family, partners, and friends.

In addition to talking, Marco said that they found writing helpful in making sense of their loss experiences and that writing had always been a way that they "processed things". They sometimes find it hard to express things verbally and "writing is a way to kind of crystallise what might be going on at the back of my head". The word "crystallise" depicts how the writing gives their thoughts form and clarity, bringing them into reflective awareness from the background hum of their mind. Marco also created and narrated videos about losing their mother and other bereavements they suffered close to their mother's passing.

All the interviewees were psychologically minded and self-aware, and everyone had experienced counselling or psychotherapy at some time in their adult life. Three people had been in counselling at the time of or following their bereavement. For example, Gillian had learned how suppressing her emotions was harmful to her physical health and made connections with her upbringing, being autistic and how she coped with grief. This insight came after being diagnosed autistic and having therapy, before which she told me she “didn't even really know what I thought or felt about anything”. When I met Gillian, she had a psychological understanding of herself and how she copes with emotional distress, making sense of her response to bereavement and other difficult situations by relating it to “a) autism, but also b) the emotional stuff”.

Gillian was in established work with a therapist before her bereavement, and in the session following her grandmother’s death, she experienced “an outpouring of completeness of grief and disbelief” that her grandma had gone. She described how the death helped her “cry about the other stuff” and it gave her “unconscious permission to cry”. It was as if her grief purged her of all her pain and sorrow and the intensity of the grief emotions had brought her into contact with herself.

Marco told me they had been considering counselling in the lead up to their mother’s death. A few days after she passed away, Marco reached out to a counsellor so the bereavement “was right on the cards from, from the start”. This was not Marco’s first experience of counselling as was discussed in the previous theme, and this time Marco “wasn't really sure what it would be”, implying that they trusted that it would be helpful and felt compelled to get it in place. When choosing the counsellor, Marco liked the fact that they shared some commonalities in terms of background and interests, together with a personal recommendation having been made for this particular practitioner. These were factors that helped Marco to feel comfortable seeing her. Counselling played a major role as a source of support through the bereavement, with Marco describing it as “Pretty significant” although the work focused on relationship issues and ongoing stressors in their life rather than it being ‘bereavement counselling’ per se. The two of them worked well together, despite the counsellor not necessarily having been “quite the right fit" for Marco. However, Marco found her to be "good. And I liked her. And it was, you know, she was helpful".

Bereavement counselling was a positive experience for Luke who appreciated having found a person and place where he could speak freely and feel understood. The counsellor was perceived as a specialist, someone experienced in relating to the bereaved:

> You could literally speak about just about anything to this lady, and she was a great way of because I think she probably saw sees so many people each week that she she knows how to sympathize with you.
>
> I say they're more or less neutral, impartial [...] They will guide you and a certain way. I love the lady at [the charitable organisation]. I basically spoke to her about my relationship with the mother, with my mother and how it all went. And sometimes these people at Bereavement. They see something what you can't (Luke)

In the above quotes, Luke is enthusiastic about the value he found in speaking to a bereavement counsellor who was able to provide insight and guidance. The above reiterates the importance of 'someone who understands' and somebody with 'experience' as valuable characteristics of the listener. Embedded in his descriptions of the counselling is a sense of how he told his story to her and reflected on his mother's life as well as their relationship.

Reflecting on the relationship with the deceased was an important part of all the participants' meaning-making and adaptation to loss. Luisa described how a positive experience of talking therapy that took place before her actual bereavement, not only helped her to reconcile and adjust to some complex and distressing aspects of the relationship with her late partner, but also consequently assisted in her grieving process following their death. Being able to access her memories of the relationship without ill feeling meant that she could successfully reminisce about the deceased and find a place for them in her ongoing life.

Not everyone was fortunate enough to have had positive outcomes form counselling and therapy. Sara took up the offer of telephone counselling from her employer which she was advised was "solution focused", and later regretted the decision:

> And then she started going into psychoanalysis and about, you know, kept talking about your relationship with your mother […] And then this counsellor said, ‘Well, you didn't have much of a mother when she was alive’. And I just had to pull the counselling. I said, ‘I can't believe you said that. That's really upsetting’ [...] I found that really, really upsetting. And and they did offer some more counselling. And I said, no, I can't I can't risk it. I thought I just didn't want to have any more after that because it was such a bad experience.
>
> But I knew the counselling would fall short in this respect because I hadn't told my counsellor I'm autistic [...] So I talked around it and kept telling her I was getting strong emotional responses when I heard certain sounds, had reminders etc. I then felt that she didn't understand because she was assuming I would experience it in the way a neurotypical person would (Sara)

In the above description of Sara’s counselling experience, she says it was “really upsetting”, simple language is used repeatedly to signify the underlying emotional complexity and distress that it caused her. While the counsellor’s interventions described above were unhelpful and insensitive, Sara realised that not disclosing being autistic created barriers in the work. However, it is understandable that she did not feel safe enough to disclose it in the therapeutic relationship they had developed, and that she was deterred from seeker further counselling.

As we’ve seen, Sara censored herself in counselling and she also avoided talking about subjects she thought the counsellor wouldn’t be interested in and by doing so subjugating herself to the other.   Another barrier to Sara accessing social support and healing conversations was the fear and avoidance of stigma which led Sara to also censor herself with friends and edit out aspects of her experience others might have considered inappropriate:

> And also some of it I want to keep private. [...] I don't want to share with people that I've Googled and looked up YouTube videos of what actually happens to the body when someone dies, because I think some people would think that that was weird. Or I've really researched and bought books about the diseases that they've had because [...] that's comforting me that I don't really want to share that stuff and I don't want to get into a conversation with them in case I have to slip it out. Or if I'm withholding that information, am I being dishonest? And so I don't yeah, I sort of try and avoid it with them.
>
> I don't know if they would understand the sensory stuff and how difficult it was being in the hospital for that length of time. And they might not understand why the social interaction is difficult at the funeral and all that sort of stuff (Sara)

Sara described withholding her interest in the biological processes of death and dying because she did not want to be perceived as “weird” or “morbid”. Full disclosure about her grieving style would have created uncertainty in how others responded to her. There was an awareness that her interest in the biological process of death and dying was not 'typical'. This created internal conflict between Sara's personal value of honesty and wanting to do the 'right thing' versus the need to conceal aspects of herself that might be unpalatable and keep herself 'safe'. The belief that others would not understand or accept the aspects of her experience related to being autistic stopped her from sharing "all that sort of stuff" with others.

In addition to the challenges and stigma of being autistic, participants were navigating their bereavements in the cultural context of the taboo of death and dying. The medicalisation of death and concealment of dying were referenced in participants' accounts for example:

> And there's certain anonymous signs which the nurse took of her and thought. She doesn't seem to be that good at the moment (Luke)
>
> We don't we don't tend to see. Um the bodies of the people who have died [...]
> We keep death sort of out of sight, really, these days (Luisa)

In Luke's quote, the mystery of death is alluded to in the language he used for the "certain anonymous signs" that only the nurse was able to decipher. Medical staff and settings featured in almost all participants' accounts, not forgetting the distressing hospital stays that featured in Sara's bereavements. Luisa made direct reference to societal avoidance of death and the way that it is kept "out of sight". She also told me that this meant it was hard for her to process the emotional impact of the sight of her mother's coffin because she could not visualise her mother inside.

The taboo of death was another barrier to talking about participants' bereavements. It is socially preferable for the bereaved to shield us from their grief and the disquieting inevitability of our own death and that of people close to us. Luke's colleagues advised him, "There's a lady to go and see, you can talk about your mother's funeral" and they would tell him to "go and have your session with, with other lady at [the counselling service]". While Luke said he felt supported by his employer and colleagues, he also indirectly expressed an awareness of the desirability to keep grief hidden, “But I think nowadays people good people don’t like to show their emotions”. The subtext of their support for his counselling implicitly denied him from talking about the difficult aspects of his grief with them. Gillian expressed her own frustration with the societal pressure to ‘move on’ from bereavement:

> And you're supposed to just be okay and move on with it, not make a fuss and just get over it as quick as you can so you don't inconvenience your workplace or your friends because your friends don't want to see you and hear you being all mopey either (Gillian)

Gillian evidently believed that the above pressure was unreasonable and oppressive, and it was another invalidating experience, reinforcing the message that her feelings and needs are an "inconvenience".

4.5.2 Subtheme 3b – Enduring love: continued connection

When a person dies, our love for them does not cease but we are tasked with finding ways to renegotiate the relationship and find a place for them in our lives. All participants described how they maintained a continued sense of connection with the deceased and/or the ways they engaged with the deceased showed themselves during the interview. Participants conveyed the sense that the deceased ‘lived on’ in their lives. Gillian gave many examples of her ongoing relationship with her grandmother and the importance of “remembering”:

> It was it was it was nice in a way, because we did start talking about her in a happy sense and laughing at all the stuff she did and everything. But at the same time, it was this thing of it was it was healing to talk about it, but it was also acknowledging the fact, yes, she's not here, but it doesn't mean she's gone completely. There's still all these memories and things we have linked to her that we can still talk about (Gillian)
>
> I do still like to talk about 'em and while I still can remember it because [...] I want to remember what I can for as long as I can (Gillian)

In the above quotes, Gillian describes how “healing” she found talking about the deceased and how important it was to keep the memories alive, a desire to hold onto them and to the continued connection with her grandmother. Through her own memories and shared grief with her family, she could feel that her grandmother was not “gone completely”. Luisa also described the role of memories in her continued relationship with the deceased:

> Happy sort of things. It's. I suppose, you know, sort of tapping into nostalgic feelings and. Yes. As I said, cooking a particular dish or. Oh, maybe going back up north soon with my daughter and visiting the old places, that sort of thing. That's. That's a way of kind of. I suppose, you know, staying connected. Yeah. Seeing in my mind's eye now the. The place where I grew up [...] So I like. You know, reminiscing. (Luisa)

Luisa told me that she had a particularly visual memory and as she was telling me the above, in her “minds eye” she could visualise a clear picture of their hometown. The memories were “happy” and the way that she says, “tapping into nostalgic feelings” shows how the reminiscing was an adaptive and healing resource she could access or draw from. Engaging in activities that participants once did with the deceased or that reminded participants of them was also a way of continuing to feel close to the deceased:

> So I cook something that she might have done. And does that. I feel that connection. (Luisa)

> Because my mum loved gardening and I grow some of the flowers and plants that she grew. And that is my way of connecting and remembering her. Yeah, there's that. […] Shared interest that we had (Sara)

There were so many things that reminded Gillian of her grandmother which reflected how big a part of her life she was. Gillian said that she wanted her to know that the family were thinking about her, that she was not forgotten. Something that might not feature in neurotypical bereavement is how Gillian “inherited” characteristics from her grandmother through imitating her for her “masked face”:

> So it's sort of like I've inherited bits from her, but I've also used parts of her to build up what I show to the world as my masked face. So it's kind of comforting in that sense to know that I've got those skills from her as well. (Gillian)

These adopted social skills were “comforting” and brought a feeling of closeness to the deceased. Again, there is the theme of her grandmother’s continued presence and living on through Gillian.

Gillian had an ongoing relationship with her deceased grandmother and the thought of making her proud brought Gillian satisfaction. Gillian conversed with her about having learned to sew which was something her grandmother had done, “Well, there you go. Look, I've not. You did teach me something. You know, I did get something from you”. It was meaningful to Gillian that the sewing was inspired by her and was a way for her grandmother’s legacy to live on. Marco made explicit reference to the creation of his mother’s legacy, “I was very concerned with. Preserving and furthering my mum's legacy”. It was a project they began together, during their mother’s illness. This will be discussed further in the final theme.

4.5.3 Subtheme 3c – Meaning making and adaptive coping

Spiritual beliefs provided comfort and connection for some of the participants. Visitations from the spirits of the deceased gave a sense of connection not only with the deceased but also to other people including family and the spiritual community. Luke visited a clairvoyant after his mother’s death, they were a family friend and somebody that Luke enjoyed re-connecting with. He said that his late ancestors came by to greet him, and their presence was always welcome. Visitations by the spirits that activated his sense of touch, smell and hearing were “rewarding”:

> She and father do come back to the house, a clock that has never been worked before suddenly goes off or the TV will change channels or something else will happen in here. And I must say even I know with my grandmother when I put something drops out of my hand. I know I can know she’s around here by sort of saying to me, “[Luke], pick that up”, and I’ll pick it up. (Luke)

The deceased held an important, intimate place in his life and there was a continued connection and relationship with his mother, “I know that her presence is around me from time to time”. He believed that one day in years to come he would “go up there and see them” again. These beliefs provided meaning and comfort in his bereavement as the prospect of reunification with his loved ones in the afterlife brought reassurance when confronted with death and mortality.

Sara also found meaning in death and loss through spirituality despite the idea of God not making sense to her because “there's logical ways of explaining things”:

> But I personally believe from the experiences I've had growing up, that there is something after death, there is something. I don't think it just ends. I think it's something

> that you're, I don't know if it's your spirit goes on to somewhere else or your soul or anything, but our family tend to let you know when they're about once they've gone (Gillian)

> Not just with me. It's happened with all my family members. Everybody's had their own weird experience (Gillian)

Gillian believed in the afterlife despite being unsure as to what happens to a person after death and described numerous experiences of visitations. Her family had amassed evidence of visitations and Sara emphasised that it is "Not just me" and were an important source of validation for her beliefs. Visitations were part of shared beliefs and experiences with her extended family, and they strengthened the cohesiveness and social ties in the 'group'.

Gillian found the spirits "Comforting" and would converse with her deceased grandparents who communicated with her. There was some self-consciousness and perhaps defensiveness or expectation of judgment, when she described this to me, saying “it sounds weird”. Gillian reasoned that her spiritual beliefs made sense because she could not find a logical explanation for such frequent events, they “can't be a coincidence”. Making sense of them as either of her grandmothers’ presences was protective and it fostered her sense of continued connection with the deceased.

Another way that participants found meaning in loss was in appreciation of the social connectedness and growth of relationships that arose from the bereavement. Marco described how the visitors to his dying mother afforded him the chance to meaningfully connect with others:

> It was nice for the most part. You know, almost all of them were people that I'd known for a long time. And all the almost all of them were people I was glad to get to spend a bit more time with (Marco)

> It was good. It was. It was lovely to get to know her a bit better (Marco)

Amidst the distress and decline of their mother’s terminal illness, Marco gained opportunities to spend time appreciating the special bond and closeness they shared. They spent one day in particular together dwelling in nature that was, “Very meaningful”.

The funeral provided the opportunity to feel socially supported and connected for Luke and Gillian and Sara:

> There's quite a few of my friends turned up those who knew us very well, those people who knew father and mother very, very well. They always tell because when you see people who knew both the parents turn up to a funeral, it gives you an awful lot of comfort and support (Luke)
>
> At one point I was just going to go to the church service and not go to the wake afterwards because I thought I won't be able to handle it. But in the end I did go right and saw some people that I haven't seen from my family and from my mum's partner's family for a long time, and that was actually quite nice (Sara)
>
> We're all upset, but we're all here and we're all remembering her. We're all thinking about her (Gillian)

In Gillian's quote above, she repeats the pronoun "we", illustrating how meaningful it felt to have the shared experience of grieving and remembering at the funeral. This augmented her sense of her grandmother's continued presence in her life and created a feeling of support and further connection with her family.

