Portfolio Volume 1: Major Research Project

Autistic Women and Birthing People's Experiences of Baby Loss

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Abstract

Background and Rationale: Research shows the unique challenges that being autistic can pose to the perinatal period, including sensory sensitivities, pain, communication differences. Systemic barriers, such as often neurotypically designed healthcare systems and lack of practitioner awareness may contribute to this. Literature exploring autistic baby loss is more limited, but the strong sense of trauma has been noted. The unique experiences of autistic baby loss are important to explore, which this research aimed to do.

Methodology: This qualitative study used Interpretative Phenomenological Analysis to explore how six autistic women and birthing people made sense of their experiences of baby loss.

Results: Five Group Experiential Themes and 12 subthemes were constructed from the data. Participants described the unpredictability and trauma of baby loss. They described the absence of care from healthcare professionals, which left them feeling unsafe, neglected, belittled, and not believed as autistic people. Participants described how heightened autistic experiences were perceived as intensifying distress, along with strong feelings of shame, guilt, and blame, both as women and birthing people and autistic people for their loss, perpetuated by the disenfranchised, silencing and stigmatised societal discourses of baby loss. Participants described the continuous embodied physical and emotional pain and grief of being physically without their babies, and a sense that autistic grief felt different to non-Autistic grief. Finding meaning and reconnecting through continuing bonds, in more practical and tangible ways were important to remember their babies.

Discussion: The research strengthens existing research and adds unique understandings of autistic baby loss. Many clinical implications arose, including the necessity for improved staff awareness, knowledge and skills in perinatal care settings, including of the unique experiences of autistic baby loss and grief and the role of a clinical psychologist in shaping this.

Key words: Pregnancy Loss, Autistic Women and Birthing People, Trauma, Grief, Maternity Care.

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Chapter 1: Introduction

This chapter will outline the epistemological position taken in completing this research. I will then set out key terms and language, before describing the current research exploring the experiences of autistic women and non-binary people more broadly, and during the perinatal period specifically. Baby loss literature across the general population and the unique experiences of autistic baby loss will then be shared and key grief theories described. This will highlight the need for more research into autistic grief and baby loss, setting the scene for the research.

Personal and Epistemological Position

Relationship to the Topic and Positionality

This project has been inspired by aspects of my personal and professional identity and interests; positioning me as both an insider and outsider researcher. Professionally, I am drawn to neurodivergence as an aspect of identity and understanding experiences of distress in this context. In addition, I witnessed women and birthing people's understandable distress and trauma arising from birth and baby loss during my time working in a Maternal Mental Health Service (MMHS). I began to question the experiences of neurodivergent women and birthing people, and how these aspects of identity intersect with grief, which led me to this research.

Positionality encompasses the researcher's worldview, identity and position in relation to research (Rowe et al., 2014). I am a white, cis-gendered, able-bodied, autistic woman. My autistic identity positions me as an insider researcher in knowing something in relation to autistic cis-gendered women's experiences but does not represent all experiences. My cis-gendered, white, western, trainee position may bring certain assumptions and gaps in knowledge as a researcher and person in the world. I am not a mother, nor have I experienced baby loss, which position me as an outsider researcher. Reflexivity as an active process helped to hold, question

and remain aware of my positions, lenses and relationships during the research, which I will describe further throughout.

Epistemological Position

A critical realist (CR) and autistic epistemology (AE) was adopted throughout this research. CR suggests that there is an observable reality through experiences and actual events in which knowledge can exist separately to the human mind, whilst recognising that knowledge is shaped by subjective experiences, constructions, and frameworks of the world in which an individual exists (Bhaskar, 1978). Power and structural influences (socio-political, historical, etc), and one's positionality in relation to these, also shape one's experience of the world (Bhaskar et al., 2013). I consider both baby loss and autism as observable realities that people experience, characterised by the real and felt physical absence of a baby and autistic differences, but mediated through intersecting aspects of identity, such as neurodivergence, gender and ethnicity, socio-political, historical contexts and tangible structures, (e.g., National Health Service [NHS] perinatal services) and current societal discourses. I was interested in how these mediating factors shape the phenomenological experiences and meaning making as reported by autistic women and birthing people.

AE has been used as a term by Beardon (2025) to critique the large amount of knowledge generation about autistic people, by non-autistic communities. Beardon (2025) considers this knowledge to be shaped by historical, socio-political structures and discourses, such as deficit-based knowledges of autism, which may be further influenced by one's positionality to power and intersecting identities, like gender. AE can be defined as ways in which autistic individuals reconstruct and describe knowledge about their experiences and may be contextualised by the Social Model of Disability, viewing disability as a socially constructed idea, which can be disabling by barriers posed in a neurotypically-designed world (Scope, n.d.). A CR and AE invites researchers to hold knowledge critically and to intentionally foreground

autistic understanding and meaning making within the social construction of knowledge, as valid and significant contributions to knowledge generation. Furthermore, a CR and AE considered these phenomenological understandings and meanings as reported by autistic women and birthing people about their experience of baby loss, as shaped by their unique relationship to power and intersecting identity, which I critically and reflexively explored through my insider, autistic researcher position.

Social and Political Contexts

I have been aware of the growth and recent changes which have shaped socio-political discourses surrounding autistic experiences more broadly. There is currently much greater awareness of autism societally, which brings opportunities to support earlier recognition (All Party Parliamentary Group on Autism, n.d.). However, there has been a sharp rise in diagnosis, with numbers still rising (NHS England, 2025), placing significant demand on services and leaving many waiting without the utility of a diagnosis which is vital to access support (National Autistic Society [NAS], 2025). Government legislation, such as the Department of Health and Social Care and Department for Education (2021) has also aimed to improve societal awareness of autism, early identification, reduce waiting times and improve autistic people's experiences of healthcare system, including access to mainstream services with use of equitable requirements (NHS England, 2025).

The national recognition has seen an increase in popular culture and academic reporting (NAS, 2025; Sample, 2024). Some of which has bought increasing doubt surrounding boundaries of diagnostic categories, particularly in relation to historically under-represented groups, including adults, women, non-binary people and people of colour (Hill, 2024). Stigmatising and stereotyping autistic discourses are also challenges, which may be perpetuated by popular culture (Mittman et al., 2024). Within this context, more active and intentional advocacy from the autistic community has grown, with first-person accounts as ways

of reclaiming and de-stigmatising autism (Mittmann et al., 2024). The Neurodiversity Movement is one example of this to challenge mainstream views, bring an end to discrimination and foreground autistic understandings (NAS, n.d.).

There continue to be societal and political discourses surrounding perinatal and birthing care experiences, within a politicised field relating to gender identity, such as trans rights. MMHS' were commissioned across England to support women and birthing people experiencing moderate to severe psychological distress (NHS England, n.d.). Recommendations to improve MMHS' include equitable healthcare for women and birthing people from marginalised groups, such as gender and neurodivergence, with practitioner training and education as part of this (Maternal Mental Health Alliance [MMHA], 2024). More broadly, obstetric, gynaecological and midwifery guidelines may be lacking in their consideration of the specific needs of autistic women and birthing people (Royal College of Obstetricians & Gynaecologists, 2016) and are currently being reviewed (Autistica, n.d.). Until recently, there was no way of recognising miscarriage and the life of a baby who died in utero in the UK (Gov.UK, n.d.). This is based on medical definitions of the legal age of viability being 24 weeks of pregnancy (Miscarriage Association, n.d.).

Researching in a highly politicised field has felt like a dance, particularly considering my relationship to the socio-political landscape described, how this positions me and how I may be positioned by others. I have considered how this may impact participants, the research, research team and readers. I have recognised the importance of thinking critically, whilst staying aligned to (and transparently reporting) my values and positionality. Whilst I recognise the tensions within the field, my position aligns strongly with the Neurodiversity Movement and Social Model of Disability. I have used self-reflexivity and reflective conversations with the research team to manage this dance and tensions described.

Key Terms

Relevant key terms are defined in Table 1.

Table 1

Key Terms and Definitions

Key Term	Definition
Baby Loss	Baby loss as a term is used to describe the experience of losing a baby throughout pregnancy and birth, including experiences of miscarriage, stillbirth and neonatal death.
Miscarriage	A miscarriage happens when a baby dies in the uterus during pregnancy (Miscarriage Association, n.d.). In the UK, this definition of miscarriage occurs within the first 23 weeks and 6 days of pregnancy (Miscarriage Association, n.d.). Miscarriage is one of the most common causes of baby loss and is estimated that 25% of women and birthing people experience a miscarriage at some point in their lifetime (Ghosh, 2021). However, experiences of miscarriage are not officially recorded, so uncertainty remains around how many miscarriages occur, with miscarriage statistics being only estimates and likely to be higher (Jurkovic et al., 2013; Sands, n.d.;).
Stillbirth	A stillbirth happens when a baby dies after 24 weeks of pregnancy in utero before they are born or during birth (Tommy's, 2025). According to data from the Office of National Statistics (ONS; 2023) in the UK, in 2022, the stillbirth rate was 3.9 per 1000 births.
Neonatal Death	A neonatal death happens when a baby dies within the first 28 days after they are born (Tommy's, n.d.) In the UK, in 2022, the neonatal

	mortality rate in England was 1.5 deaths per 1000 live births (ONS, 2023), with 34% of neonatal deaths caused by genetic conditions from birth, and 34% caused by problems relating to the brain, heart, lungs or from premature birth (before 28 weeks; Sands, n.d.).
Birthing People	The term birthing people refers to a person who can give birth and does not identify as female or woman. It is often a gender-neutral term that can be more inclusive to a range of gender identities, including non-binary and transpeople. In the context of autism, this is important, as autistic people may be more likely to identify with more diverse gender identities, compared to non-autistic people (National Autistic Society, n.d.; Walsh et al., 2018). Trans authors have also highlighted the importance of this language in perinatal services (Green & Riddington, 2020), in line with NHS guidelines (NHS Digital, 2021). Through consultation with the autistic community, Experts by Experience (EbE) and in line with personal values, this term was adopted to reflect and validate the diversity in gender identity in the autistic community.
Grief	Grief is an individual, understandable and human experience, which describes the range of emotional, psychological, behavioural, social and physiological changes that are experienced following the loss of someone or something (Pang, 2023).
Neurodivergent	A term used to describe having a brain that functions in ways that diverge from the dominant societal view of what is “typical” in terms of neuro-cognitive function and is most often societally positioned as holding less power (Walker, 2014). People may identify with a single

	type of neurodivergence, or be multiply neurodivergent e.g., autistic and ADHD.
Autism	Autism can be thought of as a type of neurodivergence, meaning that autistic brains experience the world differently to neurotypical brains (Dwyer, 2022). Autistic people can often experience communication, social interaction and the sensory world differently, which can be disabling due to navigating a neurotypically-designed world (National Autistic Society, n.d.). Autism is often still conceptualised in medicalising ways, in line with diagnostic categories, which often position autism as a deficit (Dinishak, 2016). Counter-arguments, such as the Neurodiversity Movement; a social justice movement that posits the inherent diversity and value of neurodivergent neurotypes (NAS, n.d.), and the Social Model of Disability; disability arises from structural and societal barriers as a result of neurotypically, designed and inequitable structures, rather than due to individual impairments (Union of the Physically Impaired Against Segregation (UPIAS, 1976) and has been re-invigorated to consider neurodivergence by Woods (2017).
Neurotypical	A neurotype that falls within the dominant societal standards of what is socially and culturally constructed and viewed as “typical” or “normal” neurocognitive functioning (Walker, 2014).
Ableism	A socially and culturally constructed term to describe a set of beliefs and practices that discriminate against and prejudice individuals with physical, intellectual or neurodevelopmental disabilities (Smith, n.d.). Ableism can be seen as rooted in colonialism and power, which

> "assumes and prioritises able-bodiedness, and marginalises those who are differently abled" from what society constructs is "typical" (Chouinard, 1997, p380).

Context and Experiences of Autistic Women and Non-binary People

It is estimated that 1 in 7 people are neurodivergent (NHS England, n.d.). Based on societal and cultural constructions of autism primarily effecting cis-gendered males, it is generally thought that the ratio of autistic males to females is 3:1 (Loomes et al., 2017). Autistic women and non-binary people may experience fewer social difficulties externally recognisable to others, and passions and self-regulatory behaviours may appear socially and culturally gendered (Pearson & Rose, 2021), which can help to understand experiences of mis- or under-diagnosis (NAS, n.d.). McCrossin (2022) utilised mathematical calculations to include the biases in the under-recognition and diagnosis of autistic females, which found that the ratio of 3:4 is likely to be a closer estimation.

Many autistic women and people assigned female at birth (AFAB) have described the impact of late or misdiagnosis. Leedham et al. (2020) found that navigating the world as an undiagnosed autistic person could lead to internalised beliefs about the self being 'wrong' and 'broken' arising from the differences between autistic and non-autistic culture, such as social communication. This often led to developing coping strategies such as camouflaging and masking, which were experienced as exhausting and could lead to experiences of psychological distress, such as a loss of identity (Leedham et al., 2020; Milner et al., 2019). From a Social Model of Disability lens, autistic people may be more vulnerable to experiencing psychological distress compared to non-autistic people (Lai et al., 2019). Within healthcare settings that can operate in line with diagnostic systems, autistic females may be more likely than autistic males to attract misdiagnoses under a medical, positivist epistemological position, such as "personality

disorder" [1], anxiety and mood difficulties (Kentrou et al., 2024). Several obstacles may present in accessing healthcare as an autistic person, such as communication differences, sensory environments misaligned to autistic needs, perceived stigma and a lack of autism awareness from professionals, which may result in experiences of imposed sense making to understanding distress (Doherty et al., 2022; Leedham et al., 2020; Nicolaidis et al., 2015; Tint & Weiss, 2018).

Additionally, research shows that autistic women and people AFAB's experiences of trauma and abuse are high (Cazalis et al., 2022; Dike et al., 2023; Pearson et al., 2022). Autistic women and girls may be more likely to experience bullying throughout education, which may shape beliefs about the self, others and the world (Hamstead, 2024). Many autistic women described how their autistic experiences were taken advantage of by others, such as deciphering the social rules of a neurotypical world, which led to feeling unsafe and coerced into doing things that were against their wishes and consent (Bargiela et al., 2016; Cazalis et al., 2022). Some autistic people also described the impact of isolation and fewer friendships, which led to not feeling able to ask people about the appropriateness of their experiences with the abuser (Sedgewick & Douglas, 2023). Furthermore, Pecora et al. (2020) found that autistic people AFAB were more than twice as likely to be at risk of negative sexual experience, including unwanted sexual advances.

Whilst trauma responses are a universal human experience in relation to adversity, it has been claimed that autistic people may be more likely to develop post-traumatic stress disorder (PTSD), particularly in relation to social events, which may be traumatic, and interpersonal traumas, like sexual abuse (Rumball et al., 2020). However, an autistic female vulnerability narrative assumes complicity with patriarchal, ableist structures and constructed

[1] Quotation marks around personality disorder to reflect terms used within positivist, medical models, rather than my own values and preferred ways of conceptualising.

narratives in society maintaining blame and "problem"[2] within both disabled women and non-binary people more broadly (Hirschmann, 2013). This may absolve power structures, such as sexism, misogyny, and violence against women, non-binary and trans-people (Moore et al., 2024). Nevertheless, the literature highlights the potential profound foundations and experiences of trauma for autistic women and people when navigating a structurally inequitable social and cultural context, and the resulting psychological impact.

Autistic Experiences of the Perinatal Period

In the UK, the perinatal period is defined from pregnancy up until 12 months after childbirth (NHS England, 2018). The perinatal period is both a universal and uniquely individual experience for women and birthing people (Vogels-Broeke et al., 2020). It has been identified that 0.79% of births in Wales, UK, in 2020, were to autistic women and birthing people (personal correspondence in Grant et al., 2025a). Many autistic women and birthing people described motherhood as rewarding (Pohl et al., 2020), with many utilising the natural strengths of their neurotype, such as sensory sensitivities to attune with baby and hyper-focus to gain knowledge to be the best parent they could be (Hampton et al., 2022c; Wilson & Andrassy, 2022). However, motherhood can bring challenges, universally, with unique aspects for autistic women and birthing people which Westgate et al. (2024) summarise in a systematic review, including overwhelming sensory demands, challenges in navigating and experiencing healthcare, the importance of predictability and control in labour and birth.

Research has shown that the perinatal period poses sensory challenges for autistic women and birthing people (Westgate et al., 2024). Across several sources, including a systematic review, autistic women and birthing people reported heightened sensory experiences throughout pregnancy which could lead to feelings of discomfort and anxiety triggering

[2] To reflect the sense of societally constructed narratives about who the problem is located in, reflective of positivist, medical-model conceptualisations linked to ideas related to power and privilege.

experiences of shutdowns; retreating from the environment in response to sensory or emotional overload, impacting abilities to communicate (Hampton et al., 2022a; Reframing Autism, n.d.; Samuel et al., 2022). Many autistic women and birthing people reported differences in interoception and proprioception throughout pregnancy and their changing body, either noticing internal sensations, such as feeling their baby move, or feeling disconnected; both of which could be difficult and reflective of autistic hypo- and hyper-sensory sensitivities (Hampton et al., 2023b; Talcer et al., 2023; Westgate et al., 2024). In a large empirical study, autistic women and birthing people were significantly more likely to report experiences of nausea and conditions such as pelvic girdle pain during pregnancy, than non-autistic women and birthing people (Hampton et al., 2022b), which could be explained by co-occurring disabilities such as hypermobility (Cederlöf et al., 2016).

Autistic sensory experiences could continue during labour and birth as highlighted in Westgate et al.'s (2024) systematic review. In a qualitative interpretative study, 24 autistic women reported distressing sensory experiences throughout labour and birth arising from the environment and heightened interoceptive sensory experiences, such as pain, which could be overwhelming and lead to shutdowns (Donovan, 2020). Moreover, in Hampton et al.'s (2022) thematic analysis, autistic women described sensory challenges when giving birth, particularly the hospital environment feeling misaligned to autistic sensory experiences, such as noises of babies crying and lighting, which could trigger meltdowns; externalised expressions of distress in response to sensory overload, and shutdowns (Hampton et al., 2022c; Reframing Autism, n.d.). A narrative analysis of autistic birth stories found that a misalignment between hyper-sensitive autistic sensory experiences and the birth environment could be traumatic, which impacted abilities to communicate, perpetuating a sense of helplessness (Lewis et al., 2021). Furthermore, imbalances between healthcare professionals and their approach to care could be traumatic, such as enduring procedures without consent or explanation, which led to some

reported to feel ‘violated’ and ‘powerless’ (Lewis et al., 2021, p.65). This could also exacerbate an already heightened sense of pain and hyper-sensitivity to touch (Hampton et al., 2022c; Gardner et al., 2016; Rogers et al., 2017).

Whilst these studies explore autistic sensory experiences in the perinatal period, many are reflective of mostly white, western autistic experiences and do not hear the experiences of people from the global majority. This may add additional layers of distress in the context of power and marginalised aspects of identity.

Social communication differences with healthcare professionals during the perinatal period were reported as another significant difficulty for many autistic women and birthing people (Westgate et al., 2024). As an example, in a qualitative case study, one autistic woman described feeling like she was being treated like ‘an inanimate object’ (p.92), which she made sense of as feeling that professionals did not care and that there was not enough support ‘for people like me’ (Rogers et al., 2017, p.92). Autistic women described other experiences, such as not feeling believed and their knowledge of their bodies dismissed (e.g., needing to push in labour; Donovan, 2020). Furthermore, misinterpretations occurred when trying to seek pain relief, which often led to staff viewing autistic pain as less than it was (Donovan, 2020). Some autistic women described a sense of distrust and feeling unsafe in being cared for by staff throughout their pregnancy and labour as a result (Donovan, 2020). Moreover, in a large empirical study exploring autistic experiences of childbirth, participants described how their expressions of distress were often only understood in the context of more externalised expressions, like meltdowns, rather than internalised expressions, such as being silent and shutdown (Hampton et al., 2023a).

Challenges in relation to the healthcare system, such as maternity care appeared to stem from a lack of autism awareness amongst staff and neuro-normative approaches to care designed for non-autistic people (Grant et al., 2025b; Westgate et al., 2024). For example, in

several qualitative studies, some autistic women reported experiences with professionals who described them as not being like autistic people they had met before, reflecting a lack of knowledge of autistic female experiences (Burton, 2016; Hampton et al., 2023b). The sense of negative reaction and stigma may have influenced autism disclosure, with many autistic women and birthing people choosing not to disclose due to feeling that their midwife or doctor would not know what to do with the information or would impact being taken seriously (Hampton et al., 2022b; Pohl et al., 2020; Westgate et al., 2024). Further stigmatising societal narratives could be a source of worry for some women, such as perceptions of their suitability to motherhood (Donovan, 2020). This may have been confirmed when disclosure resulted in midwives questioning their abilities during pregnancy (Hampton et al., 2023b). Positive experiences of disclosure were reported as limited, but for some, did support with person-centred care aligned to their needs (Hampton et al., 2022c). In an online survey study, Grant et al. (2025b) reported that most autistic participants reported masking when receiving maternity care, which could be due to a lack of staff awareness of autism and systemic barriers to equitable autistic care.

Additionally, aspects of the perinatal period were reported as posing significant challenges to obtaining safety in predictability in a neurotypical world, which when lost could be distressing (Westgate et al., 2024). Many autistic women and birthing people described feeling that they had received less information than they would have wanted (Hampton et al., 2022b). Labour and birth were specific contexts which threatened safety in predictability, which could lead to fear arising from new and unfamiliar environments, sensory challenges, not knowing what would happen and for how long (Hampton et al., 2023b). In the absence of equitable requirements, labour and birth could feel out of control, particularly for autistic women who were pregnant with their first child and did not have a framework to help with knowing what to expect (Donovan, 2020). This is important to consider, as these factors may precipitate experiences of

trauma, along with the many other unique challenges posed within the perinatal period, if unaddressed.

However, advocacy from a supporter, clear information in line with communication preferences, including demonstrations, continuity of care, and implementing equitable requirements were reported as key to better supporting autistic women throughout the perinatal period (Donovan, 2020; Hampton et al., 2022b, 2022c; Westgate et al., 2024). Like in other studies, autism awareness and training amongst healthcare professionals was described as paramount to improving perinatal care for autistic women, but key therapeutic skills of listening and enacting this through adaptations could be just as important (Hampton et al., 2023b; Samuel et al. 2022; Talcer et al., 2023).

This research highlights the unique challenges autistic women and birthing people face, and the gaping lack in awareness and knowledge of some professionals delivering perinatal care. However, there are intersections of the autistic community who are absent, particularly those with marginalised identities, such as gender, ethnicity and age, and who may experience additional unique challenges.

Women and Birthing People's Experiences of Baby Loss

Baby loss is a universally experienced, often devastating reality, however, continues to be a stigmatised and disenfranchised loss and grieving process enshrouded by silence (Haiter, 2025). In a thematic analysis, Wheeler et al. (2022) heard women describe baby loss and their grief as silencing, which felt like their babies' deaths and their grief were denied by others who did not know what to say. Some women described feeling that others did not know how to support them, which could be perpetuated by sensing their discomfort, and could lead to avoidance of discussing their miscarriage altogether (Bellhouse et al., 2018). When conversations did occur, many described receiving insensitive and invalidating comments, with

some people attributing blame to them personally for their miscarriage (Bellhouse et al., 2018). Similarly, trans-men and non-binary people spoke about a lack of support and understanding from healthcare professionals, friends and family, which could compound their loss and perpetuate a sense of marginalisation in the context of their gender identity (Riggs et al., 2020).

Moreover, women described how the silence of healthcare professionals implicitly confirmed the loss of their baby and felt like a transition into a silent reality, which could be internalised and lead to strong feelings of guilt and shame (Pollock et al., 2020). In a systematic review, women's experiences of guilt could be further exacerbated by an absence of care from healthcare professionals, which some women made sense of as the death of their baby being their fault (Kuforiji et al., 2023). Additionally, many women reported a strong sense of helplessness, guilt and blame for their miscarriage, which they described as a personal failure of themselves and their bodies as women (Bellhouse et al., 2019). Subsequently, this could shape highly self-critical ways of relating to themselves and their bodies (Lau et al., 2024).

Burden et al.'s (2016) systematic review of the impact of stillbirth, recognised the often-disenfranchised grief experiences of women, which could be exacerbated by the lack of recognition of the distress of baby loss, societal taboo and stigma. Furthermore, baby loss has been described as a "non-event", which can de-legitimise the personhood of the babies' who died short, but real lives (Zhuang et al., 2023). A range of grief responses have been reported by women following baby loss in both systematic and scoping reviews, such as feeling heartbroken, confused, sadness, anger, emotional numbness, anxiety, isolation and an embodied sense of emptiness and emotional pain (Fernández-Cox et al., 2025; Kuforiji et al., 2023). Moreover, feelings of shame and guilt have been reported to compound and impact the processing of grief, contextualised by the societal and cultural stigma and silence surrounding baby loss (Fernández-Cox et al., 2025; Lau et al., 2024).

Further challenges in relation to healthcare experiences have been described universally in the baby loss literature. In several empirical studies, some females described the difficulty in sitting with other pregnant women in accident and emergency (A&E; Meaney et al., 2017), waiting for long periods of time (Petro & Mcintosh, 2009) and experiences of insensitive care, such as being placed next to women on hospital wards whose babies were alive and having to listen to the sound of their heartbeats, whilst actively bleeding and having a miscarriage (Bellhouse et al., 2019). Some women reported experiencing anxiety when awaiting tests to confirm the loss of their baby, which could be further compounded by having little knowledge about what to expect while miscarrying (Bellhouse et al., 2019; Meaney et al., 2017). Moreover, Wong et al. (2003) found that follow-up appointments were not always offered following miscarriage, which could be distressing and may have been a factor contributing to high levels of guilt and blame without a sense of why baby loss happened. This may compound the high levels of stigma associated with baby loss enacted by healthcare practitioners who may have embodied and internalised such stigma too (Simelela, n.d.). The literature described the importance of healthcare professionals acknowledging and resisting the societal silence, irrespective of the gestational age of the baby to recognise women and birthing people's distress and pain (Meaney et al., 2017).

Remembering as ways to legitimise the experience of baby loss, thus the babies who died were crucial in finding ways to heal and find a new relationship with grief (Lau et al., 2024). Women and birthing people attempted to make meaning of their loss, which often involved naming, marking and finding ways to remember their baby (Bellhouse et al., 2019; Lau et al., 2024). In the context of stillbirth and neonatal death, parents appreciated and desired to spend time with their babies' by engaging in activities, such as dressing and holding them (Christiansen, 2017; Ryninks et al., 2014).

These studies highlight the range of individual and systemic challenges women and birthing people may face, along with the pain of grief in being without a baby, compounded by a sense of disenfranchised, stigmatised and silenced loss. However, neurodivergence as an aspect of identity is not considered in many studies; meaning the unique set of experiences of neurodivergent women and birthing people is not understood. Riggs et al.'s (2020) described how the sense of loss may have been compounded by intersectional aspects of identity, such as gender. This is important to consider further.

Baby loss can be a traumatic experience across different types of baby loss and the gestational age of the baby (Berry, 2022). Trauma responses can be experienced by women for up to four years after baby loss occurred, highlighting the potential psychological imprint of being without a baby (Krosch & Shakespeare-Finch, 2017). Moreover, women described an embodied experience of distress and trauma, such as, hypervigilance, triggering events as reminders of baby loss, and experiences of nightmares, which may reflect the embodied nature of baby loss (Gillis et al., 2020). In a systematic review, many aspects of baby loss could be traumatic, including learning about the prognosis of the pregnancy and baby's health, enduring labour and birth, and traumatic interactions with others (Berry, 2022). Furthermore, experiences of relational trauma, could be exacerbated by a societal expectation to carry on as usual, which could lead to disenfranchised grief; which have been found to be precipitate trauma responses (Berry, 2022; Ironside, 2003). These studies highlight the understandable traumatic nature of baby loss. However, social and cultural structures of power, such as ableism and how these structures may shape unique aspects of baby loss, are not considered, such as for neurodivergent people.

Considering autistic baby loss, Grant et al. (2025a) explored autistic people's experiences of care during baby loss using a survey methodology. A strong theme of trauma was identified to reflect the many ways in which baby loss was traumatic. Several challenges in

relationship to healthcare settings and professionals were reported. Differences in communication were a source of difficulty which could lead to challenges, such as, not being given enough information. This could be particularly distressing and contributed to ongoing psychological distress and trauma. Autistic people reported a lack of compassion and warmth from practitioners, which further exacerbated their distress of losing their baby, in a healthcare setting which felt unsupportive and not systemically adapted to autistic sensory experiences. Participants also described experiences of feeling dismissed, belittled, ridiculed, invalidated and abandoned, which for some could lead to meltdowns and shutdowns and made it more difficult to communicate their needs. Many autistic people chose not to disclose their autistic identity to healthcare professionals whilst accessing care throughout their experience of baby loss. Autistic participants described the necessity of ensuring practitioners better understand their needs and implementing equitable requirements, such as communication in line with preferences, improvements to the sensory environment and answering all questions to help obtain information (Grant et al., 2025a). This was recommended to help improve care for autistic baby loss.

Furthermore, Quinn (2021) described their experiences of baby loss, grief and grieving as an autistic person. Like universal experiences, Quinn (2021) described the taboo surrounding baby loss. This could lead to silence, not feeling able to talk about experiences of loss, and receiving invalidating comments from others, which failed to recognise the beginnings of the internal emotional connection and bonds with baby, and the shift in identity to a parent. More uniquely, Quinn described the “physical conflict” (p.131; 2021) of her baby dying and continuing to experience some sensations of pregnancy and being aware of bodily changes over time after her loss occurred. Moreover, autistic people may utilise the often logical and practical nature of their neurotype to help to process the loss of a baby. This may include processing the loss without the emotional connection to the baby, as they were yet to be born, or finding it easier to

let go and accept the loss. Furthermore, some autistic people may try for another baby as soon as they are medically able, as further ways of logically processing and coping with the loss of a hoped-for baby. Subsequently, the emotional impact and experience of grief may not be expressed until after the autistic person has processed the logical aspects of loss first, which can take time. This may also lead to differences in how an autistic person presents to others externally, which may not reflect their internal experience and processing of grief and loss (Quinn, 2021).

As Quinn describes, the loss of a baby can also be unpredictable and feel out of control for autistic people, which can add to the emotional distress of the experience, such as feelings of anger, panic and anxiety. These experiences may be exacerbated further by navigating healthcare appointments, in often neurotypically designed medical environments, which can trigger sensory overwhelm and distress, and lead to meltdowns (Quinn, 2021). Restoring safety in predictability through routines, scripts to help with managing if baby loss occurs and future planning, such as trying for another baby can be supportive for autistic people. Self-regulatory movements and sensorily calming environments can also be key when grieving. Moreover, Quinn (2021) describes how spending time alone to grieve and process the loss of a baby can be restorative and remove the additional layer of distress in grieving the loss of a baby in non-autistic ways, such as seeking out support from others and physical affection and contact like hugs during bereavement and grief. Quinn (2021) suggests that whilst there is no right or wrong way to react, grieve and process the loss of a baby, neurotypical people may view autistic grief as “callous” or “surprising” (p.131), which can add additional layers of distress, as neurotypical people may misunderstand and misinterpret expressions of grief, such as receiving a diagnosis of “adjustment disorder” for continuing to experience grief six months after the loss of a baby (Quinn, 2021).

Attachment and Caregiving Bonds in Context of Perinatal Experiences and Loss

Attachment describes the process of early emotional, psychological bonds and connection between caregivers and infants, which can shape future relationships and bonds across the lifespan (Bowlby, 1980; Antonucci et al., 2004). Attachment experiences can be shaped by intergenerational patterns of bonds and connections, which can be activated during the perinatal period as women and birthing people transition into motherhood (Franca et al., 2018). Maternal foetal attachment (MFA) describes the emotional bond between mother and unborn baby which begins during pregnancy, expressed through observable behaviours like speaking to baby, physical connection through touching the abdomen and planning (Cranley, 1981). This connection can also be grown through internal, private experiences, such as experiencing thoughts, feelings and imagined hopes and dreams, which begin to develop baby psychologically, along with one's identity as a parent in mind (Muller, 1992). Key events connected to pregnancy have been identified as further shaping the growing connection with baby, with feeling baby move for the first time, as a significant moment of heightened connection and growing attachment with baby (Robinson, Baker & Nackerud, 1999).

