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Breaking the silence: A systematic review of methodology and findings of studies on bereavement among adults with intellectual and developmental disabilities

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ABSTRACT

This study systematically reviewed the methodology and findings of 28 peer-reviewed studies on the experiences of loss, grief, and bereavement among adults with intellectual & developmental disabilities (IDD). Of these studies, five included quantitative data, 11 were qualitative studies, and 12 utilized mixed methods. Furthermore, eight of the included studies were interventions, focused on understanding grief among adults with IDD, including identifying risk- and protective-factors in the face of bereavement. Overall, results showed significant gaps in knowledge about the bereavement process among adults with IDD, and the need for more inclusive studies with increased methodological rigor. Significant themes from the studies included the relevance of understanding the concept of death, communicating about loss/death, symptoms of bereavement, coping strategies, sources of support for adults with IDD, and improving bereavement training for caregivers and staff to adults with IDD. Risk factors associated with diminished health outcomes in the face of bereavement included greater cognitive impairment and exclusion from: (a) funerals and loss rituals, (b) conversations regarding loss and death, and (c) advanced planning and end of life decisions. Effective bereavement coping strategies identified included: (a) spending time with and talking to family or friends, (b) engaging in relaxing activities, such as breathing exercises, listening to music, and/or spiritual engagement, and (c) engaging in creative activities, such as painting, drawing, or storytelling. This review highlights areas for future research to fill existing gaps in knowledge, which is needed to support the health and well-being of adults with IDD when they experience loss.

Introduction

Losing a loved one is one of the most challenging and painful life experiences, particularly in the context of disenfranchized grief. Disenfranchized grief occurs when grief is not openly acknowledged, not well understood, or when it presents differently from the majority population (Doka, 2020). Given assumptions that people with intellectual and developmental disabilities (IDD) may be limited in their ability to grasp the complexity of death and/or to cope effectively with bereavement, people with IDD may be at increased risk of disenfranchized grief (Doka, 2020). People with IDD have differences in cognitive functioning and adaptive skills, which influence how they learn, communicate, and navigate daily life. IDD is an umbrella term that includes conditions, such as autism spectrum disorder, Down syndrome, and cerebral palsy. The impact of these disabilities varies widely–some individuals may have mild differences that require minimal support, while others may need more intensive, lifelong assistance with activities like problem-solving, communication, and self-care.

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The experiences of people with IDD are diverse and shaped by both personal and societal factors. Some individuals live independently, while others rely on support from caregivers, family members, or community services. In addition to differences in ability, they often encounter barriers, such as discrimination, social exclusion, and limited access to education, employment, and healthcare (Verdonschot et al., 2009). Despite these challenges, people with IDD can lead meaningful lives, pursue personal goals, and contribute to their communities when provided with appropriate resources and support systems.

Disenfranchized grief has a detrimental impact on the health of adults with IDD. Symptoms related to the bereavement process for adults with IDD may be confused or poorly understood, increasing the risk of marginalization (Clute, 2010). Without appropriate support, resources, or intervention, adults with IDD may experience disenfranchized and prolonged grief, and its associated harmful effects (Doka, 2020). Disenfranchized grief is also associated with increased feelings of loneliness, isolation, and stress among people with IDD (Read & Elliott, 2007), as well as difficulties in everyday functioning (Clute, 2010). On a physiological level, disenfranchized grief has been linked to systemic inflammation, immune dysregulation, and biological aging, which increases risk of morbidity and mortality (Seiler et al., 2020). Adults with IDD may also be at risk for prolonged grief, also known as complicated grief, a disorder in which individuals are unable to adapt to a loss, characterized by preoccupation with loss and/or yearning for the deceased that persists beyond 6 months (ICD-11) or 12 months (DSM-5-TR) (Treml et al., 2024). Symptoms of prolonged grief include feelings of intense emotional pain, such as numbness, loneliness, guilt, anger, and sadness, maladaptive thought patterns related to the loss (e.g., rumination, regret, catastrophizing), and impaired social, cognitive, and/or physical functioning (Mughal et al., 2023; Shear, 2012).

Although research of grief among adults with IDD has grown over the past decade, additional research is needed. Previous studies have highlighted the importance of acknowledging grief and rituals, fostering supportive environments, and providing formal bereavement counseling, particularly for adults experiencing more severe grief or greater difficulties (Clute, 2010). Additionally, previous studies have identified a critical need for foundational knowledge about death, strategies to overcome stigma surrounding bereavement, and individualized assessments paired with multi-model interventions (Clute, 2010). Moreover, some key areas that warrant further exploration include a better understanding of the grief experiences of diverse adults with IDD, the challenges faced by their family and non-family caregivers, and the most effective strategies for supporting both individuals with IDD and their caregivers in the face of loss. Research is also needed on the impact of cultural values, family dynamics, or aspects of the built environment on the well-being of bereaved adults with IDD. This knowledge can help inform resources, prevention efforts, effective interventions, and policies. Given the diversity of individuals with IDD in terms of abilities, preferences, sociodemographic characteristics, and life experiences, it is essential to understand how sociocultural factors influence the bereavement process considering individual, structural, and systemic level factors.

To understand the unique needs of bereaved adults with IDD, we conducted a systematic review of the methodology and findings of studies within the past 24 years on bereavement among adults with IDD. Specific aims of this review are: (a) describe population and setting characteristics, as well as methodology used in recent studies of bereavement; (b) summarize findings, themes, and constructs assessed in the included studies; and (c) provide recommendations for future studies. Addressing these gaps in knowledge is a crucial step toward informing the response to bereavement-related needs for people with IDD and toward ensuring supportive and more equitable access to needed resources, services, and best practices for bereaved adults with IDD.

Methods

The methodology used is based on guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Liberati et al., 2009). This review includes scientific studies reporting quantitative and/or qualitative data. Inclusion criteria were that the study: (a) was published in English; (b) was published since 2000; (c) included the perspective of adults with IDD and/or the perspective of caregivers and/or staff to adults with IDD with a focus on loss, grief, and/or bereavement; and (d) included adults ages 18 years and older. Excluded studies were those published before 2000, studies that focused exclusively on personal caregiver or staff work-related experiences, single case studies, and studies that did not contain information on grief, death, or bereavement among adults with IDD. Also excluded were commentaries, book reviews, and measurement development articles.

The preliminary selection of studies was made with a literature search using multiple databases (i.e., PubMed, PsycInfo, ERIC, Medline). The last search was conducted in August 2024. Terms selected for the search were bereave* OR grief* OR griev* OR mourn* OR widow* OR loss OR death OR dying AND developmental* disab* OR developmental* delay* OR intellectual* disab* OR intellectual* impair* OR intellectual* delay* OR intellectual developmental disorder OR ASD OR autis* OR learning disab* OR retard* OR mental retard* OR mental disab* OR mental impair* OR mental* delay* OR asperger* OR delay* development OR cognitive disab*. These terms were specifically chosen to account for the comorbidities between learning disabilities and intellectual disabilities, and to ensure the search was inclusive of a global perspective. This is particularly relevant because, in countries like the United Kingdom, "learning disabilities" is often used synonymously with "intellectual disability." A total of 1487 articles were identified, with 1299 articles considered for inclusion after limiting the search to peer-reviewed studies. Following the removal of duplicates, 938 studies were screened for inclusion. Titles, abstracts, and in some cases, the complete text were reviewed for eligibility. The reference lists of selected articles were also reviewed for inclusion of relevant articles. Overall, 28 articles met the eligibility criteria and are included in this review (Figure 1).