Luke was the only participant who spoke of being supported by autism services and he expressed enormous gratitude and respect for them. On the day his mother died, he rang a local supported employment agency for help and advice, and they directed him to the specialist autism psychology team. This was how he ultimately found out about and accessed bereavement counselling. Luke appreciated the fact that these services existed in his community and considered himself fortunate that "nowadays more [...] specialists are there to help you out in dealing with the problems". A sense of connection and community was an important feature of Luke's description of how he leaned into support systems during the bereavement. Neighbours were described as "very wonderful [...] they looked after us well" and a manager was also "very, very wonderful". Work colleagues provided meaningful relationships that fostered a sense of belonging and family in the wake of losing such significant members of his family of origin:

> I still go in and sort of see them just to say hello. And when I see them, it does seem like my brother, my sister (Luke)

Finding a sense of purpose to her grief and loss was another way that Gillian created meaning from her experience:

> I like to be helpful. I like to. It sounds weird, but if stuff I've been through in any way can be useful, it's not all been. I've not suffered through it for nothing (Gillian)

In the quote above, Gillian is referring to participation in the study and how it has been an opportunity to help others so that her suffering had not been "for nothing", or meaningless. Experiencing bereavement was meaningful to participants in how it had facilitated personal growth, mastery, and resilience. For example, Luke learned the skills of independent living, how to "Cook and how to do everything else" after his mother's death. Luisa had come to live her life more fully as a result of "becoming more aware of mortality". She was inspired to "Just try things. Just do things".

Participants described a sense of mastery over bereavement itself and how with each loss, they gained knowledge and skills that helped led to improved coping and resilience. Luke told me this meant that he was better able to cope following his mother's death having experienced the death of his father prior. Gillian described how she had learned "what kind of a griever" she was, which had increased her sense of competency and resilience:

> I think I think really grief is really individual to each person. And I think that, you know, when you've never experienced it before, you don't really know what to expect. But I know. I know now what kind of a griever I am (Gillian)

The above quote implies that Gillian's increased sense of predictability about her grief was helpful. Gillian's challenging experiences of bereavement had also taught her about the importance of self-care, impressing that fellow survivors must "make sure you look after yourself".

Participants used joy and humour as adaptive and protective sources of meaning in their memories of the deceased. Luisa liked to remember "the fun times" she had with her late partner and parents. For Gillian, being able to remember her grandmother with joy and happiness felt more fitting than sadness because that had been her personality. It felt special that Gillian shared her joyful memories and funny stories in the interview, and it seemed that she enjoyed telling me them, smiling as she shared them. She said that “It's kind of hard to to get sad and be sad when things like that pop up and [...] it sets you off. Yeah, it makes you laugh”. The joyful memories could take her by surprise and stop the sadness in its tracks.

4.6 Group Experiential Theme 4 – Stories and scripts: making sense of it all

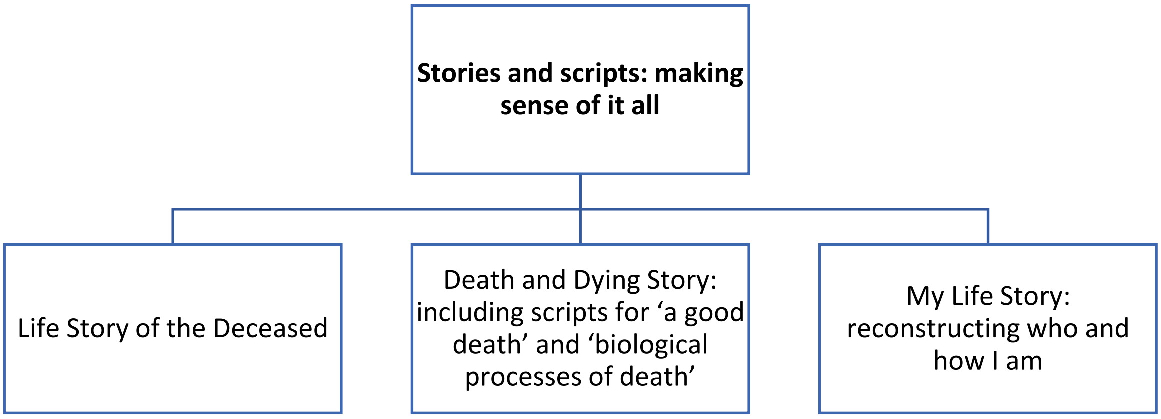

Figure 4: Group Experiential Theme 4, “Stories and scripts: making sense of it all”

The final theme describes the process of storying that was evident across all participants’ accounts. Participants situated their bereavement experiences in the context of their life story, constructing a sense of who they were in the past, who they are now and how they might be into the future. The interviews proved to be an opportunity for participants to dialogue with me, themselves, and the autobiographical story itself. The act of telling me their stories was therapeutic as it allowed them to re-story themselves, seek meaning in the death of the deceased and find a place for the deceased in their ongoing lives. This theme has been divided into three subthemes to define the significance of participants’ search for meaning in a) the life story of the deceased and b) their bereavement experiences, as subplots that were integrated into c) their overarching and evolving autobiographical stories.

4.6.1 Subtheme 4a – Life Story: the biography of the deceased

I was struck by the depth and richness of participants' descriptions of the deceased and with each interview, the significance of constructing a life story for the deceased emerged. Once the interviews were complete, the overriding feeling and impression I was left with was of how much love, care and curiosity participants had expressed. I went into the interviews wishing to know all about their experiences of bereavement, but participants wanted to tell me everything about the deceased.

Participants were focused on talking in detail about their loved ones who had, "their own particular ways of doing things. They had a particular way of life" (Luke). For Sara, reflecting on being bereaved of her mother, it had been helpful "to make sense of how she lived". Gillian's account was filled with anecdotes and descriptions of her grandmother who was "really funny", a "stereotypical little old lady" and whose role was "the heart of the family". During the interview, Marco wanted to give me "some background" and interjected the conversation to story their mother's life. Marco was engaged in situating their responses to the interview questions within the multiple stories that were constructed in the conversation. At one point, Marco explicitly prefaced a response with, "This is part of the story here is that".

> And talked about her quite a lot. You know which felt like the right thing […] You know, not not in an obligation kind of sense. Um, but in terms of. Yeah. What I needed. I think it was helpful to be able to talk about her life and legacy and all that stuff (Marco)

In Marco's quote above, they grapple with articulating exactly what it was that made all the talking about their mother feel "like the right thing" and what purpose it served. It was difficult to express how it was so helpful and my sense of it from Marco's interview, was that it felt somehow reassuring or calming. Talking about the deceased was part of regaining a sense of equilibrium after their loss. Marco explicated the meaning of this further when he described the process of writing a piece similar to a eulogy for the send-off. In the creation of this written piece, Marco had drawn from their mother's account of her life experience of growing up “weird” and included “a bit about our relationship”. It had been healing in the sense that “It helped to, crystallising things [...] pull some threads together”. Pulling all the different stories or “threads” of their mother’s life and connecting it with his own was a way to make sense of his loss. This will be explored further in the final subtheme.

There was disappointment and frustration when denied the opportunity to talk about the deceased with those who had known them. For example:

> But it's it's one of those things where even like even after my granddad died, everybody talked about him a little bit, but nobody went into detail about what he was like as a person (Gillian)
>
> … it would have been nice to, you know. Just, you know. See some of. The people again to talk about my dad [...] You know, you sort of talk to them and you hear you. You have your relationship with somebody and you everything you see is through that lens. And then to talk to somebody else and get their viewpoint on it is really. You know, it's interesting to hear things that you didn't know (Luisa)

The above quotes illustrate how participants desired to know as much as they could discover about the deceased, what they had been like and how they had lived their lives. This was especially true when information was missing from the story. Gillian had wished to talk about the details of what her grandfather had been like “as a person”, as she had had little opportunity to get to know him herself. It mattered to her to fill in the missing “detail” about his character. Luisa’s quote refers to her father’s wish not to have a funeral and how that denied the chance to talk about him with those that knew him. Luisa was very disappointed that she had not been able to talk about her dad at a funeral which left her feeling like there was “unfinished business”. It had rewarding to visit their hometown and glean new some information and share memories of her father.

Marco also expressed their interest in the missing parts of their mother’s story when they told me that “It would have been interesting. To know more of. The thoughts that went into” their mother’s wishes for the rituals that followed her death. Funerals were a fertile ground for information gathering about the deceased and when reflecting on their father's death, Marco told me:

> I felt like I probably learned more about him at his funeral and around it than I was able to really, in years of living with him (Marco)

Implied in the above quote above is the repetition of the significance of accessing all the details of the deceased's life story. We get a sense of how gratifying it was to Marco that he had the opportunity to discover more about his father at and around the funeral.

Sara's account illuminates the importance of constructing the deceased's biography as a way of making sense of loss and life. After both her parents' deaths she sought out information using a website that provided her with not only the deceased's history but also their ancestors' stories:

> And I think at that point when it happened, I wanted to sort of get deeply focused into things like find out about my mum's life and everything. And get really focused about that (Sara)
>
> He had a number of health problems towards the end of his life and I did exactly the same thing. I went on ancestry.com, I went through his life, you know, tried to make sense of it all [...] a mental health nurse said once, thought my dad was autistic. He was never assessed. And that's another story (Sara)

In the above quotes we get a sense of the intensity of Sara's interest in collating and piecing together as much of her parents' life histories as possible. The repetition and emphasis of how "focused" she was implied this was 'hyperfocus' and the kind of intense and repetitive interest that autistic people often experience. Like Marco, Sara also explicitly references her storying, saying "that's another story" and alluding to her father's struggles in life as an undiagnosed autistic person. Sara was "making sense of it all" and her quote below takes us closer to understanding what this meant:

> I suppose it's making sense of life, isn't it? Because. It life is. Oh, it sounds really crass to say that it is a journey. And I suppose it's making sense of. Of the people that are close to you and. And going through [their] life journey helps me, when it's gone I guess. (crying) I don't mean to cry so much. I like to see. It helps to know. To know about everything. Everything about their life. So that. So that I can close it and put it to bed. And there's nothing. I've joined all of the dots and there's nothing left for me to to find out sort of thing. And there are some things that I know I will never find out (Sara)

The above quote describes how the active process of storying the deceased's life helped to bring a sense of closure or resolution that helped Sara to "put it to bed". The emotion she was in touch with as she told me this, implies that this storying of the deceased also served an emotion processing function. Her metaphor of joining the dots reminds us of Marco's metaphor of pulling the threads of the deceased's life together, to understand their "life journey". There was a drive to find meaning in her parents' lives as way of finding meaning in life more broadly, and in her own life too.

4.6.2 Subtheme 4b – Death and Dying Story: including scripts for 'a good death' and 'biological processes of death'

It is unsurprising that all the participants described the events surrounding their bereavements as I asked them directly in the interview to "tell me what happened". However, this subtheme focuses on two 'social scripts' that emerged unprompted as part of the participants' process of storying their experiences: 'a good death' and 'biological processes of death'. These scripts were a way for participants to process the deaths of their loved ones and find meaning in what happened.

4.6.2.i Subtheme 4b – Death and Dying Story: Script, 'a good death'

The script for a good death was more than mere description of what happened. Participants were concerned with how and why the death occurred and the role that they played in supporting the deceased to have a successful death. Success in dying meant experiencing as little pain and distress for both the deceased and the survivor, and that the deceased's wishes had been accomplished. All the participants spoke of their loved one's illness and evaluated how much they suffered. For example, Luisa told me that she had seen their "health declining [...] she was suffering with the illness", which had been hard to witness. Sara made explicit reference to conversations she had had with her sister and the nurses saying, "she's going to die and I don't want to see her suffering". Sara told me about how agitated her mother became in the hospital and the distress of having to repeatedly guide her back into bed when she was trying to get out. Her quotes below share more detail:

> So what's quite poignant [...] what's still in my mind is, is the the difficulty she had with her health towards the end and how hard that was to manage that from a distance and support her when she was away [...] and a lot of time in the hospital and I had a lot of dealings with her hospital staff and carers, which I found very difficult (Sara)
>
> I set up a kind of like a visual system where because my mum was very anxious if one of us left the room because she didn't want to die on her own, she wanted both of us to be there. And so I set up a little thing with her notebook with like me [...] and then my sister, and then a picture where we were if we were in the toilet, if we were in the shower, if we were in the kitchen, that sort of thing. So she knew where we were, and that helped to alleviate some of her anxiety (Sara)

That Sara's mother suffered a protracted and painful illness before her death, was something that Sara was still struggling to comes to terms with at the time of the interview. It had been "very difficult" for both of them. Sara went to great lengths to ease her mother's distress and came up with a thoughtful "visual system" to communicate where the sisters were. It was so important that her mother's wish to not die alone was respected, that it meant Sara stayed in the traumatising environment of the hospital room for ten days until her mother's passing. When death came, there was a beneficial meaning to be found, as it was a "relief because she wasn't suffering any more".

There was also redemption to be found in knowing that Sara and her family had implemented her mother's wishes for her funeral, and likewise, for her father:

> The things that Mum wanted for the funeral we'd arranged. And I felt sort of happy that we'd done that because we wanted to give her the send-off that she wanted (Sara)
>
> We respected his wishes, we think (Sara)

A similar narrative of reconciling suffering and success emerged in Marco's account. Marco's mother's health had "varied" quite a bit and she ultimately was bedridden and incapacitated. Marco assisted with the "hands on care". In the final week of her life, an episode that stood out in Marco's mind was her coughing and choking after they had accidentally given her too much water. This experience "was pretty awful" for Marco whose narration of the scene was full of raw emotion. Marco's mother had expressed a desire to be in control of her death, and Marco said they "Regret not finding a way for that to happen".

Marco found positive meaning in other constituents of a good death, for example in the importance of goodbyes and successfully following the dying person's wishes:

> Died surrounded by love, having had a chance to say goodbye to many of the people that meant the most to her [...] it's nice that we had the chance to talk about what kind of send-off she would like. And the way that it worked out was very much in accordance with her wishes (Marco)

The ending of the 'death and dying story' was imbued with love and a sense of fulfilment. It meant a great deal for Marco to know that her preferences had been followed. The lasting memory of the send-off was that it had been "a beautiful event" and on the day there was a "vivid rainbow" which felt meaningful. Marco explained to me that their mum was "never religious, but she. Took spirituality seriously", and the family ensured that her death and mourning rituals represented her spiritual beliefs.

