**“The person was like the glue in the cracked pot which was no longer there”: Family-focused support for bereavement via co-production of a web-based intervention**

Natasha Camplinga\*, Susi Lunda, Alison Allama, Gail Preciousb, Michelle Myalla

a School of Health Sciences, University of Southampton, Southampton SO17 1BJ, UK.

b Childhood Bereavement Network and National Bereavement Alliance, London E8 3PN, UK.

\*Corresponding author: N.C.Campling@soton.ac.uk-

**Abstract**

**Background** Families, friends and support networks are key to managing bereavement. COVID-19 social restrictions prevented families and friends from being with the dying and participating in usual rituals to honour the dead. This resulted in social disconnection, feelings of guilt, and difficulty in making sense of the death and reconstructing relationships. In response to this context a theoretically informed, co-produced web-resource to facilitate meaning-making, which situates bereavement in the context of family and friends, was developed. This paper describes the development of the web-based intervention.

**Study aims** Toco-produce a web-based intervention theoretically informed by the family level extension Dual Process Model and Family Sense of Coherence, and pilot the intervention gaining user feedback to inform refinements in readiness for adoption and implementation.

**Design and Methods** Following a scoping review, a mixed methods study was undertaken using an online survey via questionnaire and virtual co-production workshop with bereaved people and bereavement professionals.

**Findings** Survey respondents reported the pandemic negatively affected bereavement (guilt, isolation, inability to bear witness) but also presented new opportunities to celebrate the deceased and support the bereaved (new funeral rituals, technology, remote contact, social acknowledgement of grief). Sense-making and managing bereavement were helped through information-giving, support networks, and relocating the person within the family context. A web-resource to facilitate collective grief was viewed positively and endorsed. Key content including family activities to stimulate support, information regarding the range of grief experience and dealing with the practicalities, along with other sources of support was agreed by workshop participants to form the basis of the intervention.

**Conclusion** The[Families and Friends in Bereavement](http://www.familiesandfriendsinbereavement.org.uk/) intervention encourages consideration of bereavement in the context of close social networks. It enables grief to be understood and managed within a shared experience by promoting communication and meaning-making.

**Keywords:** bereavement, grief, family-focused, theoretically-informed, web-based intervention, co-production,COVID-19

**Introduction**

COVID-19 first emerged in December 2019 and spread rapidly, becoming a global pandemic resulting in an unprecedented level of deaths, causing mass bereavement worldwide. While significant focus has been on deaths from COVID-19, the impact has been far reaching affecting all those bereaved from any cause during the pandemic. Estimates suggest. Before COVID-19, 60% of bereaved people managed their bereavement with the help of family, friends and support networks (Penny, 2020). Social restrictions resulted in significant disruption and inability to provide these usual forms of support. Furthermore restrictions, including those applied to funerals and lack of opportunity to spend time or visit the dying, disrupted social rituals marking the death leaving family members feeling they were unable to bear witness and honor their dying and dead. The ensuing social disconnections (Smith et al., 2020) and guilt (Bear et al., 2020; Torrens-Burton et al., 2022) exacerbated the challenge of bereavement. For many, death became unexpected, out of time and place.

The social disconnection between a dying person and family, caused by social distancing precautions, meant the construction of family narratives of end-of-life was compromised. A review of the international literature, across 13 countries during COVID-19, found that whilst there was diversity of experience based on culture and belief systems all countries identified significant impact on family bereavement (Stroebe & Schut, 2021). Almost half (49%) of respondents to a survey of 2,000 UK adults, carried out by Dying Matters, agreed that being unable to be with someone as they died, or attend their funeral, would make it harder for them to process the death (Penny, 2020) . It is narratives that serve to link the biography of a living family member with the death and which are important in the process of making sense of what has happened, paying tribute to the deceased and in reconstructing bonds between the bereaved and their deceased family member (Klass et al., 2014; Walter, 1996). This meaning-making process is essential for family wellbeing and resilience (Gilbert, 1996), yet it was challenged by varying COVID-19 control measures.

Most Western focused professional bereavement support interventions and services are underpinned by grief theories which concentrate predominately on the individual, mitigating psychological distress, and identifying and preventing complicated grief (Laranjeira et al., 2022). (It is difficult to determine if this is the case beyond Western societies due to paucity of evidence, and further research is required to understand the focus of interventions globally). Services are often delivered face-to-face or by telephone, others are group-based, with inequitable access dependent on the setting in which the death occurred. To address these gaps in provision, de-professionalizing bereavement for those individuals not at risk of complicated grief and shifting the focus to the wider family, this study co-produced a web-based intervention [Families and Friends in Bereavement](http://www.familiesandfriendsinbereavement.org.uk/) adopting a family-focused approach.

Family support is recognized as key to managing bereavement, yet most grief theories focus on individual rather than collective experience (Stroebe and Schut, 2015). A notable exception is the family-level extension to the Dual Process Model of Coping with Bereavement, in which Stroebe and Schut (2015) describe family level tasks influencing loss and restoration orientated coping. Loss orientation refers to dealing with processing the stressful aspects of a loss experience and focusing on the deceased (e.g. memorializing and thinking about the person who has died), restoration orientation refers to coping with other losses which manifest as a result of the bereavement (e.g. financial hardship, adapting to new routines and roles). Restrictions during the pandemic contributed to significant additional stressors and precluded the usual oscillation between loss and restoration orientated processes by disrupting everyday living which in usual times offers a degree of respite and distraction from confronting or avoiding family stressors (Stroebe and Schut, 2021).

