Review Article

PALLIATIVE MEDICINE

Palliative Medicine
2020, Vol. 34(7) 871–888

DOI: 10.1177/0269216320920533
journals.sagepub.com/home/pmj


The impacts and effectiveness of support for people bereaved through advanced illness: A systematic review and thematic synthesis

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Abstract

Background: Bereavement support is a key component of palliative care, with different types of support recommended according to need. Previous reviews have typically focused on specialised interventions and have not considered more generic forms of support, drawing on different research methodologies.

Aim: To review the quantitative and qualitative evidence on the effectiveness and impact of interventions and services providing support for adults bereaved through advanced illness.

Design: A mixed-methods systematic review was conducted, with narrative synthesis of quantitative results and thematic synthesis of qualitative results. The review protocol is published in PROSPERO (www.crd.york.ac.uk/prospero, CRD42016043530).

Data sources: The databases MEDLINE, Embase, PsycINFO, CINAHL and Social Policy and Practice were searched from 1990 to March 2019. Studies were included which reported evaluation results of bereavement interventions, following screening by two independent researchers. Study quality was assessed using GATE checklists.

Results: A total of 31 studies were included, reporting on bereavement support groups, psychological and counselling interventions and a mix of other forms of support. Improvements in study outcomes were commonly reported, but the quality of the quantitative evidence was generally poor or mixed. Three main impacts were identified in the qualitative evidence, which also varied in quality: 'loss and grief resolution', 'sense of mastery and moving ahead' and 'social support'.

Conclusion: Conclusions on effectiveness are limited by small sample sizes and heterogeneity in study populations, models of care and outcomes. The qualitative evidence suggests several cross-cutting benefits and helps explain the impact mechanisms and contextual factors that are integral to the support.

Keywords

Palliative care, systematic review, bereavement, grief

What is already known about the topic?

- The support needs of people experiencing bereavement vary significantly.
- Bereavement support in palliative care involves different types and levels of provision to accommodate these needs.
- Specialist grief therapy is known to be effective for those with high-level risk and needs.

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What this paper adds?

- Bereavement interventions were wide ranging and included bereavement support and social groups, psychological and counselling interventions and other types of support such as arts-based, befriending and relaxation interventions.
- Good quality randomised controlled trial evidence was only available for targeted family therapy and a non-targeted group–based therapy intervention, both of which were introduced during the caregiving period and found to be partially effective.
- The synthesis of qualitative evidence identified three core impacts which were common across interventions: 'loss and grief resolution', 'sense of mastery and moving ahead' and 'social support'.

Implications for practice, theory or policy

- The qualitative evidence suggests the value of peer support alongside opportunities for reflection, emotional expression and restoration-focused activities for those with moderate-level needs.
- These findings suggest the relevance of resilience and public health–based approaches to bereavement care.

Background

Grieving is a natural process, in which most people learn to adjust without a need for formal support.[1,2] However, the relationship between grief and poor mental and physical health is well established.[3,4] It is estimated that between 6% and 20% of adults experiencing a loss develop complicated grief symptoms,[2,5–7] which have been described as painful and persistent reactions associated with impaired psychological, social and daily functioning.[6,8,9] Estimates of complicated grief in bereaved caregivers also vary, with between 8% and 30% prevalence reported.[9,10]

Palliative care has an important role to play in supporting caregivers and families of patients' with advanced disease,[11–14] with recommendations that their bereavement needs are assessed and addressed with appropriate psychosocial supports.[12,13] NICE recommends a three-component model which recognises different levels and type of support,[13] and which maps closely to wider calls for a need-based three-tiered public health approach:[1,13]

- Component 1 (universal) where information is offered regarding the experience of bereavement and locally available support. Support is based within informal social networks, including family and friends.
- Component 2 (selective) which makes provision for people with moderate needs to reflect upon their grief through counselling and other forms of support. Support may be provided individually or in a group environment.
- Component 3 (indicated) which encompasses specialist interventions for those with complex needs and at high risk of prolonged grief disorder (PGD), including specialist counselling and mental health services.

Palliative care providers typically offer different types of support which cut across these three components. Examples range from drop-in events and information evenings, telephone support, mutually supportive groups, individual and group counselling and specialist counselling for those with more complex needs.[12,15,16] However, the evidence base for bereavement support in palliative care is limited, and comprehensive evidence synthesis around component one and two support has not previously been conducted. Reviews of supportive interventions for family caregivers have either excluded bereavement interventions,[17] or due to the low number of well conducted, relevant studies have been unable to draw conclusions on effectiveness.[18,19] Meta-analyses and systematic reviews of bereavement interventions are available that are not specific to bereaved caregivers with mixed results reported.[20–25] Some have shown positive effects,[24,25] while others have reported inconclusive results and limited effects.20–22,26,27 Some have also indicated that bereavement interventions may only be effective for those with more severe grief symptoms.[20,22,27–31] However, the poor quality of many of these studies has been noted,[23] including self-selecting and heterogeneous samples, absence of usual care control groups[25] and inconsistent and inappropriate outcome measurement.[20,21,26] Previous reviews have also not considered the qualitative or mixed-methods evidence for the wider range of support that is delivered in palliative care settings, which includes but is not limited to grief counselling.

This mixed-methods systematic review primarily considers the evidence on what could be considered NICE component two support, with only a small minority of studies reporting on component three type interventions targeted at high-risk groups. Evidence for component one type support (e.g. information leaflets, memorial events) is not included as these were considered too different in their purpose and content to enable meaningful comparison with the more sustained models of support considered in this review. A mixed-methods design was chosen not only to access evidence on models of support which are less

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
• Primary studies with a study population of adults bereaved through advanced illness. • Written in English and published in peer-reviewed journals between 1990 and 2019. • From the United Kingdom or comparable countries where the research is likely to be applicable to the UK setting (North America, Western Europe and Australia/New Zealand).	• Bereaved parents of children under 18 years of age and adults bereaved through unexpected deaths. • Mixed populations (e.g. current and bereaved caregivers) where it was not possible to identify the impact of the intervention on the target population. • Purely information-based support (e.g. leaflets about grief and anniversary cards) or 'one-time' forms of support (e.g. memorial services, information evenings and post-death bereavement contact by medical/nursing staff).

likely to have been evaluated in randomised controlled trials (RCTs), but also because these types of interventions represent 'complex interventions'. This means that they have multiple interacting components and outcomes, and associated challenges when it comes to evaluation.[32,33] In recognising this complexity and the importance of understanding participant experiences, this review is informed by the epistemological and ontological commitments of critical realism[34,35] and the methodological endeavours of realist and process evaluation.[36–38] It considers evidence from all study designs, aiming to unpack the relationships between context, mechanisms and outcome,[36–38] while also assessing the evidence for effectiveness.

Methods

A narrative systematic review was conducted[39] which aimed to identify bereavement interventions and services reflective of NICE component two and three support for adults bereaved through advanced illness. It considers both the quantitative and qualitative evidence for their effectiveness and impact and the key features of their effective delivery.

