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Bereavement support and Prolonged Grief Disorder:

Scoping and mapping the evidence

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Peer review

Systematic reviews for the PRP reviews facility are typically peer-reviewed to ensure their findings and conclusions are robust. Peer review was not required for this work as it is a systematic map rather than a systematic review, in other words, it provides an overview of available research rather than a synthesis and appraisal of research.

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Conflicts of interest

There were no conflicts of interest in the writing of this report.

Contributions

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List of abbreviations

BAME	Black, Asian and minority ethnic
CBT	Cognitive behavioural therapy
DHSC	Department of Health and Social Care
GP	General practitioner
HIC	High-income countries
ICU	Intensive care unit
LGBT+	Lesbian, gay, bisexual, transgender and other sexual identities
LMHIC	Low-, middle- or high-income countries
LMIC	Low- or middle-income countries
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
PGD	Prolonged Grief Disorder
PTSD	Post-traumatic stress disorder
UK	United Kingdom
USA	United States of America

EXECUTIVE SUMMARY

Background

Most people adapt successfully to bereavement over time without the need for formal support or treatment. Some individuals experience abnormally persistent and intense symptoms of grief that significantly interfere with daily functioning and increase the risk of adverse physical and mental health outcomes. This condition has been described using various terms including Prolonged Grief Disorder (PGD). The prevalence of PGD is thought to be more common in certain circumstances, for example, following the death of a partner or child, and when individuals are bereaved as a result of a sudden, unexpected, or violent death including suicide.

Death, loss and bereavement are disproportionally experienced by groups who face social and structural inequities. The combined life circumstances of these individuals may also result in greater vulnerability to PGD. It has been suggested that the COVID-19 pandemic will lead to an increase in PGD cases. Any pandemic-related increase in PGD may disproportionally affect vulnerable communities as evidence shows that COVID-19 mortality is highest amongst disadvantaged groups including people from minority ethnic communities and individuals of all ethnicities living in deprived areas.

The London-York NIHR Policy Reviews Facility was asked by the Department of Health and Social Care (DHSC) in England to identify evidence on several issues related to PGD to inform policy and practice, with the ultimate aim of reducing the prevalence of the condition and the strain on services.

Aim

We aimed to systematically scope and map the research evidence on grief, bereavement and PGD in relation to a range of questions of interest to the DHSC. We sought to identify the availability of evidence from systematic reviews on the following issues:

- the extent and nature of PGD;
- risk factors for PGD;
- grief and bereavement experiences including the needs of bereaved people and the barriers to accessing grief services; and
- the effectiveness of interventions for preventing or treating PGD.

We also sought to identify primary studies reporting on the types of bereavement support services that are available in the UK. Our objective was to provide a high-level overview of the available evidence which enables potential research gaps to be identified. We did not seek to extract, evaluate and synthesise findings from included studies.

Methods

We searched 12 databases and the websites of 18 organisations primarily for systematic reviews that focused on any of the following: the frequency or risk of PGD; the relationship between grief-related outcomes and potential risk factors; experiences of bereavement and service use; and reviews of intervention effectiveness/impact, cost-effectiveness and/or implementation. We also searched for primary studies on the type and availability of bereavement support services in the UK. All searches were limited by publication date (2015 onwards), but no language restrictions were applied.

We extracted key characteristics from reviews and primary studies which allowed us to produce a high-level descriptive summary detailing the extent and nature of the current evidence base relevant to the questions of interest to the DHSC. We also created an interactive map of the evidence, which displays our findings visually and enables users to view the bibliographical details of included reviews and primary studies.

Key findings

We screened 5627 records and included 212 reviews; 96 protocols including four protocols for reviews that were completed but not yet published; and 16 primary studies.

Broad topic focus of reviews and protocols

To assess the extent of evidence available on the key issues of interest to DHSC, we coded reviews and protocols according to the type of evidence they focused on. The largest group of reviews (n=103) and protocols (n=44) explored individuals’ grief and bereavement experiences. The second largest group of reviews and protocols focused on the effectiveness of grief-related interventions (80 reviews and 38 protocols). We identified 42 reviews and 14 protocols addressing risk and protective factors for prolonged grief. We also identified 37 reviews and six protocols that examined the relationship between specific factors and outcomes such as the severity or intensity of grief and individuals’ adjustment after bereavement rather than focusing on prolonged grief specifically. The remaining group of reviews (n=22) and protocols (n=12) focused on the extent and nature of prolonged grief amongst various groups of bereaved people. Fifty-five out of the 212 reviews and 17 out of the 96 protocols focused on two or more issues of interest. Many reviews also focused on specific populations, causes or types of death or deaths in specific settings.

Reviews and protocols focused on participants with a specific relationship to the deceased

Most reviews (n=123) and just under half of the protocols (n=44) focused on individuals who had a specific relationship with the deceased (carer, parent, spouse/partner, sibling, son/daughter, grandparent, health or care professional or work colleague). The remaining reviews (n=89) and protocols (n=52) had a generic focus on ‘family’ or ‘family and friends’ or focused on bereaved individuals with no specified relationship to the deceased.

Reviews and protocols focused on bereaved individuals with other specific characteristics

Sixty-one reviews and 34 protocols focused on bereaved adults. Sixteen reviews and eight protocols had a primary focus on bereaved children and young people. Nine reviews and three protocols focused on bereaved women. Four reviews and three protocols were about men only. Twelve reviews and two protocols had a focus on marginalised or minority populations.

Reviews and protocols focused on a specific cause/type of death

Most reviews (n=108) and protocols (n=50) focused on a specific cause or type of death. Of the 108 reviews, 90 focused on three main causes or types of death: a specific health condition or terminal illness such as cancer or dementia (n=36); perinatal loss (n=34); or suicide (n=20). The other 18 reviews examined violent or unnatural deaths (n=7); assisted suicide or euthanasia (n=3); sudden and unexpected deaths (n=2); non-violent deaths (n=2); drug-related deaths (n=2); COVID-19 related deaths (n=1); and mass events such as pandemics, natural and human-made disasters, or terrorism (n=1). Sixteen reviews did not examine a specific cause or type of death but were focused on a specific setting: intensive/critical care (n=9), acute care settings (n=3); in-hospital settings (n=2) emergency department (n=1); or long-term care (n=1). The 88 remaining reviews did not focus on a specific cause or type of death or deaths in a specific setting.

Of the 50 protocols focused on a specific cause or type of death, 16 addressed perinatal deaths and 13 focused on a specific health condition or terminal illness including one on suicide in people with dementia. Nine other protocols had a focus on suicide. Other protocols focused on deaths linked either directly or indirectly to COVID-19 (n=5); violent deaths (n=4); sudden and unexpected deaths (n=2); and epidemics (n=1). Five protocols were on deaths in a specific setting: hospital or intensive care unit (ICU) deaths (n=4) or care-home deaths (n=1). The remaining 41 protocols did not focus on a specific cause or type of death or deaths in a specific setting.

Evidence about the type of bereavement support services in the UK

Eleven out of the 16 primary studies described the type of support provided by organisations. Studies also reported on other issues: the availability of services (n=9); staff views about provision (n=6); service delivery issues (n=5); barriers to accessing services (n=2); and the socioeconomic costs of bereavement (n=1).

Eight out of the 16 studies focused on services following a specific cause of death or deaths in a specific setting. Three of the eight studies examined bereavement services following deaths from terminal illness, two of which focused specifically on hospice provision. Three studies focused on perinatal deaths, and another addressed best practice and services available for individuals bereaved by suicide. Another study focused on bereavement care in ICUs. Five studies reported on the provision of general bereavement services rather than focusing on support following a specific type of death or deaths in a specific setting. One of these studies had a specific focus on the socioeconomic costs of bereavement services in Scotland. Three other studies reported on the provision of services during the COVID-19 pandemic.

Gaps in the evidence

We identified only limited evidence on the influence of socioeconomic determinants and inequities on post-bereavement needs, experiences and service use. More broadly, the literature would benefit from a greater focus on the experiences and needs of the most marginalised and disadvantaged communities as these individuals may find it more difficult to access bereavement support and be at higher risk of PGD. Reviews exploring the bereavement experiences of different genders have focused solely on parents or the child-parent relationship. We did not identify any reviews addressing the cost-effectiveness of interventions. Reviews have evaluated a wide range of interventions; however, all but one had a primary focus on the individual level. The paucity of evidence on broader social, organisational or structural-level interventions is an important gap in the literature.

Conclusions and implications for additional synthesis work

Issues related to grief and bereavement, including PGD, have been extensively reviewed in the literature. We identified a large body of evidence addressing a range of questions of interest to the DHSC. Conducting additional syntheses may be of value if it was possible to identify a specific and focused research question to address a significant gap in knowledge. Appropriate additional work could involve supplementing existing reviews or conducting new reviews.

INTRODUCTION

Bereavement is a common experience with approximately 500,000 deaths annually in England and Wales. (1) By 2025, the number of UK deaths is forecast to exceed the number of births. (2) Research suggests that 72% of UK adults have been bereaved at least once in the previous five years. (3) Approximately 41,000 children in the UK experienced the death of a parent during 2015. (4) It is estimated that bereavement amongst employees costs the UK economy between £14 billion to £49 billion each year, the majority of which results from presenteeism. (5)

Grief is a natural reaction to bereavement and most people adapt successfully to their loss over time without the need for formal support or treatment. (6, 7) Some individuals experience abnormally persistent and intense symptoms of grief that significantly interfere with daily functioning and increase the risk of adverse physical and mental health outcomes. (8, 9) This condition has been described using various terms including chronic, complicated, pathological, prolonged, and traumatic grief; Persistent Complex Bereavement Disorder; and most recently Prolonged Grief Disorder (PGD). Terms appear to be used interchangeably in the literature, especially PGD, complicated and prolonged grief.

The prevalence of PGD amongst adults as a result of non-violent loss is estimated to be approximately 10%. (10) However, PGD is thought to be more common in certain circumstances, for example, following the death of a partner or child, and when individuals are bereaved as a result of a sudden, unexpected or violent death including suicide. (7, 11-13)

PGD has recently been recognised as a distinct mental health disorder in both the International Classification of Diseases 11th Revision (ICD-11) and the Diagnostic and Statistical Manual of Mental Disorders, revised 5th edition (DSM-5-TR), published by the World Health Organization and American Psychiatric Association, respectively. A key diagnostic criterion of PGD in both classification systems is that the duration of an individual's grief exceeds expected social, cultural or religious norms. (14, 15) However, the criteria for PGD in the ICD-11 and DSM-5-TR are not identical. For example, the DSM-5-TR requires the death of an adult to have occurred at least 12 months prior to diagnosis compared to at least six months in the ICD-11. (16)

The classification of PGD as a mental health disorder has not received universal approval. Various concerns have been raised around issues such as pathologising and medicalising grief, stigmatisation of the bereaved, and increased use/misuse of medication. (17-19) The status of PGD/complicated grief as a recognised mental health condition in the UK is unclear. According to the website of the charity Cruse Bereavement Support, there is not an accepted definition of complicated grief in the UK, and individuals are not usually diagnosed with it. (20)

Bereavement, Prolonged Grief Disorder and health inequity

It is important to consider issues of inequity in relation to bereavement and PGD, particularly as reducing health disparities forms a key part of the Government's 'Levelling Up' agenda. (21)

The concept of structural vulnerability describes how an individual's position in multiple and overlapping power hierarchies (for example, social, cultural, political and economic) puts them at increased risk of negative health outcomes. (22) It is a useful concept when applied to the study of health-related issues as it focuses attention on the way in which social and structural factors make certain individuals more susceptible to poorer outcomes by constraining agency and action and creating barriers to care. (22-26)

As a result of existing health inequities, death, loss and bereavement are disproportionally experienced by structurally vulnerable groups. (26, 27) For example, individuals living in the most deprived areas of England have higher mortality and a greater risk of death than people from the most affluent areas. (28, 29) Research from Scotland has also shown that children from the most disadvantaged households, either in terms of income, housing tenure or health status, are at greater risk of experiencing the death of a parent or sibling. (30) There is a clear link between deprivation and ethnicity with people from most minority ethnic groups being more likely than White British people to live in the most deprived neighbourhoods. (31)

The combined life circumstances of marginalised groups may result in greater vulnerability to PGD. Factors contributing to structural vulnerability such as lower socioeconomic status and low income have been linked to a higher risk of developing the condition. (16, 32) Furthermore, the types of death linked to an increased PGD risk, including suicide and violent deaths, are most common amongst disadvantaged communities. See, for example, deprivation and suicide; (33-35) homicide victimisation and minority ethnic status (36, 37) and deaths due to assault and deprivation. (38)

It has been suggested that the COVID-19 pandemic may lead to an increase in PGD cases. (6, 39, 40) Any pandemic-related increase in PGD may also disproportionally affect vulnerable communities as evidence shows that COVID-19 mortality is highest amongst disadvantaged groups including people from minority ethnic communities and individuals of all ethnicities living in deprived areas. (41-44) Furthermore, Routen et al. reported that lockdown restrictions had the biggest impact on the religious practices after death of minority ethnic groups, (45) which is one factor cited as potentially increasing the risk of PGD (for example, Groveas and Shear, 2020). (6)

Individuals on a low-income face greater difficulties accessing services following bereavement and are also more reluctant to seek support. (3, 5) Moreover, when people from deprived areas do receive care, they are significantly more likely to only rate it as poor or fair compared with individuals in the most affluent areas. (46) Rowley et al. identified a need to improve understanding of the type of support that individuals would find most helpful following bereavement within the context of poverty and deprivation. (47) More generally, it is important for informing policy and practice to gain a broader understanding of the post-bereavement experiences and needs of different groups of people, particularly those at the greatest risk of negative outcomes, and identify factors that act as barriers and enablers to care.