A standardized data abstraction form was created for coding. Information on study design and methodology, the purpose of study, sample characteristics,

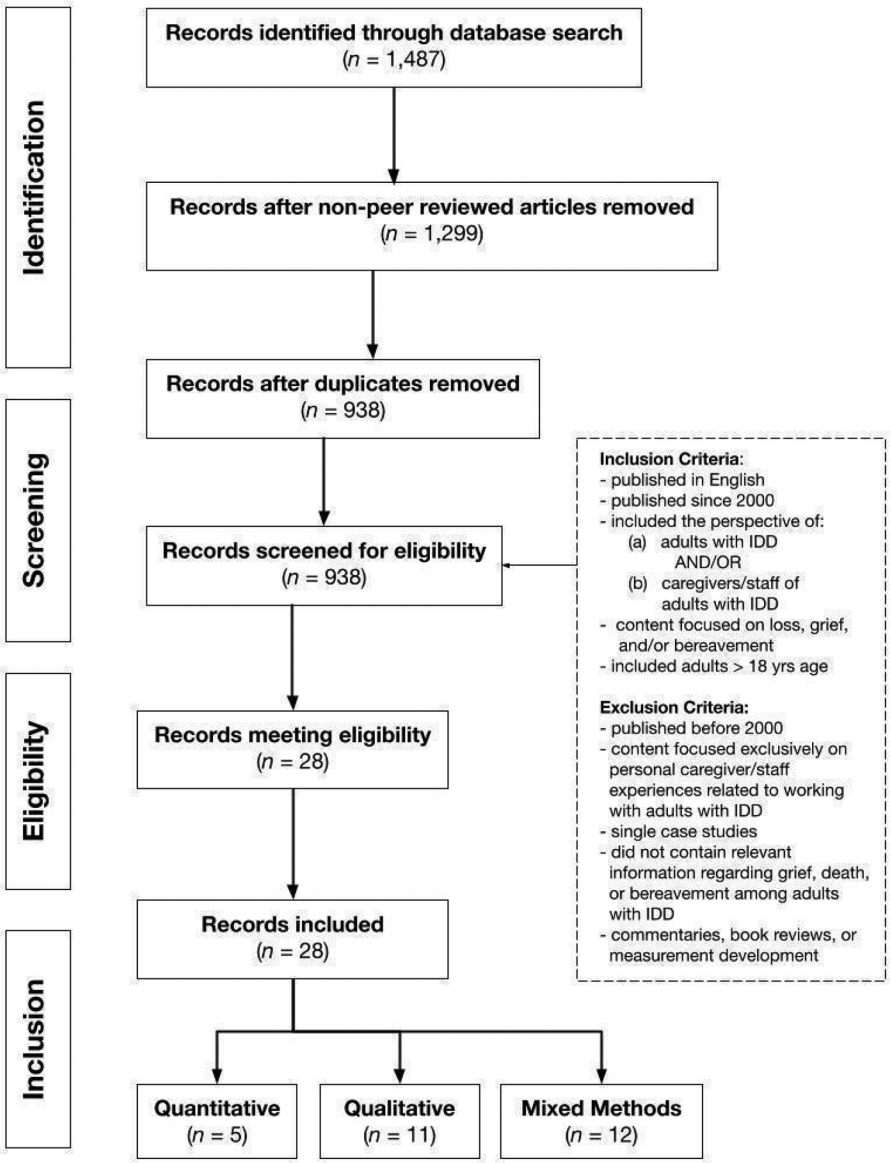

Figure 1. Eligibility of studies.

themes/constructs assessed, measures used, summary of findings/comments, and limitations were abstracted from eligible studies. Each eligible study was coded independently by two coders. Inter-rater reliability between the coder pairs ranged between 72.2 and 98.6%. Inconsistencies in coding were resolved through discussion among the coder pairs and a third reviewer. Quantitative data were entered and analyzed using R version 4.3.2 (2023-10-31; R Core Team, 2021) and R Studio Version 2023.12.1 + 402 (RStudio Team, 2019).

Results

Methodology and study design

Among the 28 studies included, five used quantitative data, 11 used qualitative data, and 12 utilized mixed methods. A summary of study design and methodology in the included studies is provided in Table 1. Overall, eight were intervention studies and 20 were non-intervention studies focused on addressing grief among adults with IDD, including identifying risk and protective factors for their well-being. Of the 20 non-intervention studies, most were cross-sectional ($n = 18$). Two non-intervention studies utilized a matched group retrospective design (Dodd et al., 2008, 2021). Study participants were recruited in varied ways, including through collaboration with community organizations, from government records, or at state-operated centers, including living care and day programs. No studies utilized random sampling methods and only six studies reported a response rate. Data were primarily collected through face-to-face surveys and via one-on-one interviews ($n = 19$), focus groups ($n = 7$), or both ($n = 2$). One study required participants to provide mailed-in written responses. Of the 28 studies, 71% focused on post-loss bereavement ($n = 20$). Data collection occurred in the United States, United Kingdom, Spain, Ireland, Australia, Canada, and Scotland. Only one study reported the year of data collection. Regarding methodology used to analyze results, studies reporting on quantitative data used descriptive and inferential statistics, whereas studies reporting on qualitative data using primarily concept and thematic analyses.

Participant characteristics

A summary of participants' characteristics in the included studies is provided in Table 2. Of the 28 studies included, 69% provided the perspective of adults with IDD ($n = 19$), 25% provided caregivers/staff perspectives ($n = 7$), and 7% provided both perspectives ($n = 2$). Of the nine total studies that provided caregiver perspectives, 11% ($n = 1$) centered on family caregivers, while 89% ($n = 8$) involved non-family caregivers/staff. Sample sizes ranged from 3 to 380 participants ($M = 40.9$; $SD = 69.1$). Only 14% of studies reported on participants' race or ethnicity ($n = 4$). Of the nine studies that provided caregiver/staff perspectives, only one study reported on race/ethnicity. Also, 24 studies reported on sex, among which 10 studies had a greater percentage of female participants, eight had a greater percentage of males, and six were split equally by sex. Participants varied in age across studies, although reporting on age was limited. For adults with IDD, participants' ages ranged from 19 to 82 years, whereas caregivers/staff ages ranged from 19 to 75 years.

Overall, only 18% of studies defined IDD ($n = 5$), and only three of these five studies provided diagnostic criteria for IDD. Terms used to describe IDD included intellectual disability, learning disability, "mental retardation," and IQ ranges. Few studies specified clinical characteristics of IDD, including mild, moderate, and severe/profound levels of IDD. For studies reporting on IQ ranges, the scores fell in the mild to moderate intelligence range. In some studies ($n = 6$), participants reported co-occurring conditions, which can include genetic syndromes, medical or psychiatric disorders, with Down Syndrome being the most common co-occurring condition reported ($n = 3$).

Regarding experiences of bereavement about half of the included studies reported the time since loss ($n = 16$), which ranged from within 1 year to 10 years post-loss. Across studies, types of bereavement included loss of a family member (i.e., parent, sibling, grandparent), friends, roommates, partners, caregivers, and pets. Some studies also addressed non-death related losses in addition to loss of a loved one, including grief related to staff changes, divorce, burglary, home foreclosure, and loss of health.

Intervention studies: methodology

A summary of methodology specifically used in intervention studies is provided in Table 3. Of the eight intervention studies, two used quantitative methodology, two used qualitative methodology, and four used mixed methods to assess the outcomes of the intervention. Only two studies randomized participants (Dowling et al., 2006; Fernández-Ávalos et al., 2023) and only one study included a non-bereaved control group (Fernández-Ávalos et al., 2023). Attrition rate was only reported by Dowling et al. (2006), and their attrition rate for an integrated bereavement

Table 1. Summary of study design and methodology used in recent studies of bereavement among adults with IDD.

Study	Prospective provided	Bereavement status	Type of data	Study design	Mode of data collection	Year of data collection	Location for data collection
Alcedo Rodríguez et al. (2018)	Adult with IDD	Post-loss	Quantitative	Cross-sectional	Face-to-face; one-on-one; survey	NR	Spain
Borsay et al. (2013)	Adult with IDD	Post-loss	Mixed methods	Intervention	Face-to-face; focus group; survey + interview	NR	United Kingdom
Bowey and McGlaughlin (2005)	Adult with IDD	Pre-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; survey + interview	NR	United Kingdom
Dodd et al. (2008)	Caregivers/staff	Post-loss	Quantitative	Retrospective, matched group	Face-to-face; one-on-one; survey	NR	Ireland
Dodd et al. (2021)	Adult with IDD	Post-loss	Quantitative	Retrospective, matched group	Face-to-face; one-on-one; survey	NR	Ireland
Dowling et al. (2006)	Adult with IDD	Post-loss	Mixed methods	Intervention, RT	Face-to-face; one-on-one; survey + interview	NR	United Kingdom
Fernández-Ávalos et al. (2023)	Adult with IDD	Post-loss	Mixed methods	Intervention, RCT	Face-to-face; one-on-one; interview	NR	Spain
Forrester-Jones (2013)	Adult with IDD	Pre-loss	Qualitative	Cross-sectional	Face-to-face; focus group; survey + interview	NR	United Kingdom
Gilrane-McGarry and Taggart (2007)	Adult with IDD	Post-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one; interview	NR	Ireland
Gray and Abendroth (2016)	Caregivers/staff	Post-loss	Qualitative	Cross-sectional	Face-to-face; focus group; interview	NR	United States, NR
Hoover et al. (2005)	Caregivers/staff	Post-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; survey	NR	United States (ND, MN)
Hoyle and McKinney (2015)	Adult with IDD	Post-loss	Mixed methods	Intervention	Face-to-face; focus group; survey + interview	2014–2015	United States (NC)
Irwin et al. (2017)	Adult with IDD, caregivers/staff	Post-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one; survey + interview	NR	Ireland
MacHale and Carey (2002)	Adult with IDD	Post-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; survey + interview	NR	Ireland
MacHale et al. (2009)	Adult with IDD, caregivers/staff	Post-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; interview	NR	Ireland
Mappin and Hanlon (2005)	Adult with IDD	Pre-loss	Quantitative	Intervention	Face-to-face; one-on-one; survey + interview	NR	United Kingdom
McEvoy and Smith (2005)	Caregivers/staff	Post-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; survey	NR	Ireland
McEvoy et al. (2002)	Adult with IDD	Pre-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; interview	NR	United Kingdom
McEvoy et al. (2012)	Adult with IDD	Pre-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; interview	NR	Ireland
McEvoy et al. (2017)	Adult with IDD	Pre-loss	Mixed methods	Cross-sectional	Face-to-face; one-on-one; interview	NR	Ireland
McRitchie et al. (2014)	Adult with IDD	Post-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one; interview	NR	Scotland
Morgan and McEvoy (2014)	Caregivers/staff	Post-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one; interview	NR	Ireland
Read and Papakosta-Harvey (2004)	Adult with IDD	Post-loss	Qualitative	Intervention	Face-to-face; focus group; interview	NR	United Kingdom
Read et al. (2000)	Adult with IDD	Post-loss	Qualitative	Intervention	Face-to-face; focus group; interview	NR	United Kingdom
Stoddart et al. (2002)	Adult with IDD	Post-loss	Quantitative	Intervention	Face-to-face; one-on-one; interview	NR	Canada
Thorp et al. (2018)	Adult with IDD	Post-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one; interview	NR	United Kingdom
Wiese et al. (2013)	Caregivers/staff	Pre-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one + focus group; interview	NR	Australia
Wiese et al. (2014)	Caregivers/staff	Pre-loss	Qualitative	Cross-sectional	Face-to-face; one-on-one + focus group; interview	NR	Australia