Searches

Following development of a review protocol (www.crd.york.ac.uk/prospero, CRD42016043530), a comprehensive search was conducted on 15 April 2016. The databases Ovid MEDLINE and MEDLINE In-Process, Ovid Embase, Ovid PsycINFO and Ebsco CINAHL were searched for studies published from 1 January 1990. This search was updated in March 2019 and included an additional database – Social Policy and Practice that was not previously available. Reference list checking, citation tracking and contacting authors of included papers were conducted to avoid missing relevant studies. Relevant systematic reviews were also examined to identify eligible primary research.

Databases were searched using index terms and keywords. A set of bereavement/grief terms were identified and combined with a set of palliative care/advanced illness/caregiver terms. The Ovid MEDLINE search strategy is detailed in Supplementary File One. Results from the searches were imported into EndNote and duplicate references were removed.

Study selection

This mixed-methods review included evaluations of bereavement interventions reflective of NICE component two and three support, which reported results on effectiveness, impact and the key features of their successful delivery. Predefined inclusion and exclusion criteria were used to select studies (Table 1).

Relevant papers were identified by two independent reviewers, following a process of title, abstract and full-paper screening. Any disagreements were resolved by discussion between the reviewers.

Data extraction and quality assessment

Data were extracted using a standardised Excel spreadsheet which was developed by the research team to summarise the included study characteristics and their results (Supplementary File Two). Quality assessment was conducted on all included studies using the appropriate GATE checklists.[40] These were completed by four researchers and 20% were assessed by a second reviewer. Studies were rated as 'good' quality when all or almost all the critical appraisal criteria were scored as good, none of the criteria were rated as poor and none of the unfulfilled criteria were of high relevance (i.e. blinding of trial arm). Papers of mixed quality had many of the criteria rated as 'good' or 'mixed' and low-quality studies were those with a few criteria rated 'good' or 'mixed', meaning that study conclusions would have high risk of bias.

Data analysis and synthesis

Due to heterogeneity in intervention design and study outcomes, meta-analysis of quantitative results was not possible and a narrative synthesis was used instead. For qualitative studies, a further thematic synthesis of results was undertaken, following a three-stage process: coding

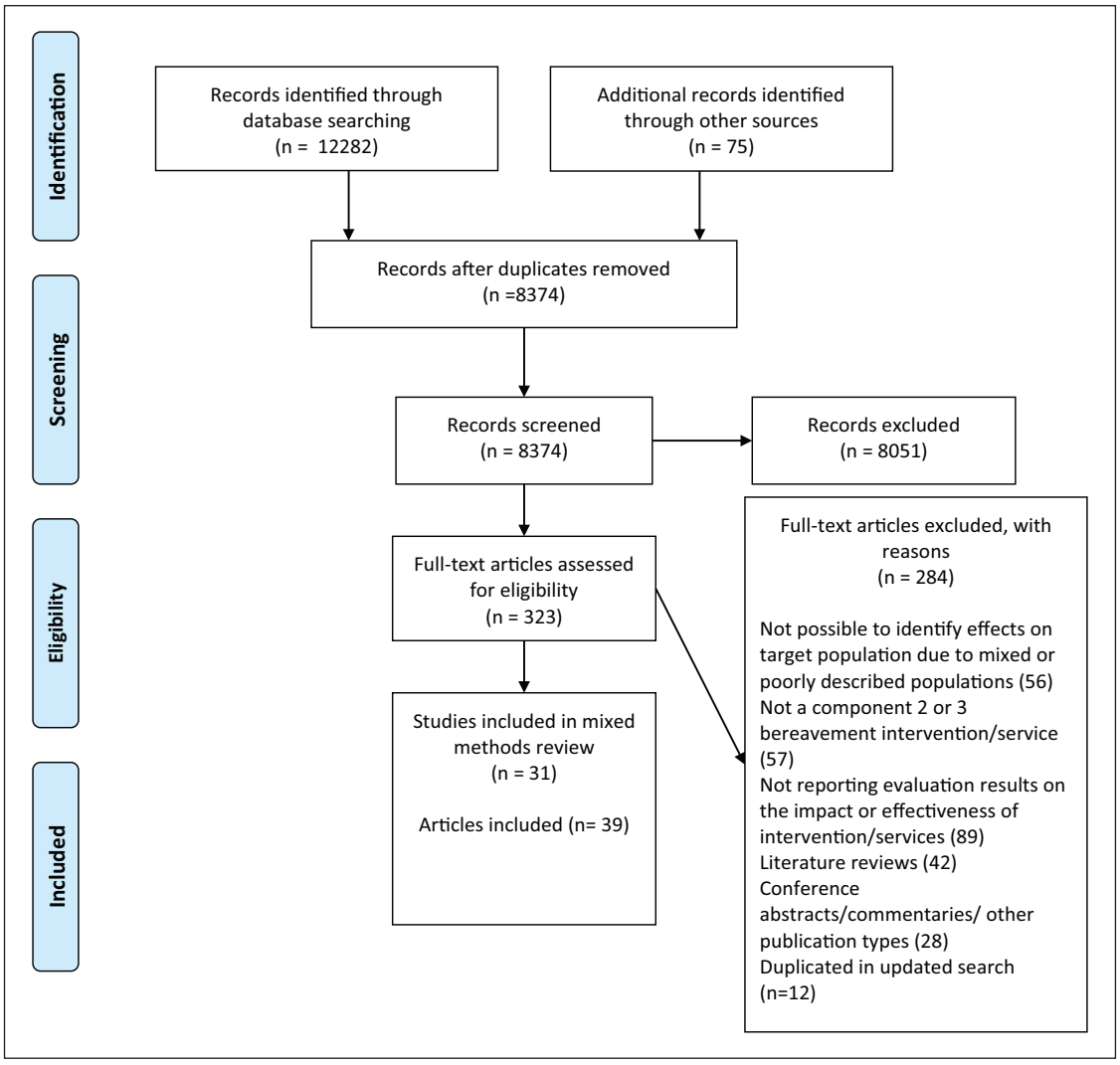

Figure 1. PRISMA 2009 flow diagram.

text; development of descriptive themes; and analytical theme generation.[41] PDF copies of included qualitative studies were uploaded into QSR NVivo V.10. Descriptive codes were inductively generated by three researchers through line-by-line coding of the relevant sections of results of each study. The data were re-reviewed by the main author to create a coding framework, and descriptive themes were organised into sets of analytical thematic hierarchies. These were reviewed and discussed by two researchers (E.H. and H.S.) to ensure rigour and reliability and to ensure that the themes reflected the results of the studies.