The concept of intersectionality recognises that multiple inequities interact to produce distinct experiences and outcomes. (48-50) Adopting an intersectional perspective therefore provides a more nuanced understanding of health issues. (49, 51) Viewing bereavement through this lens highlights how people's experiences of coping with loss and their use of services will be influenced by the interaction of social characteristics (such as gender, ethnicity, socioeconomic status and disability), structures of power, and unequal power relations. (48) Intersectionality also promotes equity by rejecting a 'one-size fits all' approach to policy development and service provision, which inevitably leaves some groups behind. (48, 51)

Policy context in relation to bereavement

The importance of bereavement support for specific groups has been recognised in a range of strategy and guidance documents published over the past 15 years. This includes, for example, individuals bereaved by suicide; (34, 52, 53) terminal illness; (54, 55) and following the death of a child or young person. (56)

Facilitating bereavement care has been identified as a key component of specialist-level palliative care. (57) The Faculty of Intensive Care Medicine also described as 'invaluable' bereavement care for families of critical-care patients (p.20). (58) Taking forward a commitment outlined in the NHS Long Term Plan, (59) the NHS Mental Health Implementation plan 2019/20-2023/24 included the target of providing post-crisis support in every local area for individuals bereaved by suicide to prevent poor mental health outcomes. (60)

Penny and Relf mapped the provision of bereavement care to indicators in multiple Health and Social Care Outcomes Frameworks, including those related to public health, NHS outcomes and adult social care. (61) Importantly, there is currently no cross-departmental strategy for bereavement care in England through which to coordinate policy and practice. (62)

Revised national service standards for bereavement care were published in 2014. (63) These standards defined a set of quality criteria applicable to all bereavement services and provided a framework against which organisations can appraise, develop, and improve care provision. (63) More recently, the National Palliative and End of Life Care Partnership, which includes NHS England and NHS Improvement, published a framework to improve palliative and end-of-life care. It comprised six 'ambitions' that reflect best practice for palliative and end-of-life care in England including bereavement and pre-bereavement care. (64) A specific national framework and associated standards also exists to improve bereavement care for parents in English NHS trusts after pregnancy or baby loss. (65)

There have been new strategy and guidance documents relating to bereavement care published recently in other countries of the UK. This includes a national framework for the delivery of bereavement care in Wales, (66) and a bereavement charter in Scotland. (67) The latter provided a set of statements and guidance on how to support bereaved individuals effectively.

Bereavement support in England

Bereavement services in England are provided through multiple sectors and agencies including acute care, local authorities, primary care and third sector organisations such as hospices and other charities. (68) Bereavement care can be commissioned across a range of services within health and social care including end-of-life care; suicide prevention and other mental health provision; support for carers; maternity services; and emergency preparedness. (61)

Concerns have been raised about variation in the availability and quality of bereavement care in England as well as its accessibility and financial sustainability. (3, 52, 62) In 2019, the National Bereavement Alliance called for greater clarity about local responsibility for commissioning and providing bereavement care, as well as better coordination, secure funding and information about available services. (62)

In 2022, the UK Commission on Bereavement published a review of bereavement support in England and other countries of the UK. (69) It produced eight key principles and related recommendations for change. These recommendations included: increasing statutory funding for bereavement and palliative care services; establishing a cross-departmental government bereavement strategy; development of guidance and minimum standards for the delivery of bereavement support; and requiring age-appropriate teaching in schools about coping with death and bereavement. They also included requiring employers and educational settings to have a bereavement policy; providing paid bereavement leave that covers all close relationships; greater provision of culturally and contextually informed bereavement training for individuals in contact with the bereaved; introducing measures to reduce the administrative and financial burden on the bereaved; and increasing focus on tackling inequality in the provision of bereavement support. (69)

Types of support

The National Institute for Health and Care Excellence (NICE) described a three-component model of bereavement support for families and carers following a death from cancer. (55) This model has since been supplemented by a public health approach to bereavement care comprising various categories of support (universal/selective or targeted/indicated) and applied to service provision more broadly. (61, 66)

(1) Universal/NICE component 1: support aimed at all bereaved individuals and 'uncomplicated grief'. It involves the provision of information about bereavement and sources of support. This may be provided as part of a conversation with health and social care professionals or supplied in written form or via online resources. At this level, support will be mostly provided by family, friends and existing social networks.

(2) Selective or targeted/NICE component 2: non-specialist, and often volunteer-based, support for bereaved individuals who are at increased risk of developing grief-related problems. Individuals are given a more formal opportunity to discuss and reflect on their loss. This type of support may take the form of self-help groups, peer support, befriending or faith groups, and trained support workers.

(3) Indicated/NICE component 3: specialist support or treatments for individuals with the most complex needs who are experiencing symptoms of a grief disorder or other mental health condition. This may involve mental health services/psychological support and bereavement counselling. (55, 61, 66)

A range of different forms of support is represented in the typology above and evidence is required on intervention effectiveness to inform and improve care provision.

Why is this review needed now?

There were approximately 200,000 deaths involving COVID-19 in the UK between March 2020 and June 2022. (70) If predictions of a COVID-related increase in PGD cases prove correct, it could place bereavement and health services under significant additional pressure as well as having implications for society more broadly, such as widening health inequities.

The London-York NIHR Policy Reviews Facility was asked by the Department of Health and Social Care (DHSC) in England to identify evidence on several issues related to PGD to inform policy and practice, with the ultimate aim of reducing the prevalence of the condition and preventing strain on services.

AIM

We aimed to systematically scope and map the research evidence on grief, bereavement and PGD in relation to a range of questions of interest to the DHSC. We sought to identify the availability of evidence from systematic reviews on the following issues:

- the extent and nature of PGD;
- risk factors for PGD;
- grief and bereavement experiences including the needs of bereaved people and the barriers to accessing grief services;
- the effectiveness of interventions for preventing or treating PGD.

We also sought to identify primary studies reporting on the types of bereavement support services that are available in the UK. Our objective was to provide a high-level overview of the available evidence which enables potential research gaps to be identified. We did not seek to extract, evaluate and synthesise findings from included studies. The questions of interest to the DHSC are available in Appendix 1, page 82.

METHODS

Identification of evidence

To identify relevant publications, we searched the following databases:

- MEDLINE
- Embase
- PsycINFO
- CINAHL
- Cochrane Database of Systematic Reviews
- Epistemonikos
- HMIC
- Social Policy & Practice
- Social Care Online
- Social Services Abstracts
- EThOS (British Library)
- PROSPERO (CRD)

We also searched the websites of the following organisations: the Center for Complicated Grief at Columbia University; Cruse Bereavement Support; National Bereavement Alliance; Sue Ryder; Marie Curie Palliative Care Research Centre; the Caresearch Project: Palliative Care Knowledge Network; Childhood Bereavement Network; Childhood Bereavement UK; Sands; the Irish Hospice Foundation; MIND; National Bereavement Service; the Good Grief Trust; the Good Grief Project; Marie Curie; NHS (bereavement support); Quakers Social Action; Winston's Wish; and Just B.

The search strategy for the academic databases was developed in Ovid MEDLINE by an Information Specialist in consultation with the review team (see Appendix 2, page 83). It consisted of broad terms for grief and bereavement, which were combined with a search filter for various review types of interest. The strategy also combined the terms with a geographic limit for the UK. The results of these separate parts of the strategy were pooled together using the Boolean operator OR and date limited from 2015 onwards to maximise the relevance of the evidence identified. The MEDLINE strategy was subsequently adapted for use with the other academic databases. No language restrictions were applied to any of the searches.

Eligibility criteria

Records were selected for inclusion in the evidence map based on the following criteria:

Study design: Any form of systematic review. A review was considered systematic if authors (i) searched at least two sources, one of which must have been a named database, (ii) reported some search terms and clear eligibility criteria covering key review components, (iii) reported the number of references retrieved and the number of studies included and (iv) provided a synthesis of findings. This could be a statistical synthesis in the form of a meta-analysis, or a narrative or realist synthesis. For the question on the types of bereavement support in the UK, we included primary studies of any design. Non-empirical publications on UK bereavement support were excluded, for example, commentaries and discussion pieces.

Population: (i) Any bereaved individuals or population group. We did not place any restrictions on the sociodemographic characteristics; health status/co-morbidity; or place of residence of the bereaved. (ii) Key informants from any relevant organisation such as those working in the health, social care or third sector.

Focus (non-interventions): Any reviews focused on (i) identifying the frequency or risk of PGD, and/or exploring the relationship between grief-related outcomes and potential risk factors. Risk factors could be on any level including individual, social, and structural factors. This could include, but was not limited to, sociodemographic factors, poverty, discrimination, and policy-level factors such as workplace policies and COVID-19 restrictions on burial/religious practices; or (ii) experiences of bereavement, grief, use of bereavement services or interactions with other individuals or organisations following a bereavement.

Also included were primary studies that surveyed, mapped or audited any type of bereavement support primarily in England, Wales, Scotland and/or Northern Ireland. Evaluations of single services were not eligible for inclusion.

Interventions: Reviews of interventions, which could be either, or both: (i) individual-level interventions, for example, the provision of information; psychological or drug therapies and bereavement counselling, or (ii) social- or structural-level interventions aimed at addressing factors that disrupt the process of grieving or coping with bereavement, for example, changes to institutional/service organisation, delivery, policy or culture. Interventions could focus on support provided before and/or after bereavement.

Comparators: Any type of comparator, where applicable. For example, interventions could be compared with usual treatment, an alternate treatment, waiting list control, no treatment, or a before and after intervention assessment.

Outcomes (non-intervention reviews): Reviews that reported findings related to any of the following: prevalence, incidence or relative risk/odds of PGD; factors that assist or impair the bereavement/grieving process; enablers and barriers to the use of bereavement support; post bereavement needs; views about using support services or other sources of support, for example, family, friends; staff views about bereavement service provision and the needs of the bereaved. Factors could be at any level, for example, personal, interpersonal, cultural, social, economic or institutional. We included primary studies that reported any outcome related to the provision of bereavement support in the UK (for example, type of support offered; description of the organisation/delivery of services).

Outcomes (intervention reviews): Reviews of interventions that reported any outcome related to the effectiveness, cost-effectiveness, safety of interventions or their impact on health inequities. Studies could also report outcomes related to the implementation of interventions and factors that influence effectiveness. For the purposes of this scoping review, effectiveness was conceptualised broadly to include findings from qualitative studies relating to the perceived impact and benefits of interventions. All included quantitative evaluations of interventions had to report outcomes related to grief, social/daily functioning, satisfaction or suicide behaviour.

Selection procedure

We uploaded records identified from database searches into EPPI-Reviewer software.(71) A sample of title and abstracts was pilot screened by three reviewers independently and their decisions compared. On achieving a high degree of agreement (90% or more) the remaining records were screened by one reviewer only. If there was any uncertainty regarding the eligibility of a record, it was discussed with a second reviewer. The full texts of all potentially relevant reviews were screened independently by two reviewers. Any disagreements on the eligibility of a review were resolved by consensus. Any papers not written in English were translated using Google Translate and then screened. Reviews were only included if the clarity of the translation was sufficient for us to understand the key sections of text.

Data extraction

For each included publication, key characteristics were extracted by one reviewer and checked by a second reviewer. The following information was captured from reviews and protocols, where relevant: aim, year of publication or registration on PROSPERO; number of included studies; review type and focus; personal characteristics of the bereaved; cause/type of death; type of support (interventions only). For primary studies of UK bereavement support, we extracted details on: study aim; design and methods; location (in other words, in which UK country it was conducted); study focus; setting/service type (for example, ICU/critical care, maternity, hospice or palliative care); personal characteristics of the bereaved; cause/type of death; and type of support.

Synthesis

The key characteristics extracted from reviews and primary studies were used to produce a high-level descriptive summary which detailed the extent and nature of the current evidence base relevant to the questions of interest to the DHSC. We also created an interactive map of the evidence using EPPI-Mapper software. (71) This displays our findings visually and enables users to view the bibliographical details of included studies.

As this mapping work was commissioned due to a possible COVID-19 related increase in PGD, we have reported review evidence related to COVID deaths separately from other health conditions such as cancer or dementia.

Post-protocol changes

Owing to the large number of reviews that met our inclusion criteria, it was not practical for us to extract as much information about each publication as we proposed in the project protocol. We therefore needed to revise our coding process and record a more limited range of information about each review. This meant that we were unable to extract detailed information about review focus and outcomes of interest as intended. For example, we could not record the exact PGD risk factors examined in reviews or what aspects of individuals' bereavement experiences were reported. We also had to restrict our focus on equity issues and could not examine fully whether reviews reported any findings disaggregated by key characteristics such as gender or whether authors applied any form of intersectional lens to their synthesis.

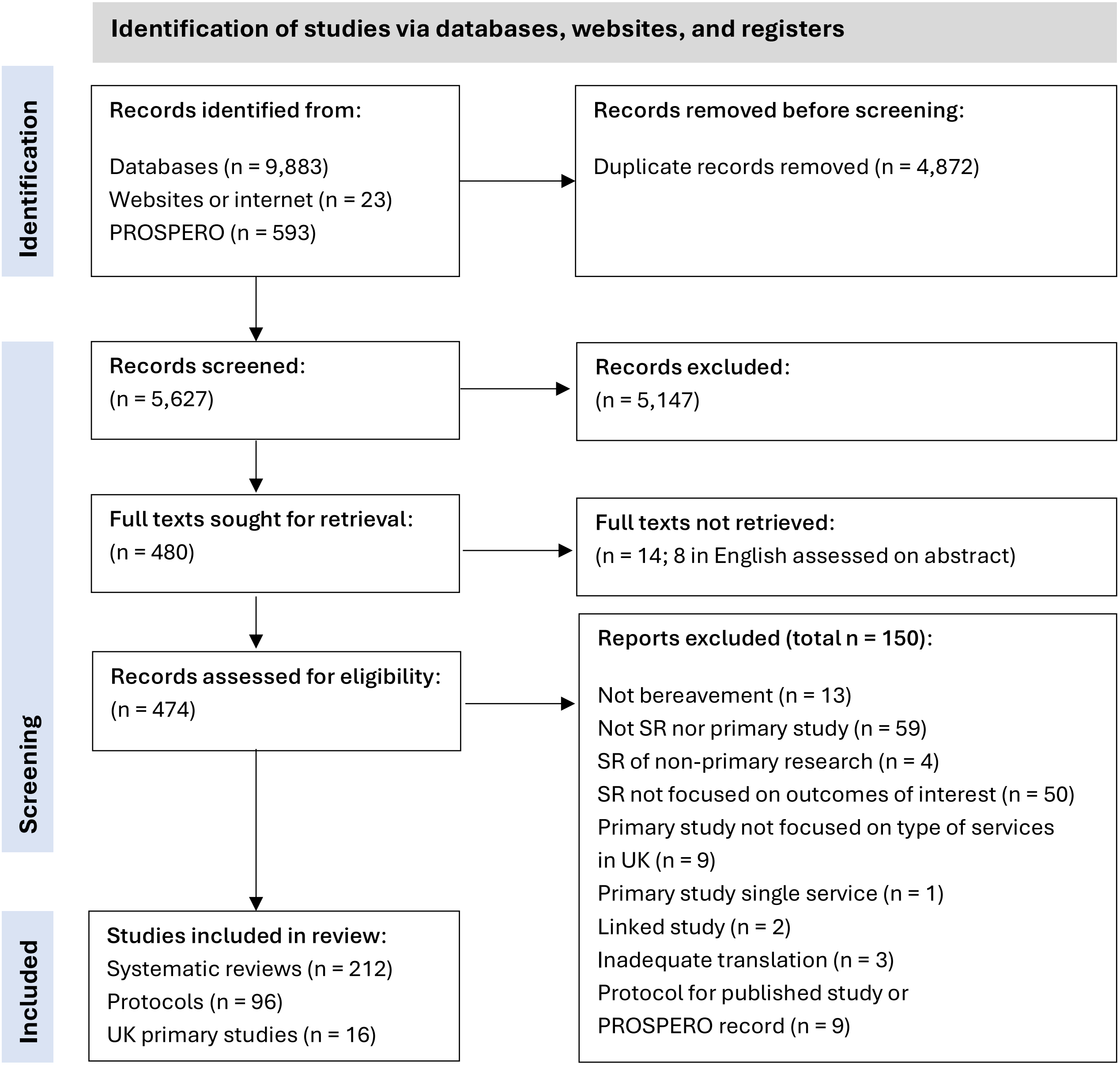
Terminology

As indicated in the introduction, a range of terms has been used, often interchangeably, in the literature to describe abnormally persistent and intense symptoms of grief. Only a minority of reviews included in our map used the term Prolonged Grief Disorder in the title or abstract, which until recently was not a recognised diagnosis. Prolonged grief and complicated grief were more commonly used terms. For this work, we use the terms prolonged grief, complicated grief and Prolonged Grief Disorder synonymously.

