

Supporting people bereaved during COVID-19: Study Report 1

Preliminary results from a survey of people bereaved in the UK during the pandemic

Background

Supporting people bereaved during COVID-19 is a mixed methods national study of bereaved people's experiences and the bereavement services supporting them. People bereaved during the COVID-19 crisis face significant challenges that shape their experiences of grief. We are conducting a survey to understand and give voice to the experiences of people bereaved in the UK of any cause since 16th March 2020. This report presents the interim findings from the first 532 respondents to the [survey](#), which remains open until 31 December 2020.

Who has responded so far?

Total sample size: 532

- **Person who died:** My father (31%); My mother (29%); My husband or male partner (18%); My grandparent (9%); My son/daughter (3%); My sibling (3%); My wife/female partner (2%); Other (18%). 14% had lost more than one person
- **Place of death:** Hospital (55%), In their home (22%), In a care home (15%), In a hospice (5%)
- **Cause of death:** Confirmed or suspected Covid-19 (46%, see table for breakdown)
- **Time since death:** Median=5 months (Range: 2 days to 7 months 6 days)
- **Age:** mean = 48.3 years (median=49 years, Range = 18 to 88)
- **Gender*:** 91% female, 8% male, 1% other/prefer not to say
- **Ethnicity*:** 17 participants (3%) from minority ethnic backgrounds

Cause of death:	n	%
Confirmed COVID-19	213	40
Suspected COVID-19	32	6
Cancer	105	20
Other (e.g. other long term conditions, heart attacks, old age, accidents)	174	33
Don't know	7	1

*For this research to be representative of the population, we encourage men and people from minority ethnic backgrounds to participate in the [survey](#), so we can understand their experiences and possible needs for bereavement support.

Death and mourning experiences

Experiences of care provided at the end of life

Using combinations of open and closed questions, participants were asked to describe their experiences at the end of life and following the death of their loved ones. In their comments, people described communication problems with healthcare providers, such as difficulty getting information about their loved one, misinformation concerning the patient's condition and hospital policies, perceived insensitivity and a lack of involvement in care or treatment decisions.

These concerns are reflected in the statistics below (note: between 12% and 21% answered 'not relevant' to these questions e.g. because they were not next of kin, or no healthcare providers were involved):

- 23% of respondents said they were 'never' involved in decisions about the care of their loved one; 21% felt 'always' involved.
- 17% said they were not at all informed about the approaching death; 33% felt fully informed.
- 36% felt not at all supported by healthcare professionals immediately after the death; 26% felt very or fairly well supported.
- 45% were not contacted by the hospital or care provider after the death; 36% were contacted.
- 51% were not provided with any information about bereavement support.
- 21% were provided this information at the time of death; 15% during a follow up call.

*When the hospital wouldn't let me in with my dad from the ambulance, that is the last time I saw him. It was a Friday and we couldn't get to speak to anyone until the Tuesday. It was hard to get through, and once when I did the person just dropped into the conversation that dad had COVID-19. It was a shock. There was very little info. and no support and no contact.
(Bereaved daughter)*

The hospice was amazing; such a breath of fresh air compared to other parts of the system. The people were lovely and the rules around visiting were much more relaxed. I got to spend some special time with [my wife] in her last four days. (Bereaved husband)

Descriptions of more positive care experiences included a sense that staff were doing their best, showing compassion and kindness, flexible visiting arrangements and relatives feeling that they were kept well-informed about their loved one's condition and care. These experiences were often, but not always, associated with hospice or specialist palliative care involvement.

