REVIEW PAPER

Understanding the Neurodiversity of Grief: A Systematic Literature Review of Experiences of Grief and Loss in the Context of Neurodevelopmental Disorders

Ally Pax Arcari Mair[1] · Emy Nimbley[1] · Doug McConachie[1] · Karen Goodall[1] · Karri Gillespie-Smith[1]

Abstract

This systematic review explores lived experiences of grief in the context of neurodevelopmental disorders (NDDs), considering mental health impacts and how these experiences are expressed/understood. Reviewing qualitative research and grey literature centred on lived experience, 39 articles were identified through a systematic search of 8 databases and 1 page-ranked search engine. The articles were critically appraised, and results synthesised using thematic analysis and meta-synthesis. Four main themes and an overarching theme, titled *Recognise the Unrecognised*, emerged: Hidden Grief, Supported and Included, Understanding My Loss, and The Double Taboo of Death and Disability. The results indicate that grief often goes unrecognised in individuals with NDDs, especially following non-death losses. The implications of these findings and recommendations for future research are discussed.

Keywords Grief · Bereavement · Neurodevelopmental disorders · Autism · Intellectual disability · Transitions

There has been a rise in studies focused on grief[1] in recent years (e.g. Eisma et al., 2020; Lee & Neimeyer, 2022; Wallace et al., 2020) given the rise of experiences of bereavement and non-death losses due to the COVID-19 pandemic (Kumar, 2021). However, there is a lack of grief research focused on individuals with neurodevelopmental disorders (NDDs), whose experiences of grief and loss can often go unaddressed or misunderstood as "*challenging behaviour*" (Fitzgerald et al., 2021). Consequently, this review aims to inform future research and improve practice related to grief in the context of NDDs to highlight and necessitate an understanding of neurodiversity and grief, which will have differential impacts and different meanings for different neurodivergent populations.

The impact of grief and loss in the general population is often reported as having a more significant effect than is actually discussed in day-to-day life, with COVID-19-related deaths accounting for what is referred to as a "*silent epidemic of grief*" (Pearce et al., 2021). Alongside this, the COVID-19 pandemic has had a significant detrimental impact on the mental health of individuals with NDDs as a result of many different individually significant death and non-death losses (O'Sullivan et al., 2021; Yılmaz et al., 2021). Moreover, the considerable difficulty with change and transition highlighted during the pandemic for individuals with NDDs (Yılmaz et al., 2021) is indicative of a precarious dialectic of grief which is simultaneously *known* and *unknown* insofar as, regardless of neurodevelopmental profile, individuals with NDDs often experience difficulty with change and transitions (American Psychiatric Association [APA], 2022; World Health Organization [WHO], 2019). In this sense, there is an awareness of the difficulties transitions and changes have for populations with NDDs without understanding what this means in grief. However, these difficulties navigating change and transitions, alongside difficulties and differences in understanding, expressing, and regulating emotions, ultimately expose neurodivergent individuals to

✉ Ally Pax Arcari Mair
a.p.a.mair@sms.ed.ac.uk

1   Department of Clinical & Health Psychology, School
of Health in Social Sciences, University of Edinburgh,
Edinburgh EH8 9AG, Scotland

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1 The experiences and reactions to the loss of persons both via death (i.e. bereavement) and non-death loss (e.g. transitions).

increased vulnerability to grief, bereavement, trauma, and non-death loss (APA, 2022; Bóveda Hermosilla & Flores Robaina, 2021; Gaines, 2022). This vulnerability is often compounded by notions of (neuro)normativity which seek to silence both experiences of grief and disability (Lavin, 2002; Oswin, 1991).

The neurodivergent population (i.e. individuals with NDDs) encompasses a broad range of traits, yet are likely to be equally vulnerable in the face of loss. This vulnerability can stem from both a difficulty in understanding neurotypicals and a difficulty in being understood by neurotypicals, as is highlighted in Milton's (2012) *double empathy problem*; in this sense, neurodivergent populations may experience feelings of disenfranchisement in how their emotional experiences are understood by others (APA, 2022; Fitzgerald et al., 2021; Lavin, 2002) which may ultimately pose as a risk factor in the development of disenfranchised grief (Gaines, 2022; Lavin, 2002).

Consequently, this review takes place in a specific landscape of research and practice which has a profound awareness of the vulnerabilities neurodivergent individuals have (APA, 2022; WHO, 2019) and the recent increase in experiences of loss (Kumar, 2021; Pearce et al., 2021). The awareness of these two phenomena is met without a cohesive and systematic understanding of what grief may mean for/to a neurodivergent population, with the exception of narrative reviews focused on a specific NDD and/or is informed by studies which focus on parent/carer observations rather than individual lived neurodivergent experience(s) of grief (e.g. Bóveda Hermosilla & Flores Robaina, 2021; Dodd et al., 2005; Gaines, 2022; Lonergan, 2020; O'Riordan et al., 2022). As a result, this review seeks to bring a systematic, cohesive, and tangible understanding of neurodivergent experiences of grief and loss to inform research and practice. The ultimate goal of this review is to highlight a phenomenology of neurodivergent grief by considering the lived experiences of grief and loss in neurodivergent individuals and to inform practice and future research which seeks to improve the well-being of neurodivergent individuals experiencing grief and loss.

Although this review will focus specifically on grief and bereavement in the context of neurodivergence in terms of search queries used, the term *loss* is used in the research questions in place of bereavement to highlight the exploratory nature of this review. This approach seeks to be inclusive of grief following bereavement whilst also accounting for the many different forms of significant loss which may emerge in studies specifically on grief (e.g. ambiguous loss, anticipatory grief, and non-death loss). This is done to ensure a (neuro)culturally sensitive approach to the review, which does not assume to know a priori what constitutes a *significant loss* to neurodivergent individuals. However, definitional parameters are set to focus the scope of the review whilst being mindful of the uniqueness and commonality found in individual loss(es); as a result, this review will only focus on grief and loss as it relates to humans. In this sense, grief, in the context of this review, refers specifically to the experiences and reactions to the loss of persons both via death (i.e. bereavement) and non-death loss (e.g. transitions). Moreover, definitional parameters for *neurodivergent*,[2] in contrast to *neurotypical*,[3] have been set to ensure clarity and consistency throughout this review.

The research questions considered have been developed concerning three critical components of research: phenomenology, epistemology, and ontology. The research questions are as follows:

1. *Phenomenological perspective*: How do neurodivergent individuals experience and understand grief and loss?
2. *Epistemological perspective*: In what ways do neurodivergent individuals (re)construct knowledge about and relay their own experiences and narratives of grief and loss?
3. *Ontological perspective*: What are the realised mental health impacts of grief and loss for neurodivergent populations?

Methods

Protocol

The study's procedures and research questions were defined a priori in a protocol published to PROSPERO (CRD42022374848), indicating the specific search strategy, inclusion/exclusion criteria, and approaches to data extraction, appraisal, and synthesis. Moreover, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were consulted and informed this study (Page et al., 2021).

Inclusion and Exclusion Criteria

Although the *SPIDER* tool (Cooke et al., 2012) was initially considered for the review due to its specificity in

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[2] *Neurodivergent*: although the term "*neurodivergent*" has broad definitions in relation to mental health and neurodiversity, for the context of this review, neurodivergent refers specifically to individuals with one or more NDDs; this is inclusive of both current (e.g. intellectual disability) and past terms (e.g. Asperger's syndrome) which align with, inform, relate to, and/or are recognised by NDDs as currently defined in the clinical literature (APA, 2022; WHO, 2019).

[3] *Neurotypical*: individuals without any NDDs (i.e. not neurodivergent).

Table 1 PICO parameters

PICO tool	Definitional parameters
P (population)	Neurodivergent people (i.e. individuals with one or more NDDs)
I (intervention)	Experiences of grief and loss
C (comparison)	Research which includes substantial qualitative data, inclusive of (but not limited to) the following: (auto)ethnographic studies, interviews, focus groups, open-ended/qualitative surveys, and the use of participatory and/or visual methods if accompanied by direct quotes as well
O (outcome)	Attitudes, beliefs, experiences, feelings, perceptions, understandings, and views of grief and loss

database searches for qualitative papers, *PICO* (see Table 1) was ultimately chosen due to the broader and more comprehensive search range it provides, which results in a greater number of hits, meaning there is reduced risk of relevant papers not being identified in database queries (Methley et al., 2014).

In this review, neurodivergent individuals refer to individuals who have one or more NDDs: this is inclusive of, but not limited to, intellectual disability, communication disorders, autism spectrum disorder, attention-deficit/hyperactivity disorder, specific learning disorders, and/or motor disorders who have experience(s) of grief and/or loss. It is important to note that, although NDDs refers to a heterogeneous group of neurodevelopmental profiles, given the overlaps and similarities in traits and the common co-occurrence of NDDs which influence development across the lifespan (Crisci et al., 2021; Dewey, 2018), NDDs have formed a broad category for the enquiry of several reviews (e.g. Dahan-Oliel et al., 2012; Dewey, 2018; Shorey et al., 2021; Valentine et al., 2021). Consequently, this review takes an orientation which acknowledges both the similarities between and co-occurrences of NDDs, whilst being mindful of that which necessitates differentiation. In this sense, this review leans into a neurodiversity-orientated ontological perspective which acknowledges the uniqueness and commonality of co-occurrence between/of these conditions and the various modes of identity and self-representation which are (in)formed and (re)produced by these diagnostic categories (e.g. neurodivergent).

In terms of the phenomenon of interest (i.e. "*intervention*" in PICO) and the review's neurodiversity-orientated ontological perspective, this review is focused on lived neurodivergent experience(s) of grief and/or loss. Lived experience(s), in the context of this review, refers specifically to phenomenological experiences of grief and/or loss understood and (re)presented in neurodivergent individuals' own voices. In this sense, studies have only been considered representative of lived experience(s) if the individual's voice is presented directly in the paper and they are actively involved in the study. Moreover, given the overall phenomenological perspective of this review, the review only considers qualitative (or mixed methods with a substantial

qualitative component) research whilst seeking to explore the lived experiences, understandings, and perceptions of grief and loss in the context of neurodivergence. Although important, observer data (e.g. parent/carer perspectives) have been excluded due to the review's exclusive focus on the lived experiences of grief and loss neurodivergent individuals face, rather than how those around the individual understand these experiences.

Search Strategy

Final search string queries for each database were included in a *full search strategy* provided as additional material in the study's pre-published protocol (Mair & Nimbley, 2022). Using the *PICO* tool, broad search terms were used to yield a large number of initial results to ensure that articles that met inclusion criteria emerged (Methley et al., 2014). The following databases were consulted: ASSIA, CINAHL, EMBASE, ERIC, MEDLINE, ProQuest, PsycINFO, and Scopus. These databases were initially searched, and results were extracted on the 14th of November 2022; following the screening, a second search was conducted on the 23rd of January 2023 prior to analysis and data synthesis to check for any additional studies that emerged since the review commenced. The following search string was adapted to meet the operational needs of each database:

((grief* or griev* or bereave* or "traumatic loss" or "ambiguous loss" or "non-death loss") OR ((grief* OR griev*) AND (death or dying or "break-up" or "life transition*" or "relationship transition*" or "school transition*" or "healthcare transition*" or "transition* to adult*" or "critical transition*"))) AND (attitude* or experience* or belief* or feeling* or perception* or understanding* or view*) AND (neurodi* or neurodevelopment* or "intellectual dis*" or "learning dis*" or developmental or atypical or "communication dis*" or autis* or asperger* or "attention deficit" or "motor dis*" or dys* or "motor skill*" or tourette* or tic* or "language dis*" or "language impairment*" or stutter*

or "mental* handicap*" or "retard*" or kanner* or "disorders of childhood" or ADHD or "speech sound dis*" or "childhood-onset" or sensory or disintegrative) AND (qualitative or interview* or autoethnograph* or ethnograph* or "focus group*" or survey* or participatory or "lived-experience*" or "lived experience*")

It should be noted that the researchers acknowledge that some search terms used are dated, such as "*Asperger's Syndrome*" and "*mental retardation*"; however, these terms were included to broaden the scope of the searches whilst being mindful of the different time periods this review draws on, as there is no exclusion criterion based on the date of publication. It is also essential to note that although this review has taken a broad transdiagnostic perspective of NDDs, given the amount of NDDs, including rare neurogenetic disorders (e.g. Fragile X Syndrome), this review cannot account for all forms of neurodivergence. Moreover, by acknowledging the limitations academic databases may have in centring narratives from lived experiences (i.e. non-academic community-driven knowledge) and to ensure rigour in the search strategy, references from eligible studies and relevant reviews were also manually searched to identify any additional eligible studies, and a PageRank-based search engine (Google Scholar, first 100 search results) was also consulted alongside database searches. The searches queried were limited to:

1. Studies published in English.
2. Qualitative research or mixed methods empirical research involving qualitative data collection.
3. Given the definitional parameters of lived experience(s) this review takes, case studies and studies without direct quotes from neurodivergent individuals were excluded.

Grey Literature

Given this review's phenomenological focus, grey literature was included to both validate the research-based literature (Benzies et al., 2006) and community-driven knowledge as legitimate epistemological enquiry (Kourti, 2021; Rosqvist et al., 2019). This is defined as non-academic literature which is not necessarily peer-reviewed but originates from within the neurodivergent community (e.g. community-produced guides and personal narratives in the form of memoirs); however, given the difficulty incurred in navigating the potential breadth of grey literature (Benzies et al., 2006; Mahood et al., 2014), it was only included if it meets the following criteria, as established a priori in the review's protocol: (1) it is pulled from the aforementioned databases or references of eligible studies identified, and (2) it is an account representing lived

neurodivergent experience(s) of grief/loss. The decision to include grey literature which meets these two criteria is set out for the following reasons: (1) it reduces publication bias; (2) it accounts for the inaccessibility that academia and academic publishing have for neurodivergent individuals to share and research their own narratives and experiences; and (3) the strict criteria, limiting the eligibility of grey literature to that which emerges in the databases above or is cited by eligible studies, accounts for the difficulty in navigating grey literature databases whilst simultaneously being open to any grey literature which emerges and has influenced eligible studies and the current research landscape.

Quality Appraisal

The Joanna Briggs Institute's (JBI, 2020) critical appraisal checklists for *qualitative research* and *text and opinion papers* were used to appraise and represent the articles in this review systematically. This measure was chosen as the JBI checklists better account for grey literature that may not have quality adequately/appropriately reflected under guidance from the Cochrane Collaboration Qualitative Methods group (Hannes, 2011). The JBI appraisal was completed independently and validated by two researchers to account for potential biases influencing quality appraisal and increase the academic rigour of this review. The JBI has different checklists for different data types.

