

## Systematic Review

# Synthesising existing research on complicated grief in intellectual disability: findings from a systematic review

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## Abstract

**Background** Complicated grief has been identified as a phenomenon in the general population, and there is an increasing body of research investigating complicated grief in people with intellectual disability. The aim of this study is to synthesise this existing knowledge from research published between 1999 and 2022.

**Methods** A structured systematic review using PRISMA guidelines was conducted, which searched three commonly used databases (Medline, PsycINFO and CINAHL) for research on the topic of bereavement and intellectual disability. The articles identified in this search were screened to identify those that addressed the issue of ‘complicated grief’, with all abstracts and subsequent full texts reviewed by two researchers.

**Results** In total, 179 abstracts were initially identified, with 34 articles eligible for full text screening and 18 papers reaching criteria for inclusion. Data relating to the studies’ objectives were extracted under the headings of definition, defining principles, signs and symptoms, risk factors and

treatments for complicated grief in intellectual disability. Thematic analysis of the extracted data was performed to identify key themes.

**Conclusions** This review highlights that people with intellectual disability are likely to experience complicated grief reactions and that complicated grief is both underestimated and a clinically significant condition for people with intellectual disability. Future research should work to clarify diagnostic criteria and identify appropriate interventions.

**Keywords** bereavement, complicated grief, intellectual disability, systematic review

## Background

Grief in response to bereavement is both a normal and inevitable part of life. However, grief can be pathological, when it is persistent, acutely distressing and functionally impairing (Shear *et al.*, 2011). This pathological grief process, known as complicated grief (CG), has received increased attention in literature for the general population. It has been shown to be both a common and clinically significant condition with a prevalence of approximately 9.8% following a bereavement (Lundorff *et al.*, 2017). Therefore, it is of no surprise that there is increasing focus in the

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medical and psychological literature on CG. This has included ongoing debate regarding the most appropriate diagnostic classification and disorder nomenclature for this condition. The upcoming International Classification of Diseases 11th Revision (ICD-11; World Health Organisation, 2019), for example, refers to prolonged grief disorder (PGD) (Killikelly & Maercker, 2017), whereas the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association) refers to persistent complex bereavement disorder (PCBD). Fundamentally, this pathological grief process is characterised in the general population by a range of symptoms including a sense of disbelief regarding the death, recurrent pangs of painful emotions, intense yearning, longing for the deceased and anger over the death (Shear *et al.*, 2005; Prigerson *et al.*, 2009). Symptoms should persist beyond 6 months after the death for a diagnosis to be made (Prigerson *et al.*, 2009). For this paper, we refer to complicated grief (CG) as this is the most common terminology used for this pathological grief process in the literature for people with intellectual disability (ID).

The increased focus on CG has led to the development of treatment approaches including individual and group psychological approaches (Johannsen *et al.*, 2019.) Supportive counselling, interpersonal therapy and antidepressant treatment have been proposed, but the evidence basis for these interventions is limited (Reynolds *et al.*, 1999; Boelen *et al.*, 2007). Complicated grief therapy, however, is a psychological intervention that has been shown to be effective in treating CG in both young and older people (Shear *et al.*, 2005; Shear *et al.*, 2014). It is a 16-session intervention that focuses on seven themes: understanding grief, managing emotions, seeing a promising future, strengthening relationships, narrating the story of the death, learning to live with reminders and connecting with memories of the person who died (Shear *et al.*, 2005).

People with ID are living longer and therefore experience a range of life events, often including the experience of bereavement. Our understanding of the impact of bereavement on people with ID has grown substantially in recent times. Original assumptions, such that people with ID do not have the capacity to understand death or experience grief (Read, 1996), has shifted to the recognition that people with ID

experience a range of grief reactions (Marsten & Clarke, 1999; Campbell & Bell, 2011). Studies have established evidence of the awareness of the concept of death among people with ID, but even in cases where a full concept of death is missing, people with ID continue to appear to experience the emotions that follow a bereavement (McEvoy *et al.*, 2002; McEvoy *et al.*, 2012). Research looking specifically at CG in people with ID is limited compared with that of the general population, but is growing (e.g. Dodd *et al.*, 2008). Considering the clinical importance of CG in the general population, it is reassuring to see CG also being considered in the context of people with ID.

### The present study

The aim of the study was to undertake a systematic review of the existing literature on CG in people with ID. To address this aim, four specific research questions were identified:

- What does the existing literature describe as the defining principles of CG in people with ID?
- What are the signs, symptoms, and outcomes of CG in people with ID?
- What are the risk factors and protective factors for CG in people with ID?
- What are the interventions and treatments for CG in people with ID?

## Methods

### Study design

A systematic review and thematic analysis of the existing literature on CG in people with ID was undertaken. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher *et al.*, 2009) were followed. The current study was part of a larger systematic review looking at the wider range of bereavement and grief reactions in people with ID. Two phases of searching were conducted: Phase 1 screened studies identified a part of the wider review for papers, which also considered complicated grief, while Phase 2 updated the review for papers on complicated grief in ID published at two timepoints since the initial search.

### Data sources and search strategy

Three commonly used databases (Medline, PsycINFO and CINAHL) were searched to identify potential papers for inclusion in the review. As part of the larger review, which focused on grief and bereavement, the titles and abstracts of papers in the databases were searched (1 April 2016) using variants of the key terms; ‘Intellectual disability’ and ‘bereavement’/‘grief’ (Box 1). Using ENDNOTE, an Excel document was formed with all potential abstracts. Duplicate papers were removed.

The search was rerun in 2019 and 2022 to identify papers published since 2016. This phase used a modified search strategy, which replaced the search terms for generic grief and bereavement with variants of the term complicated grief (Box 1), thus focusing this phase of the search on this specific phenomenon. Finally, the reference lists of all included studies were also searched for any additional publications.

#### Box 1: Search terms used in the two search phases

1 April 2016  
 disab\* OR retard\*  
 AND intellectual OR learning OR mental  
 AND death OR dying OR grief OR griev\* OR  
 bereav\* OR mourn\*.  
 17 October 2019 and 30 June 2022  
 disab\* OR retard\*  
 AND intellectual OR learning OR mental  
 AND complicated grief OR prolonged grief OR  
 traumatic grief.

### Study screening

Inclusion and exclusion criteria were agreed by two researchers prior to screening the abstracts identified in Phase 1. These were subsequently applied to the abstracts added following the Phase 2 search data.

#### Inclusion criteria:

- Papers published from inception up to and including the date of the final search.
- English only and peer reviewed journals.
- Papers that consider CG, prolonged grief or traumatic grief in people with ID.