Results

Study characteristics and methodological quality

Following a process of title, abstract and full-paper screening, 31 studies (39 articles) were identified which met the inclusion criteria for this mixed-methods review (Figure 1). These included 15 effectiveness studies (combined $n = 1893$), and eight of which used randomised designs.[42–49] The remainder of these 15 effectiveness studies used either uncontrolled before and after designs[50–54] or included self-selecting comparison groups.[55,56] Seven of these studies had very small samples sizes. The overall quality of many of these studies was therefore considered low.[44,47,51–55] The three mixed-quality studies were limited by lack of random allocation[56] or insufficient reporting on some methodological criteria.[43,48,49] Only three trials were assessed as being of 'good' quality.[42,45,46]

Twenty-one studies collected qualitative data to explore participant views or experiences of interventions, and one quantitative feedback survey was also included (combined $n = 391$). Six of these formed parts of the effectiveness studies cited above.[42,44,46,47,50,51] The overall quality of these studies or study components varied, with six assessed as 'good' quality,[50,57–61] 10 studies (11 articles) as

'mixed' quality[44,51,62–70] and six studies considered as 'low' quality.[71–76] Study characteristics and quality scores are detailed in Table 2.

Types of interventions and services

A wide variety of interventions are included in this review. Most common were bereavement support and social groups (*n* = 12) and psychological and counselling interventions (*n* = 10). Other types included creative arts, writing and music interventions (*n* = 3), befriending and home-visiting support (*n* = 4) and relaxation and massage interventions (*n* = 2). These interventions represented a mix of individual (*n* = 12), family (*n* = 2) and group-based (*n* = 19) support and varied in the number of sessions and length of time over which they ran. Most commonly, they were delivered by professionals (*n* = 25), but some were led by volunteers, which included trained volunteer counsellors as well as members of the public in 'befriending' roles (*n* = 5). Three interventions were peer- or self-led. The study populations included bereaved relatives of specific patient groups (cancer *n* = 13, dementia *n* = 2 and HIV/AIDS *n* = 3), as well as general bereaved caregiver populations (*n* = 13). Almost all studies reported on what could be considered NICE component two support (*n* = 27). Only two interventions (four studies) provided specialist (component three) support to those pre-identified as 'at risk'[45,46,58,75] and two studies evaluated hospice services which provided a mix of support.[63,70] A matrix detailing the different approaches is presented in Table 3.

Evidence for effectiveness

A total of 15 effectiveness studies (18 papers) were included in this section, and seven of which were RCTs. Three 'good-quality' RCTs introduced support for caregivers during the end-of-life period, continuing into bereavement.[42,45,46] The Existential Behaviour Therapy (EBT) intervention was delivered to groups of current and bereaved caregivers over six weekly sessions.[42] The Family Focused Grief Therapy (FFGT) intervention was evaluated in two RCTs[45,46] and delivered to families identified as at risk of poor social outcomes. The first FFGT trial was conducted in Australia and involved four to eight support sessions spread over 9–18 months, depending on individual family needs.[45] The second study was a three-arm trial conducted in the United States, with six or 10 sessions provided over 7 months.[46]

In the EBT trial, significant between-group differences were reported in self-reported anxiety and all three quality of life measures post-intervention, and in depression and one quality of life measures at 1-year follow-up.[42] In the first FFGT trial, a significant reduction in distress was identified at 13-month follow-up. No effects were found on social adjustment and depression overall, but for the 10% of families treated with FFGT who were most troubled at baseline, significant improvements in depression occurred. There were also differences by 'type' of family, with some family types benefitting more than others.[45] When conducted in the United States, using a measure of complicated grief, significant treatment effects were found for low-communicating and high-conflict families, but not for low-involvement families. No significant treatment effects were found for depression.[46]

Three 'mixed-quality' RCTs[43,48,49] and one 'mixed-quality' controlled before and after study[56] evaluated group-based interventions delivered to bereaved partners or spouses of HIV/AIDS[43,48] and cancer patients.[49,56] Participants in the HIV/AIDS-specific groups had also been diagnosed as HIV positive[43,48] or were at increased risk of such diagnosis.[43] The support was delivered over five,[56] six,[49] 10[43] and 12[48] sessions. One of the AIDS interventions used the Cognitive Behavioural Therapy (CBT),[48] and one of the cancer-specific group involved psychotherapy.[49] Significant between-group differences were reported in distress, healthcare utilisation and immunological/biological measures in the HIV/AIDS bereavement support group trial[43,77] and in distress and quality of life in the CBT trial.[48,79] No significant overall differences were found on measures of grief or depression in either trial,[48,77] but participants with higher levels of distress in the CBT group were found to have significantly lower grief severity scores than distressed participants in the comparison group who were accessing individual therapy.[78] In the psychotherapy group trial for spouses of cancer patients, significant between-group differences were found on measures of self-esteem and role strain, but not on grief, depression or other health and well-being outcomes.[49] In contrast with the CBT trial,[78] improvements were not found to be greater for at risk individuals receiving psychotherapy compared with at risk controls.[49] No benefits of the support group for bereaved cancer caregivers were found on measures of grief, anxiety or depression compared with non-participant controls.[56]

Of the eight 'low-quality' effectiveness studies, seven had 20 participants or fewer making their results at best indicative. Of these, two used randomly assigned comparison groups.[44,47] Apart from significant between-group differences in self-reported coping for a creative writing intervention,[44] differences were non-significant for all other outcomes. The other five studies were uncontrolled before and after studies, further limiting their evidence. Statistically significant improvements in study outcomes pre- and post-intervention were reported for Bereavement Life Review[54] and a bereavement support group for people bereaved through AIDS.[51] Non-significant self-reported improvements were reported for a CBT insomnia intervention,[53] relaxation training[52] and an online support group.[50] In a cross-sectional study comparing the effectiveness of two self-selecting groups (a Christian-oriented

Table 2. Study summary characteristics and results.

