# Bereavement support in the UK – a rapid evidence assessment

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**Abstract:** Bereavement can be a distressing experience and the importance of bereavement support has been recognised in policy and practice for many years. This rapid evidence assessment was undertaken to evaluate the provision and effectiveness of bereavement support in the United Kingdom (UK) and to identify gaps in service provision and areas of need with regard to bereavement services.

The main finding of the review was that the provision of bereavement support is extremely varied and there is no conclusive evidence for its effectiveness. There is widespread recognition of the potentially negative impact of bereavement on people, and a plethora of recommendations focused on raising awareness and ameliorating these effects have been made. However, the evidence for how best to support people experiencing bereavement is limited and contested.

**Keywords:** bereavement, evidence review, bereavement support, services

## Introduction

It was noted more than 10 years ago in the *End of Life Care Strategy* (DH, 2008) that a vital issue in good care after death is the provision of appropriate and comprehensive bereavement support. Yet in 2014 the National Council for Palliative Care (2014) reported that policy development in this area had been *ad hoc* leading to confusion and complexity, with no clear responsibility for meeting bereaved people's needs. Similarly, in 2011 the Scottish Government produced *Shaping Bereavement Care – a framework for action* (Scottish Government, 2011) which included 14 recommendations indicating how bereavement care could be improved. However, in a review of bereavement care service standards it was concluded that while there have been some significant developments in bereavement care, the impact is largely unknown and assessing thequality of services offered is challenging (Bereavement Services Association and Cruse Bereavement Care, 2013).

The importance of providing bereavement care services was subsequently highlighted in a number of documents and reports (National Palliative and End of Life Care Partnership, 2015; The Choice in End of Life Care Programme Board, 2015; Department of Health, 2016). Yet the lack of provision and the need for improved support remain issues of concern (see for example National Quality Board, 2018; Cruse

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Bereavement Care, 2018; Independent Age, 2018; National Council for Palliative Care, 2014). Furthermore in 2017 the National Bereavement Alliance produced a guide to commissioning bereavement services, to help commissioners prepare tender specifications for area-based bereavement services for expected and unexpected deaths. Moreover the need for bereavement support has been identified by charities and service users (Co-operative Funeral Care, 2018; Dementia Voices, 2018), yet the extent of provision is less clear. This indicates that much still needs to be done with regard to the provision of bereavement support services. Bereavement is defined here as the objective situation of having lost someone significant through death (Stroebe, Hansson, Stroebe, & Schut, 2008). It can result in clinical depression, anxiety states, panic syndromes, and post-traumatic stress disorder (Murray Parkes, 1998) as well as neuroendocrine activation, altered sleep, immune system imbalance, and heart problems (Buckley et al., 2012), and is associated with increased risk of mortality, greater use of health services, and subsequent poor mental and physical health (DH, 2010). In view of this a rapid evidence assessment (REA) was undertaken to evaluate the evidence for different forms of bereavement support provided in the UK. The review question was: What is the evidence of the extent and effectiveness of formal and informal bereavement support provision in the UK?

## Method

An initial scoping of the literature on PubMed, using ‘bereavement support’ and ‘United Kingdom’ as keywords yielded 448 results. When the term ‘support’ was removed the number of results increased to 777 and became less specific. A brief overview of the 448 ‘hits’ suggested the existing literature on bereavement support focuses on specific types of death (these include homicide and suicide; drugs and alcohol; cancer deaths; military deaths; perinatal deaths; deaths in the home setting); the psychological and physiological impact of bereavement (anxiety/distress/complicated-grief/PTSD/mortality for next of kin/risk of physical conditions); uptake of services or support received; bereavement as a public health issue; economic cost, health professionals’ perspectives; and the meaning of bereavement support. Following this preliminary search, it was evident that a rapid evidence assessment (REA) would be the most appropriate approach to address this question. The basis for this decision was threefold: first it was the most feasible approach to meet the timescale of the funder; second there was not sufficient resource to conduct a full systematic review; and third it was intended to build on an earlier evidence synthesis undertaken two years after the publication of the *End of Life Care Strategy* (DH, 2008) (Arthur, Wilson, James, Stanton, & Seymour, 2010).