RESULTS

We screened 5627 records and included 212 reviews; 96 protocols including four protocols for reviews that were completed but not yet published; and 16 primary studies. The flow of studies through the review is shown in Figure 1.

Figure 1: Flow of studies through the review



SR = systematic review; PROSPERO = International Prospective Register of Systematic Reviews

Template from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Three of the reviews were systematic reviews of reviews (overviews). Four protocols were for systematic reviews of reviews and another was for a living review (updated every six months to April 2022). Of the 96 protocols, 89 were identified from PROSPERO and seven were published in academic journals. We included five reviews based solely on information in the title and abstract as the full text was not readily available. (72-76)

On the EPPI Centre website there is an interactive map of our findings.

In the sections that follow, we first describe the characteristics of all included reviews and protocols and then describe reviews and protocols according to their specific focus.

Overview of included reviews

The broad issues addressed in included reviews are shown in Table 1. A more detailed summary of review focus is provided in Table A, Appendix 3, page 89.

Table 1: Focus of included reviews

Issue	Reviews* [a]	Protocols* [b c]	Total
Non-intervention focused reviews			
Extent and nature of PGD	22	12	34
Risk factors for PGD	42	14	56
General grief reactions	37	6	43
Grief and bereavement experiences	103	44	147
Intervention focused reviews			
Intervention effectiveness	80	38	118
Totals	212	96	308

*Some reviews and protocols focused on multiple issues. [a] Includes three reviews of reviews; [b] includes four protocols for reviews that were completed but not yet published; [c] includes protocols for two reviews of reviews.

The largest group of reviews (n=103) and protocols (n=44) explored individuals' grief and bereavement experiences. This encompassed reviews that addressed one or more of the following issues: the use of formal or informal sources of support; barriers to accessing support; equity related to grief/bereavement and the use of services; coping with grief; post bereavement needs; or views about the factors that facilitate or impair the grieving process. The second largest group of reviews and protocols focused on the effectiveness of grief-related interventions (80 reviews and 38 protocols). We identified 42 reviews and 14 protocols addressing risk and protective factors for prolonged grief, correlates of the disorder or factors moderating its prevalence. We also identified another group of 37 reviews and six protocols which we called ‘general grief reactions’. These reviews examined the relationship between specific factors and outcomes such as the severity or intensity of grief and/or individual adjustment after bereavement rather than focusing on prolonged grief specifically. The remaining group of reviews (n=22) and protocols (n=12) focused on the extent and nature (prevalence) of prolonged grief amongst various groups of bereaved people. Fifty-five out of the 212 reviews and 17 out of the 96 protocols focused on two or more issues of interest.

It is possible that some of the included protocols relate to reviews that are now published but authors did not update the PROSPERO record. An attempt was made to identify any such publication, but it is not always a straightforward task as published reviews frequently have different first authors and titles to the original protocol. Some protocols recorded as ongoing, especially those published on PROSPERO several years ago, may have been discontinued.

Year of publication

Table 2 shows the year of publication of included reviews and protocols. Sixty-one percent of reviews (n=129) were published in the last three years (2020-2023) and over three quarters were published since 2018 (n=166). Forty-six reviews were published between 2015 and 2017. Most of the protocols (70/96) were published on PROSPERO or in an academic journal since 2020.

Table 2: Year of publication

Year	Reviews	Protocols
2023	1	
2022	59	28
2021	37	26
2020	32	16
2019	27	10
2018	10	9
2017	18	3
2016	14	3
2015	14	1

Characteristics of the bereaved

Reviews

As shown in Table 3 (page 15), a majority of reviews (n=123) focused on bereaved individuals with a specific relationship to the deceased (carer, parent, spouse/partner, sibling, son/daughter, grandparent, health or care professional, or work colleague). The remaining 89 reviews had a generic focus on ‘family’ or ‘family and friends’ (n=31) or focused on bereaved individuals with no specified relationship to the deceased (n=58).

Sixty-one reviews focused on bereaved adults and 16 had a primary focus on children and young people. Thirteen reviews had inclusion restrictions related to gender with nine focusing solely on bereaved women and four were about men only. Thirty reviews applied geographical restrictions and focused solely on evidence from specific countries or regions. Two thirds of these reviews included studies from the UK, USA or other high-income countries (n=20). The remaining 10 focused on low-income countries including sub-Saharan African (n=3); China, Hong Kong or Taiwan (n=3); low- or middle-income countries (n=2); high- or middle- income countries (n=1); and the Asia-Pacific region (n=1).

Twelve reviews reported evidence related to marginalised or minority populations. Three reviews focused on minority ethnic groups; three on refugees, migrants or asylum seekers; two on LGBT+ individuals; and two on individuals with an intellectual disability. Another review comprised studies of individuals who misused drugs and one focused on those positioned as structurally vulnerable in bereavement. Forty-three reviews did not focus on bereaved individuals with a specific personal characteristic, specific relationship to the deceased or specific geographic location.

Protocols

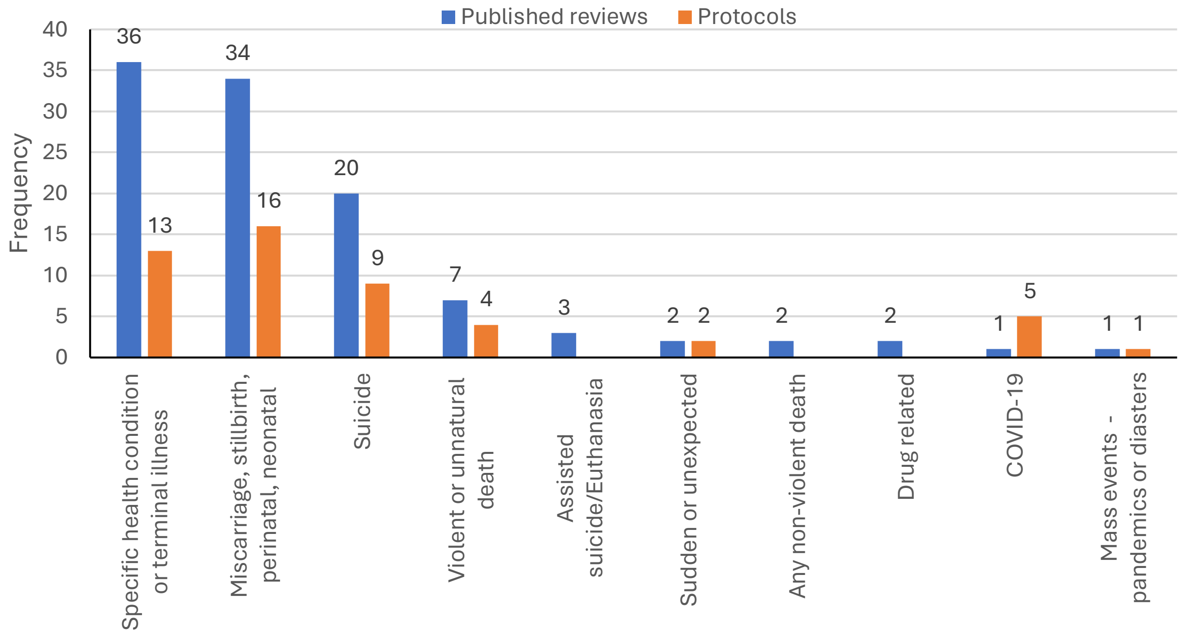
As shown in Table 4 (page 17), 44 out of the 96 protocols focused on individuals with a specific relationship to the deceased. The remaining 52 protocols had a generic focus on bereaved ‘family’ or ‘family and friends’ (n=17) or focused on bereaved individuals with no specified relationship to the deceased (n=35).

Thirty-four protocols focused on adults and eight were on children or young people (up to the age of 30 years). In terms of gender, three protocols focused on women only and three were on men. One protocol focused on bereaved LGBT+ people and another on refugees. Three protocols were restricted to low- or middle-income countries and one focused specifically on sub-Saharan Africa. Another was focused on high-income countries only and one aimed to compare studies conducted in low-, middle- and high-income countries. One protocol focused on books in Spanish.

Cause or type of death

A majority of both reviews (108/212) and protocols (50/96) focused on a specific cause or type of death. Figure 2 shows the cause or type of death reported in reviews and protocols.

Figure 2: Cause/type of death



Reviews

Ninety of the 108 reviews focused on one of three types of death: a specific health condition or terminal illness, excluding COVID-19 deaths (for example, cancer or dementia) (n=36); perinatal death (miscarriage through to neonatal loss including stillbirth, n=34); or suicide only (n=20). One of the 36 reviews coded as ‘a specific health condition or terminal illness’ focused on deaths due to medical illness but also included studies of deaths in unforeseen circumstances.

Of the remaining 18 reviews, seven examined violent or unnatural deaths, and two focused on sudden and unexpected deaths. The type of death examined in the remaining 9 reviews was: assisted suicide or euthanasia (n=3); non-violent death (n=2); drug-related death (n=2); COVID-19 related death (n=1); and mass events such as pandemics, natural and human-made disasters, or terrorism (n=1).

Two of the 36 reviews that examined bereavement following a specific health condition or terminal illness also focused on a particular health care setting. One focused on paediatric hospices and the other had a focus on adult intensive care. Two reviews examining neonatal death also focused on paediatric ICUs. One of the two reviews on sudden and unexpected deaths, also focused on ICUs, emergency departments and operating theatres.

Sixteen reviews did not examine a specific cause or type of death but were focused on a particular setting: intensive/critical care (n=9), acute care settings (n=3); in-hospital settings (n=2) emergency department (n=1); or long-term care (n=1). The 88 remaining reviews did not focus on a specific cause or type of death or deaths in a specific setting.

Protocols

Fifty of the 96 protocols focused on a specific cause of death, sixteen of which addressed perinatal death. A specific health condition or terminal illness (such as cancer, dementia, or motor neurone disease) was the focus for 13 protocols; one of these examined suicide deaths in people with dementia. Suicide was the only focus for nine other protocols. Five protocols were about deaths linked to COVID-19 either directly or indirectly. Four protocols focused on violent deaths, and two others on sudden and unexpected death. One protocol focused on epidemic deaths. Five protocols were on deaths in a specific setting: hospital or ICU deaths (n=4), or care-home deaths (n=1). The remaining 41 protocols did not focus on a specific cause of death or location. Tables 3 and 4 (pages 15 and 17) provide a summary of all reviews and protocols by focus and key characteristics.

Table 3: Number of reviews by focus and key characteristics

	Extent of PGD	Risk factors for PGD	General grief	Experiences[a]	Intervention effectiveness[b]	All reviews
Relationship						
Specific	7	14	22	74	42	123
Any family/friends	4	13	7	11	9	31
Other non-specific	11	15	8	18	29	58
All non-specific	15	28	15	29	38	89
Personal characteristics						
Adults [c]	13	21	12	15	24	61
Children [c]	1	3	6	7	7	16
Female		1		5	4	9
Male			1	4		4
LGBT+				2		2
Disability	1	1		1	1	2
Minority ethnic			1	3		3
Refugees/migrants	2	1	1	1		3
Substance misuse	1	1			1	1
Structural vulnerability				1		1
Country						
UK, USA & other high income	2	3	4	14	7	20
LMIC				2	1	2

	Extent of PGD	Risk factors for PGD	General grief	Experiences[a]	Intervention effectiveness[b]	All reviews
Low income & sub-Saharan Africa		1		3	1	3
HMIC				1		1
China, Hong Kong or Taiwan	2	1	1	1		3
Asia-Pacific				1		1
Cause/type of death						
Specific health issue/ terminal illness	6	9	6	14	15[d]	36
Perinatal		2	2	23	13	34
Suicide		1	3	13	8	20
Violent/unnatural	2	4	1	2	2	7
Assisted suicide		2	1	3		3
Sudden/unexpected				1	1	2
Non-violent	2	1				2
Drug related				2		2
COVID-19					1	1
Mass events - illness or terrorism etc					1	1
No cause of death -specific setting[e]						
Hospital settings		2		8	6	15
Long-term care			1	1		1
No specific cause of death or setting	12	21	23	36	33	88
Totals	22	42	37	103	80	212

NB: Some reviews reported findings on multiple issues. Some reviews included both primary studies and reviews. [a] Includes one review of reviews. [b] Includes three reviews of reviews. [c] Based on inclusion criteria. Other reviews may also have only reported findings from studies of adults owing to a lack of eligible child-focused research. [d] One review focused on deaths due to medical illness and unforeseen circumstances but was only included in the specific health condition category. [e] Excludes reviews focused on both a specific cause and setting.