#### Exclusion criteria:

- Papers that discuss bereavement in people with ID but do not explicitly refer to CG, prolonged or traumatic grief.
- Papers that refer to disenfranchised grief in people with ID but that do not refer to CG, prolonged or traumatic grief.
- Papers referring to CG, prolonged grief or traumatic grief in the general population but not referring to people with ID.
- Books, bibliographies, book reviews and dissertations.

Two researchers screened each abstract to identify whether the inclusion criteria were met, in that there was evidence that forms of complicated grief were considered in the paper, and if full paper, screening was warranted. If both researchers did not agree, the paper was put forward for full text screening. Papers identified at the abstract screening stage were sourced and read in full by the two researchers to identify if inclusion criteria were met. A meeting took place between both researchers to discuss cases where agreement was not reached, and a decision then made to include or exclude the paper.

### Data extraction and quality assessment

Identified papers were reviewed by researcher A, and key information on the study was extracted to Excel file. Extracted information is summarised in Box 2.

Selected papers were then reviewed for findings relevant to the four research questions, with relevant information extracted to the excel file under the following research headings:

- Definition and defining principles of CG in people with ID.
- Signs, symptoms and outcomes of CG in people with ID.
- Risk factors and protective factors for CG in people with ID.
- Interventions/treatment for CG in people with ID.

For quality review purposes, the Critical Appraisal Skills Programme (CASP) criteria (<https://casp-uk.net/>) were used. Each paper was reviewed, and the CASP criteria graded as evident or not. Papers were

not excluded on the basis of this review, but rather, the weight placed on the body of literature was moderated.

Box 2: Information extracted from included studies

- 1 What study type was used? Qualitative, quantitative, mixed methods, or review:
  - a If Quantitative: Was it a case study, focus group, interview or mixed?
  - b If Quantitative: Was it comparative, longitudinal or a survey?
  - c If Comparative: Was random allocation used?
  - d If Review: Was it systematic, traditional or opinion?
- 2 Did the paper have people with ID as subjects or direct respondents? Was carer/proxy reporting used?
- 3 Demographic data: Age range, gender, level of intellectual disability?
- 4 What was the nature of the loss? Parental, sibling or partner death?
- 5 What was the residential setting? Were the people with ID living with family, alone or a supported setting?
- 6 What data collection method was used? Interview, focus group, questionnaire or observation?
- 7 What outcome measures were used? Survey, questionnaire or assessment tool?

### Data analysis

Study characteristics were tabulated, and following this, a six-phase thematic analysis approach (Braun & Clarke, 2006) was used to analyse the extracted data related to the core research questions. To begin, the lead researcher became familiar with the data by reading and rereading both the identified papers and the extracted data prior to coding. Next, they generated initial codes within the Excel file under the key headings (definition and defining principles, signs and symptoms, and outcomes, intervention and treatment options for CG in people with ID). This

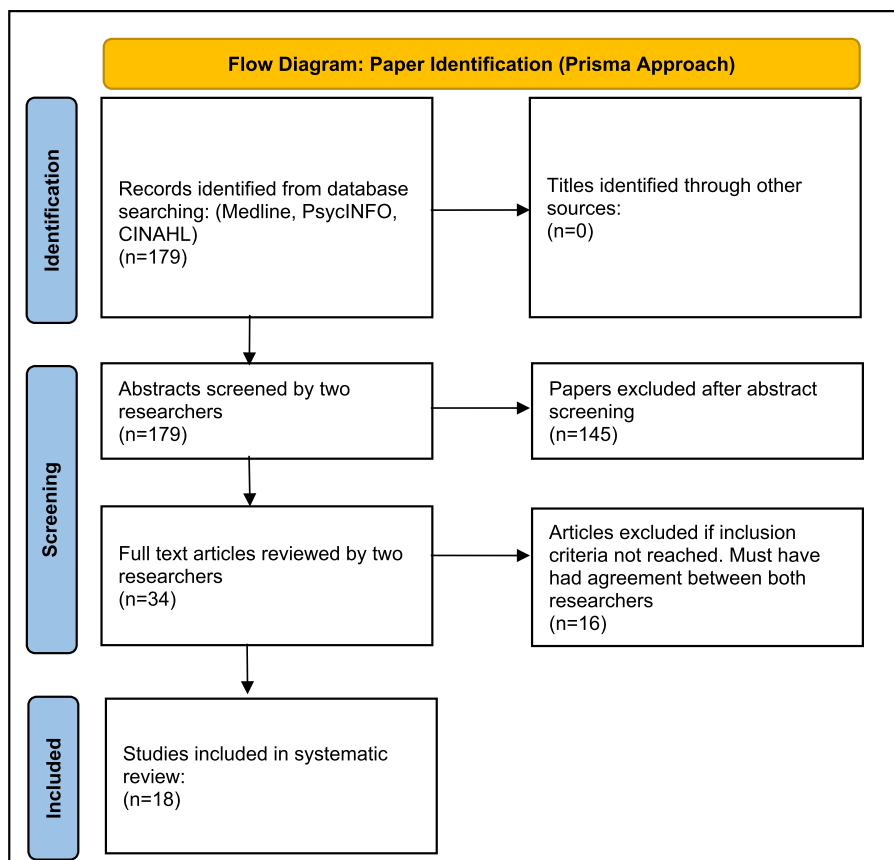
involved reviewing extracted data for statements/text relating to the research questions. A second member of the team shadowed this process, allowing for regular meetings to reflect on issues being identified in the data, ensuring a level of credibility. Following initial coding, the analysis moved to identify candidate themes. Codes were reviewed and collated extracts were read to identify any coherent patterns by the lead research and checked by the second member of the team. This allowed for discussion of and reflection on the candidate themes, which informed the researcher's review and refinement of themes. The validity of individual themes was considered in relation to the entire data set to see if refined themes reflected the meanings in the data set as a whole. This stage involved the lead researcher rereading the entire data set (i.e. the individual articles as well as the extracted data). The penultimate stage of the process allowed them to compile a clear account of each theme, including identifying illustrative examples from the included papers. Potential subthemes (themes within themes) were identified at this stage also. The second researcher again shadowed this stage. As is common with this model of thematic analysis, the writing of the narrative allowed space for final refinements of the key themes.

### Results

The search yielded 179 potential papers for consideration as part of this systematic review. The thematic analysis process resulted in 34 papers identified for full text review. Once inclusion and exclusion criteria were considered, a total of 18 papers reached criteria for inclusion. This included eight papers from the United Kingdom, seven from Ireland, two from the USA and one paper from Canada. Figure 1 outlines this process in detail.