### Design

The REA is a tool developed from the systematic review method and involves comprehensive electronic search of appropriate databases, internet sources and limited follow-up of cited references to answer specific review questions (Speirs, Gross, & Heptonstall, 2015; Thomas, Newman, & Oliver, 2013; Haby et al., 2016). The use of REA is increasing, driven to a large extent, by the need to engage policymakers, healthcare professionals, and consumers in a timely manner to provide evidence-based recommendations for healthcare practices and policies (Crawford, Boyd, Shamini, Khorsan, & Jonas, 2015; Watt et al., 2008). They provide a balanced assessment of what is known (and not known) in the scientific literature about an intervention, problem or practical issue by using a systematic methodology to search and critically appraise empirical studies. The time taken to complete an REA can range from three weeks to six months (Ganann, Ciliska, & Thomas, 2010). They have been undertaken to examine issues in a range of settings including housing (Whitehead, Monk, Burgess, Clarke, & Holmans, 2008), alcohol and criminal harm (Booth, Meier, Shapland, Wong, & Paisley, 2011), education (Carroll et al., 2017), international development (Department for International Development (DFID, 2012), health literacy (D’Eath, Barry, & Sixsmith, 2012) and end of life care (Parry, Seymour, Whittaker, Bird, & Cox, 2013) to inform policy development. In order to deliver timely reviews, some methodological concessions are made with regard to the breadth, depth and comprehensiveness of the search (Barends, Rousseau, & Briner, 2017; Davies, 2006). For example, hand searching of journals and textbooks is not undertaken to the same extent as in a full systematic review, and there is limited searching of the ‘grey’ literature. It is an approach to bringing evidence to the fore of healthcare decision-making in a timely and relevant way, but which involves some methodological ‘trade-offs’ (Khangura, Polisena, Clifford, Farrah, & Kamel, 2014). In order to ameliorate these potential limitations guidelines recommended by Davies (2004) (see below) shaped the conduct of this review:

- search the electronic and print literature as comprehensively as possible within the constraints of the policy or practice timetable;
- collate descriptive outlines of the available evidence on the topic;
- critically appraise the evidence;
- exclude poor quality studies;
- produce a summary of the evidence.