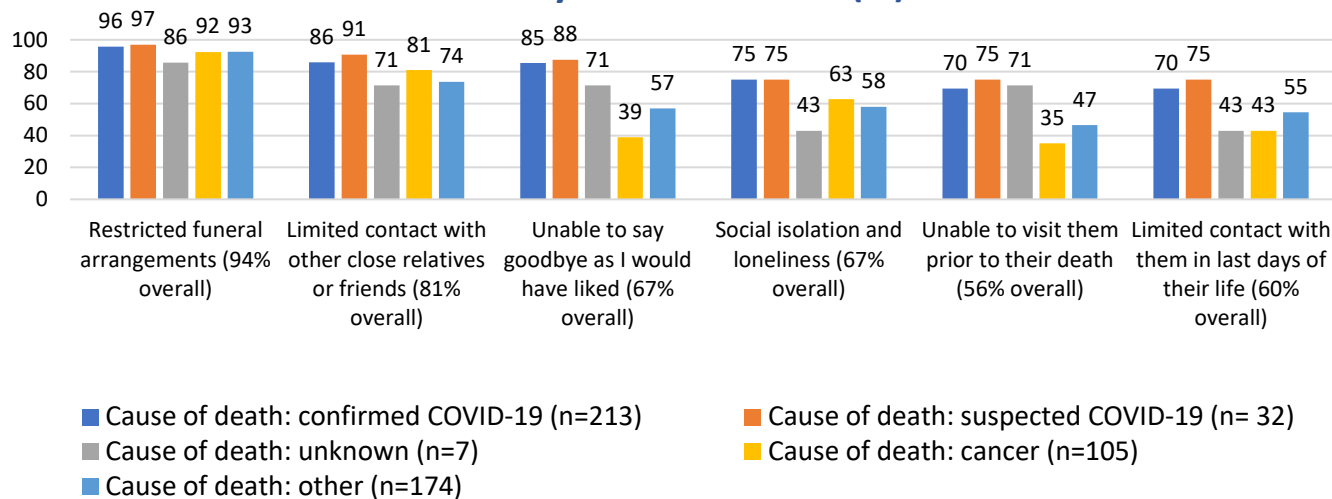
Pandemic-specific problems

The restrictions placed on family visiting in health and care settings, funerals and everyday social interaction affected almost all participants in some ways, with 51% experiencing 5 or 6 of the experiences in Figure 1.

COVID-19 deaths (confirmed or suspected) were significantly associated with higher levels of all of these problems (all $p < 0.05$), except for restricted funeral arrangements. For example, 70% of bereaved people whose loved one died of a confirmed COVID-19 infection had limited contact with them in the last days of

life compared with 43% of cancer deaths ($P < 0.001$); 85% were unable to say goodbye as they would have liked versus 39% for cancer deaths ($P < 0.001$); 75% experienced social isolation and loneliness versus 63% for cancer deaths ($P = 0.003$). Compared with hospice and home deaths, hospital and care home deaths were also significantly associated with higher levels of problems related to visiting relatives prior to death, contact in the last days of life and being unable to say goodbye as they would have liked (all $P < 0.001$).

Figure 1 End of life and bereavement experiences overall and by cause of death (%)



Participant comments further demonstrated the impacts that these experiences have on the grieving process, in terms of the distress caused by being unable to say good-bye and provide comfort to their dying loved one, and, for some, the trauma of witnessing the death remotely.

We basically listened to him die on the phone over five days, which was the most horrific experience for us and of course Dad. We can only hope that he knew we loved him and hadn't abandoned him in these last days.
(Bereaved daughter)

The consequences of funeral restrictions were also described. Being unable to host conventional services or wakes, share stories and celebrate the life of their loved ones was distressing at the time, and made it difficult to find closure and begin to grieve. People also commented on the further distress caused by having to travel to the crematorium alone, sit apart from other family members and, in some cases, return home to empty houses. Likewise, lockdown and social distancing restrictions during early bereavement disrupted the emotional support most needed from close family and friends, again affecting the grieving process.