In a recent systematic review, experiences of parental distress during the perinatal period were found to be associated with lower MFA and postpartum bonding between mother and infant, which can be crucial to psychological, cognitive and social development of infants and can be a factor precipitating experiences of distress in context of post-partum depression ((McNamara et al., 2019; Vanwalleghem et al., 2023). Attachment-informed lenses can be a supportive factor to consider when understanding the psychological wellbeing of parents and infants during the perinatal period; however, can negate the idea that distress and attachment bonds can be shaped and exist in social context. This may include experiences of trauma and adversity precipitated by external factors such as domestic violence and socioeconomic

deprivation, which may be further mediated by aspects of identity and their relationship to power structures (Ayre & McLoughlin, 2024).

Attachment and caregiving bonds have been explored in relation to baby loss. Alongside the range of experiences of psychological distress and grieving following the death of a baby, parents may also experience the loss of the anticipated parent role, which had started to be assimilated as a part of the self, thus not only losing their baby, but a part of oneself as a caregiver (Côté-Arsenault & Denney-Koelsch, 2011; Klass, 1988) and the “loss of a future”, often hoped and longed for (p.263; Robinson et al., 1999). Drawing on Bowlby’s (1980) attachment theory, baby loss can disrupt the growing emotional bonds and attachment with the baby who died, which may also shape attachment and bonds with future children. In a recent systematic review exploring the impact of attachment on the experience of baby loss, Santamaria-Gutiez et al. (2025) reported that lower levels of secure attachment were associated with greater psychological distress and grieving in bereaved parents following baby loss, thus one’s own attachment system influencing experiences of distress. Social support, quality of partnership and secure attachment were found to be inversely correlated with psychological distress, and protective in supporting the grieving process following baby loss (Caldwell et al., 2024). These findings demonstrate the impact of the loss of attachment with the baby who died, and subsequent psychological distress and grief, and how this may be shaped by parental attachment patterns and impact on coping and grieving.

However, attachment-based ideas traditionally conceptualise caregiver relationships and bonding as societally and culturally gendered, drawing on heteronormative, cis-normative and patriarchal contexts, underpinned by powerful structures. This may reduce understandings of caregiving, bonding and relationships, and may not consider the experience as shaped and mediated by marginalised aspects of identity, such as AFAB and neurodivergent people. This is important to acknowledge given the potential profound experiences of trauma and adversity

highlighted in the literature and understandable impact on trust and safety felt in relationship to others, which may activate and shape one's attachment system (The Autistic Advocate, 2025).

Theoretical Frameworks of Grief and Loss

Theoretical underpinnings of grief have evolved over time to support understandings of grief and bereavement. Early theoretical frameworks, such as Kübler-Ross' (1969) stages of grief, namely denial, to anger, bargaining, depression and acceptance, or Worden's (2009) tasks of mourning, described as accepting the reality and processing the pain of the loss, adjusting to the world without the deceased and finding an enduring connection with them, while embarking on a new life, conceptualise grief as moving through predictable, sequential, discrete stages. Several critiques of prescriptive uses of such stage models have been made, including an over-simplification of the grief process, which may risk marginalising and harming those whose grief does not follow such a trajectory (Stroebe et al., 2017). Additionally, stage-based models can be normative and reductionist to an individualistic approach to grieving, which fails to consider the broader social and cultural contexts of grief, including social and collectivist practices (Rosenblatt, 2013; Stroebe et al., 2017). However, models such as Kübler-Ross remains widely used in healthcare services and by practitioners, despite critiques in the grief literature (Stroebe et al., 2017).

Process-based approaches are considered as alternatives to understanding grief and life without the deceased as a continual process, even decades after the loss, rather than 'arriving' at a point in which grief has ended (Parrish et al., 2025). The Dual-Process Model (DPM; Stroebe & Schut, 1999) describes such a process whereby individuals oscillate between two main phases: loss-oriented and restoration-oriented. The model emphasizes the continual process of both confronting and feeling the pain and grief of loss, whilst simultaneously actively re-engaging and adjusting to a life without the deceased (Stroebe et al., 1999). A further model by Klass et al. (2014), Continuing Bonds, describes a process of finding ways to continue bonds

through forming a new relationship with the deceased, rather than grief being a severing of bonds. The process of oscillation is highlighted by Tonkin's (1996) Growing around Grief model, which suggests that instead of grief shrinking over time, grief stays the same, but one learns to grow around grief. These models continue to refute and provide alternatives to stage-based models and legitimise the oscillation of grief, which at times may be as painful as the day the deceased died (Cruse, 2025). Through actively engaging with grief in loss-orientated ways, one can begin to focus on meaning-making, which is a central process to grieving (Neimeyer, 2001). This can involve beginning to construct new meanings and narratives, which integrates the loss into one's life story, and associated with adaptive coping with the ongoing human experience of grief.

Disenfranchised grief describes grief which is not openly acknowledged, nor socially or publicly supported (Doka, 1999). This can lead to grieving in isolation, which can exacerbate distress. Disenfranchised grief may be experienced when the loss is not societally or culturally defined as significant, such as baby loss, and those with marginalised aspects of identity, which may shape assumptions about grief (in)abilities, such as autistic people (Doka, 1999). Furthermore, people who grieve differently to what is societally and culturally deemed 'acceptable' as defined by stage models may also be at risk of disenfranchised grief (Doka, 1999).

Conclusions

The empirical and theoretical literature presented has emphasized the contextual foundations through which autistic women and non-binary people may experience their position in the world and can be shaped by experiences of trauma and a lack of recognition through an autistic lens. These experiences may be further highlighted during the perinatal period, which can bring challenges universally, but may pose unique challenges in the context of social communication and sensory differences. Specific experiences of the perinatal period, such as

baby loss have been highlighted in the literature universally, which suggests how this experience may be traumatic and distressing in several ways, exacerbated by societal and cultural taboo and silence, which risks stigmatising and disenfranchising baby loss and grief. However, the unique experiences of autistic baby loss and grief are limited, with only one piece of published research identified, which emphasised the specific autistic experiences posing additional challenges and a strong sense of trauma. Taken together with a strong evidence base of autistic perinatal experiences, this provides rational for the empirical study and systematic review to better understand autistic grief and baby loss.

Chapter 2: Systematic Scoping Review

This chapter describes the development and completion of the scoping review, outlining the rationale for choosing this evidence synthesis method and decision-making process throughout. I will then detail the findings, before setting out the rationale, aims and research question for the empirical study.

Rationale for a Scoping Review

A scoping review refers to a method of systematically mapping the extent and range of literature within a chosen field, including the types of literature available, key concepts, theories and evidence sources (Arksey & O'Malley, 2005; Mak & Thomas, 2022; Munn, et al., 2018). Scoping reviews can include grey literature sources, privileging knowledges which may not be privileged within peer-reviewed journals and often excluded from systematic literature reviews (Arksey et al., 2005; Peters et al., 2020). Scoping reviews can therefore be used when systematic reviews are less appropriate (Munn et al., 2018). Scoping reviews have been utilised within emerging bodies of literature and are most typically utilised to summarise what is already known to identify and address possible knowledge gaps on a particular topic and inform future directions (Arksey et al., 2005; Peters et al., 2020). Whilst there are methodological differences with systematic reviews, scoping reviews follow a structured, systematic and iterative methodological process (Mak et al., 2022; Peters et al., 2020).

Research exploring autistic experiences of grief and bereavement, both broadly and specifically in relation to baby loss are limited within peer-reviewed research. As scoping reviews are typically suited to understanding the range of knowledges within an emerging field, and where sources may be more heterogenous, this methodology was deemed most appropriate (Peters et al., 2020). Furthermore, scoping reviews can typically be applied to examine how research is conducted on a certain topic, which was pertinent to exploring and

interrogating the gaps within peer-reviewed knowledge spaces (Munn et al., 2018). I decided to complete a scoping review to explore autistic experiences of grief, loss and bereavement, drawing on an AE position as discussed in Chapter 1 to privilege autistic constructed knowledge.

What Has Been Done Before?

Initial searches related to perinatal autistic experiences identified several PROSPERO registered reviews, including autistic women and birthing people's experiences of the perinatal period more broadly and specifically (Westgate et al., 2024; Samuel et al., 2021; Smith et al., in progress), as well as experiences of baby loss universally (Berry, 2022; Flach et al., 2023; Herbert et al., 2022; Zhaung et al., 2023). The limited research identified exploring autistic baby loss meant that this was not a feasible area to review.

A key systematic review exploring the neurodiversity of grief helped identify a gap and rationale for this scoping review (Mair et al., 2024). A key overarching theme of "*Recognise the Unrecognised"* described the often silenced, disenfranchised grief experiences of people with neurodevelopmental conditions. Further themes spoke to the taboo and silence surrounding death and disability, where experiences of disability and grief intersect, leading to stigma and discrimination. However, only seven of the 39 included papers focused on autistic grief, most being grey literature, with the majority focused on people with learning disabilities. Mair et al. (2024) recognised the unique experience of autistic grief and recommend further research and review to better understand this.

Review Question

Building on Mair et al. (2024), my review aimed to understand the unique experiences of autistic grief, loss and bereavement to answer the question:

How do autistic people experience grief, loss and bereavement?

As PROSPERO does not currently accept scoping reviews, the review was not registered but is included as an Appendix (Appendix 1).

Scoping Review Method

To ensure adherence to a systematic, methodological process, Mak et al.'s (2022) steps for conducting a scoping review guided this process.

Step 1: Identifying the Research Question

The research question was developed in collaboration with the research team, including Expert by Experience (EbE) consultants to gain their perspectives on the suitability of the chosen focus (see Chapter 3 for details on recruitment of EbE consultants). Each aspect of the empirical research question was explored to understand the current breadth and depth of the literature and any existing or current systematic literature reviews. Researchers conducting reviews identified through PROSPERO were contacted to help with identifying specific gaps in the literature where further systematic review would be beneficial.

Step 2: Identifying Relevant Sources

The search strategy was developed through running several preliminary searches, which were informed by previous reviews in relevant areas (Mair et al., 2024; Westgate et al., 2024). Search terms were developed in accordance with SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) to define key elements of the review question and ensure the search strategy captured these. Each term was checked against Medical Subject Headings (MeSH) thesaurus for relevance and the most updated terminology to ensure this could bring back the most relevant sources in the databases. Consultation with the research supervisors and subject-specific librarian supported the development of this process, including identifying criteria, searching grey-literature sources and truncation using * to gain variations of words (see Table 2).

Table 2

Search Strategy

Key Concepts	Search Terms	Variation
Autism AND	OR	"Autism spectrum disorder" or "autistic spectrum disorder" or "autism spectrum condition" or "autistic disorder" or "autistic people" or "autism in adults" or "person with autism" or neurodivergence* or neurodivergent or neurodiversity or "autistic child" or "child with autism" or neurodevelopment* or asperg*
Grief AND	OR	Grie* or griev* or bereavement* or "anticipatory grief" or "traumatic loss" or "ambiguous loss" or death or dying or "non-death loss"
Experiences	OR	Experience or understanding or view* or feeling* or perception or perspectives

Three primary databases: CINALH Plus, MedLine and Scopus, were chosen based on existing systematic reviews within the field, and their relevance of publications with a healthcare orientation. Search alerts were created for each database to help with identifying and reviewing sources in between active searches. Google scholar was accessed and searched to identify sources which may not be found via the traditional routes. A range of further sources were also accessed and searched, as described in Table 3.

Table 3

Description and Rationale for Sources Searched

Sources Accessed and Searched	Rationale
Informal journals: British Psychological Society (BPS) periodicals, such as Clinical Psychology Forum, Child and Family Clinical Psychology Review and Counselling Psychology Forum. Context and Murmurations	To identify sources which may have been written from a clinical practice lens; both within clinical psychology and systemic family therapy fields, which may include practice-based ideas, clinical work and experiences e.g., grief work and work with autistic people.
Grey literature databases: OpenGrey, PsycEXTRA, ProQuest EBSCO	To identify grey literature, such as dissertations and theses, which may not be published.
Hand searching reference lists of literature meeting inclusion.	To ensure rigorous searching to identify any additional sources which may not have been found through the variety of systematically searched databases.

The search strategy key concepts and variations were used to search grey literature databases. As some sources did not have advanced search tools, the basic key concepts were inputted in several ways to extensively search each term. Literature was assessed using the inclusion and exclusion criteria outlined in Table 4.

Table 4

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Focus on experiences of grief and bereavement for autistic neurodivergent people across the lifespan	Grief experiences of parents following diagnoses of autism or neurodivergence
Participants of all ages	Grief interventions
Language: studies written in English	Articles not related to neurodivergent grief, loss or bereavement
Peer reviewed journals: qualitative studies and mixed methods empirical research.	Literature focused on intellectual or learning disability or other neurodivergence e.g., ADHD
Book chapters; websites and blogs; technical reports	Studies or materials written in any other language
Dissertations/theses with original research related to the research topic	
Commentaries; case studies	
Informal journals and forums	

Sources from all dates

I then began searching for sources. All sources in the search strategy identified were accessed and searched between July 2024 – March 2025. I used Covidence to organise and screen papers found via CINALH, Scopus and Medline. I created an excel spreadsheet to keep an audit trail and record search terms, organise and screen papers searched and accessed via Google scholar, informal journals, grey literature and reference searching (Appendix 2). All searches followed the same process (see Table 5).

Table 5

Process for Systematically Reviewing Sources

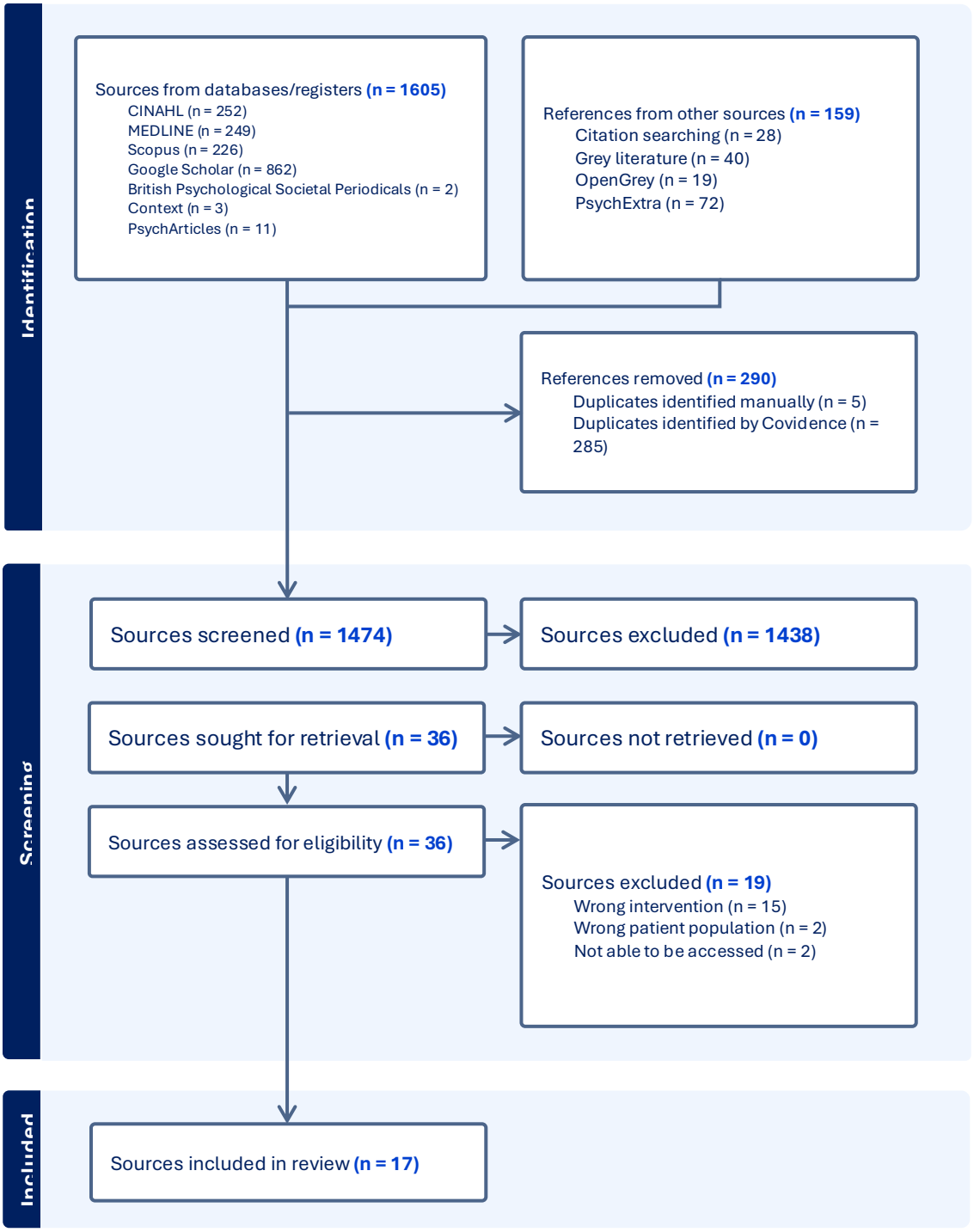
Systematic Review Process	What This Involved
Search for sources	Search via the identified sources with search terms identified
Searches extracted	All sources identified extracted via Covidence or to excel. Duplicates removed automatically (via Covidence) or manually by hand.
Title screening	Titles of each source were initially screened by title only if seeming to meet inclusion criteria. Decisions were recorded via Covidence or manually.

Abstract screening	Abstracts of the titles screened were then reviewed with inclusion and exclusion criteria applied explicitly. Decisions were recorded via Covidence or manually.
Full text review	If the sources identified met inclusion criteria, the full text was reviewed. Decisions were recorded via Covidence or manually. Reference uploaded to reference manager tool.

Whilst searching occurred independently; ongoing discussion and reflection with the research team shaped this process to ensure consistency, reflect on and refine the developing process of searching. The process is presented in the Preferred Reporting Items for Systematic Reviews extension for Scoping Reviews (PRISMA-ScR; [Tricco et al., 2018] diagram in Figure 1).

Figure 1

PRISMA-ScR Flow Chart[3]



[3] Not able to access n = 2. Sufficient efforts were made in attempts to access these sources, including inter-library loan requests to support access and direct email correspondence to the author.

Data Charting

The sources included research articles (n =4) and grey literature, firsthand accounts (n=13). I therefore created two tables to outline the methodological aspects of the identified research sources (Table 6), and key characteristics in grey literature sources, including details of the author, title of the source, year published, country of origin, the author's context and aspects of their identity to contextualise further, the type of source and primary aims, theoretical conceptualisations of autism, grief and bereavement (Table 7; Mak et al., 2022).

The data extraction table was pilot tested with the research supervisors, including refining data extraction categories (Mak et al., 2022). Whilst some of these categories can typically be found in data extraction tables across data synthesizing methods, some categories were not included, such as study limitations. This is because a large portion of the identified sources were grey literature, often with the authors sharing personal accounts of their subjective experiences of grief and bereavement. This was not something that felt applicable to the types of sources included, nor comfortable in my position as a researcher exploring an under-represented area.

Table 6

Data Charting Table of Research Sources

First author and year published	Setting Year of data collection	Country	Identity first/person first language	Any other factors which may affect results	Aim	Recruitment	Participants	Data collection	Data analysis
Barber (2022)	N/A	England, United Kingdom	Identity first	An auto-ethnographic account of one person's account following the death of spouse.	To describe personal experiences of anticipatory grief (AG) and aim to support initiation of reflective discussions around AG to shape nursing practices to improve support for grieving autistic adults.	N/A as personal account	A 63-year-old autistic male, diagnosed in late adulthood.	N/A as personal account.	N/A as personal account.

First author and year published	Setting Year of data collection	Country	Identity first/person first language	Any other factors which may affect results	Aim	Recruitment	Participants	Data collection	Data analysis
Ceney (2023)	N/A	Oxford, United Kingdom	Identity first	An autoethnographic account of the authors experience of autistic grief	To describe the differences in autistic grief to neuro-normative models of grief from the position of an autistic Christian, and to shape the understanding of the wider Church community of autistic grief.	N/A as personal account	A neurodivergent individual, who has a diagnosis of dyspraxia and non-verbal learning difficulty. Self-identified autistic, Christian, male student.	N/A as personal account.	N/A as personal account.
Kallman (2018)	Dissertation as part of Degree of Doctor of Psychology.	Chicago, United States of America	Person first	Nine were parents and one was legal guardian who were mostly all female, White and middle class. Most	To generate greater insight and understanding of the grieving	Criterion sampling strategy used.	Ten parents and legal guardians (age range: 44	In-depth interviews completed by telephone.	Transcendental Phenomenolo

First author and year published	Setting Year of data collection	Country	Identity first/person first language	Any other factors which may affect results	Aim	Recruitment	Participants	Data collection	Data analysis
	Year of data collection not available.			children were males, described as having various diagnoses, including autism, pervasive developmental disorder and Aspergers. Six children had co-occurring diagnosis including ADHD and OCD. Bereavement experiences including the death of a family pet (n=2), close relative (n=7) and both the above (n=1).	process for autistic children and young people from parent's experiences and perceptions.	Recruitment via flyers, social media posting and recruitment emails.	– 65 years old) to autistic children or adolescents (age range: 7 – 18 years old) who experienced the death of a loved one or pet within the last three years.		gical Method of Analysis.

First author and year published	Setting Year of data collection	Country	Identity first/person first language	Any other factors which may affect results	Aim	Recruitment	Participants	Data collection	Data analysis
Pang (2023)	Dissertation as part of Doctorate in Counselling Psychology and Psychotherapy. Year of data collection not available.	London, United Kingdom.	Identity first	No data describing ethnicity, gender identity, or multiply neurodivergent identities. Most describe bereavement of family member including parents and grandparents.	To understand what is like for autistic adults to experience death, bereavement and grief.	Recruitment via social media pages of the National Autistic Society and other autism charities in the British Isles.	Five participants, all with an autism diagnosis, ranging in age between 34-60	A semi-structured webcam interview, with use of adjustments e.g., stimming, raise hand function.	Interpretative Phenomenological Analysis

Table 7

Data Charting Table of Grey Literature Sources

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
Adult with Autism (2024)	Manchester, United Kingdom.	YouTube	Video	An autistic, white British male. Experienced the death of his best friend.	Identity first	To share a personal experience of loss and bereavement and describe autistic differences of grief in response to subscriber requests.	Diagnosed.	None.	None.
Aspirational Autistic (2020)	Nova Scotia, Canada.	NeuroClastic.	Blog.	A queer, autistic femme (pronouns: they/she) who experienced the death of their father.	Identity first	To share a personal experience of autistic grief, within the context of there being an absence of	Diagnosed.	None.	Social Model of Disability.

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
						resources for autism and grief.			
Autism and Grief Project (2022)	United States of America.	Hospice Foundation of America in partnership with the NLM Family Foundation	Two webpages (Resource 1: Grief after Death, and Resource 3: Changes after Death).	Autistic people were advisors in creating content. Specific author characteristics not available.	Identity first	To help autistic adults navigate and cope with the complexities of grief, which arise from death and loss.	Information not available	None.	None.
Bennie (2021)	Calgary, Canada.	Autism Awareness Centre	Blog.	White, mother to two autistic children. Blog post written during covid-19 pandemic.	Person first	To share information, resources and support about autistic grief to address a gap in support from the perspective of a	N/A	None.	Diagnostic focused conceptualisations due to language, such as autism spectrum disorder.

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
						parent to autistic children.			
Eccentrics United (2011)	United States of America.	Eccentrics United	Blog.	An autistic woman in her 40's following the death of a friend.	Person first	To share experiences of being autistic with others and to connect with autistic community, specifically grief in this blog post.	Diagnosed.	None.	None.
Fisher (2012)	Oregon, United States of America.	Thinking Person's Guide to Autism.	Blog.	A 47-year-old, autistic female adult who describes their experiences of grieving the death of their father.	Person first	To raise awareness of personal experience of grief and bereavement to address the gap in articles pertaining to autistic	Diagnosed	Fisher's (2012) Autistic Meltdown Model of Grief.	Fisher's ASD Relationship Model. Neurodiversity Movement.

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
						experiences of grief.			
Graham (2013)	West Virginia, United States of America.	The Arc - Autism Now. Originally published in Spring 2013 issue of Autism Advocate.	Blog.	An autism professional and woman, diagnosed in late adolescence with Asperger's Syndrome. The author writes following the death of her mother.	Person first	To share their preferred conceptualisation of autistic grief, and the unique challenges autistic people may face when grieving.	Diagnosed.	James & Friedman (2009) definition of grief. Kenneth Doka (1999) Disenfranchised grief. Kübler-Ross (1969) Stages of Grief Theory. Worden (2009) Task and Mediator Model of Grief.	Medical description of autistic criteria in line with the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (DSM-IV-TR; 2000).
Lesko (2022) Original date of publication was November 2016	United States of America.	The Mighty.	Online newsletter	A late diagnosed Asperger's autistic, white woman who writes following	Person first	To share a personal experience of autistic grief to reduce loneliness in	Diagnosed.	Kübler-Ross Five-Stage Grief Model.	None.

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
				the death of her mother.		grieving following the death of her mother.			
Lipsky (2013)	United States of America.	N/A	Book. Chapters 1, 2,3 & 6.	An autistic individual, speaker and trainer shaping. Draws on personal experiences of bereavement in writing the book.	Person first	A first-hand account of how autistic people grieve and cope with the death of a significant person.	Diagnosed.	Kübler-Ross Five stage Model; however, this isn't an autistic model and does not fit autistic grief as this does not happen in stages.	None.
Neurodivergentgrrrl (2021).	United States of America.	NeuroClastic	Online article	Experienced bereavement of their grandmother. No further information available.	Identity first	To share their experience of bereavement and grief.	Diagnosed.	None.	None.
Pensive Aspie (2014).	United States of America.	Pensive Aspie; personal website.	Blog.	An autistic person. No further information available. Written	Person first	To share their experience of grief and bereavement	Diagnosed.	None. The author conceptualizes grief in their own way, the	None.

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
				following the loss of their niece.		and provide a resource and personal account to support other autistic people who may be grieving.		Internal Conflict of Grief.	
Purple Ella (2018)	United Kingdom.	YouTube.	Video.	A white, neurodivergent autistic and ADHD content creator, speaker and trainer. Video draws on first-hand account of death of father and maternal grandmother.	Identity first	To describe how bereavement might affect autistic people and how best to support them and address an identified gap in resources to help understand autistic grief.	Diagnosed.	Kübler-Ross (1969) Five Stage Model; but autistic people may not follow these stages.	None.
Lynne Soraya (2014)	United States of America.	Psychology Today website.	Online blog.	An autistic woman diagnosed with Asperger's Syndrome in adulthood. Shares	Identity first	To describe how grief manifests differently for autistic people.	Diagnosed.	Fisher's (2012) Autistic Model of Grief.	None.

Author/Organisation and date published	Country	Organisation or website	Type of source	Characteristics of author/subject	Identity first or person first language	Aims of source	Self-identified or diagnoses autistic	Conceptualisations of Grief and Bereavement	Conceptualisations of Autism
				her experience of bereavement and grief following the death of her friend.					

Data Analysis

Braun and Clarke's (2019) reflexive thematic analysis were followed to analyse the sources identified, due to the limited empirical research sources and large amounts of qualitative, first-hand account sources which were identified through this systematic scoping review. Whilst time consuming, video sources were transcribed manually to capture verbatim the experiences of the authors to produce written word documents to aid analysis. All written sources were then uploaded to NVivo to aid the analytic process. Inductive line-by-line codes were developed directly from the sources. Due to the range of different sources accessed and identified, the data analysis approach was carefully considered and nuanced. More specifically, the full texts of grey literature sources and two autoethnographic qualitative research sources were analysed, due to the first-hand, subjective nature of the entirety of the sources. However, only the results section and discussion of the two phenomenological empirical research sources were analysed. More specifically, both direct quotes from participants and the researchers' interpretations were analysed during coding, in line with the phenomenological and IPA methodological approach, such as the double hermeneutic process of sense-making and interpretation, meaning the researcher becomes part of analysis and interpretation. Themes, or broad patterns of meaning were formed from the codes produced with thematic maps and diagrams refining this process further to consider how the themes and data fit together from my researcher position, lenses and biases. Reflexive journalling was key to this process. Consultation with the research supervisors occurred to refine themes and subthemes further, along with discussion of themes with EbE consultants. Producing the written narrative was the final step of analysis.

Narrative Summary of Sources

In line with a scoping review methodology, a quality appraisal is not required (Mak et al., 2022). Instead, I chose to present a narrative commentary of the sources searched and

accessed. This decision was aligned to an AE position to enact meaning and value in privileging autistic constructed knowledge as highlighted by the inclusion of many of these sources.

Despite the methodological rigour employed and an exhaustive effort to ensure all databases and sources were accessed and searched thoroughly, I was struck by the absence of empirical research available exploring autistic grief. Out of the 17 sources identified, four were research sources, only two of which had been published in peer-reviewed journals (Barber, 2022; Ceney, 2023) and used an autoethnographic methodological approach to describe and situate their personal experiences of grief and bereavement within a particular context. Barber (2022) described his experience of anticipatory grief (AG) following the death of his wife to share the personal experience of death from an autistic, older, male context. Ceney (2023) described his experience of grief following the death of his mother and situates this within a religious context. Two further unpublished research sources describe qualitative empirical research completed as part of educational courses, including doctoral research (Kallman, 2018; Pang, 2023). Both sources use Interpretative Phenomenological Analysis (IPA) to understand autistic grief experiences across the lifespan, including autistic children from parents' perspective (Kallman, 2018) and autistic adults (Pang, 2023). Despite these sources not being published, they have drawn on qualitative research methodologies and demonstrated methodological rigour through reflexivity, quality and validity in qualitative research. A strength of all four sources is the use of qualitative methodologies to explore the richness and detail of subjective experiences of grief and bereavement from an autistic perspective.

In addition, 13 grey-literature sources were identified. Most of these sources were personal blogs or articles written by autistic people describing their subjective experiences of grief and bereavement (Aspirational Autistic, 2020; Bennie, 2021; Eccentrics United, 2011; Fisher, 2012; Graham, 2013; Lesko, 2022; Neurodivergentgrrrl, 2021; Pensive Aspie, 2014; Soraya, 2014). The remaining sources included one published book (Lipsky, 2013), one web-

based resource (Autism & Grief Project, n.d.) and two videos (Adult with Autism, 2024; Purple Ella, 2018). The collection of sources each serve to advocate for the unique differences of the universal experience of grief from a range of autistic adult perspectives. Many of the sources are written by members of the autistic community who either directly share their experience, or who have been involved in co-producing information about autistic grief (Autism & Grief Project, n.d.), all of which are strengths. However, the sources may only represent the views of those who feel able and willing to share their experience publicly, which does not account for many voices that are not heard. Across the whole collection of sources, each only represents the experiences of a single author, or small sub-section of the autistic community. This could be one limitation and may limit the transferability.

The collection of sources shares personal, grief experiences in relation to different contexts and identities. Whilst self-reflexivity of the author is unclear and would not be needed given the nature of the sources, the sources reflect a range of autistic experiences in relation to different identities, predominantly age and gender. This is important with consideration to broader political challenges and discourses surrounding gender and autistic experiences, as described in Chapter 1. However, the sources focus on autistic experiences of those geographically located within the global north and therefore represent more white westernised ideologies or beliefs, particularly of grief, dying and bereavement. This means that the sources do not capture experiences of bereavement and grieving within the global south, which are limitations.

Culture, faith and religion as aspects of identity are also not acknowledged throughout the sources. Only one source contextualises experiences of grieving in relation to religion, namely Christianity (Ceney, 2023), but this is not explicitly named or considered in the remainder of sources. Moreover, the sources do not consider the ways in which culture, religion and faith intersect with grief, bereavement and dying, which are further limitations of the

sources. Whilst this is not to say that the collection of sources and existing bereavement literature are not useful, their colonial roots, which impact underlying assumptions and culturally constructed knowledge should be acknowledged, to highlight the absence of marginalised and oppressed identities and communities (Hamilton et al., 2022).

