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# **What Should Good Bereavement Service Support Look Like?: Findings from pre-pandemic workshop discussions interpreted in the context of the Covid-19 pandemic**

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# **What Should Good Bereavement Service Support Look Like?: Findings from pre-pandemic workshop discussions interpreted in the context of the Covid-19 pandemic**

## **Abstract**

**Introduction:** There has been a lack of consistency in approaches to bereavement support provision and evaluation. As part of a study which identified outcomes for adult bereavement support services in palliative care, we conducted stakeholder workshops with people from professional and lived experience backgrounds, providing a view on what support interventions should look like.

**Aims:** The aims of this first workshop were to gather stakeholder views on the purpose, impacts and outcomes of bereavement service support. In this paper we summarise these findings and consider their relevance to bereavement support during and following the Covid-19 pandemic.

**Methods:** Stakeholders were divided into three groups and asked to consider how support services should help bereaved service users and what good bereavement service support looks like. Key themes were identified from the written and verbal content of the workshop.

**Findings:** Three main themes emerged from the data; informal support and self-management; the aims and purpose of bereavement service support and the timing, accessibility and quality of support.

**Conclusion:** Workshop findings align with public health models of bereavement care and recent service standards, identifying core support functions and aspirations for bereavement services. Finding the best mechanisms and modalities for meeting these, in the context of the late/post-pandemic period, presents both challenges and opportunities.

**Keywords:** bereavement support, bereavement services, palliative care, grief

## **Implications:**

- Core functions for bereavement services include enabling coping and grief management, supporting resilience and social adjustment, and providing practical support and advice.
- Bereaved people experience difficulties with the emotional support available from their friends and family. Services can help by seeking to improve these relationships and the informal support available to people, as well as directly providing opportunities for peer-support from fellow bereaved persons, such as bereavement support groups.
- Support should be tailored to individual needs, be accessible to and accommodating of the needs of people from diverse backgrounds and available when needed, rather than according to pre-determined timeframes.
- Further research and evaluation is needed to investigate how well services fulfil the support needs and functions identified, in particular with regard to under-served groups. This evidence is especially needed as the bereavement sector negotiates the late/post-pandemic period and the changes seen in bereavement experiences and support provision at this time.

## **Introduction**

Bereavement support is a core part of health and social care provision (NICE, 2004, WHO, 2002; NICE, 2004, Aoun et al. 2012, Aoun et al. 2015), and is of heightened importance during pandemics and other mass bereavement events (Harrop et al. 2020c). However, the need for better evidence and greater consistency in the delivery of bereavement services is well recognised, with recent national and international programmes of work focused on developing sets of service standards through consensus building activities with expert stakeholders (Keegan et al. 2021, Hudson et al. 2018, Bereavement Services Association and Cruse Bereavement Care, 2013). In an endeavour to improve the quality and usefulness of the evidence for bereavement interventions we conducted a multi-methods study which, using a systematic review, stakeholder workshops and a Delphi Survey, identified two core outcomes for bereavement support services in palliative care; ‘ability to cope with grief’ and ‘quality of life and mental wellbeing’. Full results and project methodology are reported in the main study publication (anonymised ref 1). As part of this project, we conducted an initial stakeholder workshop focused on identifying and describing the purpose and impacts of bereavement support. The content of these group discussions with professional and public stakeholders was rich and insightful, and much broader in scope than the primary focus on outcome identification that is reported elsewhere (anonymised ref 1). As such we felt that the content of these more expansive discussions have timely potential to contribute to the literature and heightened interest in what good bereavement support looks like in the context of the Covid-19 pandemic, including the current UK Commission on Bereavement ([bereavementcommission.org.uk](http://bereavementcommission.org.uk)).

## **Background**

Previous research has shown that people who have been bereaved have varying needs for support, requiring different types of support according to their level of need (Aoun et al. 2015). Guidelines similarly emphasise that support should match individual risk and need (Aoun et al 2017; Bereavement Services Association and Cruse Bereavement Care 2013; Hudson et al. 2018). Public health approaches to bereavement care recognize the differing needs of bereaved people and recommend a tiered approach to support, similar to the three-component model outlined by NICE (2004). The first tier/component includes universal access to information on grief and available services, with bereaved people supported by existing social networks. The second tier includes structured, reflective support, appropriate for those with moderate needs, estimated at c.30% of the bereaved population in non-pandemic times (Aoun et al. 2015). Third-tier support, including specialist grief, mental health and psychological interventions will be required by the small minority (c.10% non-pandemic) of people at high risk of prolonged grief disorder and should be targeted accordingly (NICE, 2004, Aoun et al. 2012, Aoun et al. 2015). However, due to the unique sets of circumstances associated with the pandemic, such as traumatic deaths, social isolation and disrupted mourning, bereavement researchers have predicted and observed increases in the proportions of people experiencing prolonged grief disorder (PGD) and other mental health problems (Eisma, 2020, Pearce, 2021, Boelen et al. 2021, Palliative Care Australia 2020, Menzies et al. 2020). Lower proportions of people able to cope with only friend and