NA: not applicable; NR: not reported; RT: randomized trial; RCT: randomized control trial.

Table 2. Summary of participant characteristics in studies of bereavement among adults with IDD.

Study	Sample size (*n*)	Participant characteristics			Definition, diagnostic criteria, and specifiers of IDD	Time since loss	Person lost
		Age	Gender	Race/ethnicity			
Alcedo Rodríguez et al. (2018)	380 adults with IDD 149 caregivers/staff	Adults with IDD 21–77 years (*M* = 48; *SD* = 11)	Adults with IDD: 49% female; 51% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; mild to profound Down Syndrome (18.2%)	Within 1 year	Parent, sibling, grandparent
Borsay et al. (2013)	4 adults with IDD	Adults with IDD 26–48 years (*M*/*SD* = NR)	Adults with IDD: 75% female; 25% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; mild to moderate	Within 1 year	Family member, friend
Bowey and McGlaughlin (2005)	41 adults with IDD 41 caregivers/staff	Adults with IDD 20–82 years (*M* = 44; *SD* = NR) Caregivers/staff: range NR (*M*/*SD* = NR)	Adults with IDD: 49% female; 51% male Caregivers/staff: NR	Adults with IDD: 100% White Caregivers/Staff: NR	Definition NR; Dx NS; Specifiers: Learning disability; mild to severe	NA; COD	Caregivers
Dodd et al. (2021)	46 adults with IDD	Adults with IDD 23–67 years (*M* = 44; *SD* = 10)	Adults with IDD: 48% female; 52% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; mild, moderate, and severe/profound	Within 2 years	Parent
Dowling et al. (2006)	56 adults with IDD	Adults with IDD 18+ yrs (*M*/*SD* = NR)	Adults with IDD: 50% female; 50% male	NR	Definition NR; Dx NS; Specifiers: Learning disability; mild to severe	Within 30 years	Parent, sibling
Fernández-Ávalos et al. (2023)	38 adults with IDD	Adults with IDD (all) range NR (*M*/*SD* = NR) Intervention group: range NR (*M* = 43 years; *SD* = 11) Control group: range NR (*M* = 45 years; *SD* = 11)	Adults with IDD: 42% female; 58% male	NR	Definition: Intellectual disability based on DSM-5; Specifiers: Intellectual disability; mild to moderate	Intervention group: *M* = 16 months; *SD* = 15.0 Control group: *M* = 25 months; *SD* = 15.4	Parent, grandparent, sibling
Forrester-Jones (2013)	15 adults with IDD 10 adults without IDD (comparison)	Adults with IDD: 38–50 years (*M* = 45; *SD* = NR) Adults without IDD (comparison): 80–93 years (*M* = 86, *SD* = NR)	Adults with IDD: 40% female; 60% male Adults without IDD (comparison): 70% female; 30% male	Adults with IDD: 93% White; 7% Asian Adults without IDD (comparison): NR	Definition NR; Dx NS; Specifiers: Intellectual disability; mild to moderate	NA; COD	NS
Gray and Abendroth (2016)	60 caregivers/staff	Caregivers/staff 21–70 yrs (*M* = 42; *SD* = NR)	Caregivers/staff 83% female; 17% male	Caregivers/staff: 35% White; 47% Black; 16% Hispanic	Definition NR; Dx NS; Specifiers: Intellectual disability; NS	NR	NS
Hoover et al. (2005)	48 adults with IDD 57 caregivers/staff	Adults with IDD 30–65 years (*M* = 45; *SD* = 11) Caregivers/staff (*M* = 41; *SD* = 9)	Adults with IDD 52% female; 48% male Caregivers/staff: 75% female; 25% male	NR	Definition NR; Dx based on IQ scores <70 and clinical judgment of communication ability; Dual diagnosis: additional mental illness (*n* = 8), additional sensory impairments (*n* = 3), additional medical issues (*n* = 4), additional orthopedic disabilities (*n* = 5); Specifiers: Developmental disability; mild (*n* = 15), moderate (*n* = 13), severe/profound (*n* = 20)	Within 12 months	Loss of a loved one NS

(*Continued*)

Table 2. Continued.

Study	Sample size (*n*)	Participant characteristics			Definition, diagnostic criteria, and specifiers of IDD	Time since loss	Person lost
		Age	Gender	Race/ethnicity			
MacHale and Carey (2002)	40 adults with IDD	Adults with IDD (all) = range NR (*M* = NR; *SD* = NR) Bereaved range NR (*M* = 43; *SD* = 10) Non-bereaved = range NR (*M* = 39; *SD* = 7)	Adults with IDD = 53% female; 47% male	NR	Definition NR; Dx based on verbal skills; Specifiers: Learning disability; mild to moderate	Within 2 years	Parent, sibling, caregiver
MacHale et al. (2009)	34 adults with IDD 42 caregivers/staff	Adults with IDD 19–57 years (*M* = 35; *SD* = 9) Caregivers/staff 24–63 years (*M* = 41; *SD* = 10)	Adults with IDD: 56% female; 44% male Caregivers/staff: 62% female; 38% male	NR	Definition NR; Dx NS; Specifiers: Intellectual ability; mild (*n* = 22), moderate (*n* = 13)	NR	Parent, sibling
Mappin and Hanlon (2005)	6 adults with IDD	Adults with IDD 26–42 years (*M* = 37; *SD* = NR)	Adults with IDD = 50% female; 50% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; severe to moderate Learning disability; NS range	NA; COD	NA
McEvoy et al. (2012)	34 adults with IDD	Adults with IDD 19–57 years (*M* = 35; *SD* = 9)	Adults with IDD 56% female; 44% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; mild to moderate IQ range: 32–75 (*M* = 54, *SD* = 10.7)	NA; COD	NA
McEvoy et al. (2017)	30 adults with IDD	Adults with IDD 19–74 years (*M* = 39; *SD* = 15)	Adults with IDD 53% female; 47% male	NR	Definition NR; Dx NS; Specifiers: IQ range; mild (37%) to moderate (63%) Down Syndrome (*n* = 4)	NA; COD	NA
McRitchie et al. (2014)	13 adults with IDD	Adults with IDD 20–72 years (*M*/*SD* = NR)	Adults with IDD 61% female; 39% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; mild	Within 3 years	Grandparent, parent, friend, partner, roommate
Morgan and McEvoy (2014)	10 caregivers/staff	Caregivers/staff 28–56 years (*M*/*SD* = NR)	Caregivers/staff 100% female	NR	Definition NR; Dx NS; Specifiers: Intellectual disability NS	NR	Loss of loved one NS
Read and Papakosta-Harvey (2004)	10 adults with IDD	Adults with IDD 20–57 years (*M*/*SD* = NR)	Adults with IDD 50% female; 50% male	Adults with IDD: 100% White	Definition NR; Dx NS; Specifiers: NS	Within 5 years	Family member, friend, pet
Thorp et al. (2018)	4 adults with IDD	Adults with IDD 32–40 years (*M*/*SD* = NR)	Adults with IDD 50% female; 50% male	NR	Definition NR; Dx NS; Specifiers: Learning disability; mild to moderate	NR	Grandparent, friend, partner, stepfather, pet
Wiese et al. (2013)	33 caregivers/staff	Caregivers/staff 19–35 years (*M* = 44, *SD* = NR)	Caregivers/staff 85% female; 15% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability; NS	NS	Family member
Wiese et al. (2014)	22 caregivers/staff	Caregivers/staff 21–75 years (*M* = 48, *SD* = NR)	Caregivers/staff 91% female; 9% male	NR	Definition NR; Dx NS; Specifiers: Intellectual disability NS	NA; COD	NA

NA: not applicable; NS: not specified; Dx: diagnostic criteria; COD: concept of death.