With consideration to neurodivergence, the sources reference a range of theoretical models to help map ways in which autistic experiences are understood. Whilst many of the sources do not explicitly name these, many of the authors reference or position themselves in line with the Neurodiversity Movement (National Autistic Society, n.d.) through language choices, and ways in which experiences are described. Some describe the Social Model of Disability and its applications to neurodivergence, highlighting negative societal discourses (Woods, 2017) and resisting these through a more neuroaffirmative lens (Chapman & Botha, 2022). Some sources conceptualise autistic experiences with reference to criteria outlined by the Diagnostic and Statistical Manual (DSM; American Psychology Association [APA], 2013) which is often required in formal diagnosis. Taken together with the year of publication, drawing on a CR epistemological position, the ways in which autistic experiences are conceptualised may reflect cultural and social constructions of autism at the time (Lechêne, 2024). Furthermore, differences in conceptualisation may speak to the range of preferences in relation to language within the autistic community, including relationship with using person-first or identity-first language (Brown, 2011).

The range of sources identified can also help to map the ways in which grief and bereavement are theoretically conceptualised. Many autistic authors theorised their own experiences of grief, such as the Meltdown Model of Grief and Internal Conflict of Grief (Fisher, 2012; Pensive Aspie, 2014), which were felt to be more aligned to the unique differences of autistic grief (Barber, 2022; Ceney, 2023; Soraya, 2014). Whilst these are not recognised models within the traditional literature, these sources highlight the importance of privileging

autistic knowledges including theories to help shape societal understandings of the unique differences of grieving from the autistic community. Furthermore, a range of grief models were considered within the context of autistic grief, including the Stages of Grief Model (Kübler-Ross, 1969), Theory of Grief (Parkes and Prigerson, 2010), Tasks of Mourning (Worden, 1992), the DPM (Stroebe et al., 2010), Continuing Bonds (Klass et al., 2014) and Disenfranchised Grief (Doka, 1999). Kübler-Ross' (1969) Stage Model was most cited throughout, however, many commented how they did not follow the typical trajectory as outlined or only experienced one or two stages. Other authors critiqued the model entirely, arguing that it was designed and modelled on neuro-normative experiences of grieving, which may uphold underlying ableist messages from a Social Model of Disability perspective (Ceney, 2023). Stage models of grief have been similarly critiqued within bereavement literature, as highlighted in Chapter 1 (Streoebe et al., 2017).

Additionally, the collection of sources speak to the varied and complex nature of grief and bereavement, which can further critique normative, stage models. Barber (2022) describes AG which is often experienced before someone physically dies (Daly, 2017; Simon, 2008), whilst others describe grief following the sudden death of a loved one (Aspirational Autistic, 2020). Although grief is universal, the sources describe the nuances in grief and bereavement in different relationships to the person who died, including parents, grandparents, romantic partners and friends and resulting changes to identities and roles.

Many authors highlight the lack of research exploring grief and bereavement within adult autistic communities, which many named as a reason for sharing their own personal account (Fisher, 2012). Some authors described a sense of isolation and marginalisation as a result (Aspirational Autistic, 2020; Pensive Aspie, 2014). Some authors described how it had been invaluable to access lived experience stories from members of the autistic community (Soraya, 2014). Whilst most of these sources were not accessed through peer-reviewed empirical

journals or databases, their utility and meaning are high as they seek to provide support to autistic people navigating the universal experience of death, dying and bereavement, but where there are unique differences. It then poses the question of why local knowledges exploring the unique aspects of grieving and bereavement are not privileged or acknowledged in more formal, scientific journals. As highlighted in Chapter 1, autism is a neurotype that is less common than being non-autistic. Neurodivergence can often be an identity positioned as holding less power, in comparison to neurotypical people (Salvesen Mindroom Research Centre, 2023). This context is important to hold as one factor in contextualising the lack of autistic-constructed knowledge privileged within empirical research. This could be contextualised by a Minority Group Model of Neurodiversity, whereby autistic people can experience exclusion due to their perceived inferiority in comparison to neurotypical people, which creates ripples throughout society, including in research (Hahn, 1988; Radulski, 2022). Conversely, diagnosis-focused research may be reductionist to the universality of human grief, and the nuance of autistic grief, which may be harmful. Whilst there are challenges with empirical research, it can be co-produced, completed from a range of epistemological, insider-outsider researcher positions and draw on a range of methodological approaches (UK Research and Innovation, 2025). From a decolonising perspective, research can be critical of the realms in which it exists and be a tool for addressing social injustices to create and contribute to new understandings rooted in anti-oppressive praxis (Lorenzetti, 2013).

Despite a notable increase in awareness, discourse and research both autistic-led, and with a neurodivergence focus, neurodivergent grief and bereavement has not, as reflected by the 17 sources identified. Whilst important and highlight the value of insider accounts, they are still a relatively small contribution. As a research team, we wondered whether this absence spoke to the intersection between autism and grief and the societal taboo and silence that surround both experiences. We thought about how grief and bereavement can be

conceptualised as occurring in relationship with others, and how there continues to be stigmatising and outdated societal discourses about autistic experiences, such as a lack of empathy, emotional experience and interest in connecting with others (Jarvis, 2024). Autistic people may also be infantilised by non-autistic others, perhaps due to differences in culture between neurotypes, which may be another factor explaining the gap in autistic grief research (Stevenson et al., 2011).

The literature identified in this scoping review seeks to explore, question and address the silence and gap in autistic grief empirical research. Drawing on an AE position, the sources identified highlight that autistic people's experiences and voices are present and should be privileged and heard through research activity. This may challenge more traditional perceptions of research, emphasizing the value of insider-researcher, grey literature to make this locally constructed knowledge accessible for all. This will seek to ensure equity in our understandings of common human experiences with consideration to different neurotypes.

Reflexive Thematic Analysis Findings

Four main themes with subthemes were identified following thematic synthesis (see Table 8).

Table 8

Summary of Themes and Subthemes

Main Themes	Subthemes
1. Unrecognised Grief Experiences	a. The imposed neuro-normativity of grief
	b. The social and sensory demands of bereavement and grieving
	c. Disenfranchised autistic grieving

2.	The Major “Derailing” Uncertainty of Grief and Death	
3.	The Accumulative, All-Consuming Nature of Grief and Bereavement as an Autistic Person	a. The internal conflict between the logical brain and emotional pain of grief b. The internalised and embodied emotional distress of autistic grief c. The externalised expressions of autistic grief to the neuro-normative gaze
4.	Adapting to Change and Growing around Grief	a. The healing nature of connection b. Remembering and meaning c. Redefining and reclaiming autistic grief

Unrecognised Grief Experiences

The Imposed Neuro-normativity of Grief

Neuro-normative grief ideas underpinned 14 sources to contextualise the experience of autistic grief (Aspirational Autistic, 2020; Autism & Grief Project, 2022; Barber, 2022; Ceney, 2023; Eccentrics United, 2011; Fisher, 2012; Graham, 2013; Kallman, 2018; Lesko, 2022; Lipsky, 2013; Neurodivergentgrrrrl, 2020; Pang, 2023; Purple Ella, 2018; Soraya, 2014). Some authors described a hyper-sensitivity to whether they were grieving in ways they ought to, often feeling that their grief was wrong and *“non-standard”* in comparison to neurotypical people (Barber, 2022, p.31; Pang, 2023).

> *How well have I done? I honestly do not know. I don’t know what standard I’m being held to, and by whom [...] I’ve heard too many people talk negatively about how others grieve [...] people who, presumably, are more socially gifted than I am. (*Soraya, 2014, p.3*)*

Across the sources, autistic grief reactions were described through a neuro-normative lens appearing *"heartless"* (Purple Ella, 2018, 3:17), *"insensitive"* (Lipsky, 2013, p.14) or *"weird"* (Eccentrics United, 2011, p.2) to non-autistic others based on societal expectations of grief. Some sources described the hidden nature of autistic grief, masked by stereotypical societal discourses of autism, which led to others failing to recognise their grief (Aspirational Autistic, 2020; Eccentrics United, 2011; Pang, 2023).

> *Some community nurses did not see my perceived 'behaviour' towards themselves […] as born out of an AG […] they did not see that I needed and expected support […] they viewed and interpreted my attitudes and behaviour towards them as being verbally 'aggressive' […] completely failed to recognise the impact of autism during this difficult time […]* (Barber, 2022, p.381)

Neuro-normative stage-based models were referenced throughout as not fitting or providing a *"blueprint that fit grieving processes or the unique differences of autistic grief"* (Soraya, 2014, p.2), which Ceney (2023) described feeling in interactions with others in religious contexts like the Church.

> *The coffee chats, once useful to me for processing thoughts, were hijacked into what felt like an assessment of which stage of grief I was in. It was an exam, and I wasn't answering the questions quickly enough.* (p.44)

The Social and Sensory Demands of Bereavement and Grieving

Across the sources, neuro-normativity was experienced through the social and sensory demands of bereavement rituals and grieving as an autistic person (Adult with Autism, 2024; Aspirational Autistic, 2020; Fisher, 2012; Graham, 2013; Lesko, 2022; Lipsky, 2013; Neurodivergentgrrrl, 2021; Pang, 2023; Purple Ella, 2018; Soraya, 2014). Bereavement was described as a *"fundamentally social experience, posing distressing demands"* (Pang, 2023, p.

91). Some authors were left to figure out the unwritten social rules of bereavement rituals, which added a further layer of difficulty when social resources were already depleted (Lipsky, 2013; Neurodivergentgrrrl, 2021; Purple Ella, 2018; Soraya, 2014).

> *I have no blueprint for […] what to expect in the social situations that have come with an event like this. I have been forced to guess my way through, at a time when my typical abilities are compromised by the emotional overload brought about by loss and grief*. (Soraya, 2014, p.3)

Adult with Autism (2024) described masking to cope with attending bereavement rituals and the challenges in needing to hide grief.

> *[...] whenever you're at an event, like a funeral, you're masking, you're being someone you're not whereas you've got true feelings and true emotions over someone who matters, you don't wanna put […] that mask on and smile at people.* (24:18)

The additional sensory aspect of neuro-normative expressions of grief were described, such as, comfort through touch and hugging, which created further discomfort, exacerbated sensory sensitivities and *"added to my pain"* (Lesko, 2022, p.3; Pang, 2023). Some sources described neuro-normative expectations of being around family in bereavement rituals, which came at a significant cost.

> *It was difficult for me to be around my family […] I get the impression that neurotypical people find it comforting to be in the presence of other mourners, but I could not deal with it.* (Neurodivergentgrrrl, 2021, p.2)

Many sources spoke about the challenges in attending bereavement rituals, *"which come with too many expectations to do things in a neurotypical way*" (Pang, 2023, p.106). Some authors described difficulties with funerals due to challenges in being perceived amongst a large amount of people, which may be a source of possible alienation and negative judgement (Adult

with Autism, 2024; Pang, 2023). Despite this, many authors appreciated the opportunity to say goodbye, enduring these demands to honour and respect the person who died (Adult with Autism, 2024; Pang, 2023).

Many sources expressed a strong desire to process grief alone, contrary to neuro-normative grief rituals (Autism & Grief Project, 2022; Bennie, 2021; Fisher, 2012; Kallman, 2018; Lipsky, 2013; Neurodivergentgrrrl, 2021; Pang, 2023). Grieving alone was often a way to reduce the social and sensory demands of bereavement and *"be left alone"* by others, whose presence often *"impeded the ability to begin to journey through grief"* (Lipsky, 2013, p.45). The need to grieve alone was often communicated with a sense of shame in this being different to neuro-normative grief.

> *I had to learn the hard way that sometimes grief is […] lock yourself in your room and the world needs to go away already […] I'm still coming to terms with the fact that I prefer to mourn alone in my room.* (Aspirational Autistic 2020, p.2)

Disenfranchised Autistic Grieving

Many sources described experiences of disenfranchised grief (Adult with Autism, 2024; Aspirational Autistic, 2020; Autism & Grief Project, 2022; Barber, 2022; Ceney, 2023; Lesko, 2022; Pang, 2023), often feeling as though *"people don't understand you or your grief"* (Autism & Grief Project, 2022, p.2), due to differences in autistic grief (Lesko, 2022). This could lead to some authors experiencing guilt (Aspirational Autistic, 2020), feeling that their grief was unjustified (Pang, 2023) and a burden to others, which could impact the ability to talk about grief and *"risked grief not being fully acknowledged or understood"* (Pang, 2023, p.107).

> *[…] you do want to share it [grief], but you don't want to be a burden on the family because they can't understand why you care equally as they do, and everybody else just appears to have moved on already.* (Adult with Autism, 2024, 29:15)

Some sources described a sense of loneliness and isolation in grieving (Autism & Grief Project, 2022; Pang, 2023), which *"felt like I was being left behind"* (p.42) and led to *"a feeling of shame […] that I was still experiencing grief in this raw, sometimes terrifyingly uncontrollable way"* (Ceney, 2023, p.44). A further sense of shame and self-criticism in relation to autistic grief was described, which could be interpreted as a failure in abilities (Barber, 2022; Pang, 2023).

Disenfranchised autistic grief often became internalised and hidden to others through masking by *"silently crying"* (Barber, 2022, p.381) and *"just trying to hide it as much as possible"* (Pang, 2023, p.83). In some sources, an awareness of the universal, societal silence and taboo of death was described as *"the avoidance of death like it doesn't exist"* (Lesko, 2022, p.1), and keeping grief hidden *to "shield others from our grief as bereaved people"* (Pang, 2023, p.125), which furthered a sense of isolation. The experience of disenfranchised grief as an autistic person could compound pre-existing beliefs about the self as being *"of lower importance"* (Pang, 2023, p.112), including a sense of failure and low-self-esteem, which could often be shaped by a marginalised and inferior position in the world.

The Major "Derailing" Uncertainty of Grief and Death

Across many of the sources, the uncertainty and unpredictability of death and grief was a major defining factor of the autistic experience (Adult with Autism, 2024; Autism & Grief Project, 2022; Barber, 2022; Bennie, 2021; Fisher, 2012; Graham, 2013; Lipsky, 2013; Kallman, 2018; Neurodivergentgrrrl, 2021; Lesko, 2022; Lipsky, 2013; Pang, 2023; Purple Ella, 2018). The unpredictable nature of a palliative diagnosis and AG was described, which increased anxiety, a sense of helplessness and feeling out of control (Adult with Autism, 2024; Barber, 2022; Lesko, 2022).

> *[…] and it was like this inevitable countdown for something you had […] no control over which made you feel more and more scared and anxious and worried every day.* (Adult with Autism, 2024, 19:30)

The unpredictable nature of learning about the death of someone was described as *"snapping loved ones from existence, fracturing the safe, familiar routines of old and breaking the template for the future"* (Pang, 2023, p.79), which gave *"no time to acclimatise"* (Neurodivergentgrrrl, 2021, p.3). Death and bereavement often led to significant changes to a person's routine, due to bereavement rituals or events (Autism & Grief Project, 2022), or the death of a person involved in routines, with the intensity of distress and grief measured by their level of involvement (Lipsky, 2013; Adult with Autism, 2024).

> *My Saturdays at 11am aren't going to carry on anymore, because he's not here to meet me at the bridge anymore, and what about that person who I text every day […] I lost a huge part of me when he went. (*Adult with Autism, 2024, 23:19*)*

Across the sources, the disruption to routine and managing such change, was described as the *"hardest hitting part"* (Pang, 2023, p.80), and a *"big, unwelcome change for anyone, especially autistic folk notoriously resistant to change"* (Neurodivergentgrrrl, 2021, p.3). Purple Ella (2018) illustrated the importance of routines and safety in predictability after learning about her father's death by "*choosing to carry on with my plan"* as *"it might not occur to an autistic person to immediately to change that plan or stop that routine" (3:43).*

The unpredictability could be distressing, with anger described as a dominant emotion and *"a natural reaction to an overwhelming stressor that threatens to annihilate existing routines"* (Lipsky, 2013, p.42; Autism & Grief Project, 2022). The loss of predictability through changes to routine could lead to increased anxiety (Autism and Grief Project, 2022) and feeling *"bewildered with the task ahead"* (Pang, 2022, p.79). The challenges of trying to adapt to the

unpredictability of death *"proved to be too much, which led to experiences of meltdowns, which took me by surprise because I was trying so hard to control my anxiety"* (Lipsky, 2013, p.44) and could also precipitate mental health breakdowns (Lipsky, 2013).

Furthermore, one's own grief responses could be unpredictable and *"acts as another source of uncertainty",* which feels "*foreboding and threatening […] that creeps in slowly, creating a sense of panic about what to do now"* (Pang, 2023, p.80). The unpredictability of grief was compounded by a noticeable lack of information and resources about autistic grief (Aspirational Autistic, 2020; Barber, 2022; Ceney, 2023; Fisher, 2012; Graham, 2013; Kallman, 2018; Pensive Aspie, 2014; Purple Ella, 2018; Soraya, 2014). Conversely, Lesko (2013) described the certainty of death and grief and that when journeyed through provided safety in predictability by offering a blueprint to cope with future losses (Pang, 2023).

> *I think that […] when you've never experienced it before, you don't really know what to expect. But I know […] now what kind of a griever I am.* (Pang, 2023, p.131)

Building certainty and predictability through re-establishing or replacing routines were crucial to the grieving process (Lipsky, 2013), such as *"scheduling time to process the death emotionally"* (Autism & Grief Project, 2022, p.2). Parents also recognised the necessity of predictability amongst the chaos and unwelcome changes posed by death and grief (Kallman, 2018)

> *[…] our lives have kind of changed since she died, so just keeping him in that routine and saying no matter where we live, we're still going to do the same things*. (p.94)

The Accumulative, All-Consuming Nature of Grief and Bereavement as an Autistic Person

The Internal Conflict between the Logical Brain and Emotional Pain of Grief

Some sources described feeling *"stuck in this looping cycle between my brain and my heart"* (Pensive Aspie, 2014, p.4) to illustrate the difficulties in the use of logic to try to process grief (Barber, 2022; Bennie, 2021; Eccentrics United, 2011; Kallman, 2018; Lipsky, 2013; Pang, 2023; Soraya, 2014).

> *It is here that grieving meets scientific curiosity in trying to give closure. But of course this questioning won't give me closure. I know logically I just have to move on and accept that I'll probably never know the exact details of the accident and the aftermath* (Eccentrics United, 2011, p.1)

Kübler-Ross' stage model was referred to in some sources, which highlighted the subjective experience of grief (Barber, 2022; Kallman, 2018; Lipsky, 2013; Pensive Aspie, 2014). Some sources described how the news of death was perceived as fact, as *"the logical brain accepts that as real and skips straight to the shock part, compared to non-autistic people"* (Lipsky, 2013, p.33). This was the same for Barber (2022), who *"never denied the fact that Liz's death was inevitable"* (p.380). Some sources described knowing that death was final, which meant that some stages of grief, such as bargaining weren't followed (Kallman, 2018; Pensive Aspie, 2014).

> *[…] my brain knew she was gone. It was logical. There was no denying it […] I didn't feel the need to bargain because my logical brain understands we CANNOT go back in time*. (Pensive Aspie, 2014, p.3).

Conversely, some sources did describe experiences of disbelief and the initial shock of death, which were often connected to change, disruption to routines and the finality that can be difficult to comprehend in the early stages of death and grief (Adult with Autism, 2024; Lipsky, 2013; Pang, 2023; Purple Ella, 2018).

> *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 […]* (Pang, 2023, p.83).

The sense of shock described in some sources was exacerbated by the reality of being with the person shortly before their death (Eccentrics United, 2011; Soraya, 2014). Some sources attempted to process the reality of death logically by *"repeatedly asking questions"* (Bennie, 2021, p.1*), "recreating the accident in my mind"* (Eccentrics United, 2011, p.2) and *"replaying what I knew of my friends' last hours over and over [...]* to *"attempt to make sense of what happened"* (Soraya, 2014, p.5).

Many sources described difficulties in processing and comprehending the finality of death without physical confirmation that death had occurred. Some sources described *"checking for life"* (Barber, 2022, p.381), knowing about the biological processes of dying, sharing scientific information (Kallman, 2018) and needing concrete, physical proof of death as ways to begin to process the death (Aspirational Autistic, 2020; Eccentrics United, 2013; Fisher, 2012; Kallman, 2018; Pang, 2023; Purple Ella, 2018).

> *I needed to see his body to prove to myself that he was dead. Until I had seen that, he wasn't dead, he could still exist, I couldn't wrap my head around the concept of him being dead without seeing physical evidence of that fact.* (Purple Ella, 2018, 4:03)

Many sources described a logic-based, practical approach to grieving before being able to move into the emotional processing (Barber, 2022; Eccentrics United, 2011; Fisher, 2012; Kallman, 2018; Pang, 2023). In experiences of AG, the sources described tending to the needs of the person dying, such as providing physical care and support (Barber, 2022; Fisher, 2012; Lesko, 2013).

> *It was logical to me to be as armed as possible with knowledge […] to be of some help. As a result, I acted as the liaison between the doctors and the family, coordinating meetings for the DNR decisions, negotiating next steps […]* (Fisher, 2012, p.1).

This continued into the immediate aftermath of death through focusing on practical tasks such as *"notifying a funeral home, family, friends […] of the death"* (Graham, 2013, p.2). Some sources described how the death itself was not the difficulty, but rather the sense of powerlessness and helplessness at practically not being able to stop a loved one's suffering, which were usual ways of coping (Adult with Autism, 2024; Barber, 2022; Fisher, 2012; Neurodivergentgrrrl, 2021).

> *In some ways, it was not her death that was the problem, but seeing Liz die slowly in front of me and the powerlessness of knowing that there was very little, if anything, that I could do to prevent it, that was difficult for me to accept and process.* (Barber, 2022, p.380)

Many sources also described the emotional impact of the conflict between logic and emotion, which added a layer of distress. Some described needing *"permission to put logic on the backburner"* (Pensive Aspie, 2014, p.5) and *"permission to cry"* (Pang, 2023, p.122). Some sources described the frustration in logic not working as a strategy for sense-making and obtaining safety in the world, which death threatened and removed.

> *It was maddening. For the first time in forever, my heart trumped my brain. I was at a loss. I did not know what to do with myself.* (Pensive Aspie, 2014, p.4).

The Internalised and Embodied Emotional Distress of Autistic Grief

Across the sources, a range of hidden, internalised expressions of grief were experienced. Many sources described how grief manifested as an embodied *"more visceral"* (Pang, 2023, p.82) physical feeling in the body, like "*my lungs felt as if they were filled with*

cement" (Lesko, 2022, p.4), *"which threatened to crush the life out of me like a colossal slab of granite dropped directly onto my chest*" (Neurodivergentgrrrl, 2021, p.3). The physicality of grief was also made sense of as a precipitating factor to the onset of long-term health conditions (Adult with Autism, 2024; Autism & Grief Project, 2022).

> *[...] and it made me ill, it did, […] and that's where I strongly believe it gave birth to fibromyalgia in me, because it can be bought on by the death of a loved one, and I loved him to bits, he was my best mate*. (Adult with Autism, 2024, 20:00)

Grief could be described as an "*empty, gnawing pain*" (Lesko, 2022, p.2) and "*a physical void kind of emptiness, this great gap inside me*" (Pang, 2023, p.86), which felt like *"I'd been eviscerated*" (Neurodivergentgrrrl, 2021, p.3). This was often connected to the significant pain of losing a safe person in the world, which was often overwhelming and reported as *"feeling homesick"* (Pang, 2023, p.88; Lesko, 2022; Purple Ella, 2018). Some sources described the difficulty in navigating life and "*attempting to somehow survive*" without the person who died (Lesko, 2022, p.3; Ceney, 2023; Neurodivergentgrrrl, 2021).

> *[…] it really did feel as though the earth had given way. Picking up the fragments of glass off the floor, I knelt and felt the flood of overwhelming emotion as the anger and fear subsumed me, the earth gave way once more* (Ceney, 2023, p.39).

As in the universality of human grief, a range of emotional expressions varying in degrees of intensity and frequency were described across the sources, such as anger, frustration, anxiety and fear, which often manifested physically as shakiness and jelly legs, anguish, and sadness (Autism & Grief Project, Bennie, 2021; Ceney, 2023; Fisher, 2012; Lipsky, 2013; Kallman, 2018; Pang, 2023; Pensive Aspie, 2014). Depression was described as *"a prominent emotional experience of autistic grief"* (Lipsky, 2013, p.51), which took up processing time and space.

> *Depression, however, hit me like a brick wall. Overwhelming sadness consumed me. I felt immobilized by my sadness. Immobilized and confused […] I felt like every ounce of my energy was poured into processing the depression I was feeling.* (Pensive Aspie, 2014, p.3)

Some sources described increased levels of distress such as mental health crises (Purple Ella, 2018), precipitating the onset of pre-existing mental health difficulties, such as obsessive-compulsive behaviours (Soraya, 2014), suicidal thoughts and self-injurious behaviours (Neurodivergentgrrrl, 2021; Pang, 2023).

> *I literally believed that I would die, and had it not been for the daily fistful of antidepressants that literally keep me alive […] I don't even like thinking about what might have happened.* (Neurodivergentgrrrl, 2021, p.3)

Some sources described the experience of death and bereavement as *"really traumatic"* (Pang, 2023, p.149; Ceney, 2023). The sense of pain was profound, from *"watching my wife Liz slowly die in front of me"* (Barber, 2022, p.380) in experiences of AG, to the *"utterly devastating—traumatic"* experience of sudden death (Neurodivergentgrrrl, 2021, p.3). Some autistic people in the sources described the traumatic nature of the sensory aspects of death and bereavement (Pang, 2023).

> *[…] 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 […] triggered an emotional response for me.* (p.92)

Some of the sources described the impact of autistic alexithymia when grieving (Pang, 2023; Purple Ella, 2018; Soraya, 2014). This often led to difficulties in *"identifying and making sense of the feelings that arose"* (Pang, 2023, p.85). Some sources described a delay in

emotional processing and *"eventually making the connection"* (Soraya, 2024, p.7), whilst others described being *"flooded with emotions"* (Purple Ella, 2018, 5:55) but finding it difficult to verbalise and express often *"complex, grief-related emotions into words"* (Pang, 2023, p.161; Autism & Grief Project, 2022). Parents in Kallman's (2018) study felt that their children masked, and kept emotions bottled up.

> *[…]. I think he was getting into his teenage years, which gave him more of that isolation and that I'll just deal with it the way I deal with it, which is […] deal with it emotionally myself, and not have anyone see what it's doing to me […]* (p.87)

The Externalised Expressions of Autistic Grief to the Neuro-normative Gaze

The cumulative effect of the unique challenges of autistic grief resulted in what many sources described as an increase in autistic experiences recognisable to others (Adult with Autism, 2024; Bennie, 2021; Ceney, 2023; Fisher, 2012; Graham, 2013; Lipsky, 2013; Neurodivergentgrrrl, 2021; Pang, 2023; Purple Ella, 2018; Soraya, 2014). Bereavement could place *"polytropic demands on monotropic ways of experiencing the world, significantly overloading the autistic brain"* (Pang, 2023, p.157). Many of the sources described heightened sensory experiences (Autism & Grief Project, 2022; Bennie, 2021), such as *"noises were too loud, the world was too fast"* (Purple Ella, 2018, 8:45). This was conceptualised as *"sensory processing failure"* (Graham, 2013, p.2), because of the emotionally overwhelming nature of grief (Ceney, 2023; Soraya, 2014).

> *[…] only having so much space in which to process information, and if a very large part of that is consumed with emotions, it can easily result in failures of other areas.* (Fisher, 2012, p.2)

Additionally, many sources described frequent experiences of meltdowns and shutdowns (Fisher, 2012; Lipsky, 2013; Pang, 2023; Purple Ella, 2018). Some sources

described changes in executive functions, such as processing abilities, loss of focus, memory and attentions difficulties (Bennie, 2021; Ceney, 2023; Fisher, 2012; Neurodivergentgrrrl, 2021; Purple Ella, 2018).

> *I realized that I could no longer put pieces of data together anymore in any situation. Emails were all single entities and my program at work was nothing but lots of little pieces of data with no relationship that I could find […]* (Fisher, 2012, p.2)

Some sources described sudden changes to emotional experiences, which *"just come out of nowhere"* (Kallman, 2018, p.90) and the *"emotions beginning to leak out"* (Soraya, 2014, p.5). Many sources described expressions of grief through crying, which was an *"ocean of tears"* (Neurodivergentgrrrl, 2021, p.1; Eccentrics United, 2011; Fisher, 2012; Kallman, 2018; Pang, 2023; Pensive Aspie, 2014; Soraya, 2014). Grief manifested in other ways, such as behavioural changes like *"yelling and screaming"* (Kallman, 2018, p.90) and social and academic changes, which *"made it really hard for him to focus […] on school"* (Kallman, 2018, p.92). Some experienced developmental regressions (Bennie, 2021), such as difficulties controlling bodily functions, like toileting (Kallman, 2018) and changes to eating and appetite (Autism & Grief Project, 2022; Bennie, 2021; Kallman, 2018; Lesko, 2022; Purple Ella, 2018).

Some sources reported sleep difficulties (Autism & Grief Project, 2020; Lesko, 2022; Kallman, 2018; Pang, 2023; Soraya, 2014), such as bad dreams about the person who died (Kallman, 2018), which were often accompanied by *"real strong emotions"* (Pang, 2023, p.85). Some described *"acting normally on the outside"* (Pang, 2023, p. 105), which was *"often deceptive and a sign of emotional overload"* internally (Soraya, 2014, p.5; Kallman, 2018). Furthermore, neuro-normative misinterpretations of distress risked further disenfranchising autistic grief, arising from differences in external expressions of grief, and the internal experience, which may mean the connection with grief was missed (Kallman, 2018; Pang, 2023).

> *I think people assumed that I was depressed and […] looking back on it I don't think that I was depressed, I think I was losing executive functioning skills as a result of processing grief […]* (Purple Ella, 2018, 8:24)

Adapting to Change and Growing around Grief

The Healing Nature of Connection

Some sources described seeking comfort from the loneliness and taboo of death through safe connection with others who were grieving (Lesko, 2022; Pang, 2023). Whilst some sources described seeking time alone, the key to connection was finding emotionally safe people or communities, which humanised the experience of grief without the reprise of negative judgement and imposed neuro-normative grief (Lesko, 2022; Pang, 2023, Pensive Aspie, 2014). Online support groups could be beneficial, but as an observer and listener, rather than sharer, which could feel uncomfortable (Graham, 2013). For those who did feel comfortable to share, talking about grief was an opportunity to story all aspects of bereavement, talk in detail about the person who died and break the societal taboo surrounding death (Pang, 2023).

> *I think when it comes to death […] can't just […] 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 […]* (p.116)

Some sources also described the power of connection with the autistic community through lived experience accounts of autistic grief, which created a sense of belonging and inclusion (Ceney, 2023; Pang, 2023; Soraya, 2014).

> *Fortunately for me, at least a few adults on the spectrum have chosen to tackle the topic themselves — which has been invaluable for me as I navigate my own grief.* (Soraya, 2014, p.2)

Remembering and Finding Meaning

Many sources acknowledged the universal pain of remembering, with sudden memories of the person, or visiting a place special to them, triggering *"overwhelming feelings"* (Autism & Grief Project, 2022, p.3; Pensive Aspie, 2014). Grief was often triggered on anniversaries of the death, Christmases, religious holidays or other special events, like weddings (Lesko, 2022; Ceney, 2023; Kallman, 2018; Pang, 2023;). Pensive Aspie (2014) described the pervasive pain of remembering in the early stages of grieving.

> *The first of every month is the anniversary of her death. I used to feel that it was one month further away from her. Further away from the last time I saw her face. Further away from the last time I heard her laugh.* (p. 5)

Many sources described more practical ways of remembering and re-connecting with the person who died (Adult with Autism, 2024; Autism & Grief Project, 2022; Ceney, 2023; Fisher, 2012; Neurodivergentgrrrl, 2021; Pang, 2023). This often involved continuing to engage in activities the person who died enjoyed, which were ways of continuing bonds more tangibly (Kallman, 2018; Neurodivergentgrrrl, 2021; Pang, 2023). Some sources described how physical qualities of the person were adopted *"to build up what I show to the world as my masked face"*, to continue bonds (Pang, 2023, p.127). Many sources described the act of transforming grief to serving and helping others, so that *"suffering wouldn't have been for nothing"* (Pang, 2023, p.131; Lesko, 2022; Pensive Aspie, 2014), which helped to journey through grief (Fisher, 2012).