Data Extraction

The search strategy resulted in a total of 2,396 articles: ASSIA ($n = 46$), CINAHL ($n = 264$), EMBASE ($n = 410$), ERIC ($n = 86$), MEDLINE ($n = 251$), ProQuest ($n = 614$), PsycInfo ($n = 509$), Scholar ($n = 100$), and Scopus ($n = 116$). These articles were exported to *comma-separated values* (CSV) files, with data cleaned and combined using the CSV module in Python. The results were automatically deduplicated in Excel; however, manual checks were conducted in parallel to ensure no paper was inadvertently removed. After removing duplicates ($n = 1077$), the titles and abstracts of 1319 articles were manually screened and validated by dual independent review of $\geq 33\%$ of the articles ($n = 500$). Following the initial screen, 73 articles were sought for retrieval. When access was not readily available, authors and/or repositories were contacted; however, a small number of theses ($n = 8$) were unobtainable due to no response. As a result, 65 articles were read and screened in full (see Fig. 1), and this was validated by dual independent review once more. Inter-rater discussions were conducted during the full-text review, and a total of 27 studies were agreed upon for inclusion in the review; references of these studies and relevant reviews were manually screened, and an additional
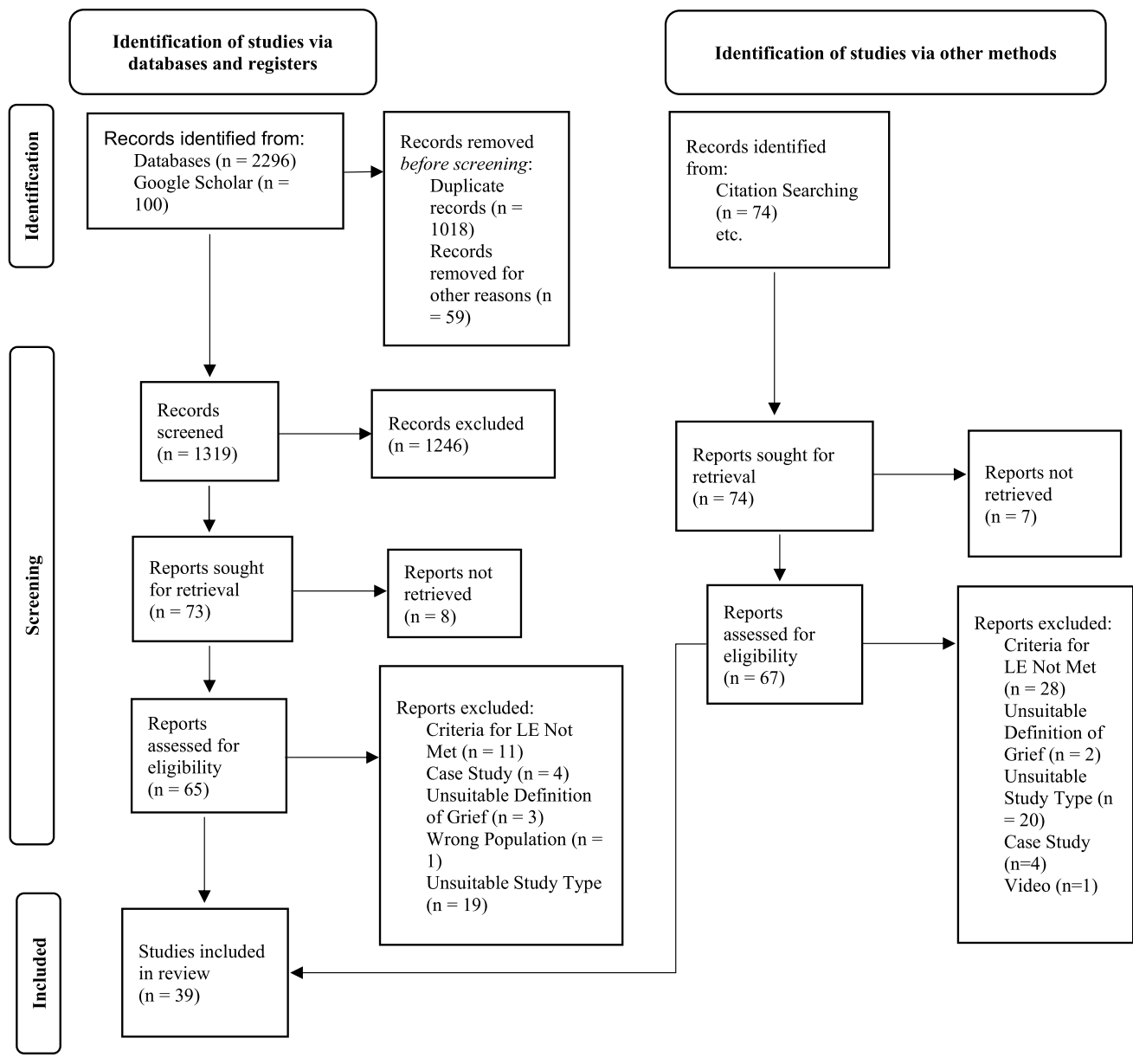
Fig. 1 PRISMA flow diagram

12 articles were selected for inclusion, with the majority of these additional studies being grey literature (*n* = 7). Overall, 39 articles are included for analysis and data synthesis.

Analysis

Given the scope of this review, which is inclusive of studies which may be mixed methods and grey literature which is not necessarily academic research but narrative from lived experience(s), and the specific research questions this review seeks to answer, an *integrated design* (Sandelowski et al., 2006) was initially considered. However, given the qualitative focus of this review, and still partially fitting with an integrated design which acknowledges the importance of analysis, which includes both the data and the questions asked of the data, a thematic analysis and meta-synthesis were adopted as the approach to qualitative synthesis. Unlike a meta-summary with an aggregative approach to synthesis, a meta-synthesis allows for a hermeneutic phenomenological approach to uncover the lived experiences which are (re) presented in the data rather than simply (re)presenting the data itself (Saini & Shlonsky, 2012). Using Saini and Shlonsky's (2012) *continuum of methods for qualitative synthesis*, a meta-synthesis informed by thematic analysis was chosen,
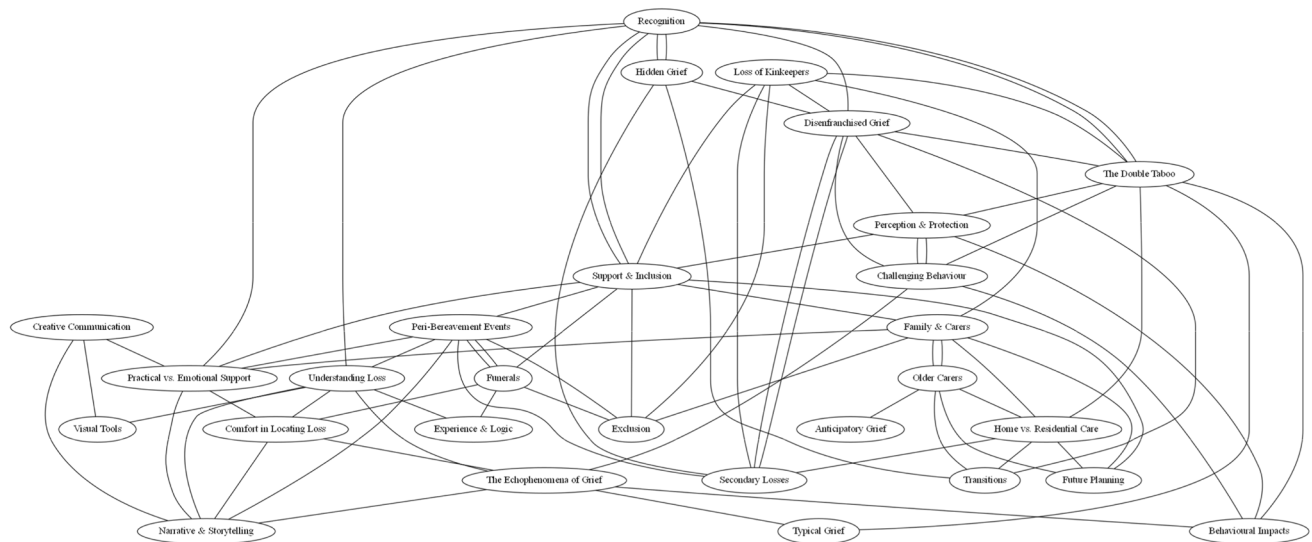
Fig. 2 Initial thematic map

as it best aligns with this review's integrative design and predefined questions.

Moreover, accounting for exploring the phenomenological understanding of grief and loss in the context of neurodivergence and an integrated design, interpretative approaches were used appropriately to (re)present a thematic analysis of the data prior to meta-synthesis. In this sense, the researcher conducted a thematic synthesis without a priori assumptions as to what the data may (re)present and which questions the data may answer to capture the research to date before considering the review's three research questions. Braun and Clarke's (2006) six-stage approach to thematic analysis guided the initial thematic synthesis.

It is important to note that, although this review focused on studies representative of lived experience(s), these studies are only that, *representations* of lived experience rather than *presentations* thereof. In this sense, only data from grey literature may be considered *presentations* of lived experience(s), as qualitative findings from the academic literature are critically reconstructed representations and analysed interpretations of lived experiences from an outside perspective, with the exception of autoethnographic studies (e.g. Barber, 2022). As such, to best avoid a *re-representation* of the data (i.e. a re-interpretive epistemological orientation), a broadly inductive approach was taken to analysis to allow themes to emerge from the data, rather than assuming and applying deductive categories for the data to fit into prior to analysis.

The six-stage approach to thematic analysis follows a process of familiarisation, coding, searching for themes, reviewing themes, defining themes, and producing (Braun & Clarke, 2006). Nevertheless, although this approach has clearly defined stages, it is essential to note that thematic analysis is ultimately a non-linear process. The researcher is already pre-reflexively engaged in the paper's production from the moment analysis commences (Clarke et al., 2015). Thus, the researcher acknowledges that analysis is (re)shaped by their own pre-reflexive positionality as a neurodivergent researcher (Braun et al., 2016; Gergen, 1990).

In *Stage 1* (*Familiarisation*), the researcher familiarised and re-familiarised themselves with the data by reading the papers multiple times. Ongoing reflexive field notes supplemented familiarisation, and autoethnographic writing exercises were also used as a mode of reflection to aid in exploring emergent themes (Mair, 2023). This was followed by *Stage 2* (*Coding*), where qualitative findings from all studies and whole texts of grey literature were systematically coded using *NVivo 20*. The researcher identified specific semantic and latent codes, labelling them and developing them into sets of aggregate nodes. Collapsing codes into emergent aggregate nodes was used as a topographical tool to better understand and identify emergent themes (Nowell et al., 2017). For greater flexibility and analytic rigour, manual data coding ran in parallel to NVivo analysis. Following this, in *Stage 3* (*Searching for Themes*), a three-columned approach to notation was used for manual code; codes with shared features were collapsed and compared with aggregate nodes produced in NVivo to check the internal validity and consistency of the analysis. From this, an initial thematic map was created using *PyDot* to visualise the relationship(s) between emergent themes (see Fig. 2). Consequently, candidate themes (*n* = 8) emerged, and theme reports were produced to understand their importance in the data better.

Informed by and reflecting on the theme reports and a better understanding of the relational and hierarchical features of the candidate themes, a developed thematic map
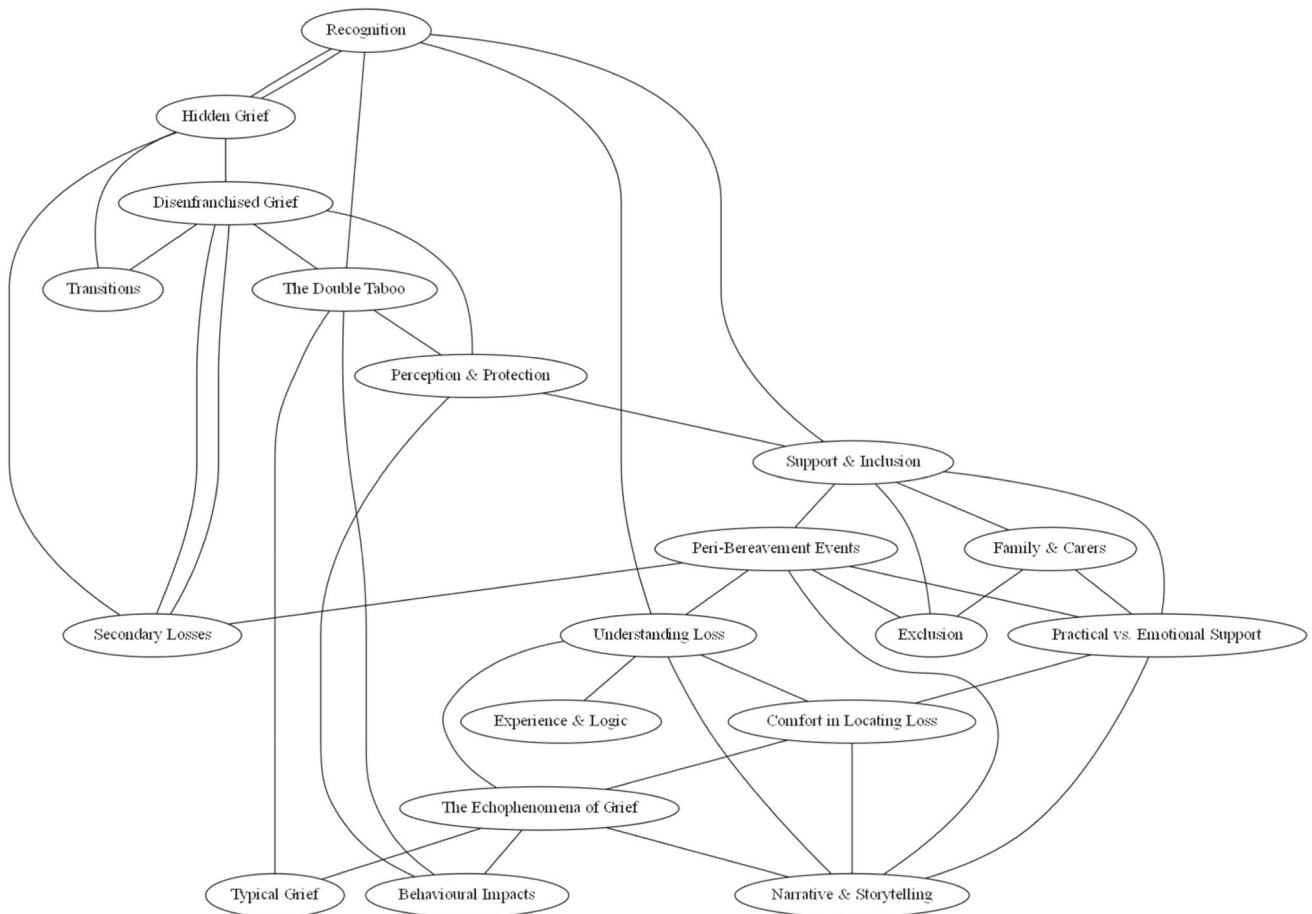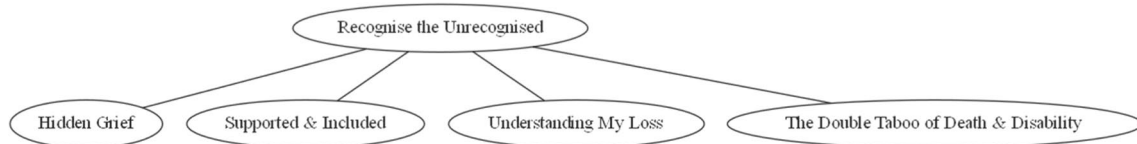
Fig. 3 Developed thematic map

Fig. 4 Final thematic map

was produced with *PyDot* (see Fig. 3) in *Stage 4* (*Reviewing Themes*). Theme definitions were written to understand their scope better and inform this study's analytic narrative (Clarke et al., 2015). Themes were renamed to reflect better the experiences represented in the analysis. These initial themes were then reviewed against the articles' findings and (re)presentations of lived experience(s) to ensure their suitability. Following review, in *Stage 5 (Defining Themes)*, the themes were finalised, and their relationship(s) within the data was visualised using PyDot in a final thematic map (see Fig. 4).

Lastly, for *Stage 6* (*Producing*), it is important to note, given the non-linear nature of the thematic analysis, production is a pre-reflective process which commences prior

to and continues past the analysis (Clarke et al., 2015). An analytic commentary which informed a subsequent narrative synthesis and discussion was produced.

Results

Search Outcome(s)

A total of 2296 papers were retrieved from searches of academic databases, with a further 100 papers retrieved from Google Scholar and 74 papers from citation searching. Following the deduplication of 1077 articles, the titles and abstracts of the papers were screened by two researchers

adhering to the a priori inclusion/exclusion criteria set out in the protocol. Seventy-three articles were sought for retrieval; of these, 8 were unobtainable, and 38 were excluded following full-text review. A further 12 studies were included following citation searches. Ultimately, a total of 39 articles were suitable for this review.