Family Sense of Coherence provides an additional theoretical foundation for family-focused support (Antonovsky and Sourani, 1988) and has informed a family support intervention in the context of life-limiting illness (Duke *et al.*, 2020). Rather than focusing on distress (ill health), Family Sense of Coherence is concerned with family strengths, resilience and meaning. In the context of bereavement, it is influenced by the comprehensibility, manageability and meaningfulness of the death. Combined, Family Sense of Coherence theory and the focus offered in the family level extension to the Dual Process Model, provided a theoretical framework to guide family orientated bereavement support.

The Families and Friends in Bereavement intervention was developed to encourage users to consider their bereavement experience in the context of family, friends and close social networks, to promote communication and meaning-making, fostering coherence and resilience (McKnight, 2015). Web-based interventions are known to provide effective and accessible psychological support (Cowpertwait & Clarke, 2013; Knowles et al., 2017; Stroebe et al., 2008); and they have the advantage of enabling users to access support when needed, increasing the potential effectiveness of bereavement support (Hewison et al., 2020). Furthermore, recent evidence has highlighted the need for a family centered and online approach for bereavement support (Harrop et al., 2020).

This paper provides a detailed description of the stages of development of the Families and Friends in Bereavement intervention including piloting.

**Aims**

The aims of the study were to :

1. Co-produce a web-based intervention with patient and public contributors (PPI) and bereavement professionals, theoretically informed by the family level extension Dual Process Model and Family Sense of Coherence.
2. Pilot the intervention and gain user feedback to inform refinements.
3. Evaluate the intervention capturing users’ experiences of accessibility, acceptability, usability and utility in readiness for adoption and implementation.

Findings from the evaluation (aim 3) will be published in a forthcoming paper.

**Methods**

**Study design**

Our approach to intervention-development was underpinned by co-production and theoretically informed by Family Sense of Coherence (Antonovsky & Sourani, 1988) and the family-level extension to the Dual Process Model (Stroebe & Schut, 2015) which were used to develop the family-focused intervention. The co-production approach (Grindell et al., 2022) developed partnerships between the research team, people with real world experience of bereavement, and community and national stakeholders. Involving people with lived experience of this specific context, leveraging their knowledge, experience and insights, to enable a deep understanding of the challenges they face; and encouraging the uptake of outputs was used to help ensure “contextual fit” (Goodyear-Smith et al., 2015) and findings that have relevance to end users of the web-resource.

The study received endorsement and support from the National Bereavement Alliance (the largest UK umbrella bereavement organization with over 80 member organizations). In consultation with people with lived experience of bereavement (personal and/or professional) and in line with UK palliative and end of life care policy (National Palliative and End of Life Care partnership, 2021), we defined family as relatives, friends, neighbors or anyone important to the bereaved.

This was a mixed methods study. Firstly, we explored in-depth the underpinning theories (Family Sense of Coherence and the family level extension to the Dual Process Model). Secondly, we carried out scoping work of the COVID-19 family-focused bereavement literature published between January 2020 and March 2021. This was specifically to identify and understand key elements of family bereavement support. Thirdly, findings from the scoping work and our theoretical framework were used to inform an online survey to gather data on personal and/or professional experiences of bereavement during the pandemic. Fourthly, the survey findings were taken to an online co-production workshop attended by members of the public with experience of bereavement and bereavement professionals working in hospice bereavement services, frontline and umbrella charities, to co-produce key content for the web-based intervention. Data gathered from the workshop discussion was used by the research team, in collaboration with an expert web designer, to produce and launch the intervention. Fifthly, users of the intervention were invited to provide feedback via a short survey embedded within a web-page of the intervention. Lastly, this feedback informed refinements to the intervention.

The process of intervention development (illustrated in Figure 1) is described below using the GUIDance for rEporting intervention Development studies in health research (GUIDED) (Duncan et al., 2020). Whilst GUIDED recommends use of the Template for Intervention Description and Replication (TiDieR) checklist (Hoffmann et al., 2014) the open accessibility and flexibility of an online intervention precluded specifying the who, how, when, how much, and where of use, therefore this checklist was not used.

**Figure 1: Study process and timeline**

insert figure 1

**Intervention development phases**

***Theoretical framework***

Family support is key to managing bereavement and in our previous work we drew on Family Sense of Coherence as a theoretical lens to facilitate family-focused support (Duke et al., 2020). Sense of coherence refers to the extent to which individuals perceive their world as meaningful, comprehensible and manageable (Antonovsky & Sourani, 1988). Antonovsky and Sourani advanced sense of coherence by applying the concept to families, demonstrating that successful coping with family stressors is associated with adaptation within the family and wider community networks.