Table 4: Number of protocols by focus and key characteristics

	Extent of PGD	Risk factors for PGD[a]	General grief	Experiences[b]	Intervention effectiveness[b]	All protocols
Relationship						
Specific		1	2	33	15	44
Any family/friends	3	5	3	6	4	17
Other non-specific	9	8	1	5	19	35
All non-specific	12	13	4	11	23	52
Personal characteristics						
Adults	6	9	3	13	10	34
Children	1	1		1	6	8
Female				1	2	3
Male				3		3
LGBT+				1		1
Refugees				1		1
Country						
LMIC				2	1	3
HIC					1	1
LMHIC				1		1
Sub-Saharan Africa	1	1				1
Spanish					1	1
Cause/type of death						
Perinatal				12	5	16
Specific health issue/terminal illness			2	8	5	13
Suicide				5[c]	5[c]	9[c]
COVID-19	4	3	1	1		5
Violent	2	2	1			4
Sudden death				1	1	2
Epidemics		1	1			1
No cause of death -specific setting [d]						
Hospital or care home		2		2	3	5
No specific cause of death or setting	6	6	1	15	19	41
Totals	12	14	6	44	38	96

NB: Some protocols coded for multiple issues. [a] Includes a protocol for one review that was completed but not yet published. [b] Includes protocols for two reviews that were completed but not yet published. [c] One protocol was coded as terminal illness (dementia) and suicide; but not included in the suicide numbers. [d] Excludes protocols focused on both a specific cause and setting.

The following sections describe the evidence according to the issues of interest. Most reviews and protocols reporting on general grief reactions also focused on other issues. These reviews are reported in the sections on the extent of PGD, risk factors for PGD, grief/bereavement experiences, and intervention effectiveness. The small number of reviews and protocols that focused solely on general grief reactions are reported separately in the section on risk factors for PGD as there exists a degree of potential overlap between these two categories.

REVIEWS ON THE EXTENT AND NATURE OF PROLONGED GRIEF DISORDER (PGD PREVALENCE)

Summary of reviews and protocols

- **Number of publications:** twenty-two reviews and 12 protocols focused on the extent and nature of PGD.
- **Specific relationship to the deceased:** three reviews focused on informal carers; two were on parents who had lost a child; one was on children following the death of a parent; and one was on bereaved spouses. None of the protocols focused on a specific relationship, but three were on families in general.
- **Other personal characteristics of the bereaved:** most reviews focused on adults, older adults, and students over the age of 18 years only (n=13). One review had a focus on children and young adults. Four reviews focused on marginalised or minority populations. Half of the protocols focused on prolonged grief among adults (n=6); one had a focus on children or young people.
- **Cause or type of death:** six reviews reported on prolonged grief following death from a terminal or advanced illness. Four reviews focused on specific types of death: non-violent causes (n=2); violent or unnatural death (n=2). Four protocols were on COVID-19 and two were on violent deaths due to any disaster (n=1) or natural disasters (n=1).
- **Geographical area:** four reviews focused on a specific geographical area: high-income countries including the UK and the USA (n=2); and China, Hong Kong or Taiwan (n=2). One protocol focused on sub-Saharan Africa.

Overview of reviews

We identified 22 reviews that reported the prevalence of prolonged grief amongst various bereaved population groups. (10, 77-97) Five reviews only reported findings on prevalence. (83, 86, 90, 94, 95) Another nine reviews reported on prevalence and risk factors for the disorder. (10, 78, 79, 84, 85, 87, 92, 96, 97) Seven reviews reported on both prevalence and risk factors as well as on general grief reactions, individuals' grief/bereavement experiences or intervention effectiveness. (77, 80, 82, 88, 89, 91, 93) One other review focused on prevalence, general grief reactions and grief/bereavement experience (81) (see also Table A, Appendix 3, page 89).

Review characteristics

Of the five reviews reporting the prevalence of prolonged grief only, three focused on specific groups of individuals; one on the Chinese population; (90) one on adult refugees, migrants or asylum seekers; (83) and one on older adults (65 years and over). (94) One review reported the prevalence of prolonged grief amongst family members bereaved as a result of chronic disease (86) and another focused on violent or unnatural death, including homicide. (95)

Specific relationships

Of the other 17 reviews that included a focus on PGD prevalence and risk factors for the disorder, and/or general grief reactions, seven reviews focused on specific family relationships, (77, 79, 81, 82, 88, 93, 97) including informal carers, parents, children, and spouses.

Informal carers

Three of the seven reviews focused on informal adult carers of patients with dementia, (77) cancer, (79) and those in any hospice or palliative/end-of-life care setting in North America. (93)

Parents

Two of the seven reviews focused on parents following the death of a child. (88, 97) One of these two reviews had a specific focus on Chinese parents who lost their only child and could not have another one ('Shidu' parents). (97)

Children and young people

One review reported findings from studies on children and young adults who had lost a parent due to terminal illness. (82)

Spouse/partner

One review focused on older adults (60+ years old) who had lost a spouse from any cause. (81)

Specific types of death

Three of the remaining ten reviews focused on adults bereaved by specific types of death. (10, 78, 87) One review addressed bereavement resulting from non-violent causes; (10) one investigated unnatural deaths; (78) and the other focused on deaths from cancer. (87)

Specific population groups

Five reviews examined prolonged grief prevalence amongst specific groups of individuals: adult refugees, migrants or asylum seekers; (84) people with an intellectual disability; (89) substance users; (91) students in higher education; (80) and adults in Spain. (92) One review reported the prevalence of prolonged grief amongst multiple population groups. (96)

Comorbidity

One review estimated the prevalence of depression, anxiety or post-traumatic stress in individuals with PGD. (85)

Protocols – the extent and nature of PGD

We identified 12 protocols on the prevalence of PGD. (98-109) Four of the 12 protocols were focused solely on prevalence. (102, 107-109) All four protocols were published on PROSPERO in 2021 or 2022. One examined the prevalence of PGD after natural disasters, (107) and another focused on the families of people who died from COVID-19. (109) The other two focused on PGD prevalence or symptomology amongst adults but were not restricted to a specific cause of death. (102, 108) One of these two focused specifically on comorbidity between PGD and other mental or physical health conditions. (108)

The remaining eight protocols all focused on both PGD prevalence and risk factors, (98-101, 103-106) and one planned to also report on general grief reactions. (106) Four of these protocols were published on PROSPERO in 2021 or 2022. (100, 101, 105, 106) Three of the four focused on the COVID-19 pandemic (101, 105, 106) and one investigated prevalence and risk factors amongst bereaved children. (100) The other four protocols were older with one published on PROSPERO in 2020, (103) two in 2018, (98, 99) and one in 2016. (104) Two of these four protocols focused on adults bereaved by any cause. (98, 104) One focused on the family or friends of people who died in disasters, (99) and the other was limited to studies conducted in sub-Saharan Africa. (103)

REVIEWS ON RISK FACTORS FOR PGD

Summary of reviews and protocols

- **Number of publications:** forty-two reviews and 14 protocols focused on risk factors for PGD.
- **Specific relationship to the deceased:** seven reviews focused on bereaved informal carers; four were on parents (n=3), or mothers (n=1), after the loss of a child; two were on children following the death of a parent and one was on children and their surviving parent. One protocol for a review that was completed but not yet published focused on carers, fellow residents or family following deaths in care homes.
- **Other personal characteristics of the bereaved:** Twenty-one reviews focused on adults or students over the age of 18 years only and three had a focus on children or young people. Three reviews focused on marginalised or minority populations. Nine of the 14 protocols were on adults, and one was on children or young people.
- **Cause or type of death/deaths in a specific setting:** nine reviews synthesised evidence on terminal or advanced illness. Two reviews focused on perinatal loss. Ten reviews examined risk factors associated with specific types of death or deaths in a specific setting: violent, traumatic or unnatural death (n=4); non-violent death (n=1); bereavement following euthanasia/medically assisted death (n=2); suicide (n=1) and deaths in the ICU (n=2). Three protocols were on COVID-19; two were on violent deaths; one was on epidemic deaths and two were on ICU deaths.
- **Geographical area:** five reviews focused on a specific geographical area: high-income countries including the UK and the USA (n=3); Low income including sub-Saharan Africa (n=1) and China, Hong Kong or Taiwan (n=1). One protocol focused on sub-Saharan Africa.

Overview of reviews

We identified 42 reviews reporting evidence on factors that potentially influence the risk of prolonged grief. Sixteen reviews were described in the previous section that reported on both PGD prevalence and risk factors. (10, 77-80, 82, 84, 85, 87-89, 91-93, 96, 97) The 26 other reviews addressed risk factors for prolonged grief without also focusing on prevalence. Ten of the 26 reviews solely reported findings on risk factors for prolonged grief. (110-119) The other 16 reviews reported findings on PGD risk factors plus general grief reactions, grief/bereavement experiences and/or the effectiveness of grief-related interventions. (120-135) (see also Table A, Appendix 3, page 89).

Review characteristics

Specific relationships

Four of the 26 reviews reported on bereaved adult carers of patients who had a terminal health condition. (115, 118, 128, 129) Four other reviews focused on parent-child relationships; (112, 125, 126, 132) one of these four reviews explored risk factors for prolonged grief in mothers who lost a baby in pregnancy up to two years old. (112) Similarly, one review focused on both parents after perinatal loss. (132) Another reported findings on grief reactions, including maladaptive grief, in children following the death of a parent. (126) The fourth review examined the parent-child relationship in widowed families and the factors impacting on adjustment to loss. (125)

Specific type of death

Eight reviews focused on risk factors amongst people bereaved by specific types of death or deaths in specific settings. (113, 117, 119, 120, 124, 131, 133, 135) Three of these reviews focused on violent, sudden or traumatic deaths; (113, 131, 133) one of which examined the impact of a single risk factor. It explored whether informal social support reduces the risk or severity of complicated grief following sudden and/or violent death. (131) Two of the eight reviews explored the risk of prolonged grief following euthanasia/medically assisted death. (120, 135) Two reviews focused on the families of adults who died in intensive care settings from non-specific causes. (117, 119) One review examined whether suicide survivors' experiences of stigma impact on their grief trajectories. (124) One other review focused on the relatives of organ-donors. (121)

Reviews with a focus on single factors

Nine reviews did not focus on specific relationships, types of death or settings; all these reviews examined the influence of a single factor on grief reactions and/or the development of PGD. Two reviews examined the relationship between prolonged grief and adult attachment style. (110, 116) One review that was conducted within the context of the COVID pandemic investigated the relationship between funeral practices and various bereavement outcomes including grief intensity, adjustment and unresolved grief. (122) Other reviews examined the relationship between prolonged grief and: family dynamics/functioning; (123) emotion regulation; (111) continuing bonds; (130) and loneliness. (134) One review investigated the neurobiological correlates of PGD, focusing specifically on the reward system. (114) Another review investigated the relationship between sleep difficulties and grief duration and severity, rather than PGD specifically (but found no studies). (127)

Protocols – risk factors for PGD

We identified 14 protocols on risk factors for PGD. Eight were on both prevalence and risk factors for PGD and were described in the previous section. (98-101, 103-106)

Four of the other six protocols focused solely on PGD risk factors, (136-139) one was on risk factors and interventions, (140) and one was on risk factors and grief reactions. (141)

One of the six protocols was for a completed review not yet published, which focused on staff, fellow residents and families following deaths in care homes. (140) Two of the other five protocols reviews examined PGD risk factors in adults without limiting to a specific cause of death, (136, 137) and another focused on adults bereaved by violent or unnatural death. (138) The remaining two protocols focused on adult family members of individuals who died during epidemics (141) or who died in the ICU. (139)

General grief reactions – reviews

We identified 37 reviews on factors that may impact on grief in general and/or individual adjustment following bereavement - general grief reactions. Thirty-one of the 37 reviews also focused on PGD prevalence, risk factors for PGD, grief/bereavement experiences and/or intervention effectiveness and these are reported elsewhere. Here we report on the six reviews that focused solely on general grief reactions. (142-147) One of the six reviews investigated the association between aspects of marital relationship and parents' adjustment to the loss of a child. (142) Another review also focused on bereaved parents and examined the relationship between feelings of guilt, shame and self-blame and grief intensity as well as adjustment to loss. (143) The factors associated with an adaptive or maladaptive grief response in children who lost a parent or sibling due to cancer was investigated in one review. (146) One review reported on adjustment to spousal bereavement amongst older adults in Western cultures in the Northern Hemisphere (147) and another examined resilience as a protective factor for coping with grief. (144) The remaining review examined the association between adjustment to bereavement amongst USA college students and spirituality/religiosity. (145)

General grief reactions – protocols

Six protocols focused on general grief reactions, two of which also focused on PGD and have been described previously. (106, 141) The other four focused solely on general grief reactions were added to PROSPERO from 2018 to 2022. (148-151) Two of the four protocols focused on carers, one comparing deaths from terminal illness at home and in hospital (148) and the other examining deaths from Motor Neurone Disease. (151) Another protocol focused on adult family or friends of people who died by homicide. (150) The remaining protocol examined how bereavement affects neurocognition. (149)

REVIEWS ON GRIEF AND BEREAVEMENT EXPERIENCES INCLUDING THE NEEDS OF BEREAVED PEOPLE AND BARRIERS TO ACCESSING GRIEF SERVICES

Summary of reviews and protocols

- **Number of publications:** one hundred and three reviews and 44 protocols focused on grief and bereavement experiences including the needs of bereaved people and barriers to accessing grief services. One of the reviews was a review of reviews. One protocol was for a review of reviews and two were for reviews that had been completed but not yet published.
- **Specific relationship to the deceased:** forty-three reviews focused on parents, mothers or fathers, a defined group of parents and other family members, or parents and health professionals. Six reviews focused on informal carers; 11 were solely on individuals who had a professional relationship to the deceased or their relatives; six were on the spouse or partner of the deceased; five were on the children or siblings of the deceased only; one was on bereaved children and spouses; one was daughters after the death of their mothers; and one was on co-workers. We identified 19 protocols focused on parents or a defined grouping of parents and other family members or parents/family and health professionals. We also identified five protocols on informal carers; four were on healthcare professionals only; two were on siblings only; one was on co-workers; one was on the spouse or partner of the deceased; and one was on the next of kin.
- **Other personal characteristics of the bereaved:** fifteen reviews had a focus on adults only. Three reviews had a specific focus on older adults (60+ years old), and one synthesised findings from studies of widowed individuals under 50 years old only. Seven reviews focused on children or young people (two of which did not focus on a specific relationship). Eight reviews had a focus on marginalised or minority populations. Thirteen protocols focused on adults only and one was on children or young people. Two protocols focused on marginalised or minority populations.
- **Cause or type of death/specific setting:** twenty-three reviews focused on perinatal death; 14 were on terminal/advanced illness; and 13 were on suicide. Other reviews focused on: assisted suicide (n=3); violent or unnatural death (n=2); drug use (n=2); and sudden or unexpected death (n=1). Nine reviews focused on various hospital settings (n=8) or long-term care (n=1). Twelve protocols focused on perinatal deaths; eight were on terminal illnesses including one on suicide in people with dementia; and five others were on suicide; one was on COVID-19 (n=1) and one was on sudden death (n=1). Two protocols focused on deaths in specific hospital settings (n=2).
- **Geographical area:** twenty-two reviews focused on a specific geographical area: high-income countries including the UK and the USA (n=14); low-income countries including sub-Saharan Africa or other ‘high burden’ countries, which

were defined as ones with a high perinatal death rate (n=3); high- and middle-income countries (n=1); low- and middle-income countries (n=2); China, Hong Kong or immigrants in Western countries (n=1) and Asia-Pacific countries (n=1). Two protocols focused on low- and middle-income countries; and one aimed to present findings separately for low-, middle- and high-income countries.