Note. We differentiated studies that examined understanding of the concept of death from experiences of bereavement; COD studies focused on an abstract conceptualization of death that often included comprehension of biological/anatomic functions of life & the life cycle, whereas, experiences of bereavement studies focused on specific, personal losses adults with IDD had faced previously.

Table 3. Summary of characteristics and methodology used in intervention studies.

Study	Sample Size	Purpose of intervention	Pre-post loss	Groups	Control group and randomization	Duration	Frequency	Measurement time points	Assessment
Borsay et al. (2013)	$n = 4$	Evaluate the effect of a bereavement support group for adults with IDD	Post-loss	Single group	No; No	8 weeks	Weekly	Pre- and post-intervention	Psychology service generic outcome measure (rank bereavement and related difficulties 1–5 on a visual analogue scale); Glasgow depression scale (GDS) (Cuthill et al., 2003); Clinical outcomes in learning disability (CORE-LD) score (Marshall & Willoughby-Booth, 2007)
Dowling et al. (2006)	$n = 56$ initially consented	Evaluate and compare the effect of traditional counseling *vs.* an integrated intervention of counseling plus group support for bereaved adults with IDD	Post-loss	Group 1: $n = 25$ (traditional counseling) Group 2: $n = 22$ (integrated intervention)	No; Yes	15 sessions	Weekly to bi-weekly	Pre- and post-intervention	Aberrant Behavior Checklist-Community (ABC-C); Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD); semi-structured qualitative interviews
Fernández-Ávalos et al. (2023)	$n = 38$	Evaluate a psychoeducational intervention on understanding of death and death related concepts among adults with IDD	Post-loss; non-bereaved	Intervention group (IG): $n = 20$ control group (CG): $n = 18$ IG bereaved group: $n = 11$ IG non-bereaved group: $n = 9$ CG bereaved group: $n = 6$ CG non-bereaved group: $n = 12$	Yes; Yes	4 weeks	Once a week	Pre- and post-intervention	Complicated Grief Questionnaire for People with ID (CGQ-ID; Guerin et al., 2009); Biological Concept of Death (Ramos et al., 2010); Interview of conceptions about death (Rodríguez-Herrero, 2012; Rodríguez-Herrero et al., 2013)
Hoyle and McKinney (2015)	$n = 3$	Evaluate the effect of music therapy on bereaved adults with IDD	Post-loss	Single group	No; No	5 weeks	Twice a week	Pre- and post-intervention	The Brief Psychiatric Rating Scale, Developmental Disabilities Version (BPRS-DD; Bodfish, 1995)
Mappin and Hanlon (2005)	$n = 6$	Evaluate the effect of a bereavement group for adults with IDD on their understanding of death and grief response	Pre-loss	Single group	No; No	4 months	Weekly or bi-weekly over 4 months (10 total sessions)	Pre- and post-intervention	Death Concept Questionnaire (based on Bihm & Elliott, 1982; Harper & Wadsworth, 1993; Lipe-Goodson & Goebel, 1983; McEvoy, 1989; Yanok & Beifus, 1993); Knowledge About Death Questionnaire (based on Yanok & Beifus, 1993); Understanding Emotions Questionnaire (adapted from Holland et al., 1999)
Read and Papakosta-Harvey (2004)	$n = 10$	Evaluate the effect of group support for bereaved adults with IDD	Post-loss	Single group	No; No	6 sessions	NR	Post-intervention; after each session	Qualitative evaluation of group dialogues and activities

(*Continued*)

Table 3. Continued.

Study	Sample Size	Purpose of intervention	Pre-post loss	Groups	Control group and randomization	Duration	Frequency	Measurement time points	Assessment
Read et al. (2000)	$n = 8$	Evaluate the effects of support groups aimed at facilitating discussion of loss and grief related changes	Post-loss	Single group	No; No	6 sessions	NR	Post-intervention	Qualitative evaluation of group dialogue and activities
Stoddart et al. (2002)	$n = 21$	Evaluate the effect of group therapy on the mental health of bereaved adults with IDD, including understanding of death and the grief process	Post-loss	Single group	No; No	8 weeks	Weekly	Pre- and post-intervention	Children's Depression Inventory-Short form (CDI-SF); Hopkin's Syndrome Checklist (HSC-25); Knowledge of Death and Bereavement Questionnaire (KDBQ)

NR: not reported.

intervention was extremely high, with only two of 22 (9%) participants completing the intervention. Most intervention studies focused on addressing bereavement after the loss of a loved one (88%; $n = 7$), rather than pre-loss as prevention. In seven of the eight intervention studies, the purpose of the intervention was to evaluate the effectiveness of a bereavement support group or program, one of which incorporated music therapy (Hoyle & McKinney, 2015) and one that examined differences between traditional counseling delivered by trained professionals and personalized "integrated" support delivered by familiar caregivers (Dowling et al., 2006). Of the interventions that reported duration and frequency, interventions lasted from four to 16 weeks with once-a-week contact being the most common ($n = 5$). Most intervention studies included pre- and post-assessments to assess the effects of the intervention ($n = 6$), but none of the included studies reported on long-term follow up outcomes.

In terms of content, interventions varied in their focus. The types of interventions included: (a) providing psychoeducation on death and grief, including increasing understanding of the concept of death, specifically knowledge of the life cycle, the dying processes, and death concepts of irreversibility, causality, and non-functionality (Fernández-Ávalos et al., 2023; Mappin & Hanlon, 2005); (b) offering psychosocial support for people experiencing bereavement (Borsay et al., 2013; Dowling et al., 2006; Stoddart et al., 2002); (c) facilitating expression and discussions of grief, primarily through group discussions, writing exercises, and art (Borsay et al., 2013; Dowling et al., 2006; Mappin & Hanlon, 2005; Read et al., 2000; Read & Papakosta-Harvey, 2004; Stoddart et al., 2002); and (d) introducing coping strategies, including the use of relaxation exercises, listening to music, and honoring rituals (Borsay et al., 2013; Fernández-Ávalos et al., 2023; Hoyle & McKinney, 2015; Mappin & Hanlon, 2005; Read et al., 2000).

Findings

Quantitative data findings: risk and resilience factors

Quantitative findings of non-intervention studies pertained to: (a) understanding death and related concepts among adults with IDD, (b) preferences and attitudes for discussing loss and death, (c) effects of participation in loss/death rituals, (d) behavioral changes and symptoms of grief post-loss, and (e) social support for adults with IDD and their caregivers after a loss (Figure 2).

Study	Themes						
	Understanding Death	Discussing Loss/Death	Symptoms of Bereavement & Behavioral Changes	Loss/Death Rituals	Coping Strategies	Social Support	Improvement of Bereavement Training
Alcedo Rodriguez et al., (2018)				❖			
Borsay et al.. (2012)		★			Δ ★	★	
Bowey, (2005)	●	❖				❖ ●	
Dodd et al., (2008)			❖	❖			
Dodd et al., (2021)			❖				
Dowling et al., (2006)					Δ		★
Fernandez-Avalos et al., (2023)	Δ	★			Δ		
Forrester-Jones, (2013)	●	●		●	●	●	●
Gilrane-McGarry, (2007)	●			●	●	●	
Gray & Abendroth, (2016)			●				
Hoover et al., (2005)			❖	●			❖
Hoyle & McKinney, (2015)					Δ ★	★	
Irwin et al., (2017)		●	●				●
MacHale & Carey, (2002)			❖				
Mappin et al., (2005)	Δ				Δ		

Key: ❖ = quantitative data; ● = qualitative data; Δ = intervention study quantitative data; ★ = intervention study qualitative data

Study	Themes						
	Understanding Death	Discussing Loss/Death	Symptoms of Bereavement & Behavioral Changes	Loss/Death Rituals	Coping Strategies	Social Support	Improvement of Bereavement Training
McEvoy & Smith, (2005)	❖	❖	❖ ●			❖	
McEvoy et al., (2002)	❖ ●						
McEvoy et al., (2012)	❖				●	❖ ●	
McEvoy et al., (2017)	❖ ●						
McRitchie et al., (2014)	●		●	●	●	●	
Morgan & McEvoy, (2014)		●	●		●	●	●
Read & Papakosta-Harvey, (2004)				★	★	★	
Read et al., (2000)				★	★	★	
Stoddart et al., (2002)	Δ		Δ				
Thorp et al., (2017)		●	●	●	●		
Wiese et al., (2013)	●	●					●
Wiese et al., (2014)	●	●		●	●	●	

Key: ❖ = quantitative data; ● = qualitative data; Δ = intervention study quantitative data; ★ = intervention study qualitative data

Figure 2. Bereavement topics addressed in the included studies.