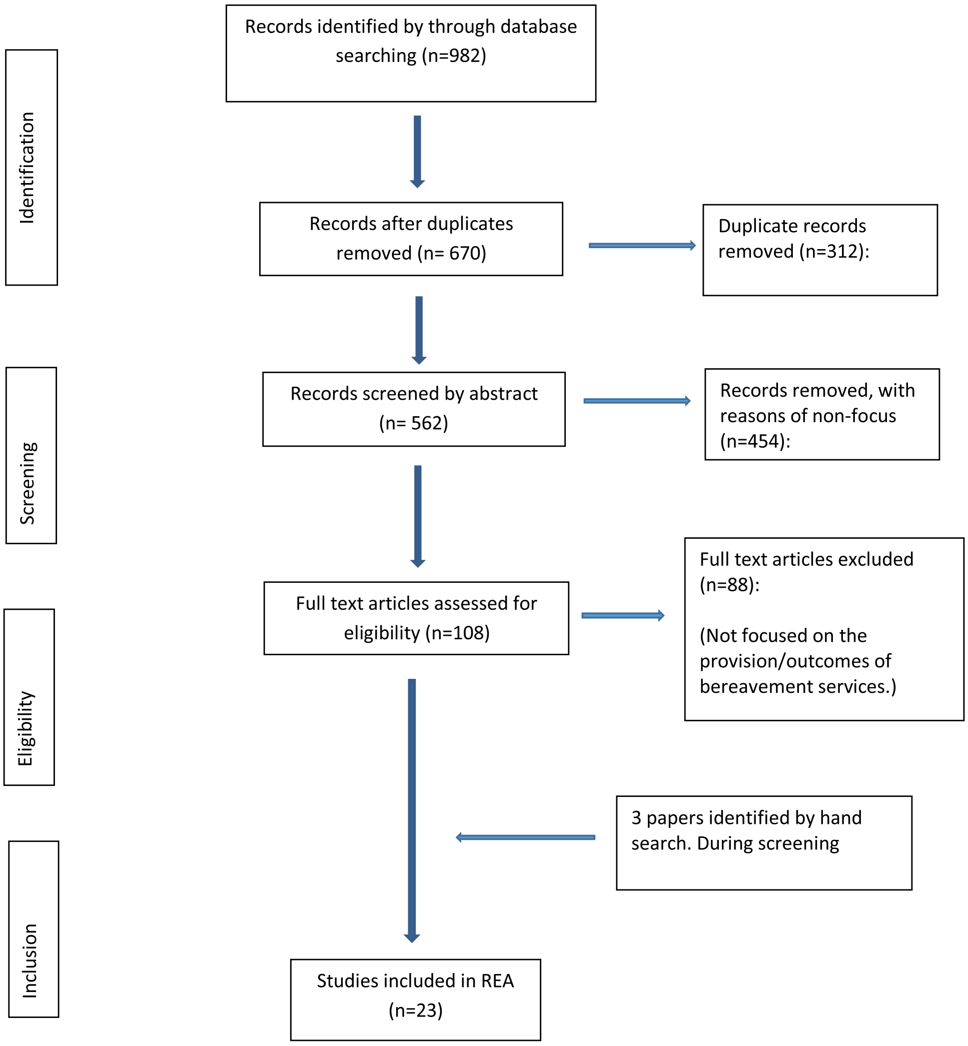

**Figure 1:** PRISMA flowchart of the review process (Moher et al., 2009).

The three main aims of the REA reported here were to:

1) Produce a summary of the evidence concerning the provision and effectiveness of bereavement support in the UK;
2) Examine the role of informal support in bereavement;
3) Determine the effect of unsupported bereavement in the UK to identify gaps in service provision and areas of need with regard to bereavement services.

## Search methods

The database searches, abstract and full text screening were undertaken during November and December 2018. The PRISMA flow chart (Moher, Liberati, Tetzlaff, & Altman, 2009) (see Figure 1) summarises the search and retrieval process which initially identified 982 papers and resulted in a final selection of 23 papers for review. The words and index terms used for the main search are included in Figure 2. Seven electronic databases were searched: Ovid MEDLINE, PsycINFO, PubMed, CINAHL, Cochrane, EMBASE and Web of Science. The inclusion and exclusion criteria are included in Figure 3. The titles and abstracts of all the papers identified were initially screened against the inclusion and exclusion criteria. Three reviewers then examined a third of the papers, and cross-checked a sample of five papers screened by the other reviewers to help ensure consistency and rigour in the selection of the 23 papers for review. A modified form of framework-based data synthesis was undertaken (Dixon-Woods, 2011; Carroll, Booth, & Cooper, 2013) which provides a pragmatic means of conducting rapid qualitative evidence synthesis and generating programme theories relating to intervention

‘bereavement’, ‘bereavement support’, ‘bereavement care, bereavement contact, bereavement counselling’, ‘grief’, ‘mourning’, ‘personal loss’, ‘bereave*’, which were checked against ‘UK’, ‘United Kingdom’, ‘Brit*’, ‘Great Britain’, ‘England’, ‘English’, ‘Wales’, ‘Welsh’, ‘Scotland’, ‘Scottish’, ‘Northern Ireland’, and ‘Northern Irish’. The filters used were adults over 18 or 18+, language = English and from years 2008 to 2018 or 2008 to present

**Figure 2:** Key words and search limits.

To be included in the review, the papers were required to:

1. Report empirical research (using quantitative, qualitative or mixed method design) or service descriptions/evaluations/audit.
2. Involve adults (aged 18 or over);
3. Investigate outcomes associated with bereavement support.
4. Investigate outcomes associated with specific intervention(s) offered within different services and including religions, ethnic minorities and groups such as LGBT.
5. Be written in English.

