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

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Study aims and methods

1. Document the grief experiences, support needs and use of bereavement support by people bereaved during the COVID-19 pandemic
   - ➢Longitudinal online survey of people bereaved in the UK since 16 March 2020 (n=711)
   - ➢Qualitative interviews with sub-sample of survey participants
   - ➢For study reports, see: **www.covidbereavement.com/reports-and-publications**

2. Understand the adaptations, challenges and innovation involved in delivering equitable bereavement support
   - ➢Cross-sectional online survey of bereavement services (n=147); qualitative interviews with 14 case study organisations

3. Inform end-of-life care processes and bereavement support during and beyond pandemic

Survey of UK bereavement service providers (March-May 2021)

Participants from 147 voluntary and community sector bereavement services:

- 53% served specific counties or smaller regions; 16% were UK-wide
- 36% were hospice or palliative care services, 15% national bereavement charities or NGOs; 12% local bereavement charities
- 68% provide support following all causes of death
- 33% after specific causes of death
- Variation in how referrals have changed:
    - 46% demand higher than usual
    - 35% demand lower than usual

Challenges reported:

- Coping with sudden, huge shift to online/telephone support
- Emotional impact on staff/volunteers – increased supervision
- Volume of clients and complexity of needs
- Implementing staff training e.g. in provision of online support
- IT use – working from home, client access/familiarity
- Financial challenges (52%) including cancellation of fundraising events
- Lack of volunteers able to work
- Access to appropriate facilities e.g. COVID-secure space

Also reported positives (more later!)

Qualitative interviews with bereavement support providers (July – December 2021)

14 organizations:

- All nations/regions of the UK
- Range of providers (n=12)
  - Large national organizations
  - Hospices
  - Small community organizations
  - Targeted support e.g. BME communities, children
  - Telephone helpline
- Online support – COVID specific (n=2)
- Changing levels of referrals
- Different support: counselling, listening ear, family support

24 Participants - range of roles:

- CEO/Founder/Director
- Clinical Lead
- Therapist/Counsellor
- Family Support Practictioner
- Social Worker
- Volunteer/Befriender
- Hub administrator
- Admin/Moderator (online)

Challenges

- **Managing fluctuating demand**
- **Increase in complexity of client needs**
- **Timing of support needs**
- Rapid move from in person to online/telephone support (pros and cons)
- Rapid adjustment of policies, procedures including safeguarding
- **Staff providing support from home**
- Financial challenges: Loss of funding streams, COVID-specific funding ending

Positives: what worked well

- **Extending reach**
- **Modernising services: blended approach**
- Expanding existing services/ developing new services
- Appreciation of teamwork
- Establishing new local collaborations
- **Enhancing the profile of hospices in local communities**
- Encouraging mutual support (online groups)
- **Opening conversations about death and dying**

Challenges: coping with changing levels of demand

- Some services reporting substantial rise in demand
- Initial fall in demand
  - e.g. bereavement helpline set up and closed down
- Some clients reticent to engage with online support
- Lack of knowledge of the availability of services
- Impact of staff and volunteer sickness

… a huge increase for BAME callers but it's because they've been hit the hardest with COVID, you know, we've got stories of you know COVID going just, just going through a whole household
(Triage team/Vol, Branch of Nat Org)

It was all on the phone and I think people were so focused on just surviving … and I think people probably presumed that a lot of the other services were either not accessible anymore or that they couldn't access them
(Senior Practitioner Family Support, Hospice)

Challenges: client needs

- Increasing complexity of client needs
  - some report rise in suicidal ideation/bereavement by suicide
- Waiting lists for mental health services/psychological support
  - some bereavement services “out of depth” or getting “inappropriate referrals” as a result
- Timing of support requests
  - early contact/“stored up grief”
- Impact of COVID on grief processes
  - Described as “complicated grief”

We’ve seen quite a big increase of people been referred to us … from IAPT often because their waiting lists are so long that they’re being signposted to us but we’ve also seen more people coming to us from the secondary mental health services
(Clinical Lead, Regional Org)

So there’s two things going on: there’s people that are accessing our service earlier for sure … as well as people are accessing the services that have been bereaved from a very long window of time as well
(Volunteer, Branch of Nat Org)

Challenges: impact on staff

- Staff providing support from home
- Importance of supervision and support for staff
- Training in remote support
- Impact on therapeutic encounter
- Changing policies, procedures
  - e.g. safeguarding

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 and it's triggered your own thoughts, that's really tough … being able to say look, you know give us a ring, have an offload afterwards, how are you doing? … we always say to clients there's a massive strength in showing your vulnerability … it's not a weakness to show that you're sad, or that you're upset or that you're anxious. But of course that also applies to us and you know that's a more tricky situation, the self-care element of practitioners and volunteers.
(Senior Practitioner Family Support, Hospice)

… they 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)

Positives - what worked well

- Accessibility: greater choice for clients
- Blended approach in future
- Collaborations with local authorities
- Raising profile of hospices
- Online groups: encouraging mutual support
- Encouraging conversations about death and dying

… what we have found is that 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
(Hub manager, Branch of Nat Org)

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)

So I think that's another good thing: the fact that we're talking about death, hopefully that in time, we've got to make it less of a taboo
(CEO, Small Org, BME)

Preliminary conclusions (analysis ongoing)

- Findings highlight the important role played by bereavement services in the context of the pandemic
- Forced “modernization” of services: blended approach to provision to continue in the future
- Differing impact on client groups: recognition that online support not suitable for all
- Staff have worked together under extreme pressure to provide services
- New and innovative services developed
- Waiting lists for mental health services: knock on impact on “listening ear” services

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Implications

- Importance of sustained funding for bereavement support services
- Further work needed to raise awareness of services
- Gaps in provision need to be addressed
- Staff wellbeing: staff and volunteers need continued support/supervision
- Evaluation of service changes needed to inform future provision (started at some services)

When I see evaluations from people and see what our support means to people, that makes you think … we make mistakes and there's things we could improve on I have no doubt about that, but … we are providing an essential support for people at a really difficult time so that kind of keeps you going

(Volunteer, Branch of Nat Org)

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