family support (as per tier one) has also been observed during the pandemic (Harrop et al. 2021), with high level needs for emotional support reported by over half of survey participants bereaved during the Covid-19 pandemic (Harrop et al. 2021).

Palliative care providers, such as hospices, typically offer different types of support which cut across these three components. Examples range from drop-in events and information evenings, telephone support, mutually supportive groups, individual and group counselling and specialist counselling for those with more complex needs (Hudson et al. 2018, Field et al. 2004, Anonymised 2). During the pandemic, on-line chat forums and support groups, web-based and self-help resources and online/telephone provision of counselling support have been commonly used across the UK, reflecting the service adaptations that needed to be made in response to infection-control measures (Harrop et al. 2021, Pearce et al. 2021). The evidence-base for bereavement interventions has historically been limited, with systematic reviews investigating their effectiveness commonly reporting inconclusive results and limited effects (e.g. Forte et al. 2005; Wittouck et al. 2011; Currier et al. 2008; Jordan et al. 2003). However, most have not considered the qualitative or mixed-methods evidence that is available for the many different types of bereavement support, and is essential for understanding intervention mechanisms, contextual influences and the lived experience of intervention participants, needed to inform service improvement (Anonymised 2). In a mixed-methods systematic review involving thematic synthesis of qualitative results we identified three core impacts and interventional mechanisms which cut across intervention types, defined as ‘grief and loss resolution’, ‘mastery and moving ahead’ and ‘social support’. In line with public health models, the review confirmed the value and benefits of social support alongside opportunities for reflection, emotional expression and restoration-focused activities for those with moderate-level needs and specialist psychological intervention for those with high-level needs (Anonymised 2).

It is also proposed that palliative care and bereavement services work in partnership with community and other organisations, helping bereaved individuals to care for themselves and enhance the natural support networks that are available to them, following compassionate communities approaches to end of life and bereavement care (Rumbold and Aoun, 2014, Aoun et al. 2018; 2019; Aoun 2020; Breen et al. 2020). Such approaches are especially needed, given the problems that bereaved people experience getting the informal and formal support that they need. These include lack of understanding and compassion amongst family and friends, and difficulties expressing their feelings and needs (Aoun et al. 2020, Breen and O’Connor, 2011, Breen et al. 2017). Such experiences have been intensified during the pandemic due to social distancing restrictions, lack of opportunity for in-person support and the wider societal strains of the pandemic (National Bereavement Alliance, 2020, Sue Ryder, 2020, Harrop et al. 2021; Pearce et al. 2021). Barriers to formal support use identified pre and during the pandemic have included lack of information and knowledge of how to get support, discomfort or reluctance to seek help from services and lack of availability of appropriate support (Sue Ryder, 2019, Wakefield et al. 2020, Harrop et al. 2021). Limited awareness of available support and a lack of culturally competent services are particular barriers for people from minority ethnic communities (Maryland et al. 2021, Murray, 2020).

By way of contribution to this literature and the heightened policy interest in improving the support available for bereaved people during and following the pandemic, we report here the broad and insightful discussions which took place during our first stakeholder workshop. In the Discussion section we consider the relevance and applicability of workshop and full study results to bereavement support provision in these late/post -pandemic times. In doing so we

draw on findings from a UK study which investigated bereavement experiences during the Covid-19 pandemic, including data collected from a 13 item Support Needs Scale directly developed from the outcomes selected and defined in this study (see Harrop et al. 2021; Selman et al. 2022b).

## Methods

A full description of overall project methodology and aims is provided in the main study publication (Anonymised 1). The specific aims of the first stakeholder workshop were:

- To gather stakeholder views on what good (component one/two) bereavement service support should look like, including the type of support that services should offer and the key benefits/impacts that it should have for service users.
- To incorporate these impacts into outcome lists already produced from a systematic review, prior to their inclusion in a Delphi Survey (reported in main study publication).
- To invite general comments and observations relating to the project and subject area.