Overview of reviews

We identified one review of reviews (152) and 102 standard reviews addressing individuals' experiences of grief and bereavement. Seventy-four reviews reported solely on grief and bereavement experiences. One review of reviews and 28 other standard reviews reported grief/bereavement experiences plus findings on the effectiveness of grief-related interventions and/or PGD prevalence, PGD risk factors or general grief reactions. (80, 81, 93, 120, 121, 133, 135, 152-173) (see also Table A, Appendix 3, page 89).

Review characteristics

Review of reviews

One review of reviews reported findings from 12 reviews on parental experiences of perinatal loss in the UK or other high-income countries. (152)

Standard reviews

Seven of the 102 standard reviews reported evidence on grief/bereavement experiences as well as PGD prevalence and/or risk factors for the condition and these were described previously. (80, 81, 93, 120, 121, 133, 135) Briefly, two of the seven reviews explored individuals' experiences following euthanasia/medically assisted death (120, 135) and one focused on the families of organ donors. (121) Three reviews focused on the experiences of: students in higher education; (80) older widows and widowers aged 60+ years (81) and children in sub-Saharan Africa following violent, sudden or traumatic death. (133) The remaining review focused on the experiences of informal carers of patients in any hospice or palliative/end-of-life care setting in North America. (93) The remaining 95 reviews that reported grief/bereavement experiences are described in the following sections.

Experiences of bereaved individuals with a specific relationship to the deceased

Experiences of informal carers

Five out of the 95 reviews reported the grief/bereavement experiences of family carers. (73, 154, 174-176) Two reviews focused on the informal carers of patients who had Alzheimer's disease and related dementias; (154) or cancer (high grade glioma). (176) Two others focused on the carers of patients who died in acute hospital settings; (73) or who received palliative care, (175) One remaining review explored the experiences of carers following euthanasia/medically assisted death. (174)

Experiences of parents

In total, 42 standard reviews reported the experiences of bereaved parents, of which 21 focused solely on them. (72, 75, 162, 164, 177-193) Ten reviews focused on a defined family grouping comprising parents and other family members such as siblings, and grandparents. (158, 163, 167, 169, 194-199) Three reviews included the experiences of both parents and health professionals. (200-202) Four reviews focused on studies conducted with mothers; (166, 203, 204 , 205) and four others focused on fathers. (171, 206-208)

Twenty-two out of 42 reviews reporting parental experiences focused on perinatal loss including miscarriage and stillbirth. (72, 75, 163, 166, 171, 177, 178, 180, 182, 184, 185, 187, 188, 194, 196, 200, 201, 203-206, 208) Five reviews reported on experiences after death from a specific health condition: four focusing on cancer (169, 183, 186, 189) and one on chronic life-limiting conditions. (181) Other reviews reported on: suicide; (167, 199) and drug death bereavement. (198)

Two reviews focused on parental experiences after the death of a child in healthcare settings. (158, 195) Ten other reviews that explored experiences following the death of a child did not focus on a specific cause of death or setting. (162, 164, 179, 190-193, 197, 202, 207)

Nine of the reviews on parental bereavement focused on a specific aspect of experience or the support provided to the bereaved. Two explored spirituality, (177, 205) and another two focused on follow-up conversations and ongoing connections with healthcare professionals. (169, 202) The other five reviews focused on: workplace support strategies and accommodations for bereaved parents; (190) experiences in the workplace following perinatal loss; (187) informal sources of support; (191) seeing and holding a stillborn baby; (184) and memory making. (75)

Experiences of children and young people

Five reviews focused on the experiences of bereaved children, adolescents or young adults. (74, 157, 172, 209, 210) One of these five reviews explored experiences following a death of a sibling by suicide and focused on the USA only. (74) One explored how bereaved young people develop a continuing bond with deceased family members. (209) Another specifically investigated sex differences in adolescent grief-related behaviour. (172) The other two reviews focused on coping by children after the death of a sibling (157) and/or parents or other family members. (210) One of these two reviews also sought to explore the implications for teachers and schools in terms of providing support to bereaved children. (210)

We also identified a review on daughters' experiences of maternal bereavement, which had a particular focus on adolescents. However, this review did include studies with individuals who were bereaved at a much older age. (211) One review explored the support experiences of both parentally bereaved children and the surviving spouse. (212)

Experiences of spouses/partners

Five reviews focused on the experiences of the spouse/partner of the deceased. (161, 173, 213-215) Two of the four reviews applied age restrictions; one focused on individuals aged 50 years or less; (213) and one explored spousal bereavement amongst older adults 65 years or older living in mainland China and Hong Kong or who migrated to a Western country. (173) Another review focused on lesbian, gay, bisexual and/or trans* people, (214) and one explored the experiences of widows from the Latino community in the USA. (161) The remaining review reported the experiences of surviving caregivers of children in parentally bereaved families. (215)

Experiences of professionals

Eleven reviews focused on individuals who had a professional relationship to the deceased or their relatives. (155, 156, 216-224) Seven of the eleven reviews reported the personal bereavement experiences of health and/or education or social care professionals following the death of a patient or client. (155, 156, 216-219, 221) The other four reviews explored the experiences of professionals who provided support to bereaved individuals. (220, 222-224) Two of these four reviews focused on nurses who cared for bereaved families in acute care (222) or in critical care settings. (224) One review reported the experiences of staff in local health and welfare services who assisted families bereaved as a result of a drug-related death. (223) Another explored the experiences of staff supporting people who have a learning disability with grief and bereavement. (220)

Experiences of co-workers

One review focused on the experiences of co-workers after the suicide of a colleague. (225)

Experiences of bereaved individuals with a general or non-specific relationship to the deceased

Twenty-four of the 95 reviews had a generic focus on ‘family’ or ‘family and friends’ or which focused on a non-specific group of bereaved individuals.

Eight of the 24 reviews synthesised evidence on experiences following a death by suicide. (153, 159, 168, 226-230) One of these eight reviews focused solely on the experiences of adolescents. (153) Four had a primary focus on a specific aspect of bereavement, or the support provided to individuals after a suicide death. These reviews focused on public stigma and the bereavement experiences of suicide survivors; (159) continuing bonds with the deceased; (226) the use and benefits of online resources for suicide survivors; (168) or social interactions whilst grieving a suicide death. (227) One other review explored bereavement resulting from homicide. (231)

Five of the 24 reviews focused on experiences after death from a ‘terminal’, ‘advanced’ or ‘life-limiting’ illness; (232-234) cancer; (235) or pandemic or infectious disease. (236) One of these five reviews focused specifically on the experiences of families following child death in hospice care (234) and another addressed experiences of anticipatory grief. (233)

Another one of the five reviews had a primary focus on social and structural inequity in bereavement. (232)

Three reviews explored the experiences of specific groups of individuals; one of these reviews focused on adult Latino/a groups. (237) Another explored the impact of faith and spirituality on the grief of sexually diverse individuals. (238) The third review examined the existing literature on bereavement care in the UK for ethnic minority communities. (239) We also identified another review with a specific focus on UK bereavement care, which reported findings on people's experiences and needs. (165)

We identified three other reviews focused on a specific health care setting; one review addressed the management of complicated grief and bereavement in primary care, which had a focus on the UK. (240) The other two reviews explored the experiences of families in hospital settings (241) and in the emergency department. (242)

Three other reviews examined the evidence on a specific issue related to grief and bereavement; one review investigated how accurately the Dual Process Model of Coping with Bereavement represents individuals' lived experience (160) and another explored the use of humour by people who are grieving. (243) The third review examined the factors that determine when individuals provide support to a bereaved person. (170)

Protocols – grief and bereavement experiences

We identified 44 protocols focused on experiences, two of which were for reviews that had been completed but not yet published. (244, 245) The two completed reviews focused on adult families of older people who died in residential aged care (244) and the use of bereavement photography after a stillbirth. (245) Another protocol was for a review of reviews that will report on fathers' experience of stillbirth. (246)

Of the remaining 41 protocols, 34 focused solely on experiences, while the other seven focused on experiences and interventions or their implementation. (247-253) Six of the 41 protocols were added to PROSPERO before 2019; (251, 254-258) and the remaining 35 were added between 2019 and 2022.

Protocols focused on the experiences of bereaved individuals with a specific relationship to the deceased

Thirty-one of the 41 protocols for ongoing standard reviews of experiences specified a relationship with the deceased.

Experiences of informal carers

Five of the 31 protocols focused on informal carers; one of which also investigated interventions and had a specific focus on carers of people who died from dementia. (253) The other four all involved the same group of investigators and focused solely on the experiences of older adults, middle-aged adults, young adults, or LGBT+ informal carers of people who died from any cause. (259-262)

Experiences of professionals

Four protocols focused on the experiences of healthcare professionals. (247, 256, 263, 264) One of these focused on clinicians' experiences after a patient suicide as well as strategies to mitigate the impact. (247) Two others explored healthcare professionals' experiences after the death of a patient from any cause; (256, 264) one specifically in paediatric healthcare. (256) The final protocol focused on midwives experiences after stillbirth. (263)

Experiences of professionals and family

Four protocols focused on the experiences of health professionals and parents or families. (251, 257, 265, 266) Two focused on parents, families and healthcare professionals in low- and middle-income countries after stillbirth. (257) or neonatal death. (266) One was on the experiences of parents and health professionals after a perinatal death, (265) and the fourth protocol was on the experiences and postvention for bereaved family members or health professionals after the suicide of a relative with dementia. (251)

Experiences of co-workers

One protocol focused on the experiences of co-workers after a colleague died by suicide. (267)

Experiences of next of kin

One protocol explored the experiences of support received by 'next of kin' after death in hospital. (268)

Gender-specific parenthood

Three of the 31 protocols were on gender-specific parents. Two were on fathers; one on neonatal deaths; (254), and the other was on deaths from terminal illness. (269) One was on mothers after miscarriage. (255)

Experiences of parents with and without other family

Ten protocols had a focus on parents with and without other family. (249, 250, 258, 270-276) Three of these reviews focused on the experiences of parents of children who died from terminal illness, (271, 272, 274) one of which also included grandparents and siblings and focused on cancer deaths. (271)

Four other protocols focused on perinatal deaths. (249, 273, 275, 276) One was on mothers, fathers or siblings after stillbirth, (276) and another also on parents after stillbirth, will analyse findings by the income status of countries (high-, low-, or middle-income countries). (273) One protocol was on mothers and/or family members after miscarriage or other types of pregnancy loss, and also focused on the impact of psychological interventions on these individuals. (249) The fourth protocol focused specifically on the experiences of parents after a death in the neonatal intensive care unit. (275)

One of the ten protocols focused on bereaved parents or siblings of children who died in hospital and aimed to examine the effectiveness of existing bereavement follow-up interventions for these families. (250) Another was on the experiences of parents or other immediate family members after the suicide of a relative. (270) The remaining protocol aimed to better understand post-traumatic growth experienced by bereaved parents, but this protocol was published in 2015 so is likely to have been completed or discontinued. (258)

Experiences of siblings

Two protocols focused on siblings bereaved by any cause; one was on adult siblings (277) and the other on children. (278)

Experiences of spouses or partners

One protocol was on the experiences and any intervention for bereaved older adult spouses or partners. (252)

Protocols focused on the experiences of bereaved individuals with a general or non-specific relationship to the deceased

Five protocols specified any type of family relationship. (279-283) These five protocols focused on: family after the suicide of a relative; (279) adult family grief during the COVID-19 pandemic; (283) adult refugees; (280) older adults; (281) and family members after the sudden death of an adult relative. (282)

Five other protocols did not specify a relationship with the deceased. (248, 284-287) One of these focused on the experiences of individuals, bereaved by suicide, who attend peer support groups, (284) and one was on experiences after a death from cancer. (287) The remaining three protocols did not specify a cause of death; one focused on adults' experiences of continuing bonds in adaptation to bereavement; (285) one had a specific focus on bereaved adults' quality of life; (286) and the third was on nurses' competence in grief counselling and the factors that affect it. (248)

Reviews on equity issues in relation to access to bereavement support services

The DHSC was interested in identifying equity issues in relation to access to bereavement support services. We examined in greater depth five reviews focused on the experiences of marginalised or minority populations to identify whether they reported any findings on access to, or use of, support services. (161, 214, 232, 237, 239) Three of the reviews had a strong focus on equity. (214, 232, 239)

The review by Mayland et al. examined bereavement care in the UK for ethnic minority communities. It identified barriers and facilitators to accessing care, explored satisfaction with service provision and investigated whether any models of care provision exist for addressing the bereavement specific needs of ethnic minority communities. (239) Bindley et al. examined the existing literature on bereavement and structural vulnerability. They reported evidence on the way in which unequal social status, related to gender, class, sexuality, ethnicity and age, influences access to, and use of, bereavement support and interactions with institutions. (232) The review by Bristowe et al. reported evidence on the barriers and stressors experienced by LGBT+ individuals in accessing support following the loss of a partner. (214)

The other two reviews also reported findings related to service access or use, both of which were focused on members of the Latino community. (161, 237) These reviews examined factors, such as cultural values, that are potentially important in terms of relationships with health care providers, the provision of services and help-seeking from formal services. One of the reviews also reported findings on individuals' perceptions and satisfaction with services. (237)

We also identified nine reviews that explored gendered experiences of grief and bereavement. (166, 171, 203-208, 211) Seven of these reviews explored experiences after perinatal loss, including miscarriage and stillbirth, of which four focused on mothers only, (166, 203-205) and three focused on fathers only. (171, 206, 208) Another review explored the experiences of fathers following the death of a child under 21 years old but excluded studies of miscarriage and stillbirth. (207) The remaining review focused on daughters' experiences of maternal bereavement. (211) Six of the nine reviews reported findings on individuals' experiences of using health services. (166, 171, 203, 204, 206, 208)

Protocols – equity issues

We identified two protocols focused on the experiences of vulnerable populations. (262, 280) One aimed to explore the support offered, and given, to bereaved LGBT+ carers and the extent to which it matches their needs. (262) The other protocol aimed to synthesise evidence on the experiences and needs of bereaved adult refugees. (280)

Four protocols were for reviews (including one review of reviews) that will potentially report evidence on the gendered experiences of bereaved mothers (255) or fathers (246, 254, 269) in relation to service use or their support needs.

