

## Bereavement support in the UK

Hewison, Alistair; Zafar, Shaz; Efstathiou, Nikolaos

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## Title

Bereavement Support in the UK- a rapid evidence assessment

## Abstract

Bereavement Support in the UK- a rapid evidence assessment

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 focussed 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.

## Key Words

Bereavement; Evidence review; bereavement support; services

## Introduction

It was noted over ten 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 fourteen recommendations indicating how bereavement care could be improved. However, in a review of bereavement care service standards it was concluded that whilst there have been some significant developments in bereavement care, their impact is largely unknown and assessing the quality 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 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 et al 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 excess risk of mortality, increased 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\* \(DH, 2008\) \(Arthur et al 2010\).](#)

## Design

The REA is a tool developed from the systematic review method and involves comprehensive electronic searches of appropriate databases, internet sources and limited follow-up of cited references to answer specific review questions (Speirs et al 2015; Thomas et al 2013, Haby 2016). The use of REA is increasing, driven to a large extent, by the need to engage policy makers, healthcare professionals, and consumers in a timely manner to provide evidence-based recommendations for healthcare practices and policies (Crawford et al 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 a REA can range from three weeks to six months (Ganann et al 2010). They have been undertaken to examine issues in a range of settings including housing (Whitehead et al 2008), alcohol and criminal harm (Booth 2012), education (Carroll et al 2017), international development (DFID 2013), health literacy (D’earth et al 2013) and end of life care (Parry et al 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 et al 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 et al 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

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, and Altman, 2009) (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 three. 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 *et al.*, 2013) which provides a pragmatic means of conducting rapid qualitative evidence synthesis and generating programme theories relating to intervention effectiveness, of relevance to researchers and policy-makers (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.

Figure 1 here

Figure 2 here

Figure 3 here

## **Results**

### **Summary of the Studies**

Twenty three papers met the inclusion criteria. Thirteen papers reported qualitative studies (13), six 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 and Cawkill 2012) and a review of a group work approach to bereavement support (Spence and Smale 2015). There was considerable variation in the scope and scale of the studies with sample sizes in the quantitative studies ranging from 35-3432 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 focussed 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 focussed 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.

Table 1 here

#### Theme 1: [The importance of interaction](#)

[This theme was evident in thirteen 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 *et al* 2009; Beardsley 2009; Rolls and 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 and Harper 2016; Valentine *et al* 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 health care staff, particularly in discussions concerning prognosis which resulted in feelings of isolation (Agnew *et al* 2008) and the need for more staff training in this area was identified (Agnew *et al* 2011; Young *et al* 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 and Cooper 2015). Stephen *et al* (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 and 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 et al 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 2018). 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 et al 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 and 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 and 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 et al 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 and Cawkill 2012; Rolls and Harper 2016). In one study a particular aspect of a support service provided- creation of a garden memorial to the deceased service person- to meet this need was found to be of great comfort to the families concerned (Rolls and 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 and 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 (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 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 impact of the bereavement support services centred on two types of approaches - group (Boyden et al 2009; Spence and Smale 2015; Finley and Payne 2010; Agnew and Duffy 2009), and individual (Newsom et al 2017a,b; Simonsen and 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 and Smale, 2015). This fostered a sense of mutuality and shared experience (Spence and 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 and Payne 2010), which was also found in a small study in another hospice (Agnew and Duffy 2009).

The impact of the interventions focussed on individuals was investigated by Newsom (2017,b) and Simonsen and Cooper (2015). In a small (7 participants) interview study involving former clients of a voluntary bereavement service the respondents reported that they found the counselling they received beneficial (Simonsen and 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 et al 2017b).

#### 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 et al (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 table 1. This 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 ten years on in 2019 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 bereavement support services' impact 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 four 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 (Newson et al 2017a). 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 (Newson et al 2017a). Evidence of the impact of counselling on the level of complicated grief experienced by bereaved people (Newsom et al 2017b) 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 more comprehensive studies are required to build the evidence base in this area.