First author and year	Design and quality score	Country	Intervention	Sample	Outcomes and measures/ qualitative methods	Results	Included in narrative synthesis and/or thematic synthesis
Agnew 2009[62]	Qualitative Study (+) Focus group	The United Kingdom	Bereavement support group, 10 monthly sessions Group support Professional led	Seven bereaved hospice caregivers	Focus group Thematic analysis	Key themes: Benefit from groups by feeling understood by others in similar situations Groups need to 'feel safe' in terms of where, when and what happens in them Groups need to offer the choice of listening or talking Groups should be inclusive and heterogeneous	Thematic synthesis
Ando 2015[54]	Uncontrolled before and after (–)	The United States	Bereavement life review, two sessions 2 weeks apart Individual support Professional led	20 bereaved Hawaiian American caregivers of cancer patients	Depression (BDI-11) Spiritual well-being (FACIT-sp)	Statistically significant increases in spirituality and decreases in depression	Narrative synthesis
Carter 2009[53]	Uncontrolled before and after (–)	The United States	CBT for chronic insomnia, two sessions 2 weeks apart Individual support Professional led	11 bereaved caregivers of cancer patients	Depressive symptoms (CESD) Sleep quality (PSQI, actigraphy, sleep logs, goal attainment scaling)	Self-reported improvements in sleep and reduction in depressive symptoms	Narrative synthesis
Cronfalk 2010[66]	Qualitative study (+)	Sweden	Soft tissue massage, eight weekly sessions Individual support Professional led	18 bereaved caregivers of cancer patients	Semi-structured interviews Qualitative content analysis	Key themes: Comfort and hope through relationships and interaction with professionals Enabling rest, relaxation and feelings of peace Space to focus on grief during session and other areas of life at other times Forming new routines and structure in daily lives Regaining mastery and achieving personal development	Thematic synthesis
Diamond 2012[63]	Mixed-methods qualitative component used (+)	The United Kingdom	Two hospice bereavement counselling services Individual support Volunteer led with professional support for more complex cases	13 volunteers 23 bereaved hospice clients	Interviews used to administer quantitative and qualitative tools (HAT) Qualitative content analysis of data collected in HAT	Key themes: Clients gained insight, hope and reassurance from therapy sessions Helped by focusing on difficult emotions and issues Helped to explore options and engage in decision-making and looking ahead Helpful talking to those other than friends and family Consistent and trusting relationship enabled clients able to open up and express feelings	Thematic synthesis
Di Mola 1990[73]	Qualitative study (–)	Italy	Family end-of-life home care with bereavement support component Individual/family support Volunteer led	33 volunteers Three groups (10–12 per group)	Focus groups Analytical approach not described	Key themes: Marginal role of volunteers in bereavement but main benefit seen as one of the continued companionship and sharing of important life events	Thematic synthesis
Durepos 2017[59]	Qualitative study (++)	Canada	Psychoeducation caregiver support programme, ongoing weekly sessions Group support Professional led	Dementia caregiver participants (n = 9, three of which were bereaved) Caregivers not attending group (n = 2) Healthcare professionals, including nurses and programme leaders (n = 5)	Semi-structured interviews Qualitative content analysis	Key themes: Strengthened community support Sharing coping strategies Sense of altruistic fulfilment by supporting others Challenges such as group dynamics, content preferences, uncertainty over attending post-death and practical difficulties with attending	Thematic synthesis

(Continued)

Table 2. (Continued)

First author and year	Design and quality score	Country	Intervention	Sample	Outcomes and measures/ qualitative methods	Results	Included in narrative synthesis and/or thematic synthesis
Fegg 2013[42] Kogler 2013[61]	RCT (++) Qualitative study (++)	Germany	Existential behavioural therapy, six weekly groups for caregivers in the last stage of life and during acute bereavement (Control: usual treatment) Group support Professional led	Main trial: 160 bereaved and current carers Interviews: 16 bereaved caregivers of patients receiving palliative care	Depression (BSI) Quality of life (SWLS, WHOQOL-BREF, QOL-NRS) Mood (PANAS) Semi-structured interviews Qualitative content analysis	Significant between-group differences in self-reported measures at 1 year for depression and one quality of life measure (QOL-NRS). Other measures are non-significant Qualitative themes: Learning coping strategies such as self-regulation, focusing on positive, mindfulness and avoiding preoccupation with negative thoughts Sharing coping strategies and learning from one another Feeling understood by peers, sense of belonging and togetherness Grief experiences understood as normal, enabling acceptance of these experiences Enabled self-disclosure and expression of emotions	Narrative synthesis Thematic synthesis
Finley 2010[65]	Qualitative study (+)	The United Kingdom	Bereavement support groups at hospice, between four and eight weekly sessions Group support Professional led	70 bereaved caregivers	Audit of group records Thematic analysis	Key themes: Family life, stories of death processes, grief and coping Themes noted in the records included loss, loneliness and practical issues	
Goldstein 1996[72]	Cross-sectional survey (–)	The United States	Bereavement support group involving psychodynamic approaches and supportive educational techniques, eight sessions Group support Professional led	Five bereaved adults from cancer centre	Five-point Likert-type scale to assess helpful features of group	Participants rated following questionnaire items as 'useful': Learning coping strategies Helping others by sharing strategies, information and offering support Normalisation of grief process Being able to speak to 'strangers' about experiences without risk of alienating family and friends	Narrative synthesis
Goodman 2009[55]	Cross-sectional survey (–)	The United States	One secular hospice support group One Christian support group Group support	83 bereaved individuals (49 attending hospice group)	Hopelessness (BHS) Religious coping (RCOPE)	No statistically significant differences between two groups	Narrative synthesis
Goodkin 1998[43] Goodkin 1999[77]	RCT (+)	The United States	Bereavement support group, 10 weekly sessions (Control: usual treatment) Group support Professional led	119 bereaved gay men (HIV positive and negative)	Immunological function (HIV-related cell counts) Neuroendocrine (plasma cortisol level) Healthcare visits Distress/grief (TRIG/POMS) Secondary measures (ad hoc complicated grief index and SIGH-AD)	At 6 months statistically significant between-group differences in some HIV-related cell counts, plasma cortisol level and healthcare utilisation At 10 weeks statistically significant between overall group differences in composite distress/grief scores and distress component of score and in controlled analysis on grief measures	Narrative synthesis

(Continued)

Table 2. (Continued)

First author and year	Design and quality score	Country	Intervention	Sample	Outcomes and measures/ qualitative methods	Results	Included in narrative synthesis and/or thematic synthesis
Holtslander 2016[44]	RCT (−) Qualitative study (+)	Canada	Finding balance writing tool with examples and exercises. Used over 2 weeks (Control: wait list) Individual support at home Self-administered tool	19 bereaved older caregivers of cancer patients	Feasibility data Hope, coping and balance (HHI, HGRC and IDWL) Qualitative questions asked at follow-up Qualitative content analysis	Statistically significant difference in self-reported coping; IDWL restoration-oriented scale Qualitative themes: Validation of emotions and helping themselves to move forward Focusing on new ideas in finding balance The timing of the intervention	Narrative synthesis Thematic synthesis
Hopmeyer 1994[74]	Cross-sectional survey (−)	Canada	Bereavement support group (closed membership), bi-weekly for six to eight sessions. Educational material presented and discussed Group support Peer facilitation with social worker in attendance	Bereaved family members of cancer patients (*n* not stated)	Free-text survey responses with ranking exercise Analysis of qualitative data not described	Key themes: Place to vent experience Chance to talk and opportunity to share grief and support Comforting not to be alone and feeling similar to others Gender differences in preferences for group content	Thematic synthesis
Houldin 1993[52]	Uncontrolled before and after (−)	The United States	Relaxation training, four weekly sessions Mix of individual and group support Professional led	Nine bereaved widows of cancer patients	Anxiety (STAI) Depression (BDI) Immunological assays (blood tests)	Self-reported mild to moderate improvements in appetite and sleep patterns	Narrative synthesis
Johnson 2015[67]	Qualitative study (+)	The United Kingdom	District nurses delivering home-based bereavement support Individual/family support Professional led	Five district nurses delivering support	Semi-structured interviews Thematic analysis	Key themes: Nurses can become too involved with clients Lack of formal training and education on bereavement, but learning through experience just as valuable Having good rapport and trust with families enables better care	Thematic synthesis
Kissane 1998[75]	Qualitative study (−) Piloting of Family Focused Grief Therapy	Australia	Development and piloting of FFGT (see Kissane et al.[45])	Three families of cancer patients used as case studies to explore how intervention helped them (15 'high-risk' families participated in pilot study)	Practitioner observation	Therapist observations: The 'family that finds it hard to trust' became more cohesive, intimate and supportive of one another The 'family that listens but doesn't hear' acted more cohesively became more communicative and understanding and experienced less conflict as a result. They were more able to comfort each other in grief The 'family hampered by conflict' became more understanding and sharing	Thematic synthesis