Study Characteristics

It is important to note that terms in this review have been reproduced in a cohesive and contemporary fashion; for example, although some older studies use terms such as "*mental retardation*" (Harper & Wadsworth, 1993; McDaniel, 1989) or current UK-based studies tend to favour the term "*learning disabilities*" (Baum & Burns, 2007; Bowey & McGlaughlin, 2005; Gould & Dodd, 2014; Kaspar, 2016; Mattison, 1998; Swainland, 2003; Thorp et al., 2018), the term intellectual disabilities (ID) has been used instead to bring clear and cohesive terminology, which is uniform throughout this review. Moreover, some studies use phrasing which de-pathologises differences in neurotype, such as "*learning difficulties*" (Manners & Carruthers, 2006), to represent ID, or "*cognitively challenged*" (Omar, 2013) to refer to NDDs, or "*Asperger's Syndrome*" (Eccentrics United, 2011; Graham, 2013; Soraya, 2014) which is now represented by autism (i.e. autism spectrum disorder) in the clinical literature (APA, 2022). All relevant study characteristics and key findings are summarised in Table 2.

Critical Appraisal

The papers were assessed following one of two JBI Checklists (JBI, 2020) as appropriate to the type of paper: *Qualitative Research* for academic articles (see Table 3) and *Text & Opinion* for grey literature (see Table 4). All of the papers were qualitative or had a significant qualitative component; the grey literature included is more reflective of narrative and/or creative writing(s). Most of the studies used one-to-one interview-based approaches. However, several studies used focus groups (Forrester-Jones, 2013) and group work-based designs (McDaniel, 1989), such as in the development/evaluation of grief interventions (McDaniel, 1989; Omar, 2013), and co-production and Participatory Action Research (PAR) design, such as the use of photovoice (Kim et al., 2021; Tajuria et al., 2017), co-produced narratives (Manners & Carruthers, 2006), and workshops (Read & Papakosta-Harvey, 2004). Several studies took a mixed-methods approach, using surveys and/or questionnaires in conjunction with interviews/focus groups (Bowey & McGlaughlin, 2005; Forrester-Jones, 2013; Gorfin & McGlaughlin, 2004; Harper & Wadsworth, 1993; McEvoy et al., 2012). Fundamental shortcomings were observed across the majority of studies in terms of researchers failing to critically assess their own positionality and in

the (re)presentation and generalisability of lived experience(s) informing the studies (Supplementary Material). Nevertheless, a key success across the majority of studies was congruity between philosophical perspective, research methodology, research question(s), and data collection, with the analysis of the majority of the studies being thematic analysis, interpretative phenomenological analysis (IPA), or content analysis. IPA appeared more commonly in dissertations/theses than in journal articles, where thematic and content analysis were more prominent (see Table 2 and 3).

Thematic Findings

Overarching Theme: Recognise the Unrecognised

An overarching theme, titled *Recognise the Unrecognised,* which links the main themes raised by the studies was identified (see Table 5). Recognition here refers to not only the experiences of visibility, or lack thereof, individuals reported in their grief experiences but also how different (neurotypical) individuals, and the participants in the studies themselves, considered the value, extent, and ability of their grief. In this sense, some participants observed that their grief experiences were recognised, included, supported, and understood, not just as a neurotypical experience of grief but within the context of their neurodivergence:

> "*All my family were there for me. My sister knew I needed to give it time. Looking back on it, we all had different ways of dealing with it. They were all crying except me. I was in shock.*" Participant in McEvoy et al. (2012)

However, the majority of participants across the studies reported key aspects of their grief reactions going unrecognised, excluded, misunderstood, and having biases around their neurodivergence shaping how others fail to recognise their individual experiences of grief and loss:

> "*We weren't allowed to go to our friend's funeral… we didn't know when his funeral was… but we were allowed to send a card to him to the funeral*" Karen (Forrester-Jones, 2013)

Ultimately, this lack of recognition to the significance of neurodivergent individuals' grief runs in contradistinction to the value placed on recognition, inclusion, and contextualised understanding raised by both participants and researchers to varying degrees in every single paper included in this review:

> "*Being involved is good: we need to know the bad stuff*" (Read & Papakosta-Harvey, 2004)

Table 2 Summary of qualitative findings

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Barber, 2022 (UK)	Reflect on the impact of anticipatory grief to help community nurses better understand autistic experiences of loss	Autoethnography (Article)	A 63-year-old autistic man who is a widower	Phenomenology; ideographic perspective	Bereavement; anticipatory grief	The article is a personal letter from the author, who is an autistic man, to community nurses about his experience with anticipatory grief and grieving. The letter is intended to initiate reflective discussions around this topic and improve the support provided by community nurses to autistic individuals	N/A
Baum & Burns, 2007 (n/a)	Explore the experience(s) and meaning(s) of losing custody of children for mothers with ID	IPA (Article)	Mothers with ID (n=8) - Sex: female (n=8) - Average age: 35 - Age range: 22 to 25	Phenomenology	Grief related to loss of custody of child(ren)	Concerns about parenting tended to be raised by others, rather than the mothers themselves. Participants observed not understanding the process of removal of their child(ren) and felt victimised, often blaming abusive partners, social workers, and/or their own ID. Participants highlighted they did not receive enough support following the removal to cope with the loss, and observed intense feelings of loss and powerlessness	- Competency as a mother - Managing a disabled identity - Relationship to support removal - Emotions and feelings about losing their child/ren - Identity associated with motherhood - Coping with the loss - Powerlessness and lack of control-promises broken - Future

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Bowey & McGlaughlin, 2005 (UK)	Explore the views of adults with ID about living with elderly family carers at home and future planning	Interviews & questionnaire (Article)	Adults with ID (n = 41) -Sex: male (n = 21); female (n = 20) - Average age: 42 - Ethnicity: White (n = 41)	Not clearly stated; phenomenology	Bereavement; anticipatory grief; secondary loss	Adults with ID demonstrate clear preferences with regards to future planning, family, and where they want to live. Participants also observed concern for their elderly carers, and this impacted their ability to plan for the future, as a co-dependency was reported. Participants demonstrated an awareness of death and ill health of family members which necessitate the importance of future planning	Areas of discussion centred on: - Support and independence - Mutual support - Desire to move - Concerns about carers - Short breaks - Planning for the future

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisati on of grief/loss	Main findings	Themes/narratives
Collings et al., 2020 (New South Wales, Australia)	Explore the role of peer support for mothers with ID who have been affected by domestic violence and the involvement of child protective services	Content analysis (Article)	Mothers with ID (n=10) - Sex: female (n=10) - Average age: 34.5±10.45	Inductive content analysis (Elo & Kyngäs, 2008)	Grief related to loss of child(ren) to child protective services	Mothers with ID affected by domestic violence have reduced social support and often face blame from child services for failing to protect their child(ren) from harm. Participants observed peer support is crucial in these circumstances, offering emotional and practical support. Participants noted feelings of loss and disenfranchised grief following the removal of their child(ren)	- The impact of intimate partner violence on mothers - The impact of child abuse on mothers - Social support after child removal - Fragile support networks - Peer support for mothers with intellectual disability - Professional sources of support
Collings et al., 2018 (New South Wales, Australia)	Identify the influence of advocacy on parents' experiences navigating the Australian child protection system	Thematic analysis (Article)	Parents with ID (n=10) - Sex: male (n=3); female (n=7) - Age ranges: 18–25 (n=6); 30–39 (n=2); 40+ (n=2) - Ethnicity: Anglo Australian (n=7); not specified (n=2)	Phenomenology; inductive thematic analysis	Grief related to loss of child(ren) to child protective services	Parents with ID are overrepresented in child protection services due to a combination of socioeconomic factors and biases. Participants observed feelings of powerlessness, as they tried to navigate the child protection and court system which often prejudged them. Participants highlight that advocates play a critical role in facilitating better understanding between parents and professionals	- Powerlessness - Dealing with trauma - Making a difference

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Dell'Aquila, 1996 (Ontario, Canada)	Explore the grief experiences of individuals with NDDs	Descriptive analysis (Dissertation as part of a Master's of Social Work)	Adults with NDDs (n=14) (and family members (n=8)) - NDDs: ID (n=8); undiagnosed NDD (n=2); TBI in early childhood (n=2) ADHD (n=2) - Sex: male (n=8); female (n=6) Age ranges: 20–29 (n=2); 30–39 (n=4); 40–49 (n=5); 50–59 (n=2); 70+ (n=1)	Phenomenological theoretical orientation (Bogdan & Taylor, 1975)	Circumstantial loss; bereavement; covert grief (Emerson, 1977)	External social factors, such as socialisation in childhood and circumstantial losses, significantly impact the grief experiences, responses, and impact on people with NDDs	- Negative image - Didactic communication - Personality and self-concept characteristics - A montage: making sense of death
Doty, 2016 (n/a)	Describe how autistic individuals may feel and experience grief, and what neurotypicals can do to support them	Narrative essay (Grey Literature-Blog Post)	An autistic adult	Autistic grief is different from neurotypical grief; lived experience(s)	Grief reactions related to death and non-death loss (e.g. bereavement and loss of a "pair of shoes")	The author observes that grief is complex and difficult for anyone to deal with, but it can be especially challenging for autistic people who may have particular vulnerabilities to loss	- The complexity of grief (i.e. more than just bereavement) - Differences between autistic and neurotypical experiences - Emotions - Coping skills and support
Dowling et al., 2006 (London, UK)	Find an effective way to improve mental health and behavioural outcomes for adults with ID following a bereavement	Mixed methods: RCT & grounded theory (Article)	Adults with ID (n=34) - Sex: male (n=14); female (n=20) - Age: <30 (n=3); 30–40 (n=8); 41–50 (n=16); 51–60 (n=6); >60 (n=1)	Stroebe & Schut's (1999) model of bereavement work; grounded theory	Bereavement	The results indicated that the traditional counselling intervention resulted in measurable improvement, both clinically and in terms of quality of life, while the second intervention (an integrated intervention delivered by carers) proved impracticable in most settings, with no improvement was observed	N/A

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Eccentrics United, 2011 (n/a)	Explore autistic experiences of grief and how an autistic person processes death	Narrative essay (Grey Literature-Blog Post)	An autistic blogger	Autistic grief is different from neurotypical grief; lived experience(s)	Bereavement	The author highlights that autistic individuals tend to be knowledge gatherers and rely on logic and information for understanding grief and loss	N/A
Fisher, 2012 (USA)	Discuss the differences between autistic grief and neurotypical grief	Narrative essay (Grey Literature-Blog Post)	An autistic adult over the age of 49	"Autistic meltdown model"; autistic grief leads to increased ASD symptoms; lived experience(s)	"Autistic grief"; "neurotypical grief"; bereavement reaction(s) and associated shutdown(s) and burnout	Autistic people may grieve differently than neurotypicals, and the author relays how their experiences are similar to an autistic shutdown	- Grieving and ASD symptoms - How do you feel? emotions, Ugh - Relationships - ASD grief things to think about - Things that may help… - For therapists and caregivers/loved ones
Forrester-Jones, 2013 (Kent & London, UK)	Understand the views and needs of older people with and without ID regarding funerals	Mixed methods: questionnaire, focus group, and thematic content analysis (Article)	Adults with mild to moderate ID (n=15) and older adults without ID (n=10) (service managers (n=40) were also surveyed) - Sex: male with ID (n=9), without ID (n=3); female with ID (n=6), without ID (n=7) - Ethnicity (with ID): Asian (n=1); White-British (n=15) ethnicity (no ID): N/A	Grounded theory	Bereavement	The results indicated few differences in the views of funerals between individuals with and without ID. The findings are suggestive of the need for more practical support for individuals with ID to engage in and attend funerals	Four key themes emerged from service users' data: - Refused entry - Respect - Rituals - Social support

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Gilrane-McGarry & Taggart, 2007 (Community residential services, West of Ireland)	Explore the peri-bereavement support individuals with ID receive from staff	Thematic content analysis (Article)	Adults with mild (n=6) and moderate (n=5) ID - Sex: male (n=9); female (n=2) - Age range: 25–72 years	Phenomenology; retrospective design	Bereavement	Participants observed practical peri-bereavement supports offered by front-line staff were helpful; however, the emotional support offered often did not meet their needs. The study highlights the need for specific education for front-line staff to better provide supports to individuals with ID; both practically and emotionally, following a loss	- An awareness of the pending death - Engaging in the rites of passage - Loss of home
Gorfin & McGlaughlin, 2004 (UK)	Understand the perspectives of adults with ID who live with older carers regarding future planning	Mixed method: questionnaire & semi-structured interviews (Article)	Adults with ID (n=41) - Sex: male (n=21); female (n=20) - Average age: 44 - Age range: 20 to 82 - Ethnicity: White (n=41)	The UK Government's Department of Health's (2001) valuing people target for PWLDs	Bereavement; anticipatory grief; secondary loss	Individuals with ID are acutely aware of the likelihood of a change to care as their carers age/die and are able to indicate their preferences for future care, with many indicating a preference for remaining in their family home. The study also highlights the difficulties experienced in secondary losses for individuals with ID following bereavement of a carer (e.g. loss of home)	- Experiences of living with older carers - Desire to move - Planning for the future

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Gould & Dodd, 2014 (Surrey, UK)	Explore the perceptions and understandings of mothers with mild ID who have had their child(ren) removed	IPA (Article)	Mothers with mild ID (n = 9) - Sex: female (n = 9) - Average age: 26.87 ± 5.97	Phenomenology	Grief related to loss of custody of child(ren); ambiguous loss (Boss, 1999)	Mothers with ID face significant struggles in being perceived as a "suitable mother"	- Suitable to be a mum? - Responses to removal - Power
Graham, 2013 (USA)	Discuss the unique autistic experiences of, and reactions to, bereavement	Narrative essay (Grey Literature-Blog Post)	An autistic woman	Task and mediator model (Worden, 2008); lived experience(s)	Bereavement	Author highlights that, despite limited research and interventions, bereavement can be a significant challenge for autistic individuals, as they may have additional difficulties with emotions and empathy, theory of mind, and literal interpretations of language	- The challenges of bereavement for autistic individuals - Lack of research - Difficulty in social interactions with other bereaved individuals - Interpreting language and metaphors literally - Understanding abstract concepts - Adapting to change and new routines - Perseveration on matters surrounding the death
Haider & Zaman, 2022 (Pakistan)	Explore the bereavement experiences of adolescents with ID	Content analysis (Article)	Bereaved adolescents with mild/moderate ID (n = 7) - Age range: 10 to 19	Piaget's (1966) theory of cognitive development; Erlingsson and Brysiewicz's (2017) approach to content analysis	Bereavement; physical transitions	Religious beliefs and customs play an important role in understanding the concept of death and associated rituals for individuals with ID and religion can be a supportive factor in navigating loss	- Meaning of death - Death rituals - Religious concepts related to death - Reasons of death - Grieving perception - Coping with grief

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Hamlin, 2003 (*Hull, UK*)	Explore the bereavement experiences of adults with ID	IPA (*Dissertation as part of a Clinical Psychology Doctorate*)	Bereaved adults with ID (*n* = 10) - Sex: male (*n* = 3); female (*n* = 7) - Age range: 29 to 66	Phenomenology	Grief as, "*the experiences associated with the loss of something that one has an emotional attachment to*"	People with ID have the same internal experiences associated with bereavement as those without ID; however, several experiences which appeared to be unique to this population were observed as a result of how others responded to both their loss and disability, such as funeral exclusion, lack of emotional and practical support, and secondary loss(es)	- Loss - Feelings - Memories of time around the death - Recovery - Obstacles to recovery
Harper & Wadsworth, 1993 (*Iowa, USA*)	Explore how adults with ID express and cope with loss	Structured interviews & survey (*Article*)	Total (*n* = 43): adults with mild (*n* = 4) and moderate/severe (*n* = 39) - Sex: male (*n* = 23); female (*n* = 20) - Average age: 46.5 - Withdrew (*n* = 4)	Piaget's theory of cognitive development	Bowlby's (1969) model of grief	Adults with ID display a range of grief reactions, similar to those reported by individuals without developmental differences, such as sadness, anger, anxiety, confusion, and physical pain. The reactions reflect a common situational response to significant loss	N/A