Understanding death and related concepts. Caregivers' perspectives showed that 82% of caregivers believed that adults with IDD do not fully grasp the concept of death (McEvoy & Smith, 2005). Results showed that the ability to comprehend death is tied to a person's cognitive abilities, with adults with mild to moderate IDD having a greater capacity for comprehending death and related concepts (Alcedo

Rodríguez et al., 2018; MacHale et al., 2009; McEvoy et al., 2002). Similarly, some studies indicated that greater receptive language skills, which are often found among adults with mild to moderate IDD, were associated with a greater understanding of death, its causes, and concepts of the afterlife (Pearson's $r = 0.67$, $p \leq .001$; $ß = 0.43$, $t = 3.5$, $p \leq .001$; McEvoy et al., 2002; see also McEvoy et al., 2012). Beyond cognitive abilities, McEvoy et al. (2002) found that greater emotional awareness or the ability to recognize and express their feelings was associated with a greater understanding of the concept of death among adults with IDD (Pearson's $r = 0.54$, $p \leq .001$; $ß = 0.43$, $t = 3.4$, $p \leq .001$, $F = 25.7$). Likewise, having a greater understanding of anatomy, organ functioning, and physiological causes associated with death were linked with a greater understanding of the concept of death (Spearman's $r = 0.457$, $p \leq .01$) (McEvoy et al., 2002; see also McEvoy et al., 2017).

Preferences and attitudes for discussing loss/death. Some of the included studies showed that talking to adults with IDD about loss is beneficial for facilitating their grief process, yet their exclusion from bereavement rituals and conversations about loss is common, particularly for those with more severe forms of impairment (Alcedo Rodríguez et al., 2018; Bowey & McGlaughlin, 2005). In addition to being left out of conversations about death, adults with IDD are rarely involved in planning their future living conditions or arrangements after the loss of a loved one, which may interfere with adaptation post-loss and a healthy bereavement process (Alcedo Rodríguez et al., 2018; Bowey & McGlaughlin, 2005). Alcedo Rodríguez et al. (2018) found that adults with more severe forms of IDD are particularly at risk of exclusion and diminished support in coping with loss ($\eta^2_{\text{partial}} = .25$, $p \leq .001$). Further, their study also demonstrated that adults with severe forms of IDD are often delayed in receiving news about losses from their families, compared to adults with mild to moderate IDD ($\eta^2_{\text{partial}} = .25$, $p \leq .001$; Alcedo Rodríguez et al., 2018). Similarly, McEvoy and Smith (2005) showed that a higher level of dependency or impairment was linked with less confidence and willingness to discuss death openly with adults with IDD ($r = -0.377$, $p = 0.028$). As a result, adults with IDD, particularly those with more severe impairment, face an elevated risk of having their grief be misunderstood, which can lead to isolation and its detrimental health and social consequences (Alcedo Rodríguez et al., 2018; Bowey & McGlaughlin, 2005).

Effects of participation in loss/death rituals. Findings were mixed about appropriate ways to involve adults with IDD in mourning rituals. However, some studies did not specify the level of support provided to participants in these rituals. Alcedo Rodríguez et al. (2018) showed that including adults with IDD in bereavement rituals may help with processing loss and reducing impairment in activities of daily living, whereas Dodd et al. (2008) found that adults with IDD who had participated in post-loss rituals, including preparing and attending the funeral, looking at photographs of the deceased, talking about the deceased, or visiting the body of the deceased, were more likely to experience complicated grief symptoms ($p = .005$). Additionally, Dodd et al. (2021) noted that how grief was acknowledged by others after participation in rituals influenced later grief experiences. These findings suggest variability in the effects of ritual involvement, depending on the type of participation, the level of understanding, and the presence of post-ritual support.

Behavioral changes and symptoms of grief post-loss. Overall, symptoms of distress for bereaved adults with IDD vary widely across individuals and levels of ability. For example, post-bereavement reactions, such as changes in mental and physical health, significantly differed based on the severity of IDD. For example, Alcedo Rodríguez et al. (2018) found that adults with mild forms of IDD exhibited fewer post-bereavement reactions compared to those with more severe forms of IDD, although the effect size was small ($\eta^2_{\text{partial}} = .02$, Scheffé $p = .02$). Several studies also highlighted notable externalizing symptoms related to distress, including sadness, anger, irritability, hearing the voices of the deceased, and crying spells—particularly when reminded of the loss (Dodd et al., 2008, 2021; Hoover et al., 2005; MacHale & Carey, 2002). Yet, there is significant variability in the duration of behavioral changes post-loss. For instance, MacHale and Carey (2002) described behavioral changes as short-lived and infrequent, occurring less than once per week, whereas Hoover et al. (2005) reported longer-lasting disruptions, including changes in sleep and eating patterns, which sometimes required medication adjustments to aid adaptation. Interestingly, one study on parental bereavement found no significant differences in complicated grief symptoms depending on whether the loss involved the mother or father (Dodd et al., 2008; $p < .05$).

While caregivers play a crucial role in the lives of individuals with IDD, their perspectives on the

presentation and duration of post-loss symptoms may be influenced by bias. For example, a study by MacHale et al. (2009) found that non-family caregivers often struggle to cognize the full spectrum of grief responses and tend to underestimate the potential for maladaptive behavior following a loss. Additionally, caregivers' perceptions of how long grief symptoms last in adults with IDD varied widely. MacHale et al. (2009) reported that nearly two-thirds of staff participants believed the duration of grief for individuals with IDD was similar to that of the general population. In contrast, McEvoy and Smith (2005) found a more diverse range of opinions: ~29% of caregivers thought the grieving process would be comparable in duration to that of the general population, while 26% believed it would be shorter, 24% thought it would be longer, and 21% were unsure.

Social support for adults with IDD and their caregivers during loss. Most studies emphasized the crucial need to provide support for adults with IDD in the face of loss; yet the most effective ways to support adults with IDD and their caregivers vary across populations and contexts. For instance, Alcedo Rodríguez et al. (2018) showed that while 85.8% of adults with IDD were given notification of their loved ones death, 31.0% had the opportunity to reminisce about the deceased, and only 32.2% had the opportunity to receive peer support from others who have also experienced loss. Similarly, in another study by McEvoy et al. (2012), less than half of adults (47%) with IDD reported that they had adequate support following the loss of a loved one. Moreover, Bowey and McGlaughlin (2005) reported that 49% of adults with IDD in his study expressed a desire for greater independence during discussions on future planning in the event of a family caregiver dying or becoming ill. Consistent with the aforementioned gap in identifying the best ways to support adults with IDD in the face of loss, MacHale et al. (2009) found that only 44% of caregivers felt confidence in providing post-loss support for adults with IDD (Spearman's $r = 0.56$, $p < .001$).

Qualitative data study findings: themes, vulnerabilities, and protective factors

Qualitative findings of the included studies pertained to: (a) understanding the concept of death, (b) opinions on discussing loss and death, (c) experiences in participating in loss/death rituals, (d) symptoms of bereavement, (e) coping strategies, (f) support for adults with IDD and their caregivers in the face of loss, and (g) improving bereavement training for caregivers and staff to adults with IDD (Figure 2).

Understanding the concept of death. Similar to the quantitative findings, qualitative studies have shown that adults with IDD are capable of grasping the concept of death and are sensitive to loss (Bowey & McGlaughlin, 2005; McEvoy et al., 2002). However, Forrester-Jones (2013) found that caregivers often view death as a "taboo" subject for adults with IDD. Indeed, there is variation in the understanding of death-related concepts, with individuals possessing higher cognitive abilities generally demonstrating a better comprehension of death (Forrester-Jones, 2013). McEvoy et al. (2002) also noted that adults with IDD often find it easier to understand post-death events and emotions, such as attending funerals, experiencing sadness, and participating in burials, but struggle with grasping the concept of non-functionality (e.g., the cessation of life-sustaining functions like breathing and heartbeat. Additionally, some research suggests that caregivers and staff may overestimate the ability of adults with IDD to understand death, which can lead to misunderstandings and increased social isolation for adults with IDD (MacHale et al., 2009).