A descriptive summary of these 18 papers was compiled (Table 1), summarising the methods, population characteristics and principal findings under the four thematic headings (definition and defining principles, signs and symptoms, risk and protective factors and treatment approaches (Table 1).

Of the 18 papers, four were literature review papers. Six papers were based on proxy reporting including proxy-reported bereavement questionnaires, complicated grief scales, staff experiences of



**Figure 1.** PRISMA flowchart showing the results of the two phases of the search process. [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

supporting people with ID with grief, a bereavement tool feasibility study, informant reported psychopathology years post bereavement, professional focus groups, thematic analysis of PTSD symptoms in people with ID and thematic analysis of CG in people with ID as perceived by direct care workers. The remaining papers consisted of three case studies, two papers based on self-reported CG symptoms in people with ID, along with conceptual papers on the impact of social, emotional and physical factors in bereavement, descriptive studies of a small NHS bereavement service and short commentary articles on what may complicate grief make up the remainder. As is evident, most papers are often opinion based with a minority based on experimentally driven data or conclusions. There was a total of 324 people with ID included across all studies, including 76 people that were included in two of the studies listed above.

The core analysis of this paper is the thematic analysis of these papers to identify themes relating to the topics of the study. These topics and themes are presented in Figure 2, followed by a narrative reporting the key findings.

### Definition and defining principles

Given the different views of CG evident in the existing mainstream literature, it is important to consider how the concept is represented in the ID literature. A key theme here is that CG is poorly described in people with ID. There are many proposed reasons for this. Firstly, there is a limited understanding/clarity about what constitutes normal bereavement processes in people with ID (Blackman, 2016; O'Keeffe *et al.*, 2019) and how this is different from grieving processes in the general adult population (Bricknell &

**Table 1** Overview of included studies (blank cells indicate not relevant information in that study)

Author, Year, Country	Title	Methodology	Population characteristics
Blackman, 2003, England.	Grief and intellectual disability: A systemic approach.	Descriptive paper of a grief treatment approach including case examples.	Two men and one woman with ID referred to ROC loss and bereavement service.
Blackman, 2008, England	The development of an assessment tool for the bereavement needs of people with learning disabilities	Feasibility study: Bereavement tool specifically for people with ID: IO question bereavement needs assessment tool (BNAT) focusing on three areas: practical, social, and emotional issues. Same trialled by six clinicians in a community setting. Commentary article/literature review.	Initial impressions of BNAT tool gathered by six experienced clinicians (two psychologists and four clinical nurses) in a community intellectual disability service setting.
Blackman, 2016, UK	Supporting people with learning disabilities through a bereavement.	Identifying factors that complicate grief and considers interventions.	N/A
Bonell-Pascual <i>et al.</i> , 1999, England	Bereavement and grief in adults with disability -a follow up study.	Follow up cohort, informant led study. Not all participants from the original study available to take part. PIMRA and ABC scales were used to check for signs of psychopathology in people with ID	41 of the original 50 people with ID were followed up post experiencing a bereavement 6-8 years ago.
Bricknell & Munir, 2008, USA	Grief and its complications in individuals with intellectual disability (ID)	6-8 years post bereavement Literature review. Apply modern theories of grief and grief resolution to individuals with ID to provide a theoretical framework for the proposition that people with ID are susceptible to CG. Provides a theoretical framework.	N/A
Dodd, Dowling, Hollins 2005, Ireland	A review of the emotional, psychiatric, and behavioural responses to bereavement in people with intellectual disabilities.	Systematic review of the phenomenology of pathological grief, ability of people with ID to understand the concept of death. Also emotional, behavioural, and psychiatric responses to bereavement.	N/A
Dodd & Guerin, 2009, Ireland	Grief and bereavement in people with intellectual disabilities.	Traditional review article aiming to present and synthesise recent research on grief and bereavement in people with intellectual disabilities. Comprising papers relating to grief and bereavement in both intellectual disability and general population.	N/A

Table 1. (Continued)

Author, Year, Country	Title	Methodology	Population characteristics
Dodd, Guerin, McEvoy, Buckley, Tyrell, Hillery 2008, Ireland	A study of complicated grief symptoms in people with intellectual disabilities (ID).	Retrospective study, based on proxy reporting by carers bereavement history questionnaire and measure, examining complicated grief symptoms, administered to carers of people with mild or moderate ID, post parental bereavement and to a matched group, who had not been bereaved.	People with ID. 76 participants (comparison group $n = 38$ . Bereaved group 38, mean age 40, gender male 58, female 41)
Dodd, McEvoy, Lockhart, Burke, O Keefe, Guerin 2021, Ireland	An exploratory study of self-reported complicated grief symptoms in parentally bereaved adults with intellectual disability	A comparative group Design. Assessing self and staff (proxy) reports for complicated grief symptoms in a group of parentally bereaved individuals and a matched group of non-bereaved individuals using the Complicated Grief Questionnaire – ID Self-Report (GCQ-ID self report)	46 individuals with ID, 30 of whom had experienced a parental bereavement within the previous 2 years. The age range was 23–67 years (mean = 43.8; SD = 10.3).
Grey, Abendroth 2016, USA	Perspectives of US direct care workers on the grief process of persons with intellectual and developmental disabilities: Implications for practice.	Thematic analysis approach used to examine the grief process of people with ID as perceived by direct care workers. Proxy reporting.	Nine focus groups with direct care workers from five community-based organisations
Guerin, Dodd, Tyrell, McEvoy, Buckley, Hillery 2009, Ireland	An initial assessment of the psychometric properties of the complicated grief questionnaire for people with intellectual disabilities (GCQ-ID)	Describe and gather psychometric data on a carer (proxy) reported complicated grief scale for people with ID that were recently bereaved. Data taken over a two-year period using a matched samples independent group design.	Adults with mild or moderate ID. One group experienced a parental death, 76 participants (Bereaved group $n = 38$ ; comparison group $n = 38$ ). Mean age 40; Male 58, female 41
Marston, Clarke 1999, England	Making contact--bereavement and Asperger's syndrome	Case review	21-year-old man with Asperger's syndrome following the death of a family member

Table 1. (Continued)