Three protocols focused on the bereavement experiences of older people. (252, 259, 281) One of these three was for a review that aimed to identify the barriers and enablers to use of formal health services for older bereaved individuals. (281) Another also focused on older bereaved adults and access to support services. Specifically, it aimed to explore the support offered and given to bereaved elderly carers. (259) The third was for a review that is examining frailty amongst bereaved spouses/partners aged 60 years and older. (252)

REVIEWS ON THE EFFECTIVENESS OF INTERVENTIONS FOR PREVENTING OR TREATING PGD

Summary of reviews and protocols

- **Number of publications:** eighty reviews and 38 protocols focused on the effectiveness of grief-related interventions. Three of the 80 reviews were reviews of reviews. Two of the 38 protocols were for reviews that had been completed but not yet published and one was for a review of reviews.
- **Specific relationship to the deceased:** we identified 23 reviews of interventions for parents, mothers only or a defined grouping of parents and other family members. Other reviews focused on interventions for informal carers (n=8); children or siblings of the deceased (n=6); the spouse or partner of the deceased (n=3); siblings, extended family and members of the community (n=1); and family members, close friends, or coworkers (n=1). Six protocols had a focus on parents, mothers and/or family, and three were on informal carers. Other protocols focused on children or siblings of the deceased only (n=1); children and/or spouse (n=1); health professionals and family (n=1); health professionals only (n=1); spouse or partner (n=1) and care home staff, residents, or family (n=1).
- **Other personal characteristics of the deceased:** twenty-four reviews focused on interventions for adults and seven had a focus on children or young people (one of which did not focus on a specific relationship). Ten protocols focused on adults and six were on children or young people (five of which did not focus on a specific relationship).
- **Cause or type of death/specific setting:** fifteen reviews examined interventions following deaths from terminal/advanced illness or other specific health conditions (acute/sudden illness). Thirteen reviews focused on perinatal death; eight were on suicide; and one was on COVID-19. Four reviews focused on specific types of death: violent/unnatural deaths (n=2); sudden/unexpected deaths (n=1); or mass bereavement events (n=1). Six reviews focused on interventions in hospital settings. Five protocols focused on suicide; five were on terminal/advanced illness and five were on perinatal death. One protocol had a focus on sudden, unexpected or traumatic deaths. Two protocols focused on support following deaths in hospital settings, and one focused on care homes.
- **Geographical area:** nine reviews focused on a specific geographical area: high-income countries including the UK and the USA (n=7); low-income countries including sub-Saharan Africa (n=1); and low- and middle-income countries (n=1). Three protocols focused on a specific geographical area: low- or middle-income countries (n=1); high-income countries (n=1); and one focused on Spanish books for children.

Overview of reviews

We identified three reviews of reviews (152, 288, 289) and 77 standard reviews reporting on the effectiveness of grief-related interventions and/or their implementation.

Two reviews of reviews (288, 289) and 60 standard reviews had a sole focus on effectiveness. One review of reviews and 17 standard reviews reported evidence on effectiveness as well as other relevant findings on grief and bereavement experiences, and/or PGD prevalence, risk factors and general grief reactions (89, 91, 127, 128, 132-134, 152, 154, 158, 160, 163-169) (see also Table A, Appendix 3, page 89).

Review characteristics

Reviews of reviews

One review of reviews reported findings from 12 systematic reviews on practices to support parents and other family members following perinatal loss in high-income countries. (152) Two other reviews of reviews synthesised evidence on the effectiveness of any grief-related intervention. (288, 289) One examined the evidence on 19 types of grief intervention identified from 16 systematic reviews. (288) The interventions examined included various types of counselling and other forms of therapy, such as cognitive behavioural therapy (CBT), as well as support groups, sending condolence letters, peer support and physical activities. (288) The other review of reviews included 18 systematic reviews of bereavement interventions and prioritised 12 for detailed synthesis. (289) Included reviews again evaluated a range of interventions, with some focused on specific population groups, formats, or settings. (289)

Standard reviews

Reviews reporting on multiple issues of interest

Seventeen reviews had a focus on intervention effectiveness in addition to reporting other relevant findings (in other words, findings on grief and bereavement experiences, PGD prevalence, risk factors and/or general grief reactions). (89, 91, 127, 128, 132-134, 154, 158, 160, 163-169) The relative focus given to intervention effectiveness varied across the 17 reviews.

Four of the 17 reviews focused on interventions and treatment for prolonged grief; specifically in relation to: prolonged grief and substance use; (91) adult informal carers in North America experiencing prolonged grief; (128) and prolonged grief in people with an intellectual disability. (89) The fourth review examined whether interventions addressing sleep disturbances also improved symptoms of prolonged grief. (127)

Four reviews addressed specific types of interventions; one review reported on the psychosocial impact of hospital-based bereavement interventions after the death of a child, (158) and one assessed the effects of online resources and interventions for people bereaved by suicide. (168) Other reviews evaluated bereavement follow-up practices after the death of a child from cancer, (169) and compared the effectiveness of interventions based on the Dual Process Model of Coping with traditional grief therapy. (160) We also identified one review that assessed the provision and effectiveness of informal and formal bereavement support in the UK. (165)

Six other reviews reported on interventions for individuals after specific types of death. These reviews focused on interventions following: perinatal death; (132, 163, 166) loss of a child in low- and middle-income countries; (164) dementia; (154) and suicide. (167)

One review reported evidence on interventions for preventing and/or managing traumatic grief amongst children in sub-Saharan Africa. (133) Another investigated the efficacy of psychotherapeutic interventions for tackling loneliness after bereavement, which was identified as a potential risk factor for experiencing difficulties adjusting to loss. (134)

Reviews only reporting on the effectiveness of interventions

Interventions for parents and defined family group

Of the 60 standard reviews that only reported relevant findings on intervention effectiveness, 15 focused primarily on interventions aimed at bereaved parents or a defined family grouping comprising parents and other family members. (290-304) One of these 15 reviews evaluated the use of intensive care unit diaries by bereaved relatives (specifically, parents, spouses, daughters, sons and close friends) of adult patients. (297) Nine of the other 14 reviews reported on bereavement interventions for parents, or mothers only, after perinatal death. (291, 292, 294, 296, 298, 299, 301, 303, 304) Five other reviews examined bereavement interventions for parents following the loss of a child but did not restrict the focus to the perinatal period. (290, 293, 295, 300, 302) One of these reviews also included evaluations of interventions for bereaved siblings. (295)

In addition to the review focused on the use of ICU diaries described above, a further eight out of the 15 reviews investigated a specific type of intervention. One review assessed the impact of parents having contact with the baby following stillbirth. (298) Two reviews focused on nursing-based interventions (296, 301) and one examined any intervention for parents delivered by health care professionals. (300) Other reviews examined psychosocial (292, 304) and psychotherapeutic (291) interventions. The remaining review assessed the effectiveness of cognitive behavioural therapy and mindfulness-based interventions to manage symptoms of complicated perinatal grief. (294) The other six reviews included studies evaluating any type of intervention for bereaved parents. (290, 293, 295, 299, 302, 303) One of these six reviews focused specifically on parents in the neonatal intensive care unit. (303)

One other review that focused on interventions following the death of a child explicitly excluded studies with parents. It investigated the effectiveness of bereavement support programmes for siblings, any extended family members (other than parents) and the wider community. (305)

Interventions for informal carers

Six reviews examined interventions for informal carers. (76, 306-310) Two of these reviews examined interventions for informal carers of people who had dementia and reported findings on any grief-focused intervention (306) or psychosocial interventions. (76)

Two reviews assessed interventions for informal carers of patients who received palliative/end-of-life care. (307, 310) One of these two reviews specifically examined group or individual focused bereavement support (307) and the other restricted inclusion to studies conducted in Canada. (310)

Another review examined bereavement services for the family carers of adults who died in intensive care. (309) The remaining review focused on bereavement support interventions for family carers of people who died of COVID-19. (308)

Interventions for children and young people

Six reviews reported the effects of bereavement support for children, adolescents or young people following the loss of a parent or sibling. (311-316) One of these reviews also included interventions targeted at the child's remaining parent. (311) Two of the six reviews focused on psychosocial interventions; one of which specifically looked at suicide support groups (315) and the other had a focus on deaths from cancer. (314) The other four reviews included studies on any form of bereavement support. (311-313, 316)

Interventions for partner/spouse

Three reviews focused on interventions for bereaved spouses or partners. (317-319) One of the three reviews specifically examined the effectiveness of Acceptance and Commitment Therapy for bereaved spouses or partners of adults who received palliative care. (318)

Interventions for other specific relationships

One review evaluated peer support services for adults after the sudden or unexpected death of a close friend, co-worker or family member. (320)

Interventions for general population groups

Twenty-eight reviews reported on interventions for a general, non-defined group of individuals such as bereaved 'people' or 'family and friends'. (321-348) Four of the 28 reviews evaluated bereavement support for relatives/families in intensive/critical care settings (324, 326, 338, 339) Two reviews examined interventions in palliative/end of life care, (329, 337) or after death from advanced illness. (330) One of these three reviews focused specifically on dignity therapy. (329)

Three reviews evaluated specific types of support for individuals bereaved by suicide; they assessed suicide postvention service models; (323) peer support; (332) and community-based support. (328) Two other reviews examined the effectiveness of any form of intervention for people who were bereaved by suicide. (322, 334)

One review reported evidence on the effectiveness of brief contact interventions. (336) Other reviews assessed the effectiveness of visual art modalities; (344) online peer support groups; (341) adult bereavement groups; (335) grief counselling; (343) and structured or formal bereavement services. (346) Another review investigated whether physical activity-based interventions can improve grief-related outcomes. (345)

Eight of the 28 reviews focused primarily on the effectiveness of interventions for individuals identified as having more complex needs or experiencing more severe grief symptoms. (321, 325, 327, 333, 340, 342, 347, 348) Three reviews specifically examined treatments for prolonged grief; these focused on: psychotherapy-based interventions for complicated grief; (327) exposure and non-exposure-based treatments for concurrent PTSD and PGD; (325) and interventions that incorporate rituals and ritualised acts for prolonged grief and/or PTSD. (347) Others did not specifically focus on PGD, but included evaluations of interventions that could be used as treatments. This included internet/mobile-based interventions; (342, 348) psychological interventions for bereaved adults (333) and relatives of homicide victims; (321) and psychotherapy and psychotropic interventions. (340)

System-level interventions

One review explored system-level responses to bereavement support following major disaster events in order to inform service provision and policy following the COVID-19 pandemic. In addition to evidence on effectiveness, the review also reported findings on the organisation and implementation of programmes and described common features of valued services. (331)

Protocols – effectiveness of interventions

We identified 38 protocols on the effectiveness of interventions and/or their implementation. Seven of the 38 protocols focused on both experiences and interventions, and these were described in the previous section. (247-253) Another protocol described previously was for a completed review still to be published on PGD risk factors and interventions related to deaths in care homes. (140)

Thirty of the 38 protocols were focused solely on interventions and/or implementation. One of these was a protocol for a review that was completed but not yet published, which focused on grief interventions for young people aged between 14 and 24 years old. (349) Another was for a review of reviews examining the efficacy of psychotherapeutic bereavement interventions. (350) Of the other 28 protocols, all but three were added to PROSPERO between 2019-2022; one was added in 2017, (351) and two in 2018. (352, 353)

Interventions for bereaved individuals with a specific relationship to the deceased

Of the 28 protocols for ongoing standard reviews of interventions only, eight focused on bereaved individuals with a specific relationship to the deceased. (351, 352, 354-359) Two of the eight protocols focused on family carers; one was on music therapy for adult informal carers before and after a death from any life-threatening illness (355) and the other was on interventions before and after a death from dementia. (358)

Four of the protocols were on parents; one focused on interventions for mothers after miscarriage, (352) and one was on psychosocial interventions for parents after perinatal death. (357) Another also focused on perinatal death, examining technology-based psychosocial interventions for bereaved parents and other family members. (356) The other protocol focused solely on the availability of interventions for mothers in low- or middle-income countries after stillbirth. (354) The remaining two protocols involved children; one was on psychosocial interventions for children and/or their surviving parent, (351) and the other was on activity-based interventions for children after the death of a parent, carer or sibling. (359)

Interventions for bereaved individuals with a general or non-specific relationship to the deceased

Four protocols had a generic focus on family. (360-363) One of the four focused on CBT for adult family members bereaved through any cause. (363) The remaining three protocols had no restriction on the type of intervention; these focused on family bereaved due to terminal illness, (360) sudden death, (362) or following a death in the ICU. (361)

Of the 16 protocols with no specific relationship focus, four focused on interventions for individuals bereaved by suicide. (364-367) Two of these focused on peer support interventions; one for young people (aged 13 to 30 years) (364) and the other for anyone bereaved by suicide. (365) One protocol was on suicide postvention services (366) and the fourth protocol focused on any intervention for suicide bereavement. (367)

Ten protocols focused on specific types of support after bereavement. Three focused on CBT for adults experiencing symptoms of PGD. (353, 368, 369) Four protocols examined psychological or psychosocial interventions for grief; (370-373) one of these focused specifically on interventions for children and adolescents; (370) one was on interventions for adults (371) and one on online interventions for adults. (373) Another protocol was for a review that aims to conduct a network meta-analysis of interventions for prolonged grief. (374) We also identified one protocol focused on physical activity-based bereavement interventions for older adults, (375) and one on nature-based interventions. (376)

Two protocols focused on the implementation of interventions only – one was on the availability of children's story books in Spanish for bereaved children, (377) and the other aimed to identify the facilitators and barriers to community-based bereavement interventions for children and young people in high-income countries. (378)

Optimum time to access bereavement support services to prevent PGD

The DHSC was interested in identifying evidence on the optimum time to access bereavement support services in order to prevent PGD. Where reported, time since loss varied considerably between reviews and across studies within reviews; it commonly ranged from a few days, weeks or months to several years or even decades post loss. Nineteen reviews reported some findings relating to the potential influence of time since loss on the effectiveness of grief-related interventions or highlighted a lack of evidence about intervention timing and effectiveness. (127, 128, 158, 160, 165, 290, 291, 293, 298, 299, 320, 321, 324, 327, 330, 332, 333, 339, 343) We did not identify any evidence relating specifically to the optimum time to access support to prevent the development of PGD.

