

Bereavement research gaps and priorities in the UK: project findings for discussion

July 2020

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Introduction

Bereavement research has a rich and significant history in the UK, across topics and disciplines. From early ground-breaking work to recent publications, UK researchers have played an important role in increasing our understanding of the nature and impact of bereavement and bereavement care. Researchers have also developed robust and creative methodologies for researching bereaved people's experiences.

However, the limits of our knowledge and understanding of these topics continue to become apparent. Social and demographic changes bring new contexts for exploration; advances in research in other countries inspire parallel studies here; and patient and public involvement bring new priorities. Most recently, the COVID-19 outbreak and infection control measures have provoked new and urgent questions about the nature of bereavement – and how best to support bereaved people - in these extraordinary times.

Research is already underway in the UK on topics in this area, and other studies are being planned. There are many opportunities for researchers to develop work that is directly related to COVID-19, but also to use the current heightened awareness of bereavement and grief as a moment to seek funding for broader projects. However, these opportunities also bring risks: of fragmentation, duplication and even over-research (Clark 2008). To minimise these risks, it is important to collaborate where possible, and for researchers and funders to prioritise research that is relevant and robust.

Short and longer-term priority topics for research in the face of COVID-19 have been identified for psychological sciences (O'Connor 2020) and mental health science research (Holmes et al 2020) but bereavement has received little attention to date. Loss and bereavement did emerge as one of four areas of concern during the pandemic in a recent rapid [virtual stakeholder consultation](#) (Johnson et al 2020) of patient and public involvement colleagues affected by serious illness in England. Their research priorities included evaluating alternative ways of connecting with loved ones who were dying, and identifying and implementing effective models of bereavement support in relation to the escalating complexities of multiple deaths and widespread grief.

In the absence of a comprehensive prioritisation exercise on bereavement research topics and approaches in the UK, such as that carried out recently in Australia (Hay et al 2019), this paper summarises relevant findings on perceived research gaps or priorities from three projects in the UK:

1. A series of consultations with National Bereavement Alliance and Childhood Bereavement Network members between September 2016 and July 2020 on their views about the gaps in evidence for practice
2. The Palliative and End of Life Care Priority Setting Partnership (PeolcPSP, 2015)
3. A scoping study of research gaps on childhood grief (Penny & Rice, 2012)

The topics and approaches identified in this paper are not exhaustive and it is likely that a more robust prioritisation exercise would be a useful next step for the field. In the meantime, the summaries presented here are intended to provide a starting point to generate discussion.

Consultations of bereavement practitioners & researchers by the National Bereavement Alliance & Childhood Bereavement Network (Sept 2016 to July 2020)

Methodology

Members of the National Bereavement Alliance and Childhood Bereavement Network have been asked periodically for their help in determining what the sector needs to know to improve bereavement care. They have been asked to submit their own topics, and to identify those questions from others (bereaved families, funders or colleagues) which they find difficult to answer. Topics were collected in three phases:

1. **September 2016 to February 2017.** NBA and CBN submitted initial thoughts via an online survey in September 2016. These were discussed and added to at an NBA meeting in November 2016 with 25 attendees, and at a series of six regional Childhood Bereavement Network meetings in October and November 2016, with a total of 89 attendees. A final round of consultation in February 2017 added further topics.
2. **December 2019.** These topics were revisited at a National Bereavement Alliance meeting with 33 participants in December 2019, and further questions added.
3. **April to July 2020.** During the coronavirus pandemic, NBA and CBN members and staff attending weekly webinars for managers and practitioners of bereavement services were invited to submit their priority research questions. Some of these were directly related to COVID-19; others were identified as wider evidence gaps by those trying to make the case for bereavement support to local and national commissioners, funders and decision-makers.

The topics identified by these three consultations were organised into broad areas, using six of the seven categories developed in a recent Delphi study of Australian grief and bereavement care providers' research priorities (Hay et al 2019). These are presented below: each topic is marked with a number, indicating at which phase of consultation (outlined above) it was first identified.

These topics have not been through further rounds of prioritisation, as in a Delphi study. Although they were identified by respondents as research gaps, checks have not been made to identify the degree to which these topics have already been studied (e.g. in the case of PICO topics, whether a recent systematic review exists).