All the participants described the significance of whether the send-off represented the deceased's personality, values, or wishes. This included details like the meaning of the coffin:

> Yes, you know, my mom's body's in the coffin, but. It's. It's just a coffin. It's almost impersonal, really (Luisa)

> She was cremated in a basket, not a coffin, because she was very environmental. Like myself (Luke)

In the above quotes, Luisa described how it was jarring when she experienced a sense of meaninglessness about the coffin that did not feel personal to her mother. This dissatisfaction contrasts with Luke's description of the coffin representing not only his mother's wishes and values but also his sense of continued connection with her. The importance of mourning rituals accurately representing the deceased in meaningful ways was also implied in participants descriptions of the mismatch occurring "when someone is in charge of a funeral who really didn't know the person at all" (Marco). Luisa also described how strange it felt at her mother's funeral listening to a story that felt as if something was "missing or something not quite right [...] it doesn't quite mesh with my own recollections [...] this is kind of second hand".

The funeral was an important event in the social script of death and dying. It was an opportunity to say goodbye to the deceased and to materialise their wishes. Most of the participants referred to the impact of the final sight of the coffin as being “the hardest part” and the difficulty in making sense of “the last you see of the coffin” (Luisa) as being the final goodbye to the deceased. Importantly, mourning rituals also provided predictability following bereavement which Sara described:

> I think for me, it started to get better after the funeral because I think the way my brain works is [...] there's this set series, sort of stages of what happens where you initially find out and then you have the funeral and then you have the wake (Gillian)
>
> And, you know, it was it was almost like this is what is expected to happen, because we followed this set thing of what was going to happen, like the funeral and then the wake (Gillian)
>
> I like to analyse things and I like to sort of understand this has happened because of this and this is the response because, and I like to sort of walk myself through it and come to an end with it. And it helps me to feel like that's the situation's ended and over with (Gillian)

In the above series of quotes from Gillian, she describes how a predictable series of “stages” from the person’s death through to the funeral and wake helped her to find a sense of closure about the initial period of the bereavement has “ended”. She couches this in a cognitive style that she describes as a need to “analyse things” in terms of predictive sequences. When the sequences were disrupted and unexpected, as they were following her paternal grandmother’s death, it severely interrupted her grief process:

> So with her there wasn't that closure that I had with my [maternal grandmother]. My [maternal grandmother] felt like closure because we did the customary funeral, wake, it's all done [...] When that was disrupted, everything went out the window. Everything completely and utterly just nosedived because everything was so disrupted from the norm. (Gillian)

When events deviated from Gillian’s predicted social script, “everything went out the window”. Gillian conveyed how devastating this was on her sense of coping and ability to find resolution in her grief, “everything completely and utterly just nosedived”. As had been the case for other participants, there was solace to be found in having carried out the deceased’s’ wishes which meant that an overall sense of success in the death and dying story could be achieved:

> ... this sense of almost like being relieved of like. I don't have to worry. We did what they wanted through to the end. They got to live in their own houses right up to the end. I don't have to worry about that [...] What more could we have done for them [...] we felt lucky for having that (Gillian)

4.6.2.ii Subtheme 4b – Death and Dying Story: Script, 'biological processes of death'

Understanding the processes and stages of dying can provide a helpful biological script for autistic survivors. These facts bring comfort and a pleasing sense of understanding and predictability about what happens and what to expect when a person dies. Sara wished to know all the facts about the process of dying:

> I found out on the Internet about what happens when the body dies. I had to know about the science behind it, but I didn't tell anyone because I thought people will think I'm a bit weird for doing that. And that's really morbid. But I wanted to to know that side of things. And I've always asked those sort of questions when people die because for me that helps me to understand it. It doesn't mean to say I respect that person less (Sara)

Above, Sara describes how she "had to know" the scientific facts about death and dying which was a coping strategy for her during her bereavements. The language she used also demonstrated her expectation of being judged as "weird" and "morbid", or uncaring and disrespectful. There was something reassuring about having this biological script for dying and in one hospital, they provided leaflets about it. When I asked if this was helpful, she said:

> ... completely. It was really, really helpful. And they left leaflets around and because we didn't really have access to the internet there, but that was so helpful [...] if I hadn't have had that, I would have been really. Yeah. Really, really stressed (Sara)

The number of times Sara said "really and "helpful" in the above quotes illustrates her desire to emphasise the significance of the information and the calming effect it had. Other participants who were not provided with information leaflets did not seek it out directly in the way that Sara had in her internet searches. However, in Luisa's interview, a strong interest in these same biological processes of dying was disclosed in her description of her first encounter with a corpse:

> Trying to take in details and see what. What is it? What? What, what's. Can I see something missing? Is there is there some big difference between somebody? You

> know, five more minutes and then here they are, dead and. Can I see? Can I. Is it something I can see? Is that. Is there some sign? Is there something that. [...] There really isn't and it's it's a how how can the. You know, what are these processes? And, you know, the fact that they sort of come to a stop and I don't know, it's it's far too complex. I don't understand it [...] I mean, eyelids closed, but the eyes were sort of sunken, and that was the only real detail (Luisa)

The questions Luisa asks in the above quote illustrate how she searched the details of the corpse' appearance for discerning signs of death. She even asks, "what are these processes", she is interrogating the subject for understanding and clues as to how a person transitions from life to death and how one ascertains a person is dead.

Gillian told me that after every bereavement she went through a period of being unsure whether the deceased was actually dead. This was partly connected to gradually accepting the reality of the bereavement but what also concerned her, was the process of dying and how we can be "certain" that a person is physically dead. When her grandmother died, she was anxious whether the doctors were "100% sure she's not in any state of coma or anything?". Marco and Luke were less explicitly focused on this aspect of their bereavement experiences, but Luke did speak of the "anonymous signs" that his mother was going to die soon. While Marco told me, "It takes a while for all activity in the brain to cease" when they described their uncertainty around whether their mother was completely dead or had heard him say his final goodbye.

4.6.3 Subtheme 4c – My Life Story: reconstructing who and how I am

When a loved one died, it broke the threads of continuity in participants' life stories. On a practical level, it disrupted established routines and expectations and on an intrapersonal level, it fractured participants' sense of identity and belonging in the world. This subtheme attempts to capture participants' meaning-making processes as they created post-loss identities. It also demonstrates how participants integrated the previous subthemes into their life stories. Although the research interview and questions were focused on participants' experiences of bereavement, the bereavement stories that emerged were presented within over-arching stories of participants' lives and self-understandings. An overview of some of key general themes and constructs in the life stories will be given, followed by examples from each participant's account.

In the telling of their stories in interview, participants were reconstructing their pasts, making sense of themselves, and reflecting on their futures in a world without the deceased. Participants' life stories contained several subplots, three of which were: i) the relationship with the deceased ii) the life story of the deceased and iii) the death and dying story. As has been discussed elsewhere, participants not only shared stories about the deceased, but they were also interested in gathering the information they could about the deceased's life, making sense of it until they felt satisfaction about the story. Constructing and reflecting on the details of the subplots ultimately helped participants to make connections that garnered a wider perspective on life and clearer view of what mattered to them. Participants found meaning in their life stories by examining what their experiences said about who they are as people.

The stories contained layers of conflict that participants attempted to resolve and integrate into their sense of identity and purpose in life. There were internal conflicts of anxiety, fear and self-doubt, and external conflicts or obstacles and challenges that were encountered. External obstacles to coping with their loss and creating satisfying meanings in their life stories were experienced on interpersonal and societal levels. Participants encountered difficulties re-storying their lives following bereavement when conflict was ongoing, or they struggled to find meaning in aspects of the stories or subplots. Those participants who were in a position to find meaning in their suffering and losses such as personal growth or increased connection in their lives, described more satisfying endings to the stories as told in interview.

Luke made sense of his post loss identity from understanding what his upbringing, relationship with his late mother, and her death meant to him. Luke reflected on the quality of their relationship and the bond they had shared. Starting in childhood, his identity developed through their relationship and the stories that his mother told him. For example, when others were unkind to him, it was because they were “jealous”, creating his sense of having desirable characteristics that set him apart from others. Luke appreciated that he had held a special place in his mother’s affections which was reinforced by his position and role in the family as her youngest child. Luke made sense of their relationship and his upbringing against a backdrop of transgenerational grief. The repercussions of traumatic child loss and unresolved grief meant, as Luke saw it, that he was over-protected:

> …mum lost her brother and my grandmother lost her son […] so mum was always quite protective of me. (Luke)

Luke reflected on how special he was to both his mother and grandmother:

> Basically, mum took mum took me for being her loving son. Mum and Gran both both doted on me and […] were always there for me (Luke)

In the above extract Luke referenced his role as ‘loving son’, alluding to his loss of social role and position in the family because of the bereavement. Losing his mother was a loss of her unconditional maternal love and emotional support. It was also a loss of the connection to his grandmother who had also occupied an important place in his life.

Luke believed that he had inherited some of his mother’s traits and values:

> And mum would sit down and she she has a great conversation. She would always engage in a great conversation. And I think that's what she left it with me. I like to get involved in great conversations with people, intellectuals as well (Luke)

Luke believed his mother had passed to him the ability to have and enjoy good conversations, attributes that he admired about her. Environmental issues were also important to her and this was a passion that he maintained as a defining value in his life. Embodying his mother’s values and traits meant that she lived on in him, and that he was able to find means to continue being her loving, devoted son.

The death of Luke's mother was also significant to him because his mother was his remaining parent. The diminishment of his family and the loss of integrity and strength in its structure that had resulted from several bereavements meant that, "parts of our family are getting a little bit thin at the moment". This brought Luke closer to his existential aloneness in the world. His mother's death meant a secondary loss of his last living connection with his heritage. The family had military connections and throughout his interview Luke referred to war and soldiers, making sense of whether this identity still fitted since his parents' deaths.

The depletion of his family had introduced fragility to his world, and this increased Luke's vulnerability and aloneness. Growing up, his mother had protected him by cosseting him within the family. This was partly achieved by physically ensconcing Luke who described having lived at home with his parents all his life which he attributed to receiving a delayed autism diagnosis. Luke and his family were aware of his difference but unsure how to fully understand him. Had they known sooner, he implied that there might have been opportunities for a more independent life. He appreciated the support family gave him as an autistic person trying to make sense of themself at a time when "nobody knew or understood the word autism". Luke attributed these circumstances and dynamics as having strengthened his bonds with them:

> …because they both my mother, my mother, father, and grandmother were kind of special to me because to say. Well, they basically brought me up at a time when I say I was trying to understand myself (Luke)

Luke emphasised the significance of his family relationships and how being autistic can mean having particularly strong attachments to parents and grandparents. He also experienced how parental loss meant a loss of protection from the outside world. Without the protective layer that his parents provided, he encountered inhospitable social spaces in which he defended his family ancestry and identity from prejudice and "so much jealousy".

Luke was thrust into a different way of life that meant he learned to adapt to new challenges. Significant changes to his way of life began before the event of her death Luke had to quickly learn the skills of independent living so that for the first time, he could run the household. This was not easy at first:

> …when mum started to lose her mind, my sister said to me, "Right, [Luke], you're going to have to sort of start doing cooking. Are you going to start doing all the cleaning everything that mum used to do? You're going to have to start doing it" (Luke)
>
> So when that hit me like a tidal wave, when I first started to do it, but after a while I thought, Okay, this is how you breathe. This is how we have to do everything everyday life. So cooking the washing and the cleaning, doing, looking after the housework, the other. And now, one does not really bat an eyelid one just gets on with it (Luke)

Luke described his initial overwhelm at the enormity of the change to his everyday life as hitting him "like a tidal wave". The taken for granted basics of everyday life were his responsibility and he needed to manage his anxiety, to remember "how you breathe". He persevered until he mastered the tasks well enough to "not really bat an eyelid".

Luke's increasing competence extended to his experience of bereavement. Comparing his response to his father's death with his mother's, he noticed in himself a greater capacity to accept and manage the reality of her passing:

> When Father died two weeks, I freaked out. But when my mother died, I felt a bit calmer. And it was just a slow acceptability that she had passed away (Luke)

He experienced an increase in his capacity to adapt to change across his life more generally. His bereavement experiences were a catalyst for personal growth, through which he developed new perspectives on his world and relationships. Luke realised that he "had to learn to just change and adapt to the world now". Luke had developed a maturity and wisdom through having lost his mother and his confidence and flexibility in adapting to change had also grown. This helped him to cultivate additional competencies and integrate his experiences and knowledge into his emerging identity as an independent adult.

Following the loss of a person so very central to his selfhood, Luke engaged in a process of renegotiating his identity and place in the world. Luke returned to the subject of his autism diagnosis throughout his account, reflecting on its interplay with his understanding of himself and his relationships with others. Receiving the diagnosis was helpful, bringing insight into his sense of difference:

> Mum always knew I was going to be different to everybody else, but I say it made a lot more sense for us when I was diagnosed back in 2013, 2014. It made one's life a little bit clearer (Luke)

During adolescence Luke had felt different at school, and whilst being autistic meant being misunderstood and suffering at the hands of bullies, Luke also described how it signified advantages including being gifted:

> …all of us as autistic people have been given, but said that I have been given a gift somehow (Luke)
>
> …we all think differently to everybody else (Luke)

The language Luke used in the above extracts such as, 'all of us' and 'we all', demonstrates the strength of his social identity as autistic and describes some of the shared attributes that differentiate autistic from allistic people. Having an autism diagnosis facilitated a new sense of belonging and collective self that positively influenced his self-esteem:

> …it's just sort of coming to understand that I'm probably like people like Albert Einstein [...] I've got some idea what my future holds [...] so to see I'm autistic. So which means Albert Einstein was autistic. So Sir Isaac Newton, there's quite a few inventors and philosophers whom I've always admired. So, yeah, I think I'm heading in the right direction now. (Luke)

Stereotypes of autistic people as 'savants' inspired Luke to see his differences as talents. It also positively influenced his orientation toward his future and himself as having the potential to be a person that others admire and value. The social identity of the special child within the family was reconstructed into his new identity as an autistic man with special gifts.

Gillian reflected on her maternal grandmother's biography and death, and on their relationship, in ways that helped her to understand how she became the person she is today. Discovering her grandmother's story of mental health struggles and institutionalisation helped her to understand why she had been so strict with her children and grandchildren about hiding emotions and behaviours that could have been considered 'abnormal'. This information helped Gillian to make sense of her emotional and physical wellbeing, and her struggle as an autistic woman, to feel safe and accepted enough to be herself with others. Gillian had based her “mask personality” on family members and that her grandmother had “helped me to become a functioning member of society to a degree”.

The internal conflict between suffering and shame featured heavily in both Sara and Gillian’s stories. The fear of being judged and stigmatised prevented them from seeking support during their bereavements. Gillian’s story was also saturated with a narrative regarding conflict with an oppressive society that had created challenges for her throughout life. A theme of social injustice and unfairness was found in her account which contaminated the story of her paternal grandmother’s death:

> I'd had to choose work to survive over going to see my own family. And that felt like a choice that was unfair and it shouldn't have been. I shouldn't have had to make that [...] And I was just very, very upset and angry that I hadn't thought to spend more time with her. I was just it was all that side of it (Gillian)

In the above quote, Gillian is describing how she felt forced to choose between working at times of the year when the family traditionally saw her grandmother or losing her job. Gillian described being discriminated against at work for being autistic, meaning that she was left feeling “very, very upset and angry” about not spending enough time with her grandmother. Such difficult feelings including guilt, made it hard for her to process her grief. In the context of Gillian’s life story, the unsatisfactory death and dying story meant that it was difficult for her to reconcile her sense of self as a loving, caring, and devoted grandchild with the conflicting bereavement related events. It also emphasised the theme and feelings of marginalisation in her life story as the death felt “unfair”. For Gillian, it “never feels fair to lose a family member”.