PRIMARY STUDIES ON THE TYPES OF BEREAVEMENT SUPPORT SERVICES AVAILABLE IN THE UK

Summary of primary studies

- **Number of studies:** sixteen primary studies reported on bereavement support services in the UK.
- **Year of publication:** most studies (n=9) were published after 2019. One study was published in 2019 and another in 2018; five studies were published between 2015 and 2017.
- **Primary focus**: most studies (n=11) reported findings on the type of support provided by different organisations. Studies also reported: the availability of services (n=9); staff views about provision (n=6); service delivery issues (n=5); barriers to accessing services (n=2); and the socioeconomic costs of bereavement (n=1).
- **Specific relationship to the deceased:** four studies focused on support for bereaved parents. Other studies had a specific focus on support for family carers (n=1); spouse (n=1), or partner and child (n=1).
- **Type of provision:** half of the studies focused on services after a specific cause of death or deaths in a specific setting (n=8). Five studies focused on the provision of general services and three others reported on service provision during the COVID-19 pandemic.

Overview of primary studies

We identified 16 primary studies on the type and nature of bereavement support services in the UK. Of the 16 primary studies, four were conducted in England only, (379-382) three were carried out in Scotland only, (383-385) and one focused on Wales only. (386) One was conducted in England and Wales; (387) and one in the UK and Ireland. (388) The remaining six studies included the whole of the UK. (69, 389-393)

Year of publication

Table 5 shows the publication year for the included primary studies. A majority of studies (9/16) were published in the last three years (2020-2023). (69, 380, 382, 383, 387-391) Five of the remaining seven studies were published between 2015 and 2017. (379, 381, 384, 385, 392) One study was published in 2018 (393) and another in 2019. (386)

Table 5: Year of publication for UK primary studies

Year	Number of studies
2022	2
2021	3
2020	4
2019	1
2018	1
2017	2
2016	1
2015	2

Study details

Thirteen studies collected data from community or voluntary organisations/groups, local authorities, NHS trusts, hospices or professional staff, such as midwives, or GPs. (379-382, 384, 386-393) Two studies collected data from organisations and the bereaved (69, 383) and one study was a secondary analysis of relevant datasets. (385) Sample size ranged from 20 units (384) to over 30,000 school children. (69) Where applicable and reported (n=10) the response rate ranged from 20% (387) to 90%. (384)

Primary focus

Table 6 shows the primary focus of included studies. Eleven of the 16 studies focused on the type of support offered by different healthcare settings and professionals. (69, 379, 381, 383, 384, 386, 387, 389, 391-393) Nine studies explored the availability of bereavement services and support. (380, 382, 383, 386-388, 390-392) Six studies reported staff views on bereavement support and provision offered; (69, 379, 381, 388, 390, 392) and five investigated service delivery issues and challenges. (379, 382, 383, 389, 391) Two studies reported findings on barriers to accessing services including during the COVID-19 pandemic. (69, 382) One study focused on socioeconomic costs of bereavement. (385)

Table 6: Primary focus of included studies

First author (year)	**Type of support**	**Availability of services**	**Staff views**	**Service delivery**	**Barriers to access**	**Costs**
Berry (2017)	x		x	x		
Cameron (2020)	x	x		x		
Cockle-Hearne (2022)	x			x		
Hackett (2021)		x	x			
Independent age (2021)		x				
Irvine (2015)	x					
Murray (2020)	x	x				
NBA (2020)	x	x		x		
O’Brien (2016)	x		x			
Ochieng (2019)	x	x				
Pearce (2021)		x	x			
Sands (2017)	x	x	x			
Sands (2018)	x					
Stephen (2015)						x
UK Commission (2022)	x		x		x	
Wakefield (2020)		x		x	x	
Total	11	9	6	5	2	1

Study characteristics

Primary studies of specific services

Eight of the 16 studies focused on services following a specific cause or type of death or deaths in a specific setting. Three studies examined bereavement services following deaths from terminal illness. (381, 389, 390) Two of the three studies also focused specifically on provision in hospices. (389, 390) One of these studies conducted a survey of UK hospices for adults to determine the bereavement support provided to families with dependent children before and after the death of a parent and to identify service delivery issues. (389) The other focused on the availability in UK hospices of cold rooms or cooling facilities for bereaved parents after the loss of a child. This study also explored staff views on these facilities and organisational policies and practices regarding their use. (390) The third study on terminal illness surveyed staff working with family carers of people who died from motor neurone disease about the support offered and staff views on provision. (381)

Three studies focused on perinatal deaths. (384, 392, 393) Two of these studies were UK wide audits of care conducted by the charity Sands, (392) and Sands together with the Bliss charity. (393) One of the two studies surveyed the heads of midwifery nationally to identify the bereavement care provision offered in maternity units. (392) The other study focused on the types of support offered to bereaved parents in 100 UK neonatal units. (393) The third study surveyed 20 out of 22 early pregnancy or maternity units in Scotland to identify the proportion that offered a memorial service and other forms of support following a miscarriage. (384)

One study addressed best practice and services available for individuals bereaved by suicide with a particular focus on Scotland. (383) Another study investigated the provision of bereavement care in adult intensive care units in England and also explored delivery issues and staff views. (379)

Primary studies of general services

Five studies reported on the general provision of bereavement services rather than focusing on support following a specific cause or type of death. (69, 380, 382, 385, 386) One study surveyed organisations in Wales on the type of bereavement support offered and the availability of services. (386) Another explored the availability and accessibility of bereavement services across the North East of England through a survey of relevant organisations and GPs. (382) The UK Commission on Bereavement conducted an online survey of bereaved adults and children as well as UK organisations. (69) It reported on various issues including types of support, barriers to access; and staff views about bereavement support. Over 60% of the adults who responded to the survey were bereaved during the COVID-19 pandemic. (69)

One study submitted a freedom of information request to all Clinical Commissioning Groups and Local Authorities in England to identify their approaches to commissioning services, the current demand for support locally, and the availability of services. (380) Another study involved a secondary data analysis of the socioeconomic costs of bereavement services in Scotland, which used both Scottish and British data on spousal bereavement (n=15,007) from 1991 to 2009, including GP, hospital and social care. (385)

Primary studies of general services and the COVID-19 pandemic

Three other studies reported findings related specifically to service provision and the COVID-19 pandemic. (387, 388, 391) One surveyed UK community and voluntary organisations to explore the type of support offered and availability of services for

BAME communities and the impact of the pandemic on provision. (387) Another explored changes in the availability of bereavement care during the COVID-19 pandemic in hospice, community, and hospital settings across the UK and Ireland. (388) The third study examined the response of bereavement services in the voluntary sector to COVID-19. (391) This study involved a survey of service managers to identify the type and availability of support services, pressures and gaps in provision, and to investigate the impact of COVID-19 on services and individuals' support needs.

DISCUSSION

This report provides a high-level descriptive overview of published and ongoing research related to grief, bereavement, and Prolonged Grief Disorder. Our goal was to produce a systematic map of the literature that could be used to inform decisions about the need for further research. We found evidence relevant to a range of questions of interest to the DHSC across 209 systematic reviews, three reviews of reviews, 96 protocols and 16 primary studies.

We grouped reviews and protocols according to the type of evidence they focused on. When categorising reviews, consideration was given to the context and aim of the work as well as the findings reported. There exists a degree of overlap between categories in terms of the nature of reported findings. For example, the categories of grief/bereavement experiences and intervention effectiveness both included some reviews that reported qualitative findings on people's perceptions of services and the benefits/impacts of specific interventions.

What review-level evidence is available on the extent and nature of Prolonged Grief Disorder?

We identified 22 reviews and 12 protocols focused on the prevalence of prolonged grief. Most reviews reported evidence on both PGD prevalence and factors that potentially influence the risk of developing the disorder. Reviews reported prevalence estimates for a broad range of bereaved population groups and causes of death. These often focused on individuals who are potentially more vulnerable to developing grief-related problems such as bereaved parents and following various types of death including violent deaths, suicides, and deaths from cancer. We identified four protocols with a central focus on the prevalence of prolonged grief amongst individuals bereaved during the COVID-19 pandemic, three of which were also focused on predictors and correlates of PGD.

What review-level evidence is available on risk factors for PGD?

We identified 42 reviews and 14 protocols which reported risk factors for PGD, correlates/predictors of the disorder or factors moderating its prevalence. The largest proportion of reviews focused on informal carers and deaths from terminal illness including cancer.

There was considerable variation in the range of factors examined by reviews. Approximately a quarter of reviews of risk factors, and one protocol, focused primarily on the impact of a single factor on the development of PGD. These mainly investigated individual-level and interpersonal factors including attachment style; informal social support; cognitive factors; family dynamics; emotional regulation; and loneliness. But we identified one review focused on a cultural factor – suicide stigma. (124) Most reviews adopted a broader perspective and reported on multiple risk factors. One review assessed 61 potential risk factors for complicated grief among family members bereaved in the intensive care unit. (117)

It was evident that reviews have investigated the relationship between PGD and a broad range of factors. However, the large number of included reviews precluded us from examining in detail, and reporting on, the specific factors that have been assessed in existing studies. Without further analysis, it remains unclear the extent to which reviews have gone beyond a focus on individual and interpersonal-level factors to consider broader social, organisational, cultural and structural factors.

The DHSC was interested in studies that investigated whether the time lag between experiencing bereavement and accessing a support service affects the likelihood of an individual developing PGD. The association between time since loss and the prevalence of prolonged grief has been examined in the literature, see for example, reviews by Djelantik et al.; (78) Heeke et al.; (113) and Kustanti et al. (87) However, it is unclear if specific evidence exists in relation to PGD risk and the length of time between bereavement and accessing support.

What review-level evidence is available on individuals' grief and bereavement experiences including the needs of bereaved people and barriers to accessing grief services?

There is a large body of literature reporting individuals' experiences of grief and bereavement. In total, we identified 103 reviews, and 44 protocols that reported experiences. It was not possible to extract details about the exact outcomes reported in each included review, but all of them reported findings on one or more of the following issues: use of support services or interactions with health professionals; use of other sources or types of support; barriers to accessing support; equity related to grief/bereavement and the use of services; coping strategies used by the bereaved; post bereavement needs; or factors reported by individuals to facilitate or impair their grieving. Findings in reviews of experiences were commonly derived from studies that used qualitative methods of data collection and analysis, including mixed methods research.

Reviews of individuals' grief and bereavement experiences are potentially valuable for informing policy and practice within the context of minimising PGD. They may facilitate a better understanding of the grieving process and what helps people cope effectively with grief as well as informing the provision of services and the development of interventions. Individual-focused interventions will not be sufficient on their own to reduce the prevalence of prolonged grief on a population level. Evidence on individuals' lived experience of grief and bereavement could be useful for informing organisational change and other preventative efforts intended to address broader social and structural factors that constrain agency and disrupt the process of grieving.

Included reviews reported a broad range of experiences, especially in terms of population groups and types of death. However, across both reviews and protocols there was a predominant focus on bereaved parents and other family members following the loss of a child, particularly in the perinatal period. We identified a sizeable number of reviews focused on experiences following common causes of bereavement including suicide (13 reviews and five protocols) and health conditions such as Alzheimer’s disease, dementia, cancer, or terminal illness (14 reviews and eight protocols).

Equity issues in relation to access

We identified three reviews with a key focus on equity issues relating to bereavement and service provision. These reviews explored the experiences of ethnic minority communities in the UK; (239) LGBT+ individuals; (214) and individuals considered structurally vulnerable in bereavement. (232) Notably, Mayland et al. reported an overall lack of research on bereavement services in the UK for individuals from ethnic minority communities and highlighted a need to strengthen the evidence base. (239) Similarly, the review by Bristowe et al., on the bereavement experiences of LGBT+ communities, was limited by a scarcity of research conducted with bereaved bisexual and trans people. They cautioned that the use of the term LGBT to describe research can be misleading when some groups are significantly underrepresented in the sample. (214)

The review by Bindley et al. published in 2019 on social and structural inequity in bereavement only identified four studies that were focused on issues related to income, employment and financial circumstances, and three of them were conducted prior to 2012. (232) This represents an important gap in the literature especially considering the difficulties in accessing bereavement services reported by individuals on a low-income and their greater reluctance to seek support. (3, 5) We are also aware of one qualitative study published in 2022 which found that housing insecurity can negatively impact bereavement and the process of grieving amongst low-income communities in the UK. (394) There may be other recently published studies examining the influence of broader socioeconomic determinants and inequities on post-bereavement needs, experience and service use, which have not yet been incorporated into evidence reviews. Additional work to identify and synthesise the findings from such studies could be beneficial for informing policy and practice.

More broadly, the literature would potentially benefit from a greater focus on the bereavement experiences and needs of the most marginalised and disadvantaged communities as these individuals, in particular, may have difficulty accessing support and be at higher risk of PGD. This includes people with a range of disabilities; Gypsy, Roma and Traveller communities; refugees and asylum seekers; and trans individuals.

In terms of issues related to gender and equity, we identified five reviews exploring the experiences of women only and four focused solely on men. All but one of these reviews focused on women as mothers or men as fathers following the death of a child or a miscarriage. Even the one study not focused on bereaved parents explored the experiences of daughters following the death of their mothers. The lack of reviews on the bereavement experiences of different genders that go beyond a focus on parents, or the child-parent relationship, represents another important evidence gap. Applying a broad gendered lens to the examination of bereavement experiences including service use is important given that some studies have identified a relationship between being a woman and experiencing PGD. (16, 113) There is also evidence that men are less likely to seek help and use services when experiencing mental health difficulties, (395) which could also include grief-related problems. Gender socialisation is recognised to play a key role in the responses of men and women to bereavement. (396, 397)

What review-level evidence is available on the effectiveness of interventions for preventing or treating PGD?