A particular concern noted in ten 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 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 et al 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 et al 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 et al (2015) who reviewed the evidence for nineteen 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 et al. (2014) in the UK- *The Range of Response to Loss Bereavement Self-Assessment tool (RRLBSA)* 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 et al (2011) and Eyre (2008) 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 (2008) suggests that following disasters, information and aftercare for those affected must be sensitive, non-judgmental 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, 2008). 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 et al 2009; Stephen et al 2013; Montgomery and Campbell 2012). The phases are anticipatory bereavement; bereavement at the time of death; and bereavement following death (Efstathiou et al 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 et al 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 et al 2016). Aoun et al (2017) 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 2017). 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 focussed 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 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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Figure 1: PRISMA flowchart of the review process (Moher et al., 2009)

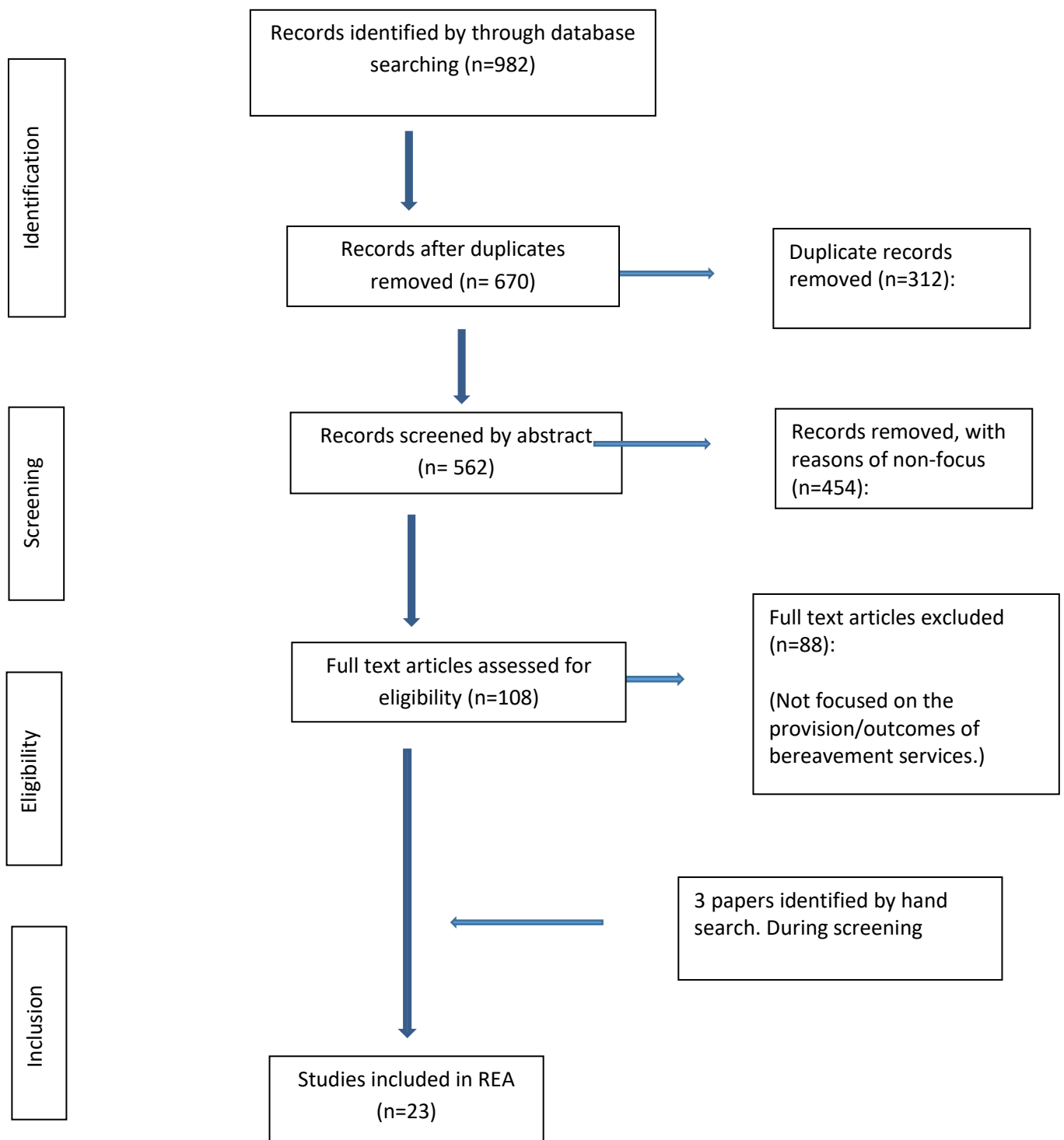


Figure 2: Key Words and Search Limits

“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 3: Inclusion and Exclusion criteria

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

1. Report empirical research (using quantitative, qualitative or mixed method design). 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.





**Table 1: Summary of Studies included in the Review**

Paper	Citation details	Title	Aims	Study Population	Design	Key Findings