Author, Year, Country	Title	Methodology	Population characteristics
Mitchell & Clegg, 2005, England	Is post-traumatic stress disorder (PTSD) a helpful concept for adults with intellectual disability?	Two focus groups comprised of professionals, produce a descriptive thematic analysis of PTSD in people with ID.	10 participants across two focus groups including professionals from psychiatry, psychology, social work, nursing, and care officers.
Morgan & McEvoy, 2014, Ireland	Exploring the bereavement experiences of older women with intellectual disability (ID) in long-term residential care: a staff perspective.	Interpretative phenomenological analysis of staff experiences of supporting individuals with varying degrees of ID through grief.	150 older women aged 55–90 with varying degrees of ID and other care needs. A sample of 10 female staff (28–56 years) were interviewed.
O'Keefe, Guerin, McEvoy, Lockhart, Dodd 2018, Ireland	The process of developing self-report measures in intellectual disability: A case study of a complicated grief scale	Case study of the experience of developing a self-report complicated grief questionnaire. Data collection using focus groups and then pilot of the questionnaire.	Participants: Over 18, recently bereaved, from six different intellectual disability services. Included five men and five women. Tool piloted with six adults with mild or moderate ID.
Read & Elliot, 2007, England	Exploring a continuum of support for bereaved people with intellectual disabilities: A strategic approach. Addressing grief and loss in adults with developmental disabilities.	A case study: Demonstrate the practicalities of an integrated bereavement support framework. Literature review, conceptualising loss in people with ID. Conceptual model of bereavement intervention proposed.	A 42-year-old woman with ID, living in a residential unit, experienced a bereavement.
Stoddart & McDonnell, 1999, Canada			N/A
Young, 2017, UK	Overcoming barriers to grief: supporting bereaved people with profound intellectual and multiple disabilities.	Conceptual paper: Assessment of the social, emotional, and physical constraints impacting the people with ID experience of bereavement.	N/A



Table 1. (Continued)

Author, Year, Country	Definition and defining principles	Signs and symptoms	Risk and Protective factor	Treatment approaches
Blackman, 2003, England.				ROC loss & bereavement service: Specialist service with a drama therapist, analytic psychotherapist, and integrative psychotherapist. Staff bereavement training. Assessment tools: Allow for appropriate response to social, emotional, and practical needs. Proposes the use of the BNAT (10 question) assessment tool.
Blackman, 2008, England			<p><b>Risk Factors:</b>            Death of a family member, insecure attachment, unrecognised secondary losses, unattended practical daily issues, poor staff confidence in supporting people with ID following a bereavement. ID specific risks: communication difficulties, cognitive difficulties/concept of death.</p> <p><b>Risk factors:</b>            Insecure attachment, deficits in the supporting environment, and the Intellectual disability itself.</p>	Relational psychotherapy - considers unconscious processes within relationships, relevant to the treatment of CG in people with ID, along with grief education and behavioural interventions.
Blackman, 2016, UK	Lack of clarity regarding normal versus complicated grieving in people with ID.			
Bonell-Pascual <i>et al.</i> , 1999, England		Grief is prolonged in people with ID. Onset of grief symptoms is delayed in people with ID. CG in people with ID can present similarly to other conditions, for example, depression.		
Bricknell & Munir, 2008, USA	Differences between ID and general population are unclear. Diagnostic uncertainty, overshadowing evident. Research is needed to clarify symptoms, accurately diagnose,		<p><b>Risk factors:</b> Secondary losses, Communication difficulties, Cognitive difficulties.</p>	Lack of bereavement specific interventions for people with ID. Suitable bereavement assessment measures are needed to allow for appropriate treatment. Targeted supportive therapy (responding to

Table 1. (Continued)

Author, Year, Country	Definition and defining principles	Signs and symptoms	Risk and Protective factor	Treatment approaches
Dodd, Dowling, Hollins 2005, Ireland	and improve care. Research challenges include communication and cognitive difficulties. Accurate assessments needed, with focus on observable outcomes.	Delayed onset of grieving in people with ID.		environmental factors and secondary losses) is a potential treatment for CG. Goal setting interventions (to restore confidence and life engagement). Communication focused counselling.
Dodd & Guerin, 2009, Ireland	Research is needed for accurate description of the symptoms, time frame and severity of CG symptoms in people with ID. Research on traumatic grief symptoms is lacking. Unclear definition: Gaps in the literature as mainly smaller studies and case reports. Research challenges: people with ID have differences in understanding death. Terminology: Prolonged grief used in general population. Complicated grief used in ID population.	CG: Separation distress symptoms are more prominent than traumatic grief symptoms in people with ID.	<b>Risk factors:</b> Secondary losses: for example, loss of family home, communication difficulties, poor understanding of the meaning of the loss. <b>Protective Factors:</b> Bereavement ritual education.	Accurate diagnosis and effective treatment, requires improved understanding of CG in people with ID. Appropriate bereavement services should be developed. There is a lack of evidence-based staff training interventions. Prospective research studies are needed. To develop effective treatment options, we must improve our understanding and diagnosis of CG.
Dodd, Guerin, McEvoy, Buckley, Tyrell, Hillery 2008, Ireland	Unclear if difficulties in people with ID post bereavement represents normal or complicated grief. Complicated grief is prevalent in people with ID: 1/3rd of participants showing signs of CG on a carer reported scale (GCQ-ID)	Grief prolonged in people with ID. Both traumatic grief and separation distress symptoms are evident. Separation distress symptoms are prominent. Carer reported scales can distinguish bereaved and non-bereaved groups.	<b>Risk factors:</b> Death of a parent. Bereavement ritual involvement. <b>Protective factors:</b> Death and bereavement ritual education.	Bereavement assessment tools, like the carer reported GCQ-ID, allow for accurate diagnosis and subsequently appropriate treatment.

Table 1. (Continued)

Author, Year, Country	Definition and defining principles	Signs and symptoms	Risk and Protective factor	Treatment approaches
Dodd, McEvoy, Lockhart, Burke, O Keefe, Guerin 2021, Ireland	GCCQ-ID self report ID to self-report personal experience of symptoms following a parental bereavement. Self report tools reported higher symptoms of CG compared to proxy report tools.	GCCQ-ID self report symptoms in people with ID following a parental bereavement. Separation distress symptoms are particularly evident.		
Grey, Abendroth 2016, USA		Separation distress symptoms are prominent: Intense longing, difficulty adapting to life after a bereavement, difficulties finding meaning in the loss.	<i>Protective factors:</i> Ritual involvement: Healing by fostering closure for people with ID	Targeted supportive treatment: Individualised treatment focusing on environmental factors, including responding to secondary losses. Staff grief training.
Guerin, Dodd, Tyrell, McEvoy, Buckley, Hillery 2009, Ireland	There are challenges in conducting research with people with ID: Including environmental factors and the non-homogenous nature of people with ID. Accurate complicated grief assessment scales are needed but general population scales may not be appropriate.	Carer reported GCCQ-ID scale and subscales (separation distress and traumatic grief) showed good internal and inter-rater reliability and can distinguish people with ID that recently experienced a bereavement from people with ID that did not. GCCQ-ID may be an appropriate tool to help identify CG in people with ID.		
Marston, Clarke 1999, England			<i>Risk factors:</i> Delayed and exaggerated grief in people with pervasive developmental disorders. <i>Risk Factors:</i> People with ID may be at a higher risk of developing PTSD post parental death, especially if they witness the death.	
Mitchell & Clegg, 2005, England				