Papers were excluded if:

1. Content focussed on bereavement following neonatal death, bereavement experienced by children, family/adult bereavement following the death of a child.
2. They reported studies, service evaluations and other themes in non-UK countries i.e. all international papers.
3. Records were of books, book chapters, or conference abstracts.

**Figure 3:** Inclusion and exclusion criteria.

effectiveness, of relevance to researchers and policymakers (Carroll et al., 2013). The approach can also encompass issues that emerge from the data. This involved meetings of the three reviewers to discuss the extent to which the papers provided evidence of the scale and effectiveness of bereavement services, as identified in the search question. Using these elements as the components of the framework the key themes were identified. As the process progressed it was necessary to consider impact as there was limited evidence of effectiveness found (see theme 4).

# Results

## Summary of the studies

Twenty-three papers met the inclusion criteria. Thirteen papers reported qualitative studies (13), five presented the findings from quantitative designs (5) and one from a mixed methods project (1). The remainder were made up of service evaluations and service descriptions (3), and one audit (1). We included service descriptions because they provide helpful detail about bereavement services for armed forces personnel (Green & Cawkill, 2012) and a review of a group work approach to bereavement support (Spence & Smale, 2015). There was considerable variation in the scope and scale of the studies with sample sizes in the quantitative studies ranging from 350–3432 and 7–59 in the qualitative studies. All of the studies were conducted in the UK as this was the focus of the review. A wide range of settings/participants were involved in the studies investigating the experiences of people bereaved by specific causes of death including: sudden death/suicide (2); heart failure (1); and cancer (1). Two papers explored the experience of people with learning disabilities, two focused on families of military personnel, one on low-income families, and one on older people. In terms of settings there was one paper reporting a hospice bereavement service and an audit of bereavement provision in intensive care. Most of the papers (15/23) were published in the last five years.

In view of the relatively limited number of papers available which report research investigations of the prevalence and impact of bereavement support services and informal support in the UK, it was not felt appropriate to conduct a quality appraisal of each paper. Given the heterogeneity of the papers included in the REA, the synthesis is a broadly narrative summary compiled from the material derived from the data extraction phase and organised thematically in line with the framework synthesis approach undertaken (Dixon-Woods, 2011; Carroll et al., 2013). The papers can be assigned to one of two broad categories: evaluation of specific support services/provision or more general studies of bereavement care and support, with a number focused specifically on the experiences of bereaved people. The five themes drawn from the findings in the papers were: the importance of interaction; provision of information; cause of death; impact; and the bereavement process. Each of these is examined below.

## Theme 1: The importance of interaction

This theme was evident in 13 of the papers and illustrates the key role of interpersonal interaction in the provision of bereavement support. For example, the need for people accessing services, or encountering staff in particular in a range of settings, to be treated with kindness and understanding was reported by respondents in a number of the papers (Boyden, Freeman, & Offen, 2009; Beardsley, 2009; Rolls & Harper, 2016). Staff and volunteers demonstrating compassion, authenticity, sensitivity and having good listening skills was appreciated by people who were experiencing bereavement (Beardsley, 2009; Rolls & Harper, 2016; Valentine, McKell, & Ford, 2018), and they expressed satisfaction with the service when met with such a response (Small et al., 2009). If this response was underpinned by a 'person-centred approach', Spence and Smale (2015) found it could enhance the impact of group-based approaches to bereavement support. However in some cases people encountered a ‘blunt and insensitive’ response from healthcare staff, particularly in discussions concerning prognosis which resulted in feelings of isolation (Agnew, Manktelow, & Donaghy, 2008) and the need for more staff training in this area was identified (Agnew, Manktelow, Haynes, & Jones, 2011; Young, Garrad, Lambe, & Higg, 2014). In one study the independence of the counsellors providing the support, who were outside the family and social network, was seen as particularly helpful because it enabled the respondents to challenge negative thoughts and ‘normalised’ the process of grief (Simonsen & Cooper, 2015). Stephen, Wimpenny, and Wilcock (2013) found that bereavement care depends on established relationships between healthcare staff and the patients’ relatives, which provide a basis of trust for the type of response people require. A willingness was expressed by some professionals to increase their engagement in bereavement work (Montgomery & Campbell, 2012), although it was acknowledged that there are some potentially complex ‘boundary issues’ to negotiate when supporting people experiencing bereavement, including concerns about how long the support relationship should last (Hayward, Makinde, & Vasudev, 2016). This theme indicates how individual interactions are at the heart of bereavement support processes and establishing a relationship with bereaved people is the foundation for support.