The workshop was held in March 2017, and was attended by 21 UK-based delegates from professional and bereaved/non-professional backgrounds. Delegates were identified through bereavement provider networks, as well as Patient and Public Involvement (PPI) networks and researcher contacts. They included academics, hospice-based counsellors and social workers, representatives from third sector bereavement organisations and people with recent close bereavement experiences and experiences of using support services. Delegates were divided into three groups: group 1 was made up of people with bereavement experiences (n=7; 2 male, 5 female) and groups 2 and 3 were made up of professional stakeholders (n=14).

In the first break-out session, which is the focus of this paper, we used a modified nominal group technique to structure the discussions (e.g. see Harvey & Holmes 2012). Group members were asked to individually identify three ways in which they believed a support service should help (impact) their service users. Each person was asked to read out their chosen 'impacts' to the rest of the group, along with an explanation of why they had chosen them. Of the two group facilitators assigned to coordinate and direct discussion, one captured the impact and its definition on a flipchart, while the other made more detailed notes on the group discussion that took place. Once all impacts had been documented on the flip chart, the group was asked to group these impacts thematically, with further discussion around these different types of impacts and the more general role and function of bereavement support. In the afternoon session these impacts were mapped to outcome lists produced from a systematic review, prior to their inclusion in a Delphi exercise, the details of which are reported elsewhere (Anonymised 1). Flip charts and researcher notes from the group discussions were analysed thematically and summarised in a report by two researchers, identifying points of agreement and consensus within and across the three groups. Sessions were audio-recorded but not transcribed, with recordings used by researchers following the event to check the accuracy of the notes. The summary report was reviewed by the team of workshop facilitators and sent to all participants following the event.

Two PPI representatives (public contributors) were actively involved in all stages of the project. They helped to refine the research question and the study protocol, ensuring that

research design, methods and study materials were appropriate for the study participants, in particular bereaved people. The public contributors helped to recruit bereaved workshop participants and facilitated group discussions at this first workshop, contributing their own experiences and views to these discussions. They were pivotal in making sure that explanations and materials used on the day were accessible and could be understood by non-professional stakeholders.

(Anonymised ethics committee) approved the project. Written informed consent was taken from participants at the start of the workshop, following provision and explanation of study information sheets.

## **Findings**

The findings from the workshop are grouped under three thematic headings: self-management and informal support; the aims and purpose of formal bereavement service support; and the timing, quality and accessibility of support. Summary tables containing the verbatim bullet points that were documented on flipcharts by each group and sent to participants following the event are provided in supplementary file one.

### ***Self-management and informal support***

A distinction was drawn by the three groups, between formal and informal networks of support. Informal support, particularly from people who could offer shared experiences and understanding, was identified as important for those dealing with grief. The social side of this – for example, mixing with other people, having gatherings of bereaved carers etc. – offered a way out of the loneliness and isolation that accompanies a bereavement and can help the person feel able to cope with day-to-day life.

Members of the bereaved group described how informal peer-based support such as coffee mornings hosted by funeral directors and online support groups (for younger members) helped them to cope with the aftermath of bereavement. It was explained that online support groups can mitigate any physical disability or social anxiety that the person may have. It was considered a positive that they were peer-based, rather than professional, as – similar to in-person gatherings – they enabled people to feel comfortable talking to others who were also experiencing bereavement. This was seen as particularly important given the difficulties that participants in the bereaved group experienced in managing the expectations of others, including the beliefs of friends and family members that they should be ‘getting over’ their grief. They described the further negative impacts of commonly-used expressions, such as ‘it was God’s will’, or ‘everything happens for a reason’, which were perceived as insensitive, harmful and distressing.

Self-management strategies identified as beneficial by bereaved participants included mindfulness and meditation, which helped to separate the person from their thoughts. Some members of this group also believed that visiting the deceased’s grave could be therapeutic. Similarly, holding onto items that reminded them of the deceased, such as photographs or clothing, were felt to offer comfort and positive memories of the person. Some members of the bereaved group discussed the importance of work as a form of self-management. Having a job was perceived as a helpful distraction from grief, and participants who were retired



struggled to cope with the amount of time they found themselves with each day following their bereavement. It was also stressed, however, that employers needed to be flexible in allowing for bereaved individuals to take as much time off as was needed – which, it was agreed, would vary from person to person.

