

The impact of the Covid-19 pandemic on bereavement support services in the UK: findings from a cross-sectional online survey and qualitative case studies

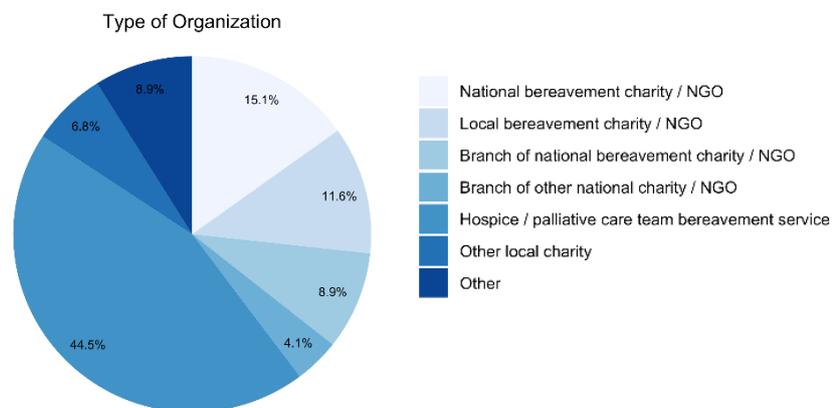
Background and study aims

There were over 695,000 deaths in the UK in 2020, making it the deadliest year since 1918, which was the height of the Spanish influenza pandemic. Restrictions and social distancing have made bereavement during the COVID-19 pandemic more challenging. However, little is known about how voluntary and community sector (VCS) bereavement services, which play a central role in supporting bereaved people, have been affected by the pandemic. We aimed to describe the impact of the pandemic on VCS bereavement services, including how they adapted and responded and the challenges they faced. This evidence is being used to inform bereavement support services and policy during and after the pandemic.

Methods

There were two steps in this study:

- An online survey of VCS bereavement services in the UK (March-May 2021)
- Interviews with staff and volunteers at selected VCS bereavement services (June-December 2021)

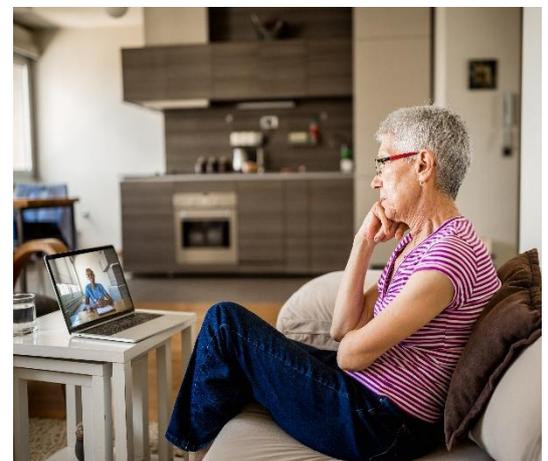


Results

Participants: 147 VCS participated in the survey (see pie chart for organisation types). In addition, 24 people across 14 organisations agreed to be interviewed by telephone. The people that we interviewed worked in a variety of paid and voluntary roles.

Survey responses

- Just less than half (46%) of organisations reported higher demand for their service whilst about a third (35%) reported lower demand
- 40.3% reported a current waiting list of more than 3 weeks
- Just over three quarters (78.2%) had changed their services during the pandemic
- About half (51.7%) had introduced new services (such as online /telephone support)
- Around two thirds (67.3%) identified specific groups not accessing their services before the pandemic, particularly people from minoritized ethnic communities (49%)
- Compared with before the pandemic, 3.4% of services were seeing more people from ethnic minority groups, 6.1% were seeing fewer; 38% didn't know/didn't collect this data



Key theme: Challenges

Client needs and impact on staff:

- There was a rise in people having a more difficult time in their grief combined with other mental health issues
- Strong feelings of grief often arose during lockdown, or when alone or isolated
- Lockdown meant sudden changes as people could not access face-to-face support so had to use phone or online services. This caused problems for some people, though others benefitted from the change
- Some clients had difficulty finding a confidential and quiet place to speak from due to lockdown
- Staff working from home had to try to ensure a confidential space from which to provide support
- Staff and volunteers needed more support and supervision working from home because of new ways of working and their own COVID-related challenges such as homeschooling, isolation or bereavement in addition to supporting clients

We've seen quite a big increase of people been referred to us... from IAPT [Improving access to psychological therapies], often because their waiting lists are so long... but we've also seen more people coming to us from the secondary mental health services. (Clinical Lead, Regional Organisation)