Table 1. (Continued)

Author, Year, Country	Definition and defining principles	Signs and symptoms	Risk and Protective factor	Treatment approaches
Morgan & McEvoy, 2014, Ireland			<p><i>Risk factors:</i> Insecure attachment. Absence of secure psychological identity. Masking of grief. Disenfranchised grief.</p> <p><i>Risk issues:</i> Secondary losses. Communication difficulties.</p>	<p>Assessment tools are needed to identify cases and allow for appropriate treatment. Self-report</p> <p>GCCQ-ID may be appropriate to use in people with ID and can have advantages over proxy reporting scales. Standardised assessment tools are needed to facilitate and enhance grief work and treatment. Carer and complicated grief training is needed for managing complicated grief. Staff communication training. Bereavement specialty services: staff should be able to recognise complicated grief and refer appropriately.</p> <p>Research is needed on grief in people with ID. Accurate measures of treatment responses are needed. Carer grief training. Systems based intervention is proposed which is a time limited intervention including bereavement group and individualised treatment.</p>
O'Keeffe, Guerin, McEvoy, Lockhart, Dodd 2018, Ireland	Unclear definition of normal grieving process in people with ID. It may be appropriate to use self-report grief scales in people with ID.		<p><i>Protective factors:</i> Consistent availability of supports before and after experiencing a bereavement. Staff/carer training on death/dying. General supports for staff/carers.</p>	
Read & Elliot, 2007, England				
Stoddart & McDonnell, 1999, Canada	Complicated grief is common in people with ID		<p><i>Risk factors:</i> Loss of a carer. Dependency on the deceased. Personality disorders. Masking of grief. Avoidance of grief by others. The death is sudden. Previous unresolved losses. Exclusion from bereavement rituals.</p>	

Table 1. (Continued)

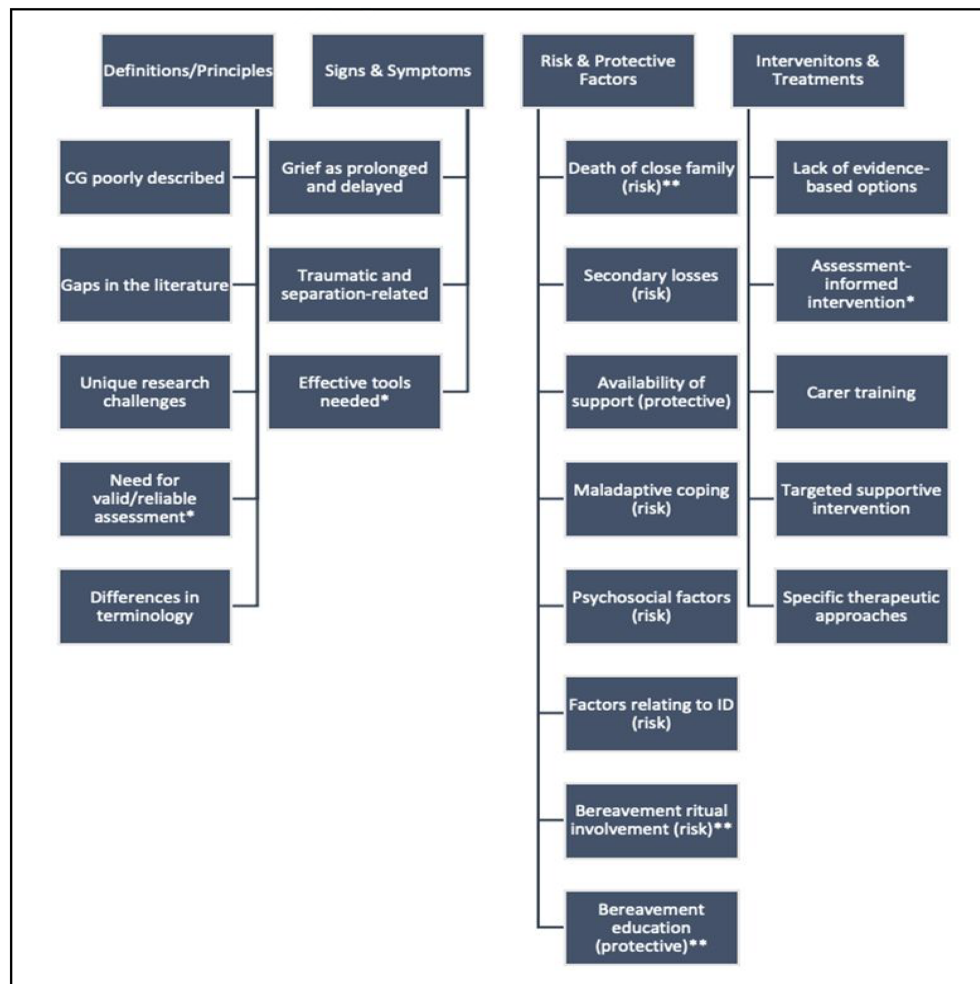
Author, Year, Country	Definition and defining principles	Signs and symptoms	Risk and Protective factor	Treatment approaches
Young, 2017, UK			Protective factors: Anticipated loss Risk issues: Attachment difficulties. Communication deficits. People with ID may lack the internal resources to manage difficult emotions. Protective factors: Bereavement ritual education. Staff/carer bereavement training.	There is a lack of evidence-based staff bereavement training interventions.

Munir, 2008). It can therefore be difficult to assess whether difficulties experienced post-bereavement represent normal or more complicated grieving processes (Bricknell & Munir, 2008; Dodd *et al.*, 2008; O'Keeffe *et al.*, 2019). Diagnostic overshadowing or the tendency to ascribe a difficulty to the disability itself can result in caregivers underestimating the impact of grief in people with ID (Bricknell & Munir, 2008).