Findings from the included studies also highlighted strategies to increase understanding of death among adults with IDD. For instance, providing greater knowledge about the human body and its functions, as well as information on the consequences of health decline, may be useful to better understand death and concepts related to loss (McEvoy et al., 2017; McRitchie et al., 2014; Wiese et al., 2013). However, the readiness of adults with IDD to discuss and receive information about human body functions, and how it pertains to death must be considered (Wiese et al., 2013). Also, facilitating a greater understanding of the concept of death can be achieved by using hypotheticals and examples, although the ability to understand euphemisms varies by cognitive ability (Wiese et al., 2013, 2014). Wiese et al. (2014) found that some adults with IDD get confused or become afraid when euphemisms, such as "sleep" are associated with dying. In addition, Gilrane-McGarry and Taggart (2007) found that having conversations about loss/death in advance or as prevention education is helpful for adults with IDD so that when a loss happens, the subject of death and loss is not a new concept.

Opinions on discussing loss and death. Discussing death can be beneficial both during and after a loss, particularly for emotion regulation—helping

individuals talk about their feelings, worries, and strategies for managing difficult emotions (Borsay et al., 2013; Wiese et al., 2013). Some of the included studies indicated that advanced planning before a loss can foster a sense of safety, security, and empowerment among adults with IDD (Bowey & McGlaughlin, 2005; Wiese et al., 2014). Examples of advanced planning included having proactive discussions about future care, changes in routine, possible relocation, and preparing for a loved one's death, which can help mitigate the shock and distress associated with such losses (Bowey & McGlaughlin, 2005). However, it's crucial to consider individual differences in ability and readiness when discussing loss (Morgan & McEvoy, 2014). For example, Thorp et al. (2018) found that whereas adults with IDD appreciated being informed about a death, they often felt frustrated when trying to identify or articulate their emotions surrounding that loss. This difficulty in expressing emotions means that adults with IDD may become gatekeepers of their own feelings, sometimes opting to keep them hidden (Irwin et al., 2017).

Adults with IDD often face significant barriers that hinder their ability to mourn authentically. McEvoy et al. (2017) found that these individuals value opportunities to share their opinions and are capable of expressing their feelings of loss. However, McRitchie et al. (2014) pointed out that adults with IDD often feel that they lack the agency to grieve in their own way, with their desire to mourn going frequently unrecognized. They reported that exclusion from funerals or mourning events restricts their ability to express grief, leaving them feeling denied a rightful opportunity to grieve. Additionally, two studies highlighted that caregiving staff often express frustration toward family members who exclude adults with IDD from discussions about loss, funeral activities, or notifications of death (Forrester-Jones, 2013; Morgan & McEvoy, 2014). Morgan and McEvoy (2014) noted that this exclusion often arises from a desire to maintain family image or status, as families may fear how others perceive their ability to care for and support a relative with IDD during emotional challenges. The desire to preserve strength and normalcy, coupled with the mistaken belief that individuals with IDD would not understand the loss, can lead to the exclusion of individuals with IDD from the grieving process.

Experiences of participating in loss/death rituals. People with IDD are often cut off from bereavement rituals due to incorrect assumptions surrounding cognitive impairment (Forrester-Jones, 2013; Hoover et al., 2005). Several studies highlighted that attending funerals can be source of pride for adults IDD (Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; McRitchie et al., 2014; Read et al., 2000; Read & Papakosta-Harvey, 2004; Thorp et al., 2018), as well as an opportunity to receive support (Forrester-Jones, 2013). Also, adults with IDD often view participation in funeral services as a sign of respect for their loved one (Forrester-Jones, 2013), and such events provide them a space for closure and acknowledging the deceased, despite the "bittersweet" nature of the goodbye and the possibility of emotional stress (Thorp et al., 2018). Some of the included studies emphasized that adults with IDD appreciate caregivers who encouraged remembrance through discussing and carrying out rituals like funerals, creating mementos of the deceased, or telling stories (Gilrane-McGarry & Taggart, 2007; Gray & Abendroth, 2016). For instance, Thorp et al. (2018) highlighted the importance of "carrying [the deceased] in [their] heart" and maintaining a "warm" connection with the deceased. Rituals, such as remembering loved ones with photos and memory crafts can be helpful in maintaining a connection with the deceased (Read & Papakosta-Harvey, 2004; Wiese et al., 2014). Caregivers expressed that adults with IDD should participate in culturally normative rituals like anyone else (Hoover et al., 2005), and that caregivers can assist adults with IDD in understanding the loss and participating in rituals to honor and remember the deceased (Gilrane-McGarry & Taggart, 2007; Wiese et al., 2014). Regardless, Wiese et al. (2014) emphasized that at times, caregiving staff are conflicted between having to comply with family's wishes concerning funeral/death arrangements and advocating for their patients/clients.

Symptoms of bereavement. The included studies identified symptoms of bereavement across externalizing and internalizing dimensions. Prevalent externalizing symptoms included: (a) increased irritability as manifested by physical & verbal aggression (Morgan & McEvoy, 2014), (b) changes in appetite (Irwin et al., 2017), (c) sleep disturbances, (d) changes in attachment patterns, such as increased attachment and separation anxiety, especially to the surviving parent in cases of parental bereavement (Irwin et al., 2017), and (5) crying (Morgan & McEvoy, 2014). Prevalent internalizing symptoms included: (a) sadness and loneliness (McEvoy & Smith, 2005; McRitchie et al., 2014), (b) worry (McRitchie et al., 2014), (c) confusion that manifested as fear of dying themselves (McEvoy & Smith, 2005), and (d)

somatic symptoms, such as "funny belly" and increased somatic pain (Irwin et al., 2017; Morgan & McEvoy, 2014; Thorp et al., 2018). Moreover, symptoms of grief and incidence of symptoms after loss varied across adults with IDD, including fluctuations of symptoms over time (Irwin et al., 2017; McRitchie et al., 2014). Caregivers observed that adults with IDD often re-experienced symptoms of grief with reminders of the loss (e.g., anniversaries, places, and times), thus, highlighting the importance of recognizing triggers (Gray & Abendroth, 2016). Compounded stress from secondary losses, such as increased responsibility, role changes for both adults with IDD and caregivers, and potential relocation, exacerbates bereavement symptoms for adults with IDD (McRitchie et al., 2014; Irwin et al., 2017), yet these issues are often inadequately addressed or discussed (Brickell & Munir, 2008).

Coping strategies. Strategies identified as useful or adaptive for adults with IDD who are grieving included: (a) talking about death or telling stories (Thorp et al., 2018; Gilrane-McGarry & Taggart, 2007); (b) relaxation (i.e., deep breathing, progressive muscle relaxation, and listening to relaxation music) (Borsay et al., 2013; Forrester-Jones, 2013); (c) art therapy; (d) bereavement counseling; (e) creating mementos to remember loved ones (i.e., pictures, drawings, memory crafts) (Gilrane-McGarry & Taggart, 2007; Gray & Abendroth, 2016; Read & Papakosta-Harvey, 2004; Thorp et al., 2018; Wiese et al., 2014); (f) humor (Read & Papakosta-Harvey, 2004); (g) spending time with others; (h) physical activity (Thorp et al., 2018); (e) spiritual engagement (i.e., praying, attending religious services) (Gilrane-McGarry & Taggart, 2007; Thorp et al., 2018); and (f) receiving social support from family and non-family caregivers or staff (Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; McEvoy et al., 2012). In some studies, religious beliefs about death and the afterlife, specifically beliefs about loved ones resting "in heaven" and the potential to meet their loved ones in the afterlife, were associated with effective coping among adults with IDD (McRitchie et al., 2014; Thorp et al., 2018). Also, maintaining a connection to the deceased was crucial for adults with IDD, as they expressed feelings of pride, obligation, and yearning as ways to process and cope with their loss (McRitchie et al., 2014). For example, adults with IDD often used humor and created tangible memories (i.e., pictures, drawings, audiovisuals) to maintain a connection with the diseased (Fernández-Ávalos et al., 2023; Read & Papakosta-Harvey, 2004). Also, Gray and Abendroth (2016) emphasized the importance of focusing on coping strategies that facilitate organizational and personal rituals, with direct care workers playing a critical role in helping adults with IDD set and accomplish priorities and new life goals. Indeed, a focus on resilience, such as encouraging adults with IDD to express their feelings and emotions, after loss was identified as an essential coping strategy (Morgan & McEvoy, 2014). In contrast, maladaptive coping strategies that interfere with adjustment to life post-loss included: (a) avoidance, for example not wanting or not able to discuss the loss (Gilrane-McGarry & Taggart, 2007; Gray & Abendroth, 2016; Morgan & McEvoy, 2014); (b) masking or hiding grief feelings to protect caregivers (Morgan & McEvoy, 2014); and (c) denial, for example referring to a loved one as if they were still present (Gilrane-McGarry & Taggart, 2007; Gray & Abendroth, 2016; Thorp et al., 2018).