1	Agnew, A Manktelow, R., Donaghy, K., <i>Practice</i> (09503153), 2008, 20, 163-180.	User perspectives on Palliative Care Services: Experiences of Middle-aged Partners Bereaved through Cancer Known to Social work Services in Northern Ireland	To explore pre and post bereavement experiences of partners bereaved through cancer.	10 participants 5 male and 5 female.	Qualitative. Semi-Structured interviews. Thematic analysis	<p>Data indicated that mental health problems were common in the sample (n=7) following bereavement and included cancer phobias, overwhelming feelings of hopelessness, depression and panic attacks.</p> <p>Seven partners were treated for depression with prescribed medication after loss of hope, energy, motivation and interest in the future.</p> <p>The majority (n=7) of participants were on a fixed low income due to ill health or part-time employment. Five participants indicated they had no concerns about money. Three returned to work due to loss of income and apprehension about coping. All participants reported feeling lonely, and experiencing social isolation exacerbated by a lack of insight on the part of family and friends on their situation. They felt society in general was impatient of their grieving and their need to express it. They experienced difficulties coping with changes to existing social networks.</p> <p>Participants reported that their spiritual beliefs were challenged, relinquished or strengthened.</p>
2	Agnew, A., Duffy, J., <i>International Journal of Palliative Care Nursing</i> , 2009, 15, 110, 112, 114-18	Effecting Positive Change with Bereaved Service Users in a Hospice Setting	To gain a deeper understanding of service user experiences of an adult bereavement group in a hospice setting. To develop a bereavement information leaflet.	7 adults who attended bereavement group support sessions at the Marie Curie Hospice, Belfast for 10 sessions	Qualitative. Focus group. Thematic analysis.	<p>Two main themes emerged from the data:</p> <ol style="list-style-type: none"> <li>1. How service users felt about their experience of attending the bereavement group meetings</li> <li>2. The language and presentation required for an appropriate bereavement group information leaflet</li> </ol> <p>A bereavement information leaflet was developed and distributed to newly bereaved service users.</p>