For the purpose of the intervention development, we applied the three Family Sense of Coherence constructs to bereavement: defining meaning as wanting to respond and create meaning as a family, comprehensibility as the ability to understand and make sense, and manageability as the ability to utilize available resources to respond to the bereavement (Figure 2).

**Figure 2: Family Sense of Coherence (applied to bereavement)**

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Stroebe and Schut (2015) expansion of their seminal theory of bereavement to include the collective family response (family level extension to the Dual Process Model) explains family level tasks both loss and restoration focused that relate to adjustment of the family as a whole as well as its individual members. For families to attend to these tasks, adaptation to these at both an individual and family level is required.

Together the models comprehensively describe the processes required as a family, in both attending to the bereavement and the consequences of the death, in order to make sense, create meaning and utilize available resources to adapt to the loss (Figure 3).

**Figure 3: The theories combined**

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Combined, Family Sense of Coherence and the family level extension to the Dual Process Model, were used to create a robust theoretical framework to guide family orientated bereavement support.

***Scoping work***

To identify and understand key elements of family bereavement support during COVID-19 we scoped the emerging evidence. This was underpinned by the question: what is known about family experiences of bereavement during the COVID-19 pandemic?

Searches were carried out in MEDLINE (EBSCO) CINAHL, Web of Science and PsycINFO using search terms related to “family bereavement” “grief” “loss” and “social support, “coping” and “resilience”. Searches were carried out in March-April 2021 (of literature published between January 2020 to March 2021) and it provided an initial indication of family experience prior to the proliferation of publications regarding bereavement during COVID-19.

From the limited evidence available at this time on bereavement during COVID-19 papers explored the nature of family experiences and support needs.

**Table 1: Experiences and support needs from the scoped literature**

|  |  |
| --- | --- |
| **Experiences** | **Support needs**  |
| Papers reported guilt and anger experienced by individuals at not being able to bear witness and the disruption to usual death rituals as a result of social restrictions applied during the pandemic, (Fernández & González-González, 2022; Hanna et al., 2021; Moore et al., 2020; Pearce et al., 2021) and a universal experience of uncertainty was expressed (Hanna et al., 2021). Some individuals described a detached experience, a sense of disbelief, and felt unable to grasp the reality of the death (Borghi & Menichetti, 2021; Fernández & González-González, 2022). Isolation during the lockdowns led to some feeling that the pandemic had “killed two times over” (Fernández & González-González, 2022; Pearce et al., 2021). First, enforced separations of people from their families before the death, and then secondly by the isolation resulting from the death itself. However, one paper reported benefits for some of the isolation as a result of social restrictions which allowed increased time to grieve independently from others and process the loss (Borghi & Menichetti, 2021). The challenge for families of having to break bad news to other relatives was reported but this could also facilitate breaking the silence and start the process of developing meaning following the death (Borghi & Menichetti, 2021). Furthermore, the need to support other family members in a practical sense required individuals to draw on internal resources and offered a distraction and a sense of purpose (Borghi & Menichetti, 2021). Two papers described how services responded to the pandemic restrictions by adapting their practice and enhanced use of technologies to provide support for families and communicate with them in novel ways (Fox et al., 2021; Pearce et al., 2021).  | Papers described the empathetic response of services including widening of access, willingness to adapt (Borghi & Menichetti, 2021; Fernández & González-González, 2022; Fox et al., 2021; Moore et al., 2020), and developing creative use of technology to provide support (Borghi & Menichetti, 2021; Fernández & González-González, 2022; Fox et al., 2021; Moore et al., 2020; Pearce et al., 2021). Communication from professionals to families was considered essential (Hanna et al., 2021; Moore et al., 2020). In particular, communication that was empathetic and provided clear and consistent information was valued (Hanna et al., 2021). Misinformation or mixed messages regarding public health or safety information contributed to family distress (Moore et al., 2020). |

***Online survey***

The online survey was informed by the scoping work and focused on experiences of people who had been bereaved and the theories we applied. Survey items addressed family experiences of bereavement during COVID-19; views on supporting family bereavement via a web-based intervention and collected demographic data from respondents (see Table 2 for key questions, responses were unlimited free text).

The online survey was piloted via distribution to seven patient and public contributors (PPI) and two bereavement organizations in February 2021. Three PPI contributors and one representative of a bereavement organization responded (n=4). Changes to language and terminology to improve clarity were made following these pilot responses.