### ***The aims and purpose of formal bereavement service support***

#### ***Managing grief and enabling coping and resilience***

The groups were asked to consider the types of support provided by bereavement services, in particular what this support should look like and how it should be helping service users. All three groups stated the need for support services to strengthen resilience and to help bereaved people manage and cope with, rather than ‘treat’ grief. As part of this, the bereaved and professional groups believed that services should be aiming to normalise the grieving process by enabling knowledge and understanding about grieving and providing reassurance that what they were feeling was normal. Bereaved participants described how they needed to be told that they were not ‘failing’ and that the ‘bad’ days where they were overwhelmed by feelings of inadequacy or the inability to cope were all part of the grieving process.

Members of the bereaved group stressed the importance of experiencing emotions associated with grief, such as sorrow, which they perceived as a positive expression of love for the deceased person. Some also described a need for help with ‘channelling’ negative emotions such as anger which can stem from negative care and end of life experiences. The professional group also saw a role for services in helping people to ‘identify and validate the positive consequences of loss’, to be able to remember and talk about the deceased without becoming overwhelmed and helping them to find meaning in and make sense of their loss and experiences. However, both bereaved and professional participants also stressed the importance of services identifying when someone had passed from what would be considered ‘normal’ grieving, to something more prolonged and serious, with service users supported to identify maladaptive thought and behaviours. Likewise, professional participants also felt that services should encourage ‘self-directed recognition of wanting to end sessions’ to avoid problems with dependency and unnecessarily pathologizing their grief.

#### ***Facilitating social adjustment, improved relationships and wellbeing***

All groups believed that services should help bereaved people to manage and maintain their relationships with others, and generally improve wellbeing. This was understood to mean helping people to feel able to ‘face the future’ (bereaved group) and make ‘incremental moves from hopelessness to optimism’ (professional group). Professional participants described a role for services in supporting the re-emergence of self-identity following a bereavement, and the individual’s ability to return to normal social roles and interactions with others, as well as equipping service users with coping and lifestyle strategies. The need for support services to address social isolation and improve social connectedness was also emphasised. The benefits of group-based support and being listened to by those with shared experiences, empathy and understanding were described in all three groups, but there was also felt to be a role for services in improving family-based support, enabling bereaved people to be better supported by their existing networks. One member of the bereaved group felt that she would have benefited from training on how to support her daughter, following the death of her ex-husband/father to their daughter. Professional participants identified ‘understanding others’ behaviours and actions’ and ‘managing conflict and



misunderstandings relating to different ways of dealing with grief' as important for enabling better relationship and communication within families. It was also noted that support services should consider the needs of those with additional caring responsibilities, and the impact this may have on bereavement experiences.

### ***Providing practical support and advice***

Practical support was seen as important as emotional support by bereaved and professional participants, with bereaved participants feeling that this was often overlooked. Examples of such support given by bereaved participants included help with the practicalities in the event of disputes or legal action, and the provision of information packs with details of necessary support services for bereaved families. Professional participants in both groups stressed the importance of helping bereaved people to deal with financial and social insecurities if needed, especially in socially-disadvantaged communities, where these needs could be more acute than emotional support needs.

### ***The timing, quality and accessibility of support***

Having the right support at different stages of the illness/bereavement process was vital. Professional and caregiver groups described the importance of having allocated support for carers during the end-of-life stage. One bereaved participant perceived that he was given false hope, and that there was a mismatch between the reality of his wife's illness – for which there were limited treatment options – and the information he was given. He felt that the impact of his wife's death was worse, because he had been equipped with unrealistic expectations. Relatedly, people in the bereaved group perceived much of the discourse and terminology on cancer to be damaging. Terms such as 'fight' or 'battle' implied that cancer could be overcome if the person was mentally strong enough. This could then lead to feelings of guilt when defeat was accepted. All groups stressed the need for more support to be available post-death. The bereaved group felt that there was reasonable support when the patient was unwell or dying, but that this disappeared afterwards, leaving the bereaved person isolated. For those with no family, the loneliness was particularly acute, and these people had a pressing need for support services.

The timing of support was seen as important, with professional and bereaved participants describing how people have different support needs at different times. Participants in the bereaved group explained how support may not be needed immediately post-bereavement, but might be six months later. Grief was unpredictable and active interventions at different time points should always be available; a 'low' period can strike at any time. People do not overcome grief, they learn to live with it, hence the need for longer-term support. Professional participants similarly spoke of the need for formal offers of support at later stages, but that there was no fixed or right time to offer support, which should be made be available when needed rather according to prescribed time frames.