Paper	Citation details	Title	Aims	Study Population	Design	Key Findings
3	Agnew, Manktelow, R., Haynes, T., Jones, L., <i>British Journal of Social Work</i> , 2011, 41, 111-130.	Bereavement Assessment Practice in Hospice Settings: Challenges for Palliative Care Social Workers	To highlight challenges in practice for palliative care social workers involved in assessing bereavement risk.	10 Marie Curie hospice bereavement service leaders across the UK	Qualitative. Telephone interviews. Thematic analysis.	Identified the nature of assessment process; timing and level of bereavement follow up; staff training.  Findings informed the development of a post-bereavement service model that has been implemented in Marie Curie hospices.
4	Berry, M., Brink, E., Metaxa, V., <i>Journal of the Intensive Care Society</i> , 2017, 18, 11-16.	Time for change? A national audit on bereavement care in intensive care units	To compare bereavement services in England against Intensive Care Society guidelines.	179 ICUs (in 144 NHS Trusts) in England	A telephone audit of all adult ICUs in England.  Using the Health and Social Care Information Centre website ( <a href="http://www.hscic.gov.uk/catalogue/PU B10416">http://www.hscic.gov.uk/catalogue/PU B10416</a> ), 153 NHS Trusts submitting critical care data were identified in England.	113 responses were received (78% of Trusts, 63% of individual ICUs). 96% had an information booklet; 53% provided appropriate training; 19% conducted audits; and 27% reported they had adequate facilities.  Bereavement care is underdeveloped in English Intensive Care Units.
5	Beardsley, C., <i>Clinical Medicine</i> , 2009, 9, 53-8	In need of further tuning': using a US patient satisfaction with chaplaincy instrument in a UK multi-faith setting, including the bereaved.	To assist the Multi-Faith Chaplaincy Team at Chelsea and Westminster Hospital to make quality improvements based on patients' evaluation of chaplaincy provision.	Pilot = 20 participants Bereaved = 27 participants Discharged = 157 participants Inpatients = 96 participants	Instrument: Patient Satisfaction Instrument for Pastoral Care – Chaplaincy (PSI-C) and updated version PSI-C-R A USA Instrument was tested in the UK.	Pastoral support highly rated and helpful. Most found the service easy to access. Monthly memorial service valued by respondents.  Instrument: Patient Satisfaction Instrument for Pastoral Care – Chaplaincy (PSI-C) and updated version PSI-C-R. Found to be suitable for use in UK.

Paper	Citation details	Title	Aims	Study Population	Design	Key Findings
6	Boyden P, Freeman A, Offen L., <i>British Journal of Learning Disabilities</i> , 2009,38:35-40	Setting up and running a loss and bereavement support group for adults with learning Disabilities	To report the setting up of a bereavement group for people with learning disabilities.	5 adults who attended the group for 8 weeks.	Five adults with learning disabilities attended a bereavement support group for 8 weeks.  Accessible evaluation forms were distributed at the end of the group and participants supported to complete them.	The group helped people to share their feelings and experiences and helped them cope with their bereavement.  It created a 'safe environment for participants'
7	Chapple A., Ziebland S., <i>Health</i> , 2011, 15 (2): 173-187	How the Internet is changing the experience of bereavement by suicide: A qualitative study in the UK	To explore how those bereaved by suicide used the Internet in the aftermath of the suicide. To consider whether the Internet may be changing the experience of such bereavements.	Forty people bereaved by suicide. Twelve men, 28 women.	Qualitative. Narrative and semi-structured interviews. Qualitative interpretative approach, combining thematic analysis with constant comparison	Respondents reported using e-mail and social networking sites to inform others about the death, making sense of the events and gaining support from an Internet community of others who had been similarly bereaved and had created website memorials.  The Internet is transforming the experience of bereavement by suicide through providing access to other people's experiences.
8	Finley R., Payne M., <i>Groupwork</i> ., 2010, 20 (2): 65-84	A retrospective records audit of bereaved carers' groups	To describe, the model for bereaved carer group. Analysis of the records maintained by the groupworker to identify report evaluations by group members.	Twenty Evaluation forms of 10 series of groups attended by 70 people.	Qualitative. Thematic analysis of evaluation records.	Favourable responses to the group experience. All respondents found it helpful. Timing and structure felt to be appropriate. Some modifications recommended by individuals. No major need for change identified.