(Continued)

Table 2. (Continued)

First author and year	Design and quality score	Country	Intervention	Sample	Outcomes and measures/ qualitative methods	Results	Included in narrative synthesis and/or thematic synthesis
Kissane 2006[45]	RCT (++) (randomised by family)	Australia	FFGT, four to eight sessions spread over 9–18 months (Control: no treatment) Family support Professional led	81 families of current becoming bereaved carers, identified as 'at risk' of poor social outcome (363 participants)	Distress (BSI) Depression (BDI) Social adjustment (SAS)	Between-group differences were non-significant except brief symptom inventory scores	Narrative synthesis
Kissane 2016[46] Mondia 2012[68] Del Gaudio 2013[69]	RCT (++) (randomised by family) Qualitative studies (+)	The United States	Family grief therapy, six or 10 sessions over 7 months (Control: standard care) Family support Professional led	170 families of current becoming bereaved caregivers of cancer patients identified as 'at risk' of poor social outcome (620 participants) Therapy sessions of eight minority ethnic families analysed[55,56]	Complicated grief (CGI) Depression (BDI-11) Recordings and supervision notes of therapy sessions analysed qualitatively	Significant treatment effects found on CGI, but not the BDI-11. Better outcomes resulted for low-communicating and high-conflict groups in the 10 session trial arm, when compared with the standard care arm. Qualitative finding: need for therapists to possess appropriate cultural knowledge when working with minority ethnic families	Narrative synthesis Thematic synthesis
Lieberman 1992[49]	RCT (+)	The United States	Brief group psychotherapy, eight sessions (Control: no treatment) Group support Professional led	56 bereaved spouses of cancer patients	Mental health: depression, anxiety and somatization (adapted HSC scales) Use of psychotropic medication and alcohol (five-item scale) Mourning (author developed scales) Positive psychological states: psychological well-being (Bradburn Affect Balance Scale) Locus of control (PCMS) Self esteem (RSES) Social adjustment: Single role strain Stigma (author scale)	Significant effects on measures of self-esteem and role strain. All other measures non-significant	Narrative synthesis
McGuinness 2011[47] McGuinness 2015[64]	RCT (−) Qualitative study (+)	Ireland	Creative arts group therapy, eight weekly sessions (Control: wait list) Group support Professional led	20 bereaved hospice caregivers	Grief (AAG and TRIG) Service evaluation questionnaires with open and closed questions Group-based feedback Content analysis of qualitative data	No significant between-group differences on quantitative outcomes Qualitative themes: Peer support and connectedness Enabled expression of grief and emotions Participants experienced increased confidence and feelings of strength when facing the loss Understanding grief as a 'process or journey' Helpful talking to 'strangers' about experiences	Narrative synthesis Thematic synthesis

(Continued)

Table 2. (Continued)

First author and year	Design and quality score	Country	Intervention	Sample	Outcomes and measures/ qualitative methods	Results	Included in narrative synthesis and/or thematic synthesis
Nappa 2015[56]	Controlled before and after (+)	Sweden	Bereavement support group, five weekly sessions Control: two groups – those 'unable to take part' and those who chose not to take part Group support Professional led	124 bereaved cancer caregivers	Grief (TRIG) Anxiety/depression (HADS)	No significant between-group differences on either outcome when comparing intervention group and those unable to take part	Narrative synthesis
Picton 2001[57]	Qualitative study (++)	Australia	Bereavement support groups, eight weekly sessions Group support Professional led	17 bereaved relatives of cancer patients	Semi-structured interviews Thematic analysis	Key themes: Majority of participants described the benefits of early participation, with minority favouring later entry to support programme	Thematic synthesis
Pomeroy 2002[51]	Uncontrolled before and after (–) Qualitative study (+)	The United States	Bereavement support group, six weekly sessions Group support Professional led	Five bereaved carers of a person with AIDS	Anxiety (STAI), Depression (BDI), Grief (grief experience inventory) Despair (despair subscale) Participant observation using field notes	Significant differences pre- and post-test for anxiety and grief symptoms Qualitative themes: Connectedness and sharing of experiences, feelings and coping strategies Movement from hopelessness to hopefulness	Narrative synthesis Thematic synthesis
Reid 2006[70] Field 2007[80]	Qualitative study (+)	The United Kingdom	Multi-faceted support at five hospices, including befriending support, formal counselling and therapeutic group	Paid and voluntary staff and bereavement service users from five hospices (*n* not stated)	Case studies involving semi-structured interviews, focus groups and documentary analysis Thematic analysis	Key themes: Bereavement counselling/befriending programmes facilitated expression of emotions, normalisation of grief process and feelings. Seen as helpful to talk to someone other than friends and family Befriending provides practical and social support, including 'listening ear', but there are concerns over when to withdraw Therapeutic group helped by meeting others in similar situations and learning coping strategies	Thematic synthesis
Roberts 2008[71]	Cross-sectional survey (–)	Ireland	Volunteer listening service (VBSS) Individual support Volunteer led	76 service user respondents to questionnaire evaluating hospice VBSS	Open and closed questions in survey Qualitative analysis not described	Key themes: Insight gained on the grief process, including understanding feelings as 'normal' Clients helped to open up and express emotions and valued feeling 'listened to' Clients valued talking to those other than friends and family and having a safe 'space' to grieve	Thematic synthesis
Sikkema 2004[48] Sikkema 2005[79] Sikkema 2006[78]	RCT (+)	The United States	Group Cognitive Behavioural Therapy, 12 weekly sessions (Control: individual therapy on request) Group support Professional led	268 bereaved individuals with HIV positive status	Grief (GRI), Psychiatric distress (SCL-90R) and Depression (SIGH-AD) Health-related quality of life (FAHI)	Significant between-group differences were only identified on measures of psychiatric distress[48] and health-related quality of life[79]	Narrative synthesis

(Continued)

Table 2. (Continued)