> *[…] it would be fitting to transform grief and grieving, […] which are natural emotions and experiences, into a life of active and compassionate service to and for others.* (Barber, 2022, p.381)

Additionally, some sources described the importance and seriousness of ensuring that mourning rituals accurately and meaningfully represented the wishes of the person who died

(Adult with Autism, 2024; Lesko, 2022; Pang, 2023). This was often connected to a sense of truth, respect and justice described in relation to autistic culture (Adult with Autism, 2024). Some sources described a sense of happiness in "*giving her the send-off that she wanted"* (Pang, 2023, p.137). Conversely, Adult with Autism (2024) described the challenges he encountered.

> *[…] when he passed away, I got twice as protective because I knew him. I knew him inside and out and one of the things I knew he detested was insincere social media posts […] he despised it […] and then unfortunately he became part of that when he died and I must have fell out with over 30 people […]* (20:24)

Religious and spiritual sense-making were described in some sources (Kallman, 2018; Pang, 2023), to make meaning of death not being the end, with heaven and the afterlife being opportunities for re-connection (Kallman, 2018; Pang, 2023). Parents of autistic bereaved children made meaning of the person who died as *"an angel"* (Kallman, 2018, p.83) and spiritual beliefs could be comforting and made more sense, especially when logical explanations weren't available (Pang, 2023).

> *Well, you know he's still with you, right? You know, you can feel him if you just—if you sit quietly and you search with your heart, you can feel him around you […] his spirit is all around you and can be with you wherever you are, even at school right now.* (Kallman, 2018, p.83)

Some sources made meaning in the loss through learning about the self, such as discovering *"resilience I didn't know I had"* (Soraya, 2014, p.7), gaining perspective and *"finding peace with who and what I am"* (Neurodivergentgrrrl, 2021, p.4; Pang, 2023). Bereavement could also lead to a greater awareness of mortality and death, which some sources *"living life more fully"* as a result (Pang, 2023, p.131).

Redefining Grief and Reclaiming Autistic Grief

Many sources described grief as a permanent part of life, which *"never dilutes"* after the death of someone significant and rejected neuro-normative, stage models of grief to reclaim the validity of autistic grief (Adult with Autism, 2024, 26:50; Aspirational Autistic, 2020; Barber, 2022; Ceney, 2023; Graham, 2013; Neurodivergentgrrrl, 2021; Pang, 2023). Many sources described the strengths of being autistic in navigating death and grief, such as the natural resource of self-regulatory behaviours (Bennie, 2021) and passions becoming *"beacons in the dark"* (Aspirational Autistic, 2020, p.3) when journeying through grief (Autism & Grief Project, 2022; Fisher, 2012; Lesko, 2022; Lipsky, 2013; Pang, 2023).

Autistic grief was also expressed in line with communication preferences, such as writing which was "*a way to kind of crystallise what might be going on at the back of my head"* (Pang, 2023, p.121). Many sources shared their own definitions of grief, such as *"the most painful expression of love"* (Aspirational Autistic, 2020, p.3) and often depicted the ongoing connection to the person who died who will be *"here with me, in my heart forever more*" (Lesko, 2022, p.6).

Some sources appeared to take an advocacy stance to different audiences, including autistic and non-autistic people, to *"normalize the honest and raw expression of autistic love"* (Aspirational Autistic, 2020, p.3), and advocate that autistic grieving is just as valid (Graham, 2013; Aspirational Autistic, 2020).

> *An alternative narrative for journeying through autistic grief may be provided via the use of 'crip time'. […] This crip time future is one without complete healing. Just as autism will always remain, so does grief in unique and personal ways.* (Ceney, 2023, p.45)

Conclusions and Rationale for Research

The sources convey the universal, human experience of death, bereavement and grief, whilst identifying the unique differences of autistic grief that may pose an additional layer of

distress. These unique differences can often be contextualised by neuro-normative ideas related to grief and abilities, which risk disenfranchising and masking autistic grief experiences. Additionally, death and grief can be unpredictable, which may pose challenges to utilising the often-logical qualities of an autistic neurotype in processing the range of emotions experienced in grief. Furthermore, autistic grief was described as often having a unique visceral feel and physicality. Autistic differences in identifying, processing and expressing emotions may make grief more challenging, all of which may lead to sensory processing difficulties and may increase externalised autistic experiences recognisable to others. Despite the range of additional challenges, autistic people may harness strengths in their neurotype to help journey through grief, remember and make meaning, as well as reclaiming and redefining autistic grief in their own words to reject neuro-normative imposed grieving.

Contrary to my initial assumptions and ideas upon commencing this review, I expected to access and identify more empirical research, peer-reviewed sources than I did. However, as outlined, autistic grief and loss appears to be an emergent field of research, with minimal empirical research studies to date as identified during the completion of this review (Barber, 2022; Ceney, 2023; Kallman, 2018; Pang, 2023). Whilst actively systematically scoping and reviewing the literature base, I was simultaneously learning about the research landscape, which challenged my initial assumptions. However, in collaboration with my research supervisors, I decided that it was important to continue with the review and centre the breadth and range of sources identified, which reflected the lack of information about autistic grief, as acknowledged across the sources, and the key systematic literature review by Mair et al. (2024).

While this provides a novel synthesis of current knowledges considering autistic grief, taking a critical lens in evaluating this review, there are several limitations to consider. Specifically, there is large amounts of heterogeneity amongst the sources identified. The

sources range in terms of their length, with some being relatively short and others being significantly longer, the breadth and diversity in source type, from blogs, to articles, to information resources and videos, which added nuance and complexity in completing this review, and therefore conclusions and implications should be held tentatively. Additionally, the four identified empirical pieces of research drew on qualitative methodologies, with only two as published, peer-reviewed articles, but all focusing on subjective, first-hand accounts of the authors or in-depth accounts of autistic participants, utilising phenomenologically focused methodologies. It is also acknowledged that the sources may challenge how peer-reviewed empirical research, and systematic reviews are more traditionally conceptualised within academic fields, but a scoping review is used here as a broad framework for synthesising current knowledge in this highly under-researched area. I conceptualised this as reflective of the double taboo of death, loss and the intersection of autistic grief, as highlighted in previous systematic reviews (Mair et al., 2024).

Whilst I recognise the value of peer-reviewed empirical research and the critiques of the review which evolved as presented, in line with an AE, the sources foreground autistic experiences, from autistic people and shine a light on the often-hidden experiences of death, bereavement and grief from an autistic perspective, which are meaningful to shaping our understanding of the universal, human experience of death, bereavement and grief. Through this, future empirical research could be completed to further explore the unique differences of autistic grief, as highlighted by the sources. This would help to build the empirical knowledge base, which may facilitate further systematic review of empirical research completed in the future to enhance understandings more systematically, when more empirical research is available.

Additional research and clinical implications were also identified. Some sources described distressing interactions with healthcare professionals who struggled to recognise

expressions of autistic grief, which was an additional layer of distress (Barber, 2022; Pang, 2023). This review highlights the importance of healthcare professionals understanding and recognising expressions of autistic grief to inform their clinical practice and offer neuroaffirmative and person-centred care to autistic grievers that does not risk disenfranchising or stigmatising their grief. Further research could seek to explore different types of loss, such as baby loss. More specifically, this research is imperative to listening to what it means to experience baby loss as an autistic woman or birthing person and the unique differences this may entail, as highlighted by the findings of this review to help shape more specific, neurodivergent-informed and person-centred care to inform future research and clinical practice.

Aims and Research Question

The study will therefore aim to understand the experiences and sense making of autistic women and birthing people who have lived through baby loss, including autistic experiences of pregnancy, baby loss and grief. It is my hope that this research will be a way to hear the experiences from autistic people directly and share through empirical research to dismantle neuro-normative expressions of grief, re-legitimise and de-silence baby loss to better understand autistic grief and baby loss. This will be explored through the main research question:

How do autistic women and birthing people make sense of their experiences of baby loss?

Chapter 3: Method

This chapter will outline the chosen methodological research design and epistemological positioning. I will describe how the study was developed, carried out and detail how each decision was made. This chapter will end by describing the processes of ensuring methodological rigour and self-reflexivity.

Consultation with Experts by Experience

Two bereaved autistic women were recruited as EbE consultants. Sands Baby Loss Charity supported with recruiting EbE consultants, which involved sharing one social media post across their platforms, including Facebook, Twitter, Instagram Story and LinkedIn. The posts invited interested people to make contact via email for a follow-up discussion. EbE consultants were valued members of the research team and were paid £20 per hour for their time across the duration of the research.

EbE involvement was sought at various times throughout the lifespan of this study, and the relationship was kept alive in quiet moments through email check-ins, updates and meetings, as required. Consultation with EbEs took place in line with individual preferences and included both online meetings to discuss aspects of the project, reviewing materials and email correspondence. As examples, EbE involvement shaped the focus of the research in its early phases, including the rationale and aims of both the scoping review and empirical study. Whilst EbE consultants were involved during the scoping review as described in Chapter 2, they were more heavily involved in the empirical study. More specifically, they were key to the design of the study, including reviewing all recruitment materials. This led to the inclusion of regular trigger warnings and ensured the language met the needs of the autistic community in a way that was inclusive and tried to encompass all views. EbE consultants played a key role in shaping the construction of the interview guide, which influenced language choices, exploring

experiences of communication with professionals and check-ins at particularly sensitive points, like questions related to descriptions of how their babies died. EbE involvement was also sought during analysis to reflect and review themes arising following participant interviews.

Design

A qualitative research design using IPA was considered most appropriate to explore autistic baby loss experiences. Qualitative research encompasses a broad range of methodologies that seek to understand participant experience and meaning through internal states, beliefs, feelings, processes and attitudes, in contrast to quantitative methodologies (Hammarberg et al., 2016; Hammersley, 2013). The subjective essence and focus on understanding the nuances of human experience are strengths of qualitative research methods.

Interpretative Phenomenological Analysis

IPA was the chosen qualitative methodology. IPA explores personal, idiographic meaning and sense-making of first-hand, phenomenological subjective accounts of lived experiences and reality, including autistic women and birthing people's experiences of baby loss (Smith & Nizza, 2002). IPA theoretically draws on a hermeneutic approach to explore human experience through interpretation and meaning ascribed to experiences (Smith et al., 2009). Researchers engage in a process of double hermeneutics to make sense of participant's descriptions and sense making of their reality, thus becoming part of the interpretative analytic process, meaning that researcher positionality and epistemological position are key to acknowledge (Eatough et al., 2011; Smith et al., 2002; Smith & Osborn, 2003). IPA is often a suitable methodology for studies with a sensitive and emotive focus, such as baby loss, along with phenomena which may be under-represented, complex and ambiguous (Smith et al., 2002; Smith & Osborn, 2015). IPA, however, typically focuses on understanding a smaller group of participants' experiences to allow for rich insight into their subjective lived experiences. IPA has

also been criticised for its focus on phenomenology and subjective experience, without explaining why, with consideration to socio-political contexts (Tuffour, 2017).

From a CR perspective, IPA's focus on language reflects personal and subjective experiences connected both to knowledge that can be physically observed and influenced by social and cultural discourses, contexts and tangible structures (Bhaskar, 1978). Baby loss and autism are observable, objective realities, characterised by the real and felt physical absence of a baby and experience of autistic differences. IPA was chosen to sit with participant's and listen to their experience. Each participant's experience of loss will be shaped by subjective social and culturally constructed contexts, which can be communicated by idiosyncratic language and communication; all of which are part of the double hermeneutic process of interpretation, meaning and sense-making (Tuffour, 2017).

Semi-structured Interviews

Semi-structured interviews were chosen in methodological alignment with IPA and offer in-depth accounts of autistic women and birthing people's experiences of baby loss (Smith et al., 2009). Semi-structured interviews were chosen in line with an AE and neuro-affirmative position to provide safety in predictability through sharing a brief framework of questions in advance, and with consideration to the sensitive topic of baby loss to support with building rapport and a safe enough space in which to share experiences.

Study Development

Recruitment

Due to barriers to access and possibly traumatic experiences of healthcare for autistic women and birthing people, particularly in the perinatal period, and the neuro-normative, cis-normative and heteropatriarchal language underpinning mainstream services, which can be exclusionary to the diversity in gender identity of the autistic community, I chose not to recruit

through NHS pathways (Pezaro et al., 2024; Westgate et al., 2024). Instead, four recruitment pathways focused on either baby loss or autistic parent and perinatal contexts were identified. All recruitment advertisement involved sharing a research poster with a small blurb and supporting alt text (Appendix 3).

Each recruitment pathway granted access to the perspective of autistic women and birthing people who have experienced baby loss (Appendix 4). Participants were recruited using a purposive and snowballing sampling technique to identify groups of people based on specific characteristics meaningful to the research question (Smith et al., 2009). Recruitment was initially considered as a possible challenge due to the emotive topic and specific target group of participants. However, a stepped approach to recruitment was devised to manage potential volume of interest; a decision informed by the recruitment of EbE consultants, during which many responses were received in a short space of time immediately after a recruitment post went live (see Table 9).

Table 9

Recruitment Strategy

Recruitment Pathway	Method of Study Advertisement	Timing of Recruitment
Sands Baby Loss Charity	Sands Baby Loss Twitter Main Facebook page Instagram via Story LinkedIn Main Sands Website Research Section	First recruitment pathway to open

Autistic Parents UK	Public and Private Facebook Groups	Two weeks after first recruitment pathway
Maternity Autism Research Group (MARG)	MARG social media including Twitter. Snowballing via each individual MARG research network	Four weeks after first recruitment pathway
Research Twitter account	Twitter posts with mentions to baby loss and autistic accounts to support reach of posts.	Two months after initial pathways opened due to quieter periods of recruitment.

A clear recruitment process was developed to ensure participants gave informed consent throughout and considered the management of distress. The recruitment process was designed foregrounding autistic experiences, including processing differences and safety in predictability by sharing each step in advance (see Table 10).

Table 10

Recruitment Process

Recruitment Process	What This Involved
1. Poster advertised via recruitment pathways.	Invitation to interested people to contact lead researcher to share their contact details for a further follow-up telephone conversation.
2. Initial email following contact received to arrange brief telephone discussion.	Lead researcher sent email template to offer follow up discussion by telephone and share screening questions in advance (see Appendix 5). This gave people opportunity to process information with more time, ask questions or change their mind to taking part in telephone call.
3. Telephone screening conversation.	Conversation via telephone to briefly describe study and discuss suitability guided by screening questions, limit chances of participant fraud and start to build relationship with possible participants. Collaboratively advise and agree if study may be good fit or not during telephone call and gain consent to share further materials if agreed.
4. Send initial information via email.	Give participant trigger warning and share Participant Information Sheet (PIS), distress management protocol and debrief document with signposts and resources.

	Agree a deadline with person in which to contact researcher (either on the day or up to 3 days later). Researcher to send reminder email on agreed date by email (e.g., would you like to hear more about this study? Please reply yes or no). If no contact, informed consent privileged and no further contact.
5. Send further information via email.	Give further trigger warning and share interview guide, brief demographic questionnaire and consent form. Agree a deadline for person to contact researcher (either on the day or up to 3 days later). Researcher to send reminder email on agreed date by email (e.g., If you would like to participate, please send back a completed and signed copy of the forms). If no contact, informed consent privileged and no further contact.
6. Arrange interview via email.	Researcher will organise interview date and time with participant via email.

19 autistic people responded to the research advert across the duration of recruitment. Initially, as expected, interest in the study was high. Over time, recruitment slowed, which was consistent with observations from some of the recruitment pathways more broadly. The recruitment adverts received a high level of engagement, as reflected by the 19 people who made contact, which suggests the importance of research in this area. I reflected on the disparity between expressions of interest and participants who decided to take part, such as how taking part in research may understandably feel vulnerable and may be distressing. I thought about this in the context of safety and communication with someone unknown, despite best attempts to create a brave and safe enough space.

Inclusion and Exclusion Criteria

IPA seeks to understand experiences of a relatively homogenous group who share similar aspects of a particular phenomenon (Smith et al., 2009). Whilst autistic experiences are not homogenous, and every autistic person is different, autistic women and birthing people who experienced baby loss were central to meaningfully exploring the research question, thus share homogeneity in these connecting experiences. A range of inclusion and exclusion criteria were centred around these experiences, which were discussed with each prospective participant as part of the pre-screening procedure and to support informed decision-making to participate. I took an open, collaborative stance and honoured participants knowledge of themselves, which felt particularly important in building trust, safety and rapport (see Table 11).

Table 11

Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria

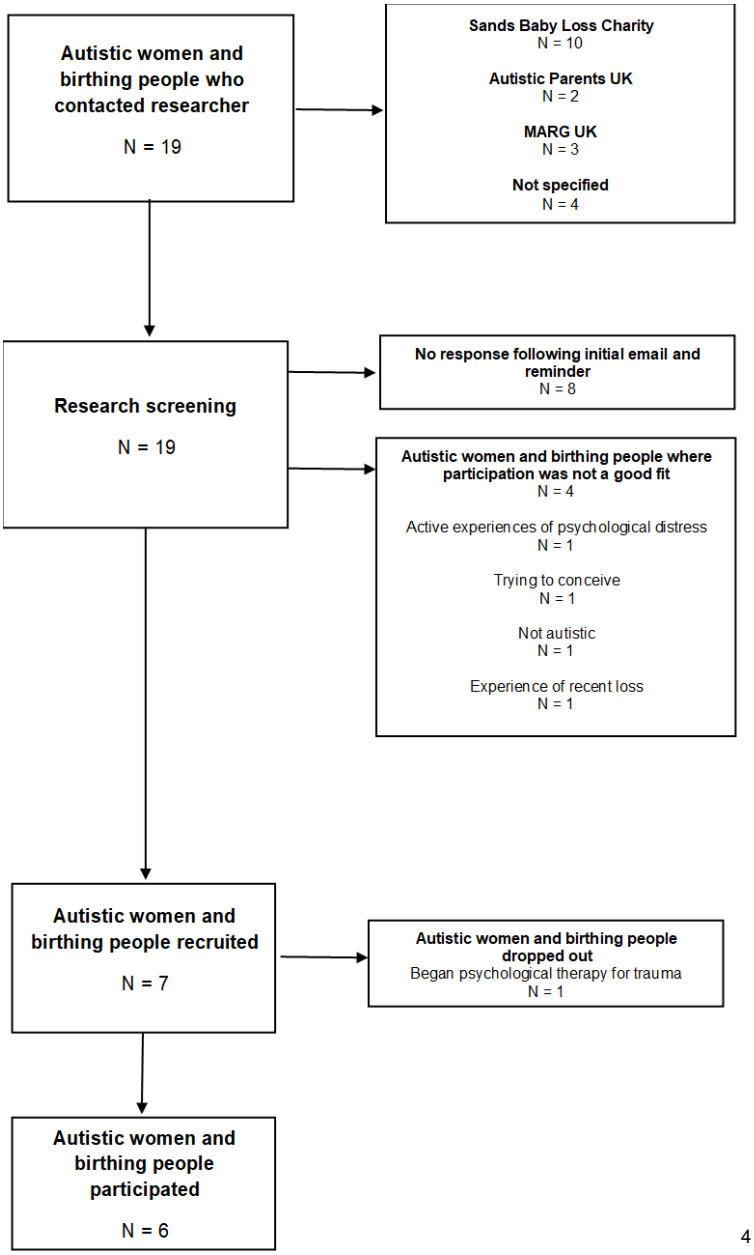
• Participants identify as an autistic woman or birthing person, inclusive to range of gender and cultural identities. • Formal or self-diagnosis as autistic • Participants who have experienced a miscarriage, stillbirth or neonatal death	• Experience of baby loss in the last six months at time of recruitment • Participants currently pregnant or trying to conceive. • Participants currently experiencing high levels of psychological distress or mental health crises.

Participants

Six autistic women and birthing people were recruited and consented to participate in this study (Figure 2). This decision was made in line with an IPA methodology and the richness of the data with meaningful points of convergence and divergence in experience noted across participants (Smith et al., 2009). As part of the process of giving consent to take part, participants completed a short demographic questionnaire to understand more about them and their context (see Table 12 and Appendix 6). Demographics are reported as described by each participant.

Figure 2

Recruitment Flowchart



[4]

[4] Not specified N = 4 indicates participants who did not share how they found out about the study in their initial email and did not respond to the initial contact email or follow-up email.

Bereavement research has shown that some bereaved participants felt it was more meaningful and respectful to keep the real names of their loved ones who died to honour their lives (Scarth, 2015). This decision was in-keeping with this to de-stigmatise and not collude with silence surrounding loss. Participants were also invited to choose whether they wished to keep their names, which was meaningful to maintain the permanence in bond and connection between parent and baby. All participants consented to keeping theirs and their baby's real names. Whilst this table may feel impersonal, participant demographics are reported in this way is to protect participants right to privacy and confidentiality in context of this.

Table 12

Participant Demographic Characteristics

Demographic Characteristics	N
Age (years)	
18 – 24	1
25 – 24	0
35 – 44	4
45 – 54	1
Gender identity and pronouns	
Female (she/her)	4
Woman (she/they)	1
Not answered	1
Ethnicity	
Not answered	2
White European	3
White British	1
Co-occurring disabilities	
Attention Deficit Hyperactivity Disorder	3
Hypermobile Ehlers-Danlos Syndrome	1
None	1
Not answered	1

Relationship status	
Married	4
Co-habiting	2
Living context	
Husband/partner and child(ren)	5
Partner	1
Living children	
No children	1
1 child	2
2 children	1
3 children	1
Number of losses	
1	3
2	2
3	0
4	0
5+	1
Type of loss experience[5]	
Miscarriage	3
Stillbirth	2
Neonatal death	2

Ethical Approval and Considerations

The project gained full ethical approval following an ethics application submitted to the University of Hertfordshire ethics committee (protocol number: LMS/PGR/UH/05620; Appendix 7). I will now discuss ethical considerations pertinent to the development of this research.

Responding to Participant Distress

[5] The total number of losses is seven, which reflects one participant experience of the death of her twins before birth and after birth.

This was a central aspect in ensuring participants were supported in person-centred ways if distress arose. To minimise potential distress, whilst, recognising that participation may trigger understandable, difficult emotions due to the nature of grief, a variety of protocols were set up in line with the BPS Code of Human Research Ethics (2021). As detailed in the recruitment process, I contacted each participant to start to build a relationship and explore screening questions to ensure that the research was a good fit at the time of recruitment. Participants were asked about access to resources, their network of support, broader context and whether they would consent to sharing details of their GP (name and telephone number). Participants were advised that contact would only be made as necessary, for example, disclosure of risk to self or others. The consideration of a specific, stepped approach to recruitment meant that participants had the right to informed decision-making about whether they wished to participate, which was sensitively attuned to the emotive nature of baby loss and range of autistic experiences. There were trigger warnings shared throughout.

A distress protocol was devised to support with managing distress, particularly during the interview phase (Appendix 8). Participants were not expected to share any information that they did not feel comfortable to during the interview, which was named at the start. A debrief sheet with a range of signposts was shared as described in the recruitment phase (Appendix 9). I also considered the personal and emotional impact of the interviews as a researcher and devised a separate protocol to manage this (Appendix 10).

Informed Consent

Participant information sheets (PIS; Appendix 11) and consent forms (Appendix 12) were provided to participants to privilege informed decision making and consent, which was viewed as a process, with consent gained at each step of recruitment and on the day of the interview. Participants were aware that their participation was entirely voluntary, and that they had the right to withdraw their interview up to two weeks after taking part. This decision was

made to ensure that analysis could commence shortly after each interview, whilst privileging participant's right to change their mind.

Confidentiality and Privacy

All participants were informed that their participation was confidential, except for any information or concerns about theirs or somebody else's safety, in which case information may be passed on to the person's GP. Participants provided informed consent to use theirs and their babies' names, and so others who knew them would be able to identify their data. Other personally identifiable information, such as the names of significant others and geographical locations were removed.

The interviews were completed via Microsoft (MS) Teams. This platform was chosen as it supported access to more potential participants, offered flexibility and participant convenience and was considered an autistic equitable requirement. However, this could pose challenges if participants disengaged from the virtual platform, particularly within the context of possible distress. Robust distress protocols were important to help mitigate this and ensuring screening protocols were followed thoroughly. The BPS ethics guidelines for internet-mediated research (2021) were also considered when setting up the research.

Each interview was audio recorded via Dictaphone and MS Teams to ensure that the interview could be captured verbatim for transcription. All project materials including signed consent forms, GP details, demographic questionnaire and audio recordings will be stored securely on my UH OneDrive until September 2025.

Data Collection

Developing the Interview Guide

An interview guide was developed (Appendix 13). The draft guide was shared with the supervisory research team and EbE consultants. EbE consultation occurred in place of a formal pilot interview in line with EbE preferences. I sought feedback on the interview guide from the first participant as part of the debrief process, which also acted as a pilot interview. Feedback was provided about the phrasing and language of the final question, which shaped this question in each subsequent interview. As there were no major changes to the process or interview, this interview was included in the dataset. The interview schedule was held flexibly, foregrounding participant narratives and honouring their experience in ways that felt most comfortable for them (Smith et al., 2002).

The Process

On the day of the interview, the space was set up foregrounding participants needs. A range of equitable requirements were discussed and implemented. Participants chose to communicate through speaking, but most interviews occurred with cameras switched off. Most participants had access to the interview questions and one participant had access to a written diary from the time when their loss occurred as part of sharing their account. Personal expressions of distress were discussed, including how support would be offered. Each interview took place in real-time to allow for in-depth exploration of experience, and to be together in a virtual space to offer support if needed. The interviews ranged in length from 1 hour and 32 minutes to 2 hours and 13 minutes. Many interviews lasted longer than the proposed time detailed on the PIS. Participants were given the choice to continue if their interviews were longer than 1.5 hours. I felt it was important to honour the space participants needed to freely share all aspects of theirs and their baby's experiences. All chose to continue and complete.

At the end of each interview, participants were given space to explore their experience of the interview and possible impact on their wellbeing. A brief discussion about post-interview

care and debrief resources were re-shared. Participants were asked to re-consent to keep theirs and their baby's real names to ensure they were still happy with their indicated decision. Participants were also asked if they would like to be contacted as part of dissemination. All participants consented to receiving a short summary of the results and copy of publication when available.

Following each interview, I met with one member of the supervisory team, which often involved a debrief, sharing initial reflections from the interview and plans to manage for the remainder of the day if needed. This meant that the research team were aware of when interviews were scheduled.

Data Analysis

I started journaling using a reflexive analytic journal after each interview. I did this by noting initial thoughts and feelings and deepening these reflections in dialogue with my research supervisors, which helped me to tune in to what came up for me, identify and acknowledge what I was drawn to and how this might influence my interpretative lens. It also helped me to notice any initial thoughts in relation to participants' experiences and sense-making, which was the beginnings of the double hermeneutic process (Appendix 14).

Each interview was transcribed. I made sure to include any notable non-verbal utterances, such as significant pauses, laughter and hesitations to aid interpretation later in analysis (Smith et al., 2009). Following this, each transcript was formatted into a table with three columns; raw data, initial noting and experiential statements (Smith et al., 2009; Smith et al., 2021; Smith & Nizza, 2022). Each step of IPA analysis and my application is described in Table 13. The process was iterative, holding in mind the 'hermeneutic circle' (Eatough et al., 2017) and these steps were a guide to ensure methodological rigour in applying IPA as an analytic

framework. Throughout the analytic process, segments of each interview were shared within a small IPA working group and research team to enrich the analytic, interpretative process.

Table 13

Data Analysis Steps

IPA Analysis Step	What I Did
1. Immersion with the data set	Starting with the first participant, I listened to the recording up to three times, which helped me to step into each participants world and imagine them speaking whilst reading. Whilst listening to the transcript, I began to highlight segments of texts and write notes and reflections about what I was drawn to and why (Appendix 15).
2. Initial noting	I then began initial noting of the transcript closely, line-by-line to explore the semantic content and language with a clear phenomenological and sense-making lens (Larkin et al., 2006; Smith et al., 2009; Smith et al., 2021; Smith et al., 2022). Levels of noting included descriptive notes, which attended to content at a surface level of the transcript, such as relationships, processes, events, values and principles and what these were like for participants from emotional responses or idiosyncrasies in how they were described (Smith et al., 2009; Smith et al., 2021; Smith et al., 2022). Linguistic notes, which focused on the language chosen to describe experience and how participants talked about their experiences. Conceptual noting, which took more of an interrogative, curious and interpretative lens to delve deeper into the double

	hermeneutic process focused on meaning-making of autistic baby loss (Smith et al., 2009). Smith's (2011) concept of the gem idea was drawn on here; both shining gems which may be more obviously illuminated with meaning, and more suggestive and secret gems to delve deeper into an interpretative position (Eatough et al., 2017). This form of noting took the longest amount of time and reflection and where self-reflexivity was utilised most.
3. Developing Experiential Statements	Experiential statements were constructed by summarising and synthesizing the three levels of initial noting I had already made. I synthesized each set of analytic notes into concise, reflective statements. This captured the essence of the layers of analytic noting for different segments of the transcript to depict a sense of understanding of both the participants sense-making and my interpretation (double hermeneutics; Smith et al., 2009; Smith et al., 2021; Smith et al., 2022).
4. Searching for connection across experiential statements	I wrote down my research question which was placed centrally and started moving around each experiential statement to think about how they fitted together. I started this process drawing on IPA techniques like abstraction; grouping statements in which were connected, for example, statements depicting the silence of baby loss. As I worked through this process, I drew on different techniques for analysis, such as Subsumption, grouping statements which felt like they captured the essence of a PET.

	Polarisation, focusing on ways in which convergent and divergent experiences, as well as Function and Context of statements to try to take a deeper, more interpretative lens rather than at a basic level of abstraction. This was a process which evolved over several days (Smith et al., 2009; Smith et al., 2021; Smith et al., 2022; Appendix 16). I made analytic notes throughout this process, commenting on how and why I had constructed statements together in particular ways. I also reflected upon aspects of my own identity to position my decision in relation to this context.
5. Naming Personal Experiential Themes (PETS)	I named each cluster of statements to describe their essence to define the PET. I linked each statement with quotes from the participants transcript. I organised this into a master themes table for each participant (Smith et al., 2009; Smith et al., 2021; Smith et al., 2022; Appendix 17).
6. Moving on to the next participant	I repeated steps 1 – 5 for each participant.
7. Looking for Patterns across all participants	I began searching for similarities and differences across all participant's PETs constructed to highlight shared connections and unique experiences to develop Group Experiential Themes (GETS; Appendix 18).
8. Writing a narrative of the GETs	The final part of analysis was writing a narrative for the results section (Chapter 4).

Self-reflexivity, Quality and Validity in Qualitative Research

Reflexivity is the hallmark of qualitative research, and essential to ensuring methodological and ethical rigour. Self-reflexivity refers to the acknowledgement of one's own biases, assumptions, identity and lenses in relation to themselves as a researcher and how this may influence the research endeavour (Olmos-Vega et al., 2022). This process is an iterative, evolving and dynamic process. Reflexive journalling supported this, both considering my insider and outsider position in relation to the topic more broadly whilst developing t8he research and throughout the analytic process. I used Yardley's (2000) four principles for assessing the quality and validity of qualitative research, specifically within an IPA context (Yardley et al., 2008; Table 14).

Table 14

Yardley's (2000) Criteria

Principles	Application to Current Study
Sensitivity to Context • Close engagement with the idiographic and phenomenon, such as existing literature • Sensitivity to participants throughout interview • Data analysis process	I demonstrated sensitivity to the existing literature which highlighted the silencing and disenfranchising experience of baby loss and to legitimise this experience through use of a CR and an AE to provide space to participants to share in ways that are aligned to individual neurodivergent needs (Yardley, 2000). I conveyed sensitivity by consulting and working with EbE consultants to ensure the research could be shaped by valuable insider perspectives (Yardley, 2000). I continued to demonstrate sensitivity to context through the development of the study, including the methodological design to support participation in ways which honoured communication preferences. I also tried to ensure that the research endeavour felt safe enough, prioritising participant wellbeing and managing distress (Yardley, 2000). I showed appreciation to participant's experiences throughout the interview process through providing space to listen to participants sharing their subjective experience in the detail that was comfortable for them. I demonstrated sensitivity to the silencing context of baby loss in recognising the silence participants may have experienced before (Yardley, 2000).