Paper	Citation details	Title	Aims	Study Population	Design	Key Findings
9	Green J., Cawkill P., <i>Bereavement Care</i> , 2012, 31 (3): 129-132	Supporting the bereaved families of Armed Forces personnel	To describe the design and implementation of a bespoke military support programme.	N/A	Development of a bespoke bereavement programme for bereaved families of Armed Forces personnel. This involved training Cruse volunteers and creating a bespoke website for families of military personnel.	Establishment of a bespoke military bereavement support infrastructure provided by Cruse, which the Armed Forces can call upon when needed. Level of uptake and benefits of the programme not reported.
10	Hawton K., Sutton L., Simkin S., Walker DM., Stacey G., Waters K., Rees S., <i>Crisis</i> , 2012, 33 (5): 254-264	Evaluation of a resource for people bereaved by suicide	To evaluate the use and impact of Help is at Hand, a hardcopy and online booklet produced as part of England's suicide-prevention strategy.	Thirty five participants completed the questionnaire  14 participated in the qualitative part of the	Mixed-Methods. Data were collected on the numbers copies distributed and online access, and on users' views about the resource through questionnaires, interviews, and a focus group.  •Department of Health website (Access to resources)  •Questionnaire (hard copy or online)  A focus group (5 participants) 9 interviews to explore bereaved participants' experience of using the Help at Hand resource.	Questionnaire The overall content of the resource was rated as helpful or extremely helpful by all the participants bereaved by suicide (n = 23), and all those in the "professional and other" group. Three of the seven people bereaved by other sudden, traumatic death rated the resource as of no help or slightly helpful. The section on experiencing bereavement was rated as "helpful" or "extremely helpful" by 32 (92%) respondents.  Focus group and interviews All participants agreed the material was well written and appropriate, although the Coroner's officer had concerns about the word "suicide" being used a lot, and that the bereaved might think that the coroner had decided in advance of an inquest that this was the verdict. Three of the four participants in the service user group found the pictures depressing and would have preferred a more abstract design, and one each of members of the charity worker and professional groups thought the pictures took up too much space.

Paper	Citation details	Title	Aims	Study Population	Design	Key Findings
11	Hayward JS., Makinde O., Vasudev NS., <i>Ecancermedi calscience</i> , 2016, 10 (642):	Letters of condolence: assessing attitudes and variability in practice amongst oncologists and palliative care doctors in Yorkshire	To explore the attitudes of oncologists and palliative care consultants towards writing letters of condolence to patient's families.	Forty seven medical consultants. 21-clinical oncologists 20 medical oncologists 6 palliative care consultants	Online Questionnaire. Descriptive statistics were used to compare the frequency of responses. Free-text comments were reviewed together with the categorical responses to help explain the reasoning behind some of the behaviours.	35/47 (75%) indicated they sent letters of condolence to families following the death of a patient. 41/47 (87%) participants responded that they occasionally (21/41; 51%), often (13/41; 32%) or always (7/41; 17%) sent condolence letters. The most common reasons that participants wrote letters were 'knowing the patient or family well' (31%), 'helping the family to grieve' (28%), and 'giving the family the opportunity to talk and ask questions about their relative' (29%). The majority of respondents (34/47; 72.3%) indicated they would not support a policy to unify practice in terms of condolence letter writing.
12	Montgomery L., Campbell A., <i>Journal of Social Work in End-of-Life &amp; Palliative Care</i> , 2012, 8 (2): 165-181.	A qualitative evaluation of the provision of bereavement care accessed by service users living in a Health and Social Care Trust area in Northern Ireland	To explore the care offered to bereaved individuals in the Trust area To identify the challenges and issues relating to this care.	Sixteen participants: 8 social workers; 5 nurses; 3 counsellors.	Exploratory qualitative method with Semi-structured interviews. Manual thematic analysis.	Bereavement work seen as important by respondents; all informants made referrals to other services; creating a safe environment for bereavement care seen to be important; trust approach lacked coordination.
13	Newsom C., Stroebe MS., Schut H., Wilson S., Birrell J., Moerbeek M., Eisma MC., <i>Psychotherapy Research</i> , 2017 (a), Sept 25: 1-13.	Community-based counselling reaches and helps bereaved people living in low-income households	To investigate the association between poverty and complicated grief (CG), and the effectiveness of a community-based bereavement counselling program for people from low-income households.	Two hundred and eighty eight Scottish residents who had been bereaved for at least six months.	Longitudinal Study-Quasi-randomised trial Data collected by postal questionnaires at three time-points: baseline (T1), 12 months post-measure (T2), and 18 months after baseline at follow up (T3). The Inventory of Complicated Grief-Revised (ICG-R) was used to assess symptoms of complicated grief (CG). A bespoke questionnaire was designed to assess demographic details.	Of all participants, 35.8% reported below poverty-threshold income, twice the general population's rate. Multiple regression analysis indicated poverty-threshold income was a predictor of Complicated Grief symptoms over and above demographic and loss-related characteristics. Three-way interaction analysis detected a significant treatment effect for study condition across time, but no differences in treatment effects across income.