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Hicks, 2022 (Texas, USA)	Personally explore the concepts of memory, confession, non-linear narrative, and visual poetry centred on loss	Creative work: poetry (Grey Literature- Master of Fine Arts Dissertation)	An adult with ADHD who has experienced multiple losses	Creative writing	Enduring loss; bereavement; loss of self	The writer notes that it is easier to acknowledge and understand their sense of grief in small fragments, rather than considering it as a whole, that they need to look at "elegies" (i.e. specific fragments of information around the loss) to understand the whole process	N/A
Kaspar, 2016 (West Midlands, UK)	Explore the views of women with ID as to what makes a good mother	IPA (Dissertation as part of a Clinical Psychology Doctorate)	Adults with mild/ moderate ID (n = 8) - Gender: women (n = 8) - Average age: 48.37 ± 4.03	Attachment theory; phenomenology	Bereavement; transition(s)	Participants, who were not mothers themselves, observed that a variety of skills are needed in an individual to be a "good mother", including self-discipline, and emotional and practical intelligence. The women also discussed the loss and grief they felt when their bonds with maternal figures have been threatened or severed, as well as the behavioural consequences	Four super-ordinate themes emerged: - Mother as provider - A two-way bond - Motherhood transcends boundaries - The same as anybody else? One theme, unrelated to motherhood and the purpose of the study, also came from the data: - A group facing loss

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Kim et al., 2021 (*Community day centres in Gyeonggi, South Korea*)	Explore the life experiences of adults with ID	Photovoice & TA (*Article*)	Total (*n*=6): adults with mild (*n*=2), moderate (*n*=2), and severe (*n*=2) ID - Sex: male (*n*=3); female (*n*=3) - Average age: 46±4.7	Phenomenology; participatory design; inductive analysis	Bereavement; anticipatory grief; loss(es) due to transitions	Adult with ID observe complex biopsychosocial issues in middle-age, such as bereavement and illness. The researchers indicate the need for inclusive spaces and meaningful social support for individuals with ID	Five major themes: - Health - Free time - Time in the centre - Family - My future in old age
Kim et al., 2018 (*Seoul, Gyeonggi-do & Busan, South Korea*)	Explore the psychosocial experiences of ageing for middle-aged Koreans with ID	Thematic Analysis (*Article*)	Adults with ID (*n*=28) - Sex: male (*n*=15); female (*n*=13) - Age ranges: 40–49 (*n*=18); 50+ (*n*=10)	Phenomenology; Korean Cultural notions of filial piety and family obligation (i.e. collectivist perspective)	Bereavement; anticipatory grief; transitions	Participants observed several key challenges with ageing, including financial constraints, narrow range of social connections, unspecified anxiety about ageing and fear of death, and lack of age-appropriate services	- Restricted personal financial autonomy - Narrower social connections - Positive opportunities through work - Unknown anxiety - Fear of death and uncertainty regarding the future

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Manners & Carruthers, 2006 (*London, UK*)	(Re)present the lived experiences of one individual with ID	Co-produced; participatory research; content analysis (*Article*)	A 29-year-old woman with a mild/moderate ID	Co-production; phenomenology	Ambiguous loss; secondary loss; bereavement; transitions	Loss is discussed in terms of loss of opportunity, longing for a normal life, experiencing multiple bereavements, and the ambiguous and secondary losses associated with transitions and changes in care. Blame is observed in difficult feelings associated with possible causes of ID and everyday losses associated with it. Anger is observed regarding marginalisation/victimisation of people with ID	- Loss - Blame - Anger
Mattison, 1998 (*London, UK*)	Explore how people with ID and staff experience the end of key working relationships in residential services	Grounded Theory (*Dissertation as part of a Clinical Psychology Doctorate*)	Adults with ID in residential care (*n* = 12) and their residential care staff (*n* = 18) - Gender (adults with ID|staff): men (*n* = 5|*n* = 7); women (*n* = 7|*n* = 11) - Average age (adults with ID|staff): 44.5 ± 12.2|32.7 ± 0.6 - Ethnicity (adults with ID): White UK (*n* = 12)|ethnicity (staff): White UK/ English (*n* = 16); Irish (*n* = 1); Afro-Caribbean (*n* = 1)	Attachment theory (Bowlby, 1988); grounded theory (Glaser & Strauss, 1967)	Bowlby's (1969) model of grief; loss when relationships with key workers end	Residents and staff have similar interpretations of their key working relationships and may experience anticipatory grief towards the end of the relationship and further grief upon its termination, which often goes unrecognised and misunderstood by other staff	Two core concepts emerged: - Dependency - Fear of dependency The analysis identified a six-part "typology": - Loss and grief - Attachment - Denial - Helplessness - Self-devaluation - Acceptance and acquiescence

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Mayes & Llewellyn, 2012 (Sydney, Australia)	Describe the everyday lives of parents with ID whose children have been removed	Narrative Inquiry (Article)	Mothers with ID who had experienced compulsory removal of a child (n=7) - Gender: women (n=7) - Average Age: 31 ± 7.3	Polkinghorne's (1988) orientation to narrative inquiry	Disenfranchised grief	Compulsory removal of child(ren) was not a singular experience for mothers with ID, rather there was often a serial nature to these losses. This serial perspective produced different narratives for each loss. Regardless of narrative, mothers remained focused on their child(ren) in care and observed the loss they felt in terms of disenfranchised grief	- Living as the mother I am - Living as the mother I should be - Not feeling like a mother anymore
McDaniel, 1989 (Massachusetts, USA)	Describe a group work experience on issues of death and dying for adults with ID	Group work; descriptive (Article)	Adults with mild ID (n=8) - Sex: male (n=8) - Age range: 40 to 65	Theoretical orientation is unclear	Bereavement; transition (e.g. residential facility director leaving); disenfranchised grief (not clearly stated as such, but described as such)	Participants openly shared their experiences of bereavement and loss, observing the inevitability of death and feelings of loneliness. Practical coping skills highlighted by the participants included: positively remembering the deceased, doing activities with family/friends, continuing on with one's daily routine, and joining in with others in conversions of remembrance	N/A

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
McEvoy et al., 2012 (UK)	Investigate how individuals with ID understand death and loss and make sense of life following a bereavement	Mixed methods: questionnaire with statistical analysis & thematic analysis (Article)	Total (n=34): adults with mild (n=21) and moderate (n=13) ID - Sex: male (n=15); female (n=19) - Average age: 35.3±8.95	Piaget's (1960) theory of cognitive development	Bereavement	One quarter of participants had a full understanding and over two-thirds had a partial understanding of the concept of death. There was a significant effect for cognitive ability, with participants of a higher cognitive ability achieving higher scores on the "irreversibility", "universality", and the "inevitability" subcomponents. Participants with higher adaptive behaviour abilities displayed a more comprehensive conceptualisation of death	- What are the causes of death? - The finality of death - The body after death - The universality of death - Acceptance of death - Experiences of and reactions to bereavement
McRitchie, 2012 (Scotland, UK)	Explore how adults with mild ID experience bereavement and grief	IPA (Dissertation as part of a Clinical Psychology Doctorate)	Adults with mild ID (n=13) - Sex: male (n=5); female (n=8) - Average age: 42.54±15.67	Attachment theory; systemic impact of bereavement (Kissane & Bloch, 1994); Phenomenology	Bereavement; secondary loss(es)	Adults with mild ID experience bereavement and grief in a manner similar to the general population and the focus in practice should centre on how they can be effectively supported in being involved and included in peri-bereavement events and in experiencing and processing the loss	- Intra- and inter-personal experiences - Core beliefs about life and death - Level of inclusion - Continuing relationship with the deceased

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
McRitchie et al., 2014 (Day services in Scotland, UK)	Explore how adults with an ID experience bereavement and grief	IPA (Article)	Adults with mild ID (n = 13) - Gender: men (n = 8); women (n = 5) - Age range: 20 to 72	The conceptual model of disenfranchised grief (Doka, 2002); phenomenology	Bereavement; disenfranchised grief; secondary losses	Individuals with ID experience grief and loss in similar ways to the general population. The study indicates the need for more open communication around death, and greater support for individuals with ID to be informed and involved in peri-bereavement events/rituals	- Intra- and interpersonal bereavement experiences - Core beliefs about life and death - Level of inclusion - Maintaining a continuing relationship with the deceased
Omar, 2013 (Gauteng, South Africa)	Explore children with NDDs' responses to a puppet theatre group grief intervention	Narrative analysis (Dissertation as part of an M.Ed degree in Educational Psychology)	Children with NDDs (n = 7) - Neurodivergences: ID (n = 7); ADHD (n = 2) - Sex: male (n = 5); female (n = 2) - Average age: 12 ± 2.56 - Ethnicity: Asian (1); Black (n = 5); Mixed (n = 1)	Vygotsky's socio-cultural framework (Berk, 1997); constructivist-interpretivist paradigm	Dual process model (Schut & Stroebe, 1999); task-based model (Worden, 2008)	The study reports a group intervention involving puppet theatre was useful in creating awareness of grief and loss among children with NDDs and supported them in understanding, expressing, and connecting to their emotions, highlighting the value of group intervention and the utility of storytelling to support children with NDDs following a loss	- Puppet theatre enabling children with NDDs to connect with sadness - Authorities and institutions associated with grief - Puppet theatre allowed for the externalization of emotions

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Pensive Aspie, 2014 (n/a)	Explore autistic experiences of grief and how an autistic person processes death	Narrative essay (*Grey Literature-Blog Post*)	An autistic woman	Autistic grief is different from neurotypical grief; lived experience(s)	Bereavement	The author explores her experiences of grief following the death of her niece. She describes how her autistic process of grief seems different from her understanding of grief and the neurotypical experiences around her, relying on logic and information gathering to help process the loss. She describes "*internal conflict*" as a key component of autistic grief, as logic and emotion are, "*at war with each other*". The author notes physical pain manifesting in her grief as well as needing support to understand that grief is not just about the deceased, but our relationship(s) with them	- Logic - Internal conflict (logic vs. emotion)

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Read et al., 2013 (*North Staffordshire, UK*)	Develop a digital tool to support communication and emotional expressions around death and loss for individuals with ID	PAR (*Article*)	Adults with ID (*n* = 7) - Sex: male (*n* = 4); female (*n* = 3)	PAR; the visual preference paradigm	Bereavement; transition; loss; disenfranchised grief; secondary loss	Participants observed experiences of disenfranchised grief, often reporting that they were discouraged from even thinking about "*sad things*". The authors note that bereavement experiences of people with ID are under-researched and that family dynamics play a significant role in people with ID experiences of grief and loss. This research offers a practical communication tool to support people with ID in expressing their experiences of grief and loss	- A sense of isolation - The lack of a "safe space" to talk about death and loss - The profound and enduring impact of loss and grief - Stories that has been lost and untold for many years
Read & Papakosta-Harvey, 2004 (*day centre, UK*)	Explore the use of workshops on loss in supporting adults with ID	Narrative analysis; grounded theory (*Article*)	Adults with ID (*n* = 10) - Sex: male (*n* = 5); female (*n* = 5) - Age range: 20 to 57 - Ethnicity: White Anglo-European (*n* = 10)	Grounded theory narrative analysis	Inductive approach to defining grief; e.g. "losses included a pet dying, death of a close friend or family member, parental divorce, relocation loss and loved ones moving on"	Key emerging themes include the importance of group facilitation, the diverse loss responses experienced by participants (both death and non-death) and associated coping strategies, such as the use of humour to offset, and possibly distract from, difficult feelings and circumstances, which is consistent with the DPM of grief	- Establishing boundaries - Loss responses - Stories of loss - Endings: the importance of preparation - What we can learn from groups

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Ryan et al., 2012 (Ireland)	Explore how adults with ID cope with the death of a parent	TA (Article)	Bereaved adults with ID (n = 8) - Sex: male (n = 2); female (n = 6) - Age: 40 s (n = 5); 60 s (n = 1); 50 s (n = 2)	Braun and Clarke's (2006) TA; D'Eath's (2005) guidelines for interviewing people with ID	Bereavement; disenfranchised grief	Family plays an important role in the participants' lives and their grief at the loss of a parent is compounded by disruptions to their familial network(s)/living arrangements	- The sense of loss experienced when family life is disrupted - The sense of loss experienced after the death of a parent
Soraya, 2014 (USA)	Discuss how grief manifests differently for autistic adults compared with neurotypicals	Online article (Grey Literature)	An autistic woman	Autistic grief is different from neurotypical grief; lived experience(s)	Bereavement	The author recounts her experiences of death, highlighting that these experiences have been more difficult due to her autism. The author observes frustration at the typical framing of autism in research which often ignores the emotional lives of autistic adults, finding little information on autism and grief to help her	- The difficulty and uniqueness of the grieving process for autistic individuals - The lack of resources and understanding surrounding autism and grief - The struggles of navigating social situations and understanding societal expectations during times of grief - The helpfulness of information from within the autistic community
Swainland, 2003 (UK)	Explore the bereavement experiences of adults with ID	IPA (Dissertation as part of Clinical Psychology Doctorate)	Bereaved adults with mild/moderate ID (n = 10) - Sex: male (n = 2); female (n = 8) - Age range: 20 to 57	Attachment theory; psychosocial transition model (Parkes, 1988)	Bereavement (inclusive of multiple losses and unrecognised grief due to a "double taboo" of death and disability)	The emotional experiences of bereavement for adults with ID were similar to those in the general population, but with specific themes, such as the participants' attempts to create meaning, the intensity of their relationships with their parents, and social factors affecting the grieving process	Two main themes emerged: - The experience of bereavement - The impact of having an ID

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Tajuria et al., 2017 (UK)	Explore the use of Photovoice as a creative method for supporting bereaved individuals with ID	Photovoice (Article)	Bereaved adults with mild to moderate ID (n = 10)	Participatory & accessible design; phenomenology	Bereavement; hidden losses (i.e. secondary loss); delayed grief; disenfranchised grief	Photovoice's effectiveness is contingent on researchers' abilities to be inclusive and adaptable in their approach to meet participants' needs. The paper outlines principles of good practice for Photovoice which centre on preparatory work, understanding, and accessibility	N/A
Thorp et al., 2018 (rural, UK)	Explore the bereavement experiences of adults with ID	IPA (Article)	Bereaved adults with mild/moderate ID (n = 4) - Sex: male (n = 2); female (n = 2) - Average age: 35.0 ± 3.1 - White British (n = 3); Afro Caribbean (n = 1)	Phenomenology	Bereavement; secondary loss; cumulative loss	People with ID observe difficulty navigating secondary losses and the meaningful bereavement experiences they have. Participants reported a desire to be involved, informed, and supported in peri-bereavement rituals and events	- Needing to know: being included - Struggling to say: the emotional experience - Love after death: a continuing relationship - Missing their presence: the wider impact of death

Table 2 (continued)

Author, year (location)	Purpose	Method/approach (source type)	Sample characteristics	Theoretical/conceptual framework	Operationalisation of grief/loss	Main findings	Themes/narratives
Tuffrey-Wijne et al., 2012 (UK)	Explore the experiences and identify support needs of people with ID who have a relative/friend with cancer	Content analysis (Article)	Adults with mild to moderate ID who have/had a friend/relative with cancer (n=21) - Sex: male (n=5); female (n=17) - Average age: 42.19±13.23	Thematic content analysis	Bereavement; anticipatory loss	Participants who had not been told about their loved one's illness felt excluded, many reported vivid memories of events and their feelings, and worried about their families. Participants observed that they lacked knowledge about cancer and wanted to know more and would have liked to share their feelings and questions with family, friends or professionals, but had not felt able to voice their questions or concerns	- Protection and inclusion - Coping with cancer - Understanding cancer - Someone to talk to