Toward the end of her story, Gillian described ways that she was overcoming some of the challenges and conflicts in her life for example, how she was learning to express herself more freely:

> I'm starting to have to learn how to stim again now, which is an interesting thing to do when you've been told for years and years, don't do this, don't do that. (Gillian)

The above quote is an example of how Gillian was learning to not allow her past to define her and to achieve her goal of improving her emotional and physical health and relationships. Part of that personal growth had come from insight she gained about herself and the importance of self-care through her experiences of grief and loss. The difficult aspects of her paternal grandmother's death were offset by the family story that, "We did our best" and the shared spiritual beliefs and a sense of ongoing connection with the deceased.

Sara explicitly described her process of investigating the biographies of her late parents to help make sense of her own identity:

> I wanted to sort of get deeply focused into things like find out about my mum's life and everything [...] one way of coping was to get highly focussed and find out [...] what I didn't know already (Sara)
>
> I suppose part of that is I was trying to make sense of, of the sort of family history (Sara)
>
> And I suppose [my father] dying sort of made me think about my identity. If he had such a struggle through life being autistic and it made me think about me (Sara)

The above quotes illustrate Sara's motivation to find missing information about her parents. This was more than simply reminiscing; it was an active reconstruction of their stories to be integrated into her own story and identity. She saw parallels with her father's struggles in life as an autistic person who was "othered", helping Sara to make sense of her experiences in a broader social context.

Another way that Sara made sense of what kind of person she is, was through exploration of her relationship with her mother. For example, thinking about whether Sara could "have been a better daughter" and her mother "been a better mum". In Sara's interview, I got a sense of how important and instinctual the process of storying and reconstructing her identity was. For example, when in dialogue about the funeral, Sara's mind wandered back to this process:

> I was thinking about. My mum's journey through life. And. And I was part of it, but not all of it, but a big part of her life. And that. Um. Sorry, What was your question again? (Sara)

In the above quote we see how Sara was tasked with understanding her new place and purpose in the world. Sara was once a “big part” of her mother’s life, and she was processing what that meant with her mother being gone. She was reconstructing the story of their relationship, including how successful they were in their roles and what that meant relative to how Sara feels about herself now.

Sara said that she still felt “confused by it all”, having not been able to satisfactorily weave the stories into her evolving sense of identity. Reflecting on the mother-daughter relationship she was still unsure how she really felt about it. Sara told me she was uncertain whether she had successfully learned “to adjust” following her bereavement, which meant that she did not “know what to think about it”. It was as if she was still living in the death and dying story and lacked the necessary distance from the events to make sense of it. As discussed in the previous subtheme, the events surrounding her mother’s death had been particularly distressing. Sara said she “dreams now about the three of us trapped in a building and trying to get out”. At the time, she was caught in the conflict of knowing it would be overwhelming but experiencing pressure to do the right thing and stay in the hospital without respite. Hospital staff “encouraged” her to stay, telling her “They had beds for family”; she found the experience “really, really traumatic” and her mother died of multiple health issues. This made it harder to construct satisfactory meanings out of what happened.

Sara expressed a desire for belonging and to unlearn masking. In interview, Sara reflected on how she used to “try and perform and sort of fit in”, telling me that she did not want to continue that anymore and was “still on that journey of how to be myself and not worry about trying to fit in”. Sara saw her bereavements as setbacks to this journey, having felt as if she was “making headway” following her diagnosis, only for it to all get “pushed back again” in the wake of her parents’ deaths. There was difficulty adjusting to the freedom of being herself once the social tasks of bereavement were over and it was hard for Sara to re-connect with her sense of self:

> Now I knew that I could be myself, which was just such a relief. But also I didn't know what to do with myself because I was so used to putting this guard up (Sara)

The relief that Sara describes above was tainted by her sense of disorientation about how to "be myself" after such intense and prolonged periods of masking.

One meaning that Sara derived from her experience of having supported her mother through numerous hospital stays and periods of ill health was related to old age and dying:

> It's made me it's made me worried about my future because I've seen the dependency that somebody is getting old and frail and has health problems their dependency on health services and care and so on (Sara)

Having seen the way that her mother's health and quality of life deteriorated led to Sara being confronted with fears regarding her own health and mortality. Growing older means becoming dependent on a system that Sara had experienced as not accepting or understanding of autistic people like herself.

There were opportunities for Sara to create more fulfilling meanings out of her loss but there were obstacles to their full realisation. For example, Sara wanted to share all the information she had researched about her mother's life with her counsellor:

> It sounds odd but I would like to have shared what I found out about her as a way of celebrating her life (Sara)

Celebrating Sara's mother's life with another person would have been a way to preserve her legacy and create meaning out of the biography of the deceased. As Sara had described it, this was a helpful way to make sense of her own sense of self in light of her loss. However, Sara chose not to share this with her counsellor, believing that they were not interested in that avenue of exploration. In the above quote, Sara prefaces her statement with "It sounds odd but", and this also alludes to the internalised stigma that contributed to Sara missing an opportunity for healing. This intrapersonal conflict was also evident when Sara described the relief she felt about her mother's death, "It sounds awful to say, but it was a relief". There was relief because the death meant and end to intense suffering for both of them, but this adaptive meaning was complicated by Sara’s sense that it was wrong to feel relief.

A source of healing in Sara’s story was the comfort she found in the final exchange with her mother:

> A bit of comfort because her last words to me before she went unconscious. She said, ‘I love you’. She looked into my eyes and said, ‘I love you’. So I felt a bit of comfort from that. (Sara)

The repetition of “I love you” illustrates how emotionally moving and meaningful these words were to her. Sara had alluded to how their mother-daughter relationship had been complex but in the end, there was love. Despite the challenges and conflicts that Sara had faced; she had managed to reach a place of acceptance about her mother’s death:

> But I've accepted it. You know, when I say to people now, Oh, my mum died, it rolls off the tongue very quickly. It felt like it wasn't real when I was saying that to start with (Sara)

Marco also reflected on the nature of the relationship with the deceased and integrated the significance of this into their post-bereavement sense of self. Marco’s history and self-identity shared commonalities with his mother’s biography and character:

> Growing up. Quite weird knowing that she was weird, but from a family where that was really quite accepted and expected (Marco)

> [She] came to identify as autistic right around the same time as I did. And I think that was kind of inevitable probably. It was like. Either of us was going to accept that we were autistic. Then there wasn't much point in the other trying to deny it anyways [smiling] (Marco)

In the above quotes, Marco reflects on their mother’s upbringing and expresses how similar they were. They were both “weird” by virtue of being autistic, and shared a deep understanding of each other’s life experiences, identifying with one another. When reflecting on what they lost when their mother died, Marco told me:

> …someone who I knew cared about me very deeply. And I cared about deeply too (Marco)

> The single person who was most like me [...] Pretty obvious that we we process the world in really quite similar ways and faced many of the same challenges (Marco)

Reading Marco's quotes, one gets a sense of how precious the relationship was. It afforded Marco a place to be profoundly understood and cared for in a world where being autistic means being different. This mutuality was deeply meaningful and validating. Marco reflected on their mother's "motivation for moving" before her death, which they interpreted as her desire, "to be closer to me". Marco had a special role in their mother's life, and they shared conversations during her illness about Marco's role in keeping her legacy alive:

> I was very concerned with. Preserving and furthering my mum's legacy [...] And you know, we got to talk quite a lot about it [...] I wanted to get things in place (Marco)

> …looking after her legacy, you know, like making sure that she she knew that her work would live on [...] Played a huge role in how okay she felt about the fact that she was dying (Marco)

Marco and their mother had agreed a way to preserve and further her legacy. This helped her to face her mortality and was a joint project that Marco would continue after her death. However, after she died, Marco found themself in social conflict that prevented them from completing the project in the way that their mother had set out. For Marco, this was "the single hardest thing about the whole" of their bereavement experience. Co-creating their mother's legacy had brought significant meaning to Marco, it offered them a way to have a continued relationship with their mother and maintain a sense of alignment with her values and what she stood for. The disruption to the project and the intractable social conflict meant Marco was not able to keep a promise which disrupted the continuity that the project had created in their life story, the relationship with their mother and in the grieving process itself. Marco had struggled to re-story their life satisfactorily when this happened. Both Sara and Marco had sought meaning in their mothers' lives, to know that their lives had mattered and to keep their legacy alive. Although Marco felt a "deep sense of loss" and "sadness" after their mother died, they also felt "some degree of satisfaction" knowing "that she was quite satisfied with her life".

Marco's natural tendency for storying was evident from the very start of the interview. They wanted to hear something about my biography and interests and asked me:

> You're not autistic?

> So what sparked your particular interest in this area?
>
> So you've been a counsellor for a while? (Marco)

The above quotes exemplify how Marco interviewed the interviewer, ascertaining something of my backstory and values before engaging with my questions. This reminded me of the way Marco had referred to similar background information about the counsellor they reached out to following their mother's death. Asking me whether I was autistic implies perhaps some scepticism about the research and whether I could safely and respectfully hold and write about Marco's embodied experience of grief. Peppered through the interview were other direct references to storying in Marco's account for example when he told me he wanted to give "background" and tell me "part of the story".

In Luisa's interview, she dialogued with her life story by reflecting on her sense of personal development and growth. Re-working the story of her youth, she saw a naivety in herself, telling me that when one is young, "You think you're bulletproof". The deaths of her parents and others close to her had brought her into confrontation with mortality. The theme of increased vulnerability was emphasised when reflecting on life without her parents:

> So there was always there's always somebody and you know, that I could somebody I could turn to, somebody I could go to. Yeah. And realizing that. I didn't [have that] anymore. Yeah. Um. Kind of felt very vulnerable […] It's a difficult thing to come to terms with and deal with it. Really, that that's probably the. The biggest thing. So there was always that kind of sense of security. And even even now, when it sort of when I know, sort of become conscious of it again, it still, you know, affects me a lot. (Luisa).

Luisa's sense of aloneness and vulnerability in the wake of parental loss was the hardest aspect of her bereavement. She also made sense of her grief feeling more intense with every anniversary of her mother's death as being connected to an increased death awareness. It was as if every loss and grief trigger was a reminder that she was getting older and will herself die one day.

The theme of constructing the deceased's biography was significant in Luisa's account. The process of storying her father's life fulfilled a dual purpose. There was a reminiscing aspect to it, but she was also making sense of the change she experienced in her own way of being since becoming more aware of mortality. Luisa had begun to "Just try things" and live life to the fullest. I felt a sense of freedom hearing Luisa’s description of her newly discovered joy at being spontaneous and adventurous. She was no longer procrastinating but following through on plans like the description of a trip she made, "I'm going to travel and come and visit next year. And I did". Luisa had reworked her philosophy of living which she compared to how her father started trying new things after her mother died. There was comfort and validation to be found in this meaning to her post-loss attitude to life. It also fostered a continued sense of closeness with her father, feeling that she was following in his footsteps.

5. DISCUSSION

5.1 Introduction

Autistic adults' experiences of bereavement have been hitherto under-researched. This qualitative study aims to further the understanding of autistic people's lived experiences of grief and loss through an interpretative phenomenological analysis of the accounts of five autistic individuals bereaved of people close to them. The interviews yielded rich data with findings underscoring grief as a social process and bereavement as an instigator of narrative identity reconstruction. Some of the participants' grief experiences and meaning-making processes fit with existing bereavement literature, while others appear specific to characteristics of autism such as sensory issues and intense interests in the biological process of death and the biography of the deceased. Participants described the major impacts of the death of significant others in the socio-cultural context of their marginalised experiences of being autistic which is a stigmatised social category in a neuro-normative society. Bereavement and grief presented particular social challenges for autistic adults experiencing social communication difficulties, creating potential barriers to attaining satisfactory resolutions to their grief.

This section takes each group experiential theme in turn, discussing the findings in relation to existing literature.

5.2 Discussion of the Group Experiential Themes

Several themes that emerged from the data were not anticipated in the planning stages and the analysis process took me into "new and unanticipated territory" (Smith, Flowers & Larkin, 2022: 116). It is beyond the scope of this thesis to refer to all extant literature that could be seen as relevant for discussion in relation to the themes and as such, a selection is presented below.

f5.2.1 Group Experiential Theme 1 – Impacts of change, loss and uncertainty

Consistent with the existing grief literature, the participants' grief reactions were individual and varied for each loss (Zisook & Shear, 2009). Most people's reactions fall into what Bonanno and Kaltman (2001) describe as the 'common grief' pattern whereby participants experienced disruptions in cognitive, emotional, physical, or interpersonal functioning during the initial months after their loss. All but one participant appeared to have transitioned to integrated grief (Shear and Mulhare, 2008) at the point of interview. Luisa described her grief as feeling more intense each year when triggered by the anniversary of her mother's death whilst at other times of the year her usual levels of functioning were restored. This is similar to the experience of some spousally bereaved parents who reported experiencing the reactivation of their grief over time and being "overwhelmed by sudden memories or going through rough patches several years after the loss" (Holmgren, 2022b, p.507).

Some reported grief reactions do not appear to be documented in current literature. For example, two participants explicitly cited changes in sensory issues with increased hyper- and hypo-sensitivity that were outside their usual everyday sensory experiences. Sensory disturbances are a common feature in autism and are included in the ICD-11 diagnostic criterion for autism:

> Lifelong excessive and persistent hypersensitivity or hyposensitivity to sensory stimuli or unusual interest in a sensory stimulus, which may include actual or anticipated sounds, light, textures (especially clothing and food), odors and tastes, heat, cold, or pain. (WHO, 2019)

Leekham et al.'s (2007) study found that "sensory abnormalities are pervasive and multimodal and persistent across age and ability" (p.894) for autistic children and adults with a 90% prevalence rate for sensory issues among the 200 autistic adult participants. The cause of sensory differences is unclear, with inconclusive evidence for an underlying deficit in sensory integration (Reynolds & Lane, 2008). Autistic participants taking part in a focus group (Robertson & Simmons, 2015) described how sensory differences caused them general discomfort, headaches, negative emotions, and physical reactions. Negative emotional states reportedly affected sensory perception for example, decreasing tolerance for stimuli or by reducing the ability to perceive pain (Ibid). These findings potentially connect with the effects on sensory experiences in the present study at a time when participants were managing difficult and intense grief-related emotions. Jordan (2011) notes how sensory issues can also be considered as a potential source of stress that likely interacts with cognitive and/or social demands and calls for potentially disturbing stimuli to be reduced or for periods of respite from stimulation. Thus, the stress of the cognitive, emotional and social demands associated with bereavement, likely interacts with existing sensory issues for autistic survivors.