I felt alone and isolated when she died, unable to grieve properly with my family. [I] met up with my family after her death, but felt it was against the 'rules', [the] funeral was small and [I] still feel we haven't properly said goodbye. So many of her friends often ask when we will be able to do a memorial service. [It] feels as though her life has gone and [she has] not been fully recognised for the person she was.
(Bereaved sister)

Support needs, vulnerability and resilience

Vulnerability and resilience were measured using the Adult Attitude to Grief Scale [1], and needs for practical, emotional and psycho-social support using a 5-point scale (from 'high' to 'no support needed'). Overall, participants demonstrated moderate to high levels of support needs and vulnerability in grief, with the following observations:

- Over half of participants demonstrated high or severe levels of overall vulnerability in grief (severe = 28%, high = 24%, low = 48%). 62% of participants reported high or fairly high needs for support with 'dealing with my feelings about the way my loved one died', and over 50% with 'expressing my feelings and feeling understood by others', 'feelings of anxiety and depression' and 'loneliness and social isolation'.
- More overwhelming grief ($P = 0.004$) and higher support needs ($P < 0.001$) were significantly associated with hospital deaths compared with other places of death. Including family members in decisions about the care of their loved ones slightly decreased family members' emotional support needs ($P < 0.001$) and their vulnerability in grief ($P = 0.003$) and was associated with slightly increased resilience ($P = 0.001$). Providing better support immediately after the death also slightly decreased family members' emotional support needs ($P < 0.001$) and was associated with slightly increased resilience ($P = 0.011$).
- COVID-19 deaths (confirmed or suspected) were also associated with slightly higher support needs ($P < 0.001$) and levels of vulnerability ($P < 0.05$) as compared to other deaths.

In their comments, people bereaved by COVID-19 described additional anxieties about catching or spreading the virus, distress caused by other people questioning its seriousness or not observing social distancing rules, and feelings of anger over the Government's handling of the pandemic. The need to share experiences with others who had been through the same was also reported, with many reflecting on the unique nature of being bereaved during the pandemic.

The world seems to have moved on, but I can't because Dad's not here, but the virus still is. I have huge levels of anxiety about being in the outside world, doing normal things, and guilt for trying to. Also, there is a lot of vitriol and unkindness around, with people saying it's a hoax, and that I should prove how Dad died. People are no longer social distancing and are demonstrating against masks.. (Bereaved daughter)

Support use and access to support

People reported using a range of formal and informal sources of support to help with their bereavement. 88% received support from friends and family, with 31% accessing support via online communities, which included chat forums and resources provided by bereavement organisations as well as specific COVID-19 Facebook support groups set up by the bereaved. 13% used telephone helplines and more than half (56%) had used more than one type of support. One in four participants were accessing more formal counselling, with most provided on an individual basis.

Participants described how counselling (via telephone or video call) enabled them to talk about and work through their feelings of loss and grief, develop coping strategies, whilst also helping with feelings of loneliness and isolation.

It has been very helpful thus far. It's a person centred approach, so the counsellor suggests strategies based on what I say. ...What's the most important thing is to be heard and listened to. (Bereaved daughter)

Benefits of on-line community groups such as chat forums and Facebook groups related to sharing experiences with others who have been through the same. They included feelings of empathy and being understood, comfort and reassurance and not feeling so alone in their grief and anger about the way that their loved ones died. Examples were given of friendships forged, advice given and resources shared, with some also accessing formal counselling via these groups.

Those from the Facebook group have made me feel less alone. They have offered advice from their own losses prior to mine. I have gained a friend of a similar age to me...It's been a relief to have found her as we are going through the same emotions during our day to day challenges. (Bereaved)

Barriers and difficulties accessing support

Friends and family:

Although most respondents received support from family and friends, 41% of participants had experienced some difficulties accessing this type of support. 26% said family or friends had not been able to support them the way they wanted and 20% felt uncomfortable asking for help or support from friends or family.

Participants described struggling without face-to-face contact and opportunities for physical comfort. They experienced difficulties sharing their feelings, and often felt that others didn't understand. Some felt that people have less time, empathy and support to give due to the ongoing pandemic.

Bereavement services:

59% of respondents had not tried to access support from a bereavement service. Of those people who had sought support, 56% experienced difficulties accessing these services.