Article peer reviewed article in an academic journal, *IPA* interpretative phenomenological analysis, *N/A* information not available, *PAR* participatory action research, *RCT* randomised controlled trial

Table 3 JBI critical appraisal checklist—qualitative research

Author (year)	Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Barber (2022)	Y	U	Y	Y	N	Y	Y	–	N	Y
Baum and Burns (2007)	Y	Y	Y	Y	Y	N	Y	Y	U	Y
Bowey and McGlaughlin (2005)	Y	Y	Y	U	U	N	Y	Y	N	Y
Collings et al. (2018)	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Collings et al. (2020)	Y	Y	Y	Y	Y	Y	Y	U	Y	Y
Dell'Aquila (1996)	Y	Y	Y	U	U	N	Y	Y	Y	U
Dowling et al. (2006)	Y	Y	Y	Y	Y	N	N	N	U	Y
Forrester-Jones (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gilrane-McGarry and Taggart (2007)	U	Y	U	Y	Y	N	Y	Y	Y	Y
Gorfin and McGlaughlin (2004)	U	Y	Y	N	U	N	Y	N	N	U
Gould & Dodd, (2014)	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Haider and Zaman (2022)	Y	Y	Y	U	U	N	Y	N	Y	U
Hamlin (2003)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Harper and Wadsworth (1993)	Y	Y	N	Y	Y	N	N	N	U	Y
Kaspar (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 3 (continued)

Author (year)	Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Kim et al. (2018)	Y	Y	U	N	U	U	Y	Y	Y	U
Kim et al. (2021)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Manners and Carruthers (2006)	Y	Y	Y	Y	Y	Y	Y	Y	U	U
Mattison (1998)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mayes and Llewellyn (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
McDaniel (1989)	U	U	Y	U	N	N	Y	N	N	U
McEvoy et al. (2012)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
McRitchie (2012)	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
McRitchie et al. (2014)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Omar (2013)	Y	Y	Y	Y	N	Y	Y	Y	Y	N
Read and Papakosta-Harvey (2004)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Read et al. (2013)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Ryan et al. (2012)	Y	Y	Y	N	U	N	Y	Y	Y	U
Swainland (2003)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Table 3 (continued)

Author (year)	Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Tajuria et al. (2017)	Y	Y	U	N	N	N	Y	N	Y	U
Thorp et al. (2018)	Y	Y	Y	Y	Y	Y	Y	U	Y	Y
Tuffrey-Wijne et al. (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Y yes, *N* no, *U* unclear, "–" not applicable

Theme 1: Hidden Grief

The theme of *Hidden Grief* is profoundly centred on the overarching theme of *Recognise the Unrecognised*, situating an understanding of the grief reactions which go unrecognised, unseen, and unheard:

> "*You may be shocked, for example, because your son seems to be trivializing his beloved grandpa's death. But it is very likely that this is not the case. It may be his way of seeking closure for a death that he is having a hard time coming to terms with.*" (Eccentrics United, 2011)

This notion of *Hidden Grief* is not concerned with neurodivergent individuals being unaware of their own grief reactions. The majority of the participants across the studies are acutely aware of their grief for both death and non-death loss(es), even when they do not have the emotional literacy to express it as "grief":

> "*It is difficult when someone leaves - it means there's a gap to fill, and it may take some time to fill the gap. And it's hard - it's hard.*" R8 (Mattison, 1998)

Moreover, some participants observed an awareness of their own positionality within collective bereavement reactions, highlighting that they will attempt to hide their own grief so as not to further burden those around them:

> "*I don't want my dad to be sad, so I don't talk to him that I miss my mom.*" Daehyun (Kim et al., 2021)

Others, especially autistic accounts, expressed less understanding of the broader impacts of their grief at the time, yet observed attempts to educate themselves on this:

> "*After her death, I felt like my grief was somehow different than the rest of my family. Like a typical Aspie, I tried to research it*." (Pensive Aspie, 2014)

These attempts were often coupled with echoing social behaviours and masking to fit into the broader social context of the grief whilst purposely hiding a lack of understanding as to what the grief may mean to others:

> "*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)

However, *Hidden Grief* is often more about a lack of recognition from neurotypicals than a purposeful concealment of the grief experienced for their benefit, with three sub-themes identifying this: *Disenfranchised Grief*, *Loss on Loss*; and *Imposed Transitions*.

Table 4 JBI critical appraisal checklist—grey literature (text and opinion)

Author (year)	Is the source of the opinion clearly identified?	Does the source of opinion have standing in the field of expertise?	Are the interests of the relevant population the central focus of the opinion?	Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	Is there reference to the extant literature?	Is any incongruence with the literature/ sources logically defended?
Doty (2016)	Y	Y	Y	Y	N	U
Eccentrics United (2011)	N	Y	Y	Y	N	–
Fisher (2012)	Y	Y	Y	Y	U	Y
Graham (2013)	Y	Y	Y	Y	Y	Y
Hicks (2022)	Y	Y	–	–	Y	–
Pensive Aspie (2014)	N	Y	Y	Y	Y	Y
Soraya (2014)	Y	Y	Y	Y	Y	Y

All are considered experts by lived experience

Y yes, *N* no, *U* unclear, *"–"* not applicable

Table 5 Themes from thematic analysis

Overarching theme	Theme	Sub-theme
Recognise the unrecognised	*1. Hidden grief*	1a. Disenfranchised grief
		1b. Loss on loss
		1c. Imposed transitions
	2. Supported & included	2a. Peri-bereavement events
		2b. Supported to be included
		2c. "I kept it to myself"
	3. Understanding my loss	3a. Narrative & storytelling
		3b. Experience & logic
		3c. Comfort in locating loss
		3d. The echophenomena of grief
	4. The double taboo of death & disability	4a. "Typical" grief
		4b. Perception & overprotection
		4c. Misunderstood behaviour

Sub-theme 1a: Disenfranchised Grief

Several studies raised Doka's (2002) understanding of *disenfranchised grief* (i.e. grief which is not recognised or validated as grief) (Graham, 2013; Mayes & Llewellyn, 2012; McRitchie, 2012; McRitchie et al., 2014; Tajuria et al., 2017), and every paper produced narratives of grief and loss where participants experienced disenfranchised grief to some degree, regardless of whether it was explicitly described as such. For example, some studies considered aspects of a *typical* grief reaction, such as a wish to see the body or spread the ashes, which can go unrecognised, unheard, and/or ignored in neurodivergent individuals:

"*If you are in bad form and they [staff] say, oh you're just whinging . . . you are not really, you are just try-ing to get your point across but some people just don't want to listen.*" Participant 6 (Gilrane-McGarry & Taggart, 2007)

Others recounted more unique experiences of grief which can go unrecognised under a neuronormative perspective of grief, such as the impact of alexithymia on grief:

"*He leaned forward and encouraged me to describe how crying felt. I thought about it for a moment and told him very sincerely that it made my eyes hurt ... It was only much later that I realized he meant the other felt. I still don't know how to answer that one... How does crying feel?*" (Fisher, 2012)

There were several studies (Baum & Burns, 2007; Collings et al., 2018, 2020; Gould & Dodd, 2014; Mayes &

Llewellyn, 2012) which focused in on the unique, often unrecognised and unsupported, experiences of ambiguous loss those with ID feel following the removal of their child(ren) by social services and the social biases and prejudice against them being parents in the first place:

"*Social Services wanted me to get her…aborted, and I said no. Don't you tell me to get an abortion. They said, go on, go down the doctors and have an abortion*." Helen (Gould & Dodd, 2014)

Others reported unique experiences specific to neurodivergence, such as a sense of grief from the loss of the possibility for a "*normal*" life as a result of their own neurodivergence:

"*And it is difficult to think about how and why I have a learning disability. Everybody doesn't understand. I want to know what caused it. Doctors should be able to save me. The midwife should have kept an eye on me when I was growing in my mum's tummy. Mum and dad should have looked after me properly. This shouldn't happen in the first place.*" Emma (Manners & Carruthers, 2006)

Others observed the unique experiences of "*autistic grief*" in contrast to "*neurotypical grief*":

"*[T]he duration and intensity of our grief can be far greater compared to the neurotypical population*." (Doty, 2016)

A key aspect of these experiences of different and disenfranchised grief was not just the loss itself, but the losses which followed an initial loss.

Sub-theme 1b: Loss on Loss

Loss on Loss (i.e. secondary losses following an initial loss, such as a change in living circumstances following a bereavement) was observed by most of the participants. Yet, the significance of secondary loss(es) was often regarded as being unrecognised by staff, carers, and family members:

"*I said to [staff member] . . . now is not the time to dump me into [residential centre] when my mother died.*" Participant 1 (Gilrane-McGarry & Taggart, 2007)

Whilst discussing future planning, participants consistently highlighted a desire to be supported to remain in their family home or to live more independently in the local area following the death of elderly family carers or their reduced ability to provide care:

"*I've talked to Mum and Dad. I'd probably want to live on my own with someone coming in to help me, but I*

don't want to until I have to. I'm happy here, but I'd prefer a flat around here somewhere when I have to go." Susan (Bowey & McGlaughlin, 2005)

However, participants across the studies who had experienced such a loss, and several who reported they had wanted to remain at home, observed the loss of their family home as a secondary loss following the death of a parent:

"*I had to move out. I was told 'Just move out right away'.*'' Jack (McRitchie et al., 2014)

Moreover, this loss of a home was often coupled with a loss of support and connections and unwanted loss of independence, as individuals were placed into residential care:

"*I said to Mammy that I did not like the place and she said that she did not put me into it, my social worker did. I do not know how many years I have been in here now*." Anne (Ryan et al., 2012)

Some other key examples of *Loss on Loss* were further loss of family following the death of a family member who served the role of a *kin keeper* (i.e. a family member who helps facilitate the inter-family relationships which the neurodivergent individual may struggle to do independently) and the loss of special activities due to a loss of support to continue participating in them:

"*My mom had a great big family cos she wanted it you see. Anything happened they come down and see me but nobody's been down since mom died..*" Tracy (Kaspar, 2016)

Ultimately, these examples of *Loss on Loss*, such as a change in living circumstances and loss of support, are all centred-on further life transitions which are typically imposed rather than chosen by the individual and the associated difficulties raised in transitions in the context of neurodivergence.

Sub-theme 1c: Imposed Transitions

Participants across every included paper reported transitions as factors which are both products and producers of grief. In this sense, although the grief reactions to more significant transitions (e.g. bereavement and moving into residential care) were often recognised and supported, the grief felt in response to perceptually small transitions was often left unrecognised by those in supporting roles:

"*Another challenge is adapting to change. Since individuals on the spectrum like routine and doing things the same way, this can be a challenge with the third task of mourning: external adjustments. New routines have to be established, especially if the deceased per-*

son was part of the individual's daily life." (Graham, 2013)

The lack of recognition of grief in response to transitions (i.e. non-death losses) was observed by many of the participants as something which reinforced their grief and produced further feelings of disenfranchisement:

"*Try to pretend they are not there. Cope by switching off. Cry when I'm on my own. Feel lonely*." Participant A (Baum & Burns, 2007)

A key point of transition noted across studies was transition in care; for example, when a support worker or member of staff in a residential care facility leaves:

"*It made me think of my friend dying*." R6 (Mattison, 1998)

Furthermore, beyond the grief felt at the loss of support workers/staff going unrecognised, individuals considered that others perceived their reactions to loss as "*challenging behaviour*" instead of grief reactions. Moreover, several participants came to understand their own reactions in terms of how it was perceived and the impact it may have, rather than considering the significance of the thoughts and feelings driving their reactions:

"*I kind of like just cried for ten minutes, and then I pulled myself together and I said, 'I'll make you all a cup of tea' and my uncle said 'Stop bossing everyone about' and I wasn't*." Kimberley (Swainland, 2003)

When the sadness of the loss was acknowledged, participants reported it to be done so in such a way that their grief was seen as an inconvenience and rushed along:

"*I did talk to [staff member] about it but sometimes I felt that it never amounted to much … nobody asks me how I'm feeling really*" Participant 6 (Gilrane-McGarry & Taggart, 2007)

Overall, neurodivergent individuals are not only aware of their grief, but are often either acutely aware of it in the social context they are living in or actively seek out knowledge to understand the broader social impacts of loss better. However, despite their ability to understand and/or learn to recognise the broader impacts of grief, those around them often fail to do the same to understand neurodivergent experiences of grief better. Consequently, much of the grief experiences of neurodivergent individuals remain *hidden* from neurotypical families and carers. As such, many neurodivergent individuals experience disenfranchised grief, where the loss, significance, and/or grief reaction itself are left un- or under-recognised. Experiences of disenfranchised grief were most acutely felt in secondary loss(es), typically following the death of a primary/elderly carer and in the context of transitions.

Theme 2: Supported and Included

Supported and Included emerged in all papers and is associated with the overarching theme *of Recognise the Unrecognised* insofar as recognition of the individual's grief and their understanding of it as valid significantly mediated the amount of inclusion and support offered by staff, family, and broader social connections. In this sense, where grief and the understanding and/or significance of the grief go unrecognised, support is not offered, and the grief experience(s) is that of disenfranchised grief.

"*We just told him to quit feeling...No, we don't have time for that*." N's sister, Mrs. W (Dell'Aquila, 1996)

Moreover, when the grief is recognised but an understanding thereof is not or supporting attendance in peri-bereavement events is deemed too difficult due to an individual's perceived understanding and/or "*challenging behaviour*", then exclusion from sharing in their grief often follows:

"*It's up to the staff at [day centre] what they do with me… probably they decided what to do with Mum's ashes.*" Jeremy (McRitchie, 2012)

However, when the grief and the understanding and/or significance of the grief are recognised, then support, inclusion, and information were observed as being more readily available by participants across the studies:

"*Yeah I mean it didn't bother me. It didn't bother me that I didn't go to the funeral but I was glad that I was told to be honest*." Edward (Thorp et al., 2018)

Key areas of *Supported and Included*, or lack thereof, were identified as three sub-themes: *Peri-Bereavement Events*, *Supported to be Included,* and *"I kept it to myself"*.

Sub-theme 2a: Peri-bereavement Events

Peri-Bereavement Events (i.e. events before and after a death) were identified as being inclusive of visiting friends/relatives in palliative care, attending funerals, being involved in the planning and decisions for and following a loss, and, ultimately, being informed:

"*When presented with the story of 'Jim', which left it open whether or not he had been told about his father's cancer … participants answered to the question what was worrying Jim: 'Nobody's told him'.*" (Tuffrey-Wijne et al., 2012)

However, peri-loss events were also identified in relation to non-death loss(es), such as in planning for transitions in care:

"*In the centre, members must be between 35 and 55 years of age to be served. It makes me feel so sad. I want to stay here as long as possible because I could not see my friends here when I graduate. I would miss my friends so much. I worry*." Jaewoo (Kim et al., 2021)

The necessity for anticipatory planning and debriefing in transitions is highlighted for not just the individual but others around them too, as some participants, with no information about a friend's transition of care into another residential facility, believed their friend had died:

"*But I don't know where Patricia went Patricia died, I think. Nobody told me about that. But I think she's dead*." Melissa (Swainland, 2003)

Moreover, a key concern raised by participants across the studies was that of the lack of control, choice, and information given leading to a loss and following a loss:

"*I didn't know anything about it at all, with my mum or my sisters. It's like talking about it and I didn't know anything. They put me in a room and I didn't hear about it, I didn't know about it. It's not nice*." Participant 11 (Tuffrey-Wijne et al., 2012)

As such, participants often reported feelings of anticipatory grief, which they felt unable to discuss explicitly:

"*I tried to express that grief through acts of love and compassion towards Liz, almost as acts of vigil by her side*." (Barber, 2022)

Moreover, although a small number of participants who chose not to attend the funeral were content with their decision:

"*I didn't want [to attend], yes I know why because I don't want more crying*." David (Thorp et al., 2018)

All who were not given the choice of whether to attend but were just excluded expressed regret and sadness about not being able to participate in the funeral:

"*(Did you go to the funeral?) 'No I didn't I was at school' … (Did you want to go?) 'Yes, I did'*." Interview 9 (Hamlin, 2003)

Moreover, the participants who were able to choose to attend funerals placed a great deal of value on the ability to say goodbye, and some participants even took pride in being able to attend:

"*It's important for me, it's important for me because, he's, he is a good guy to me*." Rachel (Thorp et al., 2018)

Overall, a key point highlighted repeatedly across studies, and often observed with frustration, was the need to feel *Supported to be Included*, especially by family and carers, in peri-bereavement events and to feel supported to make an informed choice regarding attending these events.