Paper	Citation details	Title	Aims	Study Population	Design	Key Findings
14	Newsom C., Schut H., Stroebe MS., Wilson S., Birrell J., Moerbeek M., Eisma MC. <i>Clinical Psychology &amp; Psychotherapy</i> 2017(b), 1-12.	Effectiveness of bereavement counselling through a community-based organization: A naturalistic, controlled trial	To establish whether grief counselling offered through a community-based organization to help-seeking, highly distressed, and/or high-risk bereaved individuals was effective in improving psychological and social functioning relative to a no-intervention control.	344 people experiencing bereavement. 75% had lost partner or parent in previous 2 years Females-79%.	Naturalistic Controlled Trial Data collected at three time points: baseline, T1; post treatment, T2 (T1 + 12 months); and follow-up, T3 (T1 + 18 months).  A random effects model. A stepwise serial gatekeeping procedure to address multiple hypotheses testing. Normality of residuals at both the repeated measures level and subject level was checked by means of Quantile-Quantile (QQ) plots. Homoscedasticity of the residuals at both levels was checked by means of scatter plots.	A main finding was that, contrary to expectations, counselling intervention and control group participants experienced a similar reduction in Complicated Grief symptoms.  Intervention participants demonstrated a greater reduction in symptom levels at follow-up (M= 53.64; d= .33) compared to the control group (M= 62.00).
15	Pitman AL., Rantell K., Moran P., Sireling L., Marston L., King M., Osborn D., <i>BMJ Open</i> , 2017, 7 (5), 1-12	Support received after bereavement by suicide and other sudden deaths: a cross-sectional UK study of 3432 young bereaved adults	To test the hypothesis that people bereaved by suicide are less likely to receive formal or informal support than people bereaved by other causes of sudden death.	3432 eligible respondents aged 18–40 years bereaved by the sudden death of a close friend or relative	Cross-sectional survey Tools used: Online questionnaire sociodemographic and clinical characteristics. Adult Psychiatric Morbidity Survey Composite International Diagnostic Interview screen for lifetime depression Stigma subscale of the Grief Experience Questionnaire Likert-style responses to 10 items Two tick-box questions probed help received, whether sought or offered, after the bereavement.	21% (725/3432) of the sample of bereaved adults reported receiving no formal or informal bereavement support, with no evidence for group differences. People bereaved by suicide were less likely to have received informal support than those bereaved by sudden natural causes but did not differ from either comparison group on receipt of formal support. People bereaved by suicide were less likely to have received immediate support and more likely to report delayed receipt of support than people bereaved by sudden natural causes. Overall 6% reported having attempted suicide since the bereavement, of which 67% (141/210) had not sought help for any episode of self-harm occurring post-bereavement. In those who had sought help, the most common source was a general practitioner (20%).