**Table 2: Key survey questions**

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| --- | --- |
| **Experiences** | **Question underpinned by:** |
| It is recognized that bereavement is a stressful life event and families and family members may react in different ways. Family tasks in bereavement have been described as including sharing experiences of grief; caring and supporting each other; and sharing memories but this will not be the case for all families. Please tell us if these examples reflect your experience, either as a bereaved person or bereavement professional. If you have different examples, please also tell us about these.  | Family level extension to the Dual Process Model |
| We know that bereavement is influenced by factors such as witnessing good care for a dying family member, being able to provide comfort, being present with the dying person and with those important to us and the dying person and by marking their death with others in funerals and other social gatherings. From your experience, what has been the impact of the COVID-19 pandemic on bereavement?  | Scoping work |
| Has the pandemic offered any opportunities to express grief or support for the bereaved in alternative ways? | Scoping work |
| From your experience, are there things that helped your family / help families make sense of a bereavement? | Family Sense of Coherence – Meaning + Comprehensibility |
| From your experience, are there things that helped your family / help families manage a bereavement? | Family Sense of Coherence - Manageability |
| From your experience, how do you think the ongoing COVID-19 social restrictions have impacted bereavement in a family context (positive or negative)? | Scoping work |
| **Developing a web (online) resource to support family bereavement** |
| From your experience, what do you think about providing family bereavement support via a web (online) resource? |
| When developing a resource to support family bereavement what kinds of things would be helpful regarding content and format? (e.g. an information page on grief and how it should be presented) |
| How could the resource encourage a family/social/collective response to bereavement? |
| How could the resource help ease the social isolation imposed by COVID-19 or that can be experienced at other times? |
| Please tell us if you have any experience of web (online) bereavement support resources. If so, please provide examples and say what did you liked and what you did not like about them? |
| In your experience what would encourage you to use a web (online) resource? e.g. colors, images, being interactive |
| Please use the box below to tell us about anything else you think is important to consider when developing the web (online) resource. |

The survey was distributed via the National Bereavement Alliance; Hospice UK; a large patient and public involvement network; and social media. It ran for three months between April and July 2021 using Microsoft Forms.

Thirty-two responses were received with an average completion time of 32 minutes. Thirteen completed the survey from a professional perspective, 12 from a professional and personal perspective, and the remaining seven from a personal perspective. Respondents who were bereavement professionals (those with professional experience), or those with both professional and personal experience reported working in health care, including hospices (n=19); third sector (n=4) and other (n=4) which included private and digital technology sectors. One respondent did not provide details. They worked in a range of roles, with varying levels of seniority and length of experience. Demographic information for bereaved respondents (those with personal experience, or those with both personal and professional experience) is provided in Table 3.

**Table 3: Characteristics of bereaved survey respondents**

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| --- |
| **About you – if you have been bereaved** (if you are completing the survey based on personal experiences n=19) |
| **Age**  |  |
| 40-49 | 1 |
| 50-59 | 7 |
| 60-69 | 7 |
| 70-79 | 3 |
| 80+ | 1 |
| **Sex** |  |
| Female | 18 |
| Male | 1 |
| **Relationship to the person who died** (\*1 missing response, total greater than 18 as includes multiple bereavements) |  |
| Daughter/son  | 6 |
| Spouse/partner  | 4 |
| Sibling  | 2 |
| Friend  | 3 |
| Parent  | 2 |
| Aunt/uncle  | 1 |
| Niece/nephew  | 1 |
| Daughter/son  | 6 |
| Spouse/partner  | 4 |
| **What was your bereavement the result of?** |  |
| COVID-19  | 1 |
| Other injury, condition or illness  | 16 |
| Both (COVD-19 and other illness/condition/injury) | 2 |
| **How long have you been bereaved?**  |  |
| 1-6 months | 7 |
| 7-12 months | 3 |
| 1-2 years | 4 |
| 2 years + (other bereavements prior to COVID-19) | 5 |

***Data analysis***

Survey results were analyzed using Framework Analysis (Ritchie et al., 1994) by NC, SL, MM following the five stages of data familiarization, framework identification, indexing, charting, and mapping and interpretation, and generated key themes outlined below.

**Results**

Findings demonstrated that family tasks in bereavement included managing practicalities around the death including organizing the funeral and sorting the estate, living with the loss and learning to adapt, and acknowledging that family members experience and move through grief in different ways utilizing a variety of coping strategies.

*…Family tasks have been interrupted due to COVID - for example not being able to meet to care and support each other, to talk about the loved one, to go through possessions and keep sakes, to sort out the affairs of the loved ones etc. - this has all been difficult due to family members not being able to mix, to go indoors etc. It was also hard at the funeral having to be socially distanced and not able to talk with and hug family members. At the same time, it was amazing we had over 1000 people watch the live streamed/recorded funeral service for my dad… (Participant 08, personal and professional)*

*…I found that my siblings and myself all had different grief stages and experiences when our parents died (Dad then Mum a few months later), and we did not really support each other as we were at different stages. We also had different ways of coping and this caused issues (i.e. drinking heavily)… (Participant 17, personal)*

COVID-19 impacted bereavement in a number of ways. For example, feelings of guilt, an inability to bear witness, putting grief on hold as a result of the imposed lockdowns, and the impact of media reporting of daily death tolls led to feelings of their loss being seen ‘as just a number’. Isolation resulting from social restrictions resulted in lack of control and choice over mourning including an inability to share collective memories and undertake cultural rituals and rites of passage usually enacted by a death.