Research on CG in people with ID has improved, but gaps in the literature certainly remain. This has been highlighted throughout the literature where smaller studies and descriptive case reports make up a significant portion of the available research (Dodd & Guerin, 2009). Further research is needed to allow for accurate description of the symptoms, time frame and severity of CG symptoms in this population (Dodd *et al.*, 2005). This is needed to allow for improved clinical care of people with ID (Bricknell & Munir, 2008). It has been highlighted that research focusing on traumatic grief symptoms is particularly lacking (Dodd *et al.*, 2005). In addition, there are a range of underlying causes of ID associated with the research participants, including various genetic factors. Future research on CG should consider defining people with ID into groups based on genetic factors as distinctive patterns of grieving may be evident in different genetic groups (Bricknell & Munir, 2008).

Research challenges associated with people with ID have been highlighted as possible factors to explain the lack of available research of CG. Examples include varying levels of understanding death (Dodd & Guerin, 2009), along with environmental factors, and the non-homogenous nature of this group (Guerin *et al.*, 2009). Moreover, differences in ability in people with ID, including cognition and communication difficulties, can make it difficult for the person to convey thoughts and feelings to investigators undertaking research (Bricknell & Munir, 2008).

Despite gaps in the literature and challenges in research with this population, there is evidence showing not only similarities but also noticeable differences in terminology used between people with ID and the general population. Prolonged grief disorder is the diagnostic term most often used in the general population, whereas complicated grief is most used when referring to people with ID (Dodd &



**Figure 2.** Overview of themes identified from the analysis of the extracted data. \*Findings contributing to the overarching theme of assessment. \*\*Risk/protective factors with empirical support. [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

Guerin, 2009; Dodd *et al.*, 2021). The literature also refers to people with ID being at higher risk of developing traumatic grief, a term sometimes used to describe complicated grief (Mitchell & Clegg, 2005; Gray & Abendroth, 2016).

### Signs and symptoms

Across the papers included in this review, a range of signs and symptoms of CG in people with ID have been identified. Firstly, CG may be especially prevalent in people with ID (Stoddart & McDonnell, 1999; Dodd *et al.*, 2008). Indeed, one third of bereaved people with ID experienced 10 or

more clinically apparent symptoms of complicated grief, following the bereavement of a parent. This includes missing the deceased person so much they cannot tolerate it, avoiding reminders of the deceased person and struggling to engage in normal activities (Dodd *et al.*, 2008). Grief also appears to be prolonged in people with ID following a parental bereavement (Bonell-Pascual *et al.*, 1999; Dodd *et al.*, 2008). Moreover, a delayed onset of grieving has been highlighted in parentally bereaved people with ID (Bonell-Pascual *et al.*, 1999; Dodd *et al.*, 2005). In people with ID, both traumatic grief symptoms (disbelief and bitterness over the loss) and separation distress symptoms (yearning for the

deceased, being unable to think about anything other than the deceased, and distrust of others) are present post bereavement (Dodd *et al.*, 2008; Dodd *et al.*, 2021). Dodd *et al.* (2008) used a carer reported questionnaire, the Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID), to compare parentally bereaved people with ID to a control group of non-bereaved individuals with ID. Dodd *et al.* (2021), using a self-reported complicated grief questionnaire (GCQ-ID self report), demonstrated the capacity of people with ID to self-report personal experience of symptoms of complicated grief. Interestingly, both papers identified that separation distress symptoms appear to occur more frequently than traumatic grief-type symptoms (Dodd *et al.*, 2008; Dodd & Guerin, 2009; Gray & Abendroth, 2016; Dodd *et al.*, 2021). Dodd *et al.* (2008) cited Bowlby's (1980) proposition that grief can be considered a general response to separation where an attachment has been broken. People with ID may therefore be more vulnerable to developing attachment difficulties.

### Risk and protective factors

Overall, 12 of 18 papers referred to risk or protective factors for CG in people with ID, presenting a range of overlapping factors. It should be noted that most of the risk factors proposed in the literature are theoretical in nature as opposed to being experimentally proven. The majority of empirical papers reporting risk/protective factors were case study/qualitative papers ( $n = 6$ ), with only one paper conducting a larger quantitative assessment (Dodd *et al.*, 2008). While providing some empirical basis for these risk factors, it is noted that this paper shows a correlation between complicated grief and these factors and is based on proxy report, thus limiting the extent to which these are evidenced. The risk and protective factors noted by Dodd *et al.* (2008) are noted in Figure 2; however, the factors identified across the papers included are discussed here.

The death of a close family member is considered a risk factor for CG in people with ID (Stoddart & McDonnell, 1999; Blackman, 2008; Dodd *et al.*, 2008; Dodd *et al.*, 2021). Dodd *et al.* (2008) found that one-third of people with ID showed 10 or more symptoms of CG following the death of a parent. The parent's gender did not significantly

impact the results and neither did the strength of the relationship between the people with ID and the deceased parent (Dodd *et al.*, 2008). When the loss is sudden or if unresolved previous losses are present, this risk may increase further. When the loss is anticipated, it is likely protective against CG in people with ID (Stoddart & McDonnell, 1999).

Secondary losses such as loss of the family home and having to move in with paid carers have been highlighted as proposed risk factors for CG (Bricknell & Munir, 2008; Dodd & Guerin, 2009; O'Keeffe *et al.*, 2019). These can often go unrecognised, compounding the original grief (Blackman, 2008). Not attending to these losses or the practical daily needs of the person will likely increase the risk of CG further (Blackman, 2008). Deficits may include poor access to social supports (Blackman, 2016), lack of staff training and low staff confidence in supporting bereaved people with ID (Blackman, 2008). Indeed, a consistent availability of support for the people with ID both during and after the death are likely protective against the development of CG (Read & Elliot, 2007). Disenfranchised grief or grief that is not acknowledged has been proposed as a risk factor for CG in people with ID (Morgan & McEvoy, 2014). Interestingly, people with ID may be negatively influenced when grief is avoided by others, potentially increasing the risk of CG further (Stoddart & McDonnell, 1999). This highlights the importance of providing appropriate staff/carer training on death and dying including how best to support the bereaved people with ID (Read & Elliot, 2007; Young, 2017). General supports for staff and carers are also important so that the carer is best able to support the people with ID (Read & Elliot, 2007).

A study looking at staff experience supporting older people with ID living in a residential setting highlighted how people with ID can tend to mask or hide their grief, a maladaptive coping strategy that may increase the risk of CG further (Morgan & McEvoy, 2014). Masking of grief may be common because people with ID may not always be able to verbally express the many feelings involved in grief, likely increasing the risk of CG further (Stoddart & McDonnell, 1999). Other papers have highlighted how psychosocial factors, such as insecure attachment and the associated absence of a secure psychological identity in people with ID, may increase the probability of complicated grief in this group

(Blackman, 2008; Morgan & McEvoy, 2014; Blackman, 2016; Young, 2017). Personality disorders and unresolved emotional issues may also increase risk in people with ID (Stoddart & McDonnell, 1999). Indeed, people with ID may lack the internal resources to manage difficult emotions following the death and importantly may lack the ability to seek and obtain external support systems when needed (Young, 2017).