Bereavement places polytropic demands on monotropic ways of being, overwhelming autistic survivors' processing capabilities. Some of the participants explicitly described how coping with the sudden changes, especially to routines, brought about by bereavement were the hardest aspect of their experience. This can be understood in the framework of monotropic attention:

> To a person in an attention tunnel every unanticipated change is abrupt and is truly, if briefly, catastrophic: a complete disconnection from a previous safe state, a plunge into a meaningless blizzard of sensations, a frightening experience which may occur many times in a single day (Murray et al., 2005; p. 147)

The response to a change event as described above, is that the person focuses attention on actions that are familiar and reassuring, for example by engaging in stimming that aids the re-establishment of a sense of equilibrium. It is suggested that self-stimulatory behaviour such as the vocalisations that Gillian described, provides relief not only in new, unpredictable, and overwhelming circumstances (Pellicano & Burr, 2012), but also from excessive sensory stimulation and heightened emotional arousal (Leekham, Prior & Uljarevic, 2011).

Time is required to adjust to abrupt change (Lawson, 2001). Participants said that bereavement is always an abrupt experience, one which is accompanied by multiple demands and tasks. Multi-tasking is only possible when there is sufficient available attention together with enough energy resources within a person's interest tunnel (Murray et al., 2005). All participants referenced how they had learned about themselves as grievers and loss in general through their experiences of bereavement which gave them greater skills and resilience in dealing with loss. Bonanno et al. (2010) note that prior experience with similar potentially traumatic events and losses predicts better adjustment at subsequent exposures, with prior experience helping a person prepare for and understand the forthcoming sequence of events. I believe that this is particularly salient for autistic survivors.

Gillian's description of how the disruption to the expected sequence of events following a person's death can also be understood in a monotropic framework of wellbeing in which the focus is on a need for "order, familiarity and reassurance" and the sense of not being able to "'move on' unless certain ritualistic expectations are met" (Murray et al., 2005; p. 146). Monotropic attention distribution is purported to make sense of autistic phenomena such as a variety of integration issues, hyper and hypo sensitivities, issues with set switching and all or nothing thinking (Murray, 2018). Sara's lack of awareness of the pain of breaking her elbow can be understood as monotropism resulting in significant areas of "potential information not being registered" (Murray et al., 2005; p. 146) while her attention was focused on caring for her mother and managing anticipatory grief.

Another feature of autistic experience is difficulty switching between tasks (Murray et al., 2005, Hill, 2004). Considering how "the grief process typically proceeds in fits and starts, with attention oscillating to and from the painful reality of the death" (Zisook & Shear, 2009, p.68), one can understand how this may be particularly difficult for autistic survivors to manage and provides a helpful context for participants' descriptions of needing "time and space" to grieve. For example, Marco's description of how their counselling helped them to "make space" for their bereavement can be seen as affording them the opportunity to focus solely on the embodied experience of grief. Only a single issue can be fully and successfully attended to at any one time, including grief and loss.

For most of the participants, the competing demands and depleting nature of bereavement led to an increase in the frequency and severity of inertia, meltdown, shutdown, and burnout. This finding accords with existing qualitative literature that has identified these phenomena as important aspects of the lived experience of being autistic (Belek, 2018, Phung et al., 2021; Raymaker et al., 2020, Welch et al., 2020).

Luke's description of his brain being in "neutral" at the funeral aligns with the inertia found in Welch et al.'s (2020) study that is the experience of an autistic individual's mental state becoming 'stuck', leading to the person becoming physically unable to engage in desired activities. Sara's experience at the hospital where she could not contain her distress and frustration with the staff fits existing descriptions of meltdowns resulting from feeling completely overwhelmed because of social demands, frustration, communication challenges, emotional triggers, overwhelming aversive stimuli, and cumulative stress (Ibid). Gillian and Luisa described their shutdowns as requiring them to withdraw and let their emotional pain run its course. In line with Belek's (2018) findings, these were internal experiences that varied in their intensity. Sometimes participants were able to function enough to walk around and talk to others whilst internally shutdown and at other times they were lying in the foetal position unable to move or communicate.

Many of the participants' experiences of bereavement included features consistent with 'autistic burnout'. This is a term "often used by autistic adults to describe a state of incapacitation, exhaustion, and distress in every area of life" that is clinically distinguishable from depression and occupational burnout (Raymaker et al., 2020, p.134). For example, Sara was left exhausted, unable to function, traumatised from sensory overstimulation and burnt-out with “mind collapse”. Gillian’s reduced tolerance to stimulus, exhaustion and withdrawal are also characteristic of autistic burnout (Ibid).

Raymaker et al. (Ibid) conceptualise autistic burnout as a syndrome “resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports” (p.133). Their findings suggested that life-stresses alone did not lead to burnout rather, it was the barriers to finding relief from the load of the stresses together with being expected to do more than they were capable of that tipped the balance. The findings of the current study corroborate this conceptualisation as participants described how it was not the experience of the death of a loved one itself alone that caused the greatest difficulty. Participant accounts depict how social demands and expectations, unaccommodating environments, barriers to support, stigma, masking, not being afforded enough time off work or time alone, and being misunderstood or dismissed were cumulative factors to their difficulties, and periods of overwhelm and autistic burnout, that were experienced following bereavement.

Some of the participants explicitly connected their burnout to the cost of masking autistic traits, which can occur outside of a person’s awareness, yet require sustained effort, particularly in response to the increased social demands during the lead up to a loved one’s death and in the immediate period following. Participants described the cost of suppressing stimming which is commonly perceived as socially inappropriate and necessitating concealment. This is in keeping with the first-person accounts of autistic adults’ experiences and views on stimming in a qualitative study by Kapp et al. (2019) in which stimming suppression was also described as “depleting” (p.1788). The potential deleterious health and wellbeing effects of camouflaging or masking for autistic people is documented in existing literature (e.g., Hull et al., 2017; Lawson, 2020) and in research identifying it as a significant contributing factor in autistic burnout (Arnold et al., 2023; Raymaker et al., 2020).

All participants expressed a need for ‘time and space’ to recover from and process their bereavement related experiences. This corresponds with a theme identified by Arnold et al., (2023) in their survey of 141 autistic adults about the nature of prior episodes of autistic burnout. In the section on “characteristics of recovery, support and consequences” the authors identified a theme of “space and time” that referred to how autistic people have a need for time alone with sensory deprivation and ‘space’ to process everything.

Some of the participants experienced a lag in the emotional processing of their bereavement and described being in a shock-like state in the initial aftermath of the death. This aligns with Shear and Mulhare’s (2008) acute grief process, during which grievers alternate between confrontation with the painful reality and “defensive exclusion, in the form of numbing, focus on positive memories, imagined reunion, and other forms of respite in which attention is directed toward neutral or positive thoughts” (p. 662). Participants’ accounts in this study referred to a sense of emotions building up yet remaining largely inaccessible while individuals were attempting to process the multiple meanings and implications of the death on a cognitive level, rather than attending to neutral or positive thoughts.

Delayed grief has been largely assumed to be the result of minimisation or avoidance of grief-related distress during the initial months following a death (Bonnano & Kaltman, 2001). This assumption has led to the potentially adaptive value of such avoidance being overlooked when in fact there is evidence that “minimising the experience and expression of grief-related negative emotions” can facilitate adjustment during bereavement (Ibid). There is potentially adaptive value in delayed experiencing of emotional distress for autistic survivors, as it protects them from difficulties in concurrently processing the intense social, emotional, physical, and cognitive impacts of bereavement.

Participants found it difficult to put complex, grief-related emotional experiences into words. This could be attributable to the emotional processing difficulties of alexithymia, which has high rates of co-occurrence in autistic individuals (Kinnaird, et al., 2019). From an existential perspective, several participants experienced a feeling of ‘strangeness’ whilst grieving, particularly in the immediate days and weeks following the death. These experiences exemplify existential anxiety (Heidegger, 1927/1962), that occurs when one’s world shifts from being homely, and meaningful (heimlich) to uncanny, meaningless, and strange (unheimlich). In such moments of groundlessness, the world no longer provides a sense of certainty about one’s possibilities, and one feels estranged and self-aware. Bereavement, as a confrontation with death and finitude, is one of Jasper’s (1927/1997) ‘boundary situations’ that invokes existential Angst, fear without a concrete object. Jaspers gives an example of such an atmosphere of unattached feelings:

> The environment is somehow different – not to a gross degree – perception is unaltered in itself but there is some change which envelops everything with subtle, pervasive and strangely uncertain light. A living-room which formerly was felt as neutral or friendly now becomes dominated by some indefinable atmosphere (p.98)

The above description of an experience of the ‘uncanny’ bears a striking similarity to Gillian’s account of being in her grandmother’s house on the day she died, where it “didn't feel homey anymore”, and it was “like the light had gone out the house”. Most of the participants spoke about this ineffable strangeness following bereavement, demonstrating that they were likely experiencing fundamental anxiety, or the ‘uncanniness’ of not-being-at-home in familiar environments that Heidegger considered the “essential trait of human beings” (1942: 89).

5.2.2 Group Experiential Theme 2 – Marginalisation: the sociocultural context of autistic grief

Autistic survivors bring their marginalised histories, sense of internalised difference and expectations of negative evaluation, and experiences of not being seen or understood into their bereavement-related experiences. Autistic people are in the neurominority, and abuse and silencing are pervasive themes in their lives (Bascom, 2012). All participants described experiences of discrimination or referenced the stigma of autistic group identity which is perceived as a shortcoming that disqualifies autistic people from full social acceptance (Goffman, 1963).

Identity management through concealment, or “passing” has long been recognised as a way of managing “undisclosed discrediting information about self" (Ibid: p.42). Sara and Gillian described masking to avoid feeling shame about not meeting the neurotypical standards of the dominant cultural group. They also hid their autistic identity and atypical grief reactions to avoid negative consequences in social encounters through masking or camouflaging which are acts of resistance to social oppression in a social world that threatens their sense of safety (Kanuha, 1999). Although passing is intended as protective, it is usually disabling in itself and “sometimes destroys, the self it is meant to safeguard” (Leary, 1999: p.85). This was also echoed by some participants in their accounts of the struggle to re-connect with their sense of self after the intensity of the first weeks and months of increased masking following their bereavements.

Most participants described histories of abusive relationships and victimisation in addition to an increased sense of vulnerability to, and experiences of, victimisation as a direct result of their bereavements. The experience of abuse perpetrated by someone they know is common for autistic people, something that has been evidenced in a recent qualitative study and report by Pearson et al. (2022) that explored autistic adults’ experiences of interpersonal violence and victimisation (IPV). Their findings suggest that between 50-89% of autistic people have been victimised by someone they know and that poor mental health outcomes are related to the high prevalence figures. The trauma of victimisation led to autistic people concealing or masking their minority identity which was exhausting and led to burnout.

According to Meyer’s (2003) minority stress model, IPV and the victimisation described by participants in this study are examples of ‘distal’ stressors which refers to objective, external prejudice events that occur at an individual and structural level. The second type of stressor described by this model is ‘proximal’, referring to the more subjective stress processes that relate to self-identity. As per the minority stress model, the social and personal meanings attached to being autistic provoke varying protective responses from individuals that include vigilance in interactions with others (expectations of rejection), hiding their identity for fear of harm (concealment), or internalising stigma (internalised ableism). Autistic individuals, as members of a stigmatised social category, are therefore exposed to excess, ‘minority stress’ related to stigma and prejudice resulting from their minority societal position and stress (Ibid).

The minority stress model was formulated by Meyer (2003) to explain mental and physical health disparities for sexual and ethnic minorities while Jóhannsdóttir et al. (2021) have investigated the “physical and psychological strain of navigating a world designed for and run by nondisabled people” (p.373). They argue that internalised ableism is a health and wellbeing issue that begins early in an individual’s life. Some people, like Gillian for example, are raised in families that identify with dominating ideas and echo such discourse to children. This is implicated in the person’s development of feelings of unworthiness and disconnection that results in “core shame identity” (Ashley, 2020: p.5). Characteristic of core shame is a fear of exposure as flawed or deficient. A person might then experience a loss in self-empathy in inhospitable environments. Micro-aggression and micro-invalidation (through looks, words, or actions), “even if it's unconscious bias” (Sara), can lead to self-blame and contribute to the internalisation of ableism (David, 2013). The marginalised individual harbours inside themselves, “the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure” (Mason, 1992: p.27). This resonates with Gillian’s metaphor of “little sticks”. The consequences of such internalised oppression has been likened to emotional abuse for its deleterious effects on self-esteem and self-respect (Reeve, 2014).

Sartre’s existential, being-oriented theory provides a perspective on “why a person might substitute the distortions of others for his or her own reflections on self” (Cannon, 1991: 145).

Sartre’s ‘being-for-others’ is an ontological category (as are the world and consciousness) that is part of our being (Sartre, 2003/1943). We come into being through the gaze of the other and we only gain knowledge that others have consciousness through this experience of being looked at by them. Being looked at can produce shame; the other is free to look at us and describe us truly or falsely as a thing laid bare and we feel the embodied experience of ‘the look’ as a kind of fear. The other makes us a thing-like object and we are tempted to accept their labels and adopt their view of us in place of our own, this avoids the anguish of experiencing our existential freedom. In an ableist society, the look of the other is often that of the perfect, abled body through which everything is decided from the “nondisabled gaze” (Hughes, 2000).

Botha and Frost (2020) have recently reported a survey study of 142 autistic participants providing preliminary support for the usefulness of extending the minority stress model to understand psychological distress, health and wellbeing issues faced by autistic people. They found that diminished well-being and heightened psychological distress were consistently predicted by minority stressors such as victimisation and discrimination, everyday discrimination, expectation of rejection, outness, internalised stigma and physical concealment of autism. Examples of all the above minority stressors were described across the participants’ accounts providing the context to their experience and sense-making of bereavement. Following bereavement, it seems plausible to suggest that the unique and additive negative effect of minority stress on health (Frost et al., 2015, Botha & Frost, 2020) means that autistic people are charged with navigating the challenges of one of life’s most stressful events from a place of disadvantage in terms of existing demands on their resources.

Minority stress has the potential to exacerbate the stress and demands of bereavement. The participants in this study who described greater minority stress, also described greater distress in the aftermath of the death of somebody close. With a small sample in an idiographic study, it is not possible to draw conclusions, but the significance of the minority context of the participants and all autistic survivors ought not be overlooked. This is particularly so for those autistic survivors who engage in masking to conceal their autistic identity, as discussed above.