First author and year	Design and quality score	Country	Intervention	Sample	Outcomes and measures/ qualitative methods	Results	Included in narrative synthesis and/or thematic synthesis
Supiano 2017[58]	Qualitative study (++)	The United States	Complicated grief group therapy, five weekly sessions over 16 weeks Group support Professional led	16 bereaved dementia caregivers, three treatment groups	Observation of three therapy sessions in RCT Sessions coded using the 'meaning of loss codebook'	Key observations: Over time, participants demonstrated positive gains in the domain of 'moving on with life' Participant interpretations of the death transitioned from negative to positive and positive memories started to be shared	Thematic synthesis
Wittenberg-Lyles 2015[50]	Uncontrolled before and after (–) Qualitative study (++)	The United States	Closed Facebook group Online support group Written information and guidance provided to facilitate discussion	16 bereaved hospice carers	Depression-patient health questionnaire (PHQ-9) Generalised anxiety disorder Screening tool (GAD-7) Qualitative content analysis of online posts	Lower levels of anxiety and depression pre-/post-test. Not reported if these were significant Qualitative themes: Sharing of coping strategies, advice and storytelling Sense of community and mutual support Understanding feelings as normal	Narrative synthesis Thematic synthesis
Yopp[76]	Qualitative study (–)	The United States	Bereavement support group for widowed fathers, seven monthly sessions Group support Professional led	Six bereaved husbands (with dependent children) at cancer centre	Focus group Analysis not described	Key themes: Feeling understood by others in similar situations and comforted by not being alone Understanding grief experiences as normal Learning and sharing coping strategies, including those relating to parental competencies and concerns	Thematic synthesis
Young 2018[60]	Qualitative study (++)	Canada	Music therapy, six singing sessions over 3 months Group support Professional led	Seven bereaved female caregivers	Semi-structured interviews Interpretative phenomenological analysis	Key themes: Enabled profound emotional expression and mutual support Facilitated emotional and spiritual connection to the deceased Helpful opportunity for grief resolution Some experienced discomfort, nervousness and anxiety	Thematic synthesis

BDI: Beck Depression Inventory; FACIT-sp: spiritual well-being scale; CBT: Cognitive Behavioural Therapy; CESD: Centre for Epidemiological Studies Depression Scale; PSQI: Pittsburgh Sleep Quality Index; HAT: Helpful Aspects of Therapy; RCT: randomised controlled trials; BSI: Brief Symptom Inventory; SWLS: Satisfaction With Life Scale; WHOQOL-BREF: WHO Quality of Life – BREF; QOL-NRS: Numeric Rating Scale for Quality of Life; PANAS: Positive and Negative Affect Scale; BHS: Beck Hopelessness Scale; RCOPE: Religious Coping Scale; TRIG: Texas Revised Inventory of Grief; POMS: Profile of Moods States; SIGH-AD: Structured Interview Guide for Hamilton Anxiety and Depression; HHI: Herth Hope Index; HGRC: Hogan Grief Reaction Checklist; IDWL: Inventory of Daily Widowed Life; FFGT: Family Focused Grief Therapy; SAS: Social Adjustment Scale; CGI: Complicated Grief Inventory; HSC: Hopkins Symptom Checklist; PCMS: Pearlin Coping Mastery Scale; RSES: Rosenberg Self-Esteem Scale; AAG: Adult Attitude to Grief Scale; HADS: Hospital Anxiety and Depression Scale; STAI: State Trait Anxiety Inventory; VBSS: Volunteer Bereavement Support Service; GRI: Grief Reaction Index; SCL-90R: Symptom Checklist Revised; FAHI: Functional Assessment of Human Immunodeficiency Virus Infection; PHQ-9: Patient Health Questionnaire-9; GAD-7: Generalised Anxiety Disorder Screening Tool.
Quality score: ++ (good quality), + (mixed quality) and – (low quality).[40]

Table 3. Types of bereavement support interventions.

	One-to-one/family setting	Group setting
Professional led	Psychological and counselling: Family Focused Grief Therapy (FFGT)[a45,46,75] Supportive counselling[a63,70] Cognitive Behavioural Therapy (CBT) for chronic insomnia[53] Bereavement Life Review[54] Others: Relaxation training[52] Home support[67] Soft tissue massage[66]	Bereavement support groups[43,51,55,56,57,59,62,70,76] Psychological and counselling: Psychodynamic therapy with supportive educational techniques[72] Complicated Grief Group Therapy[a58] Existential Behaviour Therapy (EBT)[42] CBT[48] Group psychotherapy[49] Others: Creative arts therapy[47] Music therapy[60] Relaxation training[52]
Volunteer led	Supportive counselling[63,70] Informal home visits[73] Volunteer bereavement support/befriending services[70,71]	
Peer/self-led	Finding Balance writing tool[44]	Social groups (face to face)[74] Social groups (online)[50]

[a]Included targeted support for high-risk groups.

approach with a psychological-oriented one), no significant differences were found between groups in measures of coping or hopelessness.[55]

Evidence on the impact of interventions

Twenty-one studies used qualitative or mixed-methods and one study used a quantitative survey design. Six of these (eight papers) collected qualitative data as part of the effectiveness studies reported above.[44,47,50,51,61,64,68,69] Through thematic synthesis, many positive impacts for participants were identified. The results of the quantitative survey are also reported in relation to these themes.[72] The impact-related themes are described under the headings: 'loss and grief resolution', 'sense of mastery and moving ahead' and 'social support'.

Loss and grief resolution. Three studies described how individual counselling helped service users gain insight and perspective and facilitated the normalisation of the grief process.[63,70,71] Positive relationships with counsellors enabled clients to open up, feel 'listened to' and facilitated their expression of emotions.[63,70,71] Participants in these studies also noted the importance of being able to talk to those other than friends and family[63,70,71] and having a safe 'space' to grieve:[71]

> "Talking helped to make sense of it" (client); "It showed all her low times were during school holiday . . . something she'd known but had not acknowledged. It's much clearer particularly about the low times". (Volunteer)[63]

Similar therapeutic impacts were observed in 11 studies which evaluated group-based interventions[44,47,50,51,58,60,61,64,72,74,76] and a self-led writing intervention.[44] In a Complicated Grief Group Therapy intervention, it was observed how participant interpretations of the death transitioned from negative to positive over the course of the treatment.[58] More generally, the sharing of experiences helped service users to understand their grief experiences as normal[44,60,61,72,76] and as a process or journey.[44,47] These understandings in turn helped them to accept these experiences[61] and 'not fear' their feelings.[47] Groups in five studies were found to be helpful for enabling self-disclosure and the expression of grief, emotions and the 'venting' of experience,[51,60,61,64,74] as well as pleasant memories.[58] In the music therapy group, participants described how the spiritual connection to the deceased that they experienced helped to resolve their grief.[60] In an AIDS-specific support group, members became able to see the positive impact of their loved one in their present life, as they transitioned from feelings of hopelessness to hopefulness.[51] The importance of being able to speak to 'strangers' about their experiences, without risk of alienating family and friends, was also observed.[47,70,72] It was noted, however, that some participants had trouble revealing their emotions:[47]