*…Instances where the family have not been able to be present have caused increases in distress and have factored into the complexity of feelings that must be managed in grief. Bereaved people being more often alone and isolated also adds more space for rumination. Having said this, I think many bereaved families have created support bubbles, moved in together, or just elected to ignore some restrictions for the greater good of caring for one another. Frequent phone calls and virtual meetings have also been prevalent… (Participant 05, professional)*

*…Due to rapid deterioration often experienced, these [COVID] deaths have not been good and are not seen as good deaths at the time as people close to the patient don't have time to process what's happening. The restrictions on funeral numbers have been particularly challenging especially for some cultures who would normally have had large gatherings as a result of death… (Participant 06, professional)*

*…For some it has a negative impact due to limited support networks and opportunities for meaningful activity as a distraction etc., but for others there can have a positive impact as pace of life has slowed down, people are at home more, etc… (Participant 18, professional)*

*…I feel that I wasn't able to give him the celebration in life he deserved in the final weeks as friends and family could not visit. I do not feel that I was able to give him the funeral he deserved because of restrictions in numbers. Everyday there was a change in government restrictions. The three weeks in planning were a nightmare. I was able to have a pretty pathetic excuse for a Wake. I feel I failed him, but my friends and family say I did all I could under the restrictions… (Participant 21, personal)*

*…We are left with thinking we 'should' have another remembrance event, with an expectation from people who couldn't be there, but this just feels stressful. Had we had a 'normal' funeral, then this would be over, and no one would expect another event.
My friends didn't visit me in a way that I suspect they would have done pre pandemic. I received lots of text/WhatsApp messages, but few people actually picked up the phone and called me which I really wanted. I felt very isolated and as if it had to be me that contacted people, but I just couldn't… (Participant 22, personal)*

*…Humans are social, we grieve together, and our grief is healed by being with others who understand. Despite restrictions being all but gone, people are still out of step with seeing each other. Their support networks have shrunk… (Participant 31, professional)*

Survey analysis confirmed findings from the scoping review that the pandemic presented opportunities to express grief and support the bereaved in different ways. Technology was utilized in novel and diverse ways both by professionals and the bereaved to enable social connections and facilitate support, this included online streaming of funerals and increased use of digital platforms. For some the social restrictions were viewed positively, such as smaller scale funerals and protected time to grieve.

*…Live streaming the funeral - it gave the opportunity for many more people to attend than we would ever of (sic) had in person. We also have a recording of the service as a memory and have looked back at it on several occasions… (Participant 08, personal and professional)*

*…I think it has given people space and an "excuse" to not be sociable - and take more time in their grief. I think for most, the pandemic has shown them who is really important and who is really there for them… (Participant 12, professional)*

*…Virtual meeting has meant that miles are no object in being able to have conversations with support people (friends and family). It's not the same as meeting in person, but there are some people I couldn't have had contact with otherwise… (Participant 28, personal)*

Respondents identified factors that helped make sense of and manage bereavement. Having information and guidance about the practical tasks that needed to be taken following a death was felt to be essential. Information on the emotional impact of grief, how it can affect families and the diversity and commonality of experience was equally necessary. Being able to relocate the person who had died within the family context and ensure an ongoing bond was considered important in helping to adapt to the loss. The ability to draw on support networks, share stories to help make sense of the death, and having time to reflect as well as legacy projects to remember and honor the dead were also valued.

*…Mostly support from other members of the family and people who shared memories and good times with the departed, talking about the condition and how we were or were not able to intervene and make a difference for our loved one… (Participant 32, personal and professional)*

The idea of a web-based intervention was positively viewed and acknowledged as a means to widen access. However, it was recognized that this was reliant on possessing some level of IT literacy. To ensure accessibility respondents desired ease of navigation, and succinct information utilizing varied media (images and music). Regarding content, information on the experience and range of manifestations of grief, signposting to other organizations and support, and information on how to support one another were deemed important. Respondents thought, for the intervention to facilitate a family response to grief, it should include questions and prompts for conversations and activities for capturing and sharing memories and feelings. Respondents offered suggestions for encouraging use of the intervention, these included images, use of colors, and avoidance of clichés. Essentially the intervention should be simple, straightforward and honest, relatable, and clear in what it adds and how it differs from existing resources.

*…It would be helpful to have sections on emotional support - what kind of things people need and how to get them, links to relevant organizations, and practical support on how to face tackling the things you have to do because the person has died. Also, some ideas, both for the bereaved person and those supporting them of things they might be able to do to help them feel a bit better. For example, a friend gave me a bag of 'crap day' presents, so if I was having a particularly awful day, I could open one. I've done that for other friends since, and it was something I really valued as it reminded me that my friend was supporting me even at the worst times. Other ideas of activities that allow people to talk about their loved one without feeling awkward would be helpful… (Participant 28, personal)*

***Co-production workshop***

Participants were sought through respondents to the survey (who were asked to indicate their interest in the workshop), social media e.g., Twitter, patient and public involvement networks, professional bereavement organizations, and carers’ organizations. Twelve individuals expressed an interest to participate, eight were able to attend on the date set, with five attending on the day (one was unwell, one had technical issues and one had unanticipated work pressures on the day).

The two-hour online workshop (via Microsoft Teams) was held in September 2021. Of the five participants, one was a person with lived experience, one was representative of a carers’ organization, two were from hospice bereavement services (one professional and one volunteer) and was one from a bereavement organization. The workshop was facilitated by the research team, and in response to the survey findings that highlighted the importance of creative activities, an artist and musician contributed to the intervention content.