	I modelled sensitivity to context throughout data analysis by immersing myself in the data and attending fully to participants' experiences as they described. I ensured that the participant was held centrally whilst engaging at a more interpretative level and selected a variety of quotes from each participant to facilitate readers hearing their voices and to verify my interpretations (Yardley, 2000).
Commitment and Rigour • Attentiveness to participants during data collection and analysis • Quality of the interview and completeness of the analysis	Commitment and sensitivity to context can be demonstrated similarly (Smith et al., 2002). I maintained a commitment to each participant's idiographic, subjective experiences throughout my research, particularly during data collection and analysis (Yardley, 2000). I ensured that the interview space was tailored to each participant's individual needs, attending to specific equitable requirements as a commitment to honouring and viewing autistic experiences as real, drawing on my insider position as an autistic person to understand the necessity of this. I demonstrated rigour and thoughtfulness when considering the target population for this study and suitable recruitment pathways to ensure the diversity in the autistic community could be welcomed and included through the research process. I also made attempts to get to know each participant throughout the recruitment pathway. I demonstrated this at the beginning of each interview to try to understand idiographic signs or changes in presentations, which may help me to pick up on cues to help with the double hermeneutic process.

	Whilst I have developed my skills as a qualitative researcher across the breadth of my career, I drew on the collective knowledge of my research team to build my knowledge of IPA and reflect on the process. This was particularly helpful during data analysis to ensure an interpretative stance was taken to ensure methodological rigour. In providing a narrative of all participant accounts, quotes voicing each participant's experiences were selected and shared equally.
Transparency and Coherence • Transparency and clarity in research methodology, data analysis, write-up and research positionality and reflexivity. • Coherence and alignment in write-up and theoretical approach.	I have modelled transparency throughout the research, which is demonstrated by providing detailed, step-by-step processes to describe the exactly how the research was completed, and decisions made. I have been open and transparent in acknowledging my own position as a researcher, including insider perspectives and epistemological positions as described in Chapter 1. I have demonstrated reflection throughout the analytic process to recognise and reflect on aspects of my perspective and its influence on the process of interpretation. Segments of the transcript were also reviewed in collaboration with the research team to aid and refine analysis and active reflections captured throughout. Yardley (2000) describes coherence reflected in being IPA in essence and nature. I have held autistic baby loss experiences centrally throughout, keeping participant's voice and subjective experience central to the analysis and narrative shared in Chapter 4.

Impact and Importance • Tells the reader something interesting, important or useful	The research highlights and foregrounds the universal pain and distress of baby loss, along with the unique aspects which may be understood through an autistic lens. I hope that these research findings resonate with other autistic women who have experienced baby loss. More broadly, autistic baby loss research is an underrepresented area. These findings may help to better understand and support autistic women and birthing people who may experience baby loss.

Chapter 4: Results

This chapter presents the findings from an Interpretative Phenomenological Analysis (IPA) of six autistic women and birthing people's experiences of baby loss (Table 15).

Table 15

Names of Participants and Their Babies

Name of Participant and Baby
Adrienne and Pepito
Jem and Oliver
Liz and Oscar and Felix
Han and Poppy
Hayley and Dahlia
Bethany and Seren

Following several stages of analysis and interpretation, five Group Experiential Themes (GETs) and subthemes were constructed (Table 16). I will describe these themes illustrated with quotes from participants to hear their voices and evidence my interpretations (Smith et al., 2002). I will detail areas of convergence and divergence across participants and within themes. As discussed, my interpretations are shaped by my insider-outsider researcher position, lenses and biases through which I see the world and a CR, AE position adopted within this thesis.

Table 16

A Summary of GETs and Subthemes

GETs	Subthemes

1. The Unpredictability of Baby Loss	a. The *"double stress"* of the loss of a baby and predictability b. Needing information to feel safe
2. The Horror and Trauma of Baby Loss	a. The terror of losing a baby. b. Heightened autistic sensory experiences during baby loss. c. *"The way they were treating me":* experiencing de-humanising and neglectful care
3. Stigmatised and Disenfranchised Loss	a. The non-event and silencing of baby loss b. The internalised blame, shame and guilt of baby loss c. "*The best worst club in the world'*: safe connections to resist silence
4. The Forever Pain of Grief in Baby Loss	a. The unbearable pain of baby loss b. Grief feeling *"different"* as an autistic person. c. The permanence of grief and love in baby loss
5. Meaning Making, (Re)connecting and Experiencing Continuing Bonds with Baby	a. Finding meaning in baby loss. b. Remembering and continuing bonds to '*show they existed'*

Group Experiential Theme 1: The Unpredictability of Baby Loss

This GET illustrates the struggle and stress of baby loss in being thrust into uncertainty, where predictability was lost throughout participant's experiences, and the impact this had for them. It also highlights the importance of information to build safety in predictability through knowing what to expect. Some participants describe glimpses of personalised, helpful care when information was given to them by healthcare professionals and the strengths in seeking this for themselves; both of which helped to obtain predictability.

The "Double Stress" of the Loss of a Baby and Predictability

This subtheme describes the impact of losing a baby and the secondary loss of safety in predictability in not knowing what to expect in more detail, as both pregnancy and birth were new experiences for some, as well as losing their baby. Jem described feeling *"scared"* in anticipation of giving birth to Oliver, connected to uncertainty in not knowing what was going to happen and how long he would survive.

> *I knew that there wasn't gonna be a good outcome or if it was, I was gonna have him […] it was gonna be brief. And I was scared, and I didn't know what was gonna happen.*

Adrienne described how going into labour unexpectedly with Pepito was "*so awful*" because there was "*no NCT class to explain how labour [...] everything is working".* Han also described a sense of stress during her experience of miscarriage due to unexpected changes about medical procedures, such as the scan and navigating a new, unknown hospital environment which she had *"never been to"* and *"didn't know how A&E worked".* These aspects added an additional layer of distress when waiting to find out if she had experienced a miscarriage.

> *We went for the scan [...] obviously they couldn't find a heartbeat [...] well, let's do a trans vaginal scan and just double check, but you'll need to go to the loo first. So, I then have to go [...] I can picture it now [...] Go and find the loo [...] (Han).*

Furthermore, Hayley described a sense of fear whilst actively miscarrying Dahlia. This was a new experience for Hayley, which was unpredictable, and added to her distress.

> *I phoned Tommy's helpline and the woman on there was lovely […] She really calmed my nerves, but there's only so much you can calm someone's nerves when they haven't been through something like this before.*

Needing Information to Feel Safe

This subtheme describes the profound unpredictable nature of baby loss, and participants' sense of necessity to create and obtain predictability to understand what was happening to feel safe. A sense of safety was often connected to seeking information, which participants described healthcare professionals failed to share. This impacted participants in several ways, such as shutdowns, lack of control and uncertainty. Jem described a sense of stress and overwhelm at not being given enough information to understand Oliver's health condition and continually trying to gain access to information to manage a sense of fear.

> *I wanted like more information and it […] was just […] I've just kind of shut down at that point (Jem).*

Whilst it was difficult for Han to connect back with her experiences, she felt that the lack of information "*had quite an impact on me […] you know, lack of information, feeling out of control".* Similarly, Hayley described the impact of an absence of information, which conveyed fear and anxiety through the sense of questioning, suggesting multiple aspects of the unpredictability of miscarriage. Two participants reported *"reading lots"* and searching for information themselves to relieve the unpredictability and compensate for the absence of information healthcare professionals failed to share, which even then was not always helpful.

> *I had no information from the early pregnancy unit […] what I had Googled wasn't what happened. I didn't know if it was safe or do I need to tell you, tell someone and do I need to take medication to make it, I didn't know what to do (Hayley).*

Conversely, participants described glimmers of helpful interactions with healthcare professionals who provided more information about aspects of the loss experience which were personalised and attuned to their experiences in the moment, such as understanding medical conditions from practitioners who *"drew us a picture of the heart, explained it all, that stuff sticks*

in my mind, I liked it" (Liz) and knowing where Pepito "*will be, that stayed in my head" (Adrienne)*. The use of specific, science-based language may suggest how important the offer of information was and conveys a sense of support in managing anxiety and knowing more about what was happening. However, for Jem, no amount of information could contain the sense of distress and unpredictability of not knowing whether Oliver would survive.

> *He went into more details saying your baby has LUTO, Lower Urinary Tract Obstruction and were just given bits of information [...] but he couldn't he said that it was up to us whether or not we carried out the pregnancy (Jem).*

Group Experiential Theme 2: The Horror and Trauma of Baby Loss

This GET illustrates the fear and distress arising from baby loss which for many participants was a traumatic and terrifying experience. Many participants acknowledge the traumatic nature of loss and describe memories from their experience which have stayed with them as reminders of the fear they experienced and continue to navigate. Participants also describe the additional aspects of heightened sensory sensitivities throughout baby loss and the way they experienced care and felt in relationship to healthcare professionals which exacerbated a sense of feeling out of control, powerless and scared.

The Terror of Losing a Baby

This subtheme describes the traumatic nature of baby loss described by participants. It depicts how participants made sense of their experiences, including aspects that felt most distressing and the lasting imprint of trauma. Many participants described a sense of trauma when actively losing or witnessing their baby die, which was different for participants depending on the nature of their loss. Hayley and Bethany described the most salient aspects of their miscarriages, such as the "*visceral and bloody"* physicality and aspects of affect, such as a

sense of shock, fear and confusion. A sense of unpredictability and feeling out of control was also woven throughout.

> *And then suddenly I was in a lot of pain screaming on the bed [...] and then that's when I passed what looked like a baby [...] I don't know what I was thinking, but I remember just bursting out crying, [...] I was confused and upset at the same time, and I think I probably was scared as well, like obviously didn't know when I was pregnant, so I didn't expect that to happen (Bethany).*

Adrienne described the moment she gave birth to Pepito who had died, with sensory aspects of the memory central to her narrative and the sense of awfulness in giving birth and her baby dying at the same time.

> *I had a huge contraction [...] I could hear a lot of water and a boom and that was the baby actually [...] then they put the baby on me, he was still moving a bit, you know, like wiggling and [...] it was done [...] and it was absolutely awful [...] the baby was still moving, so I told them, can't you do something? They said no he's too little we can't do anything [...] it was awful.*

Liz described the distressing nature of giving birth to Oscar who had died, and then later watching Felix, her surviving twin, die. She described feeling *"scared"* when being *"rushed for an emergency c-section*". Both Liz and Jem describe the fear of watching their babies fight for their lives after being born, such as memories of Oliver being *"resuscitated"* who was *"fighting"*, and remembering the *"breath, the gasping",* which was distressing and led to Jem being "*out of it"*. They described a sense of helplessness and powerlessness in not being able to help their babies. Their narratives also described a sense of disconnect and dissociation in the moment which may reflect the horror and terror of witnessing their babies' distress and death.

[...] and we watched him die slowly of heart failure. It was awful. His little abdomen swelled up, his head swelled up (sigh) [...] we couldn't do anything at that point [...] so they delivered Oscar, he was very delicate. He'd been dead for six weeks (big heavy breath) [...] Felix was in NICU [...] we just stood there [...] until his heart stopped again and all the machines, the flat lining noise, the incubators collapse so they have quick access to them (wavering; breathless; Liz).

Some participants *"remember being really terrified that I was going to die" (Hayley)* and that the fear was *"like no fear I've ever experienced before, absolute terror" (Liz)*. Adrienne, Hayley and Liz acknowledge and make sense of aspects of their experience as being *"traumatic",* with specific dates associated with more trauma. Jem described the impact of the traumatic nature of loss by sharing that she *"has been diagnosed with PTSD because of it".* Across the accounts, participants' narratives appeared fragmented, moving back and forth in retelling their experience, which further conveyed a sense of fear and trauma of their loss influencing their recollection and memory. Some participants described having *"blank spaces" (Liz)* which Bethany made sense of as "*a way to kind of protect me"*.

Heightened Autistic Sensory Experiences During Baby Loss

This subtheme describes the additional layer of stress participants experienced from a range of heightened sensory sensitivities whilst losing their babies'. Bethany described a sense of hyper-sensitivity to touch whilst miscarrying, Seren, particularly in relation to the sensation of blood which led to feeling anxiety and disgust.

[...] guess it was just the feeling of blood on me [...] I think that was more what I was worried about, which is strange, when you're going through such a thing to think, oh, this is disgusting, I'd be more worried about blood getting on you.

Some participants spoke about aspects of the sensory environment which added a layer of distress. Whilst it was difficult for Han to connect with in the moment, which may reflect the distressing nature of her miscarriage, both Han and Jem described the *"utter nightmare"* of the hospital environment, such as *"the smells, sounds, lights" (Han)* which were "*just too much to go through" (Jem)*. Liz named how "*autistic and hospitals don't mix"* due to a lack of agency, choice and a hypersensitivity to the *"blue lights in NICU".* Furthermore, Jem and Hayley described a heightened internal sense of their bodies throughout their experiences. Hayley described noticing bodily changes, such as *"the taste of metal subsiding rather than increasing"*, which she interpreted as something going wrong in her pregnancy before her miscarriage was confirmed. Jem described a heightened sense of bodily sensations during labour, which was distressing.

> *And they did the spinal tap, they'd given me some drugs as well to make me a bit out of it so that made me feel like, really funny [...] I wasn't expecting it, but I thought I was gonna pass out (Jem).*

Additionally, participants spoke about the heightened sensation of pain throughout losing their babies', described as *"agony" (Han), "unlike any type of pain" (Bethany)* and *"a lot worse than I'd ever experienced before" (Hayley)*. Hayley and Han also described challenges in receiving pain relief during their miscarriages despite the pain they were experiencing internally, which could have added to the intensity of these experiences. Furthermore, Adrienne described her experience of pain during her stillbirth and how she usually copes and communicates her pain to others. This may reflect a mismatch between her external presentation and internal experience of pain.

> *I was in so much pain, and it was hard for me in regarding that because I'm not someone who is like, "oh, Ouch". You know (Adrienne).*

"The Way They Were Treating Me": Experiencing De-humanising and Neglectful Care

This subtheme describes the sense of distress participants experienced from the felt absence of care from healthcare professionals throughout baby loss and the meaning and impact of these experiences, including the additional context of being autistic. Bethany described *"feeling let down"* and *"neglected by the system, which was hurtful",* particularly "*for something so upsetting",* which conveyed a sense of disbelief in how she was treated. The sense of hurt was exacerbated by the absence of care despite *"knowing they'd seen my notes" (Jem)* and *"that I was having a miscarriage" (Han) "in a place where you should be safe" (Hayley)* and "*treated with a bit more humanity*" *(Han).* This reflected a sense of de-humanised care and what was absent, which Han described further whilst actively bleeding and miscarrying in A&E, which she compared to a *"criminal"*, further conveying a sense of her rights being taken away.

> *By this time my trousers are saturated with blood [...] I'm regularly going backwards and forwards to the loo and I'm dealing with it. The only problem was on one occasion I got up to go to the loo and a nice police officer, said I'm really sorry you can't go in the loo [...] basically the police officer was there with someone who was under arrest in handcuffs [...] I was less important than a criminal who was under arrest during my miscarriage experience is how I felt (Han).*

Adrienne and Jem described a sense of pain and sadness at the insensitivity of healthcare professionals who failed to recognise the impact of having just lost their babies by placing them on maternity wards, *"which made my heart crush just listening to another woman with a heartbeat of her baby" (Adrienne),* and was a reminder that *"I didn't have my baby with me" (Jem).* After her twins, Oscar and Felix died, Liz described the aftermath of trying to seek justice and pursue an investigation for her experiences in hospital, where she felt that

healthcare staff failed to listen to her and her husband's concerns or take them seriously. Liz's experiences depict the continued sense of mistreatment from healthcare professionals.

> *We pushed for an investigation because we told the nurse [...] something wasn't right, and she reassured us he was all fine [...] Never went anywhere. We've got copies of the notes that just have a blank space for a good couple of hours where there's nothing where it really should have mentioned our concerns (Liz).*

In addition, participants described a sense of feeling belittled, infantilised and not believed throughout their experiences of baby loss, which was made sense of in the context of autism. Adrienne described the additional distress of feeling belittled in her internal experience of heightened pain, which the doctor did not fully acknowledge, and left her questioning her internal experience and sense of herself.

> *I thought I had a high-pressure pain threshold, but after that I didn't [...] the doctor told me no, you have a good pain threshold [...] I felt so belittled because I was in so much pain (Adrienne).*

Similarly, Jem and Hayley recalled aspects of their experiences where their internal sense of their bodies were not believed or taken seriously, such as a nurse doubting whether *"you've not just wet yourself"* when Jem's waters broke, which also conveyed a sense of internal questioning, and having to prove this to others.

> *So, when I was having a miscarriage and when I was pregnant [...] I was saying I felt these changes and I felt this and I felt that and people and midwives or GPs or consultants would say no, no, you can't have felt, it's too early, or mothers don't feel when that happens, and I absolutely did (Hayley).*

Hayley described a sense of sadness and feeling misunderstood by healthcare professionals who failed to understand the function of her sharing information *"to comfort myself*

with facts and try to form a rapport with them". Hayley also made sense of this in relation to power through her sense of being perceived as *"trying to take their authority"*. This conveys a sense of being positioned as having less power in knowing about her body and the lack of practitioner understanding of autistic experiences, such as communication, particularly when feeling fearful about what was happening. Furthermore, Hayley described the impact of healthcare professionals failing to consider her autistic experiences, which left her feeling overwhelmed and vulnerable during her miscarriage.

> *Something that came to mind then [...] was not having my boundaries respected, add on to that that your stress response is to shut down and not be able to speak verbally, that can make you super vulnerable.*

Moreover, Han reflected on how she is perceived by others when attempting to communicate her experiences of distress, which often does not reflect externally how she feels internally. This may have underpinned her experiences with healthcare professionals during her miscarriage, as she was perceived to be *"generally still quite articulate".*

> *[...] I'm no good at turning up at the GP in floods of tears and a shivering mess for them to take me seriously [...] I seem like I'm OK, so it's a real struggle to get anyone to actually understand what my brain is thinking of, it's actually mental torture.*

Group Experiential Theme 3: Stigmatised and Disenfranchised Loss

This GET depicts participants' experiences of baby loss being un-recognised by others, which had a profound impact on participants' meaning-making process of their babies dying. Participants described experiences of silence, invalidation and diminishing comments and actions from others, which they understood within the societal context and taboo of loss. They describe the psychological imprint of these experiences, such as an internalised sense of loss

and feelings of shame and guilt. Conversely, participants described the power of finding safe connection and belonging with others who have experienced baby loss.

The Non-Event and Silencing of Baby Loss

This subtheme depicts the societal and *"cultural"* silence and taboo of baby loss across many layers and the impact, which is *"not talked about enough that it's a fucking awful experience" (Han)* and could lead to hiding the impact of loss and their grief.

Participants recalled the silencing and non-event of baby loss enacted by healthcare professionals in different ways when their babies died, such as being *"really silent which was the hardest thing" (Jem)* after birth and implicitly communicated *"that everything was over" (Adrienne).* Liz described how a professional spoke about Oscar by *"dropping her voice to a whisper"*, which failed to acknowledge her reality of pain and grief. Some participants spoke about a sense of ambiguity surrounding their miscarriages and there being *"certainly no scan to look for a heartbeat" (Han)*, which may have served to legitimise their loss. Han used sarcasm, which I interpreted as a coping strategy to mask the extent of her sadness, whilst Bethany voiced her continued struggle with the undefined nature of her miscarriage, which failed to recognise and confirm the loss of Seren.

> *[...] other people who've had a miscarriage have that positive test, or maybe a scan photo to show like that their pregnancy was real, that their pregnancy did happen, I don't [...] it was kind of just, it happened, there's nothing we can do, you decide what you do with Seren [...] there will be no intervention [...] I think that's something that I struggle with as well (Bethany).*

Whilst Han and Jem experienced different types of baby loss, they both expressed a sense of abandonment, which felt as though the deaths of Poppy and Oliver were not recognised nor were their experiences of possible trauma, pain and grief. They described the

sense of feeling forced to move on and being *"kicked out the door" (Han)* by professionals, which was *"absolutely shocking" (Jem),* creating a sense of dissonance with their internal realities when not physically or emotionally ready to navigate the psychological impact of baby loss.

Participants described experiences of minimisation and invalidation from family and friends. Bethany described experiences which minimised her miscarriage and Seren's life, such as family members expressing that they *"don't care about Seren dying"*. Hayley described the sense of pain and hurt triggered by responses from others which failed to recognise or acknowledge both the physical and emotional pain of losing a longed-for baby and future.

> *She said maybe it worked out for the best […] that phrase, maybe it was for the best, when your whole body is cramping and releasing the thing that you want to keep the most is just a horrendous thing (Hayley).*

Furthermore, participants described the impact of the *"taboo*" of baby loss on relationships, such as *"seeing the split of people who do a runner and try to look after you" (Liz)* and people *"trying to avoid you or saying stupid things" (Adrienne)* that invalidate the reality of life without their babies and grief. Jem spoke about contact with people after losing Oliver and a longing to connect and be supported by safe people, like her best friend, but who *"never come to visit or reached out […] it were like she didn't know what to say",* thus encountering more silence. Liz described how talking about the "*twins stops a conversation"* to demonstrate the taboo and stigma surrounding baby loss.

Participants described the impact of navigating the silence, which often became internalised, and led to hiding the pain of grief from others, as a form of self-preservation to avoid negative judgement and criticism. Participants described the impact of disenfranchising and stigmatising comments, which led to an internalised sense of questioning their miscarriage,

such as *"am I losing my baby, or is this just bleeding?" (Han).* Bethany described this as being cyclical, which I interpreted as an internal conflict in trying to re-legitimise her experience and the felt physical absence of being without Seren.

> *[...] especially the probably was just a blood clot, like because he did look a bit like a blood clot to me and then with the whole thing of questioning like that, like provokes the full questioning of like, did I actually have a miscarriage and starts that cycle again (Bethany).*

Participants also talked about *"keeping [grief] to myself" (Bethany).* Adrienne shared how she "*just stopped my feelings, my thoughts, didn't say anything",* which led to mentally falling into a *"really dark place".* Hayley described the *"emotion and exhaustion"* as an autistic person triggered by others not believing her internal experiences, which "*added to the isolation".* Jem described the impact of silence and noticeable discomfort from others, choosing to keep this hidden, which conveyed a sense of her loss and grief being unacceptable.

> *I was quite wanting to speak about it, so it was just it was difficult because when they'd ask me and I saw how uncomfortable it made them, I just didn't speak about it anymore (tearful) I think that's why I've like suppressed a lot of my emotions about it um and try to bury it deep down (Jem).*

Across participants accounts, I sensed hypervigilance to the gaze of others. I interpreted this in the context of experiences of invalidation and silencing from others, which in turn may have led to participants coping by suppressing and hiding their internal experiences from others. Adrienne was noted to apologise and seemed prepared to minimise her experience *"it it's too much"* throughout. Han was tentative in how much to share, noting that she did not *"want to be too gruesome in the detail".* Participants were also tentative in their re-telling at times, using phrases such as *"I guess"* and *"I mean"* and were also checking back frequently with inferences such as *"does that make sense?" (Bethany)* and *"I hope that answers" (Liz & Han).* I interpreted these linguistic aspects of the narrative as reflective of making their experiences more palatable

for others, seeking permission to share more fully and checking out the legitimacy of their experience.

The Internalised Blame, Shame and Guilt of Baby Loss

This subtheme conveys the profound sense of shame, guilt and internalised blame participants felt for the death of their babies, as women, birthing people and being autistic. Participants described a sense of innate shame and blame towards their bodies in feeling as though they were not able to do *the "most innate seemingly basic function that my body is almost designed to do" (Hayley)*. Adrienne described a strong sense of self-criticism in her narration, suggesting high levels of shame and guilt, exacerbated by a context of multiple losses.

> *My body was like not a machine to procreate but a machine to get people dead, I was creating things that my body was killing [...] it was awful. What's wrong with me? My body is like a cemetery (Adrienne).*

Furthermore, Han described feeling *"fucking useless […] inadequate and embarrassed".* She expressed how *"sorry"* she was to Poppy that *"you died inside me and that I couldn't support you"* which she made sense of as *"blaming myself for it all"*. Jem also recalled *"saying I'm so sorry cause I felt so bad, and I felt guilt to make that decision to let him go"*, which suggested a sense of blame as Oliver's mother. Similarly, Liz described a sense of blame towards herself for not being able to keep Oscar, one of her twins who was stillborn, safe in utero. This led to a sense of urgency and fear in wanting *"Felix out because I figured he was safer in the real world".* Bethany described a strong sense of guilt in flushing Seren down the toilet, an action I interpreted that she is still berating herself for and trying to find ways to absolve the guilt for.

> *I had flushed Seren down the toilet before I went to the hospital, cause I was in such shock and [...] I didn't know what to do [...] I'll always regret the decision that I made. I don't think I will ever forgive myself for that.*

Some participants also spoke about the sense of blame and guilt in relation to their autistic identity, which Hayley described in the context of a lifetime of being perceived differently to others and named the impact of ableism, as an autistic person navigating a neurotypically designed world.

> *It was tied into being a disabled person as well, and that my body had failed me and people going, that's probably, you know, this is underlying [...] this whole idea that Hayley's not quite right, so no wonder she can't do anything right […] like have a healthy pregnancy, so I think there's ableism, kind of woven through (Hayley).*

Han and Jem described a sense of guilt in relation to their autistic experiences, which was *"another reason to feel inadequate in life and [...] useless again" (Han),* suggesting a sense of continued failure in not meeting a perceived societal standard or *"norm"* in her abilities and life. Jem described how falling pregnant felt like *"I was doing something right with my life [...] like I was like everybody else*". This illustrates the sense of inadequacy Han described in her miscarriage as an autistic person and that Jem may have also experienced when Oliver died shortly after birth. Conversely, Liz described a sense of guilt and blame attributed to her communication abilities and autistic neurotype, which suggested that if she were not autistic, the death of Oscar and Felix may have been different. Liz's narrative also highlights Hayley's acknowledgment of ableism, which Liz may have internalised.

> *I feel a lot of guilt that I didn't stand up for him, that maybe if I hadn't have been autistic, I would have been a bit more out there with my- I do looking back, think that's maybe part of me saying I'm not very good verbally. If I'd have pushed that better (Liz).*

"The Best, Worst Club in the World": Safe Connections to Resist Silence

Participants described the power of safe connections, often with other women and birthing people who had experienced baby loss. Hayley and Han described a sense of strength

and bravery in *"opening up"* about their experiences of miscarriage, which led to pockets of connection and further illuminated the societal stigma and silence surrounding this type of loss.

> *It's only […] through my own bravery and acknowledging to other people I had a miscarriage, so then other people have opened up to me and even my mum said she'd had a miscarriage. I was like, well, I didn't know that […] and no one talks about it (Han).*

Three participants described how it is *"really nice to just hear from other people in the same situation" (Liz)*, despite the initial anxiety of being in a group, and the felt sense of care, and empathy enacted through *"someone from this community who had sent Seren a birthday card" (Bethany)*. Adrienne used metaphor to depict a sense of belonging, which suggests how excluded and silenced she felt before connecting with the loss community.

> *It's more coming into a room where people are happy to see you, you know, and not just trying to open a room and see, "hey, is there anyone there [...] and they say meh maybe come try or […] no one is answering you (Adrienne).*

Group Experiential Theme 4: The Forever Pain of Grief in Baby Loss

This GET depicts the profound and universal emotional and physical pain of baby loss, whilst also describing the unique aspects of autistic grief, the permanent dance with grief and navigating life without their babies.

The Unbearable Pain of Baby Loss

This subtheme describes participant's subjective experiences of the rawness of grief, as they begin to navigate and process life without the physical presence of their babies. Participants described an embodied pain and emptiness using imagery and metaphor, *"kind of like an empty vessel, like part of me had died" (Jem)* to depict grieving and their pain. Adrienne used language like *"Halloween"* and being *"cut",* which I interpreted as depicting the darkness of grief and sense of pain in being physically without Pepito.

I never felt emptiness like this […] seriously, it was like I'd been cut, you know, like pumpkin at Halloween you and there was no light in it and it yeah, it felt like a deep hole (Adrienne).

Similarly, Hayley's use of metaphor suggests a sense of a home being re-built, which had connotations with the innate, biological sense of what it means to be a woman. Hayley spoke with a sense of disconnect and powerlessness over her body and what was happening, which I interpreted as being misaligned to the longing for Dahlia and a baby; the pain of which was exacerbated by a heightened sense of feeling her internal sensations.

[…] when you're being rebuilt after a loss, your body is rebuilding itself brick by brick and I felt every brick it wasn't, oh, I'm […] slowly getting over it. I felt every body change bit by bit go back to normal when I didn't want it to be (Hayley).

Bethany and Liz also described the embodied pain of their grief and loss, which Liz described thinking *"the pain was gonna kill me"*, depicting the profoundness of the emotional and physical pain, which was *"overwhelming".* Bethany described a sense of desperation and *"begging"* to escape the reality of being without Seren, reflecting the unbearable pain felt in his absence.

When I first lost Seren […] I was begging, begging for a day where I didn't remember him, because every time I remembered him I'd get upset and I was begging for a day where I'd be like, please, just let me forget about him for one day [...] it felt like a sort of physical pain, especially in my heart, like when I was crying […] it's like a physical pain in my chest.

I interpreted the embodied sense of grief around the heart as representing the unspent love for Seren. This also connected to Adrienne's conceptualisation of being *"stuck with a bubble of love that is starting to rot"* when a baby dies. Han described more psychological expressions depicting the pain of grief, which led to feeling *"quite low and knowing me, probably suicidal"*. Han's account and use of word *"probably",* suggests a sense of disconnection and

detachment with her miscarriage and grief, which conveys the overwhelming and unbearable sense of trying to process losing a baby. Han also expressed a sense of sadness at all the things lost through her miscarriage.

> *I'm sad that I didn't get to feel you kicking my belly or watching my belly move in random directions as you squirm around inside me. I'm sad that I won't hear you laugh or cry. I'm sad that I didn't get to watch you grow and develop (Han).*

This suggested a sense of beginning to imagine her baby in mind, as well as beginning to grow Poppy physically; the pain of baby loss reflecting both the physical and emotional aspects of connection, thus grief of baby loss. Liz also conveyed a sense of disbelief and disconnect with her lived reality shortly after Oscar and Felix died, which I interpreted as wishing to escape from the *"awfulness"* of a reality with her twins.

> *[…] all I wanted was somebody to text me back and say my baby died, but it came back to life and everything was fine. I remember that [...] (Liz).*

Grief Feeling "Different" as an Autistic Person

This subtheme describes participants sense of grief feeling *"different to others" (Bethany),* which added distress to the universal grief for their babies. Some participants described a sense of internal conflict between their brain's natural focus on logic and knowledge and the painful emotional manifestations of grief, which were profound and unexpected.

> *My brain's trying to rationalise it by saying that […] I've got enough medical knowledge to know that it's quite common that miscarriages happen and scientific black or white point of view that miscarriages happen, however [...] it's quite shocking to me how much it really did impact me and actually [...] it was awful (Han).*

Some participants described difficulties in understanding the *"concept of death that people could be here and then they're not"* and needing a *"physical place where I can go" (Bethany)* to grieve Seren. Conversely, Jem described a continued struggle with comprehending

Oliver's death, which was reflected in her present tense re-telling and active questioning suggesting an ongoing internalised processes in navigating life without Oliver.

> *I just have like loads of questions like [...] why couldn't they have done a kidney transplant on him? He was at a good size; he was a big chunky baby who'd already had an operation on his lungs [...] (Jem).*

Participants expressed difficulties in identifying or making sense of their internal emotional and physical sensations, *"I feel dot dot dot dot as in I don't know how I feel" (Han)*. This was overwhelming and confusing in *"trying to find the words that my body is changing"* and *"the emotional labour" (Hayley)* of talking about strong and painful internal sensations. When emotions were identified, participants described feeling *"so angry" (Adrienne)*, *"at everybody through what we've been through" (Jem),* which participants made sense of in relation to the injustice and pain of baby loss and trying to navigate a life physically without their babies'. Liz depicted her *"rage"* through mental imagery, reporting *"I just wanted to push the cars off 1 by 1 and watch them smash. I just remember that going through my head",* reflecting the intensity of her grief.