Sub-theme 2.b: Supported to Be Included

Participants across the articles observed the desire to both be and feel *Supported to be Included*, with family and carers being identified as playing a pivotal role in the amount of inclusion and support offered to neurodivergent individuals following a loss. This ranges from facilitating inclusion at funerals to other loss/death rituals, which were regarded as more purposeful than normal interactions, as Hick's (2022) sums in poetic verse:

"*They came to sweep it up, so all I could give was my song,*
'Amazing Grace' hanging in the air over your casket, and I clutch
my hymnal despite knowing the words. Our family members stare at me
with wide, bleary eyes as my voice rings out around them.
This is the last time I'll see most of them on purpose." (Hicks, 2022)

To facilitating understanding and information about the loss itself:

"*He said, 'Why did (the brother-in-law) have to die?! Why did he have to die?!' Like he was reliving the whole bad adventure. And of course I was glad that our sons-in-law were there because they held him in their arms and said, 'That's the way life goes. Bad things happen to good people'.*" L's sister, Mrs R (Dell'Aquila, 1996)

However, for some participants, strong and supportive family networks were observed as dissipating and facing problems in loss, either through the loss of elderly carers where mutual dependency for support inhibited the development of broader social support and/or kin keepers who held family relationships together:

"*There is my family in the picture. They do not want to know me*." Betty (Ryan et al., 2012)

In this sense, the studies often pointed to the need for future planning and the development of robust social support

networks outwith the family itself were considered a protective factor in the event of a loss:

> "*You've got to go out. See more people. You can't depend on your family.*" Mike (McDaniel, 1989)

As such, the development of greater social support, independence outwith the family setting, and other modes of practical and emotional support were broadly considered pre-loss within the context of the family, especially with elderly carers who were increasing in support needs themselves with age:

> "*I think it'll be good to be more independent. I want to make sure I've got enough support, like helping with my money and that, with the cooking and that and at night if I'm feeling poorly.*" (Gorfin & McGlaughlin, 2004)

Sub-theme 2c: "I Kept It to Myself"

Although participants across studies broadly indicated a want for more emotional support and were keen to discuss and share their experiences of grief and loss:

> "*If you share it with somebody it makes it a whole lot lighter than trying to deal with it yourself.*" Bill (McRitchie, 2012)

Most of the participants observed that the provision of emotional support available to them by staff/support workers was broadly ineffective and typically worsened their feelings of grief:

> "*I did talk to [staff member] about it but sometimes I felt that it never amounted to much … nobody asks me how I'm feeling really … it's more about how my day was and I don't really want to talk about how my day is … it's easier if somebody sits down and listens to me now and not feel that I'm wasting their time.*" Participant 6 (Gilrane-McGarry & Taggart, 2007)

As such, some individuals employed avoidance tactics to distance themselves from the adverse effects of what was perceived as inappropriate support. This was done via affective and relational practices of avoidance, as a participant in one study concisely sums up:

> "*I kept it to myself.*" (McEvoy et al., 2012)

Moreover, spatial avoidance was also utilised insofar as to express one's grief privately, away from unwanted emotional support from both family and staff, which was perceived as actively unhelpful; for example, Melissa's (Swainland, 2003) adaptive response to lack of privacy in residential care to express her grief was to try to, "*go outside sometimes*", as staff often failed to recognise the

need for privacy at these times. Nevertheless, some participants found great comfort in both supporting and being supported in their ability to share their grief with their families:

> "*Seeing me family, going out. That makes you feel better.*" Interview 6 (Hamlin, 2003)

However, most autistic individuals identified across the articles express great difficulty with family following a loss, as they struggled to understand, relate to, and/or tolerate others' expressions of grief:

> "*I cried a tiny bit in the weeks that he stayed in the hospital in a dark coma, but mostly I was uncomfortable with all the weeping and emotions from my other family members during this time.*" (Fisher, 2012)

Moreover, many of the participants also observed anxieties around further burdening their families with their grief reactions, so they sought to hide their grief and not seek emotional support within their families:

> "*My family don't talk about it. I find it easier to talk to someone else … It's not always easy to find someone. It's a good thing to talk about worries but if there is no one around it's difficult.*" Participant 18 (Tuffrey-Wijne et al., 2012)

Emotional support for grief and loss was chiefly only considered beneficial when it was delivered by a specialised service which understood both grief and neurodivergence, though this was rarely provided:

> "*Nobody offered us counselling; this might have helped.*" (Read & Papakosta-Harvey, 2004)

As such, with a lack of specialist provision reported across the studies, participants often sought out more practical support and diversional activities:

> "*At the end of the day, sometimes all that's required is some company and something to take our minds off the grief.*" (Doty, 2016)

Key areas of practical support observed were generally focused on support to attend peri-bereavement events; however, other key areas of practical support included making/providing objects to remember the deceased by and inclusion in and support to be involved in handovers of care and other transition events:

> "*[Researcher]: So you'd like a picture of him. How would that help you? …*
> *Alan: He'd be closer to me …*
> *[Researcher]: Yeah, what are you going to do with it when you've got the picture?*

Alan: Put it in my wallet." (Swainland, 2003)

Overall, *Supported and Included* centres on how neurodivergent individuals are understood and recognised in their grief, supported in navigating the loss, and included in both events related to the loss and the broader intra-personal grief experiences following a loss. Appropriate support and inclusion were highlighted in enabling neurodivergent individuals to have informed choices and be supported in attending peri-bereavement (and peri-loss) events. Moreover, family and carers were observed as playing a pivotal role in facilitating *Support to be Included*; however, it was also noted that support, especially in the context of elderly carers, should involve the development of social networks outside the family. Lastly, although attempts are often made to provide emotional support, participants highlighted that these attempts were often inadequate and left them feeling worse or as though they needed to hide their grief; however, emotional support from specialist services and practical support from family and carers were found to be of great benefit to the neurodivergent individuals across the articles.

Theme 3: Understanding My Loss

Understanding My Loss stems from an individual interaction with the overarching theme of *Recognise the Unrecognised* insofar as it centres on recognising one's own loss and the measures neurodivergent individuals take to understand grief and loss. For example, some individuals observe understanding loss via information given to them following the loss from family, and many others had developed a prior understanding of loss via religion:

"*One dies of God's will. Death is from God.*" Participant 6 (Haider & Zaman, 2022)

Those who understand loss in the context of religion often reported finding comfort in this understanding and a hope for reunification with their loved ones following their own death:

"*I wish they came back from God and Jesus because I feel very sad. I wish they would come back to see me. Like tomorrow, I'm going home to see my dad.*" H (Dell'Aquila, 1996)

Others, specifically autistic individuals, observed developing a keen fascination with death and gathering information surrounding it to understand the loss better:

"*After her death, I felt like my grief was somehow different than the rest of my family. Like a typical Aspie, I tried to research it.*" (Pensive Aspie, 2014)

Others tended to develop, represent, and express their understanding through perseveration and echophenomena:

"*With the tendency for those with autism spectrum disorder to perseverate on topics of their interest, matters surrounding the death can become their new interest.*" (Graham, 2013)

However, one key area where there was almost unanimous agreement across the research and grey literature was that neurodivergent individuals tend to understand and express their understandings of grief and loss through narrative and storytelling:

"*[My writing] is mostly a work of memory, confession, fragmentation/noon-linear narrative, and visual poetry.*" (Hicks, 2022)

Sub-theme 3a: Narrative and Storytelling

Narrative and Storytelling play an important role for the majority of participants across the studies, not just in understanding the loss, but also in communicating one's own experiences of loss. Moreover, participants often observed a very strong want and willingness to share their experiences when/if the opportunity was presented to them; for example, in one study by Kaspar (2016), all participants used the opportunity of having a space to be listened to in order to discuss their experiences of grief and loss, despite the study's initial scope and questions not considering grief or loss. Moreover, one participant in another study, not wanting to "*bother*" staff had masked her pain and not discussed her mother's death for four years and tactically decided to use the interview to ask personally important questions about death she had not felt able to before (Gilrane-McGarry & Taggart, 2007). The need for this space to unmask the pain of grief and talk openly is summed up by an autistic author of an autoethnographic study:

"*What I needed was compassion and the opportunity to talk, to share my experiences, to be listened to, to be understood, to be validated, to be cared for and to have a shoulder to cry on.*" (Barber, 2022)

This want to share and find comfort in community was also evident in online spaces of neurodivergent communities accessed by autistic individuals who used blogs to write narrative accounts of their grief and the concept of autistic grief:

"*I reached out to my Aspie community [online]. Those who had experienced a loss were very supportive.*" (Pensive Aspie, 2014)

Narrative was also evident as a tool for better understanding grief and loss following a loss; for example, some individuals found meaning in making family trees and memory books; however, storytelling was observed as a valuable tool

for better understanding future loss(es) and normalise both the grief experience and discussing loss:

> "*I hope that more of us will do as Karla [autistic blogger] did, and share their stories. You never know when it might help someone else. It certainly did me.*" (Soraya, 2014)

Storytelling was also used as a therapeutic tool for expressing feelings emerging from the loss, such as in a puppet theatre-based intervention and the use of creative writing and poetry:

> "*Researcher: Is that a duck [from the puppet theatre story]? What did it do?*
> *Participant: Died died.*
> *Researcher: It died.*
> *Participant: Yes.*
> *Researcher: And how did the friends feel?*
> *Participant: Sad.*" (Omar, 2013)

Furthermore, understanding and integrating loss was reported by some in comfort found in religious narratives of an afterlife:

> "*Angels take away soul.*" Participant 1 (Haider & Zaman, 2022)
> "*[T]hey can carry onto heaven, into the next life and there won't be, there would be no worries in heaven.*" Edward (Thorp et al., 2018)

Whilst others sought greater comfort in the narratives of loss they could (re)produce with logic:

> "*I was pretty rational and emotionally regulated compared to them and also highly interested in the science, research, and medical facts. It was logical to me to be as armed as possible with knowledge in order to be of some help.*" (Fisher, 2012)

Sub-theme 3b: Experience and Logic

Logic was a central component in both the research and grey literature for understanding and processing loss for autistic individuals:

> "*Even though a piece of my heart wanted to believe that she was still "in there", my brain knew she was gone. It would not allow my heart to fantasize that some day she might come back to us. She was gone. It was logical. There was no denying it.*" (Pensive Aspie, 2014)
> "*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)

These individuals observed a need to know as much information about the loss as possible. They would spend a great deal of time reading and learn about the specific loss, as well as more general conceptualisations of grief:

> "*My mom's death and my later diagnosis have influenced me to take a special interest in the uniqueness of bereavement in individuals with autism spectrum disorder.*" (Graham, 2013)

This need for logic was also seen in participants' understanding of loss through language across many of the studies and across different neurotypes, as clear, precise, and literal language was broadly favoured in how a loss ought to be communicated, and confusion was expressed about how one *appropriately* (i.e. neurotypically) discusses loss; for example, Florence took the euphemistic term "*lost*" literally when being told of her father's death:

> "*Me dad is sad, he's worried, he thinks we don't want him, I'll tell him to come home when he sees me next time. He doesn't know me mum's gone, I'll tell him that too. I waited all day on Sunday and he didn't see me.*" Florence (Dowling et al., 2006)

Others observed confusion about expressive language and what to say following a loss:

> "'*Congratulations!' I felt he knew he was supposed to say something that acknowledged the death but did not realize that we do not say congratulations at a funeral.*" (Graham, 2013)

Several papers (Graham, 2013; Haider & Zaman, 2022; McDaniel, 1989; McEvoy et al., 2002, 2012; Omar, 2013; Soraya, 2014; Tuffrey-Wijne et al., 2012) suggest that life experience, both through real loss and/or stories and narrative, plays a vital role in understanding loss, and this may be of greater importance in understanding loss than the mode of communicating loss or the cognitive abilities of the individual receiving news of the loss; Graham (2013) sums this up:

> "*Knowing about previous losses can be helpful in supporting individuals in their grief process.*" (Graham, 2013)

This is reflected in the cyclical nature of presence and loss observed in the experiences of becoming accustomed to and understanding the inevitability of the loss of key workers:

> "*It was hard for me, but I got used to it.*" R2 (Mattison, 1998)

Nevertheless, regardless of prior experience, one of the most challenging factors observed by participants in understanding the loss was the apparent illogical nature of grief:

"*I still struggle with grief. I still attempt to understand why I grieve. It isn't logical, but like I said, the heart trumps the brain on this one.*" (Pensive Aspie, 2014)

As a result, many participants sought tangible ways to better understand the more intangible nature of grief insofar as they found comfort in locating the loss.

Sub-theme 3c: Comfort in Locating Loss

Neurodivergent individuals across the articles highlight the difficulty in navigating and expressing the many intangible components of grief:

"*I remember during my own grief therapy when my therapist asked me how I felt and I could not answer. He then got a little more specific and asked me what did I do when I experienced death. Not sure again how to answer, I answered how most people react. I told him that I cried..*" (Fisher, 2012)
"*I don't know why they have to leave when I don't want them to.*" R2 (Mattison, 1998)

As such, when and where individuals could situate a loss more tangibly, they often sought to do so and found great comfort in locating their loss:

"*Well, she's still in the graveyard. She's along with her man you see. They're both together you see.*" Kevin (McRitchie, 2012)
"*...a nice stone 'cos it shows when a person died and who they are...*" Mark (Forrester-Jones, 2013)

Participants reported the value and importance of continuing bonds with the deceased:

"*I talk to [mum] sometimes.*" Michelle (Thorp et al., 2018)
"*Each time I hear classical music or attend the theater to see a live show or a musical, I always think of my mom and feel her spiritual presence with me.*" (Graham, 2013)

Modes of locating loss ranged from keeping and viewing photographs of the deceased:

"*Well we always talk about her cause we've got a photo of her.*" Interview 6 (Hamlin, 2003)

To hold on to particular items which either belonged to or had a connection with the deceased:

"*My mom went to heaven last year. I still keep her cellphone because I miss her so much.*" Daehyun (Kim et al., 2021)

To locate the thoughts and feelings associated with the loss of comfort found in others with relatable experiences or a sense of purpose found in the other and their legacy:

"*I like to get out and be in a group... with people that have [also] gotten their kids taken off them.*" Vanessa (Collings et al., 2020)
"*That was and is Liz's legacy, and it would be fitting to transform grief and grieving, both of which are natural emotions and experiences, into a life of active and compassionate service to and for others.*" (Barber, 2022)

It is important to note that participants reported significant distress when they were unable to locate the loss in more tangible terms, such as not knowing where a particular grave was or, if they did, not being able to access it:

"*I want to go up there, I do want to go up because I want to say 'Hello' to him but I don't know where it is. I know where the crematorium is but I don't know where he is.*" Kimberley (Swainland, 2003)

This distress was also highlighted in confusion over figurative language, which appeared to locate the loss in more uncomfortable ways:

"*Right. And she put her arm around me and said that, that, she said 'your dad is you know, you know where err, heaven is', upstairs, so she that, and said to her that 'heaven is upstairs' and she said that me dad had, I remember now, she said that he'd died of a heart attack.*" Interview 8 (Hamlin, 2003)