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16	Rolls L., Harper M., <i>Death Studies</i> , 2016, 40:2, 88-101	The impact of practical support on parental bereavement: Reflections from a study involving parents bereaved through military death	To describe the impact on UK bereaved parents of sons who died during military service, of the practical support provided by the charity forces support.	15 parents (12 mothers and three fathers) bereaved of a son whilst on military service	Qualitative interviews. Recursive grounded theory. Thematic analysis.	The parents appreciated the work done; felt they could be 'authentic' with the workers as they knew the situation of the parents; preferred that it was a charity not the MOD organising the work; pleased that workers made all the necessary arrangements (purchasing materials and so on); appreciated the respectful compassionate approach of workers. Experience of normality and inclusivity; humour 'banter' of workers was welcomed; Transformative effect of the improved environment on their life reported. Provided a peaceful space (garden work)-in some cases a sanctuary where memories could be accessed with greater ease; physical reminder (although not specified-generally a memorial of some sort in the garden)
17	Simonsen G, Cooper M, <i>Counselling and Psychotherapy Research</i> , 2015, 15(2), 119-127.	Helpful aspects of bereavement counselling: An interpretative phenomenological analysis	To deepen understanding of the practices that bereaved clients find helpful in counselling	Seven former clients of a voluntary bereavement counselling agency in Scotland.	Qualitative. Semi-structured interviews. Interpretative phenomenological analysis (IPA).	Respondents reported the independence of the counsellors, who <b>were outside the family and social network</b> , was important as it enabled free communication. Skilled listening-felt to be important. Recognized by participants as helpful. Non-directivity-valued by participants. Challenging un-helpful thinking-different ways of thinking. Normalising-validation that grieving was 'normal' process and discussion of process felt to be helpful.
18	Small N., Barnes S., Gott M., Parker P Payne S., Seamark D., Gariballa S., <i>BMC Palliative Care</i> , 2009, 8:6, 1-10.	Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK	To explore carers' views of dying, death and bereavement following recent death from heart failure.	20 bereaved carers.	Qualitative. Semi-structured interviews with bereaved carers in their home or by telephone. Thematic analysis. NUD*IST used.	Dissatisfaction with unnecessary interventions while patient was dying in hospital. Planned deaths at home considered to be 'good deaths'. Many of the family carers were satisfied with the professional bereavement support they received. A small number had taken up bereavement support. The main source of support was friends and family. Some of the carers described how grief had affected them, the coping strategies they used and how, in some cases, their bereavement had been followed by depression.
19	Spence, S., Smale U., <i>Person-centred Experiential Psychotherapies</i> , 2015, 14:1, 3-17.	Group work with bereaved people: developing person-centered practice	To describe the experience of setting-up and developing group support for bereaved people.	Number of participants not specified. Close persons of hospice patients who had died.	Descriptive review of the Living with Grief group. Not framed in a research design. Some participants' statements included-however not collected using a recognized data collection method.	The sharing each week of what has been significant for participants in learning how to better identify and respond to their specific situations and personal needs was valued. The group offered an environment which supported expression, clarification, and normalization of feelings. Helped establish different patterns of living. Participants described and valued a sense of mutuality developed by this sharing.