The aim of the workshop was to co- produce the content of the intervention. To do so the research team provided an overview of the study, presented findings from the survey, and discussed potential content including family ‘activities’ to stimulate family interactions and communication describing how these linked to the study’s theoretical underpinnings. It was explained that the survey had endorsed the following content: a landing page – what the web-resource is about (the unique selling point of the resource); about grief – outlining the range of experience; dealing with practicalities; what to say (or not); and links to other sources of information and advice (for specific types of bereavement). However, the focus of the co-production discussion was on the theoretical underpinning of the intervention (and why this helps to support family bereavement), views on a reflective zone consisting of music and art, and family ‘activities’ to aid support.

An outline of the underpinning theories (as in the theoretical framework above) was presented and participants endorsed the value of the theories and their understanding of them in relation to family bereavement. They wanted the theoretical underpinning to be available on the intervention site to show users the robust foundations of the intervention, as well as the links between the family ‘activities’ and theory. Workshop participants supported the value of art (and music) in aiding ‘time out’ from considering bereavement, rather than necessarily aiding reflection. For some the images and music encouraged a sense of calm and mindfulness. Nonetheless, it was recognized that art preferences are individual and therefore there was support for maximizing options such as the ability to look at different visual images, with or without music.

The mainstay of the discussion revolved around potential family ‘activities’ of which three (mapping family networks, creating a family repository of memories, and questions to support families to talk together) were presented to the participants. For each activity the participants were asked to consider whether it made sense to them, if they could see it working with families and others to facilitate communication, and finally what changes they would suggest.

1. *Mapping family networks (Family Sense of Coherence –* ***Manageability****)*

Participants supported asking intervention users to consider who is in their family network, then using this to identify the strengths and coping strategies of those identified, including the benefits of each relationship, and what effect the bereavement has had on each member of the network. Participants suggested completed exemplars of family maps would be useful and that one exemplar should be for an individual with limited family (i.e. representing the diversity of family and social networks such as neighbors/friends not just kin).

*…Family mapping might be quite useful to encourage people to think, oh yes, I can see how I could put members of my family on a piece of paper and I can see how it works…, by just putting one or two little examples. And I think I personally would feel confident enough to continue and do the task if I had that…. (Hospice bereavement service provider – volunteer)*

*…If several family members actually drew this map separately and then sort of brought them together… You could have a think about it and see how similar or different they were and that might help people to understand that each person’s family maps are different even though they're in the same group….” (Hospice bereavement service provider – professional)*

1. *Creating a family repository of memories (Family Sense of Coherence –* ***Meaning****)*

The workshop participants felt that encouraging families to create collections of memories and stories was important. With the increasing use of and familiarization with technology during the pandemic, there was recognition that this did not need to be a physical collection. Instead, digital memorialization such as legacy walls were viewed as a sharing innovation developed through COVID-19 which could be shared with distant family members in other countries.

*…Encouraging each individual to supply something that they feel is important to remember the person...” (Hospice bereavement service provider – volunteer)*

*“…Whether it's a physical or a digital thing… if families are overseas for example, or the things that people want to keep are of a particular nature that might make it easier for them to be digitized for sharing… I do think that there's a place for both of those things... (Hospice bereavement service provider – professional)*

1. *Questions to help families talk together (Family Sense of Coherence –* ***Meaning****,* ***Comprehensibility*** *and* ***Manageability****)*

The questions in Table 4 were taken to the workshop as suggestions linked to the theoretical constructs of Family Sense of Coherence to aid family coping via creating meaning, sense making, and the management of resources. The person with lived experience, and representative of a carers’ organization liked the questions but suggested some shortening of wording and refinements to more everyday language.

**Table 4: Questions to help families and friends talk together (linked to the Family Sense of Coherence constructs)**

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| --- |
| **Meaning** |
| What did they mean to you? |
| What do you miss most about them? Is there anything you won’t miss? |
| What will you always remember? |
| What are you finding hardest? Is there anything that helps with this? |
| How has the bereavement led to relationship changes - within the family or between some family members? |
| If they were sitting next to you, what would you want to say to them? Is there anything you wished you had or had not said? |
| **Sense making (Comprehensibility)** |
| Have you talked about the death itself? What went well or not so well? If you haven’t talked, is there a reason for this? |
| Have you talked to any health and care workers involved? Has anyone in the family had any feedback that has helped to make sense of things? |
| **Manageability** |
| How can you help each other? What are the different strengths of family members that could be used now? Have you noticed people taking on new or changed roles? What other sources of support could you draw on as a family? |
| Are you keeping to usual family routines, or have you created new ones? |
| How do you want others in the family to relate to you? |

Bereavement service participants also liked the questions as prompts to start and encourage families to talk together.