Several participants described how the full depth of their grief was not visible to those around them and that sometimes they felt they did not have the right to grieve as deeply as they were. Sara described being caught in a ‘catch 22’ situation, where outing herself as autistic risked “getting other assumptions and prejudices that I lack empathy and therefore can't be that upset that my mum has died” when in fact she felt “distraught”. Or where concealing being autistic risked her grief not being fully acknowledged or understood. All the above fit the experience of disenfranchised grief:

> …that results when a person experiences a significant loss and the resultant grief is not openly acknowledged, socially validated, or publicly mourned. In short, although the individual is experiencing a grief reaction, there is no social recognition that the person has a right to grieve or a claim for social sympathy or support (Doka, 2008: 223)

Stereotypes of autistic people as cold, lacking empathy and not being relationally motivated compound the likelihood that autistic grievers are not recognised as capable of grieving which disenfranchises their grief further. Marginalised autistic grief can be invisible, and the feeling of being invisible can equate with the sense of not mattering (Flett, 2018). According to Flett, (Ibid) the death of an important person of an autistic individual, has the potential to be a “critical incident” due to the “stress and distress involved when a person transitions from mattering a great deal to no longer mattering or not mattering as much as before” (p.17). The sociocultural context of autistic survivor’s grief does not foster a sense of mattering for autistic adults. In Luke’s account he described how he successfully transitioned from mattering immensely to his mother, to adopting a positive autistic identity as a gifted person. For other participants, this transition was harder to accomplish.

The participants’ awareness of their areas of difficulty and perceived shortcomings was evident in the analysis of their accounts. There was concern for being helpful, considerate, and wanting to ‘get it right’. Cultural norms create an environment where autistic people are socialised with dominant beliefs that they are ‘mentally disordered’ and that who and how they are is wrong or deficient. This is captured in the following extract from an autistic writer’s blog:

> Autistic people with strong senses of right and wrong are not perfect. Of course not. Which actually makes it harder [...] I am hyperaware of my actions and desperately try to do the right thing all the time. Usually resulting in allowing myself to be vulnerable and manipulated to others benefit.
>
> It is easy to convince me that what I have done is wrong, because I am so desperate to do right.
>
> At the same time if there is doubt in my mind if an action is ‘right or wrong’ then I will veer towards wrong, and not do it, in fear of ever doing something unacceptable. I am nothing short of terrified of being a ‘bad person’ and desperate to be ‘good’ (Weldon (2021).

Autistic survivors’ sensitivity to, and concerns about, whether they are grieving in the way they ought to, or their perceived failure at adapting to loss can be viewed as compounding pre-existing self-doubt, sense of failure and low self-esteem. Some participants persisted in believing that they had not grieved correctly despite their conceptual knowledge that grief is individual. This is understandable given the sociocultural context of autistic grief and the dichotomous thinking styles of autistic individuals.

5.2.3 Group Experiential Theme 3 – Adapting to change and loss: meaning and connection

Consistent with contemporary grief theory that meaning-making is central to grieving (Neimeyer, 2001), several different ways of constructing meaning out of participants’ bereavements as part of the adaptation process were identified in the current study. For example, the importance of talking about the deceased and how participants were maintaining a relationship with them after the death including through the internalisation of positive memories of the deceased, is consistent with constructivist literature on meaning reconstruction in the experience of loss (Neimeyer, 2004; Neimeyer & Currier, 2009).

Rather than relinquishing the emotional connection with the deceased, in line with Klass et al.'s (1996) grief theory, all participants developed a continued bond that helped to support the resolution of their grief. Participants did not stop loving the people that died, instead they held memories dear, and it mattered that they continue to remember and honour the life and projects of the deceased. Attig (2001) suggests that cherishing memories and furthering the legacies of the deceased are ways that survivors "transition to lasting love" and give the deceased "symbolic immortality" (p.46). All participants in this study found reminiscing about the deceased healing which can be further understood as part of the transformation of their relationship and continued sense of closeness through 'embracing' the deceased's memory (Harvey, 1996).

Participants expressed the importance of talking about their bereavement and described preferences regarding the qualities of the listener or confidant in line with those outlined in the work of Harvey et al. (2001). For example, that the listener be someone in whom the survivor has confidence regarding their ability to listen and understand grief and loss, who can assist to reframe and generate insight, and who is caring and dependable. The importance of confiding and sharing stories about the deceased and grieving are said to be that it permits acknowledgement of the shared human experience of loss and enhances the deceased's life and contributions (Ibid). However, the findings of this study contradict those of Rime et al. (1991), who propose that people prefer to talk about emotionally intense events with those close to them rather than strangers. For autistic survivors, talking to an appropriately trained professional listener is potentially an emotionally safer option that occurs in a less ambiguous and more structured social interaction, reducing the risk of upsetting the listener.

Participants' disappointment and frustration at missed opportunities and barriers to talking and reminiscing about their loved one and their death demonstrates that for autistic survivors, as is reported in the literature:

> “Mourning is fundamentally an intersubjective process, and many problems arising from bereavement are due to the failure of other survivors to engage with the bereaved person in mourning together” (Hagman, 2001; p.25)

If grief affects are “efforts to communicate” (Ibid), and mutual misunderstandings occur in interactions between autistic and neurotypical people (Milton, 2018), it is perhaps unsurprising that in this study, some autistic grievers had unsatisfactory experiences of talking about their loss to friends and family, and even in bereavement counselling. For those participants, there was a sense of “unfinished business” (Luisa) or of finding it to harder to process the loss without empathic friendships (Gillian), supporting research that discouraging experiences of confiding can impede successful coping following stressful and traumatic life events (Harvey et al., 1991). Autistic counselling clients like Sara, can be negatively impacted or possibly further traumatised when their counsellor or therapist lacks understanding and insight into autism (Hallett & Kerr, 2020). A recent study reported that only 53% of psychotherapists had experience of working with autistic clients and merely 13% had undertaken specialist CPD in working with autism (Garrett, 2022). A survey of therapists adapting CBT for autistic clients found that barriers to therapeutic work with autistic clients can include communication issues, the need to use written and visual materials, rigidity of thinking, difficulties recognising and understanding emotions, co-occurring problems, problem identification and sensory issues (Cooper et al., 2018).

The adaptive ways in which participants constructed meaning out of loss align with the two different processes of meaning making that Davis et al. (1998) propose are predictive of emotional adjustment following bereavement: making sense of the loss and finding benefits in the loss. Participants considered their loss in the terms of their existing worldviews for example, making sense of the death as natural, predictable, or consistent with spiritual beliefs. The participants’ accounts of benefits resulting from loss are in keeping with the three categories described by Davis et al. (Ibid), that the loss i) led to a growth in character, ii) a gain in perspective, and iii) a strengthening of relationships. More recent research has found that sense making predicts better grief outcomes overall (Holland et al., 2006) and in this study, the participant who was still struggling to satisfactorily make sense of their bereavement at the time of interview, also described poorer adaptation to the event.

5.2.4 Group Experiential Theme 4 – Stories and scripts: making sense of it all

The autistic research participants in this study were ardent narrators of their experiences. They not only enacted their stories to me about what happened, who was there and what they were thinking and feeling at specific bereavement related events, but also showed a drive to weave those events into their autobiographical stories from childhood experiences through to imagined futures. Multiple short stories contributed to a broader narrative about participants' sense of who they are, consistent with narrative identity theories (Dunlop, 2018; McAdams, 2018, McLean et al., 2007).

The concept of identity as a life story, or 'narrative identity' refers to a special kind of story "about how I came to be the person I am becoming" (McAdams, 2018; p. 364). Participants expressed elements of their storied selves that were "inseparable combinations of internal representations and elements" of their "immediate and broader social and cultural milieu" (Dunlop, 2017; p. 153). In the interviews, participants reconstructed their pasts, created self-understandings, and reflected on their futures in a world without the deceased. Participants lost parts of their identity when the deceased died, in keeping with research demonstrating that major losses deeply effect people's identities (Harvey et al., 2001). As Neimeyer (2001) emphasises, loss challenges us to reconstruct meaning at every level in our lives, from the basic daily structures and routines, through our identities in a social world, to personal and collective spiritual beliefs. This meaning-making process is social and situated rather than private and individual. There is a cathartic function to storying bereavement, "Each time I tell my story it occupies less space and grief in my soul" (Downs, 1993; p.303). People pay attention to stories that they can relate to, and the process of constructing a story takes effort therefore a person needs a good reason to do so (Shank, 1990). Despite it being adaptive, the connection between narrativity and personhood and the need to construct stories may therefore pose another demand on stretched resources for autistic grievers.

Bereavement disrupts a person's self-narrative and sense of self-continuity (Neimeyer et al., 2014). One of the sub-stories identified in this study was the "Death and Dying Story" which corresponds to Neimeyer at al.'s (Ibid) 'event story' of a person's loss. The process of assimilating the event into the self-narrative assists in restoring coherence to the survivors' life stories altered by loss. From this perspective, reflecting on the back story of their relationship with the deceased is part of the construction of a continued bond with their loved one that allows them to access a healing sense of ongoing connection (Ibid; Attig, 2001). According to Hagman (2001), participants' reflections on the relationship with their loved one were part of their grieving process, through which they were transforming the meanings and affects associated with the relationship. This created a sense of continuity to the experience of the relationship with the deceased in the context of survivors' "experience of disruption in self-organisation due to the loss of the function of the relationship with the other in sustaining self-experience" (Ibid; p.24)

Within the accounts, or "storylike constructions" that participants used to explain reality to themselves (Harvey et al., 1992), scripts emerged relating to 'a good death' and 'the biological processes of death'. According to Shank (1990), "a script is a set of expectations about what will happen next in a well-understood situation" (p.7). It is possible to understand how the development of scripts can be helpful to autistic grievers as they provide knowledge on "how to act and on how others will act in given stereotyped situations (Ibid)." Participants' scripts for a good death contained themes that correspond with research on perceptions of successful dying, for example: preparation for death, pain-free status, preferences for the dying process, life completion and saying goodbye (Meier et al., 2016).

Important themes running through the participants' stories included increased existential awareness, personal growth, and vulnerability. Yalom asserts that bereavement increases death awareness and brings an existential dimension to therapy. Grief can be an 'awakening experience', making us mindful of our being (Yalom, 2011). This is a view shared by Young (2009), who notes how the theme of facing up to our mortality recurs in bereavement work, "the death of another can bring us face to face with our vulnerability and mortality" (p.169). Yalom (2008) gives the example of losing a parent and how it brings us in contact with our vulnerability, an experience that several participants reported in this study.

Maintaining self-continuity relies on autobiographical memory. Impaired meaning-making capacity, lower clarity of self-concept and less coherent identity has been reported in autistic adults (Berna et al., 2016; Coutelle et al.,2020). Evidence for deficits of episodic autobiographical memory in autistic adults has been conflicting. For example, Crane & Goddard (2008) found personal episodic memory deficits and a "distinctive pattern of remembering" for autistic adults. Coutelle at al. (2021) on the other hand found no such deficits in their more recent study.

This study did not assess or measure participants' memory function. However, it was noted in the analysis that most interviewees were able to recall memories when given sufficient time but struggled with sequencing bereavement related events. Creating accurate linear chronological sequences for events was important to participants and frustrating when difficult to do so. This finding aligs with the literature suggesting that creation of coherent narratives relies on the ability to establish temporal, biographical, causal, and thematic coherence (Habermas & Bluck, 2000). Problems with these competencies impinge on the formation of narrative identity (Ibid). Causal coherence refers to explanations of a person's behaviour. Several participants struggled with this. For example, Luisa told me she never held grudges but did not understand the cause of this trait. Marco was unsure whether the stress of the conflict surrounding the legacy project was related to bereavement when it appeared to be directly connected to his grieving process and continued bond with the deceased (Attig, 2001, Doka & Martin, 2010).

A potential explanation for the above frustration and uncertainty expressed by participants could be that it related to the obstacles in creating coherent narratives and self-understanding for autistic adults that made it harder to “reach a sense of completion” (Harvey et al., 1992; p.104) about their post-loss stories. Autistic adults who use masking as a social strategy may also encounter challenges creating a cohesive self-concept post loss as bereavement poses an increased number of ‘onstage’ social demands, disrupting the development of their ‘offstage’ identity (Goffman, 1959). There is also some evidence that individuals with less certain world assumptions, including lower self-worth, may be more likely to face difficulties following bereavement as the loss potentially provides further evidence of the unpredictability and injustice of life (Currier, et a., 2009). This appears pertinent for Gillian, who struggled with how it “never feels fair to lose a family member”. Having a marginalised identity means that autistic grievers are perhaps more vulnerable to this risk.

Constructing the biography of the deceased was an important part of participants’ grief process and they were especially interested to discover, hear and research previously unknown biographical information. Participants grappled with describing how this was part of a process of attaining some kind of resolution to their bereavement experience and a need for closure. This could be understood an expression of autistic survivors’ enhanced desire for conclusive answers to questions and attenuation of ambiguity (Kossowska et al., 2015) borne from cognitive inflexibility. It could also relate to the importance of the kind of meaning making described by Frankl (1969), which is reached on an emotional level bringing a sense of inner peace.

The connection between embodied meaning making and biography construction is similar to Attwood’s (2007; p,.190) account of how an autistic “child or adult may collect information on a topic that is causing emotional distress or confusion, as a means of understanding a feeling or situation". While this is calming and healing, Attwood also cautions that the interest could rise to a level that is "no longer pleasurable or of intellectual psychological value" (Ibid). This is in keeping with bereavement studies that indicate that an unremitting search for meaning can be a sign of prolonged distress, especially if the survivor is attempting to make sense of their loss through ruminative coping (Davis et al., 2000; Nolen-Hoeksema, 2001).

According to Walter's (1996) biographical model of grief, the participants' desire to talk about the deceased with those who knew them was connected to finding an appropriate place for the deceased in in their ongoing life. Walter proposes that needing "to gain an accurate picture of the deceased" (p.13) and constructing an enduring biography for them, is the central task in grieving. Survivors write the 'last chapter' of the deceased's life in eulogy or informally construct it between family and friends in terms of "what the deceased was actually like, what they actually did and how they actually died" (p.19). Walter suggests that this is achieved mainly through conversation and that it is the social sharing of biographies that brings about adjustment to loss. Several participants in this study described obstacles to conversations and preferred other methods. Participants' methods accord with Attig's (2001) 'relearning the world' theory of meaning-making in grief which encompasses learning "more about those who died through researching their lives, exploring diaries, letters, and other records" (p.47).

Walter (1996) is critical of traditional grief models whereby grief is the working through of emotion and by extension, he argues against the emphasis on 'emotion work' in bereavement counselling. Doka & Martin (2010) also warn how an insistence on talking and exploring feelings makes a single dimension of the varied grief responses the primary way to respond. The grief responses of the participants in this study could be categorised into the patterns suggested by Doka & Martin (Ibid). Intuitive grieving is an emotion-based coping style and 'intuitive grievers' are said to experience grief as feelings that are openly expressed. 'Instrumental grievers' talk about their loss but not in emotional terms and experience grief more cognitively and physically. ‘Dissonant grievers’ experience grief one way but struggle to find ways to express and adapt to their loss due to constraints (e.g., social, familial). For example, Gillian responded to loss with intense emotions that she repressed. Many people are ‘blended grievers’, a combination of both emotional and cognitive responses.