Overall, 26% of respondents felt uncomfortable asking for support from bereavement services, whilst 13% reported not knowing how to get support from bereavement services.

In their comments, participants described limited availability and long waiting lists for bereavement support in some areas; feeling put off by remote support options; and a lack of information about where to get help. Some perceived a need for COVID-19 death-specific support, whilst others who lost loved ones to non-COVID illnesses described feeling less entitled to support.

COVID-19 lockdown has used up empathy normally available from friends, family. Also just normal social interactions had stopped so it felt unreal my father had died, there was no one to tell. It almost felt like an irrelevant secret because everyone was dealing with the lockdown. (Bereaved daughter)

I am thinking about contacting a bereavement service for some support and I might do it, but feel a bit nervous. I also feel that losing my Mum at 85 after a long and happy life, and she didn't die of COVID, I feel a bit of a fraud needing help, when other people are going through much more trauma than I am. (Bereaved daughter)

Everything is done via phone or some sort of media platform... When I couldn't even see my family because of isolation, and having just lost the person I most loved, the last thing I needed was to talk to an unknown faceless person at the end of a phone... [I] really need contact.. face to face. (Bereaved wife)

Conclusions

These interim results from a UK-wide survey demonstrate the exceptionally difficult sets of experiences associated with bereavement during the pandemic, with a high level of disruption to end of life, death and mourning practices, as well as social support networks. Participants demonstrated moderate to high levels of vulnerability in grief, which correspond with similar levels of need for emotional support. COVID-19 deaths were significantly associated with higher levels of problematic end of life and bereavement experiences, with those bereaved due to the virus reporting slightly higher support needs and levels of vulnerability in grief.

Communication issues with healthcare providers were a source of distress, with level of perceived support at the end of life and following death also shown to impact upon participant grief and support needs. The detrimental effects of being unable to visit and say goodbye, grieve collectively with family and friends and of social isolation and diminished social networks were also vividly described.

Participants use a range of informal and formal support to help them as they continue along their bereavement journey. However, many experience difficulties both in the support they receive from friends and family, as well as access to more formal support from bereavement services, with unmet needs for support indicated.

Main implications

- Steps are taken to reduce the trauma of bad death experiences. Communication with healthcare professionals at the end of life should be improved by ensuring a known point and method of contact with healthcare teams, regular updates and supporting family involvement in decision-making about their loved one's care.
- Family visiting is enabled as far as is safely possible, with accessible remote communication methods (e.g. facetime) readily available for connecting families/patients where visiting is restricted.
- Healthcare providers work to better support families after a death, including opportunities for discussion of questions relating to patient care and the death, information about locally and nationally available bereavement support and ensuring that such approaches are integrated within their formal COVID-19 response plans.
- Increased public information on bereavement support options. GPs should also be provided with this information and supported to assess and appropriately signpost/refer bereaved patients seeking support.
- Increased provision of bereavement services in areas which currently have long waiting lists and consideration given to ways of providing safe face to face and group based support.
- Flexible support bubble arrangements for the recently bereaved to tackle social isolation and vulnerability in early bereavement and during funerals.
- Identification of alternative ways of enabling collective mourning and celebrations of life, with consideration also given to providing financial support for funeral costs for families experiencing economic hardship.
- For this research to be representative of the population, we encourage men and people from minority ethnic backgrounds to participate in the [survey](#), so we can determine their experiences and possible needs for additional support.

[1] Sim J, Machin L, Bartlam B. Identifying vulnerability in grief: psychometric properties of the Adult Attitude to Grief Scale. *Quality of Life Research*. 2014 May 1;23(4):1211-20.

Report authors: Emily Harrop, Damian Farnell, Mirella Longo, Silvia Goss, Eileen Sutton, Kathy Seddon, Annmarie Nelson, Anthony Byrne, Lucy Selman

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Further information: This survey is part of a larger project examining bereavement during the pandemic. Please see www.covidbereavement.com for more details.