Nevertheless, participants also would locate the loss in more intangible terms and derive comfort from this too, as the majority of participants reported remembering the deceased fondly and carrying their memory in terms of continuing bonds:

"*She's still in my heart. She speaks to me in my sleep.*" Norman (McRitchie, 2012)

Sub-theme 3d: The Echophenomena of Grief

Whilst participants often sought to "*carry*" the grief in tangible and intangible ways, some also located their grief and understanding in modes of perseveration and echophenomena (i.e. repetition of words, sounds, and actions, as in echolalia or echopraxia). Perseveration often centred around specific memories around and about the loss itself or how the loss was communicated to the individual:

"*This loop of brain vs. heart vs. brain vs. heart continued because I could not stop hurting no matter how logically I tried to process it.*" (Pensive Aspie, 2014)

"*When my mom died, obituaries became my interest. I would go online and sign obituary guest books of people who died in a similar way as my mom. I have no siblings so doing this helped me cope and feel less alone.*" (Graham, 2013)

Consequently, individuals would sometimes engage in modes of repeatedly (re)experiencing how they were informed of the loss or the loss itself and may seek out further information on the loss or media which represents it to understand the loss better:

"*I also found myself recreating the accident in my mind. I wondered what her last thoughts where and how quickly she died. I tried to picture exactly how the accident played out. I wondered what her body looked like. I even searched the Internet for information about how the decomposition process works. Why? This is not some perverse fascination with death. It is because I have such a hard time wrapping my head around how someone can be alive and happy one minute and essentially cease to exist the next.*" (Eccentrics United, 2011)

This is inclusive of various echophenomena in relation to grief (either internally, externally, and/or verbally):

"*For the first two months after my mom's death, when I walked home from school I would shout, 'Hello, mom!' I was not in denial of her death; it was just out of habit until I got used to not saying it when I got home from school.*" (Graham, 2013)

"*My first sign of trouble were … feelings, physical sensations, stims, tics, or behaviors that serve as indicators that I have emotions brewing of which I'm not fully aware.*" (Soraya, 2014)

This sort of *echothanatologia* (i.e. repetition of words centred on death) was more commonly reported by autistic individuals. However, neurodivergent individuals across the studies observed echoing and mirroring others in grief, both consciously and unconsciously, in order to better fit into the social context following a loss and to express their own grief in a way in which they believe others will understand; for example, participants in a grief intervention by Omar (2013) often echoed others' verbal answers to show agreement. Further examples can be seen in mirroring others' responses and in grief reactions observed by others:

"*Err, it's strange, errrr, yeah, I think I was, a little bit more like, a little bit, a little bit, yeah, a little bit upset, because what happened was me Auntie was upset about it because she really liked him.*" Interview 8 (Hamlin, 2003)

"*Apparently she became very withdrawn, repetitive speech became more [in response to learning her key worker was leaving]. A very articulate lady, but when people spoke to her she would switch off, and start doing all the repetitive stuff.*" SI (Mattison, 1998)

Moreover, this echoing was often evident in its communicative value:

"*Most of the participants could remember the exact words that were used when they told the news of their relative's death. 'I've got some bad news for you, your grandma S has died'.*" Interview 9 (Hamlin, 2003)

Overall, the studies report that neurodivergent individuals often go to great lengths to better understand loss and their position in the social context(s) which may follow a loss. Prior understanding of grief and loss gained via stories and/or experience was often helpful in understanding a loss's significance and what is expected from the grieving process. Moreover, following a loss, narrative and storytelling often play a critical role in integrating and expressing the loss. These forms of expression were closely tied to memory and comfort in locating a loss in a more tangible sense, such as through pictures, special objects, and creative therapeutic projects. Lastly, expression of the loss and understanding was also reported in terms of perseveration and *echothanatologia* insofar as neurodivergent individuals observed repeating thoughts, words, and actions as a mode of developing an understanding of and communicating thoughts and feelings about loss.

Theme 4: The Double Taboo of Death and Disability

The Double Taboo of Death and Disability centres on specific cultural notions associated with the spaces in which each study was produced in which experiences of both death/significant loss and disability are bound up with societal stigma and discrimination. This relates to the overarching theme of *Recognise the Unrecognised,* as individuals report difficulty in even accessing recognition from others for their loss. As one participant discussed in relation to other neurodivergent individuals who may have different levels of understanding:

"*They do (grieve). But they don't understand because people don't explain them. Mom and Dad passed away, they wonder why. They want an answer. Nobody will ever answer the question. A doctor might say to you, your Mom passed away with a heart attack. How do you accept that. You have to be very … because a handicapped person, you don't know, cause you got to have patience to sit down and say … put it on the table.*" F (Dell'Aquila, 1996)

Which is further complicated by the type of loss and type of neurodivergence, such as in the context of the removal of children from mothers with ID:

> "*They didn't even let me see her [my baby]*." Jessica (Collings et al., 2018)

In this sense, both loss and neurodivergence are regarded as uncomfortable topics for many, and this influences how others interact with neurodivergent individuals in the context of grief:

> "*Some people try and help you. Some just, more or less, just leave you… when they don't bother speaking to you and things like that… and just tell you, 'Come on. Come on, you'll be alright'… [That makes me] just more a bit sad*." Jack (McRitchie, 2012)

This *double taboo* is particularly impactful for those who are met with societal biases about their own level of understanding; for example, some individuals with ID reported being treated as though they could not understand the significance of a loss, and autistic individuals observed others treating them differently in loss than their non-autistic peers:

> "*I wish they had [asked if I wanted to go to the funeral] … I haven't seen it yet. I would like to see it. Her name. On the stone*." Beth (McRitchie, 2012)

However, perhaps this *double taboo* is most clearly demonstrated in the lack of phenomenological studies on neurodivergence and grief, as the majority of studies were on ID, the only papers focused on autism were by autistic authors, and ADHD was only considered in one study and one piece of grey literature but was not the focus in either. No other form of neurodivergence was reported. This is emblematic of the *double taboo*, as these populations will have different lived experiences of grief and loss than the general population, such as navigating a funeral experience with Tourette's or being dyslexic and trying to access psychoeducation materials about grief, which are predominately written texts. Yet, these neurodivergent experiences remain unaccounted for in the academic literature.

Sub-theme 4a: "Typical" Grief

Participants tended to perceive their own responses to grief and loss to be unusual or not (neuro)typical:

> "*But looking at it now it didn't hit me straight away like it would with any normal person*." Interview 1 (Hamlin, 2003)

The uniqueness of these experiences was often a result of the social context in which they originated and the *double taboo*, such as funeral exclusion. As such, internal emotional experiences of grief and loss were often reported as being similar to that of neurotypicals (though alexithymia increased difficulty in understanding these experiences for some), instead it was the medical and social consequences and biases of neurodivergence which mediated differential demographic experiences of grief and loss:

> "*[T]hem tranquillisers, them big tablets, I had them to calm me down*." Interview 7 (Hamlin, 2003)
> "*Just like NTs, people with ASD like to share things like this, but our language will sometimes be sufficiently different that we will find comfort only within our own kind*." (Fisher, 2012)

However, the grey literature from autistic authors, although in agreement with the social consequences of neurodivergence producing different experiences of grief, stood in contrast to the academic literature, which was more focused on ID, by stating that "*autistic grief is not like neurotypical grief*"(Fisher, 2012):

> "*People on the spectrum can actually feel grief over many things, not just over losing someone important*." (Doty, 2016)

Despite these differences in internal perceptions of the grief, both the academic and grey literatures broadly understood the perception of others and neuronormativity as key factors in shaping experiences of grief and loss.

Sub-theme 4b: Perception and Overprotection

The neuronormative perceptions of others were observed as producing two processes of recognition which run in contradistinction from one another, which was often met with further difficulty when those supporting the neurodivergent individual in their grief were also grieving the same loss:

> "*(If you were crying what would your mum do?) She'd be upset too*." Interview 9 (Hamlin, 2003)

The first process centres on a lack of recognition, such as in the belief that neurodivergent individuals have an inability or limited capacity for grief:

> "*I don't really think about him when I'm there because she tells me not to dwell on it. But I have a right to dwell on it*." Alan (Swainland, 2003)

This process often left individuals feeling further isolated in their grief:

> "*I was on my own in the beginning but then I got to saying, I can't be bothered doing this, I can't be bothered doing that'… I think I was kind of lonely a bit because the house was empty*." Katie (McRitchie, 2012)

"*Older sister, younger sibling. Well, we don't see each other because they are busy making their livings.*" Participant 12 (Kim et al., 2018)

Moreover, it tended to minimise and disregard the impact of non-death loss(es), such as transitions and loss of autonomy:

"*The truth of the matter is that those on the spectrum can and do grieve over losing something as seemingly trivial as a book or a pair of shoes.*" (Doty, 2016)

The second process perceives loss in the context of neurodivergence with a greater sense of protection than the support offered to neurotypicals. Although this support may be received favourably when it appropriately meets the individual's needs, it often overextends into processes of infantilisation and shielding the individual from key pieces of information:

"*Having learning difficulties … is stopping me from getting what I want and it is being called a child and being treated like a child.*" Emma (Manners & Carruthers, 2006)

Despite both processes taking very different perspectives on neurodivergent experiences of grief, one area of convergence was observed in how they perceive the behavioural consequences of grief.

Sub-theme 4c: Misunderstood Behaviour

The majority of studies account for a sense of hidden grief in which communicative behaviour of distress in grief is often only recognised as "*challenging*" or "*difficult*" behaviour rather than communication and the result of the challenge/difficulty of grief itself:

"*They did not see that I needed and expected support. Some, but by no means all, of the community nurses viewed and interpreted my attitudes and behaviour towards them as being verbally 'aggressive' and reacted accordingly.*" (Barber, 2022)

However, despite the majority of papers recognising this, participants often reported that their behaviour in response to a loss, especially in the context of transitions, was often viewed as a difficulty or inconvenience rather than an expression of grief:

"*My key worker couldn't cope with me. It felt embarrassing when she said she couldn't cope with two of us.*" R4 (Mattison, 1998)

Moreover, in the lack of recognition afforded to participants for their grief, many sought to mask it, which may, in turn, feed into the lack of recognition afforded, which

produces a serial nature to failing to recognise and hiding grief:

"*Even though I'm considered higher-functioning, I still have difficulty with grief, too, and I oftentimes have tried to suppress what I've felt—however, that's never a good strategy.*" (Doty, 2016)

Some were completely overwhelmed by the news of the loss and had meltdowns and/or shutdowns:

"*I got a little bit upset because I was at school. So I pulled my personal alarm and I smashed some plates and…I got mental … Staff tried to put me down... I got up again. Slapped the staff as well… I just got a bit upset. But I can't help that… I HAD to go! Because it's MY grandad [begins to cry].*" Norman (McRitchie, 2012)
"*In my case, I did not have outward meltdowns in the traditional sense, but instead I had shutdowns whereby I lost actual abilities.*" (Fisher, 2012)

Some key behavioural impacts that participants observed in themselves were greater difficulty with everyday tasks following a loss and an accompanied sense of depression and/or burnout:

"*I developed challenges with executive functioning. I lost my focus, forgot things, and had trouble getting organized. I re-developed checking compulsions I thought I'd long since conquered.*" (Soraya, 2014)
"*Depression, however, hit me like a brick wall. Overwhelming sadness consumed me. I felt immobilized by my sadness. Immobilized and confused.*" (Pensive Aspie, 2014)

An important thing to note is that many of the participants observed a concerted effort to control their behavioural responses from the grief for the benefit of those around them, which often forced them to mask their neurodivergence and their thoughts, feelings, and behaviours in response to loss:

"*[Researcher] - No, you don't talk to him about when your mum died?*
[Participant] - (shakes head)
[Researcher] -No
[Participant] - No he cries (makes gesture of tears)"
Interview 10 (Hamlin, 2003)

Overall, the *Double Taboo of Death and Disability* centres on the sociocultural responses to neurodivergent experiences of grief rather than how those experiences may differ categorically as neurodivergent. In this sense, this theme of *the double taboo* highlights that many, but not all, of the unique difficulties of grief and neurodivergence stem from societal expectations and biases regarding what it means to grieve and what it means to be neurodivergent. Societal

biases of neurodivergence were often reported as either a producer of hidden grief, which was left unrecognised, or in an overextension of support in grief, which reduced information provided and the individuals autonomy, and saw a lack of ability in being able to cope in grief rather than in lack of ability in understanding it. Lastly, this dual process of *unrecognised grief vs. unrecognised ability* often informed how behaviour was (mis)understood and expressed in grief, as behavioural responses were either left misunderstood or individuals actively sought to modify their behaviour to be better understood.

Discussion

Summary

Overall, an overarching theme, titled *Recognise the Unrecognised,* tended to mediate the themes identified in the literature; for example, when *Hidden Grief* and the processes behind it were recognised, participants across the studies reported their experiences as being more positive and understanding, whereas when the *Hidden Grief* remained unrecognised feelings of loneliness and isolation and demands with poorer mental health outcomes, such as masking, were often observed by the participants. Under this overarching theme of Recognition, the analysis identified four themes with associated sub-themes: (1) *Hidden Grief*, (2) *Supported and Included*, (3) *Understanding My Loss*, and (4) *The Double Taboo of Death and Disability.*

Hidden Grief accounted for feelings of *disenfranchised grief*, *loss on loss*, and the often-unrecognised grief reactions emerging from *imposed transitions. Supported and Included* considered how individuals are involved or excluded before and after a loss, identifying that family and carers play a crucial role in supporting inclusion or excluding neurodivergent individuals from peri-loss events. In sub-theme 2c, "*I kept it to myself*", practical vs. emotional support was also considered, highlighting the value found in inclusion in family discussions on grief and the possible unintended negative emotional consequences stemming from emotional support being offered by staff who are not equipped to provide appropriate grief support to neurodivergent individuals. However, practical support to both be and feel included and tangible forms of expression were observed as positive emotional experiences. The theme of *Understanding My Loss* raised the importance of narrative and storytelling for understanding and expressing grief; however, the experience of a prior loss was also observed to be an essential factor in understanding loss, regardless of cognitive abilities. Lastly, the theme of *The Double Taboo of Death and Disability* considered how socio-cultural perspectives of loss and neurodivergence often influence neurodivergent individuals' grief

experiences through neuronormative bias and exclusion; this also accounts for how neurodivergent individuals' behaviours communicating their feelings about and expressions of grief are often misunderstood or not fully recognised as grief reactions.

Given the information derived from the thematic analysis of the literature, which highlights the importance of different themes within the papers, this review now orientates discussion in the form of a *meta-synthesis* of the literature to explore the review's three research questions before considering the implications for practice and research.

Phenomenology

The phenomenological question of this review centred on understanding the lived experience(s) of grief and loss in the context of neurodivergence. Although the majority of papers considered lived experience(s) in terms of individuals with ID, a minority of the papers, mainly from the grey literature, considered lived experience(s) from the perspective of autism and ADHD. Therefore, it is essential to note that this review, despite its intentionality to consider grief in the context of NDDs, can only be representative of ID, autism, and ADHD, and is significantly more limited in scope for the two latter conditions. However, although many of the studies sought to exclude participants due to dual neurodevelopmental diagnoses due to a belief that this may limit communication in an interview, it is important to note an estimated 88.5% of individuals with one NDD will have another co-occurring NDD and 23% will meet criteria for two or more co-occurring NDDs (Francés et al., 2022). In this sense, taking a transdiagnostic perspective of neurodivergence, which accounts for co-occurrence being the norm rather than the exception (APA, 2022; Francés et al., 2022), it is important to note that, although not explicitly stated, participants across the studies will likely have other forms of neurodivergence which inform their experiences. As such, it is apt to consider a neurodivergent phenomenology of grief from the papers included in this review whilst being mindful of the impact conditions which are not explicitly considered may have, such as neurodevelopmental motor disorders and specific learning disorders.