## Theme 2: Provision of information

One of the main forms of support people needed when bereaved was timely and helpful information. This took many forms and was explored in seven of the papers included in the review. The provision of information about support services can be a form of support in itself. In one study palliative care social workers expressed the view that most bereaved people do not require follow-up, but that offering information on bereavement support services increases resilience and promotes autonomy (Agnew et al., 2011). Information was provided in a range of formats. For example in an evaluation of the ‘Help is at Hand’ resource, produced as part of England’s suicide prevention strategy, it was reported that the information content was helpful or extremely helpful by the participants bereaved by suicide (Hawton et al., 2012). However the availability and suitability of information was identified as an issue of concern in some of the studies. Young et al. (2014) found there was little information about bereavement for people with learning disabilities and developed a resource pack to address this deficit, and Green and Cawkill (2012) designed a specific ‘military’ web page providing information about bereavement support for service families. In a small single focus group study, the development of an information leaflet for people experiencing bereavement following the death of a family member or close person in a hospice was reported (Agnew et al., 2008). The appearance and content of the leaflet was discussed in some detail and the importance of taking care over decisions concerning terminology was emphasised. For example the respondents felt inclusion of the word ‘counselling’ in the leaflet would deter people from attending an informal, bereavement support group (Agnew & Duffy, 2009). This desire for information by people who have shared experience of bereavement is resulting in greater use of email and social media. Examples include seeking support from an internet community of people who have suffered bereavement as a result of suicide and creating website memorials (Chapple & Ziebland, 2011). They conclude that in view of this greater use of the internet by bereaved people, the effect on relationships between potential service users and the health professions requires further research (Chapple & Ziebland, 2011). The need for accurate, timely and appropriate information about bereavement support provision is essential for people experiencing bereavement, however information alone is not sufficient. In a national audit of bereavement care in intensive care services, it was found that even though 96% of the units that responded had an information booklet about bereavement, the audit demonstrated that bereavement care was underdeveloped in English intensive care units (Berry, Brink, & Metaxa, 2017). This demonstrates that the provision of information is important and people have a complex range of needs with regard to the amount and type of information they require when bereaved. What is also clear though is that the information needs to be readily available, comprehensive without being overwhelming, and offered alongside other sources of support.

## Theme 3: Cause of death

The specific cause of death and its impact on the bereavement process was examined in six papers. The need for specialist support and bespoke sources of information to support people experiencing bereavement following a military death was identified because of how it differed from other deaths (Green & Cawkill, 2012; Rolls & Harper, 2016). In one study a particular aspect of a support service provided to meet this need – creation of a garden memorial to the deceased service person –was found to be of great comfort to the families concerned (Rolls & Harper, 2016). This was a specific element of the service to meet the needs of people bereaved in this way.