Participants also described expressions of distress and grief which exacerbated autistic experiences, such as *"huge meltdowns" (Adrienne)*, *"a big decrease in masking" (Liz)* and social and sensory experiences, such as *"not understanding people and struggling with sensory" (Jem).* Participants described a need to grieve alone in the early days after losing their babies feeling unable to *"speak to anyone" (Adrienne)* and *"not wanting to talk or get asked" (Liz)*. Hayley described this as an intentional act to *"shut the world out and heal in our own way, in our own time".* Whilst some longed to connect to speak about their loss and babies, through being met with silence and invalidation, some participants wished *"to be alone" (Jem)* perhaps to mitigate further experiences of stigma. Furthermore, some participants described a sense of imposed grieving when in relationship to others, which may have exacerbated a sense of grief

feeling different as an autistic person and confirmed the safety in being alone, as "*people were trying to get me to speak about it, where I needed just that time [...] and people were pressing me" (Jem).*

The Permanence of Grief and Love in Baby Loss

Participants described their relationship and experience of their grief for their babies changing over time, but always being felt, reflecting the forever physical absence of their babies. Participant's used metaphor to describe how grief is something they *"live with"*, which is never far and always around, *"like in my pocket or in my bag" (Hayley)*. This may reflect the everyday triggers and reminders of being without Dahlia. Bethany described how grief *"comes in waves",* which suggests that her grief is always there in the background.

> *Grief does come in waves, and when it does come as a wave, it creeps up on you like there's been days where I've been absolutely fine and then all of a sudden bang, it just hits me [...] I cry, and I say I want my baby back (Bethany).*

Adrienne and Jem described a sense of continued grief and *"pure sadness which has never left" (Jem)* in being physically living without their babies, which also had an embodied, physical sense.

> *It still crushes my heart, but it doesn't make me want to die [...] Now it's more a heaviness (Adrienne).*

Group Experiential Theme 5: Meaning making, (Re)connecting and Experiencing Continued Bonds with Baby.

This GET describes the ways in which participants ascribed and made meaning of their babies' deaths and continue to reconnect, remember and continue bonds with them in memory and through intentional, practical actions to honour and legitimise their short but valued lives.

Finding Meaning in Baby Loss

Participants described the sense of meaning made through their experience of baby loss. Adrienne and Hayley described how Pepito and Dahlia led to a discovery of values, hopes and dreams, including future living children and discoveries about themselves, which *"because of him we know we are autistic" (Adrienne)*. Their meaning reflected a sense of their babies' lives continuing to live on, which for Hayley was healing.

> *My healthy happy neurodivergent children are everything that that baby taught us we wanted, they're everything and more so I heal a little bit more everyday (tearful; Hayley).*

Jem also described attempts to make *"some sense"* and meaning from Oliver's death practically through organ donation, which was a way of Oliver gifting life to another baby through the life he did not get to live. Jem's agency and attempts to make meaning in this way were disrupted when Oliver's heart became contaminated, meaning that it could no longer be donated, which led to a sense of sadness and hurt.

> *I said I want to donate his heart to save someone so that it feels like this makes some sense out of it (tearful) [...] it was a heart (tearful) they could have saved another baby and how someone could contaminate it when it's supposed to be so sterile an environment (Jem).*

Liz also described how the meaning of Oscar and Felix's death influenced her beliefs of safety and coping in the world, which I interpreted in relation to being an autistic person trying to manage the anxiety of navigating a neurotypically designed world.

> *All the safety things I've built into my life [...], as in stupid rules that mean you won't die in a car crash [...] were blown away [...] it's completely meaningless […] we had better odds of winning the lottery than what happened to us with the twins. So, my way of*

coping with anxiety […] was looking at stuff like that making sense of it by […] numbers, and none of that works anymore.

Remembering and Continuing Bonds to "Show They Existed"

This subtheme describes the significance of remembering their babies and finding ways to reconnect and continue meaningful bonds to legitimise their lives and participants' experience of baby loss. Participants described the *"really tricky" (Liz)*, painful nature of remembering birthdays, anniversaries of their deaths and other significant events like births in the family, which led to waves of pain and grief. Participants described physical and tangible ways of honouring and remembering their babies to acknowledge and mark their grief and their babies' lives each year, such as *"visiting the grave when we're sad" (Liz)* and *"lighting a candle on Oliver's birthday" (Jem).* Some ways of remembering hold meaning and are symbolic of participants' experience of baby loss, such as "*planting Dahlias every year" (Hayley)* to represent the name she chose for the daughter she imagined. Despite remembering being *"sad"*, Bethany described a sense of transforming grief to honour Seren's legacy and continue birthday traditions she would have begun if Seren were physically alive.

This year [...] he's got a badge, some balloons that I'm going to blow up for him. We've got bunting. Obviously, we're having a picnic. He's got a cake, got him some new ornaments for his grave. Some toys, some books that I can go and read, obviously, if he was here, he would be spoiled (Bethany).

Liz described a similar notion of "*honouring*" Oscar and Felix, each year on their birthdays to transform the sadness, such as "*random acts of kindness, year they turned 6 I did six different things".* Some participants found meaning in nature and incorporated this into remembering and continuing connection with their babies, such as "*butterflies",* which represent "*Seren saying hello"*, and stars, connected to meaning, as *"Seren's name means star"*

(Bethany). This suggested a sense of their babies being part of something bigger, always present and felt in the world, whilst not being physically with them.

> *[...] robins, they were coming with us, singing […] it's Pepito [...] flowers blooming, starlings [...] it felt less heavy thinking he was being part of that, going everywhere with the wind (Adrienne).*

Han, Jem and Liz described their personal ways of remembering Poppy, Oliver, Oscar and Felix by placing *"ashes in a nice flowerpot" (Jem)* and continuing bonds through *"two bears; we've got one, the other one is buried" (Liz),* all of which convey the sense of a forever-felt presence to symbolise the felt physical absence and loss of their babies.

> *I've got a pair of earrings that are actually poppies to mark have something that links you back to [...] the baby (Han).*

Participants also described an internal sense of connection with their babies in day-to-day life. Adrienne and Liz described thinking of their babies every day, which Liz compared to her living children *"like all my kids they're always there"*. Bethany described experiences of remembering triggered by aspects of daily life which led to thinking about who Seren would be if physically alive.

> *He's always in the back of my mind like he never leaves the back of my mind [...] things like I'll be in the shop and see something and I'll be like, "Oh, Seren might have like that" […].*

Hayley described a similar experience and the importance of *"intentionally"* making space to talk about the *"would have beens"* and noticing grief triggered by seeing *"other children who have a similar complexion*" to what she imagined Dahlia might have if physically living. Jem described experiences of dreams, which held meaning in feeling re-connected with Oliver.

I've had a couple of dreams where Oliver's come into bed and give me a cuddle but it's just little things like that um that make me feel like he's still around (Jem).

All participants named their babies before they died and spoke about them throughout the interview, which felt like a way to remember, story and legitimise the experience of baby loss and their babies' lives, in detail. This is both reflected in the duration of the interviews and meaning of taking part. Han thanked me for using the name she chose for her baby, Poppy, and Hayley shared what it was like to hear the name she chose, Dahlia, spoken by someone else which made her *"smile"*. Adrienne reflected how participating *"made her happy that this made Pepito real".*

Chapter 5: Discussion

This chapter explores the findings in relation to the research question, existing literature and theory. I will then critically consider the clinical implications, strengths and limitations and avenues for further research. The chapter will end with final personal reflections and a conclusion.

Summary of Findings

This study aimed to understand how six autistic women and birthing people made sense of their experience of baby loss, which led to constructing five GETs with several subthemes. They told us about the horror and trauma of losing their babies, which was terrifying and distressing and exacerbated by a sense of neglect and abandonment from a healthcare system who they hoped would look after them. Their distress was intensified by their autistic sensory experiences and a need for information to feel safe and gain predictability. They shared experiences of feeling belittled and their sense of their bodies and autonomy not believed by healthcare professionals. They shared their continued emotional and physical pain in navigating the world physically without their babies and the unspent love they have for them, whilst grappling with a strong sense of blame, shame and guilt in not being able to keep their babies' safe and alive as women and birthing people. An additional sense of internalised ableism was woven throughout their shame and sense of failure as autistic people in a disabling world. Their grief and experience of loss had the power to overwhelm their autistic logical brain. This was bewildering when experiencing the physical internal bodily sensations and emotional distress, which were difficult to language and served as a painful reminder of their loss. They showed us their strength in how they resist silence and continue to re-connect and remember their babies to legitimise their short but meaningful and real lives. This is reflective of the forever imprint of them in their hearts, bodies and minds, and uniquely autistic tangible ways of re-connecting.

The specific GETs will now be explored in more detail in relation to the existing literature and theoretical frameworks.

The Unpredictability of Baby Loss

Participants described the profound unpredictable nature and impact of baby loss and the need for safety and predictability through access to information. Contextualising this within the wider research, universally, baby loss can be anxiety-provoking for women and birthing people, particularly with little knowledge about what to expect whilst actively miscarrying (Meaney et al., 2017). Consistent with autistic research across the perinatal period including systematic reviews, the findings highlight the deep distress caused by the loss of predictability for those who endured labour and gave birth to their stillborn babies or who died shortly after birth (Hampton et al., 2023b; Quinn, 2021; Westgate et al., 2024). The findings highlight the impact of additional factors which may contribute to unpredictability, such as unexpected medical procedures and birth, labour and baby loss being new experiences (Donovan, 2020). These experiences may be compounded by the misalignment between being autistic and the hospital sensory environment, which added layers of distress when losing a baby (Grant et al., 2025a; Quinn, 2021; Westgate et al., 2024).

Furthermore, the findings highlight the psychological impact of not being given enough information, which led to fear, anxiety, uncertainty, feeling out of control, shutdowns and loss of abilities, and strengthen our understanding of the overarching traumatic nature of baby loss (Grant et al., 2025a; Quinn, 2021). Participants described seeking information themselves to obtain predictability and build safety to manage the psychological impact when absent, which may offer new understandings of the importance of safety in predictability. However, the information accessed may not always relieve the sense of unpredictability, particularly in relation to the unfolding medical situation of baby loss, such as actively miscarrying, babies' prognosis and health after birth in neonatal death and trying to process the reality that one's baby may die.

The rich phenomenology of participants' experience strengthens our understanding of the importance of healthcare professionals offering personalised and attuned care and support, in neuro-affirmative ways as previous research highlights (Grant et al., 2025a, 2025b; Quinn, 2021). Specific equitable requirements may include offering all information required to manage anxiety and providing as much predictability as can be offered to build safety when losing a baby, which can precipitate and perpetuate trauma and the psychological wellbeing of autistic women and birthing people (Grant et al., 2025a).

The Horror and Traumatic Nature of Baby Loss

Consistent with the general population, autistic experiences of baby loss were associated with high levels of fear, shock and feeling out of control, particularly when recalling specific memories of actively losing their babies (Berry, 2022; Grant et al., 2025a; Jones et al., 2019). The findings support the strong prevalence of trauma across different types of baby loss and over time, which suggests the imprint of pain, as a reminder of being physically without their babies (Krosch et al., 2017). Participants described distressing memories, physical sensations during re-telling, such as shaking and breathlessness, and a sense of disconnect and dissociation. Their narratives were fragmented, which may be their brain's way of trying to protect them, highlighting the traumatic and terrifying nature of baby loss, which may fit theoretical conceptualisations of our understanding of trauma (PTSD UK, 2025). Common trauma responses are described in Table 17 (NHS, 2022).

Table 17

Common Trauma Responses

Trauma Response	What This Can Look Like
Re-experiencing the traumatic experience	This if often involuntarily, and can include experiences of re-occurring memories, distressing thoughts, images, feelings and physical sensations, like sweating or trembling.
Trying to avoid being reminded of the traumatic experience	This can include avoiding talking about the trauma, feeling emotionally disconnected to try to avoid distressing feelings and difficulties remembering details of the trauma.
A sense of hypervigilance	This may reflect a heightened sense of threat or looking out for possible threats.
Strong emotions	This may include experiencing strong emotions like fear, sadness, anger, guilt, blame or shame, which may be distressing. These emotions may influence beliefs about oneself, others and the world.

Furthermore, peritraumatic beliefs and appraisals of the loss, such as fear, helplessness and horror have been associated with an increased risk of trauma and PTSD following baby loss (Christiansen, 2017). All participants described several trauma responses both in their subjective accounts of losing their babies and in their re-telling, with some participants naming trauma and PTSD as resulting psychological impacts. The findings illustrate the importance of

holding a trauma-informed lens; the recognition of experiences of trauma for individuals and communities, so that experiences of trauma are not absent from our understanding of autistic women and birthing people's distress to ensure they access support they may need (Emsley et al., 2022; Rumball et al.,2020).

Consistent with autistic baby loss research, autistic experiences may pose additional layers of trauma in the context of navigating neurotypically designed structural environments (Grant et al., 2025a). The Social Model of Disability (UPIAS, 1976) may contextualise this further. Moreover, participants described intense experiences of pain throughout baby loss, which could be understood as a heightened sense of interoception, in line with previous autistic research in the perinatal period (Hampton et al., 2023b; Westgate et al., 2024). This may have been further compounded by healthcare staff who failed to understand these experiences through an autistic lens, due to differences in the ways autistic people may express pain (Donovan, 2020), which may risk their pain going un-recognised (Grant et al., 2025a). Furthermore, the healthcare environment may not be conducive to feeling safe or able to communicate this, perpetuating a sense of vulnerability and distress (Lewis et al., 2021). The unique challenges of the traumatic nature of autistic baby loss can be contextualised by research which recognises the interpersonal traumas autistic people may experience, further highlighting structural inequities in a neurotypical world (Rumball et al., 2020; Kerns et al., 2022). However, interpersonal traumas connected to social events, may not be conceptualised as being traumatic from a neuro-normative perspective, which may further risk the extent of autistic women and birthing people's distress going unrecognised (Rumball et al., 2020).

In addition to the universality of experiences of insensitive care and mistreatment which created dissonance with the upsetting and traumatic reality of baby loss, the findings highlight additional challenges faced by autistic women and birthing people (Berry, 2022; Meaney et al., 2017; Petrou & Mcintosh, 2009; Wong et al., 2003). Consistent with Grant et al. (2025a),

participants described feeling belittled, misunderstood and not believed by healthcare professionals throughout baby loss, which left participants feeling vulnerable, unsafe and overwhelmed.

Disenfranchised and Stigmatised Loss

The findings further highlight the disenfranchised and stigmatised nature of baby loss enacted by others including healthcare professionals, friends and family (Meaney et al., 2017; Quinn, 2021; Riggs et al., 2020; Wheeler et al., 2022). The societal taboo and stigma felt within healthcare systems were reported to communicate a sense that baby loss cannot be tolerated by others, leaving women and birthing people alone and isolated in their distress and grief, like previous firsthand accounts of baby loss (Quinn, 2021). This can be contextualised by Doka's (1999) idea of disenfranchised grief. This is reflected in participants' accounts of choosing to suppress and hide their grief in response to invalidation and hurt from others, which may have exacerbated their distress. Drawing on Crenshaw's (1989) idea of intersectionality; that aspects of identity intersect to create unique relationships to power, autistic women and birthing people may be further at risk of disenfranchised grief, due to neuro-normative grieving ideas which may assume autistic people cannot grieve (Doka, 1999). This supports the systematic review findings, which suggests that autistic people may experience unique challenges when grieving, which may not fit with societal constructions of how grief "should be", risking experiences of disenfranchised and unrecognised grief (Aspirational Autistic, 2020).

Consistent with previous literature, women and birthing people experienced strong feelings of shame, guilt and self-blame, which were connected to gendered societal and cultural constructions of what it means to be a woman and birthing person (Bellhouse et al., 2019; Kuforiji et al., 2023; Lau et al., 2024). To the best of my knowledge, the findings add a new understanding of the internalised sense of baby loss at the intersection of autism and the interwoven layer of ableism. Participants described this in the context of a lifetime of being

perceived differently and their sense of worthlessness in comparison to non-autistic others. Leedham et al.'s (2020) research may contextualise these findings further – they reported the impact of living as an unidentified autistic woman and the subsequent core beliefs about oneself as being 'broken' and 'wrong', shaped by one's position and experience of the world. Participants in the current study described how pregnancy was a chance to fit in and appear like others, which may have seemed to confirm and strengthen negative beliefs about the self when their babies died (Leedham et al., 2020). However, the research highlights women and birthing people's strength in trying to resist silence, particularly through connection with others in the baby loss community, which universally can create a sense of solidarity (Conroy et al., 2023; Riggs et al., 2020).

Stigma can be conceptualised as the labelling of a person, characteristic or experience, which may be perceived as different and linked to "undesirable characteristics" (p.367; Anderson et al., 2022). Link and Phelan's (2001) theory of stigma describe the key role of power in stigma, including intersectionality, which may further mediate and shape one's relationship to power structures, including social, economic and political influences, thus stigma (Andersen et al., 2022), which can lead to discrediting an individual's identity, and experiences of stereotyping, rejection, exclusion and discrimination (Goffman, 1968; Link et al., 2001). A recent systematic literature review exploring autism and stigma reported that autism can be understood as a stigmatised identity, with many autistic people being aware of experiences of stereotyping, judgement and discrimination (Han et al., 2022). Stigma may be an underlying experience felt by autistic women and birthing people within this study, such as autistic stereotypes which may have shaped healthcare professionals' misperceptions of sensory and interoceptive experiences, such as differences in experiences and expressions of pain. Moreover, participants also described how falling pregnant initially was connected to a sense of increased self-worth to "be like everyone else", which can further be contextualised by these theories and

the role of stigma in how baby loss can perpetuate and shape one's view of oneself, as previously described (Leedham et al., 2020).

Additionally, Goffman (1968) identified several attributes which can be commonly stigmatised, including blemishes of character and the abomination of the body. Goffman's attributes of commonly stigmatised experienced may contextualise the findings reported by autistic women and birthing people who felt that their bodies, both as women and disabled people did not meet societal and cultural norms in physically gestating or birthing a live baby, depending on the loss experience, thus experiencing abomination of the body (Goffman, 1968; Pollock et al., 2020). Drawing again on Crenshaw's (1989) idea of intersectionality, the findings suggest that autistic women and birthing people may be more at risk of experiences of stigma during experiences of baby loss, at the intersect between gender and disability, which can precipitate and perpetuate distress, in addition to the devastation, grief and pain, experienced universally for women and birthing people.

Furthermore, the strong sense of shame, blame and guilt connected to experiences of baby loss, as reported by participants, along with experiences of being avoided by others, a sense of isolation, and silence across a range of groups of people, including healthcare professionals, friends and family, could also be understood in the context of stigma, in line with previous research (Murphy, 2012; Pollock et al., 2020). Whilst not explicitly named, autistic women and birthing people appeared to describe experiences of stigma throughout their accounts, which may have added an additional layer of distress whilst losing their babies.

The Forever Pain of Grief in Baby Loss

Consistent with the universal experience of baby loss, including Fernández-Cox et al.'s (2025) scoping review, participants described the profound pain and rawness of grief, depicted by a strong sense of emptiness, numbness, embodied pain and psychological distress, such as

sadness and suicidality (Kuforiji et al., 2023). Bruschweiler-Stern's (1998) idea of Gestating the Baby in Mind can be drawn on to understand the sense of grief participant's experienced, not just from the physical loss, but the imagined loss of hopes, dreams and time spent together, which were being gestated and grown in mind. This internal process may not have been openly shared by women and birthing people, particularly in the context of disenfranchised and stigmatised loss as similarly described in previous accounts of baby loss (Quinn, 2021). This may be an additional layer of the invisibility of baby loss to others who do not recognise the psychological meaning and identities attached to pregnancy and growing connection mentally with their baby (Perinatal Training Centre, 2025). Furthermore, participants in the current study described how their grief changed over time, but was always present, which reflects the lifelong felt physical absence of being without their babies. These findings can also be contextualised by theoretical frameworks of grief, supporting process-based understandings, like Stroebe and Schut's (1999) DPM; oscillating between the loss and grief, and restoration and re-engagement with life and Tonkin's (1996) Growing around Grief model, with grief coming in waves as the findings highlight.

The rich qualitative findings strengthen understandings of the unique experiences of autistic baby loss, such as the continued heightened sense of interoception participants described, which served as a reminder of their loss and grief (Quinn, 2021). As previously highlighted, participants expressed a strong sense of embodied and physical pain whilst grieving their babies, which may have been another expression of their sense of interoception, and intensified internal sensations, like grief (Grant et al., 2025; Westgate et al., 2024). This also strengthens the systematic review findings, which highlight the often overwhelming, embodied, physical manifestations of grief from a range of lived experience sources (Lesko, 2022; Neurodivergentgrrrl, 2021; Pang, 2023; Purple Ella, 2018). In addition, participants described feeling that their grief was different, such as experiencing an internal conflict between

their heads and hearts and the unique challenge in struggling to make sense of internal sensations (Purple Ella, 2018; Soraya, 2014). Autistic alexithymia may help to understand this experience, which may add a layer of distress in trying to identify and make sense of the multiplicity of internal experiences (Pang, 2023). Furthermore, the findings highlight the sense of safety in grieving alone, particularly if safe relationships were not available to participants, which risked their grief and loss being disenfranchised and stigmatised. This could be further understood in the context of neuro-normative expressions of grief highlighted in the systematic review and autistic baby loss literature, which the unique experiences of autistic grief may not fit (Kallman, 2018; Pang, 2023; Quinn, 2021).

Whilst a range of similarities have been identified between the empirical findings and systematic literature review more broadly pertaining to experiences of autistic grief, there are unique similarities and differences when considering the experience of death and grief from an attachment lens. As highlighted, the loss of a baby can lead to the loss of an anticipated caregiving role and identity which begins to form with the unborn baby (Côté-Arsenault et al., 2011), and can result in losing a part of oneself, as well as a baby. Bruschweiler-Stern's (1998) gestating the baby in mind can contextualise this further, and in essence, describes the maternal foetal attachment (MFA), where women and birthing people begin to grow and form attachment bonds psychologically in mind with their growing physical baby during pregnancy. The loss of a baby can therefore physically and psychologically disrupt the growing emotional bonds and attachment the woman or birthing person in their caregiving role begins to form with their baby, which can be a factor in understanding the universal, human experience of distress and grief experienced (Bowlby, 1980).

Similarly, the first-hand accounts identified in the systematic literature review, describe a range of bereavement experiences, including the death of parents and grandparents. These roles may also form attachment and caregiving relationships, which may trigger the bereaved

person's attachment system following their death, thus physical separation from a key attachment figure (Bowlby, 1980). In contrast, the range of sources described experiences of bereavement and the death of significant others, such as friends and romantic partners. Whilst often distressing, this may be different to the bereavement and death of someone who may be an attachment figure involved in caring for the bereaved person, which may have developed in infancy and been shaped throughout their adult life.

Bowlby (1980) also described the importance of adjusting to the loss of a loved one through continuing and maintaining bonds. This may be a unique difference between baby loss and the death of other caregiving roles more broadly, particularly in relation to the role of stigma that surrounds baby loss. For example, stigma may be a barrier in acknowledging the growing attachment and psychological connection with the baby who died at any gestational age, and the societal and cultural silence, which can minimise women and birthing peoples' experiences grieving experience (Perinatal Training Centre, 2025). This may make it difficult to maintain and continue bonds with their baby, which from an attachment perspective may increase distress felt in both physical and symbolic separation between caregiver and infant. Furthermore, Arnold and Gemma (1994) describe how the death of an adult can be the "loss of the past", whilst the death of a baby is the "loss of the future" (p263). This idea may shape societal and cultural understandings of the significance of baby loss and be a barrier to facilitating dialogue about experience of baby loss, in contrast to bereavement and death of other significant people in adulthood, as highlighted in the systematic review (Robinson et al., et al., 1999).

Finding Meaning, (Re)connecting and Continuing Bonds

The findings continue to strengthen the understanding that grief is a process, which is forever experienced, along with remembering and continuing bonds with participants' babies' who died. Participants making new meaning can be understood by considering Neimeyer (2001). Meaning making was positive and more challenging, as baby loss served to confirm

some participant's position in the world as an autistic person. The Minority Stress Model (Botha & Frost, 2018), highlighting how marginalised groups experience greater stress due to discrimination, prejudice and stigma, and the Social Model of Disability (UPIAS, 1976) can help to understand this and the continued impact of navigating a structurally neurotypical world. Some participants described a range of coping mechanisms designed to obtain more safety in the world as autistic people, which the reality of baby loss threatened. This may have subsequently increased stress and anxiety, through experiences of structural barriers and discrimination, which may lead to internalised stigma as a range of qualitative research has shown (e.g., Botha et al., 2018; Leedham et al., 2020).

Furthermore, participants described the importance of finding ways of continuing bonds with their babies, consistent with the broader baby loss literature (Bellhouse et al., 2019; Lau et al., 2024). This strengthens the importance of process models of grieving, such as Klass et al.'s (2014) continuing bonds. Participants described more tangible and physical ways of re-connecting with their babies, such as pairs of teddies, planting flowers, nature and positive acts of kindness to transform grief. This may shape our understanding of autistic baby loss and grief, which was consistent with the systematic review (Adult with Autism, 2024; Ceney, 2023; Neurodivergentgrrrl, 2021; Pang, 2023). Furthermore, the findings can be contextualised by bereavement literature, such as Schroedel (2009) who highlighted the importance of storying, talking about babies who died and naming them, to make them real and legitimise their meaningful and longed-for lives.

Overall, this research strengthens our existing understanding of the unique challenges that the perinatal period may bring and further supports the limited research considering autistic baby loss. More uniquely, this research offers a detailed understanding of the impact of the unpredictability of baby loss and the need for information to build safety, which participants tried to obtain themselves. It sheds new light on our understanding of the stigmatised nature of baby

loss, which can lead to strong feelings of blame interwoven with internalised ableism through an autistic lens. Finally, the research offers a unique contribution to our understanding of autistic grief and bereavement, within a neuro-normative context, and highlights the more tangible ways in which participants continue to remember and reconnect with their babies.

Clinical Implications

A range of clinical implications were identified through this research, from individually to more systemically. These implications will be considered in context of the role of a clinical psychologist, which will now be discussed.

Responding to Autistic Grief

As in the systematic review, the findings highlight the need for healthcare professionals to understand the breadth of autistic grief experiences. The findings strengthen the use of process models of grief, particularly when considering autistic grief, which may also be at risk of being disenfranchised within a context of neuro-normativity. This study highlights that baby loss remains a silent, hidden and stigmatised loss, which can leave women experiencing strong feelings of shame, guilt and blame, and may further disenfranchise their grief. This emphasizes the importance of finding ways to resist the societal silence to re-legitimise and humanise their valid distress, grief and baby loss through an autism lens. First-person accounts are effective ways to counter stigma (Thornicroft et al., 2016). The sources identified in the systematic review are examples of this, which centre autistic people who shared their experiences of grief and bereavement to advocate and de-stigmatise autistic grief. This study is another example which foregrounds the rich phenomenological accounts of baby loss from autistic women and birthing people. Moreover, the autistic authors of the systematic review sources and participants talked about the safety and solidarity in connection with others to re-legitimise their pain, grief and

experiences of loss. These groups can also be seen as advocating for autistic grief and baby loss to de-stigmatise and re-enfranchise their experiences.

Signposting to peer-support services, such as Sands or Autistic Parents UK or creating peer-support spaces as part of service provision could be ways to enact this. This should be co-produced with autistic women and birthing people, which may include the development of peer-support roles (Toms & Nolte, in press). Baby loss certificates: a way of legally and formally recognising the loss of a baby through miscarriage (Gov.uk, 2025), should be noted as a resource for re-legitimising and resisting the silence surrounding baby loss, as the findings highlight.

Furthermore, the stigma surrounding grief and baby loss can be enacted by healthcare professionals within perinatal care settings. Clinical psychologists can bring awareness to systemic influences, such as stigma, through contributing to multi-disciplinary teams (MDTs). Reflective practice and supervision may be offered as ways to support medical staff in navigating their relationship, personally and professionally to baby loss, death and bereavement more broadly. Whilst clinical psychologists may not sit directly within maternity and obstetrics, the provision of specialist MMHS', which combine maternity care and psychological therapy, may be a way to bridge this gap with the broader maternity care settings (NHS England, 2023).

Autistic Informed Perinatal Care

This research adds to existing research that highlights the need for healthcare professionals across maternity and perinatal care, to understand the nuanced experiences of autistic women and birthing people. This is central to understanding and avoiding undue distress, and includes: (1) the loss of safety in predictability; (2) specific sensory experiences, including hyper- and hypo-sensitivities to the seven senses with specific consideration to interoception and how this may shape experiences of pain; and (3) communication and

information processing preferences, including the necessity of clear, sensitive, specific, personalised and continuous communication shared in line with specific communication needs, for example, written information and demonstrations. The Care Quality Commission (CQC) Maternity report (2024) highlights the impact of poor communication on birth experience. Furthermore, collaboration and shared decision-making is a central facet to perinatal care, which can be facilitated by clear explanations and honest answers to questions from clinicians, including questions about more technical aspects and medical procedures in high-risk antenatal contexts (Hilder et al., 2020) and scripts where possible to help restore safety in predictability (Quinn, 2021). This is particularly important in the current study given the need to obtain safety in predictability through information to help manage what is often an unpredictable and changeable medical situation.

Clinical psychologists in maternity and perinatal services are imperative to developing services equitably with consideration to neurodivergence, which should include clear guidelines about what can help from women and birthing people and best practice. Regular training focused on understanding autistic women and birthing people's experiences, including baby loss could be considered. Additionally, challenges related to autism disclosure have been noted within the literature (Westgate et al., 2024). Autism, and neurodiversity, more broadly may not currently be recorded routinely upon referral or access to services, including self-identification which should be considered valid. The research strengthens a recommendation for services to consider collecting this data routinely as additional ways of raising awareness of neurodivergence and to be used meaningfully as information to help understand and implement personalised care and equitable requirements. However, this data should be collected sensitively and skilfully by staff, particularly as fear of judgement and stigma are obstacles to disclosure (Westgate et al., 2024). Supporting staff awareness, skills and knowledge through supervision, training and reflective practice could be offered. This may invite dialogue about

aspects of identity, which may be hidden, such as neurodivergence, alongside other intersectional identities drawing on Burnham's (1992) Social Graces, the multiple facets of one's identity, and Crenshaw's (1989) intersectionality. Regular consultation spaces could be offered to discuss clinical cases and formulate the specific needs and experiences of autistic women and birthing people. This may include considering equitable requirements and how to implement and review these to support medical staff in tailoring their approach. Practitioners could, for example, incorporate neurodivergent needs into individualised trauma-informed birth plans to help plan and prepare for birth, and support with future planning following baby loss (Quinn, 2021).

Co-production is a central clinical implication arising from this research to raising awareness and developing training to ensure that perinatal settings are developed and improved with bereaved autistic women and birthing people, for their community (Think Local Act Personal, n.d.). This study provides an example of the impactful nature of first-person accounts, highlighting further the potential of first-person informed co-produced materials and services (Thornicroft et al., 2016).

Trauma-informed Responses to Baby Loss

The findings highlight the traumatic nature of baby loss, and the felt absence of care from healthcare professionals universally and the unique autistic experiences of feeling belittled, not believed and infantilised. Trauma-informed practice is the recognition of trauma and the impact it can have on an individual's worldview (Scottish Government, 2021), which can be implemented through key principles (Office for Health Improvement & Disparities, 2022; Table 18). This may be an important approach to adopt across maternity services, particularly considering the possible trauma autistic people may have experienced and to reduce the risk of re-traumatisation (Rumball, 2022).