Professionals described the importance of an individualised approach to support, which focused on individual needs and differences, with services establishing what each person wanted to get out of the support. There is no one size fits all and there needs to be a range of support available, accessible when needed. Participants in the professional groups also described the need for services to understand how different spiritual and belief systems and cultural and religious identities shape bereavement experiences and to be committed to equity of service provision across socio-cultural groups. One of the professional groups discussed

the importance of the organisational culture of a support service, including a commitment to evidence-based knowledge and the Bereavement Care Standards, and adequate provision of staff training and development.

Professional and bereaved groups emphasised the importance of removing barriers to support use. Professionals described a need for accessible information about grief and services, better signposting, collaboration and partnership-working between healthcare and bereavement services, including a role for bereavement services in influencing public and professional (e.g. GP's) understandings of grief and how to manage it. The bereaved group similarly explained that support services should be better publicised, so that bereaved people knew they were there, as a 'safety net', even if they chose not to use them.

## **Discussion**

These workshop group discussions, conducted as part of a larger study on bereavement support outcomes, provide insight into the role, purpose and delivery of informal and formal support for bereaved people, from the perspectives of bereaved, service provider and academic stakeholders. Key findings include the importance of, and difficulties with informal social support and consistent with the full study results, the supportive role for services in enabling grief management, coping, resilience and adjustment, as well as providing practical support and advice to bereaved people. The need for individualised support to be accessible and available from pre-bereavement onwards, without prescribed timeframes was also discussed. These themes align with public health models of bereavement care and service standards recently developed, as well as support needs identified for people bereaved during the Covid-19 pandemic, adding to the literature and heightened policy interest in what good bereavement support looks like in these late/post-pandemic times.

There was strong agreement across professional and bereaved groups that support services should be concerned with promoting resilience and helping bereaved people to manage and cope with their grief rather than attempting to 'treat' grief. To achieve these goals, services should enable knowledge and understanding about grief reactions, provide reassurance and help to normalise (rather than pathologise) grief experiences. Services have a role in helping people to remember their loved ones without feeling overwhelmed and in helping them to find meaning in and make sense of their loss and experiences. These sentiments were confirmed in the wider consultation exercises and full study results which confirmed two main outcomes 'ability to cope with grief' and 'quality of life and mental wellbeing'. The selected outcome dimensions that were associated with the first outcome 'ability to cope' included 'acceptance of grief experiences as normal'; 'understanding, acceptance, finding meaning in loss'; 'positive reminiscence and remembering of the deceased' (Anonymised 1). These support functions also fit well with interventional mechanisms relating to 'loss and grief resolution' that were identified in a recent systematic review (Anonymised 2) and theoretical models which emphasise loss-oriented coping and the critical role of meaning reconstruction within this (Stroebe and Schut, 1999, Neimeyer, 2001).

These support functions appear also to reflect the needs of people bereaved during the Covid-19 pandemic. The unprecedented social and clinical restrictions introduced to control the spread of the virus meant that bereaved people experienced profound disruption to end of life, death and mourning practices, and in turn found it harder to process their feelings, find closure and begin to grieve, often themselves reflecting on the 'uniqueness' of pandemic grief

(Harrop et al. 2021; Selman et al. 2022a; Torrens-Burton et al. 2022). The ‘disrupted meaning’ caused by such experiences was identified as a factor contributing to worse grief outcomes in a US study (Breen et al. 2022) and it is striking that the highest-level of support-need reported in the UK study was for ‘dealing with my feelings about the way my loved-one died’, followed by ‘dealing with my feelings about being without my loved-one’(Harrop et al. 2021). Such findings suggest the critical role for bereavement services in supporting meaning-making at this time, but also the unique pandemic-related challenges associated with achieving this, including the possibilities for understanding grief experiences as ‘normal’. When supporting people bereaved during the pandemic providers need to recognise and respond to context-specific differences in people’s grieving during these unprecedented times; a need articulated by people bereaved both during the pandemic and other mass-bereavement events (Harrop et al. 2020; 2021). These pandemic-research findings also add weight to the important role described for services in identifying and responding to those with prolonged and serious grief symptoms (NICE, 2004, Aoun et al. 2015), recognising the higher proportions of bereaved people likely to require more specialised interventions (Palliative Care Australia 2020; Eisma, 2020, Boelen et al. 2021, Menzies et al. 2020).