Findings

Determining grief processes

- Annual statistics on the prevalence of bereavement in the population (2)
- Long term impact of bereavement across the life course, using data from UK longitudinal/birth cohort studies (1)
- The proportion of bereaved adults and children who need support or intervention at different levels among the general bereaved population in the UK (with sub-group analysis by age, gender, relationship to the person who died, faith, ethnicity, type of death, income) – ideally carried out in the aftermath of the pandemic and then repeated cross-sectionally six months or a year later to compare cohorts – potentially matching as closely as possible to international data e.g. Aoun et al (2015) (1,3)
- Predictors of complicated grief reactions (1)
- The impact of the duty of candour on grief (1)
- Impact of assisted dying or assisted suicide on grief experiences (2)
- The interplay between social isolation, loneliness and bereavement (2)
- Experiences of bereaved adults and children grieving during the pandemic (3)

- Impact of COVID-19 related risk factors on grief, mental health and functioning among adults and children (e.g. not being with the person when they were dying, or seeing them afterwards, few attendees at the funeral, having unanswered questions and 'what-if's', social isolation including schools being closed, different levels of confidence in using technology, economic pressures, perceived hierarchy of grief) (3)

Exploring social/community concerns

- Understandings of a 'good death' among different communities and how this impacts on grief; and how these elements can best be preserved during physical distancing (3)
- What bereaved people value about a supportive response from their existing networks (including community groups, schools and employers) and how these networks can best be equipped to provide this (3)
- The impact of digital media on grief experiences (e.g. hearing of the death, memorialisation) (1)
- How bereavement affects friendships (including among children and young people) (1)
- Bereaved people's experiences at work (2)
- Financial impact of bereavement on the individual and society (in England) (2)
- Impact of changing family dynamics on grief (2)

Improving grief interventions

- Nature, extent and quality of bereavement support across the UK in different settings (1)
- Levels of unmet need in the bereaved population (2)
- Optimum time since the death to provide support in different settings (1) and the effectiveness of early support (1)
- Appropriate timing of support in the COVID-19 context (3)
- The difference that pre-bereavement support makes to post-bereavement outcomes (1)
- Ways of preventing and treating Prolonged Grief Disorder and their effectiveness (3)
- Effectiveness of drop in/café-style groups (3)
- How support can best be provided remotely (1) and the effectiveness of this support (3)
- How to match delivery of support (e.g. in-person vs over the phone) to need (3)
- How processes in the delivery of bereavement support influence outcomes (3)
- Whether providing bereavement support in an acute setting influences numbers of complaints (1)
- Therapeutic value of group support in addressing PTSD (1)
- The cost-effectiveness of different types of support (1) (and their social return on investment (2)) including those that aim to enhance resilience among the majority of people who do not need intensive therapeutic interventions. These analyses to consider a wide range of costed outcomes for bereaved people and wider society (1)
- Health landscape for bereavement and the role of commissioning (2)
- Models of commissioning bereavement services (3)
- Impact of the pandemic on the organisation and funding of bereavement services (3)

Developing grief measures

- Methods for evidencing bereavement support outcomes at 6-12 months follow up (1)

Enriching health professionals' training and support

- Experiences and outcomes for those delivering bereavement care during the pandemic, including remotely (3)
- Benefits of networking regionally and nationally across bereavement services (2)
- Impact of deaths of patients/residents on frontline staff including care homes (3)

Understanding experiences and meeting the needs of specific types of losses and grievers

- Appropriate models of support to meet differing cultural understandings of grief and help-seeking, with evidence of effectiveness (1)
- Accessibility and outcomes of support for particular priority groups, including bereaved people from different Black, Asian and Minority Ethnic (BAME) communities (3)
- The impact of bereavement on certain under-researched groups (identified groups were bereaved young carers; children whose sibling died before they were born; those bereaved by suicide beyond the immediate family) (1)
- Associations with or risk of negative outcomes among bereaved children and young people (identified outcomes were sexual exploitation, violence, self-harm and educational achievement) (1)
- Approaches to supporting bereaved children and adults with learning difficulties (1)
- Approaches to supporting bereaved young people aged 18-25 as they experience other transitions (1)
- Ways of supporting young children who do not have memories of the person who died (1)
- Value of organising child bereavement services so that children and young people can re-access support if they face new grieving challenges as they develop (1)
- Appropriate thresholds for referring children and young people for treatment for PTSD (1)

Research priorities from the Palliative and End of Life Care Priority Setting Partnership

Final report published January 2015 (PeolcPSP, 2015)

Methodology

The Palliative and End of Life Care Priority Setting Partnership was initiated by Marie Curie in 2013. Around 30 other organisations and groups were involved, and the partnership was facilitated by the James Lind Alliance (JLA) using their robust methodology for bringing together patients, carers and clinicians in a given area of healthcare and clinical intervention, to identify and prioritise the top 10 unanswered questions that they agree are the most important.