All the participants responded in ways that fit the characterisation of instrumental grieving insomuch as they responded behaviourally, expressing grief by reminiscing and talking about the deceased or through “immersion in some kind of activity” related to their loss (Doka & Martin, 2010; p.9). Instrumental grievers are said to be more likely to have their grief reactions disenfranchised as ‘talking and doing’ and thinking through one’s grief are not always recognised as expressions of grief as Western cultural norms persist with the display and expression of emotions as the appropriate reactions to death.

5.3 Clinical implications

This study aimed to explore the experience of bereavement from the perspective of autistic adults. The findings highlight that autistic survivors share grief reactions that align with existing grief research and that practitioners will be familiar with encountering in counselling psychology and psychotherapy practice. However, autism specific grief reactions, styles of grieving and barriers to accessing support identified in this study can inform the following recommendations for practice. The term ‘therapist’ will be used to refer to psychologists, psychotherapists, and counsellors.

The demands on autistic survivors following bereavement may increase the risk of autistic burnout and strategies for education, prevention and recovery are recommended. Therapists and other professionals such as GP’s need to be familiar with the signs of autistic burnout and its relevance to grieving autistic individuals. Awareness of autistic burnout is important for professionals, friends, family, and employers of autistic survivors including the understanding and respecting of the autistic person’s need for ‘time and space’ to recover following bereavement. Sensory issues may increase following bereavement and care is required to create autism friendly therapy spaces as well as in hospitals and palliative care settings. Bereavement and hospice settings could consider making leaflets available with accessible information on the biological processes of death and dying. It is also important to provide therapeutic spaces and relationships in which autistic clients do not feel the need to mask and where they are explicitly invited to stim or request accommodations.

The findings highlight the danger of referring to or endorsing stage models of grief for autistic survivors as they create unhelpful and potentially harmful expectations. Autistic survivors may use bereavement related scripts to process their loss and if their grief process or aspects of death and dying do not match the script this may cause distress, self-criticism, and rumination, and disrupt the recovery process. The practised model of therapy ought to be neurodiversity-affirming, ensuring that it does not reinforce a medical model perspective that could lead to the autistic survivor feeling as if they need to be fixed or are failing. Caution is advised when engaging in therapy interventions that heavily emphasise the traditional paradigm of working through feelings in grief counselling. Therapeutic questions could focus on, “how did you react or respond”, rather than, “how did you feel”? The autistic survivor’s individual grief responses and processing style need to be validated and therapists are recommended to be reflexively aware of their own biases about grief.

Supporting survivors with further knowledge regarding how aspects of bereavement are particularly challenging for autistic people may go some way in ameliorating concerns about whether they are grieving the ‘right way’. This would be similar to how the adults in Young et al.’s (2008) study, who after receiving a late diagnosis of ADHD, fostered greater self-acceptance and less self-blame about problems they had faced. This helped them to shift the internal attribution of personal responsibility for their difficulties to the external attribution of neurodiversity as the explanation.

Borgona and Aita (2023) propose that clinicians consider minority stress processes as relevant to formulation and treatment planning with sexual minority patients. As minority stress processes are also relevant to autistic clients (Botha & Frost, 2020) and bereavement presents potentially marginalising demands, I suggest that these processes are also considered when working with neurominority grievers and "at a minimum providers need to be mindful of their own role within existing social power structures" (Borgona & Aita, 2023; p.8).

This study demonstrates that the assumptions of social constructionist accounts of grief and narration of meaning can be applied to autistic individuals' grief processes. The power to own and tell a personal story is a fundamental human capacity (Coles, 1989). The significant role that narrative processes played in this study points to the utility of narrative interventions in grief therapy and bereavement instigated counselling or psychotherapy for autistic adults. Storytelling is central to both stability and change in one's sense of self (McLean et al., 2007). Following bereavement, practitioners might note that sharing stories and exploring dreams about the deceased, narrating emotional experiences, or searching for spiritual meanings are ways that people seek to reassert order and significance in worlds disrupted by loss (Nadeau, 1997). Therapy could include inviting the autistic survivor to talk about the deceased in as much detail as they wish and offering them the opportunity to bring photographs and mementos to sessions to talk about. Drawing genograms with clients might also be a productive and satisfying joint exercise.

Autistic people might find it easier to open up to a professional about problematic grief or about any other problems of living, rather than seek support from people in their family or social network. This means that access to professional support has a potentially significant role to play in supporting autistic people's grief recovery and wellbeing. Access to autism specific services and support agencies also have a role to play in extending support networks, especially when survivors are bereaved of their parents and might be lacking safe spaces and sources of trusted and reliable guidance and support. Neurodiversity training is recommended for therapists working not only with autistic survivors but also more broadly as part of all counselling psychology and psychotherapy core trainings, as well as specialist supervision (Cooper et al., 2018).

5.4 Strengths and limitations of the study

There is currently little to no extant research into this important topic, making this study one of the first to qualitatively examine how autistic adults experience bereavement. Autism and neurodiversity is also an under-represented area in counselling psychology. Men have historically been overrepresented in autism research and in this study three of the participants were women. Autistic advisers were engaged at the planning stage of the study, to provide their insider perspectives of the interview schedule and procedures. Participants provided rich data highlighting the particular and unique challenges posed by bereavement for autistic adults. The findings offer several clinically relevant and timely recommendations for practice and areas for future research, enhancing the validity of the study:

> "…the real validity lies in whether it tells the reader something interesting, important or useful" (Smith et al., 2009; p.183).

Individuals were excluded from participation if they had learning disabilities and other co-morbidities when it is common for autistic people to have comorbidities (Al-Beltagi, 2021; Fombonne, 2003) which is a limitation of the study. I was also unable to independently verify participants' autism diagnosis. However, only participants who reported receiving a formal diagnosis from a healthcare professional were included in the sample.

Self-selected participants were all verbally articulate and the recruitment criteria might have precluded or discouraged autistic individuals with different autism profiles from taking part. This is likely to have created "elite bias" in the data (Miles & Huberman, 1994) which is an unfortunate and frequent characteristic of qualitative research. Also typical of other qualitative research, the small sample size limits the generalisability of the findings. The sample comprised of five participants and six data points which is at the lower end of the range of sample sizes commonly employed in doctoral IPA studies. The decision about the sample size was taken to enable an in-depth analysis and reflective process that would otherwise not have been achievable. As McLeod specifies:

> “Small-scale qualitative research offers nuanced narratives of autistic lives that cannot be captured by purely quantitative means” (McLeod, 2019: 60).

One of the autistic advisers, an experienced researcher and academic, also advised that it was preferable to go in-depth, with a small number of people.

5.5 Further research

The current study has provided preliminary findings in previously unchartered territory and identifies several fertile directions for future research. Research focused on each of the identified themes could be carried out. For example, further exploring the relationship between autistic burnout and bereavement, extending the minority stress model to understanding adjustment to grief or the comparative study of narrative reconstruction processes for autistic and non-autistic survivors. Research exploring autistic adults’ experiences of bereavement counselling would complement studies of bereavement and grief. The lived experience of traumatic bereavement for autistic adults would also be a worthwhile area of enquiry. Future studies could include mixed methods research using surveys, scales of adjustment to grief together with semi-structured interviews.

Further IPA studies of bereavement could be conducted with different participant groups, including autistic participants with learning difficulties. It may also be of interest to explore the bereavement experiences of survivors with a diagnosis of ADHD with or without comorbid autism when between 30-80% of autistic people fit the criteria for a diagnosis of ADHD and both conditions originate in part from similar heritability factors (Rommelse et al., 2010).

Future research could utilise visual methods, with participants invited to bring photographs to interviews or write about their experiences and qualitatively analysing the resulting texts. This would make participation more accessible to autistic adults who are less verbally able or feel discouraged from participating in research because of the social interaction involved in the interview process. This type of research could also be more autistic led than the current study or better yet, designed to be fully co-produced with autistic co-researchers.

5.6 Summary and conclusions

Bereavement is one of the most stressful and life changing events that a person will experience, confronting us with the existential task of coming “to terms with the great mysteries of finiteness, change, imperfection, uncertainty and vulnerability” (Attig, 2001; 45). It means the irrevocable loss of a loved one, the disruption to daily and life routines, breaking the continuity of one’s life story and sense of selfhood. Grieving is an unpredictable, ambiguous, and individual process that is emotionally and physically intense and without a definitive end. Bereavement, grief, and mourning are social phenomena and when a loved one is dying and dies, there are also social, financial, and practical tasks to be done. These combined characteristics of the experience of bereavement pose significant challenges for autistic survivors who are already burdened with the stress of living in an unaccommodating neurotypical world, and who struggle to accept uncertainty, unpredictability, and categorical uncertainty (Murray et al., 2005).

Autistic survivors bring their marginalised histories, sense of internalised difference and expectations of negative evaluation, not being seen or understood into their bereavement-related experiences. Autistic people can experience disenfranchised grief when their grief is misunderstood, concealed for self-protection, or considered outside of societal norms of grieving. The autistic person's embodied experience of grief can be intense, including heightened sensory issues, the multiple costs of increased masking, and the potential for autistic burnout.

Talking and doing are valid grief processes and storying the bereavement in different ways is a fundamental part of the healing process for autistic people who are reconstructing their post loss identities in the wake of death. Finding a place for the deceased in the survivor's ongoing life by reflecting on the deceased's life, death, and legacy, is helpful to autistic grievers in maintaining a sense of connection with the person who has died and creating a cohesive sense of self. It is imperative that more research is undertaken in this area, putting autistic voices front and centre, and finding ways of creating safe spaces and relationships that invite autistic people to talk about their grief with the freedom to express and be who they truly are.

This in-depth study is written from a hermeneutic phenomenological perspective with IPA as the emergent research method. The flexibility of this approach and of semi-structured interviews allowed participants to co-create their accounts of bereavement with me and in doing so lead me to the issues that genuinely concerned them. My hope is that this research can be part of the movement toward:

> …reframing of autism itself from a social communication disorder to a description of a broad range of developmental differences and embodied experiences and how they play out in specific social and cultural contexts (Milton et al., 2022; p. 1902)

As Milton suggests when writing about the concept of the double empathy problem, the findings of this study has aimed to emphasise taking "a position of humility in the face of difference, the need to build rapport and understanding and not assume a lack of capacity for understanding", reminding "us of the social situatedness of the lives of autistic people and those who support them" (Ibid.).

5.7 Final reflections

Borne out of my personal experiences of grief, loss and a concern for my autistic sibling, this research is undeniably meaningful to me, but it also feels genuinely timely and important. The discourse around autism has come a long way since the beginning of this project. Whilst it has taken true grit and determination to see this research through to the final stage, at this juncture I am able to appreciate that the study is improved for the delays in the process. The neurodiversity movement and the growth of autistic self-advocacy have stimulated new ethical, theoretical, and ideological debates within autism theory, research, and practice (Leadbitter et al., 2021).

Of course, when I dispassionately refer to “delays in the process”, I’m really talking about my mother’s untimely death that occurred whilst I was in the final stages of obtaining ethical approval for the study. It was a seismic event in not only my life, but also my autistic sister’s life. I am not the person I was when I wrote the research proposal; suffering and loss transforms us and deepens our capacity for compassion and empathy. I have walked the fine line between drawing on these life experiences as a useful resource and contaminating the findings. Storying happens in dialogue and in taking the role of listener, I am the co-author of the accounts in this study.

When I look back at what I thought I knew about what it means to be autistic, I realise how little I actually understood, how much I have learned, and how far I still have to go. If one thing has not changed throughout this process, it is my belief that autistic people are “complete, complex, human beings leading rich and meaningful existences and deserving dignity, respect, human rights, and the primary voice in the conversation” about them (Bascom, 2012: p.10).

Having read the literature, written this thesis and spoken in depth with autistic survivors, what is missing from the dominant narrative is how much autistic people care about what others think and feel. Autistic people, like all humans, are hardwired for attachment and belonging, we are all fundamentally the same. The lifeworld matters to autistic people. Reflecting on the participants' interviews, words that come to mind are caring, articulate, kind, curious, helpful, generous, loving, insightful, existentially aware, humorous, open, and conscientious. But the word I'm left with most is "integrity". The autistic people I met on this journey have integrity; right and wrong matters, they value wholeness, completeness, and fairness. They desired their bereavement stories to have integrity, that their actions had integrity. The integrity of their worlds and sense of self shattered when their loved ones died. This is nothing like the objectified, stereotypical tropes of autistic people that 'scientific' research has manufactured. I have loved and cared for an autistic person most of my life, so this is not exactly news to me. But now I realise how important and great a task it is to communicate the importance of seeing the bigger societal picture, the inherent politics of every individual interaction in the creation of the cultural 'other'.

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7. APPENDICES

Appendix 1 – Ethical Approval

NSPC

NEW SCHOOL OF PSYCHOTHERAPY AND COUNSELLING
NSPC Limited
Existential Academy
61–63 Fortune Green Road
London NW6 1DR

Jo Pang
Wroxham
Norfolk

11 March 2021

Dear Jo

Re: Ethics Approval

We held an Ethics Board on 11th March 2021 and the following decisions were made.

Ethics Approval

Your application was approved with no conditions.

Please note that it is a condition of this ethics approval that recruitment, interviewing, or other contact with research participants only takes place when you are enrolled in a research supervision module.

Yours sincerely

Claire Arnold-Baker

Claire Arnold-Baker, Chair of NSPC Ethics Committee

Appendix 2 – Participant Information Sheet

NSPC Ltd
Existential Academy
61-63 Fortune Green Road
London
NW6 1DR

Middlesex University
The Burroughs
London
NW4 4BT

Research Project Information Sheet:

Understanding how Autistic Adults Experience Bereavement: An Interpretative Phenomenological Study

Research study being carried out by:

Joanna Pang as a requirement for a Doctorate in Counselling Psychology and Psychotherapy by Professional Studies from NSPC and Middlesex University

Dated: January 2023

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

<u>What is the purpose of the research</u>?

This study is being carried out as part of my studies at NSPC Ltd and Middlesex University. You are being invited to take part in this research study about how people with a formal diagnosis of autism experience bereavement. This means it is about what it is like when a loved one dies, from the perspective of autistic adults whose bereavement occurred between twelve months and ten years ago. These experiences have not yet been explored in autism research, yet everybody will experience bereavement at some point in their life. This study will help professionals and the community understand autistic adults better.

What will happen to me if I take part?

This study involves an online webcam interview with one person at a time. If you decide to take part, we will arrange a Zoom meeting so that I can ask you for some background information about yourself then conduct the interview with you. You will be asked to talk about your experiences of bereavement. A copy of some example interview questions will be emailed to you before you take part so that you will have an idea of what to expect. You are free to bring any notes or drawings in with you if that helps you to talk about your experience. If your preferred way of communicating is in writing, you may wish to type a written account of your experience to send to me then we will discuss it together in the interview.

The Interview will take place from your home. To take part you will need to have access to a quiet, confidential space at your home as well as reliable and secure internet connection and a suitable device such as a laptop, iPad, or computer.