*…I liked the prompts. The questions that you asked or suggested for families to think about, and I particularly like the fact that you've included some balance in there. You know that actually acknowledgement that there may be things that you won't miss and there might be things that you wish had been different and that might vary between family members… that actually sometimes there is a sense of relief when someone dies, particularly if they've suffered, or if the relationships been very difficult, perhaps towards the end or long term, and it's something that often people feel very guilty for admitting that they feel anything but sadness… So relief, maybe even anger… We know that those are normal parts of grieving, and I wonder if perhaps some questions that just give permission for people to speak about those feelings that they feel a little bit taboo… (Hospice bereavement service provider – professional)*

It was suggested that using prompts to explore secondary losses as a result of the bereavement would be of value too:

*…Secondary losses that you might have as a result, you might want to explore that a little bit. So if there's been an additional loss because that person has died, so perhaps somebody has had to move house or they've had to move the communities. They're not just losing their loved one... (Bereavement organization participant)*

Following the workshop, the research team further developed the content of the respective webpages and their format/appearance (addressing all the suggestions highlighted above) based on Framework Analysis of the workshop transcript. The expert web designer then implemented these, followed by a cycle of amendments. The web-based intervention was then launched to coincide with National Grief Awareness Week (2-8 December 2021) following an invitation from the National Bereavement Alliance to publicize and demonstrate the intervention at their monthly webinar the previous week.

***Feedback phase***

Feedback on the intervention was invited through a dedicated page on the pilot website. Respondents were asked to complete a questionnaire via Microsoft Forms between December 2021 and January 2022. A total of 13 anonymous responses were returned. Bereavements were reported as resulting from COVID-19 (n=1); COVID-19 alongside other illness (n=2), other illnesses (n=8) and two did not provide details of the cause of death. Bereavement related to both family members and friends. A further nine respondents (six professionals, two bereaved and one bereaved professional) contacted the research team via email rather than completing the feedback form.

Additional feedback was provided from 18 participants when the intervention was presented at a national bereavement webinar. Comments were positive and constructive, and those supporting the bereaved highlighted the family activities as being something they would use with clients.

Questions related to accessibility, acceptability, usability and perceived benefits of the resource. A summary of key responses is provided below in Table 5.

**Table 5: Summary of feedback from pilot website**

|  |  |  |
| --- | --- | --- |
|  | **Positive comments** | **Suggestions for further consideration** |
| Accessibility | The resource is easy to use, and no new skills are required to use the resource | The ‘Evidence Used’ page would be better situated towards the end of the resource rather than at the beginning.*“…I think the 'Evidence' section could be made a bit clearer…”* (Bereaved person) |
|  | Some of the website content is too dense, risks information overload and language is too academic in places. *“…Pages are very wordy. It would be better to have sub sections to be less overwhelmed by blocks of text…”* (Bereaved person) |
| Acceptability | The ‘Dealing with practicalities’ page is helpful |  |
| The ‘Space to pause’ page is novel but need to recognize may not be to everyone’s liking. | A warning needs to be included regarding accessing this page in a public space due to it containing sound |
| Colors are appropriate, calming and inviting. | Use of graphics and bullet points would help to break up dense text. |
| Resource is accessible and can be used flexibly by the user.  | Further contacts page is helpful but further suggestions of additional organizations to include were offered. |
| ‘Family activities’ page is novel and helpful, although may not be something all users might embrace.*“…I liked the look of the exercises. I am glad that you provided some examples. That makes it feel very achievable to complete the task..*.” (Bereavement professional)*“…We had circled around some of the ideas previously, but this was helpful to focus our thoughts and energies…”* (Bereaved person) | Include information about pre bereavement and suggestions for how to start a conversation with others*“…In my experience it is the person who has the direct connection who often needs the most support. They are not open to talking about their grief in the first place, so it would be nice to have more on starting a conversation…”* (Bereaved person) |
| Usability | Navigating the resource is largely straightforward and simple to do.*“…I really, really like it and wish that more websites followed your example. It is utterly straightforward and the common top bar for all pages makes navigating the site refreshingly simple…”* (Bereaved person) | Page headings require clearer description  |
| Benefits | Resource is helpful for providing support for both new and previous bereavements.*“…I will be talking about the resource with others. I think that if people are aware of the resource from when the death occurs, they can access it at a point which is right for them… I think it is helpful in relation to previous bereavements…”* (Bereaved person/ bereavement professional) |  |

***Refinement of the web-based intervention***

Following analysis of the feedback, the first cycle of iterative changes was undertaken. Webpages were condensed, so that a separate page on ‘*how to support each other’* was removed, with the information incorporated into the ‘*about grief’* page. The standalone ‘*activities to support grief’* page was added to the ‘*home’* page, to emphasize the intervention’s unique focus and content. A new page was inserted called ‘*bereavement during COVID’* which drew on the survey findings to outline personal experiences of bereavement during the pandemic (including the positive developments that occurred). Text refinements were made to all webpages to break-up sections of text using images and edited for succinctness. In terms of appearance the font size across the site was increased to enhance readability.

**Discussion**

This paper reports on a study to co-produce a theoretically informed web-based intervention to support family and friends’ bereavement. The intervention was developed during COVID-19 as a resource to bridge an existing gap in bereavement support that became apparent during the social restrictions at the time. Our findings showed that the pandemic impacted bereavement in a variety of ways. Participants felt unable to prepare for the death of the person because of enforced separations, guilt at being unable to bear witness, or participate in goodbye rituals. There was a sense of disbelief and for some disconnection to the extent it was like “the person [who] was like the glue in the cracked pot was no longer there”(Participant 15, personal and professional). The disruption to these inherently important customs resulted in a loss of agency (Vieveen et al., 2023) and powerlessness for families and friends who were prevented from participating in the care of their relative or being present as end of life approached. This combined with a lack of connectedness with usual support networks resulted in disruption to the meaning-making process to enable families and friends to understand and make sense of the death. Meaning-making has been shown to be essential to bereavement in terms of wellbeing, resilience and emotionally adjusting to the loss (Barboza et al., 2022; Breen et al., 2019; Cardoso et al., 2020). Being able to attribute meaning to a death also enables the bereaved to reconstruct bonds with the deceased (Rothaupt & Becker, 2007) and begin to move forward with their lives following an unwanted and unexpected life transition (Fuchs, 2018; Shear, 2012).