The identified role for services in helping bereaved people to become more optimistic and experience improvements in their identity, functioning and relationships is consistent with the second outcome that was selected and defined at the end of the study, ‘quality of life and mental wellbeing’. Dimensions associated with this outcome included; participation in work/daily activities, social functioning and relationships and sense of meaning, purpose, optimism and hopefulness. This role similarly reflects the interventional impacts of ‘mastery and moving ahead’ observed in a recent systematic review (Anonymised 2), conceptualisations of ‘balanced’ responses to the emotional and practical consequences of loss (Machin, 2001) and the construct of ‘restoration-oriented’ coping, as defined in the Dual Process Model of bereavement (Stroebe and Schut, 1999). This model describes how people oscillate between dealing with the loss of the deceased person and negotiating the practical and psychosocial changes to their lives that occur as a result of the bereavement (restoration-oriented coping) (Stroebe and Schut, 1999). These support functions also align with the psychosocial support needs reported by pandemic-bereaved survey participants, most of whom reported moderate to high-level needs for help with ‘finding balance between grieving and other areas of life’, ‘regaining sense of purpose and meaning in life’ and with ‘managing and maintaining my relationships with friends and family’ (Harrop et al. 2021). Specific pandemic-related disruption to restoration-oriented coping, including the difficulties bereaved people face finding new meaning, purpose or respite from their grief at times of social restrictions and anxieties relating to the virus have also been observed (Stroebe & Shut 2021; Torrens-Burton et al. 2022). This again suggests both the importance and the challenges of providing support which meets these needs during times of pandemic and beyond.

As in previous research, the value and benefits of social support for enabling coping were well recognised (Aoun 2018; 2019), with online and in-person peer-support groups enabling bereaved people to connect with those with shared experiences, helping them to feel understood and less isolated (Anonymised 2, Harrop et al. 2020c, Harrop et al. 2021). Such opportunities were especially valued given the difficulties that both bereaved and professional participants recognised with the informal support available from existing social networks. These observations are consistent with other research findings (Aoun et al. 2020, Breen et al. 2011, Breen et al. 2017, Harrop et al. 2021) and the high-level needs for help with ‘loneliness and social isolation’ and ‘expressing feelings and feeling understood by others’ reported by people bereaved during the Covid-19 pandemic (Harrop et al. 2021).

These findings therefore also suggest the value of developing a compassionate communities approach to bereavement support, which empowers communities and existing social networks to better support bereaved members, rather than focusing exclusively on specialist palliative care or bereavement services to provide support (Aoun et al. 2018; 2019). Practical and financial support was also seen as an important part of bereavement service provision, particularly in socially disadvantaged areas, an observation again mirrored in full study results (Anonymised 1). In the pandemic survey findings, just under half of bereaved participants experienced moderate to high-level needs for support with ‘getting relevant information and advice, e.g. legal, financial, available support’ (Harrop et al. 2021). Difficulties relating to death-administration and accessing support were also commonly described (Torrens-Burton et al 2022), again suggesting the need for this type of support to be widely available during and following the pandemic.

In line with recent support standards (Hudson et al. 2018, Bereavement Services Association and Cruse Bereavement Care, 2013) and previous research (Aoun et al. 2017), the workshop participants emphasised the need for individualised approaches, which respond to the unique and varying needs of individuals, and culturally competent approaches which understand how different cultural and religious identities and beliefs shape bereavement experiences (Murray 2020; Mayland et al. 2021; Anonymised 2; Harrop et al. 2020c; Selman et al. 2022). This is of especial importance given the differential impacts of the pandemic on minority ethnic communities and the related need for support which is both cultural and crisis competent (Harrop et al. 2021; Selman et al. 2022c). Consistent with review and survey findings (Aoun et al. 2017; Anonymised 2), and the principle of individualised and person-centred approaches, there was agreement that there is no fixed or right time to offer support, which should be made available according to self-identified need rather than pre-determined timeframes. Better co-ordination and collaboration between statutory and voluntary services, and information and signposting to services (e.g. via GP practices, community pharmacies) is also needed to address some of the barriers to accessing support, including lack of knowledge or understanding of bereavement support options and services, as identified in pandemic and pre-pandemic times (Sue Ryder, 2019, Wakefield et al. 2020, Harrop et al. 2021).