> Everybody has cried at least once. One doesn't have to hide it, that's the nice thing. And we shared this with each other. (Participant)[61]

Sense of mastery and moving ahead. Twelve studies described benefits relating to coping, mastery and moving ahead. The massage intervention was recognised as having provided participants with the 'space' to focus on their grief during the session. This enabled them to focus on other areas of life at other times, while also helping them to start forming new routines and structure in their daily lives. By accessing help, they experienced a sense of mastery and personal

development, which gave them hope for the future.[66] The 'finding balance' writing intervention was similarly identified as helping participants identify new ways of achieving balance in their lives.[44] Counselling services in two hospice-based studies were also seen to have enabled participants to explore options and engage in decision-making and looking ahead, again supporting feelings of hope and reassurance:[63,70]

> . . . it helps me in talking over things but it actually picks me up and puts me back on another set of rails so that I can go forwards. (Service user)[70]

Similar benefits were identified in group support interventions. Eight studies positively described the learning and sharing of coping strategies within the groups.[50,51,59,61,70,72,74,76] In the EBT group, such strategies included self-regulation, focusing on the positives, mindfulness and avoiding preoccupation with negative thoughts.[61] Participants in the online group shared examples of 'turning points' in their own coping and restorative processes, as well as practical strategies for dealing with loss-related stressors.[50] Positive gains in the domain of 'moving on with life' were similarly observed in the complicated grief therapy group.[58] Bereaved participants in the writing intervention and group for current and bereaved dementia caregivers were reported to achieve a sense of purpose and altruistic fulfilment by helping others through sharing their experiences and stories:[44,59]

> It (mindfulness) is like meditating. And the important thing is not to hold on to these bad thoughts or things, but rather to know that they are there and that that is okay, but that one will get out of this again. (Participant)[61]

In the group for bereaved fathers, the guidance and support shared between members helped with doubts and concerns relating to parenting.[76]

Social support. Social benefits of group-based support were identified in 11 studies, including one online community.[50] These included benefits such as emotional support, sharing and feeling understood by others in similar situations,[47,50,51,59,61,62,65,70,74,76] feelings of belonging, community and connectedness[50,51,59,60,61,64,76] and comfort from not being alone.[47,74,76] Continuing contact and improvements to social lives after the groups had finished were also noted:[70,76]

> I don't feel so alone and lost, it has made me feel stronger and I feel we have united like friends when you most need a friend. (Participant)[64]

Interpersonal benefits were also identified for four individual-level interventions[66,70,71,73] and one family-based intervention.[75] It was noted how support from volunteers provided 'companionship',[73] practical and social support and a 'listening ear'.[70,71] In the massage intervention, participants valued having their feelings recognised and took comfort and hope from these relationships.[66] In a qualitative study used to develop the family grief therapy intervention, social benefits were reported relating to family functioning and dynamics. These included improved cohesion, support, understanding and sharing within the family.[76]

Features of effective delivery

Several themes were identified in relation to the contexts and processes underpinning effective intervention delivery. Interpersonal factors such as positive relationships between group members, clients and counsellors were seen as critical to the success of the support,[61,63,71,73,76,80] as was the need for therapists and volunteers to possess appropriate cultural and experiential knowledge of community grief processes and norms.[67–69] The importance of continuity between pre- and post-bereavement support for families was also widely acknowledged, seen as leading to better bereavement care, either by provision of information about bereaved relatives or by the rapport and trust that was needed to support families after death.[61,67,73,80] However, potential difficulties associated with service users becoming dependent on the support, and related 'boundary' issues for volunteers were identified in two studies.[67,70]

In terms of group content and composition, the need for groups to be informal, but with an explicit purpose and structure was identified.[62] The value of inclusive and heterogeneous groups for optimising shared learning opportunities was also recognised.[61,62] With regard to the timing of support, participant preferences varied within and between studies suggesting that there is no 'right time' to offer support.[44,57,63]

Discussion

Main findings of the review

This mixed-methods systematic review has considered the evidence on a wide range of interventions for people bereaved through advanced disease. Lack of high-quality RCTs and heterogeneity in study outcomes, intervention design and populations meant that the conclusions that can be drawn on effectiveness are limited. The thematic synthesis of qualitative results, however, identified consistent benefits for participants across studies and intervention types, and helps illuminate the mechanisms through which this support impacts upon participant experiences. Although the interventions varied considerably, three core impacts are identified which connect with

the concepts of resilience and public health approaches to bereavement care.

What this review adds

Small sample sizes and uncontrolled study designs meant that just over half of the effectiveness studies included in this review were graded as low quality and their results were of limited value. Results from the larger, better quality studies varied, but almost all reported significant positive effects on some study outcomes. Among the four 'mixed-quality' studies of group-based interventions, significant effects were found on measures of distress,[48,77] quality of life,[48] immunological function and health[43] for the two HIV/AIDS-specific groups, but not grief or depression.[48,77] Evaluations of group psychotherapy[49] and a bereavement support group[56] for bereaved cancer caregivers also found no effects of the interventions on grief or depression,[49,56] although significant effects were reported on measures of self-esteem and role strain for the psychotherapy intervention.[49]

Only three good-quality RCTs were included. Two of these evaluated FFGT interventions delivered to 'at-risk' families in Australia and the United States.[45,46] There was a significant reduction in distress reported in the Australian study[45] and significant improvements in complicated grief symptoms in the American study.[46] Variations by type of family were also observed,[45,46] and for families most troubled at baseline, significant improvements in depression occurred.[45] These results suggest that FFGT can improve psychological and grief outcomes for some at-risk families. This fits with findings of other reviews on the enhanced benefits of grief therapy for most at risk/symptomatic groups.[20,22,24,27,28,31] The other good-quality trial was of a group-based EBT intervention for family caregivers conducted in Germany. This reported significant intervention effects on anxiety, depression and quality of life,[42] with benefits also identified in the associated qualitative evaluation.[61] Both interventions were introduced to family caregivers in the end-of-life period, indicating the value of such approaches. The qualitative evidence reported in this review,[59,61,67,73,80] and other studies[81] also suggests the benefits of continuity between pre- and post-death support and is in-line with guidance recommending that bereavement risk assessment and targeted support begins in the pre-death period.[12,13]

In the thematic synthesis, three core impacts and mechanisms of impact were identified which cut across the different types of support. These are described as 'loss and grief resolution', 'sense of mastery and moving ahead' and 'social support'. Only three of the 21 studies included in the synthesis were targeted at populations categorised as 'high risk'.[58,68,69,75] Therapeutic benefits relating to loss and grief resolution were apparent in many individual counselling and group-based programmes of support. By facilitating emotional expression, the discussion of troubling concerns and the normalisation of grief, service users gained insight and perspective on their experiences and became more accepting of their grief. Through mastery of specific coping techniques such as channelling, mindfulness and positive thinking, as well as more general decision-making capabilities, participants experienced enhanced feelings of control, hopefulness and an ability to look ahead and move forwards. These apparent impact pathways fit well with the Dual Process Model (DPM) of grief adaptation,[82] as well as conceptualisations of 'balanced' responses to the emotional and practical consequences of loss.[83] The DPM model posits that bereaved people oscillate between dealing with the loss of the deceased person (loss-orientated coping) and negotiating the practical and psychosocial changes to their lives that occur as a result of the bereavement (restoration-orientated coping). These two processes both appear to be positively enhanced by interventions included in the synthesis through the mechanisms described above. These findings also suggest the critical role of meaning reconstruction[84,85] within this loss-oriented grief work, as bereaved people strive to make sense of and come to terms with their loss.