The COVID-19 pandemic prevented many families and friends from accessing and assimilating the ‘active ingredients’ of meaning-making and threatened their capacity to experience the meaning of a death (Derkx et al., 2020). Findings from our study demonstrated the importance placed on the exchange of experiences with others within their social network and highlighted the need to discuss feelings and emotions in order to make sense of the death, regain a level of control in their lives, and “hold on to things differently” (Vieveen et al., 2023). They also highlighted the use of technology to enable social connections and facilitate support online at a time when this was prohibited face to face. It is in response to these insights that the Families and Friends in Bereavement intervention was co-produced. However, while the web-resource was developed during COVID-19 the content is designed to ensure ongoing relevance and legacy beyond this specific context.

The intervention is novel in shifting the professional gaze of bereavement to one that strengthens a social response to grief through family, friends and social networks. While every bereavement is experienced individually the intervention promotes ways to understand, make meaning and manage the bereavement collectively. While family relationships can add complexity to meaning-making in the grief process, they have also been shown to provide an invaluable resource for dealing with it (Kissane et al., 2008). Activities offered within the intervention stimulate social interactions and encourage communication to enable users to consider the strengths of their network and how reciprocal support may be realized. In doing so, the loss of agency experienced during the death of the person can be re-gained as the web-resource offers a mechanism for agency in the bereavement process through flexibility in how it can be used and engaged with.

Feedback obtained during intervention development and piloting has indicated that it is accessible, acceptable, usable and importantly has value and benefit. We are now undertaking a qualitative evaluation utilizing semi-structured interviews and focus groups. Evaluation data will inform a second cycle of refinements to develop the final version of the intervention, including metrics on the use of the resource, in readiness for adoption and implementation.

**Strengths and limitations**

An important strength of this study is the combined use of the two underpinning theories, Family Sense of Coherence (Antonovsky & Sourani, 1988) and the family level extension to the Dual Process Model (Stroebe & Schut, 2015) which have provided a robust framework for data collection, analysis and intervention development. The explicit use of the two theories identified key constructs and mechanisms to guide our focus and informed the content of the intervention. A further strength is the use of co-production to develop the intervention. We approached the study from the position that those who are affected by the research and potential users of its outputs have experiences and knowledge that can offer invaluable insights to inform understanding. By drawing on the views and experiences of those who are bereaved, and bereavement professionals who support them, has ensured the intervention has relevance and utility for those it seeks to support. As with all studies there are limitations. It might be argued that the scoping work undertaken was partial. At the time we reviewed the literature, the evidence base on bereavement experience and support needs during COVID-19 was emerging and the plethora of papers which have been published since were not available to us at the time the intervention was under initial development. We recognize that this may be considered a potential limitation but would argue it does not compromise the robustness of the resource due to it being theoretically informed and grounded in real world experience. In addition, literature that has been published subsequently concurs with our findings (Burrell & Selman, 2022; Mayland et al., 2020; Selman et al., 2022; Selman et al., 2021; Torrens-Burton et al., 2022).

**Conclusion**

Families, friends and support networks are essential to managing bereavement. COVID-19 social restrictions prevented families and friends from being with the dying and participating in usual rituals to honor the dead. This resulted in social disconnection, feelings of guilt, and difficulty in making sense of the death and reconstructing relationships. The Families and Friends in Bereavement intervention was developed during the pandemic with the aim of promoting communication and meaning-making, fostering coherence and resilience. However, while designed during COVID-19 the content has continuing relevance beyond this context. We have provided a platform (with family-focused tools) to process the death and family narrative, and begin to make sense of what has happened, and reconstruct bonds and adjust to altered family roles and structure. The web-resource provides a framework to promote meaning-making, comprehensibility and manageability, therefore providing a mechanism to rebuild, reconfigure and begin to glue back the pieces of the cracked family pot.

**Ethical considerations**

The study was approved via the Faculty Research Ethics Committee at the University of Southampton (Ethics/ERGO number: 63208). At the start of both the online survey and feedback form on the pilot website respondents had to indicate that they had read and understood the study information sheet, were 18 or over and agreed to take part. Full written consent was obtained for participation in the co-production workshop.

**Data availability**

*Underlying data*

Study participants consented only to their data being used for the sole purpose of this study and not to sharing for secondary analysis purposes. Data not available.

*Extended data*

The questionnaire for the online survey is available at [DOI 10.17605/OSF.IO/WAVR7](https://osf.io/wavr7%20DOI%C2%A010.17605/OSF.IO/WAVR7)

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