Support for adults with IDD and their caregivers in the face of loss. The included studies showed that support for bereaved adults with IDD include social, emotional, and physical acts of care, which is helpful to facilitate the processing of loss. Several studies highlighted that effective support comes from a collaborative approach that includes families, friends, residential staff, and bereavement counselors. For instance, Bowey and McGlaughlin (2005) found that families and friends provided crucial emotional and interpersonal support, particularly by engaging in advanced planning and facilitating open communication about death. Indeed, this study showed that preparing for the eventual loss of a caregiver improved the bereavement experiences for adults with IDD (Bowey & McGlaughlin, 2005). Additionally, Gilrane-McGarry and Taggart (2007) emphasized that encouraging and facilitating open communication between caregivers and adults with IDD is key to facilitating the grieving process and fostering resilience. Beyond family and non-family caregivers, bereavement counseling and support groups led by trained facilitators also contribute to an adaptive bereavement process (Dowling et al., 2006). Effective bereavement counseling and support groups should be clear about the purpose of the group, address anxiety before participation, and ensure appropriate timing of group involvement following bereavement (Borsay et al., 2013; Dowling et al., 2006).

Regarding physical acts of care as sources of support for adults with IDD during loss, spending time with family and friends was identified as particularly helpful (Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; McEvoy et al., 2012). Other objective

forms of physical acts of support included: (a) sending cards or flowers, (b) receiving photos of the deceased, or (c) getting back personal items from the deceased; these services or acts play a crucial role in conveying messages of care for adults with IDD (Forrester-Jones, 2013).

Improving bereavement training for caregivers/staff. Some of the included studies highlighted a significant gap in training and knowledge about bereavement within this population, underscoring the need for targeted training programs (Irwin et al., 2017; Morgan & McEvoy, 2014). Despite these challenges, Dowling et al. (2006) showed that volunteer bereavement counselors can adapt their existing skills to support individuals with IDD, even in the absence of specialized training and with limited resources. Caregiving staff often observe how deeply death and loss can affect the lives of adults with IDD (Wiese et al., 2013), and the witnessing of disenfranchized grief can be particularly difficult for caregivers, who may have strong bonds with their patients but often lack adequate support themselves (Morgan & McEvoy, 2014). Compounding this issue is the necessity for caregivers to navigate complex family dynamics on behalf of their patients (Forrester-Jones, 2013; Irwin et al., 2017).

Findings from intervention studies

Quantitative findings. Bereavement interventions in the included studies comprised bereavement support groups, individual counseling, creative arts exposure, and psychoeducation to increase understanding of death. Regarding bereavement support groups, most of the relevant studies supported the positive health effects of support groups post-loss. For example, participation in bereavement support groups, particularly in group settings with other adults with IDD who shared similar loss experiences, was associated with reduced symptoms of depression and symptoms of complicated grief [$F(1,15) = 11.05$, $p = .005$; Fernández-Ávalos et al., 2023]. Additional benefits of bereavement support groups for adults with IDD included reduced feelings of sadness, persistent yearning, and avoidance (Borsay et al., 2013; Hoyle & McKinney, 2015; Mappin & Hanlon, 2005; Stoddart et al., 2002). Stoddart et al. (2002) found that the benefits of participating in bereavement support groups were greater for reducing symptoms of depression for adults with IDD with comorbid conditions when compared to those with single diagnosis (HSC-25 depression scale $p < .05$; CDI-SF $p < .01$); although no improvement in symptoms of anxiety were noted (p-value not reported). Also, Mappin and Hanlon (2005) reported that exposure to a bereavement support group intervention post-loss was associated with increased emotional awareness ($p = .05$). In other areas, Dowling et al. (2006) found that an individual counseling intervention post-loss was associated with reduced symptoms of irritability ($p \leq .001$), diminished lethargy ($p = .001$), less social withdrawal or loneliness, less stereotypic behavior (e.g., abnormal repetitive movements) ($p = .005$), reduced hyperactivity ($p = .001$), less non-compliance (e.g., disobedience, uncooperative), and less inappropriate speech (e.g., screaming/yelling, excessive talking) ($p = .039$).

Pertaining to creative arts exposure post-loss, one study assessed the effect of a music therapy intervention on grief symptoms among adults with IDD. Overall, exposure to music therapy was beneficial in decreasing maladaptive behaviors, specifically reducing obsessions with negative events, decreasing overeating, and increasing willingness to work, although the findings were not statistically significant. However, exposure to music therapy was associated with increased ability to recognize, deal with, and reduce anger to prevent self-harm, harm to others, and damage to surrounding physical spaces (Hoyle & McKinney, 2015). In this study, the effects of the music therapy exposure were bigger for adults with IDD who had lived longer with their families and had closer family relationships, compared to those who had lived longer at residential centers (p-values not reported; Hoyle & McKinney, 2015).

Studies examining the impact of psychoeducation to enhance understanding of death-related concepts among adults with IDD reveal mixed outcomes. For example, Fernández-Ávalos et al. (2023) found that a four-week psychoeducational intervention on the concepts of death, showed a significant improvement post-intervention in understanding death as a state of non-functionality (e.g., the body no longer functions/is alive) [$F(1.36) = 8.51$, $p = .007$, Cohen's $d = 0.7$] and as an inevitable event [$F(1.36) = 4.53$, $p = .040$, Cohen's $d = 0.68$], although the intervention did not significantly improve comprehension of death's irreversibility [$F(0.43)$, $p = .515$, Cohen's $d = 0.36$] or universality [$F(1.7)$, $p = .200$, Cohen's $d = 0.8$]. The effect sizes range from medium to large. Similarly, Mappin and Hanlon (2005) showed that a pre-loss intervention focused on helping adults with IDD understand death reported that most participants showed significant gains in understanding the concept of death following the intervention ($p = .05$), although variations in the

type of concepts understood emerged. Specifically, participants showed greater understanding of more concrete aspects of death (e.g., "what is a grave?", "what does cremate mean?", "what is a coffin?"), but struggled with concepts of irreversibility, causality, and separation (*p*-values not reported). Conversely, Stoddart et al. (2002) found that an eight-week psychoeducational intervention focused on discussions of loss did not significantly enhance participants' understanding of death or of the bereavement process (*p*-value not reported).

Qualitative findings. Overall, bereavement support groups following loss were well-received by adults with IDD. Specific benefits of participating in support groups post-loss included: (a) having a safe space to ask questions and clarify topics about death and loss (Borsay et al., 2013; Read et al., 2000; Read & Papakosta-Harvey, 2004); (b) facilitated opportunities to make new friends and connect with others sharing similar experiences, which was associated with increased feelings of hope and optimism (Read et al., 2000); and (c) provided opportunities to explore and develop coping skills to manage bereavement-related challenges, including feelings of isolation, changes in self-image after loss, health losses (i.e., loss of mobility), and anger suppression (Borsay et al., 2013; Read et al., 2000). Learning how to use such coping strategies post-loss was associated with growth in self-confidence and assertiveness (Read & Papakosta-Harvey, 2004). Also, support group interventions post-loss were important for sharing stories and understanding individual differences in the grieving process (Read et al., 2000; Read & Papakosta-Harvey, 2004). Regarding psychoeducational interventions to facilitate the understanding of death, Fernández-Ávalos et al. (2023) highlighted that these psychoeducational activities were helpful to "face death in a better way" and provided participating adults with IDD with a space to openly talk about loss.

Beyond bereavement support group interventions, adults with IDD expressed positive engagement in interventions that incorporated the creative arts as coping strategies. Indeed, adults with IDD expressed that music therapy helped them with emotional processing of the loss (Hoyle & McKinney, 2015). For instance, during a music therapy intervention, a participant processed the death of her parents by playing "sadness" on the drums (Hoyle & McKinney, 2015). Bereaved participants also had the opportunity to engage in songwriting which "exposed participants to vocabulary and strategies for coping with sadness and anger" (Hoyle & McKinney, 2015). Adults with IDD who participated in the music therapy were better able to express their emotions surrounding grief (both verbally and musically) and contributed productively to the group session. Further, adults with IDD exhibited a greater ability to express emotions, improved social skills, and an increased tendency to seek out social activities following participation in music therapy (Hoyle & McKinney, 2015).