The interview is expected to last around one hour and no more than 90 minutes. For some people the time taken may be less than this. You may stop the interview any time you want to. If you need to get up and move around during the interview to feel comfortable, that is fine. You're also welcome to have a stim toy or any sensory aid with you that will help you to feel calm and focused in the interview. Breaks will be offered during interview if you feel you need them. Once we have finished the interview, there will be time to think about the interview and what it was like for you to talk about your experiences with me. You may ask me any questions you might have about the study. You are free to contact me with any information you feel you left out or need to correct, for up to one week following the interview.

What will you do with the information that I provide?

I will be recording what we say in the interview on a digital audio recorder. The recording will be transferred onto an encrypted USB stick and deleted from the recorder. I will make sure the file is kept safe on until it has been typed up. When it is typed up, your full and last name are removed and identifiable details are changed. The interview will be transcribed by another person who will not be able to identify who you are. All of the information that you provide me will be identified only with a project code and stored either on the encrypted USB stick, or in a locked filing cabinet. I will keep the key that links your details with the project code in a locked filing cabinet.

I will use a qualitative research method to extract the main themes of what you and other people tell me about their experiences of bereavement. Information gathered from this study may be presented in publications (a counselling psychology doctoral thesis, related journal and magazine articles, books or chapters in books, online blogs and posts) or at scientific meetings. However, I will not use your name or any identifying information about you so that your data is as anonymised as possible. Some of your words from the interview will be quoted directly.

The study data will be kept for ten years and will be treated as confidential. Although it is very unlikely, should you tell me something that I am required by law to pass on to a third person, I will have to do so. For example, if you are at serious risk of harming yourself or others or if there are concerns for the safety of children. Otherwise, whatever you tell me will be confidential.

Data will be stored according to UK General Data Protection Regulation (GDPR).

What are the possible disadvantages of taking part?

There are no physical risks of taking part, but you will be talking about experiences that might be upsetting to think about. If you do become upset or wish to stop the interview for any reason, please let me know and we will stop. You can let me know by raising a hand up if that is easier than telling me verbally, and I will understand that you wish to stop the interview.

What are the possible benefits of taking part?

There are no direct benefits to taking part. Some people see the interview as an opportunity to reflect on their experience of bereavement with someone who is good at listening and may find this beneficial.

Consent

You will be given a copy of this information sheet for your personal records, and if you agree to take part, you will be asked to sign the attached consent form before the study begins.

Participation in this research is entirely voluntary. You do not have to take part if you do not want to. If you decide to take part, you may withdraw at any time without giving a reason. Should you decide to withdraw from the study, this will not in any way affect your access to treatment and support from your local autism services.

Who is organising and funding the research?

This research is not sponsored by an external body. I am doing this research as part of the requirements for a Doctorate in Counselling Psychology and Psychotherapy by Professional Studies from NSPC and Middlesex University.

Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study

Expenses

Any travel or incidental expenses that occur as a result of participation will not be refunded.

Thank you for reading this information sheet. If you do decide to take part in the study, please contact me directly to discuss a suitable time and date for the interview.

If you have any further questions, you can contact me at:

Jo Pang

NSPC Ltd, 61 – 63 Fortune Green Road
London NW6 1DR
jp925@live.mdx.ac.uk

If you any concerns about the conduct of the study, you may contact my supervisor:

Dr. Chloe Mitchell
NSPC Ltd, 61 – 63 Fortune Green Road
London NW6 1DR
office@nspc.org.uk

Or

The Principal
NSPC Ltd. 61 – 63 Fortune Green Road
London NW6 1DR
office@nspc.org.uk
0044 (0) 20 7435 8067

Appendix 3 – Interview Schedule

Interview Schedule

Section 1 – Background and rapport building:

1. Could you describe what your relationship with the deceased was like?
2. What would you like to share about the circumstances of their death?

Section 2 – Setting the parameters of the interview, the co-researcher's experience:

1. How would you describe what bereavement is?

   Prompt: Any words or images that come to mind? Can you tell me about experiences you've had that support this idea?

2. What was your experience of bereavement?
   Prompt: Looking back - how do you feel about this bereavement now? How was your experience similar or different to your expectations of bereavement?

Section 3 – Other possible areas for discussion, if relevant:

1. How has this bereavement affected your life?

   Prompt: How have things changed? How have you adapted to your loss?

2. Can you describe how this bereavement has impacted you personally?

   Prompt: How have you been physically/emotionally? Any effect on your mental well-being or sensory difficulties? Immediately after/in the first weeks after their death and longer term – how is it to live with the bereavement now?

3. What has been helpful/unhelpful for you in managing this experience of bereavement?

   Prompt: What are your ways of coping with bereavement? What did you need following your bereavement? What's been the hardest thing about this? What advice would you give to someone going through a bereavement?

4. How understood by those around you have you felt?

   Prompt: What social rituals or traditions took place and how did you experience them (give examples: wake, funeral)? What was expected of you? Can you describe how you perceived the those around you to be responding to the death?

5. How would you say this person’s death has affected your outlook on life, if at all?

   Prompt: Changes to how you think about life/death/relationships? Any affect on how you choose to live your life following this experience? How do you perceive the future following this loss? What positives, if any, have come from this experience?

General questions and prompts:

- I’m interested to hear as much detail as you can remember.
- What was it was like for you when…?
- Can you tell me a bit more about that?
- And what did you think about that?
- How did you deal with those thoughts and feelings?
- Is there an image/picture in your mind as we talk about…? Could you describe it?
- Is there anything else you would like to add?

Appendix 4 – Consent Form

Middlesex University School of Science and Technology
Psychology Department
Written Informed Consent

Title of study:	Understanding how Autistic Adults Experience Bereavement: An Interpretative Phenomenological Study
Academic year:	2020-2021.
Researcher's name:	Joanna Pang – JP925@live.mdx.ac.uk
Supervisor's name and email*:*	Dr. Chloe Mitchell - office@nspc.org.uk

- I have understood the details of the research as explained to me by the researcher and confirm that I have consented to act as a participant.

- I have been given contact details for the researcher in the information sheet.

- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from participating in the project at any time without any obligation to explain my reasons for doing so.

- I understand that I can ask for my data to be withdrawn from the project until data analysis begins. Data analysis will commence one month from the date of interview.

- I further understand that the data I provide may be used for analysis and subsequent publication and I provide my consent that this may occur. Specifically, the publications include the researcher's Counselling Psychology doctoral thesis, related journal and magazine articles, books or chapters in books, online blogs and posts.

- In addition, I consent that the data collected may be transcribed by a professional agency which is bound to confidentiality and my data will be held with strict adherence to confidentiality in encrypted form.

____________________________ ____________________________
Print name Sign Name

date: ___________________________

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ___________

Appendix 5 – Example single case analysis

PET	Subtheme	Statement	Transcript	Exploratory Notes
The additional burdens of bereavement for autistic adults	Heightened sensory sensitivities and social demands	Hospital environment: challenging for an autistic person with sensory sensitivities	the **beeps that the sound of the beeps from those machines stayed with me for weeks** afterwards. And if any noise like that came up on the telly, **I just went into such a state**,	"sound of the beeps" haunted her after the hospital - auditory flashbacks, sound "stayed with me". Went "into such a state" when triggered by similar sounds - re-experiencing the distress from the experience of the hospital room etc. At the time/in the hosp she appeared outwardly calm but afterward with the flashbacks she wasn't.
Navigating grief in a hostile NT world: Forced underground	Masking - the cost of conformity	Oppressed and violated by NT social norms: hugging was distressing because of sensory & social interaction difficulties	the **hugging**, because people think they're being kind by hugging. Yeah, **I don't want it. And I didn't feel that I could say I don't want that.** So when people her friends came to visit and all that and the nurses **were hugging and I just wanted to push people away and I didn't think that I could** and I also.	Felt there's no choice but to conform to NT social norm of hugging. Unable to disclose ASD or to state her needs with friends or hospital staff. Also something like sense of being trapped in this situation/description - similar to the dream of being trapped in the room. Trapped socially, no way out? Violated. Language brings to mind similarities with a description of sexual assault or abuse and feeling of captivity.
Navigating grief in a hostile NT world: Forced underground	Dilemma and risk in disclosing autism diagnosis	Reservations about disclosing being autistic mean that personal boundaries are transgressed	I was diagnosed at that point, and **I didn't feel that I could tell the nurses that that I'm autistic and, you know, please don't hug me and just be wary that I might need space because, A), I didn't think they'd understand. And B), I thought, well, it's it's my mum they're looking after, not me. So. So I just sort of put up with it. But it was really, really hard.**	Lack of perceived understanding from NT staff/friends about ASD and that her needs weren't the priority/important enough to be expressed and cared for. "But it was really, really hard" - she emphasises the words here but it's hard to express how hard this was, words can't fully sum this up. Gruelling. Unable to maintain her boundaries, "I might need space".

Appendix 6 – Table of group experiential themes with illustrative quotes

		Line
Group Experiential Theme 1. Impacts of change, loss, and uncertainty 1a. So much change: the gradual processing of change and loss		
Luke:	*And then the shock sort of the shock, even though, you know, they're going, they're going to pass away.*	22
Luisa:	*It's it doesn't hit as such. It's not it's not a sudden sensation of anything. And. It's something that kind of creeps in very slowly…*	152
Sara:	*I'd had such a change to my routine, not knowing what would happen next etc.*	289
Gillian:	*…I think, that hit the most the realization that this lifelong set of routines we'd always done was completely gone (..) that was the hardest hitting part.*	185
Marco:	*I felt a pretty intense sense of loss. Um. Kind of emptiness at times.*	313
1b. Depletion of resources: social, emotional, physical and sensory demands		
Luke:	*I did feel drained of energy, drained of energy.*	204
Luisa:	*I think just the the intensity of the emotion just overwhelms everything.*	361
Sara:	*And I had all of the sensory stuff, the sensory experiences of the hospital and all the interaction and everything.*	36
Gillian:	*But when the grief was on, it was literally trying to do several things at once, but completely not having the ability to. It's like juggling, but with one hand.*	406-407
Marco:	*…weird acrimony that I really didn't want to be dealing with at that time. Um, yeah. So that greatly added to the stress of it.*	83
Group Experiential Theme 2. Marginalisation: the sociocultural context of autistic grief 2a. Experiences of stigma and alienation: isolation, concealment, and shame		
Luke:	*I got a certain amount of bullying*	59
Luisa:	*It was a really unhealthy environment in the end.*	114

Sara:	*I've grown up with it, experience it, still experience it now. And you know, even if it's unconscious bias.*	243
Gillian:	*So I kind of thought anything other than acting like a pretty much a robot in public is frowned upon*	108
Marco:	*I felt quite disapproved of by him*	127
2b. Am I doing it right: internalised discrimination and subordination		
Luke:	*But I think nowadays people good people don't like to show their emotions.*	179
Luisa:	*Am I doing well? Am I?*	166
Sara:	*I didn't feel that I could. Be open. And I felt that if I if I did say something, they'd think I was making a fuss*	161
Gillian:	*I will grieve on my own. So I don't burden anybody else with my emotional outbursts…*	97
Marco:	*Well, I'm not. Quite getting to the actual question yet*	204
2c. Finding inclusion, belonging and emotional safety		
Luke:	*I still go in and sort of see them just to say hello. And when I see them, it does seem like my brother, my sister.*	213
Luisa:	*So go home to mum and dad and, you know, at least then somewhere I feel safe.*	78
Sara:	*I'm still on that journey of how to be myself and not worry about trying to fit in.*	247
Gillian:	*You know, it is okay to talk about this and it's been a really weird experience having somebody say you can talk about all the good or the bad and I'm not going to judge you for it.*	341
Marco:	*My life would have been a lot harder if I'd. Being as weird as I am, but grew up in an environment where that was seen as a problem.*	474
Group Experiential Theme 3. Adapting to change and loss: meaning and connection. 3a. Social support and the healing power of talking		
Luke:	*I basically spoke to her about my relationship with the mother, with my mother and how it all went.*	143
Luisa:	*I find it much easier to talk about with somebody who um. I guess where there is no emotional connection.*	286

Sara:	*So it's this catch 22 situation, should I disclose being autistic and risk getting other assumptions and prejudices that I lack empathy and therefore can't be that upset that my mum has died (when I was totally distraught and didn't know what had hit me), or do I conceal it and her not fully understand.*	293
Gillian:	*I'm trying to find useful, interesting ways of bringing them into the conversation without getting them upset.*	472
Marco:	*And talked about her quite a lot. You know which felt like right thing.*	314
3b. Enduring love: continued connection		
Luke:	*And when I find mother or father's writing or photographs of them, I treasure them and I put them to one side and I put them in a special place.*	134
Luisa:	*And, you know, the memories are definitely very happy ones. So I like. You know, reminiscing.*	179
Sara:	*Because my mum loved gardening and I grow some of the flowers and plants that she grew. And that is my way of connecting and remembering her.*	198
Gillian:	*It's not like she's completely gone.*	201
Marco:	*I was very concerned with. Preserving and furthering my mum's legacy.*	99
3c. Meaning-making and adaptive coping		
Luke:	*But I knew sort of from time to time, she does come back to the house.*	29
Luisa:	*Maybe that's a factor in feeling it more, becoming more aware of mortality.*	252
Sara:	*But in the end I did go right and saw some people that I haven't seen from my family and from my mum's partner's family for a long time, and that was actually quite nice.*	101
Gillian:	*I've not suffered through it for nothing.*	452
Marco:	*And all the almost all of them were people I was glad to get to spend a bit more time with.*	169

Group Experiential Theme 4. Stories and scripts: making sense of it all. 4a. Life Story: the biography of the deceased		
Luke:	*We sort of found out a bit more about mum. Then when then when she was alive, so.*	24
Luisa:	*You have your relationship with somebody and you everything you see is through that lens. And then to talk to somebody else and get their viewpoint on it is really. You know, it's interesting to hear things that you didn't know or.*	185
Sara:	*…one way of coping was to get highly focused and find out as much as I could about my mum's life, what I didn't know already.*	298
Gillian:	*I think it was just because she'd had a very tough life.*	59
Marco:	*I think it was helpful to be able to talk about her life and legacy and all that stuff.*	315
4b. Death and Dying Story: including scripts for 'a good death' and 'biological processes of death'		
Luke:	*She was cremated in a basket, not a coffin, because she was very environmental.*	76
Luisa:	*Yeah, there were a lot of people there. She was very well, very well liked.*	204
Sara:	*… they explained what actually happens in the process of death, what happens to the body (..) to me I find that helpful.*	79
Gillian:	*But there's this set series, sort of stages of what happens where you initially find out and then you have the funeral and then you have the wake.*	187
Marco:	*That's what she would have wanted as we understood it.*	225
4c. My Story: reconstructing who and how I am		
Luke:	*I've got some idea what my future holds.*	367
Luisa:	*I've not necessarily changed in myself, and I think I'm probably the same person.*	316
Sara:	*And I suppose him him dying sort of made me think about my identity.*	222
Gillian:	*…she's helped me to become a functioning member of society.*	217
Marco:	*The single person who was most like me.*	328