There may be CG risk factors relating specifically to ID itself (Blackman, 2016). Communication difficulties, for example, especially difficulties communicating grief following a death, have been proposed many times as a risk factor for CG (Bricknell & Munir, 2008; Dodd & Guerin, 2009; O'Keeffe *et al.*, 2019). Communication deficits can make adjusting to a world without the deceased even more challenging (Young, 2017). This is especially true if the person with ID is dependent on the deceased person (Blackman, 2008), which can leave the person unskilled and unprepared for losses and the future (Stoddart & McDonnell, 1999). Cognitive difficulties may increase this risk if the person with ID has a delay in developing a concept of death (Blackman, 2008). Some people with ID may struggle to understand the meaning of this loss, increasing the risk further (Bricknell & Munir, 2008; Dodd & Guerin, 2009). Delayed and exaggerated grief has been shown in people with pervasive development disorder, possible by virtue of social and cognitive impairment (Marsten & Clarke, 1999). It is clear that factors relating to the intellectual disability itself may be important risk factors in developing CG.

Interestingly, bereavement ritual involvement has been shown, in some circumstances, to increase the risk of CG in people with ID (Dodd *et al.*, 2008). Dodd acknowledges how meaningful ritual involvement can be for the individual but highlights how bereavement involvement may exacerbate separation distress symptoms, especially if the people with ID has limited previous exposure to ritual involvement or has limited prior understanding of what is involved in the bereavement ritual (Dodd *et al.*, 2008). In contrast, the importance of bereavement involvement has been highlighted by emphasising its important role in the healing process by helping to foster closure for the people with ID (Gray & Abendroth, 2016). Exclusion from bereavement rituals may indeed be a risk for CG

(Stoddart & McDonnell, 1999). In this context, it has been proposed that death education and education on bereavement rituals prior to the death are potentially important protective factors against developing CG in this population (Dodd *et al.*, 2008; Young, 2017).

### Interventions and treatments

Overall, 11 of the 18 papers discuss the treatment of CG for people with ID. A lack of evidence-based treatment options for CG in people with ID was particularly evident, including evidence-based staff training interventions (Dodd & Guerin, 2009; Young, 2017) and specific interventions for people with ID (Bricknell & Munir, 2008). It has been proposed that future research, including prospective studies on grief in people with ID, are needed to improve our understanding, allow for accurate identification of CG in people with ID and inform the subsequent development of effective treatment options (Stoddart & McDonnell, 1999; Dodd *et al.*, 2005; Dodd & Guerin, 2009). Moreover, research measuring treatment outcomes (Stoddart & McDonnell, 1999) is equally important.

The importance of carer training in managing grief and CG has been highlighted in the literature numerous times (Stoddart & McDonnell, 1999; Read & Elliot, 2007; Gray & Abendroth, 2016). For example, staff communication training can facilitate a skilled approach to deliver difficult news, facilitate and communicate grief in an accessible manner for the people with ID (Read & Elliot, 2007). Moreover, appropriate staff training can facilitate tailored support systems, helping people with ID work through or even bypass traumatic grief reactions along with helping staff to manage their own grief symptoms (Gray & Abendroth, 2016).

Looking at the formal interventions discussed, targeted supportive interventions focusing on environmental factors including responding to secondary losses have been proposed for the treatment of CG (Bricknell & Munir, 2008). Bereavement services for people with ID may play an important role in treating CG in this population (Blackman, 2003; Dodd *et al.*, 2005; Read & Elliot, 2007). The ROC loss and bereavement therapeutic service is a specialist UK service aimed at providing therapy to adults with intellectual impairments experiencing difficulties connected to a



bereavement or loss. It is composed of a drama therapist, an analytic psychotherapist and an integrative psychotherapist (Blackman, 2003). Staff training on supporting a bereaved person with ID is important, in particular ensuring staff are not only confident in supporting individuals but are able to identify when referral to specialty services such as ROC is appropriate (Blackman, 2003). Dodd *et al.* (2005) also promote the idea of having specialty bereavement services, but these services should be based on a clear understanding of CG in people with ID (Dodd *et al.*, 2005). Similarly, the importance of carer-directed tailored support systems has been highlighted by Gray and Abendroth (2016).

Although grief education and behavioural interventions are important, the literature does propose specific therapeutic approaches for managing CG in people with ID. Blackman (2016) proposes the use of relational psychotherapy, an approach that considers the unconscious processes at play within relationships, such as the relationship between the paid carer and the client. With this approach, staff may better understand the dynamics within their supportive relationships enabling them to provide skilled and insightful care reducing the impact of CG (Blackman, 2016). Goal setting interventions may prove to be important whereby the therapist can help restore those individuals' self-confidence and engagement in life (Bricknell & Munir, 2008). Moreover, as people with ID may have few opportunities to talk about their feelings following a loss, communication-focused counselling sessions may prove to be beneficial (Bricknell & Munir, 2008), whereas Stoddart and McDonnell advocate for the use of a systems-based approach including a model for a time limited intervention consisting of both bereavement group and individualised treatment (Stoddart & McDonnell, 1999). Finally, a systems-based intervention comprising both individual and group work has been proposed and aims to help the bereaved people with ID move towards creating a new life without the deceased and to assist the person with mourning (Stoddart & McDonnell, 1999).

### An overarching theme

Across the topics examined in this analysis, the importance and indeed challenges of assessing CG in

this population were identified. In the context of defining CG, the analysis identified that valid and reliable CG assessment scales are needed to allow services to identify and support individuals with CG (Guerin *et al.*, 2009). This is vital in helping to produce a clear definition of CG in this population. General population grief scales and questionnaires can use complex language and may not be appropriate for use in this group (Bricknell & Munir, 2008; Guerin *et al.*, 2009). Effective assessment is especially important where carers often underestimate grief (Bricknell & Munir, 2008). CG assessment for this population may benefit from having a focus on practical measurable outcomes, such as the ability to perform everyday tasks (Bricknell & Munir, 2008). More recent papers highlight however that self-report scales, such as the Self Report version of the CGQ-ID, can be appropriate to use in an ID population (O'Keeffe *et al.*, 2019). People with ID using the self-report GCQ-ID, following a parental death, reported higher levels of CG symptoms compared with CG symptoms identified by carers using the carer reported GCQ-ID (Dodd *et al.*, 2021). This indicates that people with ID not only have the capacity to self-report their personal experience of CG symptoms but also that self-reported scales may be more sensitive than proxy scales at identifying CG symptoms.