In the case of death from suicide it can render the bereavement process more complex because it is ‘surrounded by stigma’, and the involvement of the coroner may mean details concerning the precise circumstances of the death take time to be confirmed (Hawton et al., 2012). Furthermore, Pitman et al. (2017) found that 21% of their sample of people bereaved by suicide reported receiving no formal or informal bereavement support. Of most concern was the finding that 6% (210) of their sample reported attempting suicide since their bereavement (Pitman et al., 2017). This demonstrates the impact the cause of death can have on those experiencing bereavement as a result. Although it was found in other work that experiencing traumatic, sudden or multiple deaths made it more likely people would seek bereavement support (Montgomery & Campbell, 2012), Pitman et al. (2017) suggest that those bereaved by suicide may not avail themselves of support services. Death from substance abuse also adds another layer of complexity to bereavement. As Valentine et al. (2018) found, the 'system' is complex after any death, however for substance-related deaths there are added complexities related to establishing the cause of death. Inconsiderate media reporting can also exacerbate the distress experienced in bereavement from this type of death (Valentine et al., 2018).

## Theme 4: Impact

One of the key aims of the review was to examine the effectiveness of bereavement services, however there is a lack of definitive evidence to demonstrate this and so a broader summary of impact was derived from the seven papers that examined this aspect of the provision of bereavement services. The evidence for impact of bereavement support services centred on two types: group (Boyden et al., 2009; Spence & Smale, 2015; Finley & Payne, 2010; Agnew & Duffy, 2009), and individual (Newsom, Schut, et al., 2017; Newsom, Stroebe, et al., 2017; Simonsen & Cooper, 2015). The feedback concerning a loss and bereavement support group for people with learning disabilities indicated that the participants found the experience helpful and that they would recommend it to a friend in similar circumstances (Boyden et al., 2009). Participation also had additional benefits in that getting out of the house and meeting new people met the respondents' social needs (Boyden et al., 2009). Similarly, a Living with Grief group provided a distraction from grief and provided opportunities for participants to share experiences, ideas and suggestions with others in the group (Spence & Smale, 2015). This fostered a sense of mutuality and shared experience (Spence & Smale, 2015). An evaluation of a hospice bereavement support group service was reported to be helpful, particularly the opportunity to share feelings with others in the same situation (Finley & Payne, 2010), which was also found in a small study in another hospice (Agnew & Duffy, 2009).

The impact of the interventions focused on individuals was investigated by Newsom, Schut, et al. (2017) and Simonsen and Cooper (2015). In a small (seven participants) interview study involving former clients of a voluntary bereavement service the respondents reported that they found the counselling they received beneficial (Simonsen & Cooper, 2015). However, in a large naturalistic controlled trial, participants in the counselling intervention group and control group experienced a similar reduction in the symptoms of complex grief, although the intervention group had a greater reduction in symptom level at a later follow-up data collection point, suggesting community-based bereavement counselling may have long-term beneficial effects (Newsom, Schut, et al., 2017).

## Theme 5: The bereavement process

Four of the papers identified elements of the bereavement process it is important to consider when supporting people experiencing bereavement. When carers of people who had died from heart failure discussed their experiences of bereavement, they framed their accounts in line with three time periods: the period prior to death, the death itself, and the bereavement period (Small et al., 2009). Agnew and Duffy (2009, also focus on pre- and post-bereavement experiences as distinct albeit connected elements of the process. The need for people to be supported as they prepare for bereavement was reported by Stephen et al. (2013) and staff in their study felt that facilitating anticipatory grief was their main role in bereavement care. In a similar vein a pre-bereavement phase is discussed by Montgomery and Campbell (2012) when individuals facing their own death seek help to prepare their family members for bereavement. This theme is considered further in the discussion section.

## Discussion

It is evident from this review that the provision of bereavement support is extremely varied, ranging from individual counselling, to group support, through to internet-based information provision. The diversity of approaches is summarised in the Appendix (online supplementary material). The lack of research on services provided for the bereaved means there is no clear estimate of the service requirement from health and social care staff across the sectors (Stephen et al., 2009). If there is no extensive evidence for which services have the most beneficial effect for people experiencing bereavement, than planning services becomes problematic. The situation in 2020 appears to be largely unchanged, in that there are many approaches to bereavement support on offer, their accessibility and suitability are dependent on what is available in a particular setting or geographical area and this in turn is often reliant on the enthusiasm and contribution of key individuals, and the evidence for their effectiveness is limited.