Table 18

Key Principles of Trauma-informed Care

Key Principles	Description
Safety	Centring physical, emotional and psychological safety through asking people what they need to build safety and trying to prevent re-traumatisation.
Trustworthiness	Building trust through open and transparent communication and doing and meaning what you say. Recognising the impact of difficulties with trust in the context of past experiences of trauma and adversity.
Choice	Offering choice, agency and control through shared decision-making and active listening to wishes and needs.
Collaboration	Making decisions collaboratively to work alongside individuals, including peer-support and involving EbEs.
Empowerment	Sharing power to empower people through choice and agency.
Cultural consideration	Acknowledging power and dismantling societal and cultural constructs of protected characteristics, such as offering “gender responsive services”, and offering culturally competent and humble services (Office for Health Improvement & Disparities, 2022).

These principles also highlight how universally, individualised, personalised care may be supportive for all women and birthing people, offered routinely as part of good clinical care, but also align to the needs of autistic women and birthing people as natural equitable requirements, such as clear and honest communication with access to as much information as possible (Grant

et al., 2025a). This is in line with the current guidance for trauma-informed MMHS', which recommends the importance of recognising diversity when offering individualised care (Benton et al., 2024). As part of the leadership role of a clinical psychologist, service policies and guidelines could be amended to include trauma-informed principles. Trauma-informed principles may be further disseminated through staff training and supervision, as discussed.

Individual Therapy for Autistic Women and Birthing People

The findings highlight several clinical implications when working directly with autistic women and birthing people experiencing psychological distress arising from baby loss. Through the commissioning of MMHS', service provision is becoming more available, however, this may not consistently be offered to all women and birthing people who experience baby loss. This is a recognised area for action to ensure consistent care across the country (MMHA, 2024). Trauma responses may be expressed and experienced in physical and embodied ways by autistic people, which may be connected to a heightened interoceptive sense (Rumball, 2022). Eye Movement Desensitization Reprocessing (EMDR) is psychological, NICE recommended trauma therapy, which supports people to process distressing images, emotions and bodily sensations connected to a traumatic memory (Havens, n.d.; NICE, 2018). EMDR has good clinical evidence with autistic adults delivered with equitable requirements in person-centred ways (Fisher et al., 2023). EMDR as an approach may also be supportive for those with communication differences (Fisher et al., 2022).

Furthermore, participants described strong feelings of shame, blame and guilt following baby loss (Lau et al., 2024). Compassion-focused therapy (CFT) is a therapeutic approach aimed at growing compassion and soothing to support experiences of psychological distress (Gilbert, 2014) and has been evidenced to support with strong feelings of shame (Gilbert & Procter, 2006). CFT can also be supportive in baby loss and grief to cultivate a compassionate self (Harris, 2023). Additionally, narrative ideas, like externalising, which view difficulties

externally to the self (White, 1995), may help to name broader societal and structural influences and narratives as the “problem”. This may help explore core beliefs shaped by these ideas, which become internalised (Carey & Russell, 2004). The findings support the use of process-based grief models therapeutically, particularly the DPM (Stroebe & Schut, 1999), meaning-making (Neimeyer, 2000), and continuing bonds (Klass et al., 2014) with a specific consideration of more practical and tangible ways of marking, remembering and reconnecting with their grief and babies. For example, practitioners could think with autistic people about significant places or objects to remember and reconnect with their babies. Strength-based, neuro-affirmative ideas could also be drawn on to legitimise and validate the unique differences of autistic grief and how the autistic neurotype offers many natural resources, such as encouraging self-regulatory movements, sensorily calming environments and transforming grief into something to honour their babies (Quinn, 2021). Practitioners could explore interests to consider how these may support the process of grieving and specific activities, which may help mark grief more practically.

Clinical psychologists should seek to understand subjective experiences of autistic women and birthing people to audit and monitor service changes in line with the range of clinical implications shared. This will be important to understand if these changes make a difference to autistic women and birthing people’s experiences of maternity care, and those who lose their babies.

Critical Evaluation and Areas for Further Research

To the best of my knowledge, this is one of the first empirical studies exploring autistic baby loss with a qualitative methodological approach, using IPA to centre their subjective lived experiences. This was a particular strength to re-legitimise and de-silence their experiences through time and space, in an area that is silenced including baby loss, the taboo of death and bereavement and at the intersection of autism. Ethically, this research centred the safety and

care of participants in many ways, to reduce the risk of further distress in participating in an understandably evocative study, whilst recognising and re-humanising the grief and emotions of talking about baby loss. A further strength is the use of an AE, which foregrounded the autistic neurotype and aligned with more neuro-affirmative approaches shaped by bereaved autistic women, while recognising the socio-political context of autism research. This was a strength in developing the current study, such as recruitment and data collection to ensure that equitable requirements supported access and engagement.

There are also limitations of the current study. Participant's experiences were incredibly valued; however, most were between 35 – 54 years old, identified as female, with she/her pronouns, from predominantly white western cultural backgrounds. While within an IPA methodology, representation is not the aim, this does pose the question of whose voices are not heard or represented within the study. Autistic women and birthing people who may have aspects of their identity which hold less power and are marginalised in further ways, such as those from the global majority, who are gender diverse and are younger might have shared different experiences that could further deepen our understanding of autistic baby loss. Therefore, the additional unique layers of experience of those who do not identify as cis-gendered, white western autistic women, would be important areas for further research, to inform equitable healthcare services for all women and birthing people. Many of the participants reported multiply neurodivergent identities alongside autism, most commonly ADHD. Future research could consider the experiences of multiply neurodivergent women and birthing people.

As the existing literature is limited, experiences of baby loss included a range of loss experiences from miscarriage to neonatal death, which was distributed evenly across the different loss experiences. Future research could build on this by focusing on autistic women and birthing people's experiences of different types of baby loss to develop a more nuanced and detailed understanding.

Finally, the study highlighted the unpredictability of baby loss for autistic women and birthing people and its profound impact, which was noted in previous autistic baby loss literature, and the perinatal period (Grant et al., 2025; Westgate et al., 2024). The psychological impact of the unpredictability of baby loss as a unique aspect of the autistic experience, could be explored further in future research. Further research may also consider the use of AE to ensure that autistic people are represented throughout research equitably to generate knowledge in ways best aligned to their neurotype, which may continue to reclaim and re-define aspects of autistic experiences within a context which has historically been more deficit-focused (Beardon, 2025). The current study and systematic review highlight the unique aspects of autistic grief and bereavement, in a limited empirical research base. Future research may wish to explore autistic loss and grief more generally to build this evidence-based and further shape our understanding.

The Critical Appraisal Skills Programme (CASP) Checklist for qualitative studies was completed to critically evaluate this research (see Table 19).

Table 19

Critical Evaluation using the CASP Checklist

Section A – Are the results valid?			
	Yes	No	Can't Tell
1. Was there a clear statement of the aims of the research?	✓ - the research aims were clearly stated situated in the context of empirical literature, theoretical frameworks and the systematic literature review.		
2. Is a qualitative methodology appropriate?	✓ - the research seeks to understand the rich and detailed subjective experience of baby loss for autistic women and birthing people, which to the best of my knowledge is the first IPA study.		
3. Was the research design appropriate to address the aims of the research?	✓ - as highlighted in Chapter 3, the rationale for methodological design and decision making have been explored fully.		
4. Was the recruitment strategy appropriate to the aims of the research?	✓ - Chapter 3 highlights the considered approach to recruitment, particularly aligned to an autistic epistemology, as well as a recruitment flow-chart to understand participant decision-making across the duration of study recruitment. As described in the limitations section, participants were of a certain demographic. Future research could add to the recruitment strategy to try to reach other participants.		

5. Was the data collected in a way that addressed the research issue?	✓ - IPA was considered most appropriate to understand the subjective, idiographic experiences of baby loss for autistic women and birthing people, with full details of the development of the study highlighted in Chapter 3, as evidenced in the appendices.		
6. Has the relationship between researcher and participants been adequately considered?	✓ - the research is contextualised epistemologically and in relation to reflexivity in Chapter 1, and throughout the research. Supervision and reflective journalling supported this process, as evidenced in the appendices.		
Section B: What are the results?			
	Yes	No	Can't Tell
7. Have ethical issues been considered?	✓ - ethical considerations were foregrounded throughout the study, as detailed in Chapter 3, which was imperative to the sensitive nature of the study topic and obtained ethical approval prior to commencement.		
8. Was the data analysis sufficiently rigorous?	✓ - the researcher's approach to IPA is detailed in Chapter 3, with copies of the different stages evidence in the appendices. The researcher placed significant importance on ensuring participant's voices were central to the analysis and narrative shared and used a reflective diary to support with bracketing and acknowledging one's own position, assumption and lenses throughout analysis. Detailed discussions in the supervisory team supported this process.		

9. Is there a clear statement of findings?	✓ - the findings are provided in Chapter 4, with a summary of the results at the start of this chapter, which state what could be understood as the unique aspects of baby loss for autistic women and birthing people, and universally across the general population in relation to the research question.		
Section C: How will the results help locally?			
	Yes	No	Can't Tell
10. How valuable is this research?	✓ - the value and impact of this research has been discussed in relation to previous empirical research and new contributions, as well as outlining a range of clinical implications, strengths, limitations and areas for continued research.		

Dissemination

This research is a platform for participants' experiences to be heard and listened to and their babies honoured and remembered as a tool of social change, therefore, dissemination is important. Whilst completing the research, a range of dissemination plans were identified. I plan to present my research to various services to inform the way we think about supporting autistic women and birthing people and improving equitable service provision. I plan to disseminate this research through several publications, including both the SLR and empirical research (targeted journals being *Advances in Autism* and *Autism*). I plan to share written summaries of the results with each participant and consult with EbEs to consider further dissemination routes, including creating a professional infographic to be shared widely, e.g., via social media. Finally, my role as a clinical psychologist working within autism or perinatal services will be a way of continuing to advocate and disseminate this research.

Final reflections

It has been an honour to meet the six autistic women and birthing people who trusted me enough to participate in this study, and to meet their babies through memory, heart and dialogue throughout this process. Whilst it has been hard to listen to the distressing experiences participants endured, it has been a gift to be able to offer this, bear witness and sit with them in their understandable, valid and real pain and grief for their babies. In return, I have had the privilege of hearing about them and their babies to ensure their voices are heard, and we can together facilitate their hopes in trying to advocate for change for future autistic women and birthing people who experience baby loss.

Personally, as an autistic cis-gendered woman wishing to one day have children, I have learnt something about the reality of pregnancy, birth, labour and motherhood and could not help but think about what this might be like for me. I have also been reminded of personal

experiences of how I am positioned in relation to my autistic identity in a neurotypical world, which was foregrounded at different times throughout this research in context of my personal and professional experiences. The multiplicity of these contexts and experiences have been challenging at times, with support, passions and supervision from the broader research team being key to sustaining my wellbeing. This journey of research, connecting with participants and their babies will be one I will never forget and will carry with me in the hope of creating a more equitable world for autistic people more broadly and more specifically, autistic women and birthing people and their babies.

Conclusion

Universally, baby loss is a devastating experience, but this research has helped us to understand the unique challenges experienced by autistic women and birthing people. The use of IPA facilitated hearing directly from autistic women and birthing people to stand in their shoes, listen to and feel the distress, trauma, emotional pain, shame, blame and grief they have endured through losing and living physically without their babies. Listening to their experiences also showed us the unpredictable nature of baby loss, along with heightened autistic sensory experiences, belittling and infantilising care within a structurally ableist context, which shaped a sense of powerlessness, lack of safety and pain when losing their babies. We learnt of their babies meaningful and beautiful lives, which we miss out on if we embody the societal stigma through silence and need to resist to ensure their lives are remembered and participants' grief and pain heard. These are important findings which should motivate us to reflect on and resist further layers of misinterpretations of the autistic experience that may limit us from listening to and better supporting autistic women and birthing people in navigating the ***"heart crushing"*** reality of losing a baby.

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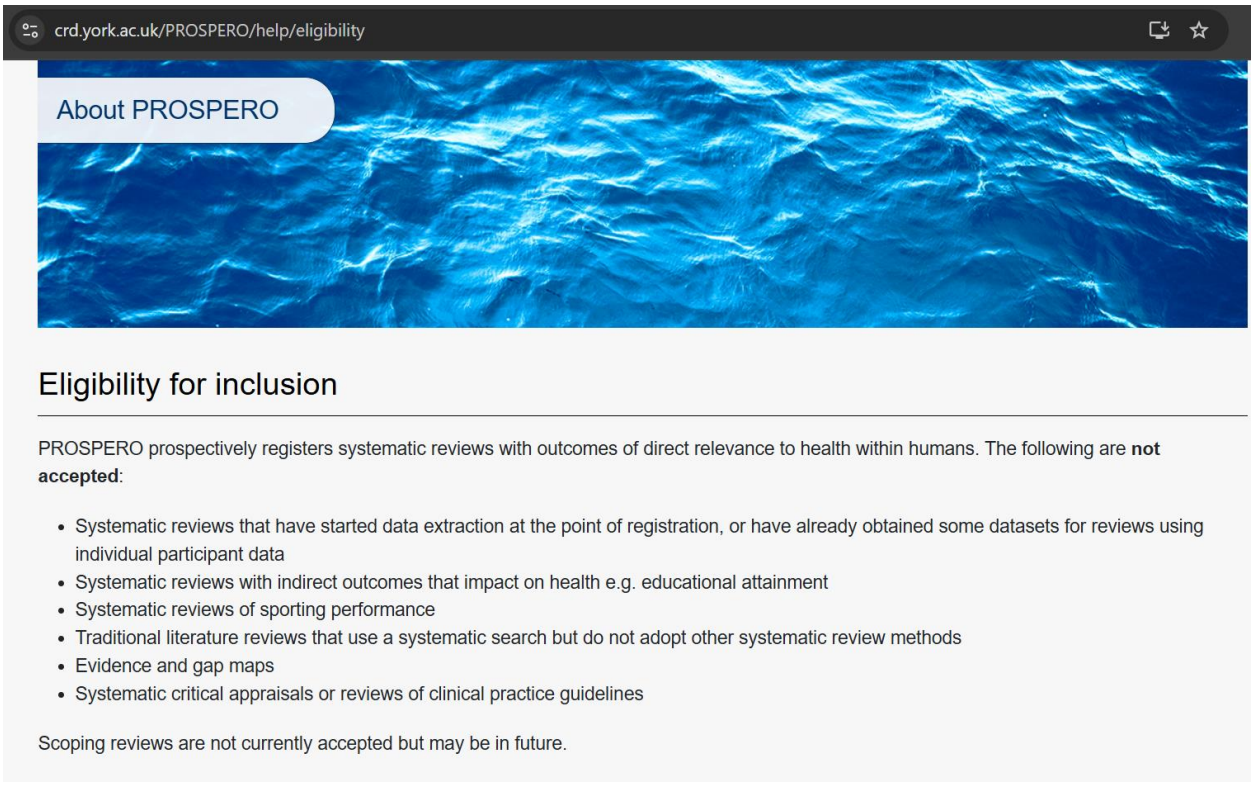
Appendix 1

PROSPERO Eligibility for Inclusion



Appendix 2

Scoping review spreadsheet

Scoping review spreadsheet

Search date	Search source	Search terms	Sources found	Outcome	Details:	Actions:	Final outcome:	Reason:
11/7/2024	CINAHL Plus	Autism or Autism spectrum disorder or autism spectrum condition or autistic disorder or autistic people or autism in adults or person with autism or neurodiverg* or neurodiversity or autistic child or child with autism AND grief or Grie* or griev* or bereavement* or anticipatory grief or traumatic loss or ambiguous loss or death or dying AND experience or Experience or understanding or view* or feeling* or perspectives	76	1	Barber (2022)	Abstract screened, full text screened.	Included	
11/7/2024	Backwards citation searchers from Barber (2022)		3	3	Graham (2013)	Full text screened	Included	
	As above				Fisher (2012)	Full text screened	Included	
	As above				Bennie (2021)	Full text screened.	Included	How to support
	Backwards citation searchers from Bennie (2021)		12 (3 duplicates) = 9	1	Soraya (2014)	Full text screened	Included	
11/7/2024	MEDLINE	spectrum condition or autistic disorder or autistic people or autism in adults or person with autism or neurodiverg* or neurodiversity or autistic child or child with autism AND grief or Grie* or griev* or bereavement* or anticipatory grief or traumatic loss or ambiguous loss or death or dying AND experience or Experience or understanding or view* or feeling* or perspectives	210	1	Barber (2022)	Duplicate	N/A	
18/07/2024	Reference searching literature review (excluded due to review)		1	0	Burlton (2018)	Mostly LD population	Excluded	Wrong populati
18/07/2024	Reference searching literature review (excluded due to review)		1	1	Kallman (2018) A phenomenological exploration of grief in children with autism according to the lived experience of parents	Full text screened	Included	
18/07/2024	Google scholar	autism or autism spectrum disorder or autistic disorder or autistic people or autism in adults or neurodiverg* or neurodiversity or autistic child or child with autism and grief or grieving or bereavement or death or dying and experiences or experience or perspectives or view or understanding	90	2	Pang (2023)	Full text screened	Included	
7/18/2024	ProQuest Dissertations and Theses	autism or autism spectrum disorder or autistic disorder or autistic people or autism in adults or neurodiverg* or neurodiversity or autistic child or child with autism and grief or grieving or bereavement or death or dying and experiences or experience or perspectives or view or understanding	1	0			Excluded	Not specific to
26/07/2024	Google scholar	neurodivergence or autistic or autism and grief or bereavement or death and experiences or experience or perspective or views or understanding	672(2 duplicates) = 670	1	Ceney (2023)	Full text screened	Included	
26/07/2024	The British Psychological Society (including CPF, Child and Family	autism and bereavement	2	0	Chandler (1996)	Abstract screen; full text screened	Excluded	Intervention fo
26/07/2024	Context AFT journal	autism and grief; autism and bereavement; neurodivergent and grief	3	0	Not relevant			
8/8/2024	Scopus	"Autism spectrum disorder" OR "autistic spectru	206	2 (1 duplicate,	Koeler (2011)	Full text screened	Excluded	Intervention fo
8/8/2024	google scholar	autism and experiences and grief	45000 - first 10 pages screened = 100	3	Graham (2013; duplicate); Barber (duplicate); Mair et al. (2024) - T	Mair et al (2024) to be screened and full text screened - requested as ILL. Sent only abstract of poster presentation. Full text not available. Email to corresponding author. https://osf.io/gfk9u/	Excluded	Not able to be a
8/8/2024	OpenGrey	autism AND grief AND experiences	0	0				
8/8/2024	OpenGrey	grief	19	0				
8/8/2024	PsycEXTRA	autism and grief	71	0				
8/8/2024	PsycEXTRA	neurodivergent grief	1	0				
16/08/2024	Autism Speaks - found through reference searching key article (Pa	grief	19	0				
"	Autism and Grief project - found through reference searching key article (Pang) - For Autistic Adults section			1	Grief after Death - experiences of what grief might be like - website page written by autistic contributors/people		Included	

Appendix 3

Recruitment materials

3a. Recruitment poster

Autistic women's and birthing people's experiences of baby loss

What is the study about?

I hope to explore and understand what it is like for autistic women and birthing people to live through the loss of a baby and the sense you make of this experience.

Who can take part?

I would love to hear from you if you:

- Identify as an autistic woman or birthing person (inclusive to range of gender identities including non-binary and trans and all cultural backgrounds)
- Formally or self-identify as being autistic
- Have experienced the loss of your baby through a miscarriage, stillbirth or neonatal death at any time during your life, but not within the last six months.

What will the study involve?

You will be invited to meet with me to speak about your experience of losing your baby in an online research interview via MS Teams with equitable requirements e.g., cameras off, use of the chat function.

The aim of the interview will be to understand your experiences as an autistic person of pregnancy and losing your baby; and what it was like for you to go through this.

What should I do next?

My name is Phoebe and I am an autistic Trainee Clinical Psychologist at the University of Hertfordshire.

If you are interested and would like further information, please email me and your preferred contact details to my email address: pt22aak@herts.ac.uk. Please also share any reasonable adjustments you need.

You do not need to share any personal information about the loss you experienced at this point.

University of Hertfordshire UH Ethics Committee

This is an official notification by a student of the University of Hertfordshire in respect of a study involving human participants.

3b. Supporting Alt Text for Research Advert

Image of research poster to recruit participants to take part in an online research interview to understand autistic women and birthing people's experiences of baby loss.

The poster invites people who identify as an autistic woman or birthing person (which can include a range of gender identifies, such as non-binary, trans and cis-women and inclusive to all cultural backgrounds), formally or self-identifies as autistic and has experienced the loss of their baby through miscarriage, stillbirth or neonatal death at any time during your life, but not within the last six months.

The research advert requests those who are interested and who fit the description to take part to contact Phoebe, an autistic Trainee Clinical Psychologist and lead researcher for the project.

The research project has ethical approval from the University of Hertfordshire Health, Science, Engineering and Technology ECDA.

Appendix 4

Permissions from Recruitment Pathways

4a. Sands Baby Loss Charity:

From: research <research@sands.org.uk>
Sent: Tuesday, October 17, 2023 17:07
To: Phoebe Toms [Student-LMS] <p.toms@herts.ac.uk>
Subject: RE: Research advice

Dear Phoebe,

Yes thanks, apologies for the delay.

I'm happy to say that we would like to support your research project and it would be great to have a meeting soon to discuss next steps and how planning is going. Is there a time in the next couple of weeks that works well for you?

Thanks,

[redacted]

[redacted]

[redacted]

[redacted] | www.sands.org.uk

Sands Helpline: 0808 164 3332 | helpline@sands.org.uk |sands.org.uk/support

4b. Autistic Parents UK:

From: [redacted]@autisticparentsuk.org
Sent: 27 January 2024 21:01
To: Phoebe Toms [Student-LMS] <p.toms@herts.ac.uk>
Subject: Sharing research participation poster

Hi Phoebe,

Sorry there's been a delay with this. We are happy to help your recruitment for your study. Not only does it meet our criteria, but I feel it's such a vital area of research.

Can you share your recruitment poster with me please?

Kind regards,

[redacted]

4c. MARG:

From: [redacted]
Sent: Friday, June 28, 2024 13:01
To: Phoebe Toms [Student-LMS] <p.toms@herts.ac.uk>
Subject: RE: Research Study - MARG comments

Hi Phoebe

Just to confirm we're happy to support participant recruitment.

I've noted that the go live date for MARG is w/c 5th August – I'll organise for that to be scheduled.

Best wishes

[redacted]

Appendix 5

Email Template to Invite Initial Recruitment Discussion

Thank you so much for contacting me about my research exploring autistic people's experiences of baby loss. I will now share some further information to help you to decide whether you wish to take part.

The first step is to go through some initial questions to make sure that this research is a good fit for you, as there are some factors which may prevent people from being able to take part.

You will not be expected to share any specific details of your loss, but rather to start to get to know one another, to hear more about you and think together about whether this research is for you. My aim is to ensure this feels right which we can decide together.

I appreciate that talking on the phone may be difficult because of communication differences, however, the next step will involve a short telephone conversation which will be guided by the following questions:

1. Are you an autistic person? Yes/No
2. Are you formally identified or self-identified as autistic? (how long/your sense of this and relationship to your experiences/identification)
3. Have you experienced perinatal loss in the past six months? Yes/No. (When did you experience your loss, general check in about how things are currently in terms of mental health and wellbeing, how might this feel to participate in a study asking about experiences of loss?)
4. Are you currently pregnant or trying to conceive? Yes/No.
5. Are you currently receiving any active treatment or intervention for any mental health or psychological difficulties? Yes/No (more details e.g., what this consists of, with who, current contexts or difficulties)
6. Who do you have around you to support you? (e.g., social support – family, friends, current lifestyle, resources [passions, hobbies])
7. Would you be willing to share your GP's name and contact details? This would only be used in the context of becoming aware of any risk to self or others during the interview. GPs will not be contacted outside of this remit.

Please note that if questions **3, 4 and 5** apply to you and your current situation, unfortunately, you will not be able to take part in this research. This is because we want to ensure that possible participants are protected from harm and these factors may mean that participation may not be a good fit at this time. Thank you for your interest.

If questions 3, 4 and 5, do not apply to you or your current situation, please respond to this email to let me know when a convenient time for me to phone you would be.

Appendix 6

Demographic Questionnaire

This is a brief questionnaire to find out a bit more about you. Please complete the questionnaire by providing answers to the questions below. Please only share what you feel comfortable with sharing.

1. How old are you?

2. How would you describe your gender identity and what are your pronouns?

3. How would you best describe your ethnicity and cultural background?

4. Do you consider yourself to have any other disability alongside being autistic? If yes, please feel free to give brief details e.g., ADHD, learning disability.

5. What is your current relationship status?

6. Who do you currently live with?

7. Do you have any living children? If yes, how many?

Appendix 7

Evidence of Ethical Approval

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Phoebe Toms
CC	Dr Lizette Nolte
FROM	Dr Rosemary Godbold, Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	17/05/2024

Protocol number: **LMS/PGR/UH/05620**

Title of study: Autistic women's and birthing people's experiences of baby loss.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Sophie Doswell (external; South London and Maudsley NHS Trust)

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 17/05/2024

To: 31/12/2024

Appendix 8

Distress Protocol for Participants

8a. Participant Becomes Distressed

1. As part of the initial setting up of the interview space, the researcher/participant will explore what distress looks like to help with identifying possible distress e.g., how will I know if you're finding things more difficult e.g., long pauses, becoming quieter.
2. If distress arises, the interview will be paused, and a break offered.
3. The researcher will draw on therapeutic skills to contain participant's distress in the moment. However, the researcher will not be able to offer any therapeutic support or advice as the participant has consented to research not therapy.
4. Participants will be reminded that they do not need to carry on with the interview or can terminate the interview at any time, passing on any questions that feel too difficult.
5. Participants will be asked how they are feeling throughout as a check-in.
6. Participants will be offered a debrief space at the end of the interview. This will involve a brief check-in, reflection on the experience of the interview and what participants have planned as a way to transition from the interview.
7. Participants will be given a list of resources and signposts as part of the debrief.
8. If any risk to self or others is shared or identified during the interviews, the researcher will raise this with the participant and may need to break confidentiality by contacting the person's GP.

8b. Participant Leaves the Interview

1. Researcher to assess context in which disengagement/drop off from the call arises e.g., has internet connectivity issues arisen, topic of conversation before participant left.
2. Research will wait 2-3 minutes to see if participant rejoins.
3. Contact participant by email to notice that they have left the call and re-share MS Teams link.
4. If no response, re-share signposts and resources and encourage self-care and access to things that help including social support that would have already been identified during screening.

Appendix 9

Debrief: signposts and resources

Thank you so much for sharing your experiences within our study. Your participation is appreciated.

Sharing your story and experiences of losing your baby may have been an emotional experience for you, so thank you again for taking part.

What is the purpose of this study?

This study hoped to explore and understand what it is like for autistic women and birthing people to live through the loss of a baby. We specifically hoped to understand how autistic people make sense of their experiences of loss, which we hope will help to shape how society understands and supports autistic people within the maternity and parenting context, specifically, experiences of baby loss.

What if I was impacted by the study?

Sharing and talking about the sense you made of your loss experience may understandably bring up difficult feelings for you, which you may not expect. We hope that some of the resources will be helpful should you find yourself needing some additional support.

The professional code of conduct and ethical approval for this study means that Phoebe Toms cannot personally support individuals beyond the remit of the study. With this, we have created this debrief sheet with a list of contact details for further support, alongside the processes you have put in place with Phoebe before agreeing to take part in this study.

- **Sands Baby Loss helpline**: *If you have been affected by pregnancy loss or the death of a baby you can speak in confidence to our Bereavement Support team by calling the Sands helpline, open Mon-Fri 10am-3pm and Tue-Thur 6-9pm on 0808 164 3332 or emailing helpline@sands.org.uk*

More details about the support we offer can be found here: How we offer support | Sands - Saving babies' lives. Supporting bereaved families.

- **Tommy's**: *a range of resources and signposts can be found on their website, including a baby loss Facebook support group. https://www.tommys.org/*

- **The Miscarriage Association:** *support and information by anyone affected by miscarriage, ectopic pregnancy or molar pregnancy. Staff pregnancy loss telephone line on 01924 200799 or via our web address: https://www.miscarriageassociation.org.uk/. (Please note that this is support rather than counselling, and information rather than medical advice.)*

- **Cruse Bereavement Support UK:** *support and information for anyone who been bereaved at any point in their journey. Contact the service by telephone on 0808 808 1677 for support from trained bereavement volunteers to help you to make sense of how you're feeling. https://www.cruse.org.uk/*

- **National Autistic Society:** *a range of information, resources and communities to connect with other autistic people: https://www.autism.org.uk/*

- **Autistic Parents UK:** *an autistic-led charity committed to supporting autistic parents within the UK in a number of ways including peer-support and resources: https://www.autisticparentsuk.org/*

Alternatively, you may wish to seek further advice or support from your GP for more specialised and specific support available to you locally.

Appendix 10

Distress Protocol for Researcher

Emotional support for researcher

The main researcher will share plans (date and time) for each interview with the principal supervisor in advance so that they are aware of research activity and be contactable should concerns arise or advice required.

The principal supervisor will be contactable for debrief if needed after each interview.

The main researcher will ask to meet with the principal supervisor every two weeks to debrief after the interviews that week.

Self-care for the researcher will be prioritized and drawn on where needed, particularly during the interview and transcription phase due to resonances with aspects of their own identity and the study topic.

A self-reflective journal will be kept as a way to make note of and reflect on my own emotional wellbeing, as a way to keep note of any challenges or delays in processing following interviews and transcription and lean into support or self-care when needed.

Appendix 11

Participant Information Sheet

1 Title of study

Autistic women and birthing people's experiences of baby loss. (Version 3, January 2024)

2 Introduction

My name is Phoebe, and I am an autistic, Trainee Clinical Psychologist. I am currently completing my Doctorate in Clinical Psychology at the University of Hertfordshire, which is a professional training to become a Clinical Psychologist.

As part of my training, I am required to complete a piece of research. I am the lead researcher for this project. I have a small team of researchers around me including Expert by Experience consultants to ensure the project meets the needs of bereaved autistic women and birthing people.

I would like to invite you to take part in research. Before you decide whether to do so, it is important that you understand the reasons I am hoping to complete this research and what your involvement will look like if you decide to take part.

Please take the time to read the following information and discuss it with others if you wish. Please contact me to ask a question if something is not clear or if you would like any further information to help you make your decision. Please take care of yourself when reading this information sheet and do what you need to support your wellbeing.

3 What is the purpose of this study?

I hope to explore and understand what it is like for autistic women and birthing people to live through the loss of a baby. I specifically hope to understand how autistic people make sense of their experiences of loss, which I hope will help to shape how society understands and supports autistic people within the maternity and parenting context.

4 Do I have to take part?

It is completely up to you whether you decide to take part in this study. I would value your participation to hear your experience of your loss, but participation is entirely optional, and you have the right to make an informed decision based on what feels right for you.

If you do decide to take part, you will have this information sheet to keep and will be asked to sign a consent form and complete a brief demographic questionnaire. However, even if you agree to participate in the study, this does not mean that your decision is fixed. You are free to change your mind and have the right to withdraw your interview up to two weeks after, without needing to give a reason.

5 Who can take part?

This study invites people who:

- identify as an autistic woman or birthing person (inclusive to those identifying as non-binary, trans and cis-gendered women) and to those from a diverse range of cultural backgrounds,
- formally or self-identify as an autistic person,
- have experienced baby loss in the past at any point during your life, which may include a miscarriage (loss of your baby before 23 weeks of pregnancy), stillbirth (loss of your baby after 24 weeks of pregnancy) or neonatal death (loss of your baby up to 28 days after birth).

There are some factors that will prevent you from taking part, which are:

- your loss happened within the last six months,
- you are currently pregnant or trying to conceive,
- you are currently struggling with high levels of distress and/or actively accessing support for your mental health and psychological wellbeing.

6 How long will my part in the study take?

You will be invited to meet with me via Microsoft Teams for up to 1.5 hours at a time to suit you to speak about your experiences of losing your baby in a research interview. This will involve me guiding you through a range of questions about you as an autistic person, your experiences of pregnancy and losing your baby; specifically thinking about what it was like for you to go through this. You will be able to see the interview questions in advance to help with knowing what to expect and the sort of questions that will help guide our conversation.

There are no additional requirements after you have taken part in your interview.