When considering the signs and symptoms of CG, it was noted CG may present in a manner similar to other conditions such as mood disorders, anxiety disorders and disturbances in conduct and emotions (Bonell-Pascual *et al.*, 1999). Therefore, objective measures and screening tools are crucial. Carer reported scales such as the CGQ-ID have been shown to accurately distinguish bereaved and non-bereaved people with ID (Dodd *et al.*, 2008). Guerin *et al.* (2009) reported that the scale and subscales of the CGQ-ID showed very good internal and inter-rater reliability and was able to distinguish bereaved and non-bereaved people with ID. Guerin *et al.* suggest that this is evidence for the potential use of the scale in identifying symptoms of complicated grief in this group. It is likely a combination of self-report and proxy-report scales will prove to be pivotal in assessing the signs and symptoms of CG, but further research is required.

Finally, when considering interventions for CG, the importance of assessment tools in identifying and

responding to specific social, emotional and practical needs is evident (Read & Elliot, 2007; Blackman, 2008; Dodd *et al.*, 2008; O'Keeffe *et al.*, 2019). Blackman (2008) proposes the use of a 10-question bereavement needs assessment tool called BNAT to inform appropriate response to these bereavement needs (Blackman, 2008). To facilitate and enhance grief work and treatment options, carers need to be able to adequately assess the bereavement needs of the individual, and therefore, standardised bereavement assessment tools should be developed (Read & Elliot, 2007).

## Discussion

We believe this is the first systematic literature review investigating CG in people with ID, covering the topics of definition and defining principles, signs and symptoms, risk and protective factors, and treatment options.

There is a growing body of evidence available supporting the hypothesis that people with ID experience CG and importantly that it is a clinically relevant condition. This paper highlights how research specifically looking at CG for people with ID is often based on case reports and opinion pieces. Therefore, larger scale empirical studies are needed to enhance our understanding of this condition and to provide evidence on how best to support people with ID who experience CG symptoms. Within the general population, diagnostic criteria are defined and there are well-validated interventions such as complicated grief therapy for people of varying ages experiencing CG or prolonged grief disorder. The literature investigating CG in people with ID continues to present uncertainties around diagnostic criteria and treatment approaches.

A pertinent finding of this review indicates that CG is prevalent in people with ID with initial data indicating it may be more frequent for people with ID compared with the general population (33% vs. 9.8%). Grief symptoms are often prolonged, and the onset of symptoms are delayed in people with ID. Therefore, CG presents as a clinically important condition within this population and is currently likely missed or misdiagnosed. We recommend clinicians consider CG in their differential diagnosis for people with ID, even if symptoms develop some time after the death. Moreover, people with ID

experience both traumatic grief and separation distress symptoms, although separation distress symptoms are more frequent, highlighting possible vulnerabilities to attachment difficulties in people with ID. An overarching theme across the literature relates to the importance of developing valid and reliable assessment/screening tools not only to allow for accurate identification of cases but also as a vital step in allowing for appropriate treatment of this condition. Encouragingly, the GCQ-ID assessment scale along with self-report versions seems to be effective at identifying symptoms of complicated grief for this population. We are encouraged by these findings along with the potential of other tools such as the bereavement needs assessment tool (BNAT). We propose a combination of self-reported and proxy-reported CG questionnaires to help screen for CG symptoms going forward.

Although many papers discussed risk and protective factors, it is pertinent to highlight that the majority of risk factors discussed in the literature available are not empirically derived but are instead theoretical in nature. This highlights the need for longer-term empirical studies to help clarify the risk factors for this condition. Despite these limitations, the proposed risk factors may indeed be clinically important and include the death of a family member, secondary losses, psychologically based risk factors and risk factors associated with the learning disability itself. It may be difficult to address or alleviate all of these risk factors, but clinicians should assess for their presence when considering a diagnosis of CG. We also agree with recommendations that addressing secondary losses, along with appropriate staff/carer grief training would hopefully reduce some of the risk factors highlighted. Of the risk factors identified, bereavement ritual involvement may be the most interesting as it is one of the few experimentally identified risk factors. We understand, however, that ritual involvement can play an important, core role in the grieving process for many people. We do however agree with recommendations that death education and bereavement ritual education should be considered to reduce this risk.

The findings suggest that a lack of evidence-based CG treatment options remain, including evidence-based staff communication, grief and complicated grief training approaches. A number of approaches have been proposed in the literature, but

the authors note that they have yet to be evaluated in a comprehensive empirical manner within this population. It does appear that a dual approach including supportive interventions addressing environmental factors and secondary losses along with specialist bereavement/psychological interventions be considered. Indeed, a number of specific therapeutic approaches have been proposed including relational psychotherapy, communication focused counselling and systems-based interventions. We conclude that further work is needed in developing and testing treatment approaches for CG. We recommend that evidence-based approaches such as complicated grief therapy in use in the general population be adapted, trialled and evaluated for an intellectual disability population.

Before drawing conclusions, there are a number of strengths and limitations in the methodology of this review that should be considered. To begin, rigorous methods based on the PRISMA guidelines were used to develop the search. However, the original search aimed to identify papers on the broader topic of bereavement/grief in ID, with a second round of screening conducted to identify papers on the specific topic of complicated grief. There is no doubt that the variety of terms used to refer to the concept named here as complicated grief had the potential to undermine the search process, however the use of multiple screeners and the review of papers where there was disagreement contributes to confidence in the search process. Finally, the decision to rerun the search prior to completing the analysis ensured that more recent papers were identified for inclusion. On balance, we are confident that the key literature has been identified as part of this search.

To conclude, this systematic review provides evidence that CG is indeed a common and important condition for people with ID and we note several key clinical findings. CG remains poorly defined for people with ID, particularly when trying to separate normal from complicated grieving processes. This may be secondary to deficits in the available literature, arising in the context of unique research challenges associated with people with ID. We are encouraged that there is clearly a growing recognition of this condition in the literature, but reliable assessment scales and clear diagnostic criteria are needed in order to help clinicians to accurately identify this condition. There is then a need for larger scale empirical studies

and a need to develop and trial therapeutic approaches for this condition.

### Acknowledgements

Anyone who contributed to the project in a significant way are co-authors.

Open access funding provided by IReL.

### Source of funding

No external funding was received for the research reported in the paper.

### Conflict of interest

None to report.

### Data availability statement

Not applicable.

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Accepted 5 August 2022