If you've had a tough client session on the phone, you put the phone down and then you're sitting on your own staring at the fire... that's really tough... not being able to... offload afterwards... it's not a weakness to show that you're sad, or that you're upset or that you're anxious. (Senior Practitioner Family Support, Hospice)

Service challenges:

- Rapid adjustments were necessary in policies and procedures including safeguarding
- Financial challenges occurred including loss of funding streams and COVID-specific funding ending

Absolutely seeing clients presenting with more complex needs and higher risks. Intrusive images and flashbacks due to covid restrictions seem to be highly prevalent. (Team Leader/ counsellor, NHS hospice/palliative care team)

An increase in the number of safeguarding concerns raised. Bereavements through suicide have increased and self-harm is an increasing feature of young people's coping mechanisms. (Service Manager, Local bereavement charity)

... they [staff and volunteers] have to use extra listening skills and reading between the lines because they can't see the person, they can't see what's going on with them... If they've got suicidal ideation, you can't see any of that on the telephone. (Head of Wellbeing, Hospice)

Virtual support and counselling whether by video or telephone can be extremely challenging when people are living within a family and family life is going on around them. It can be extremely difficult to establish a safe and private space free from interruption and distraction. (Head of Pastoral Care and Education, hospice/palliative care team)

Key theme: Opportunities

Access and service development:

- Changes to offering online and phone support meant services were accessible to more people (e.g. younger people, men, rural communities)
- Services were modernized by offering a choice of platforms for interaction (online groups, one-to-one phone calls, door step check-in), based on service users' needs and preferences
- New services were developed including grief groups, grief cafés, walk-and-talk groups, a forest school for children and young people, and interactive bereavement packs to send out to families
- Some services encouraged mutual client support (by phone and online)

Coordination and streamlining:

- Urgency in response to COVID enabled more streamlined innovation in services' processes and delivery
- Local Authorities and Clinical Commissioning Groups increased efforts to link and coordinate regional bereavement services, while bereavement services also instigated local collaborations
- Better coordination and networking of provision enabled sharing of work, resources and sometimes clients to reduce waiting times

Stronger links and referrals from hospitals/social prescribers at GP surgeries/nursing homes. Many of the usual barriers were not there meaning you could start a new service more quickly, organisations were more open to it. (National hospice/NGO)

I think it's raised our profile massively, we have responded at the time when we needed to put additional services in, we have helped to avoid admissions into the acute trust. (Director of Care, Hospice)

Younger people, and particularly men, have preferred the telephone support to face-to-face... because, again, it's that sort of anonymity. They don't need to come anywhere and see us... the telephone provides them with a bit of a mask and maybe allows them to feel a bit more comfortable. (Regional Manager, Branch of National Organisation)

The [Clinical Commissioning Group] CCG have recently started a forum to bring together local bereavement organisations. They are also going to fund a project manager role to develop more joined up working. (Local bereavement charity/NGO)

Positives for staff:

- Both paid and voluntary staff pulled together to support each other in caring for bereaved people
- More familiarity with online working enabled staff and volunteers working from home to access national and regional training resources

Societal:

- People became more aware of the valuable work done by hospices in their communities
- More conversations about death, dying and bereavement have been necessary, reducing taboos

I think that's another good thing - the fact that we're talking about death - in time, we've got to make it less of a taboo. (CEO, Organisation supporting minoritised ethnic community)

Conclusions and implications for future provision

- UK bereavement services changed quickly during the pandemic, despite facing major challenges.
- Over two thirds of VCS bereavement services recognise unfairness in who accesses support, with people from Black and minoritized ethnic groups in particular not accessing support despite needing it. Monitoring who accesses bereavement services, reaching into diverse communities and ensuring services are culturally appropriate are important to make sure that everyone has an equal opportunity to benefit.
- Most managers of bereavement services plan to provide a mix of online and face-to-face appointments in the future. Even so, we know that online support is not suitable for all and that we still need to make sure that enough services of different kinds are available.
- Waiting lists for mental health services have made things worse, as clients with more difficult needs are being referred to bereavement services originally designed to provide a “listening ear” rather than to give specialist mental health support.
- The pandemic has brought about some positive changes, such as services working together, widening their reach and offering different types of support. To make sure that positive changes carry on in future, we need to ask clients, volunteers and staff how they have managed to adapt and change and how acceptable the new services are.
- The pandemic motivated some national organisations, local authorities and health boards to support bereavement services. To meet increased demand, VCS bereavement services need guaranteed funding in the future.
- For more details about the study, its findings and outputs, see www.covidbereavement.com

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