People likely to be within the last years of life, current and bereaved carers, and health and social care professionals were surveyed for their unanswered questions about palliative and end of life care. The 1,403 responses from across the UK were analysed to draw out research questions, which were combined where appropriate. Researchers assessed whether any of these questions had already been answered by an up to date systematic review of existing research. From this, a longlist of 83 unanswered questions was produced. These questions were then ranked in priority by a

second survey, again of people likely to be within the last years of life, current and bereaved carers, and health and social care professionals. The 1,331 responses were reviewed by the steering group, which produced a shortlist of 28 questions. A final prioritisation workshop identified the top 10 unanswered research questions from this shortlist.

Findings

Some of the questions identified in the longlist of 83 unanswered questions were about support for carers and bereaved people. These are reproduced below. Questions marked * made it into the shortlist of 28 questions (alongside questions about other aspects of palliative and end of life care), and questions marked ** made it into the top ten priorities.

Support for carers and families

- Does respite for people caring for a family member or friend who is dying benefit the patient's care and the quality of life for both the patient and carer? What is the best way to provide respite?
- How can carers and families be encouraged to seek support for themselves at the right time?
- What information and training do carers and families need to provide the best care for their loved one who is dying? **
- Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?
- What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?
- What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?
- Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?
- What are the best approaches to support carers and families of people at the end of life where there are substance and/or alcohol addiction and/or domestic violence issues?
- What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support*
- What are the best ways and times to meet the emotional support needs of patients, carers and families, including one-on-one peer support, support groups and professional counselling?
- How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?

Bereavement

- Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?
- How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?
- What are the benefits of bereavement support, including preventing depression and other illness?
- When is the best time to introduce bereavement support, and for how long? Should it be offered before the death of a loved one? How can this support be catered to individual needs, including access to 24-hour support?

Longlisted questions in other thematic areas were also relevant. These included

- What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?
- Much palliative and end of life care is provided by charities. What are the benefits and risks of this and is it sustainable and efficient?
- Is there evidence that some volunteer services that provide support for patients, carers and families reduce the need for paid trained staff?
- How can the spiritual support needs of palliative care patients and their carers and families best be met in a way that is appropriate for people of different religions and people who are not religious?

For the full list of long-listed questions, please see the [final report](#) from the Priority Setting Partnership.

Gaps in UK research on children's grief

In 2012, the Childhood Bereavement Network identified a number of gaps in research on children's grief as part of a wider scoping of a virtual research centre (Penny and Rice, 2012). While these are now somewhat old, the general findings are still worth presenting here.

Methodology

The evidence presented here came from six main sources:

- Literature on childhood bereavement, drawing heavily on two reviews (Ribbens McCarthy 2006; Ribbens McCarthy 2005 with Jessop), and exploring literature published between these and 2012;
- Interviews with five academics and practitioners with an understanding of childhood bereavement issues, either directly or through related areas such as end of life care;
- Interviews with two individuals involved in other research collaborations;
- Desk research into the activities of other research collaborations (both related and not related to death and bereavement);
- Discussions with practitioners and managers of child bereavement services at CBN's regional seminars in Spring 2011; and a meeting of senior researchers in the field.

Findings

The scoping study identified a number of gaps (at 2012)

- An absence of **baseline data** to enable a robust assessment of the scale of bereavement in childhood, and detailed segmentation of this data to understand the range of experiences by type of bereavement and according to various socio-demographic characteristics;
- An absence of **longitudinal data** for a cohort of children and young people to track their experience of bereavement, and the impact this has on their life course over the short, medium and long term. This would need to be contextualised by comparing children who had experienced bereavement in childhood against a control group of those who had not experienced such an event. This type of data would be particularly important in helping to answer questions such as what factors are important in determining 'risk' of, and 'resilience' towards, negative consequences resulting from such a major disruption;
- Limited evidence on - but discussion about – the notion of **complicated or prolonged grief in children and young people**;
- Inconclusive research into the **effectiveness of different approaches** to working with bereaved children, young people and their families, and a dearth of appropriate tools & mixed methods;
- Very limited evidence on the **socio-economic costs** of bereavement in childhood and the **cost-effectiveness of providing services**;
- Significant gaps in sampling **children, young people & families who have not accessed services**;