7 What will happen to me if I take part?

If you decide to take part, you will be asked to return a signed consent form and brief demographic questionnaire to me by email. The questionnaire will ask about you and aspects of your identity, such as your age, gender and ethnicity. This information will be used to describe the demographics and features of identity of participants who take part in the study.

I will then contact you via email or telephone (which ever you prefer) to arrange a suitable date and time for the interview. We can also discuss any equitable requirements and how best you would like the space to be set up e.g., speaking verbally, using the chat function, any communication preferences, cameras on or off.

On the day of the research interview, we can construct some guidelines to help the space to feel brave and comfortable as much as possible. I am interested in the meaning and what it was like for you as an autistic person to experience and live through the loss of your baby, but please only share what you feel comfortable with. At the end of the interview, we will discuss how the interview was for you, let you know about what happens next and share some resources and signposts with you.

The interview will be audio recorded so that our conversation can be captured exactly as you have described your experience. I will then transcribe exactly what you have shared and anonymize it by removing any personally identifiable information you talk about (e.g., names, ages, dates, geographical locations) to protect your confidentiality. The anonymized transcript will then be used for analysis to understand how autistic people make sense of their experiences of losing a baby.

If you wish to withdraw your interview, that is okay. Please let me know up to two weeks after the date of your interview. All study materials, such as GP details, consent forms, demographic questionnaires will be deleted.

If you opt to receive it, you will also be sent a small summary of the results of the study. We can discuss how you would like this presented e.g., as a visual or written summary.

8 What are the possible disadvantages, risks or side effects of taking part?

Even though a robust number of steps have been considered to ensure that initially making the decision to take part feels right, sharing your loss experience may understandably bring up difficult feelings for you, which you may not expect.

We will work together to put a plan in place to help you feel supported. As part of our initial conversation before agreeing to take part, we will have discussed a range of questions including your current wellbeing and mental health, access to resources and social support around you and what you might do should any difficult feelings arise. We will have also talked about the rationale for sharing your GP details (name and contact telephone number) and gained your consent for this. I will only contact your GP if you share any information that makes me worried or concerned about any risk to you or to anyone else in your life. Information would be shared if necessary to ensure yours or someone else's continued safety.

At the beginning of the interview, we can discuss together how I might know if you were experiencing any difficult feelings and agree a way to manage this e.g., I might see you crying, you may be saying less or are quiet. If I notice that you are experiencing any distress, we will stop the interview to make sure you are okay. We may then decide to carry on if you feel comfortable, or decide to end the interview, which is okay. There will be frequent check-ins throughout the interview, which can be stopped at any time.

At the end of the interview, I will provide a range of resources and signposts (which will be shared with you prior to the interview). We can also create some space to check-in to see how you experienced the interview and help you to think about anything that might help you transition to your next activity. Self-care will be encouraged.

9 How will my participation in this study be acknowledged?

A £15 Love2Shop voucher will be made available to you following participation as an expression of appreciation and thanks. Following participation, you will be asked to sign a pay agreement, which will be stored on the secure UH OneDrive until completion of the project. The vouchers will be sent via email and can be redeemed via a link.

10 What are the possible benefits of taking part?

I hope that taking part in this research interview will be an opportunity for you to share your story and have your experiences heard. I hope this will help people to understand what it is like as an autistic person to live through the loss of a baby.

Baby loss is an experience which is not spoken about enough, whilst being an understandably difficult life experience, particularly in addition to the set of experiences which come with being autistic. My hope is that this research will help to hear the experiences of autistic people starting with those who have shared with me through this research. I hope that this will increase understanding of autistic experiences of baby loss through research and improve care and support within the maternity and parenting context as guided by autistic experiences.

11 How will my taking part in this study be kept confidential?

Your participation will not be discussed with anyone who is not involved in the project and as part of the guidelines we construct together, it is important that you know that what you share will not be discussed with anyone who is not present in the interview.

There may be circumstances that I may need to break confidentiality, for example, if I was to become aware of any information that made me feel worried about you or somebody else, such as risks to your safety. If this were to happen then I may wish to share this with your GP. However, before doing anything, I would share these worries with you and let you know my intentions and plans.

Your participation will be kept confidential, and your privacy will be maintained as any personally identifiable information that you share, such as your name, the names of any significant others you may talk about, dates and geographical locations will be removed or changed during the transcription process. The details about your identity and demographics as captured through the brief questionnaire will be used as part of the write up to provide context about the people who have taken part in the project, but these will not be identifiable to you.

Pseudonyms can be used, and you will be asked if you would like to choose a pseudonym for yourself and/or for your baby, for example, a name. You may also choose to keep yours and/or your baby's real names, if this would feel more comfortable for you. As part of giving consent to participate in this study, you will be asked to indicate your preferences for you and your baby. We will also discuss this as part of the ending of the research interview. These names will then be used throughout the analysis and write up of the project.

Excerpts of the anonymized interview transcripts will be shared with the wider research team for data analysis purposes and with a group of qualitative researchers using the same analytic method.

All materials including your signed consent form, demographic questionnaire and transcribed written document will be stored securely on my University of Hertfordshire OneDrive which requires a multi-factor authentication, which is only accessible by me. Materials which contain personally identifiable information, such as signed consent forms, demographic questionnaires, interview recordings and GP details will be stored until project completion in September 2025 in line with university data storage and governance procedures, after which will then be permanently deleted. Anonymised materials, such as the written transcript of the research interview will be stored for up to five years for dissemination purposes.

12 Audio-visual material

As described, your interview will be audio recorded using a Dictaphone and Microsoft Teams record function. The recording will be used to ensure that our conversation can be captured exactly as you have intended and be anonymously analysed to understand what it was like for you to lose your baby.

After the interview, recordings will be immediately transferred to my University of Hertfordshire OneDrive account and deleted from the Dictaphone. Audio recordings will be stored securely on my University OneDrive account until completion of the project in September 2025, and will be permanently deleted after this time.

If you decide to take part in the interview, but later wish to withdraw, that is okay. Please let me know up to two weeks after the date of the research interview, so your interview can be withdrawn from analysis.

13 What will happen to the data collected within this study?

The transcribed, anonymized written document of your interview will be stored on Phoebe's University of Hertfordshire OneDrive for five years for dissemination purposes, after which, it will be permanently deleted.

Your anonymized experiences will be analysed and used to create a written research dissertation, which will be submitted to the University of Hertfordshire in fulfilment of my Doctorate in Clinical Psychology training.

Additionally, it is important to me that the stories shared from this research are shared more broadly, particularly given that baby loss is often not talked about, nor are the specific experiences which come with being autistic. Th research available in this area is currently very limited, therefore, I would love to be able to publish this as a piece of research available to others to hear and learn from your experiences of being autistic and living through baby loss. Direct quotes will be used throughout this written paper, however, will be anonymised to ensure the continued protection of your confidentiality and privacy.

14 Will the data be required for use in further studies?

The data that is collected will be used for this study only and will not be used in any further studies.

15 Who has reviewed this study?

This study has been reviewed and approved by:

The University of Hertfordshire Health, Science, Engineering & Technology ECDA.

Protocol number: LMS/PGR/UH/05620

16 Who can I contact if I have any questions?

I would really value your participation and would welcome any questions you may have if this would help you to make a decision! Please feel free to contact me directly as per contact details below:

Phoebe Toms

pt22aak@herts.ac.uk

Details of the supervisory team are as followed:

Principal Supervisor:

Dr Lizette Nolte

l.nolte@herts.ac.uk

Second Supervisor:

Dr Sophie Doswell

Sophie.doswell@slam.nhs.uk

I look forward to the possibility of meeting you and hearing about your experiences.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix 12

Consent Form

CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here*, *in BLOCK CAPITALS]*

……
…

hereby freely agree to take part in the study entitled '*Autistic women and birthing people's experiences of baby loss'*

……
…..

(UH Protocol number: LMS/PGR/UH/05620).

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) which gives information about the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants.

2 I have also been informed of how my personal information on this form will be stored and for how long.

3 I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed and asked to renew my consent to participate in it.

4 I have been assured that I may withdraw from the study without disadvantage or having to give a reason. I have been told that I can withdraw my interview up to two weeks after to ensure my experiences are not included in the researcher's formal analysis or dissertation.

5 In giving my consent to participate in this study, I understand that voice and video recording will take place and I have been informed of how this recording will be stored and used to inform analysis.

6 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

7 I have been told my participation will remain confidential and that personally identifiable information may be change or removed.

I am aware that pseudonyms may be used in this study for me and my baby. I am aware that I will be given the choice to choose pseudonyms for me and/or my baby, or the option to keep my and/or my baby's real name. I am aware that these names I choose will be used in written reports or dissemination related to this research. Please indicate your choice below by ticking the appropriate boxes below:

I give my consent to choose a pseudonym, for:

Myself My baby (please tick)

I give my consent to keep the real name for:

Myself My baby (please tick)

Signature of participant: Date……

Signature of (principal) investigator: P.Toms Date……

Name of (principal) investigator *[in BLOCK CAPITALS please]*

PHOEBE TOMS

Appendix 13

Interview guide

1. Could you tell me a bit about your journey to discovering that you are autistic?

Prompts: When did you start to wonder if you could be autistic? What led you to wonder whether you were autistic? Who was around/what support did you have? What was going through your mind and what did you notice? If formally identified, what was it like to find out you were autistic? When did you start to identify as being autistic? When do you identify with being autistic (then vs now)? What is that like for you? Where do you identify with being autistic (then vs now)? What is your relationship like with your autistic identity (now vs then?) What's that like for you? How did finding out influence your relationships with others? How did that make you feel (emotionally, in your body, thoughts)? How has finding out influenced how you see yourself? How has this influenced how you think others see you?

2. What is it like for you to be autistic?

Prompts: how does being autistic impact everyday life, for example, planning, tasks of daily living, using transport, attending appointments? Are there particular differences that can be difficult for you, for example, sensory sensitivities or communication differences? How does that make you feel? How you/others see yourself/you? How have experiences where there may have been communication differences/sensory sensitivities etc impacted you? How would you describe your relationship with the autistic community or autistic others? What impact does this have on you? Wellbeing? Support? Could you tell me about anything you see as a strength about being autistic? How does that make you feel? What's that like for you? How has that influenced how you see yourself? Or how you think others see you?

3. Changing our focus now, I would like to hear more about your pregnancy and losing your baby. Can you tell me about getting pregnant and your experiences of pregnancy?

Prompts: Were you wishing to fall pregnant when you did? How easy was it for you to fall pregnant? How long had you been trying to conceive? Had you been pregnant before? What was pregnancy like? How did you feel? What was going through your mind? What was your experience of healthcare professionals or appointments during pregnancy? What was that like? How did that make you feel? What was going through your mind? What did pregnancy mean to you? What was it like for you to think about becoming a parent? How did this make you feel? What had you started to imagine for yourself as a parent/mother? For your baby? For you as a family? For your life? Dreams? What did that mean to you? Why was that important? **OFFER CHECK-IN.**

4. Could you tell me about your experience of losing your baby?

Prompts: When did you realize something was not right? What did you notice or experience? What was that like? What was going through your mind? How were you feeling emotionally? In your body? Who was around you during this time? What was that like? What happened? Who was involved? What was it like to meet with healthcare professionals during this experience? What was communication with others like? How did you lose your baby? If relevant to

experience, what was your experience of birth like? What happened after? (naming, spending time with baby, memory boxes). What did you notice? What was that like? Who was involved? What was contact or communication with healthcare professionals like for you? What was your experience of support from professionals? What was that like? What was going through your mind? How did you feel (either emotionally or in your body?)

What was it like to go through the experience of losing your baby at the time? What was their name? Who was around? How did others respond? What was it like for you to go through this, with what you had been imagining for you? Baby? Family? How has this changed how you see yourself? Or how you think others see you? How did this impact your relationships? How did this change over time? Where do you feel you are now, in thinking about and remembering your baby you lost? How does this loss continue to be part of your everyday life? How do you remember your baby? What is important to you and your family? What is this like for you emotionally? **OFFER CHECK-IN.**

5. Could you tell me about your experiences of grieving your baby?

Prompts: How would you describe this? What was this like for you? How did it feel in your body? What was going through your mind at the time (thoughts/images/memories)? What was that like? What sense did you make of how you were feeling? How did others respond? How did that impact your experiences? How did this change over time? Where are you with those experiences now? How is this / or is it not part of your life now? When does your baby and the loss come into your mind most often nowadays? What is that like? What sense do you make of this now? What is it like to think back and reflect? What memory do you bring to mind to keep your baby's memory alive?

6. What is your sense of how being autistic influenced your experience of losing your baby?

Prompts: Can you tell me about what losing your baby was like in relation to [any differences named previously?] e.g., sensory sensitivities, communication differences, processing time, hyper-empathy, shutdowns/meltdowns, anxiety, uncertainty. In relation to the experience of losing your baby? Grieving? Others involved? Healthcare settings? Professionals? What was that like for you? How do you think others saw your experience of this at the time?

Appendix 14

Reflective Journal Diary Entries

23.08.2024

First interview post-reflections

- I noticed a real sense of heaviness in my chest during and after the interview, which I think was in relation to her experiences being very difficult to hear at times. It took me a while to connect to this heaviness feeling, but I could feel it and I am noticing it still. It makes me wonder about how much of this heaviness is a reflection of a felt internal sense of how Adrienne feels.

- Struck by the length of the interview, which was longer than I anticipated – 1 hour 54 and went over 1.5 hours. It felt important to give the space so long as Adrienne needed it, so I checked in and she consent to continue on. I really noticed and felt the power of giving space to story and to talk, using her babies' real name, being able to share her experience freely, which speaks to the sense of silence or not feeling able to speak as freely as she might have hoped due to a sense of silence and stigma as people didn't know how to respond or what to say. This really affirms my why.

- Initial reflections in terms of personal experiences. There was a real sense of being different, not good enough in relation to autistic experiences across her life before experiencing baby loss, which then autism provided a more compassionate lens to make sense of her experiences. Her experience of loss was silenced – often people didn't know what to do, which created this sense of internalised blame. Very visceral and emotive when describing this. Considering grief – range of emotions; anger; sadness. More specifically to autistic experiences may be a sense of wanting to research and seek predictability through the safety of research about death, pregnancy, psychology etc. Intensified sensory sensitivities throughout birth and pregnancy and labour. Lots of visual metaphor to describe experience, which really bought this to life.

06.09.2024

Second interview post-reflections

- I noticed again how visceral her story was, which connected me back to a physical internal feeling in my chest. This again feels like it has meaning, perhaps reflecting the pain of grieving for a baby and the connection at the heart. It's interesting that this has come up for the second time.

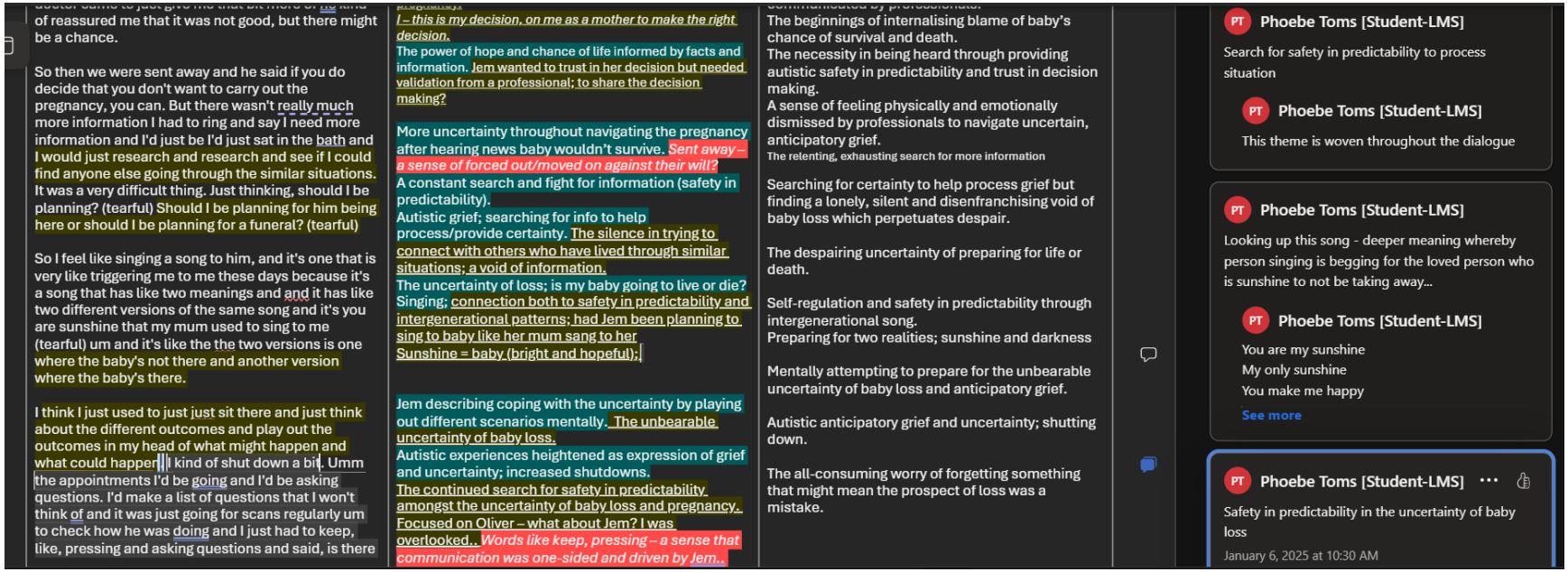
- I really felt I had more freedom to experience her experiences fully, because of the equitable requirement of our camera's being off. This made me think back to the first interview, where I felt like I was more aware of how I was coming across, particularly in the context of the sense of silence surrounding the loss and not wanting to come across in any way that I couldn't hear or be with her experience. With this absence, perhaps the sense of monitoring I wondered that I was doing, and the first participant might have

been doing was taken away, and as a result I felt like the stepping-in to her shoes felt stronger. I felt really close to her re-telling and experience, which made it feel more painful for me as a researcher.

- I noticed the importance of giving space to share and talk as the themes of silence were strong around the death of her baby and the idea of the reciprocity of gifts; the gift of space in return for the gift of re-legitimising and giving space that perhaps as been absent or in the minority in the breadth of silence and stigma surrounding baby loss.

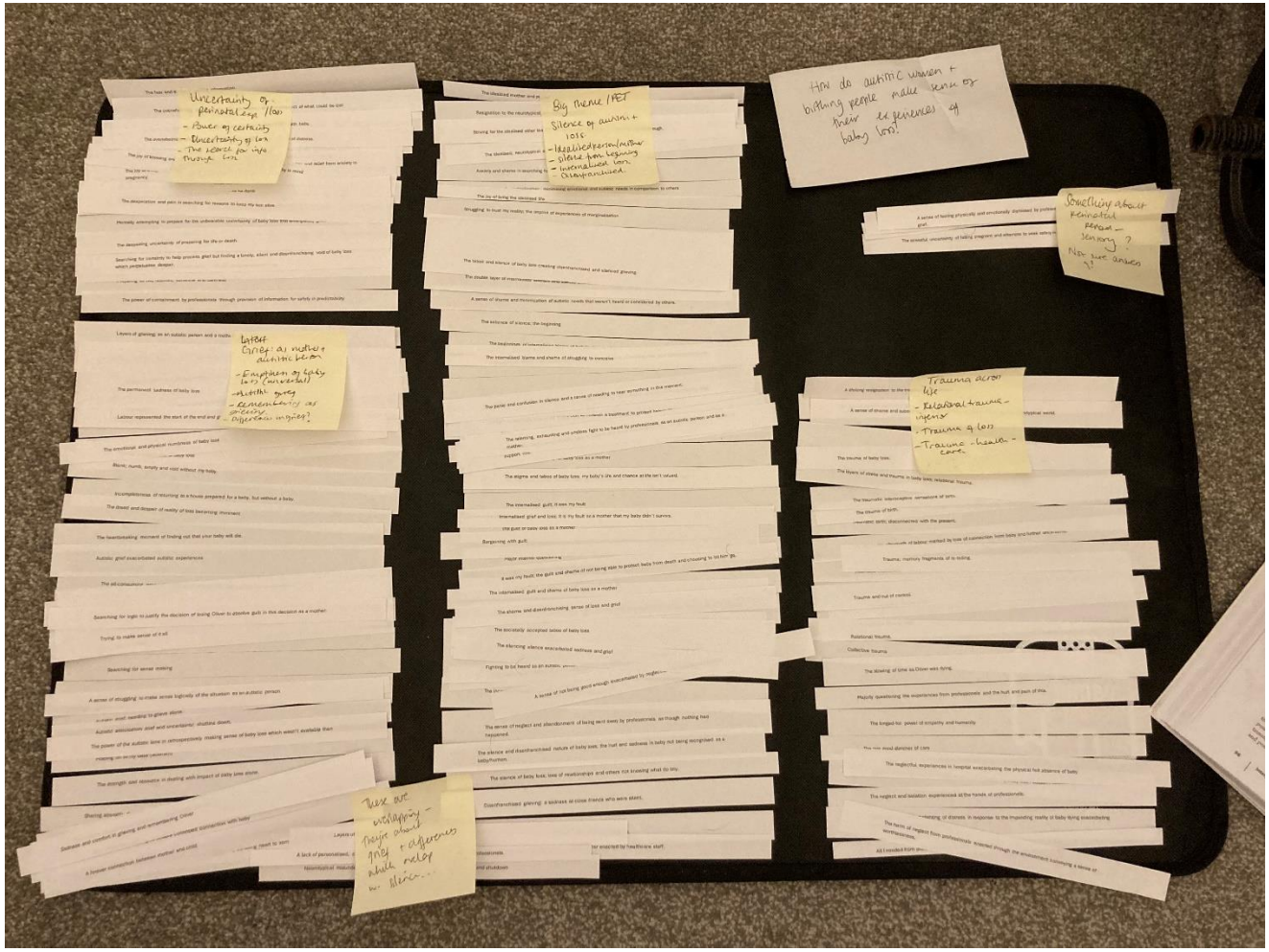
Appendix 15

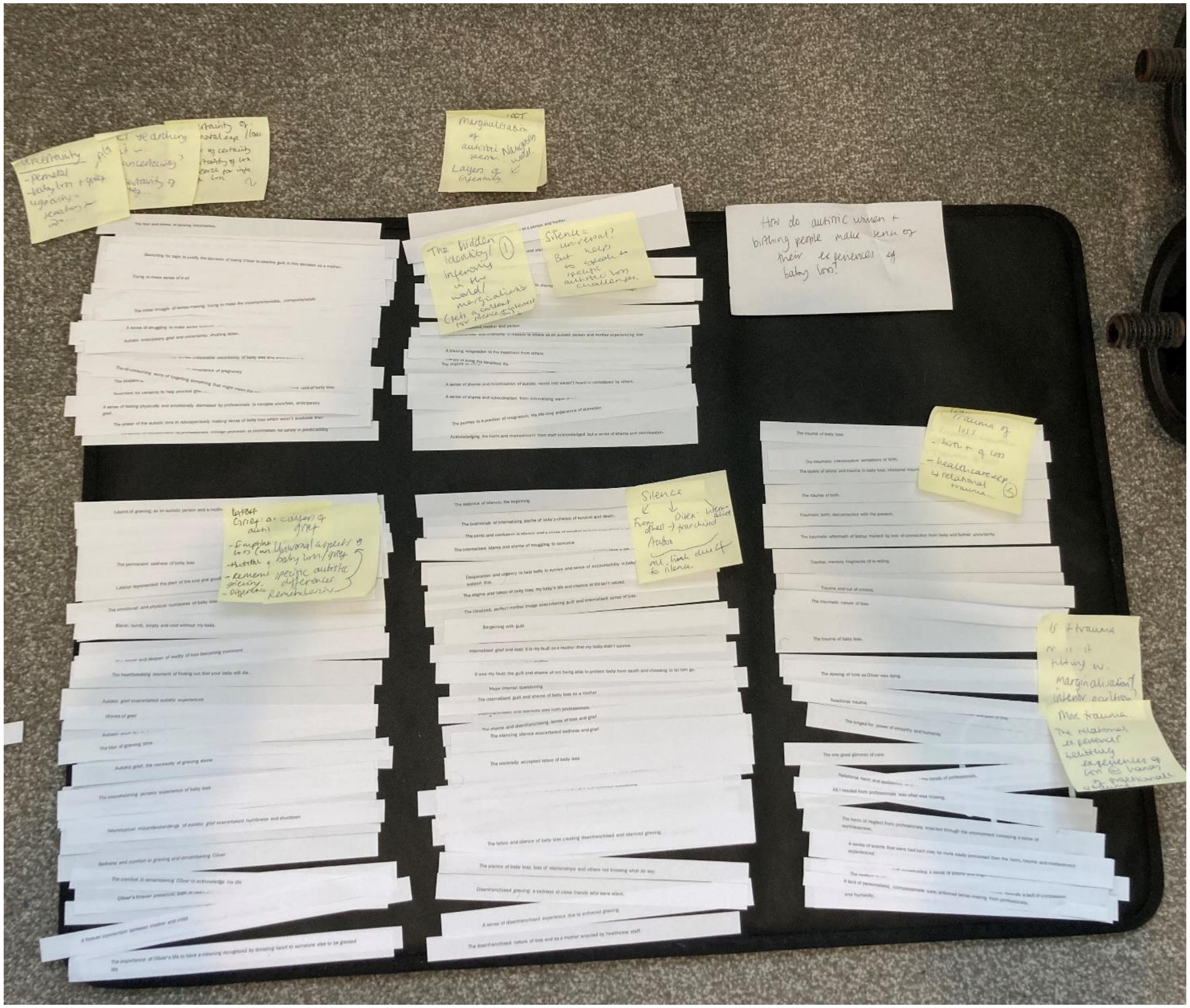
IPA Immersion with Data



Appendix 16

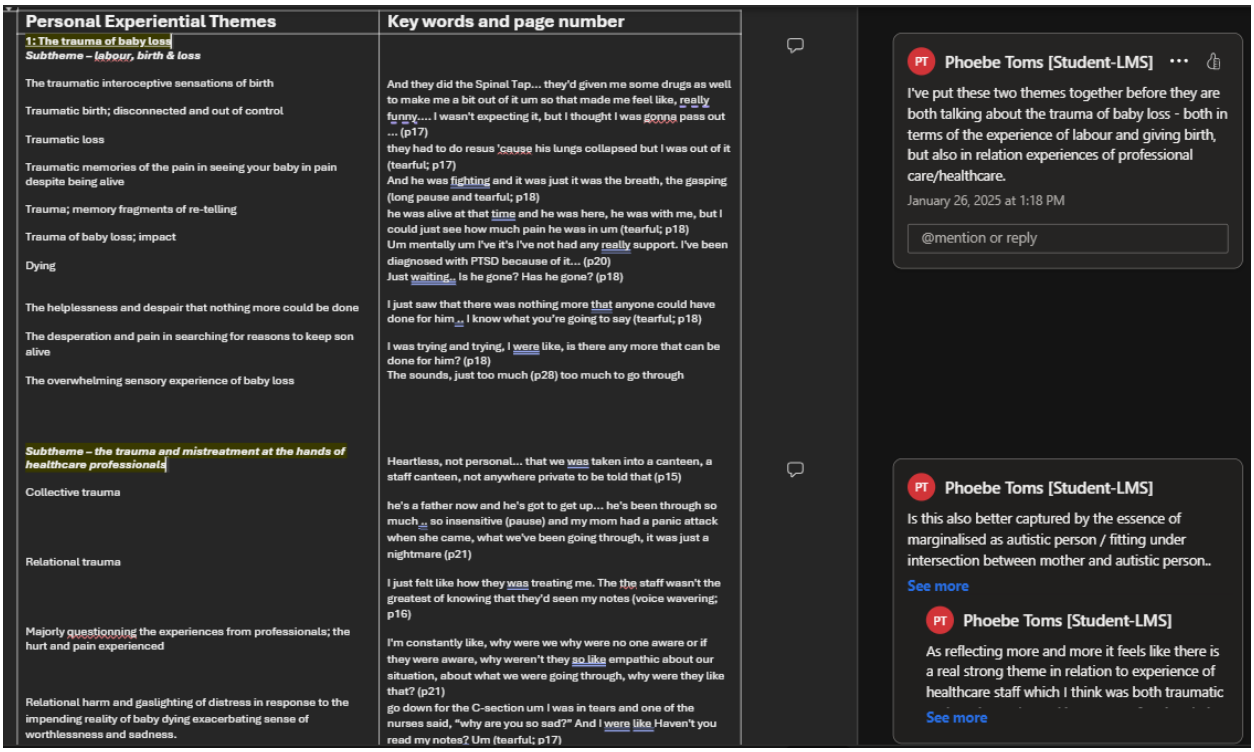
IPA Step 4 Process of Constructing PETS





Appendix 17

IPA Step 5 Excerpt of Table of Personal Experiential Themes



Personal Experiential Themes	Key words and page number
1: The trauma of baby loss	
Subtheme – labour, birth & loss	
The traumatic interoceptive sensations of birth	And they did the Spinal Tap… they'd given me some drugs as well to make me a bit out of it um so that made me feel like, really funny…. I wasn't expecting it, but I thought I was gonna pass out … (p17)
Traumatic birth; disconnected and out of control	they had to do resus 'cause his lungs collapsed but I was out of it (tearful; p17)
Traumatic loss	And he was fighting and it was just it was the breath, the gasping (long pause and tearful; p18)
Traumatic memories of the pain in seeing your baby in pain despite being alive	he was alive at that time and he was here, he was with me, but I could just see how much pain he was in um (tearful; p18)
Trauma; memory fragments of re-telling	Um mentally um I've it's I've not had any really support. I've been diagnosed with PTSD because of it… (p20)
Trauma of baby loss; impact	Just waiting.. Is he gone? Has he gone? (p18)
Dying	
The helplessness and despair that nothing more could be done	I just saw that there was nothing more that anyone could have done for him .. I know what you're going to say (tearful; p18)
The desperation and pain in searching for reasons to keep son alive	I was trying and trying, I were like, is there any more that can be done for him? (p18)
The overwhelming sensory experience of baby loss	The sounds, just too much (p28) too much to go through
Subtheme – the trauma and mistreatment at the hands of healthcare professionals	Heartless, not personal… that we was taken into a canteen, a staff canteen, not anywhere private to be told that (p15)
Collective trauma	he's a father now and he's got to get up… he's been through so much .. so insensitive (pause) and my mom had a panic attack when she came, what we've been going through, it was just a nightmare (p21)
Relational trauma	I just felt like how they was treating me. The the staff wasn't the greatest of knowing that they'd seen my notes (voice wavering; p16)
Majorly questionning the experiences from professionals; the hurt and pain experienced	I'm constantly like, why were we why were no one aware or if they were aware, why weren't they so like empathic about our situation, about what we were going through, why were they like that? (p21)
Relational harm and gaslighting of distress in response to the impending reality of baby dying exacerbating sense of worthlessness and sadness.	go down for the C-section um I was in tears and one of the nurses said, "why are you so sad?" And I were like Haven't you read my notes? Um (tearful; p17)

Appendix 18

IPA Cross-Case Analysis of GETS

GETs	Subthemes	Adrienne	Jem	Liz	Han	Hayley	Bethany
The unpredictability of baby loss	The "double stress" of the loss of a baby and predictability	x	x	x	x	x	
	Needing information to feel safe		X	x	x	x	
The horror and trauma of baby loss	The terror of losing a baby	X	X	X	X	X	X
	Heightened autistic sensory experiences during baby loss	X	X	X	X	X	X
	"The way they were treating me": experiencing de-humanising and neglectful care	x	x	x	x	x	x
Stigmatised and disenfranchised loss	The non-event and silencing of baby loss	X	x	x	x	x	x
	The internalised blame, shame and guilt of baby loss	x	x	x	x	x	x
	'The best worst club in the world': safe connections to resist silence	x		x	x	x	X
The forever pain of grief in baby loss	The unbearable pain of baby loss	x	x	x	x	x	x
	Grief feeling "different" as an autistic person	x	x	x	x	x	x

	The permanence of grief and love in baby loss	x	x	x	x	x	X
Meaning making, re-connecting and experiencing continuing bonds with baby	Finding meaning in baby loss	x	x	x		x	
	Remembering and continuing bonds to "show they existed"	x	x	x	x	x	x