For group-based programmes, various social support–related benefits were also widely reported, including feelings of connectedness, belonging and comfort. These were linked with the sharing of experiences and sense of understanding developed between those in similar situations. The benefits of companionship with volunteer 'befrienders' and the comfort derived from empathetic relationships with professional counsellors were also observed for some individual-level interventions. The opportunity to confide in those outside of existing networks was valued for individual- and group-based models. Although perceived lack of social support is recognised as a risk factor for problematic grief experiences,[86,87] social support is often overlooked in quantitative evaluations of bereavement care.[88] However, as this synthesis suggests, this type of impact is widely valued and of high perceived importance to service users. This fits with public health approaches which recognise the importance of existing social networks for all bereaved people, but also advocate for a second tier of non-specialist, community–based support for those at moderate risk of complex grief, and who may lack adequate social support.[1,2]

Taken together these three main types of impacts (loss resolution, moving ahead and social support) also fit with broader resilience and meaning-based coping frameworks in public health research. Such frameworks converge over their identification of individual, family and community level resources which facilitate coping and adaptation to adversity.[89] The role of meaning making, comprehensibility

and feelings of manageability in maintaining one's 'sense of coherence' is also theorised in salutogenic approaches to maintaining health and well-being, thus again resonating with some of the mechanistic themes identified here.[89,90] The concept of resilience has been used by some bereavement researchers and practitioners to theorise healthy adaptations to grief,[15,83,91,92] with calls for further work to explore strategies which promote resilience in bereavement.[15,92] This synthesis suggests the value of such approaches for conceptualising and targeting the mechanisms through which bereavement support can improve the resilience and coping capabilities of service users.

Strengths and limitations of the review

By focusing on support for people bereaved through advanced illness, and adopting a mixed-methods approach, this review has addressed some of the gaps in the review-level evidence relating to bereavement support in palliative care. Through the thematic synthesis of qualitative results, it has identified several core mechanisms through which this support benefits participants, and which can help inform future service design. However, by restricting to these population groups, it is likely that we missed potentially relevant specialist counselling and grief therapy interventions. These are not typically restricted in this way, but have been the subject of previously discussed reviews. By defining our population in this way, our final set of interventions included those involving general palliative care populations as well as disease-specific populations such as HIV/AIDS and dementia. The distinctive emotional and psychosocial issues associated with loss through dementia[58,59] and loss through/living with HIV/AIDS[43,48,51] may also mean that these study results do not fully generalise beyond those specific populations. A further limitation is that the review only included research which was published in English and based in the United Kingdom and countries considered most comparable in terms of cultures, economic and social and healthcare systems. As such we may have missed out on potentially informative studies from the wider international literature.

Implications for further research

A key finding of this review, in common with others, has been the poor quality of many of the included studies. Only a small number of RCTs were identified, while small sample sizes and heterogeneity in populations, models of care and study outcomes further compromised the usefulness of the quantitative evidence. The apparent contrast between the pathological outcomes most commonly used in the quantitative studies (e.g. depression and distress) and the coping and support-oriented impacts that were identified in the thematic synthesis also raises questions over the appropriateness of some of these outcomes for evaluating bereavement care.[26,88] The recent stakeholder-based identification of two core outcomes for evaluating bereavement support in palliative care ('ability to cope with grief' and 'quality of life and mental well-being') outlines a more consistent and seemingly appropriate way forward for outcome measurement in this area of research,[88] with potential to improve the comparability and relevance of study results.

More generally, there is a need for more high-quality quantitative and qualitative evaluations of these types of bereavement support. Given the difficulties associated with conducting RCTs of complex interventions generally,[32] and in palliative care specifically,[93,94] we adopt a critical position which challenges traditional evidence hierarchies[95] in favour of more inclusive approaches to public health evidence production and utilisation. Further consideration should be given not just to improving trial design through embedded qualitative studies and process evaluations,[32,38] but also the contribution that alternative practice-based evaluation methods might make.[96] The value of thematic synthesis for exploring causal mechanisms and contextual factors was well-demonstrated in this review and should be further utilised for evidence reviews of these types of complex interventions, along with more theory-driven, mixed-methods approaches such as realist synthesis.[33,36]

Conclusion

A variety of bereavement interventions were considered in this review; however, the overall conclusions that may be drawn on their effectiveness are limited by the quality and comparability of the quantitative evidence. Good-quality trial evidence was only available for targeted Family Grief Therapy and a non-targeted group–based therapy intervention, both of which were introduced during the caregiving period and found to be at least partially effective. The thematic synthesis identified several core benefits that were common across a range of individual- and group-level interventions, most of which were not targeted at high-risk groups. These benefits related to loss resolution, moving ahead and social support. The synthesis identified key mechanisms which produce these impacts, and in doing so suggests the value of peer support alongside opportunities for reflection, emotional expression and restoration-focused activities for those with moderate-level needs. These findings reiterate the importance of tiered public health approaches to bereavement care, with different types of support available and accessed appropriately according to need. High-quality, mixed-methods evaluations are needed to further determine and explain the relative value of such support for different groups of bereaved populations.

Author contributions

E.H. drafted the paper and oversaw the project. A.B., A.N., J.F., K.S., S.S., E.H. and F.M. developed the search strategy and F.M. conducted the searches. E.H., L.S., F.M. and H.S. screened

articles for inclusion and were involved in data extraction and quality appraisal. M.L. also assisted with quality appraisal of included studies. E.H. conducted the thematic synthesis with assistance from H.S. and L.S. All authors contributed to the drafting of the paper and read and approved the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This study was funded by the Marie Curie Research Grant (grant no. MCCC-RP-16-A20999). The project was also supported by the Marie Curie core grant funding to the Marie Curie Research Centre, Cardiff University (grant no. MCCC-FCO-11-C). E.H., A.N., A.B., S.S. and M.L. posts are supported by the Marie Curie core grant funding (grant no. MCCC-FCO-11-C). The funder was not involved in the study design, implementation, analysis or interpretation of results, and has not contributed to this manuscript.

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Supplemental material

Supplemental material for this article is available online.

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