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20	Stephen, A I., Wimpenny, P, Unwin, R, Work F, Dempster P, MacDuff C. Wilcock S E, Brown A., <i>Death Studies</i> , 2009, 33:3, 239-261,	Bereavement and Bereavement Care in Health and Social Care: Provision and Practice in Scotland	To identify current views and practices in bereavement care and perceived priorities for service development in Scotland. To identify perspectives in health and social care settings, from both the statutory and voluntary sectors	Fifty nine participants interviewed.  Staff in the statutory, voluntary, and independent sectors-mainly Scotland (some in England).	Qualitative. Semi-structured interviews, Thematic Analysis.	Interviewees reported that the full extent of the impact of bereavement on statutory health and social care services and the voluntary sector is unknown. There is a lack of clarity, particularly in primary care, about the amount of time and resources required. Services led by enthusiasts. Staff on hospital wards lack confidence and feel under unsupported in managing bereavement. There was less provision in rural areas and areas of deprivation. No national standards/guidance for bereavement care/services were identified. Education for staff required-however often not well funded The lack of research and suitable data on the bereaved and on services provided for them, means that there is no clear estimate of the impact on the health of the bereaved or on the workload of health and social care staff across the sectors
21	Stephen, A I., Wimpenny, P, Wilcock S E, <i>Journal of Older People Nursing</i> 2013, 8, 279-289	Bereavement care for older people in healthcare settings: qualitative study of experiences	To explore the experiences of healthcare staff of caring for bereaved older people, and older people's experiences of bereavement care	39 Participants  33 health care staff. 6 people bereaved of a relative or close friend who had died in hospital, at home or in a Care Home	A qualitative design drawing on phenomenological methodology. . Semi-structured interviews. Thematic analysis.	Relationships are crucial if bereavement support is going to be provided.  Preparation phase- staff feel this is the time they can make a real contribution-discussion of prognosis, withdrawal of treatment.  Continuum of preparation- preparation of older people for the death of their spouse or other relative lies somewhere along a continuum from poorly prepared to well-prepared.  Facilitating anticipatory grief was seen by healthcare staff in all practice settings as their main role in bereavement care

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22	Valentine C., McKell, J., Ford A., <i>Journal of Interprofessional Care</i> , 2018, 32:3, 295-303.	Service failures and challenges in responding to people bereaved through drugs and alcohol: An interprofessional analysis	<p>To understand the experiences and needs of people bereaved by substance use.</p> <p>To develop guidelines to improve how services respond</p>	<p>Number of participants not specified. Adults bereaved through substance use. (stage 1)</p> <p>Practitioners from a broad range of services that encounter this type of bereavement (Stage 2)</p>	<p>Qualitative. Individual interviews, Focus Groups and Thematic analysis.</p> <p>Stage 1: Sixty-six semi-structured interviews were conducted in South West England and 34 in Scotland.</p> <p>Stage 2: Four Focus Groups (South West England) Two Focus Groups (Scotland)</p>	<p>There is a daunting and complex array of services and related processes and procedures that people bereaved by substance use may need to negotiate at a time when they are least able to cope.</p> <p>The 'system' is complex after any death, but for substance-related deaths there are added complexities related to establishing the cause of death.</p> <p>No coherent national or local Strategy for the way services respond to this group of bereaved people exists.</p> <p>Response of professionals is important (compassion, language and sensitive judgment in encounters, crucial)</p> <p>Coordination of system is important-some respondents reported it worked well, others that it was fragmented and unhelpful.</p> <p>Working together poses challenges for organisations, particularly where different types of services and disparate working cultures are involved</p> <p>Inconsiderate media reporting had an adverse effect on the experience of the bereaved</p>
23	Young H, Garrad B, Lambe L, Higg J., <i>Learning Disability Practice</i> , 2014, 17 (6), 16-20	Helping people cope with bereavement	<p>To address the lack of research on bereavement among people with PMLDs and their carers</p> <p>To develop resources to support both groups,</p>	<p>Ten family carers, 9 parents and 1 sibling, and 14 paid carers from 2 services.</p>	<p>Qualitative semi-structured interviews and Focus Groups</p> <p>8 focus groups with 32 parents, four focus groups with 7 professionals (to develop resources)</p> <p>Interpretative phenomenological analysis. NVivo software</p>	<p>People with learning disabilities may not fully understand the concept of death, but experienced loss</p> <p>They experienced a lack of support and there was a breakdown in social support networks following death.</p> <p>Wanted accessible written information, which was not available.</p> <p>Concern for staff-need training and parents concerned about wellbeing of paid staff.</p> <p>Experiences of palliative care-problems with communication during palliative care.</p>

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