### ***Strengths, limitations and implications for further research***

This phase of the study had a number of strengths. Using open-discussion groups it captured the perspectives of bereaved individuals, as well as bereavement professional and academic stakeholders, with views generally well aligned across groups. In addition to generating ideas on outcomes and outcomes dimensions, which were ultimately incorporated into lists included in the Delphi survey, these more broadly focused discussions also captured views on key features of service function and delivery, whilst also providing a more contextualised consideration of bereavement service outcomes. A limitation of the workshop was that there was just one group of bereaved/public stakeholders, involving only two men and no participants from minority ethnic backgrounds. This meant that these perspectives and experiences were unfortunately lacking, as in other studies (e.g. Harrop et al. 2021, Mayland et al. 2021). However, bereavement professionals working in areas which were ethnically diverse and socially disadvantaged brought their experiences of working with these communities to the discussions. As demonstrated here many of the observations made during the consensus day were also validated through the Delphi exercise (n=240), involving a much larger number of bereaved participants (n=69) (Anonymised 1). Indeed, it is notable that the

workshop observations proved pivotal to the overall study results, clearly underlining the importance of using qualitative methods to capture stakeholder views, and using these as a key element of the consensus-gathering process (Anonymised 1).

Further research and evaluation is needed to investigate how well services and interventions meet the support needs and fulfil the functions identified in this paper, and in turn achieve the associated coping and wellbeing outcomes that were defined in the wider study (Anonymised 1). By seeking to advance understandings of context-mechanism-outcome relationships, defined in realist evaluation methodology, and addressing the related question; what works, for whom, in what circumstances and why? (Pawson et al. 1997, 2005), the usefulness and practical relevance of the evidence-base for service design and delivery could be greatly enhanced. Given the considerable adaptations and innovations that have been made to services as a result of pandemic restrictions (Pearce et al. 2020, NBA 2020), this evidence will be all the more salient as the bereavement sector negotiates and plans for the late/post-pandemic period. Increasing the representation of diverse socio-cultural groups within future research is also critical for effectively answering these questions and developing services that meet the needs of groups that have historically been less well served by bereavement organisations.

## **Conclusion**

These workshop findings support tiered public health models and compassionate communities' approaches to bereavement support (Aoun et al. 2012, Rumbold and Aoun, 2014, Breen et al. 2020), sharing similarities with service standards recently developed (Hudson et al 2018) and aligning well with the support needs of people bereaved during the Covid-19 pandemic (Harrop et al. 2021). They confirm the importance of social support for bereaved people, and the role of bereavement services in enabling coping, resilience and adjustment, as well as providing practical support and advice. Support should be tailored to individual needs, be widely accessible and accommodating of the needs of people from diverse sociocultural backgrounds, and available at different stages of the bereavement process. Identifying and responding to those with more complex grief or mental health problems is also vital. Finding the best mechanisms and modalities for fulfilling these support functions and aspirations, in the context of pandemic-impacts on bereavement experiences and services is both the challenge and opportunity of the moment.

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Supplementary File: Lists of bereavement service impacts and features captured on flipcharts from workshop group discussions

**1. Desired impacts of Bereavement Service Support for Services Users: Living and coping with grief**

Group One- Bereaved group	Group Two- Professional group	Group Three- Professional Group
<p><i>Dealing with grief:</i></p> <ul style="list-style-type: none"> <li>• Minimise negative consequences of grief</li> <li>• Information and understanding of bereavement and coping process (that experiences are normal, will have good days and bad days)</li> <li>• Having time to think about the person and enjoy memories</li> <li>• Channelling/being able to deal with anger (that comes from negative care experiences, etc.)</li> </ul> <p><i>Coping:</i></p> <ul style="list-style-type: none"> <li>• Recognising that coping is multidimensional (not just supported by counselling, e.g. accessing social support)</li> <li>• Being able to face the future</li> <li>• Meditation – helps to give distance (this should be more widely offered)</li> <li>• Being able to ‘enjoy’ sorrow (guilt-free, pure grief)</li> </ul>	<p><i>Resilience and coping:</i></p> <ul style="list-style-type: none"> <li>• Impact on personal coping/living with the grief:</li> <li>• Visits to GP/ primary care related to bereavement (physical/emotional wellbeing)</li> <li>• Ability to address finances</li> <li>• Ability to remember/talk about deceased person without being overwhelmed</li> <li>• Emotional and self-resilience and ability to function</li> <li>• Incremental moves from hopelessness to optimism</li> <li>• Ability to return to work</li> <li>• Being bereaved with additional caring responsibilities</li> </ul> <p><i>Identity/sense of self:</i></p> <ul style="list-style-type: none"> <li>• Impact on/re-emergence of sense of self-identity (short and longer term)</li> <li>• Self-directed recognition of wanting to end sessions (not pathologising/medicalising grief)</li> </ul>	<p><i>Psychological – understanding normality of grieving process:</i></p> <ul style="list-style-type: none"> <li>• Help with psychological wellbeing and capacity to bear</li> <li>• Coping with feelings of loss and grief</li> <li>• Discovering and strengthening resilience</li> <li>• Ability to self-manage and rely less on health services</li> </ul> <p><i>Psychological – processing feelings:</i></p> <ul style="list-style-type: none"> <li>• Reduce anxiety</li> <li>• Reduce panic</li> <li>• Improve sleep quality</li> <li>• Understanding difference between depression and grief</li> </ul> <p><i>Cognitive:</i></p> <ul style="list-style-type: none"> <li>• Making sense of experience</li> <li>• Understanding normality of grief and the consequences for others</li> <li>• Understanding others’ behaviours and actions</li> <li>• Identifying</li> </ul>