Discussion

In this systematic review, we evaluated methodology and findings of recent studies about bereavement among adults with IDD. Through our analysis, we identified methodological weaknesses that need to be addressed in future research. Specifically, many studies lacked detailed information necessary to assess the quality of study design, the representativeness of participants, and the validity of their findings. For example, intervention studies often failed to incorporate randomization or control groups, which are essential for establishing causality and ensuring that the results are both reliable and generalizable. Additionally, inconsistencies in the use of standardized measures for assessing grief exist, which can lead to inconsistencies in findings and make it difficult to compare results across studies. There is also a significant need for longitudinal research that tracks the experiences of bereaved individuals with IDD or the long-term effects of interventions. Such studies could fill critical gaps in understanding the evolving nature of grief and the long-term impacts of bereavement in this population. Intervention studies with follow-up periods are crucial to understanding the lasting effects of interventions on participants' health outcomes, behavior changes, and overall quality of life. These studies would also help identify potential risks or benefits that may not be immediately apparent during the intervention phase. Improving the methodology of bereavement research for individuals with IDD is essential for providing a clearer context for findings, ensuring practical application, and avoiding harm. By employing rigorous study designs, including mixed methods approaches that integrate both quantitative and qualitative data, future research can provide a more comprehensive understanding of the bereavement process in this population. These methodological improvements will not only strengthen the validity of the research but also help inform more effective interventions and support systems tailored to the unique needs of individuals with IDD.

Overall, our findings emphasize a pressing need for studies that better explore the intersectionality among individuals with IDD. Future research should prioritize including participants with diverse intersectional identities, encompassing factors, such as ethnicity, race, gender, sociodemographic backgrounds, geographic origin, level of ability, living environments, and lived experiences. For instance, among the 28 studies reviewed, only five reported the race or ethnicity of their participants, and 80% of those studies predominantly included White participants. Similarly, important cultural and contextual factors, such as religious background or socioeconomic status, were often omitted, despite their potential impact on how grief is experienced, and the type of support individuals may need. Furthermore, few studies addressed the role of religious beliefs or spirituality, which may shape how grief is experienced, expressed, and supported. Religious and spiritual beliefs can influence a person's ability to understand and find meaning in loss as well as engage in mourning practices and coping mechanisms. Future research should consider how religious and spiritual beliefs affect grief expression and serve as a source of comfort. Another key consideration for future research is exploring how differences in cultural backgrounds or lived experiences between caregiving staff and individuals with IDD may intersect to influence health and behavioral outcomes. Including a broader range of perspectives in research is crucial for identifying factors that can be generalized to the larger IDD community while also highlighting important variations within the community, including differences between caregiving staff and their clients. Incorporating these diverse viewpoints is vital for developing resources, interventions, and best practices that are more responsive to the unique needs of various subgroups within the IDD population. Addressing this knowledge gap is essential not only for enhancing the effectiveness of support services but also for promoting health equity within the IDD community (Akbar et al., 2022; Kover & Abbeduto, 2023). By better understanding the multifaceted experiences of bereavement in the IDD community, we can ensure that interventions and practices are culturally and contextually sensitive, ultimately improving outcomes for this population.

Despite the methodological challenges outlined, our findings underscore the urgent need to create pathways that prevent disenfranchized grief among individuals with IDD. These individuals are often excluded from important discussions and decision-making processes, especially those related to the loss of loved ones (Meeusen et al., 2006). However, our results highlight that individuals with IDD deeply value and benefit from being included in conversations and rituals surrounding loss. To better support them in times of loss, further research is needed to develop inclusive strategies that create safe spaces for discussing death and grief. This research should also clarify whether the accounts come from self-reports by individuals with IDD or are supplemented by input from staff and family, as this distinction affects the validity of the findings. Additionally, distinguishing between direct measures (e.g., knowledge tests) and subjective assessments (e.g., staff perceptions) of knowledge and attitudes is crucial to avoid biases. A recent study by Anderson-Kittow et al. (2024) highlights the value of inclusive methodologies that center the voices of individuals with IDD, co-designing resources that meet their needs and those of their families. Proactive measures, such as advanced planning and pre-loss conversations about bereavement, are also essential to mitigate the risk of disenfranchized grief. Moreover, given the critical role of social support in resilience, future studies should explore how to build multi-layered support systems to help individuals with IDD cope with grief. While several intervention studies in the review included some form of adaptation for people with IDD, such as training counselors on communication strategies, using concrete language, or applying visual tools like picture books, there was variability in the extent and consistency of these accommodations. Some studies relied on general bereavement approaches or used measures that were not clearly tailored for individuals with IDD. Future research and interventions should aim to expand and evaluate interventions that are intentionally designed for the range of cognitive, communicative, and support needs of adults with IDD. Greater attention is needed to ensure that grief interventions are effective for all individuals including those living in residential or institutional settings where they may face different barriers in accessing support. Like their non-disabled peers, adults with IDD need individualized, comprehensive support, which requires a combination of resources. Addressing these gaps is vital for developing effective interventions that support both individuals with IDD and their caregivers.

In addition to the benefits of support amid loss, this review identified additional protective factors to the well-being of bereaved adults with IDD. For instance, incorporating creative arts and offering psychoeducational information can help adults with IDD grasp concrete concepts of death. Future studies are essential for advancing evidence-based practices that utilize creative arts and related activities to facilitate

the bereavement process in adults with IDD, taking into account individual differences, varying abilities, and preferred learning styles. Addressing the complex and multifaceted experiences of bereavement in adults with IDD also requires a deeper exploration of cognitive processes, emotion regulation, and physical challenges they faced. Our findings indicate that adults with IDD often experience both physical and emotional symptoms of bereavement, which can be exacerbated by secondary losses, adding to their stress (Brickell & Munir, 2008). Research in this area is limited, and further investigation is needed to identify the varied triggers of stress associated with bereavement, as well as to develop strategies for recognizing and addressing the wide range of emotional and physical responses to loss among adults with IDD. Additionally, understanding how to manage changes in routine and living situations during and post-loss, while minimizing disruption, is critical. Supporting rituals and activities that facilitate healing must also be tailored to account for individual differences and contextual factors. To effectively address these challenges, it is imperative to cultivate empathetic relationships and enhance the training of caregivers and staff, ensuring that adults with IDD receive the comprehensive and compassionate support and the resources they need during times of loss.

Finally, empowering bereaved adults with IDD and elevating their voices is essential. Much of existing research with this population tends to focus on the perspectives of caregivers, often neglecting the lived experiences and insights of adults with IDD. Our findings revealed mixed results regarding caregivers' abilities to accurately predict or assess the understanding of topics related to loss and death among adults with IDD (Alcedo Rodríguez et al., 2018; MacHale et al., 2009). Given that adults with IDD value being included in discussion and having their opinions heard during significant life events, such as loss, it is crucial for research to amplify their voices and perspectives. This can be achieved by actively involving adults with IDD as participants in the research process. We strongly advocate for community-engaged research practices that prioritize collaboration with community partners who work directly with adults with IDD. These partnerships can help ensure that the voices of individuals with IDD are represented and that their unique experiences inform the development, dissemination, and implementation of interventions, support services, and best practices for providers and/or organizations working with the IDD community. By placing adults with IDD at the center of research efforts, we can create more inclusive and effective approaches that accurately reflect their needs and perspectives.

Limitations

This review adds to the bereavement literature by providing a detailed analysis of methodology and findings from peer-review studies on bereavement among adults with IDD, as well as highlights knowledge deficits and directions for future research. Nevertheless, this study has some limitations. First, comparison of findings across studies was difficult given differences in the measures used, variations in the associations reported, and limited definitions of IDD that were provided (e.g., intellectual disability, learning disability, retardation, etc.). This points to a pressing need for studies focused on reproducing existing studies and studies with stronger methodological rigor. Second, only studies of adults with IDD were included in this review. It is important that similar reviews be done among youth with IDD, given that their experiences of loss may be different to their adult counterparts. Third, despite using comprehensive search strategies, there is a possibility that some relevant studies were missed, especially if they were published in languages other than English or if not indexed in the databases searched. Additionally, this review narrows the scope of understanding by excluding broader literature on significant life events and trauma among the IDD population, in which death and grief often play a central role. Finally, given differences across subgroups of adults with IDD, making generalizations about their experiences of loss and grief may be problematic.

Conclusion

Adults with IDD will inevitably face grief and loss as part of life. Understanding their unique experiences and providing evidence-based support and resources is critical to protect their well-being, facilitate the adaptation process, and reduce risk of disenfranchized grief. Important gaps in knowledge remain to be filled and diverse voices are yet to be included. Future research is needed to inform evidence-based and systemic interventions that can promote inclusiveness, equity, and empowerment of the IDD community amid loss in ways that are culturally and contextually appropriate. Indeed, support for adults with IDD is far from one-dimensional. We advocate for future research that not only explores but also systematically integrates diverse and creative bereavement coping strategies

across individual, community, and societal levels, emphasizing the inherent resilience and strengths within this vulnerable yet resilient community.

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