What is also clear from the review is that the conclusion drawn in 2013 (Bereavement Services Association and Cruse Bereavement Care, 2013) that the impact of bereavement support services is largely unknown and assessing the quality of services offered is challenging, still applies. There remains a lack of high-quality evidence relating to the extent and impact of bereavement services in the UK. In terms of the of the research itself, it is a mixed picture with the work being qualitative in the main, and although this provides helpful insights on the experiences of bereaved people and the staff and volunteers providing support for them, it does not provide definitive evidence of effectiveness. The five quantitative studies included in the review examined different aspects of bereavement and sought to uncover the impact of particular factors, for example the relationship of low income on complicated grief (Newsom, Stroebe, et al., 2017). This longitudinal study investigated the association between poverty and complicated grief, and the effectiveness of a community-based bereavement counselling programme in low-income households. The main findings were that low income is a key predictor of complicated grief symptoms and that the effectiveness of one-to-one bereavement counselling does not appear to differ according to income level (Newsom, Stroebe, et al., 2017). Evidence of the impact of counselling on the level of complicated grief experienced by bereaved people (Newsom, Schut, et al., 2017) and the amount of support received by people bereaved by suicide (Pitman et al., 2017) was also gathered using quantitative methods, however it is relatively limited. This indicates that more comprehensive studies are required to build the evidence base in this area.

A particular concern noted in 10 of the papers in the review was the representativeness of the sample involved in the research, particularly with regard to gender. Most of the respondents/participants in the studies included in the review were women. For example in one study 79% of the participants were women (Valentine et al., 2018). This means that in terms of reliability, the findings of all the studies have to be treated with a certain degree of caution because of the under-representation of men.

There is a paucity of evidence to indicate what the best approach to bereavement support is; for example a recent study found that participation in bereavement groups did not produce any effects on grief, anxiety, or depression in comparison to non-participants who were unable to participate (Näppä, Lundgren, & Axelsson, 2016). Similarly Schut and Stroebe (2010) concluded no evidence has been found that care for bereaved people provided by institutions is effective, particularly when initiated and provided routinely by organisations rather than the bereaved themselves. This is of concern given the evidence of the adverse health effects bereavement can have (Stroebe, Schut, & Stroebe, 2007).

## Assessment

One particular area that requires further work in terms of developing the evidence base is accurate assessment of the need for bereavement support. Some people can adapt to new situations, including bereavement, because of their inherent resilience, resourcefulness and/or level of informal support from family and friends and so will not require formal bereavement support. However, it is important to identify those who are more vulnerable in their grief and require therapeutic support to make efficient use of limited resources. Work in this area includes that of Sealey, Breen, O'Connor, and Aoun (2015) who reviewed the evidence for 19 bereavement risk assessment measures appropriate for different points in the caring and bereavement trajectories, and evaluated their psychometric properties and feasibility for use in palliative care. They found that most had acceptable psychometric properties although their feasibility for use in palliative care varied substantially. Also, a promising tool has been pilot tested by Brocklehurst, Hearnshaw, and Machin (2014) in the UK, *The Range of Response to Loss Bereavement Self-Assessment tool (RRL BSA),* which consists of paired self-report statements on a Likert scale spectrum from resilient to vulnerable and is completed by a client as a means of assessing their level of bereavement need. Clinician participants in this pilot study reported that the responses to the assessment tool reflected the clients' expressed bereavement needs. This suggests there is promise in developing a rigorous assessment tool that can be used by practitioners and services to better identify bereavement need. The work to develop such measures continues, for example the Bereavement Risk Inventory and Screening Questionnaire (BRISQ) is in the process of being tested (Roberts et al., 2017). These measures have the potential to enable practitioners to more readily identify those in need of support. However there remains a need to investigate which approaches to bereavement support initiated on the basis of such assessment are effective in particular settings and with particular groups of people.