- Limited investigation of the issue from a **sociological perspective**. While much of the existing research has considered the issue from an individual (psychological) perspective, little attention has been given to understanding how bereavement is construed and dealt with at the level of society, and from different cultural standpoints. This is important to provide a broader context within which other data can be viewed, allowing socially patterned differences within and between research samples to be recognised. This could help to explain some of the contradictions in the existing data which continue to cloud our broader understanding;
- Very limited incidence of **child-centred research**. Many studies mediate children's input through adult caregivers, or are based on adults retrospectively telling their stories of the experience in childhood. While there are clear ethical issues to resolve when considering involving children and young people in research such as this, it is thought to be in the best interests of children to be involved in order to give them a voice both in terms of articulating what it means to them to be bereaved, and in shaping the policies, services and information intended to support them;
- Little evidence on **parents' perspectives**. As noted above, while parents are often involved in research in lieu of their children, relatively little is known about the reasons why some parents accept and others decline help for their child, leaving a significant gap in knowledge about the 'harder-to-reach' populations and their perceptions of services.

Discussion

The research priority topics identified by these three projects ranged across bereavement experiences and outcomes of adults and children. Some of the topics are long-standing gaps in evidence, pre-dating the COVID-19 outbreak. However, the pandemic has increased the urgency of filling these gaps, because of the need to develop evidence-based practice and policy responses at speed. Other topics are specific to the COVID-19 context. The dynamic and temporal nature of current research prioritisation exercises has been noted in wider studies (Norton et al 2020).

Some topics will require new primary research, drawing on a range of methodologies including mixed methods designs and interdisciplinary approaches where appropriate. Others may require secondary analysis, summarising and synthesizing existing literature.

Identifying the gaps in evidence can help to encourage more relevant research, but on its own this activity does not necessarily encourage more robust research. It is crucial that as well as considering relevance, researchers (and funders) use appropriate designs and methods to rise above some of the known and long-standing weaknesses in the field. These include a lack of theory-driven research, small and non-representative samples limiting sub-group analyses and generalisability, diverse measurement tools, lack of control groups, short follow up, and lack of attention to cultural contexts and social processes (Ribbens McCarthy with Jessop 2005; Stroebe et al 2008).

Much bereavement research is practitioner-led which, while often highly relevant to practice, may need a degree of coordination to ensure that specific interests have the potential to contribute to a wider, coherent body of work. These studies are typically less resourced and smaller scale than a well-funded academic research programme (Penny and Rice 2012). Stronger partnerships between practitioners and academics, and across disciplines, could help (Neimeyer and Harris 2011).

Even when research is relevant and robust, it must still be known and used. Some of the research topics identified in this paper may already have been explored in high quality research studies, but these findings are not sufficiently well known. The gap between research and practice in bereavement care is a theme in the literature (Neimeyer and Harris 2011). Existing studies may need better dissemination or implementation to influence practice (Breen and Moullin, 2020) or policy.

Limitations of this paper

One of the projects summarised here (PeolcPSP) focused on research topics in palliative and end of life care, so the bereavement topics identified as part of this process did not include those specifically around sudden death including suicide, homicide or accident. Two of the three projects (PeolcPSP and consultations with CBN and NBA members) had a particular focus on topics around intervention and support, so there is a bias towards applied research. Two of the projects

(consultations with CBN and NBA members, and scoping study on childhood grief research) did not involve bereaved people or their family members or friends in eliciting bereavement topics. Although 44 people with experience of serious illness were involved in a recent scoping of palliative care research during the COVID-19 pandemic (Johnson et al 2020), bereaved people's own research priorities remain under-explored.

Conclusion

The research priorities presented here provide a starting point to aid discussions about future projects and collaborations across the bereavement research community in the UK. This paper is not exhaustive, and further topics and areas for exploration will emerge, particularly when greater account is taken of the research priorities of other stakeholders, including bereaved people themselves. A more comprehensive prioritisation exercise is likely to be useful. However, more attention to methodological issues, more collaborative working, and stronger dissemination of findings will also be needed to drive the bereavement research agenda forward in the UK, in the interests of those facing bereavement and grief, now and in the future.

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The Childhood Bereavement Network and the National Bereavement Alliance are hosted by the National Children's Bureau, registered charity no 258825

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