We identified 80 reviews and 38 protocols that reported on the effectiveness of grief-focused interventions and/or their implementation. We did not identify any reviews focused primarily on the cost-effectiveness of interventions. Evaluated interventions were often aimed at groups of individuals considered to be at increased risk of PGD such as informal carers, bereaved parents and individuals bereaved by suicide.

Reviews have evaluated a wide range of different interventions, almost all of which focused on the individual level. There is a paucity of evidence concerning social, organisational or structural-level interventions, which is significant. By specifically targeting inequities and other modifiable factors that increase the risk of impaired grieving and PGD before individuals develop problematic symptoms, social/organisational/structural-level interventions have an important role in terms of prevention.

Some interventions such as brief contact support, and other initiatives for bereaved families and parents, including the use of intensive care diaries and having contact with the baby following stillbirth, appear to be primarily aimed at providing support during the early stages after a loss. Other reviews had a clear focus on treatments for individuals with more complex needs who are experiencing symptoms of a grief disorder. Often however, it was difficult to determine without specialist knowledge whether the interventions assessed in the reviews were secondary prevention/early intervention, treatment or specialist support for persistent grief, or a combination of support types. Some reviews explicitly stated that interventions represented multiple levels of bereavement support.

Whilst we did not examine all reviews in depth, it was noted that the duration and severity of symptoms experienced by intervention participants varied or was unclear, which has potential implications for the usefulness of findings. Some reviews reported variation in whether included studies even applied a threshold for participation based on the severity or intensity of grief. (334, 340)

The optimum time to access bereavement support services in order to prevent PGD

We identified limited evidence on the relationship between time since loss and intervention effectiveness. Some review authors highlighted a need to treat this evidence with caution owing to wide variations in the reported time since loss of participants in included studies. (292, 343)

We did not identify evidence specifically relating to the optimum time to access bereavement support services to prevent PGD. However, we are not certain that this is something that researchers or health practitioners would seek to prescribe. A 'one size fits all' approach to grief has been criticised (398) and its nature would appear to preclude the existence of a universally applicable optimum period of time for preventative PGD interventions. Grief is recognised to be a unique, unpredictable, and non-linear process. (398-400) A person's experience of grief is not the same after each bereavement, and it also varies across cultures and between different people who experience the same type of loss. (398, 400) It has also been suggested that the routine and early provision of formal bereavement support is overtreatment which is potentially detrimental to the grieving process and risks pathologising normal grief. (7, 62, 343) Problems may be created if people develop the belief that their grief and related sadness following the loss of a loved one is an abnormal condition that requires psychological intervention. (401) We noted that in one review examining bereavement following advanced illness, the authors suggested that there was not a 'right time' to receive support. This was based on the finding that individuals' preferences regarding the timing of support varied within and across studies. (330)

What evidence is available from primary studies about the types of bereavement services provided in the UK?

We identified evidence from 16 primary studies on the type and nature of bereavement support services available in the UK. While conducting this mapping review, we also became aware of an online directory and signposting website for bereavement services in the UK (https://www.ataloss.org). There are currently 1,400 local and national bereavement support services listed in a searchable database on the website.

We are also aware of a research programme being conducted at the Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College, London. The Better End of Life Project, funded by Marie Curie aims to understand the outcomes and experiences of individuals affected by death, dying, and bereavement in the UK – https://www.kcl.ac.uk/research/better-end-of-life-project.

As part of the research, the team is seeking to map the availability of care and services in the UK to identify gaps and inequalities. It is not clear from the information on the website whether the focus will be restricted to palliative care settings or whether it will also encompass services more broadly.

To what extent do available services reflect those that have been evaluated?

Several primary studies examined services for individuals bereaved following death from specific health conditions, or in specific settings, that have been the focus of reviews. For example, interventions and services after bereavement by terminal illness, perinatal death, and deaths in critical care settings. We also identified three reviews with a specific focus on UK bereavement care, which reported findings related to experiences and/or impact and effectiveness. (165, 239, 240)

Strengths and limitations

Our map of the evidence was conducted using systematic methods which included comprehensive searching, clearly defined inclusion criteria and systematic coding of key characteristics.

We captured a range of key information about each review in our evidence map including details on its focus, the participants in included studies, and where applicable, the nature of the intervention being evaluated. Our map is limited by the quality of reporting on included studies by review authors. For example, some details about included studies may have been omitted or reported inaccurately by review authors. Being unable to extract and report as much detail about each review as we originally proposed, owing to the large number identified, should be recognised as a limitation of our work.

We identified multiple reviews with a similar topic focus and study aim, particularly in relation to bereavement resulting from perinatal death, terminal/chronic illness or suicide. Consequently, there could exist considerable overlap in the primary studies included across reviews. When the same study or studies are included in multiple reviews it can offer reassurance that individual reviews were conducted in a consistent manner and their results reflect the existing literature. (402) However, study overlap may result in an overestimation of the size and strength of the evidence base as well as the over-representation in the literature of those studies that are included in multiple reviews. (402, 403) The over-representation of specific studies can be a source of bias, which is important to note if readers access the findings of individual reviews included in our map of the literature.

CONCLUSIONS AND IMPLICATIONS FOR ADDITIONAL SYNTHESIS WORK

Our systematic map of the literature reveals that issues related to grief and bereavement, including PGD, have been extensively researched. We found 212 reviews, 96 protocols and 16 primary studies that addressed a range of questions of interest to the DHSC. Conducting additional synthesis work may be of value if it was possible to identify a specific and focused research question, arising from our map of the literature, which would address a significant gap in knowledge. Appropriate additional work could involve supplementing existing reviews or conducting a new evidence review.

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APPENDIX 1: QUESTIONS OF INTEREST TO THE DHSC

- What is the extent and nature of PGD? How widely is it experienced and by who?
- What factors make an individual more likely to develop PGD? Are these individual or situational factors? Does the time lag between experiencing bereavement and accessing a support service affect the likelihood of an individual developing PGD?
- What are the needs of bereaved people, including in relation to support and services, and what policies would be beneficial?
- What are the barriers to accessing grief services and what are the equity issues in relation to access?
- What interventions are effective for preventing PGD? When is the optimum time to access bereavement support services in order to prevent PGD?
- What types of bereavement support services are available in the UK? To what extent do available services reflect those that have been evaluated?

APPENDIX 2: SEARCH STRATEGY

Ovid MEDLINE(R) ALL

via Ovid http://ovidsp.ovid.com/

Date range: 1946 to October 27, 2022

Records retrieved: 1639

The MEDLINE strategy below includes an adapted version of the DARE systematic review search filter for Ovid MEDLINE and the NICE UK search filter for Ovid MEDLINE.

Search Strategies (n.d.). About the Databases, Centre for Reviews and Dissemination. https://www.crd.york.ac.uk/crdweb/searchstrategies.asp Accessed: 20/10/2022

Ayiku L, Levay P, Hudson T, Craven J, Barrett E, Finnegan A and Adams R. The MEDLINE UK filter: development and validation of a geographic search filter to retrieve research about the UK from OVID MEDLINE. Health Information and Libraries Journal, 2017 34 (3): 200-216. (Publisher: Wiley. © 2017 Crown copyright. Health Information and Libraries Journal © 2017 Health Libraries Group).

1 exp Grief/ (9907)

2 Prolonged Grief Disorder/ (37)

3 Bereavement/ (6459)

4 (grief* or griev* or bereave* or mourn*).ti,ab,kw. (18380)

5 or/1-4 (23580)

6 systematic review/ (210522)

7 systematic$ review$.ti,ab. (268123)

8 exp meta-analysis as topic/ (25835)

9 meta-analysis/ (169629)

10 meta-analytic$.ti,ab. (9192)

11 meta-analysis.ti,ab,pt. (244080)

12 metanalysis.ti,ab. (475)

13 metaanalysis.ti,ab. (1782)

14 meta analysis.ti,ab. (213917)

15 meta-synthesis.ti,ab. (1344)

16 metasynthesis.ti,ab. (420)

17 meta synthesis.ti,ab. (1344)

18 meta-regression.ti,ab. (11716)

19 metaregression.ti,ab. (907)

20 meta regression.ti,ab. (11716)

21 (synthes$ adj3 literature).ti,ab. (5262)

22 (synthes$ adj3 evidence).ti,ab. (15785)

23 integrative review.ti,ab. (4416)

24 data synthesis.ti,ab. (13662)

25 (research synthesis or narrative synthesis).ti,ab. (6046)

26 (systematic study or systematic studies).ti,ab. (14395)

27 (systematic comparison$ or systematic overview$).ti,ab. (4270)

28 evidence based review.ti,ab. (2336)

29 comprehensive review.ti,ab. (22385)

30 critical review.ti,ab. (18704)

31 ((quantitativ* or qualitativ*) adj2 review*).ti,ab. (9016)

32 structured review.ti,ab. (989)

33 realist review.ti,ab. (536)

34 realist synthesis.ti,ab. (307)

35 ((mixed or multiple or indirect) adj treatment$ comparison$).ti,ab. (932)

36 or/6-35 (501097)

37 review.pt. (3064650)

38 medline.ab. (153541)

39 pubmed.ab. (185654)

40 cochrane.ab. (122030)

41 embase.ab. (138998)

42 cinahl.ab. (40473)

43 psyc?lit.ab. (917)

44 psyc?info.ab. (53436)

45 (literature adj3 search$).ab. (84452)

46 (database$ adj3 search$).ab. (88072)

47 (bibliographic adj3 search$).ab. (3482)

48 (electronic adj3 search$).ab. (30750)

49 (electronic adj3 database$).ab. (43088)

50 (computeri?ed adj3 search$).ab. (3851)

51 (internet adj3 search$).ab. (4083)

52 included studies.ab. (38984)

53 (inclusion adj3 studies).ab. (23226)

54 inclusion criteria.ab. (119326)

55 selection criteria.ab. (34739)

56 predefined criteria.ab. (2404)

57 predetermined criteria.ab. (1255)

58 (assess$ adj3 (quality or validity)).ab. (105460)

59 (select$ adj3 (study or studies)).ab. (85379)

60 (data adj3 extract$).ab. (89684)

61 extracted data.ab. (19343)

62 (data adj2 abstracted).ab. (6277)

63 (data adj3 abstraction).ab. (2150)

64 published intervention$.ab. (236)

65 ((study or studies) adj2 evaluat$).ab. (233907)

66 (intervention$ adj2 evaluat$).ab. (14496)

67 confidence interval$.ab. (526794)

68 heterogeneity.ab. (216078)

69 pooled.ab. (118997)

70 pooling.ab. (15549)

71 odds ratio$.ab. (343443)

72 (Jadad or coding).ab. (222910)

73 or/38-72 (1870519)

74 37 and 73 (315552)

75 review.ti. (637497)

76 75 and 73 (237222)

77 (review$ adj4 (papers or trials or studies or evidence or intervention$ or evaluation$)).ti,ab. (240198)

78 ((quantitativ* or qualitativ*) adj2 synth*).ti,ab. (8994)

79 ((scoping or rapid) adj2 (review* or stud*)).ti,ab. (23116)

80 36 or 74 or 76 or 77 or 78 or 79 (790772)

81 5 and 80 (998)

82 limit 81 to yr="2015 -Current" (656)

83 exp United Kingdom/ (386814)

84 (national health service* or nhs*).ti,ab,in. (254732)

85 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (46560)

86 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in. (2362607)

87 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or

("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in. (1669388)

88 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in. (66879)

89 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in. (246093)

90 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in. (32063)

91 or/83-90 (2965673)

92 (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/) (3251818)

93 91 not 92 (2809273)

94 5 and 93 (3165)

95 limit 94 to yr="2015 -Current" (1296)

96 82 or 95 (1762)

97 exp animals/ not humans/ (5058782)

98 96 not 97 (1755)

99 letter.pt. (1197110)

100 editorial.pt. (624133)

101 comment.pt. (983795)

102 exp historical article/ (409053)

103 anecdotes as topic/ (4746)

104 or/99-103 (2495022)

105 98 not 104 (1646)

106 remove duplicates from 105 (1639)

Key:

/ or .sh. = indexing term (Medical Subject Heading: MeSH)

exp = exploded indexing term (MeSH)

* or $ = truncation

ti,ab,kw = terms in either title, abstract, keyword fields

in = institution field

adj3 = terms within three words of each other (any order)

? = optional wild card character for zero or one letters

pt = publication type

APPENDIX 3: FOCUS OF INCLUDED REVIEWS (DETAILED)

Table A: Focus of included reviews

Focus	Reviews	Protocols
Prevalence only	83, 86, 90, 94, 95	102, 107-109
PGD risk factors only	110-119	136-139
General grief reactions only	142-147	148-151
Interventions only	76, 288-348	349-378
Grief and bereavement experiences only	72-75, 174-243	244-246, 254-287
Prevalence; PGD risk factors	10, 78, 79, 84, 85, 87, 92, 96, 97	98-101, 103-105
Prevalence; PGD risk factors; general grief reactions	77, 82, 88	106
Prevalence; PGD risk factors; general grief reactions; grief/bereavement experiences	80, 93	
Prevalence; PGD risk factors; interventions	89, 91	
Prevalence; general grief reactions; grief/bereavement experiences	81	
PGD risk factors; general grief reactions	122-126, 129-131	141
PGD risk factors; general grief reactions; interventions	132, 134	
PGD risk factors; grief/bereavement experiences	120	
PGD risk factors; grief/bereavement experiences; interventions	133	
PGD risk factors; general grief reactions; grief/bereavement experiences	121, 135	
PGD risk factors; interventions	127, 128	140
Grief/bereavement experiences; general grief reactions	153, 155-157, 159, 161, 162, 170-173	
Grief/bereavement experiences; interventions	152, 158, 163-169	247-253
Grief/bereavement experiences; general grief reactions; interventions	154, 160	

Reviews of reviews: #152, #288, #289; Protocols for reviews completed but not yet published: #140, #244, #245, #349

The NIHR Policy Research Programme Reviews Facility puts the evidence into development and implementation of health policy through:

- **Undertaking policy-relevant systematic reviews of health and social care research**
- **Developing capacity for undertaking and using reviews**
- **Producing new and improved methods for undertaking reviews**
- **Promoting global awareness and use of systematic reviews in decision-making**

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UCL Social Research Institute, University College London;
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