	<ul style="list-style-type: none"> <li>Identifying and validating the positive consequences of loss</li> </ul>	maladaptive thoughts and behaviours <i>Spiritual and belief systems</i> <ul style="list-style-type: none"> <li>Making sense of loss</li> <li>Impact on personal identity (cultural and religious)</li> </ul>
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## 2. Desired impacts of Bereavement Service Support for Services Users: Social support, interaction and adjustment

Group one:	Group two	Group three
<b>Peer support:</b> <ul style="list-style-type: none"> <li>Being listened to about all the little things (experiencing warmth, empathy, understanding)</li> <li>Value of online, round-the-clock support (people to listen and talk to)</li> <li>Need support of those with shared experiences and understanding (Expectations of friends and family can be difficult to manage- just 'getting over it' is not always that simple)</li> </ul>	<b>Interactions:</b> <ul style="list-style-type: none"> <li>Impact on social isolation (how it is managed)</li> <li>Return to normal functioning in the external world for the bereaved person</li> <li>Relationships with others and with their community</li> <li>Did it help? Continuum of useful to useless</li> <li>Managing how others treat them</li> <li>Improved wellbeing (however or whatever that may be)</li> </ul>	<b>Social – individual:</b> <ul style="list-style-type: none"> <li>Adapting to change, e.g. 'post carer' role</li> <li>Normality (expected, common)</li> <li>Healthy coping and lifestyle strategies</li> </ul> <b>Social – family/ wider society</b> <ul style="list-style-type: none"> <li>Help with connectedness and feeling less isolated</li> <li>Ability to function in life roles and responsibilities</li> <li>Relationships and communication</li> <li>Managing conflict and misunderstanding (of different ways of dealing with grief)</li> <li>Ability to deal with social and financial</li> </ul>

		insecurities and circumstantial factors
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## Features of service quality and effective delivery

Group One	Group Two	Group Three
<p><b>Service level approaches to offering and giving help:</b></p> <ul style="list-style-type: none"> <li>• Allocated support for carer as well as patient (during end of life period)</li> <li>• Having formal offers of support at later stages (e.g. 6 months down the line – but not a case of a fixed time, need for the option of access at different times)</li> <li>• Recognising both emotional and practical difficulties/need for help</li> <li>• Publicity of services to raise awareness of what help is available</li> <li>• Provide insight/support for other family members so that they better understand what the bereaved person is going through.</li> <li>• Help with practicalities such as how to manage their possessions</li> </ul>	<p><b>Service provision:</b></p> <ul style="list-style-type: none"> <li>• Equity of service provision across all groups</li> <li>• Response to individual differences</li> <li>• What do participants want to get out of a BSS?</li> </ul>	<p><b>Organisational culture:</b></p> <ul style="list-style-type: none"> <li>• Transport links/accessibility</li> <li>• Information, signposting, navigation to/about service</li> <li>• Range of support with integration (with ‘self’ or ‘others’) – accessible when needed and in accessible formats</li> <li>• Staff, development, training and support</li> <li>• Recognition of and sensitivity to difference</li> <li>• Culture of integrity (including evidence-based knowledge) and commitment to Bereavement Care (BC) Standards.</li> <li>• Clarity of scope</li> </ul> <p><b>Accessibility:</b></p> <ul style="list-style-type: none"> <li>• Location</li> <li>• Timing</li> <li>• Formats (information – about service,</li> </ul>

		<p>about grief, about other services)</p> <p><b>Integration:</b></p> <ul style="list-style-type: none"><li>• Signposting</li><li>• Collaboration and partnership</li></ul>
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