## The nature of bereavement

The specific needs of people experiencing bereavement are also determined in part by the nature of their bereavement. People bereaved by suicide, or death in military service, require a level of understanding and sensitivity based on knowledge of their particular needs. Bereavement can become more complicated in instances when the death is a result of traumatic or emergency events, such as murder, road and railway accidents, bomb explosions or fire related. Chapple & Ziebland, (2011) and Eyre (2006) found that following these traumatic events people seek support from family, friends, support groups, counselling professionals, the church and even mediums in pursuit of a connection with the dead. Eyre (2006) suggests that following disasters, information and aftercare for those affected must be sensitive, non-judgemental and context specific. After traumatic and emergency events, the focus tends to be on the immediate aftercare of those affected and in addressing questions of 'how, where, what and when' in relation to the traumatic event (Eyre, 2006). Lobb et al. (2010) found that previous loss, exposure to trauma, previous psychiatric history, attachment style, and the relationship to the deceased were also important factors, which illustrates the complex and multifaceted nature of grief. This in turn indicates that professionals, volunteers and services more generally need to have access to up-to-date evidence about the nature of bereavement and its effects and more research is needed, particularly longitudinal studies, to determine the most effective types of support, both in terms of delivery and impact.

One promising theoretical development that emerged in the review was a three-phase perspective of the bereavement process (Small et al., 2009; Agnew & Duffy, 2009; Stephen et al., 2013; Montgomery & Campbell, 2012). The phases are anticipatory bereavement; bereavement at the time of death; and bereavement following death (Efstathiou, Walker, Metcalfe, & Vanderspank, 2018; Independent Age, 2018). This is consistent with the findings of a recent systematic review which identified anticipatory bereavement, bereavement at the time of death, and bereavement following death as common themes in bereavement research conducted in intensive care units (Efstathiou, Walker, Metcalfe, & Vanderspank, 2018). For example it has been found that high levels of anticipatory grief and low levels of preparedness during caregiving are associated with poor bereavement outcomes such as complicated grief (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). Aoun, Ewing, Grande, Toye, and Bear (2018) suggest there are benefits for caregivers in being engaged in early assessment of their support needs before bereavement, which reinforces the need for palliative care services to effectively identify and support caregivers before the patient's death (Aoun et al., 2018). This demonstrates the potential of the model for informing policy and service development in this area. However the work included here only represents the temporal dimension. Other elements such as place and the nature of the death need to be explored to build a conceptual model that will fully explain the phenomenon and uncover its potential.

## Conclusion

The main finding of this review is that the provision of bereavement support is extremely varied and there is no conclusive evidence for its effectiveness. There is widespread recognition of the potentially negative impact of bereavement on people, and a plethora of recommendations focused on raising awareness and ameliorating these effects have been made. However, the evidence for how best to support people experiencing bereavement is limited and contested. Further research is needed to map the need for bereavement support and to determine current provision. More evidence to demonstrate the effectiveness of particular approaches to bereavement support is also needed to inform policy and practice. Development of the anticipatory bereavement, bereavement at the time of death, and bereavement following death conceptualisation would provide a useful framework to better address the complex nature of bereavement. It could also serve as a means of comparing studies investigating different aspects of bereavement support. This needs to be underpinned by more rigorous work, including RCTs, which examines the impact and outcomes of different forms of bereavement support (eg individual counselling [with the mode specified]; group counselling [with the mode identified]; online approaches; locality based models). If there is to be a move from recognition of the issue to addressing it and supporting people in need, then this research agenda requires urgent action.

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## Supplemental data

Supplemental data for this article can be accessed here. https://doi.org/10.1080/02682621.2020.1728086

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