The themes raised in the analysis indicate a unique neurodivergent phenomenology of/to grief which is often mediated by neuronormative social biases and expectations as to who is capable of experiencing grief and how one should express their grief. In this sense, *Hidden Grief* was observed as playing a key role in neurodivergent experiences of grief; this was seen across almost all papers included in attempts to hide and mask neurodivergent responses to the grief to meet the expectations of neuronormative spaces, to mirror and echo responses to grief in order to be understood as a grieving individual, and to protect loved one's from the

perceived burden of their own grief and neurodivergence. Moreover, Hidden Grief reflects the lived experience(s) of *disenfranchised grief* (Doka, 2002), which participants acutely observed. Disenfranchised grief was framed in terms of recognition of grief, as neurodivergent individuals often observed recognising their own grief and their positionality within broader social contexts of loss (e.g. Dell'Aquila, 1996; McRitchie, 2012; Thorp et al., 2018). Moreover, autistic participants tended to actively seek to learn about these broader impacts of their grief and loss (Eccentrics United, 2011; Fisher, 2012; Graham, 2013; Pensive Aspie, 2014; Soraya, 2014); however, despite recognising their own grief, neurodivergent individuals often reported that their experiences of grief were not recognised by those around them. This lack of recognition was particularly the case in terms of non-death loss(es) and transitions (Mattison, 1998), where grief reactions were often considered as an inconvenience, challenging behaviour, and/or misunderstood or simply not understood as genuine expressions of grief and loss (Graham, 2013; Mattison, 1998; McRitchie, 2012; McRitchie et al., 2014).

Lastly, an essential feature of the lived experience(s) of Hidden Grief came in secondary loss(es). These were tangible (e.g. loss of home, family and social networks following the death of a kin keeper, etc.) and intangible (e.g. an unwanted loss of autonomy, a loss of special feelings and experiences, a loss of what might have been, etc.).

Moreover, the lived experience(s) of neurodivergent grief also accounted for several unique non-death losses which were often disregarded and not given appropriate support, if any, such as the loss of a child to child protective service (Baum & Burns, 2007; Collings et al., 2018, 2020; Gould & Dodd, 2014), the loss of staff/support workers and the difficulty adjusting to new staff whilst still grieving the former staff member leaving (Mattison, 1998), the loss of friends and relationships with staff when ageing out of services (Kim et al., 2018, 2021) and/or transitioning into a new service, such as in the transition from community services to residential care (Bowey & McGlaughlin, 2005; Gorfin & McGlaughlin, 2004).

Another key area observed by participants across the studies was on participation in peri-bereavement/loss events, such as visiting relatives in palliative care (Tuffey-Wijne et al., 2012), attending funerals (Forrester-Jones, 2013; Graham, 2013; McRitchie, 2012; Soraya, 2014; Thorp et al., 2018), and being involved in handovers in support/care (Bowey & McGlaughlin, 2005; Gorfin & McGlaughlin, 2004; Mattison, 1998). Neurodivergent individuals across the studies broadly reported positive experiences when they were actively involved in peri-loss events, with some individuals feeling proud to have done so (Thorp et al., 2018); moreover, individuals who chose not to participate remained in agreement with their choice and difficulty only emerged

when the choice to engage in these events was removed or not offered (McRitchie, 2012; McRitchie et al., 2014; Thorp et al., 2018; Tuffey-Wijne et al., 2012), with participants observing feelings of isolation, frustration, and sadness in not being able to engage with these events. Participants who were not given a choice to engage often reported knowing less about the loss, as less information was offered or explicitly hidden from the individual.

Overall, the phenomenology of grief for neurodivergent individuals is reported as being broadly similar to neurotypical experiences of grief; however, social processes which contribute to the double taboo of death and disability often modify and undermine the grief experiences of neurodivergent individuals, often placing them in a precarious position of having grief which is either wholly disenfranchised or having recognised grief but an unrecognised ability to be able to integrate and live with the loss. Nevertheless, the unique grief experiences in neurodivergence are not wholly social and differential demographic experiences are also the product of neurotype in terms of perception of the social processes of grief (Fisher, 2012; Graham, 2013) and language used to discuss grief, such as literal vs. figurative with autistic individuals preferring the former for expressing grief (Fisher, 2012; Graham, 2013; Pensive Aspie, 2014) and those with ID appearing to show a preference for the latter (Thorp et al., 2018; Tuffey-Wijne et al., 2012), whilst both seem to prefer the former for being informed about a loss. Overall, the lived neurodivergent experiences of grief and loss are often similar to that of neurotypical experiences. However, sociocultural biases and aspects of individual differences across neurotypes will modify the grief experience.

Epistemology

This review's epistemological question is concerned with how neurodivergent individuals (re)construct and relay their own experiences of grief and loss. From the analysis, the theme of *Understanding My Loss* lends to understanding neurodivergent epistemologies of grief, which centre on *Narrative and Storytelling*, *Experience and Logic*, *Comfort in Locating Loss* and *the Echophenomena of Grief*. In terms of narrative, all autistic perspectives accounted for in this review took this approach; for example, in the academic literature, an autoethnography of autistic grief was identified (Barber, 2022), and the majority of autistic perspectives accounted for were from grey literature which broadly took the approach of narrative essay and blog posts (Doty, 2016; Eccentrics United, 2011; Fisher, 2012; Graham, 2013; Pensive Aspie, 2014). Community-produced epistemologies of autistic grief tended to highlight frustration in the lack of academic research on autistic grief (Fisher, 2012; Soraya, 2014) and used readily accessible platforms and comfort found in the autistic community to produce their

own knowledge on and about autistic grief. The community-driven narratives, in contrast to the lack of research on autistic experiences of grief, ultimately situate themselves as a call for research to be done in this area, as it is a clear want within the autistic community (Fisher, 2012). Moreover, valuing community-produced knowledge(s) as valid contributions to academic discourse, as this review has done, is also a call for more research developing knowledge produced in these spaces and valuing the contributions made within them (Kourti, 2021).

Alongside narrative, storytelling also plays a vital role in both understanding and communicating grief and loss. For example, creative approaches involving poetry were taken by an individual with ADHD to express their experiences of grief which were observed as feeling more fragmented than those around them (Hicks, 2022). Moreover, individuals with ID often derived benefits in understanding both the concept and expectations of loss from the experience of and/or stories about loss prior to a loss occurring (Graham, 2013; Haider & Zaman, 2022; Omar, 2013; Tuffrey-Wijne et al., 2012). Moreover, following a loss, storytelling and other creative methods were considered positive experiences for expressing and integrating a loss (Forrester-Jones, 2013; Omar, 2013). Lastly, narratives about conceptualisations of an afterlife in a religious context often aided individuals in both understanding and living with the loss (Haider & Zaman, 2022; Thorp et al., 2018). Some expressed hope for reunification with their loved ones following their own death (Hamlin, 2003; Swainland, 2003), and this hope was typically viewed as positive and providing comfort (Thorp et al., 2018). However, given the need for information, and the processes of mirroring and *echothanatologia* observed (Eccentrics United, 2011; Graham, 2013; Pensive Aspie, 2014; Soraya, 2014), the researcher would urge caution in the language used to discuss afterlife beliefs. Due to the mental health components which may lead to depression, suicidality, and (self-)injurious behaviours (Fisher, 2012; Graham, 2013; Mattison, 1998; McRitchie, 2012), alongside an understanding of increased rates of suicidality and impulsivity in neurodivergent populations evidenced in the clinical literature (APA, 2022; WHO, 2019), there is tentative evidence from the synthesis to suggest that a hope for reunification coupled with *echothanatologia* may extend into action/praxis to *echothanatopraxia* (i.e. echoing the action which caused death) in order to hasten reunification.

Logic and information gathering also played an essential role in understanding and expressing reactions to a loss, especially in the context of autism (Pensive Aspie, 2014). However, the need for information and clarity was observed across all neurotypes. Information gathering was often reported in terms of perseveration (Fisher, 2012; Graham, 2013) and was frequently intertwined with unique echophenomena in which individuals repeated and/or sought to (re)

experience the communication of the loss and/or the loss itself (Eccentrics United, 2011; Graham, 2013; Pensive Aspie, 2014).

Overall, the epistemologies of neurodivergent grief account for community-driven narratives formed out of frustration due to lack of research (Fisher, 2012), creative expressions of grief and loss (Barber, 2022; Hicks, 2022), and research produced which tends to focus primarily on individuals with ID. Expressions and understandings of grief in the context of neurodivergence often take the form of and are benefited by, narrative and storytelling, and modes of further expressing and understanding to be, in turn, more understood, centre on taking logical perspectives to grief, information gathering and perseveration, and echoing, mirroring, and masking.

Ontology

The ontological question was concerned with the realised mental health impacts of grief and loss for neurodivergent populations. Although all the studies were retrospective, and with the exception of participatory research and group work which lasted for several months (Kim et al., 2021; McDaniel, 1989; Omar, 2013; Tajuria et al., 2017), none of the studies were longitudinal to the extent where the long-term mental health impacts of grief are readily apparent; however, the retrospective focus of the studies allows for critical discussions from lived experience(s) concerning discernible mental health impacts. Moreover, some of the behavioural impacts reported can be assessed in terms of current understandings of the mental health impacts of those behaviours; for example, masking was reported in several papers, and the negative mental health consequences of masking are well-established in the literature (Chapman et al., 2022; Mandy, 2019).

Autistic accounts of grief and loss expressed highlighted an increase in their overall self-perception of their *autistic traits* (Fisher, 2012; Soraya, 2014) and experiences which clearly depicted *autistic burnout* were documented (Fisher, 2012; Graham, 2013; Soraya, 2014), which is when demands exceed current ability and can lead to reduced energy levels, increased sensory sensitivities and meltdowns/shutdowns, and even suicidality (Raymaker et al., 2020).

The majority of participants across all the studies reported disenfranchised grief to varying degrees, and the mental health impacts of this were often increased feelings of loneliness, sadness, anger, frustration, and a lack of a need for support being recognised before significant levels of support were needed. The mental health impacts across the studies typically indicated depressive symptoms and typical grief reactions with associated feelings of sadness, anger, confusion, etc.; however, one key mental health outcome, which was observed by participants across studies as being mediated by levels of inclusion, was feelings of isolation

and loneliness (Forrester-Jones, 2013; Mattison, 1998; McRitchie, 2012; McRitchie et al., 2014; Thorp et al., 2018; Tuffrey-Wijne et al., 2012). Moreover, these feelings were also produced when others, such as support workers and carers, failed to recognise grief reactions which increased feelings of frustration, isolation in grief, and disenfranchisement (Mattison, 1998; McRitchie, 2012).

Although emotional support and an ability to discuss one's feelings of grief are considered a protective factor, the ability of neurodivergent individuals to do so appropriately with support workers/carers was often lacking and typically made the individual feel worse (Hamlin, 2003; Mattison, 1998). This is because many frontline support staff across the studies have little, if any, training in emotionally supporting neurodivergent individuals experiencing grief and/or often fail to recognise that neurodivergent individuals are actually experiencing grief, especially in the context of transitions of care (Kim et al., 2021; McRitchie, 2012; McRitchie et al., 2014). However, when specialist services trained in both neurodivergence and grief offered emotional support, neurodivergent individuals observed it as positively impacting their well-being following a loss (Fisher, 2012; Graham, 2013; Pensive Aspie, 2014; Tuffrey-Wijne et al., 2012).

Despite the generally ineffective impact of emotional support from frontline support workers, carers, and residential staff, the practical support they offered was observed as protective of mental well-being by neurodivergent individuals (Collings et al., 2020; Gilrane-McGarry & Taggart, 2007). Some key areas of practical support highlighted were centred on supporting and enabling inclusion, attendance, and involvement with peri-loss events, such as funerals and handovers of care (Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; Thorp et al., 2018). However, there were some practical and creative therapeutic exercises which were effective in promoting feelings of well-being and inclusion following a loss and also facilitated emotional support that participants were generally more receptive to, such as making a family tree, looking through photographs, discussing special objects, making memory books, and other creative approaches to expressing both grief and remembrance which helped locate the loss in a more tangible way (Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; McDaniel, 1989; McRitchie, 2012; Omar, 2013; Thorp et al., 2018), and enabling and supporting in peer-to-peer discussions where individuals may find a greater sense of relatability (Collings et al., 2020; Graham, 2013; McDaniel, 1989; Soraya, 2014; Tajuria et al., 2017).

Overall, the mental health impacts of grief for neurodivergent individuals are broadly not considered from the perspective of lived experience; however, an increase in burnout, feelings of isolation, frustration, and low mood, as well as meltdowns and shutdowns, are reported across the studies. Nevertheless, despite the lack of research on these lived mental health outcomes, there is agreement on several protective and risk factors. Risk factors for poorer self-reported mental health outcomes following a loss are associated with feeling excluded, grief going unrecognised and unsupported, and not being provided with adequate and appropriate information. Protective factors centre on inclusion, appropriate information being provided, grief being recognised and expression being allowed in the individual's own time, emotional support from family in the form of discussing the loss and emotional support provided by individuals trained in both neurodivergence and grief, and practical support to enable and support inclusion in peri-loss events and expressions of grief from carers, support workers, and family.

Limitations and Strengths

Although this review took a broad approach to operationalising grief, the focus on grief as loss of persons via death and non-death loss is limiting insofar as it does not acknowledge grief reactions to ambiguous loss in relation to the self and self-identity, as has been noted in studies on late-diagnoses of autism and ADHD, where participants grieved for their younger self, and the misunderstanding they dealt with in their childhood as a result of their neurodivergence not being recognised (e.g. Young et al., 2008); grief in this context acknowledges a disruption to one's assumptive world with the revelation(s) and process(es) of self-understanding which accompany diagnosis and recognition. Not including an operationalisation of grief and loss as being inclusive of loss of the self, both intangible and ambiguous losses, as seen in identity and illness, and tangible losses, as seen in preparation and an anticipatory grief in one's own death, identify a key limitation with this review, that it is interpersonally-orientated, and does not account for the intrapersonal experiences of grief as it relates to self-identity and one's own death. Moreover, the scope of this review focusing only on studies written in English was done as such due to both the difficulty navigating translation and possibilities for misrepresentation in the translation of qualitative data and different sets of language abilities the raters had (i.e. lack of shared second language between reviewers). The limitations to language meant that potentially valuable studies, such as a review on the bereavement reactions of individuals with autism and intellectual disabilities (Bóveda Hermosilla & Flores Robaina, 2021) in Spanish, were not considered.

Implications for Future Research

Although this review succeeded in being inclusive of voices typically excluded from research, such as in the grey literature, which identified a unique autistic experience of

grief, the majority of the studies were focused exclusively on ID. As such, despite the high co-occurrence among NDDs, which frames a neurodivergent and trans-neurodevelopmental perspective as apt (APA, 2022; Francés et al., 2022), the scope of this review in terms of neurodivergent grief is somewhat limited as it only accounts for ID, autism, and ADHD, as explicitly stated in the studies, with other forms of neurodivergence and grief appearing wholly unresearched. As such, this review calls for further research on neurodivergence and grief, specifically on NDDs other than ID, which is overrepresented in the research compared to other forms of neurodivergence.

Furthermore, it is essential to note that the papers on autism in this review are broadly community-driven. Researchers should note this want for further information and discussion on autism and grief for future research. Moreover, despite the inclusion of grey literature, given the format of this review, videos and social media posts were excluded, despite emerging in links attached to grey literature, and one community-produced video was identified when screening references; as such, like with the photovoice studies included in this review (Kim et al., 2021; Tajuria et al., 2017), researchers ought to note that neurodivergent epistemologies often take different forms than and formats from academic spaces and written work which can be inaccessible for many; consequently, future research should consider visual methods, community-produced work, and digital neurodivergent communities in the production of knowledge of and about neurodivergent grief and neurodivergence more broadly.

Declarations

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